School of Occupational Therapy, Social Work and Speech Pathology

The Cooperative Research Centre for Living with Autism (Autism CRC)

Specialist Peer Mentoring of Autistic University Students

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Author's declaration

To the best of my knowledge and belief this thesis contains no material previously published by any other person except where due acknowledgment has been made.

This thesis contains no material which has been accepted for the award of any other degree or diploma in any university.

The research presented and reported in this thesis was conducted in accordance with the National Health and Medical Research Council National Statement on Ethical Conduct in Human Research (2007) – updated March 2014. The proposed research study received human research ethics approval from the Curtin University Human Research Ethics Committee (EC00262), Approval Number HR16/2014.

Signature:

Date: 20/3/2020

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The nature and extent of the intellectual input by the candidate and co-authors has been validated by all authors:

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Abstract

Autism spectrum disorder (ASD) is defined by the constellation of traits including social communication deficits, and restricted or repetitive behaviours. The lifelong experience of these core deficits have manifested as low levels of adult outcomes, such as post-secondary education. Children have historically been the focus of intervention, services, and research. This has resulted in a lack of evidence-based approaches to improve outcomes in adulthood. Post-secondary education is one avenue that has the potential to improve adult outcomes for autistic people, and while there has been a gradual improvement in the completion rates of secondary education, this has not been mirrored in university studies.

Peer mentoring is one strategy whereby novices are assisted in managing their participation, performance, and their environment. In peer mentoring, experienced individuals share their experience, knowledge, and expertise. Peer mentoring has been used in education and been recognised as being beneficial to both mentors and mentees. It has also been shown to improve retention rates. However, standard peer mentoring may not be appropriate to mentor autistic university students because academic support is unlikely to be their key focus. Instead, autistic university students require assistance to manage the core challenges of the diagnosis, such as social communication issues and/or their restricted or repetitive behaviours. Adding to standard peer mentoring by targeting the core deficits and challenges of autistic university students, Specialist Peer Mentoring (SPM) has been trialled with some success in the UK, USA, and Canada, but the experiences of Australian autistic university students supported by SPM and the effect it had on them, their mentors, and their parents remain unknown. To explore this topic it is necessary to firstly understand the existing viewpoints and approaches to supporting autistic adults. With the emergence of SPM as a novel approach to support autistic university students it is important to understand the effects that this has on participation and the impact this may have on their family. Therefore, this thesis was underpinned by three objectives:

 Objective 1 was to explore the existing viewpoints and approaches to participating in university studies from the perspectives of autistic adults, their parents, and their supporters.

 Objective 2 was to investigate a specialist peer mentoring program for autistic university students and how it affected mentors and mentees.

 Objective 3 was to explore the unexpected effects of specialist peer mentoring of autistic university students on their parents.

The thesis comprises of seven chapters based on five separate studies (papers I-V).

The aim of paper I (chapter 2) was to explore the experiences of parents during the transition to adulthood of young adults with ASD. This aim was achieved by conducting four focus groups with 19 parents of young autistic adults. Three themes emerged from the focus groups: *to be understood*, *to understand the world*, and *to succeed.* The focus group data were linked to the International Classification of Functioning and Disability (ICF) identifying the domains participation and environmental factors as having the greatest potential to influence transition outcomes. The findings highlighted the potential of modifying the environment as an approach in working with young autistic adults. Such environmental adaptations could augment other interventions for young autistic adults and ultimately serve to support their participation in major life areas. Transition to adulthood represents a critical period for young autistic adults and their families, a time when supports are needed to maximise the opportunities for young autistic adults to achieve their ambitions and participate fully in society.

The aim of paper II (chapter 3) of this thesis was to explore the viewpoints on successful navigation of university for autistic students, from the perspectives of the students and those that support them through a Q-methodology study with 57 participants. Three viewpoints emerged; *individualised support, contextual support,* and *social support.* The findings of paper II suggest that it would be beneficial for universities to employ individualised and strength-based approaches in supporting autistic students, with support best provided by one single person with understanding of the nuances of each individual, and extending that understanding to contextual and social supports. Interventions guided by these principles could potentially facilitate the success of autistic university students, ultimately improving lifelong outcomes.

Paper III (chapter 4) aimed to explore the contexts required for peer mentoring of autistic university students, the mechanisms that occur in peer mentoring and the outcomes of it both for mentees and their mentors. Paper III also aimed to inform the development of a refined program model describing the relationships between context, mechanism and outcomes, potentially informing future peer mentoring programs for autistic university students. In total, 23 neurotypical peer mentors and 24 autistic university students engaged in the Specialist Peer Mentoring Program (SPMP) at Curtin University and University of Western Australia provided data on the links between the contexts, mechanisms and outcomes associated with the SPMP. The contexts that suggest a SPMP would be required were 'environmental conditions',

'university course demands' and 'aspects of ASD'. The mechanisms required for an effective SPMP were the 'mentor', 'communication and social interaction', 'problem solving' and 'training and supervision'. These mechanisms led to the outcomes of 'identifying personal strengths', 'increased autonomy', 'achieving goals', 'relationships' and 'positive mentor outcomes'. Programs like the SPMP, have the potential to improve the outcomes of young autistic people, supporting them in achieving their goals in major areas of life, such as university education.

The aim of paper IV (chapter 5) was, to explore the experiences of undergraduate autistic university students participating in SPM to identify active ingredients in the peer mentoring process and to examine the impact of SPM on social communication. This aim was explored through multiple methods with a total of 30 undergraduate autistic university students. The participants engaged in interviews and completed an assessment battery at the beginning and at the end of the academic year. Four themes emerged from the interviews: *Developing Partnership and Understanding, Modelling and Practising Communication, Psychological Support* and *Grading and Planning Skills.* Improvements were noted at post-test on the Social Responsiveness Scale-2 total score (p=0.02), and its Social Communication, (p=0.03) and Social Motivation (p=0.03) sub-scales. This study demonstrated that social communication and social motivation can improve for autistic students participating in SPM, as they developed a working partnership to manage their social and study challenges at university. Finally, this paper demonstrated that the engagement in a mentor-mentee partnership within a SPM program can influence social competence in autistic university students.

The aim of paper V (chapter 6) was to explore the experiences of parents of specialist peer mentored autistic university students. This aim was explored through semi-structured interviews with 13 parents (11 mothers and two fathers). Thematic analysis of the interviews identified five interrelated themes: *The mentoring relationship is a facilitator, Developing skills for university, Mentoring changes lives, Mentoring is not a substitute for other supports,* and *'University' is an emotional rollercoaster.* The interview data were also linked to the Comprehensive ICF core set for autism spectrum disorder, which identified that from the parents' perspective the SPM intervention focused predominantly on facilitating participation and on modifying environmental factors. The results of this study indicated that as a consequence of their young adult's participation in SPM at university, parents broadened their own participation in important activities, suggesting that SPM benefits not only young autistic

adults, but also their parents. These results and others from similar studies indicate that when developing supports such as SPM, the relationship between the environment and the autistic students must carefully be examined.

This thesis has demonstrated that SPM can assist autistic university students' successful participation at university. Post-secondary education facilitated by SPM supports autistic university students to successfully navigate university and promotes their transition to adult life. This may facilitate opportunities for employment, providing opportunity to successfully transition to adult life. Overall, the results indicate that the relationships developed between the autistic students and their mentors are crucial for SPM. The development of this relationship is purposeful, with mentors using communication strategies to create partnership. The dyadic nature of this relationship assists autistic university students in developing social competence. Autistic university students can also develop executive functioning strategies through their participation in the SPMP, which will facilitate participation at university. Finally, this thesis demonstrated the unexpected effects that SPM can have on others associated with the autistic university students, such as their parents, whereby parents noted improvements in their relationship with their adult autistic child and mentors, who gained invaluable experience for their future careers.

Acknowledgements

My sincere thanks go to everyone associated with the Curtin Specialist Mentor Program. I especially want to thank the program coordinators, Dr Jasmine MacDonald and Dr Theresa Kidd, your support of this research was invaluable. The assistance provided to advertise the research and provide general support facilitated the successful completion of the project. Furthermore, without the successful development of the specialist peer mentoring program, none of this would have been possible. I would also like to thanks all of the mentors and the mentees (autistic university students) for making this research project possible.

I would like to thank the Autism CRC for facilitating my PhD and being a catalyst for research. The Autism CRC has fostered autism research and supported my development as a researcher who is dedicated to co-producing future research. I especially want to thank Cheryl Mangan for your friendship and support. I would also like to acknowledge the contribution of the Australian Government Research Training Program Scholarship in supporting this research.

I am pleased to have shared my PhD journey in the area of autism and adulthood with my friends Dr Melissa Scott and Dr Megan Hatfield. I want to thank both of you for sharing journal articles and knowledge. Thank you also for sharing podcasts, conferences, beers, laughs, and tears. Nobody can do this alone, and only those on the same path can truly understand the experience. I also want to extend warm thanks to the remainder of the group of PhD students: Dr Melissa Black and Julia Tang. Without this group of PhD students, this journey would have been a great deal more lonely and stressful. I want to extend special thanks to Melissa Scott, who has offered her assistance with proofreading this thesis. Melissa, I am very grateful for your challenging questions and thoughts as I prepared this thesis – thank you.

Finally, I want to thanks and acknowledge my family. My parents and my sister, Gail, who have supported and encouraged me to pursue my education to its fullest and without both of you this long journey, would not have started. My parents have provided me with the opportunities they never had and have steadfastly encouraged me to pursue my studies.

To my wife, Caitlin, I need to thank you for your suggestion that I should study occupational therapy over seventeen years ago and without this I would never have started this journey. You continued to support my change of career to become an occupational therapist, and even when I started talking about embarking on a PhD, which had implications for my whole family, you continued to support my journey. I also have to thank you for believing in me and continuing

to encourage me to take on the challenge of this PhD. When we married we promised to support each other in our journeys, and you have truly followed through on this vow – thank you.

Finally, I want to thank my two young sons Louis and Carus. You have both shown a great degree of understanding while I have been all consumed in my PhD and did not go to the park to kick the football.

Dedication

The journey of completing a PhD is a long one and it affects everyone in the life of the candidate. However, there are those who provide the motivation to keep going. In my case the people that keep me going, even in the challenging times are my two sons: Louis and Carus. When things are challenging and I am stressed and worried about this piece of work you would give me a hug and help me through it. Louis and Carus, I am sure you do not know how important you both were to me during this journey, but without you both I could not have successfully completed this work. I dedicate this work to you both.

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List of published manuscripts

Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018a). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *PLoS ONE, 13*(3), e0194758. doi:10.1371/journal.pone.0194758. Impact factor 2.776; 23 citations.

Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018b). Viewpoints on how students with autism can best navigate university. *Scandinavian Journal of Occupational Therapy*, 1-12. doi:10.1080/11038128.2018.1495761. Impact factor 1.316; 4 citations.

Thompson, C., Falkmer, T., Evans, K., Bölte, S., & Girdler, S. (2018). A realist evaluation of peer mentoring support for university students with autism. *British Journal of Special Education, 45*(4), 412-434. doi:10.1111/1467-8578.12241. impact factor 0.845; 2 citation.

Thompson, C., McDonald, J., Kidd, T., Falkmer, T., Bölte, S., & Girdler, S. (2020). "I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students. *Scandinavian Journal of Occupational Therapy, Online*. doi:10.1080/11038128.2020.1738545. Impact factor 1.316.

Submitted manuscript

Thompson, C., Milbourn, B., Taylor, J. L., Falkmer, T., Bölte, S., Evans, K., & Girdler, S. (2020). University is an emotional rollercoaster: Experiences of parents of specialist peer mentored autistic university students. *Developmental Neurorehabilitation, Under review*. Impact factor 0.759.

List of conference presentations

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2018). Changing lives of parents of autistic university students through specialist peer mentoring ASFAR: Gold Coast, Queensland, Australia.

Thompson, C., Falkmer, T., Taylor, S., Bölte, S. & Girdler, S. (2017). Realist evaluation of specialist peer mentoring for university students with ASD. Panel presentation IMFAR: San Francisco, USA.

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2016). Transition to adult life for young on the Autism spectrum: A parents' perspective. ASFAR: Perth, Australia.

List of conference poster presentations

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2019). "Our relationship has matured": Improving parental relationships through specialist peer mentoring for autistic university students. INSAR: Montreal, Canada.

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2019). The active ingredients of specialist peer mentoring for autistic university students. INSAR: Montreal, Canada.

Thompson, C., Falkmer, T., Bölte, S. Kidd, T., McDonald, J. & Girdler, S. (2018). The development of social competence in autistic university students through specialist peer mentoring. ASFAR: Gold Coast, Queensland, Australia.

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2017). Facilitating success for students with Autism Spectrum Disorder at university. IMFAR: San Francisco, USA.

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2017). Transition to Adulthood for Young People on the Autism Spectrum. IMFAR: San Francisco, USA.

Thompson, C., Falkmer, T., Bölte, S. & Girdler, S. (2016). Facilitating success for students with Autism Spectrum Disorder at university. ASFAR: Perth, Australia.

Thompson, C., Girdler, S., Bölte, S., & Falkmer, T. (2015). The perspectives of parents on the transition to adulthood for young adults with high functioning Autism Spectrum Disorders. Asia Pacific Regional IMFAR: Shanghai, China.

Award

Autism CRC Early Career Researcher Travel Scholarship (2017)

Key Abbreviations

ACSPMP: Autism CRC Specialist Peer Mentor Program

ASD: Autism Spectrum Disorder

Autism CRC: Cooperative Research Centre for Living with Autism

DSM-IV-TR: Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition Text Revision

DSM 5: Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition

GSE: Generalised Self-efficacy Scale

ICF: International Classification of Functioning, Disability and Health

NT: Neurotypical

PRCA: Personal Report of Communication Apprehension

SPM: Specialist Peer Mentoring

SPMP: Specialist Peer Mentoring Program

SPS: Social Provisions Scale

SPSS: Statistical Package for the Social Sciences

SRS-2: Social Responsiveness Scale, second edition

UK: United Kingdom

USA: United States of America

Preface

Throughout my career as an occupational therapist, I have been dedicated to seek equity for my clients. Since I moved from working clinically to educating future occupational therapists I have seen how education can change and help them develop people. As I have seen students grow throughout their education, I do believe everyone should have this opportunity.

The majority of my clinical career was spent working with people who had mental health difficulties. One of the first clients was an autistic adult experiencing anxiety and depression. He lived in shared accommodation and worked part-time, but needed a great deal of support from his parents. His experiences of anxiety and depression were triggered by issues at work and by his housemates. Unfortunately, the paucity of available evidence-based interventions ten years ago made it difficult for me to effectively work with him, given his autism diagnosis. I also felt that unlike with my other clients I did not develop a strong therapeutic relationship with him. These shortcomings made me feel inadequate in my efforts to provide effective support to him.

This feeling of inadequacy and my desire to overcome it drove me to start my PhD. Consequently, my passion for pursuing knowledge was born. I commenced a journey to understand how to facilitate developing equity and opportunities for autistic adults. This thesis is the first milestone of this lifelong journey.

Without education, you are not going anywhere in this world.

- Malcolm X

Explanation of terms and delineation of thesis

This thesis was completed as part of the Cooperative Research Centre for Living with Autism (Autism CRC; https://www.autismcrc.com.au/about-us). Established in 2013 by the Australian Government's Cooperative Research Centres Program and including 56 participant organisations the Autism CRC provides the first national cooperative research program to focus on autism. The Autism CRC has an inclusive and holistic research program by engaging in co-production research practices across the lifespan. The Autism CRC has three programs; program one focuses on improving the diagnostic processes so that appropriate interventions can start as early as possible, program two focuses on improving the experience of autistic individuals at school, and program three focuses on improving opportunities in adult life for autistic people. This thesis was part of program three and contributed to the theme of improving participation in adult life.

Autism spectrum disorder (ASD) has until recently been described and labelled by its diagnostic name. This naming convention was congruent with person-first language frequently used in healthcare. However, there has been a recent desire expressed by stakeholders to use identity-first language such as "autistic adults" or "autistic students" [145, 155]. Consequently, the terminology used in this thesis has progressed and changed with that of the autistic community. This language preference has emerged over the life of this thesis, and as a consequence, the terms used in the publications in this thesis have evolved with the preferences of the stakeholders. The language used throughout this thesis has also mirrored the evolution of the Autism CRC style guide [22]. This also dictated that people without a diagnosis of ASD would be described as being "neurotypical" throughout this thesis. The language and referencing in this thesis is partially related to the guidelines where the manuscripts were submitted. Consequently, the manuscripts that constitute this thesis vary in appearance, structure, spelling and referencing styles. The remaining chapters of the thesis have been written in Australian English and used Medicine referencing style.

This thesis examined the participation of autistic adults at university. The participants of this research self-reported their diagnosis, as they were required to provide evidence to the disability services at Curtin University and University of Western Australia, in order to receive assistance with their studies. Consequently, it was not deemed appropriate and, in fact,

unethical to request participants to partake in further assessment of their diagnosis. Furthermore, this thesis does not take any stance on the diagnostic criteria or processes. The differing criteria such as Asperger's Syndrome, Autism Spectrum Disorder, Pervasive Developmental Disorder – Not Otherwise Specified, etc. were collapsed into a single criterion. This thesis also asked participants to self-report as not having a co-occurring intellectual disability before joining the projects.

This thesis aimed to explore the experiences of participating in university for autistic university students supported by specialist peer mentoring and the effect it had on them, their mentors, and their parents. This focus incorporates an exploration of the transition into university education. This exploration also included an examination of the use of strengths to manage the challenges experienced by autistic university students. Specialist peer mentoring is the vehicle to be utilised throughout this thesis to facilitate the strengths-based approach. This thesis also examined the impact of specialist peer mentoring and university education on the parents of autistic students, as well as the impact on the mentors involved in specialist peer mentoring.

While the present thesis examined participation during one single year of university studies for autistic adults, it did not examine the academic results of participants because the mentors were not matched by the academic course the autistic students were studying in and therefore were not subject matter experts that could assist with their studies. Furthermore, the thesis did not explore the areas of study autistic students were engaged in, nor the standard accommodations used at university to support their studies. The students who participated in the research that constituted this thesis were engaged in the Autism CRC Specialist Peer Mentor Program (ACSPMP).

The research project at the centre of this thesis did not utilise a control group when exploring the impact of specialist peer mentoring on autistic adults, the ethical rationale being that withholding the intervention may have been detrimental to participation at university for the group not engaged in specialist peer mentoring. Therefore, it was not possible to only offer the potentially effective intervention with positive anecdotal evidence only to half of the autistic students at the university. When the project commenced, it was decided that separating autistic university students into an intervention group and a control group would have further reduced the statistical power of the project.

In the exploration of the experience of autistic adults participating in the ACSPMP, this thesis did not explore autism throughout childhood or other aspects of adulthood more broadly. ASD is a lifelong condition, but the experiences other than those associated with university education or ACSPMP were beyond the scope of this thesis. Specifically, this thesis did not examine the experience of autistic individuals at school or in paid work. Furthermore, it did not examine independent living for autistic adults.

Lastly, the present thesis did not explore autistic adults' relationships in general, nor romantic relationships or friendships of autistic adults specifically. However, this thesis did examine the relationship between autistic university students and their mentors and the relationship between the autistic university student and their parents.

Chapter 1: Introduction

Background

Autism spectrum disorder (ASD) is a neurodevelopmental condition that has a lifelong trajectory with wide-ranging implications. The condition of ASD is defined by the constellation of traits including social communication deficits, and restricted or repetitive behaviours [7]. The lifelong experience of these core deficits have manifested as low levels of adult outcomes, such as post-secondary education. These poor adult outcomes are particularly concerning considering the observed gradually increasing prevalence rates. In 2010 it was estimated that 0.76% of children worldwide had ASD and in 2019, this estimation has now doubled, i.e. 1.5% [30]. Considering the lifelong nature of ASD, this increased prevalence in childhood will result in an increasing number of autistic adults [101]. Children have historically been the focus of intervention, services, and research. This has resulted in a lack of evidence-based approaches to improve outcomes in adulthood.

One avenue for improving adult outcomes is post-secondary education, but the process of moving into this adult domain is challenging for autistic adults. However, there has been a gradual improvement in the completion rates of secondary education [5, 23]. This has resulted in a significant increase of autistic students enrolling in post-secondary education between 2010 and 2016 [25]. The provision of scaffolding and supports, as well as the structured nature of school is facilitating the improvement of completion rates of secondary education [5, 23, 76], but when autistic adults enter post-secondary education they need to self-disclose their ASD diagnosis to receive the assistance they require to manage the challenges they encounter at university [51]. Some autistic university students also have difficulties managing the unpredictable, loud and busy university environments [251]. These sensory and social challenges combined with the autistic adults' difficulties with executive functioning, makes university studies even more complex [48]. These challenges are exacerbated by the exploration and assessment of abstract concepts [8, 118, 151, 172]. The high frequency of peer work or group assessments provide further obstacles for autistic university students [114, 172, 225, 251]. These difficulties may even manifest in bullying [225] or exclusion by their peers [151]. To access support, autistic adults are required to self-advocate to succeed at university, which is problematic for many [4]. With effective self-advocacy, however, the autistic adults may be able to manage the physical and social environment of university [256]. Traditionally, university services mismatch

the expressed needs and offer academic supports rather than supporting the social and emotional needs of the autistic students [151, 193].

The exact numbers of autistic students at university are hard to estimate, but it has been observed that approximately a third of autistic adults attend post-secondary education [215]. In Australia, approximately 20% of autistic adults complete post-secondary education, which is considerably less than the 60% of people without disabilities who obtain further qualifications [19]. This is a missed opportunity, as the provision of services for autistic adults at university might promote participation by maximising the fit between the environment and the required tasks [14].

Peer mentoring is a strategy whereby novices are assisted in managing their participation, performance, and their environment. In peer mentoring, experienced individuals share their experience, knowledge, and expertise. Peer mentoring has been used in business, healthcare, and education. It has been recognised that mentoring can be beneficial to both mentors and mentees [72]. In education settings improving retention rates is one major benefit [236, 266]. It has been proposed that the potential improvements in retention are a consequence of improved belongingness that is fostered as a consequence of peer mentoring [6]. This belongingness has also been shown to have positive effects on emotional wellbeing, academic results, and motivation [45]. Peer mentoring of university students with disabilities has recently been identified as a successful strategy, but provided mentors with distinct challenges that required training and support to overcome [125].

The mentoring process also has the potential to improve academic success [72]. The process of mentoring continues to be used extensively, but there remains a lack of consensus of its definition and structure [81]. A proposed model includes the provision of psychological support, goal-setting support, academic support, and role modelling [81]. However, this model may not be appropriate to mentor autistic university students because academic support is unlikely to be the key focus. Instead, autistic university students require assistance to manage the core challenges of the diagnosis, such as social communication issues and/or their restricted or repetitive behaviours. Therefore, mentors who partner with autistic university students need specialist knowledge and skills.

Table 1.1 Overview of the mentor training program

Training topics
Understanding of the different experiences of autistic university students
Understanding the mentor role
Exploring strategies to develop a relationship with a mentee
Development of strategies to set individualised goals with mentees
Development of strategies to utilise individualised supports for mentees
The importance of boundaries and crisis management
Policies and procedures of the specialist peer mentoring program

Unfortunately, there continues to be a lack of evidence-based interventions for autistic adults at university. However, specialist peer mentoring has been trialled with some success in Australia [224], UK [170], USA [122], and Canada [204]. The process of specialist peer mentoring adds to standard peer mentoring by targeting the core deficits and challenges of autistic university students [181, 182, 224]. The ACSPMP [181, 182] was developed independently of this research project and is the first widely available intervention of its kind and the results of the pilot trial suggested positive outcomes [224]. The ACSPMP has been manualised (Appendix A) for ease of broad implementation and has three components: mentor support, specialist peer mentoring, and a social group [181]. The program is coordinated by staff associated with Disability services at the Curtin University and the University of Western Australia. Graduate students from Occupational Therapy, Psychology and Speech Pathology apply to participate in the program and successful applicants are matched by the coordinators based on their interests to an autistic university student. The mentoring students are selected by the coordinators of the ACSPMP because of their experience at university, social skills, and pre-clinical knowledge congruent with participating in the program, such as their knowledge of goal setting. The specialist peer mentor then participates in training (Table 1.1) to develop their understanding of ASD, including how to communicate with autistic university students. The training also focuses on how to assist autistic university students to set individualised goals and to engage in problem-solving. The specialist peer mentors and the autistic university students start their relationship by setting goals for the academic year. Autistic university students meet their specialist peer mentor weekly, but may communicate more frequently. Throughout the academic year the specialist peer mentor and the autistic adults work together to manage the social, academic,

and environmental challenges experienced. Run as part of the ACSPMP, the social group is co-facilitated by autistic university students and mentors, providing opportunities to practise social skills and learn topics that might support their development. The dyadic partnership between the autistic university student and their specialist peer mentor is unique, allowing the program to focus on individual challenges and be strengths-based.
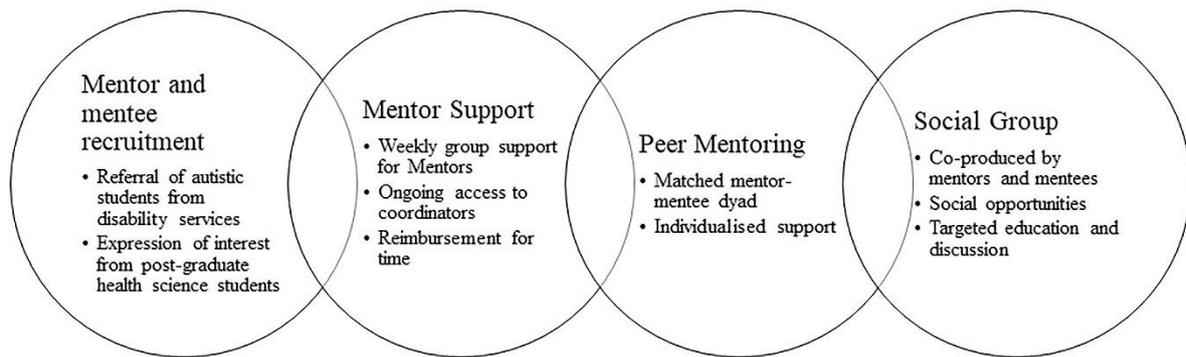
Figure 1.1: The specialist peer mentoring model examined in this thesis.

The Curtin Specialist Mentoring Program commenced in 2014 and this developed further to the manualised ACSPMP. The program commenced with 17 autistic university students and gradually increased participant numbers. The ACSPMP is lead by program coordinators who facilitated the recruitment of mentors and mentees (autistic university students), as well as the training and support of those involved in the program. The program operates over four stages (Figure 1.1). The initial phase is the recruitment of the mentors and mentees. The mentees are recruited through referrals from university disability services. The mentees are screened to ensure they are appropriate for a student-lead mentor program. The mentors are recruited through an expression of interest process with post-graduate health science students are from occupational therapy, psychology, and speech pathology. Following the expression of interest process the successful candidates are interviewed before being invited into the ACSPMP. The second phase of the ACSPMP focuses on educating and training the mentors to work with autistic university students. The training process aims to help the mentors gain a greater understanding of autistic adults. Furthermore, the mentors training outlines their roles and delineates the boundaries of the ACSPMP. The mentor training also aims to improve the mentors' skills in goal setting and problem-solving. The mentors gain ongoing support and supervision on a weekly basis from the program coordinators. The third aspect is the actual

mentoring partnership between the neurotypical mentor and the autistic university student (mentee). The individual mentee sets the priorities and goals for the intervention. The mentoring dyad commonly meets face-to-face once a week to explore the challenges and they communicate via email throughout the week. The fourth component of the ACSPMP is the social group for the mentees. The social group is an opportunity for autistic students to socialise, to test social skills, and learn skills for university or work. The social group is co-produced by the mentors and mentees.

The strengths of autistic individuals are used as potential avenues to promote participation in major life areas. These strengths have been identified as including attention to detail, a preference for monotonous tasks, loyalty, and an exceptional memory [85]. These various strengths may be particularly beneficial for completing university studies. However, the challenges experienced by autistic university students may prevent them from utilising their strengths [10]. The traditional intervention approaches across the lifespan for people on the autism spectrum focus on reducing the impact of deficits. It has recently become apparent that families and individuals on the autism spectrum would prefer interventions focusing on utilising strengths and abilities to facilitate success [117]. However, there is a limited understanding of how to ensure that interventions utilise these strengths, while assisting with challenges experiences.

The International Classification of Functioning, Disability and Health (ICF; Figure 1.2) is a framework that could promote a strength-based approach. The ICF framework can assist researchers and clinicians to understand the experiences of autistic adults and objectively examine interventions. The ICF is a biopsychosocial framework comprised of domains, chapters, and codes [267]. The domain of *Body Function and Structures* captures the physical, mental, and cognitive aspects. The *Activity* domain refers to the completion of tasks and the *Participation* domain captures the involvement in life situations. The domain of *Environmental Factors* refers to the contextual aspects that mediate participation; these include the physical, environment, and attitudes. *Personal factors* were not originally classified, but they relate to aspects such as culture, temperament, and personality. The ICF has been used to understand experiences and assesses strengths as well as deficits [85]. However, due to the number of codes in the ICF it is cumbersome and not used extensively in clinical practice [84]. To increase the usability of the ICF, a series of core-sets related to specific health conditions have been developed [268]. Recently, the ICF Core Set for ASD has been developed to promote the usability

for people on the spectrum [41]. This thesis used the ICF and the ICF Core Set for ASD as a framework to understand the results.


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                          ┌─────────────────────────┐
                          │     Health Condition    │
                          │                         │
                          │  Autism Spectrum Disorder│
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Body Function and Structures	Activities	Participation
b117 Intellectual functions	d161 Directing attention	d820 School education
b125 Dispositions and intra-personal functions	d330 Speaking	d910 Community life
b126 Temperament and personality functions	d710 Basic interpersonal interactions	d920 Recreation and leisure

Environmental Factors	Personal Factors
e310 Immediate family	i1100 Chronological age
e355 Health professionals	i320 Reliability
e460 Societal attitudes	i360 Memory factors

Figure 1.2 The International Classification of Functioning, Disability and Health (ICF) [267]. Illustrative ICF categories selected from the Comprehensive International Classification of Functioning, Disability and Health core set for Autism Spectrum Disorder for Body Function and Structures, Activities, Participation and Environmental factors [41] and illustrative Personal factor categories [107].

7

Aims and objectives

Thesis aim

This thesis aimed to explore the experiences of autistic university students participating in their studies supported by SPM and the effect this mentoring had on them, their mentors, and their parents.

This thesis aim was underpinned by three objectives:

Objective 1 was to explore the existing viewpoints and approaches to participating in university studies from the perspectives of autistic adults, their parents, and their supporters. The specific aims were to:

Chapter 1 explore the experience of parents during the transition to adulthood for young adults with ASD; and,

Chapter 2 explore the viewpoints on successful navigation of university for students with ASD, from the perspectives of the students and those that support them.

Objective 2 was to investigate a specialist peer mentoring program (SPMP) for autistic university students and how it affected mentors and mentees. The specific aims were to:

1. explore the contexts required for peer mentoring of university students with ASD, the mechanisms that occur in peer mentoring and the outcomes of peer mentoring both for mentees and their mentors;

2. inform the development of a refined program model describing the relationships between context, mechanism and outcomes, potentially informing future peer mentoring programs for students with ASD; and,

3. explore the experiences of autistic university students participating in a SPMP to identify active ingredients in the peer mentoring process and to examine the impact of specialist peer mentoring on the core symptoms of ASD.

Objective 3 was to explore the unexpected effects of SPM of autistic university students on their parents. The specific aim was to:

1. explore the experiences of parents of specialist peer mentored autistic university students.

Thesis structure

The thesis comprises of seven chapters, illustrated in Figure 1.3. The information presented in this chapter outlines the purpose and contribution of the five papers (chapters 2-6) in this thesis (Figure 1.3). A variety of methods were utilised to examine and explore the experiences of participating in university for autistic university students supported by SPM and the effect it had on them, their mentors, and their parents, as shown in Table 1.1.
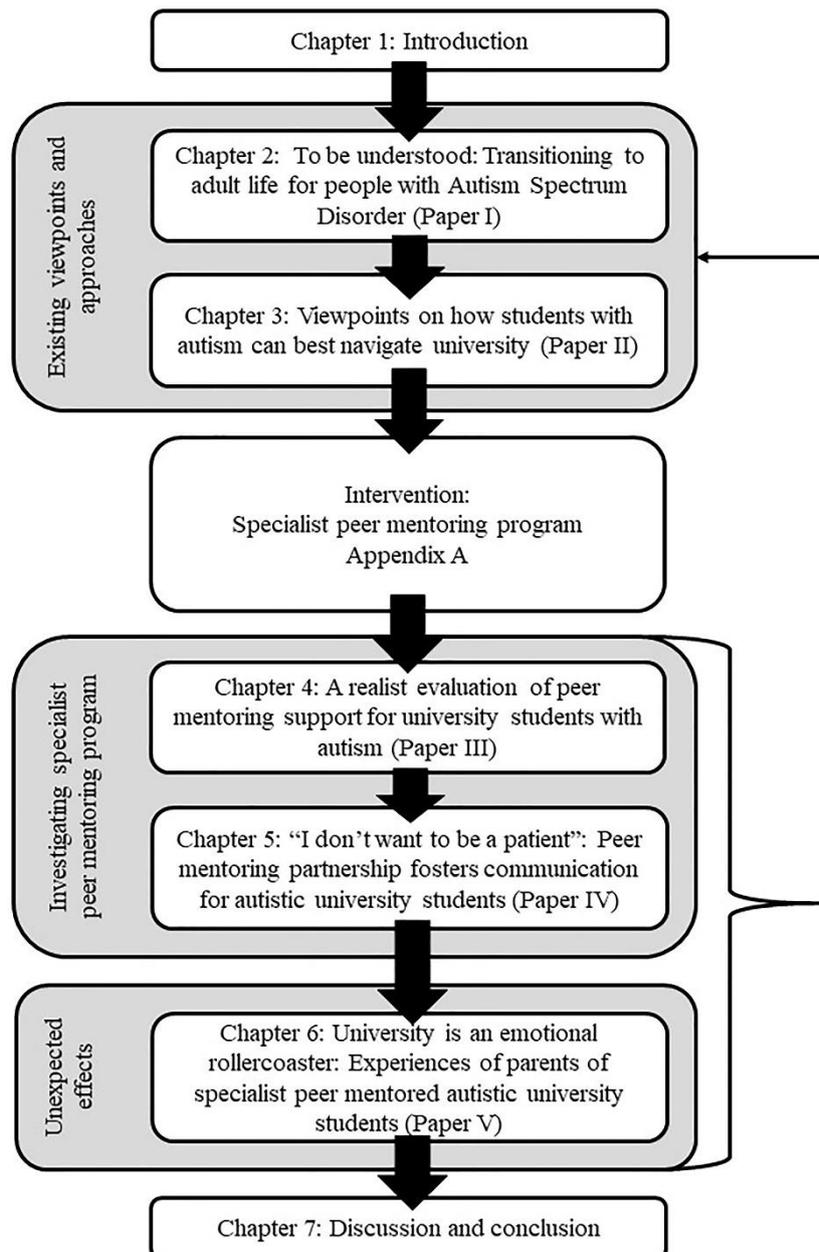
Figure 1.3: Thesis structure and relationship between the chapters.

Paper I: Focus group study

The manuscript reporting structured focus groups (chapter 2) explored the experiences of parents during the transition to adulthood for young adults with ASD. Using structured focus groups, this paper explored the experiences of parents of autistic individuals over 18-years of age. These focus groups were structured through the use of stimulus material to develop discussion and by the use of the in-vivo analysis and member checking. This process of in-vivo analysis with the participants and immediate member checking assisted in the development of rigour in this method. Using focus groups with parents does mean that this paper explored observations of the transition to adult life rather than the lived experience of this process. However, the parents' observations were meaningful because they were closely involved in the transition and thus provided valuable support in the period of transitioning to adult life. Also, parents had effective communication skills which meant that they could outline their lived experience of observing their child progressing into adult life. The use of focus groups with autistic individuals would have been challenging, due to the inherent communication difficulties that they experience so the data collected would not have been as rich. Paper I contributed to this thesis by providing parental viewpoints of the existing understanding of what assists the transition to adult life. This paper also identified that parents wanted an increased focus on the abilities of their autistic children and suggested that modifying the environment could be an effective strategy. A key potential area to assist the transition to adult life was facilitating participating in further education. This parental viewpoint was expanded upon in paper II that sought the viewpoints of how to autistic university students could successfully manage studying from the perspectives of autistic individuals, their parents, and those that support them.

Paper I, published in *PLoS ONE*; impact factor 2.776; 23 citations.

> Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018a). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *PLoS ONE, 13*(3), e0194758. doi:10.1371/journal.pone.0194758

Paper II: Viewpoint study

The Q methodology (chapter 3) explored the viewpoints of successful navigation of university for students with ASD, from their perspectives and from those that support them. The Q methodology was conducted by presenting participants with a concourse of statements representing the topic. The concourse was developed by exploring current literature,

consultation with stakeholders, and piloting of the statements [258]. Participants rated their agreement with the statements of the concourse based upon what they thought assisted autistic university students to manage their studies. The resultant viewpoints emerged from the data through by-person varimax factor analysis of the ranks from the concourse statement from autistic university students, their parents, their mentors, and disability support staff [258]. The Q methodology facilitated the gathering of the viewpoints and through the use of the concourse served to minimise the impact of the verbal communication challenges of autistic individuals. Concurrently, the Q methodology assessed the data, which provided a time-efficient method of gathering participants' viewpoints on the topic of navigating university successfully. Paper II contributed to the thesis by highlighting the importance of contextual, environmental and social supports of how autistic university students can navigate their studies. These results provided preliminary evidence to suggest that individualised and strength-based approaches, such as SPMPs, could be effective in supporting autistic university students. The concept of what might make a SPMP successful was explored in paper III.

Paper II, published in the *Scandinavian Journal of Occupational Therapy*; impact factor 1.316; 4 citations.

> Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018b). Viewpoints on how students with autism can best navigate university. *Scandinavian Journal of Occupational Therapy*, 1-12. doi:10.1080/11038128.2018.1495761

Paper III: Realist evaluation study

The realist evaluation method (chapter 4) was used to explore the contexts required for peer mentoring of university students with ASD, including the mechanisms and the outcomes that occur in peer mentoring both for mentees and their mentors. The realist evaluation study utilised interviews to identify the components of the SPMP. These interviews explored specialist peer mentoring from the perspectives of the autistic university students and the mentors involved in the program. To facilitate interviews with autistic university students, they were provided with the questions before the interview. The realist evaluation approach facilitates the development of evidence-based policies and programs [189, 190]. The realist evaluation allowed for the examination of the program as it ran. In utilising the realist evaluation the environmental aspects or situations that facilitated the program were identified. Also, the realist evaluation process explored what aspects of the people involved in the program were important to the success of it. This evaluation process also identified the mechanisms of

the program that were important in specialist peer mentoring, as previously it was unclear what the key components of the program were. Paper III contributed to this thesis by identifying when specialist peer mentoring is required. This paper also identified the aspects or mechanisms of SPMP, which facilitated participation at university. Furthermore, paper III also outlined the intended and unintended outcomes of the SPMP. Paper IV expanded on the findings of the mechanisms from paper III to identify active ingredients that assisted autistic university students to participate in their studies.

Paper III, published in the *British Journal of Special Education*; impact factor 0.845; 2 citation.

Thompson, C., Falkmer, T., Evans, K., Bölte, S., & Girdler, S. (2018). A realist evaluation of peer mentoring support for university students with autism. *British Journal of Special Education, 45*(4), 412-434. doi:10.1111/1467-8578.12241.

Paper IV: Multiple methods study

Multiple methods (chapter 5) were utilised in exploring the experiences of autistic university students participating in specialist peer mentoring, which further assisted in identifying the active ingredients in the program. This study also examined the impact of specialist peer mentoring on the core symptoms of ASD. They were examined using several pre-post questionnaires, including the Social Responsiveness Scale (2nd edition) [73]. Autistic university students completed these questionnaires at the beginning and the end of the academic year. Interviews were also conducted with autistic university students to explore their experiences, facilitating a deeper understanding of the results from the pre-post questionnaires. Interpretative phenomenological analysis was used to explore the lived experience of autistic university students. Combining these approaches served to minimise the limitations posed by the small sample size on the research process. Paper IV contributed to this thesis by identifying that the mentors provided psychological support to the autistic university student as they developed partnerships, practised social communication, and developed planning skills with their mentors. This paper also identified how the specialist peer mentor program (SPMP) impacted on the autistic traits of the mentees. This process resulted in further identification of the active ingredients of the SPMP. The experiences of engaging in specialist peer mentoring also impacted on others who were close to the autistic university students. The effects of specialist peer mentoring on parents were explored in paper V.

Paper IV published in the *Scandinavian Journal of Occupational Therapy*; impact factor 1.316.

Thompson, C., McDonald, J., Kidd, T., Falkmer, T., Bölte, S., & Girdler, S. (2020). "I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students. *Scandinavian Journal of Occupational Therapy, Online*. doi:10.1080/11038128.2020.1738545

Paper V: Interview study

The interviews in paper V (chapter 6) were utilised to explore the experiences of parents of specialist peer mentored autistic university students. This study facilitated an understanding of the program from an alternative perspective. The parents were interviewed to explore their observations of the specialist peer mentor program. The parents did not directly participate in the program but were able to provide valuable feedback, given they had previously been 'mentoring' their autistic university student. Paper V contributed to this thesis by identifying an unexpected result of specialist peer mentoring, which was to improve the relationship between the autistic university students and their parents. The parents' observations were mapped against the International Classification of Functioning, Disability and Health (ICF). When mapped against the ICF, this identified that the majority of the intervention aimed to modify or manage the environment. This paper also contributed to this thesis by triangulating the results from paper I, as it demonstrated that the SPMP did not aim to minimise deficits, but instead attempts to maximise strengths by managing and moderating the university environment.

Paper V submitted for publication in *Developmental Neurorehabilitation*; impact factor 1.239.

Thompson, C., Milbourn, B., Taylor, J. L., Falkmer, T., Bölte, S., Evans, K., & Girdler, S. (2020). University is an emotional rollercoaster: Experiences of parents of specialist peer mentored autistic university students. *Developmental Neurorehabilitation, Under review*.

Thesis discussion

The thesis discussion (chapter 7) synthesised the results of papers I-V, explored the implications of these findings. The results and implications were also discussed in relation to the limitations of papers I-V. The general discussion provided a critique of the methods utilised

in this thesis. The general discussion contributed to this thesis by emphasising the importance of developing a partnership between mentors and autistic university students, which resulted in individualised and strengths-based approaches to managing challenges. The general discussion also served to highlight the positive impact that the SPMP had on parents of autistic university students.

Thesis methods

Table 0.2: Outline of samples and methods used throughout this thesis.

Aspect	Paper I	Paper II	Paper III	Paper IV	Paper V
Design	Focus group study	Q methodology study	Realist evaluation	Multiple methods	Interview study
Description	Structured focus groups to explore what assisted the transition to adult life for young people autistic adults	Examination of viewpoints in navigating university for autistic university students	Exploration of the contexts, mechanisms, and outcomes associated with a SPMP using interviews	Examination of the impact and exploration of participation in specialist peer mentoring for autistic university students	Examination and exploration of the impact of SPMP from the parents' perspective
Sample	N=19 parents (14 mothers) participated in four focus groups	N=57, including parents (n=12), student mentors (n=19), disability services staff (n=3) and autistic university students (n=23)	N=47, including autistic university students (n=24), and neurotypical mentors (n=23)	N=30 autistic university students. Participants completing both the questionnaires and interview component n=18. Questionnaire participation only n=7, interview participation only n=5	N=13 (11 mothers) participated in the semi-structured interviews
Data analysis	Descriptive statistics, in-vivo analysis with participants to identify meaningful units, linking to ICF, and thematic analysis of meaningful units	Descriptive statistics, by-person factor analysis, and factor interpretation.	Thematic analysis and descriptive statistics	Interpretive phenomenological analysis, paired t-tests, and descriptive statistics	Identification of meaningful units, thematic analysis, linking to ICF, and descriptive statistics

NB. Of the 166 participants, 94 participated in one study, 54 were participating in two studies and 6 were participating in three studies.

Chapter 2: Paper I-To be understood: Transitioning to adult life for people with Autism Spectrum Disorder

This chapter presents a focus group study exploring the experience of Australian parents during the transition to adulthood for their young autistic adults. Specific research objectives include identifying factors that support the transition process and unmet needs during this period. This chapter also identifies existing thoughts of parents of autistic adults on how to improve the transition to adulthood. The ICF is utilised to identify the domains best suited for interventions that could improve this transition for young autistic people.
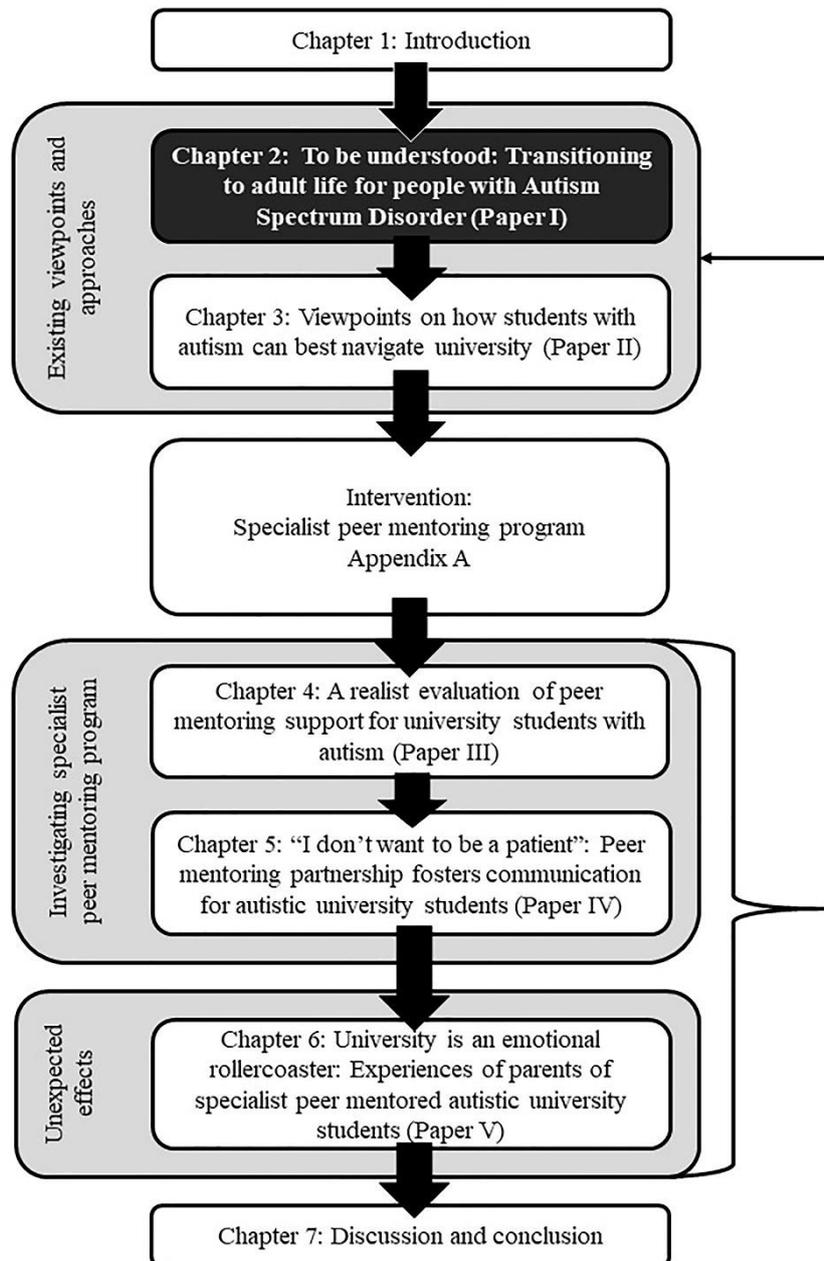
RESEARCH ARTICLE

To be understood: Transitioning to adult life for people with Autism Spectrum Disorder

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Abstract

Introduction

The purpose of this study was to explore the viewpoints of parents of young people with Autism Spectrum Disorder (ASD) in relation to their child's transition to adulthood.

Methods

Data were collected during four structured focus groups with 19 parents of young people with ASD with average to high intellectual capacities. Condensed meaning units were identified and checked during focus groups, and were subsequently linked to the International Classification of Functioning, Disability and Health (ICF).

Results

Three major themes emerged: to be understood, to understand the world and to succeed. The ICF domains of activity and participation and environmental factors emerged as having the greatest potential to influence transition outcomes.

Conclusions

Policies and services should focus on strengths to maximise participation in higher education, employment and independent living amongst young people with ASD. Interventions targeting environmental factors could be effective in improving participation in adult life. Person-centred and individualised approaches could further complement this approach supporting the transition to adulthood for people with ASD, ultimately improving outcomes in adulthood.

Introduction

Leaving school and transitioning to adulthood presents challenges for all adolescents and their families, however this can be particularly stressful period for families living with disabilities including Autism Spectrum Disorder (ASD) [1]. The estimated prevalence of ASD has been gradually increasing and is now thought to be approximately 1% across the lifespan [2, 3]. This trend is likely to continue as evidenced by the Australian context, where 75% of people diagnosed with ASD are 19 years old or younger [4]. While young people with ASD are ambitious and aspirational [5], they commonly experience poor transition outcomes including unemployment [6], limited participation in further education [7] and low rates of independent living [8], with most having few friendships [9, 10].

Poor vocational and educational outcomes are sustained across the lifespan for those with ASD with average or above average intellectual capacities [11], outcomes resulting at least in part from the limited appropriate and affordable services available to this population as they transition into adulthood [5]. Current services are constrained by funding limitations and professionals appropriately trained to work with adults with ASD [11, 12]; having been criticised for lacking coherence and evidence to support the efficacy of their interventions [13, 14]. This service environment results in many young people with ASD and their families experiencing high levels of unmet needs [5], and struggling to navigate the transition process largely by themselves [15].

Education is recognised as a basic human right [16]; in Australia equity in education has been supported by the Disability Discrimination Act (DDA) [17]. The DDA [17] has a strong focus on promotion of equity through social inclusion, and has positively impacted the education of people with disabilities[18] evidenced by the 94% increase in students with disabilities attending university since 2008 [19]. However, the DDA [17] does not mandate transition planning, a recognised gap in the current system [20], with many young people with disabilities still struggling to find clear pathways during their transition to adulthood.

Families are an integral support to their young person with ASD as they transition to adulthood [21]. Parents continue to be a major source of support and advocacy for young people with ASD even as they move into adult life [22], and focuss primarily on securing an acceptable future for their young person's life [23]. The value of familial support in improving transition outcomes is evident in its positive impact on employment post-school [24], and in the role that parental expectations play in mediating the relationship between leaving school and outcomes in adulthood [25]. However, the finding that parental expectations for transition outcomes are lower for parents of children with ASD than for parents of children with intellectual disability or multiple disabilities is cause for concern [26].

Person-centred approaches have been suggested as a means of addressing the needs of the young person with ASD during the transition to adulthood [27]. However, the development of such approaches are constrained by a lack of knowledge and understanding of the experiences, hopes and wishes of parents of young people with ASD as they transition to adulthood. This is problematic, as support services decrease as young people with ASD move into adult life [28]. The overall aim of this study was to explore the experience of parents during the transition to adulthood for young adults with ASD. Specific research objectives included identifying factors that supported the transition process and unmet needs during this period in Australia.

Method

Design

An inductive approach was utilised to gain an understanding of the experience of families of young adults with ASD in normative IQ range as they transition to adulthood [29], from here on in this article this population of interest will be referred to by the term ASD. Structured focus groups were selected as the most appropriate data collection strategy, as the group dynamics allowed parents to construct a shared understanding of the experiences, expanding on the perspectives of individual participants, and enabling coverage of a wide range of topics in an efficient manner [30]. Structured focus group method is a variant on the traditional focus group method in that it provides the participants with information to guide the discussion after commencing with an open-ended question [30]. The group process was guided using stimulus questions that focused the discussion on transition to adulthood for young people with ASD [31]. The International Classification of Functioning, Disability and Health (ICF) [32] guided data collection and analysis, as part of a directed content analysis approach [33]. The ICF is a biopsychosocial model that conceptualises the dynamic and bi-directional interaction between health conditions, activities and contextual factors [32, 34]. Education is recognised as a basic human right [16]; in Australia equity in education has been supported by the Disability Discrimination Act (DDA) [17]. The DDA [17] has a strong focus on promotion of equity through social inclusion, and has positively impacted the education of people with disabilities[18] evidenced by the 94% increase in students with disabilities attending university since 2008 [19]. However, the DDA [17] does not mandate transition planning, a recognised gap in the current system [18], with many young people with disability still struggling to find clear pathways during their transition to adulthood.

Participants

Nineteen parents of young people with ASD, including Asperger's Syndrome, were recruited to participate in four structured focus groups. Recruitment was conducted using purposive and snowball sampling, via the Autism Association of Western Australia and Autism West. Participants self-selected as a "parent of a young person (aged 18–30) with ASD". Parents required adequate English language skills to participate in a group discussion and needed to be available to attend one of the four scheduled groups. Although 21 parents initially agreed to participate in the focus groups, two parents did not attend due to other commitments.

Of the 19 parents who participated in the structured focus groups, the majority were mothers (n = 14), four were fathers and one was a step-father. Thirteen participants were partnered and they tended to have good socioeconomic status, with higher than average incomes (median = AU$80,000 –AU$100,000 per year, with a range of less than AU$20,000 to more than AU$100,000). All but two parents held university qualifications and 14 parents were in paid employment. Five of the parents were not in employment, citing their child's ASD as the reason for their lack of workforce participation.

The parents reported on 15 male and seven female young people with ASD (Table 1), with an average age of 20.1 years (*SD* = 2.0). The young people had typically received a diagnosis on average at 4.5 years of age (*SD* = 1.0) with an average overall total score on the Social Responsiveness Scale—Second Edition (SRS-2) [35] as reported by their parents of 105.04 (SD = 25.9), with a range of 31 to 144, equating to very low to severe symptomology (S1 Table). The range of results from the SRS Restricted Interests and Repetitive Behaviour sub-scale was 6–34 (mean = 20.3; SD = 6.2) and the SRS Social Communication and Interaction was 41–114 (mean = 83.7; SD = 20.8), suggestive of a range of very mild to severe symptomology. At the

Table 1. Demographic description of young adults with ASD discussed by parents in the focus groups.

Young person with ASD	Age	Gender	Employment status	Highest education	Living arrangements
1.	23	Male	Unemployed, looking for work	University education	Living in family home
2.	19	Male	Studying full-time	Post-secondary non- university education	Living in family home
3.	20	Female	Studying full-time	Post-secondary non- university education	Living in family home
4.	20	Male	Unemployed, looking for work	Post-secondary non- university education	Living in family home
5.	18	Female	Studying full-time	Secondary education	Living in family home
6.	18	Female	Studying full-time	Secondary education	Living in family home
7.	20	Male	Studying full-time	Secondary education	Living in family home
8.	20	Male	Studying full-time	Secondary education	Living in family home
9.	18	Male	Unemployed, looking for work	Secondary education	Living in family home
10.	20	Male	Unemployed, looking for work	Secondary education	Living in family home
11.	22	Female	Employed part-time (15 hours/week)	Secondary education	Living in family home
12.	20	Female	Studying full-time	Some secondary education	Living in family home
13.	20	Male	Studying full-time	Some secondary education	Living in family home
14.	18	Male	Studying full-time	Some secondary education	Living in family home
15.	18	Female	Participating in alternative employment	Some secondary education	Living in family home
16.	19	Male	Unemployed, not looking for work	Some secondary education	Living in family home
17.	21	Male	Unemployed, not looking for work	Some secondary education	Living in family home
18.	20	Male	Unemployed, looking for work	Some secondary education	Living in family home
19.	19	Male	Employed part-time (12 hours/week)	Primary education	Living in family home
20.	23	Male	Studying full-time	University education	Living in individual accommodation with support
21.	26	Male	Employed full-time	Post-secondary non-university education	Living in individual accommodation with support
22.	20	Female	Unemployed, not looking for work	Some secondary education	Living in individual accommodation without support

time of the focus groups eight of the young people had completed a university qualification, with six yet to complete secondary schooling, ten were studying full-time and three were in paid employment. Three of the young people were unemployed, but not seeking work and a further five were seeking work and one was participating in an alternative to employment programme. The vast majority (19) of the young people were living in the family home; however, two lived in individual accommodation with support and one in shared accommodation with support.

Instruments

Demographics questionnaire. A sociodemographic questionnaire was constructed based on a similar project undertaken by the Curtin Autism Research Group [36], enabling a description of study participants.

Social Responsiveness Scale-2. The Social Responsiveness Scale-2 (SRS-2) [35] was employed to gauge the severity of current autistic symptoms by proxy parent report. The SRS-2 has been widely used in clinical practice and research to quantify autistic traits demonstrating high sensitivity and specificity [37–39]. A recent study of people with ASD across the

lifespan utilised the SRS-2 to corroborate DSM-5 ASD diagnostic criteria with good convergence [40].

Procedure

The structured focus groups took place at a private clinic in the Perth metropolitan region, scheduled across four weekday evenings, lasting between two to three hours. Prior to commencing each group, parents had had no prior contact with any of the researchers. Following informed consent, parents completed the sociodemographic questionnaire [36] and SRS-2 [35]. The lead author, a researcher with psychology and occupational therapy qualifications, facilitated the focus groups. The facilitator was supported by another researcher who recorded data (key statements) into a spreadsheet and took field notes. Digital voice recorders allowed for post-hoc revision of key statements.

At the commencement of each group, parents were provided with stimulus material in both written and verbal form. The stimulus question was based on contemporary views of young adulthood proposed by Blatterer [41] and posed the question, *"Thinking about your child with ASD what would help them move into adult life?"* Parents were encouraged to think broadly about their children's transition to adulthood, encompassing leaving school, seeking employment, intimate relationships, learning to drive, changes in accommodation and self-determination in decisions. Prior to the focus groups, the stimulus material was piloted in a forum with 11 participants who had a range of personal and professional relationships with people with ASD. The question fostered initial open discussion between participants, with follow-up questions from the facilitator promoting interaction and discussion.

Data collection and in-vivo data analysis. Group discussions began with the facilitator recording keywords of the discussion on a whiteboard. Subsequently, participants added to the discussion and expanded their ideas. In collaboration with participants, meaning units raised were grouped together, with duplicates removed and units defined and condensed on a whiteboard. This strategy of expanding and then refining discussions allowed the researcher to code the condensed meaning units in-vivo with the participants. A second researcher transcribed these condensed meaning units into Microsoft Excel which were then provided to participants for member checking [42].

After a refreshment break a printed copy of the condensed meaning units was provided to each participant who were then asked to rank the three most important requirements for a person with ASD to successfully transition to adult life. Subsequently, participants were asked to rate each condensed meaning unit according to current status of the requirements for successful transition (on a 5 point scale, where 1 = poor current status and 5 = excellent current status). Participants were unaware that they would rate current status at the time they ranked the three most important condensed meaning units. The rankings and ratings were immediately entered into Microsoft Excel enabling in situ comparison and group discussion of the relative importance and status of units (see S2 Table). Participants considered whether the output was an accurate representation of the discussion and if anything had been omitted from the discussion. This process simultaneously served to identify the subcategories from focus group discussions and enable member checking, therefore increasing the trustworthiness of the data [43]. Patterns in the data of the fourth focus group supported the conclsion that saturation had been achieved, so data collection ceased [30].

Data analysis. Data analysis occurred in three stages: (1) in-vivo analysis during the focus groups (as described above), (2) coding findings against the ICF and (3) thematic analysis of the data. Secondary coding of the findings involved compiling the condensed meaning units from the four focus groups into codes and linking these to the ICF according to the process

identified by Cieza and colleagues [44]. This involved identifying the meaningful concepts within each unit, and linking it with the most appropriate code(s). For example the code "mentoring at work and study" is associated with the condensed meaning unit "having access to supports at work", which contains the meaningful concepts of "access", "supports" and "work". Hence, the ICF constructs of "interpersonal interactions and relationships, other specified (d798)", "maintaining a job (d8451)" and "support and relationships, other specified (e398)" were selected. Systematically linking the condensed meaning units to all applicable ICF constructs [44] was completed through a process of consensus between the authors. This linking process was aided by visually representing the coded meaning units in relation to ICF constructs using Microsoft Visio.

Finally, the third stage of data analysis involved thematic analysis of the condensed meaning units grouping them into themes, associated categories and sub-categories using directed content analysis [33]. This process occurred through collaboration between researchers, and involved review of the meaning units identified during the focus groups.

Ethical issues

This study was approved by the Curtin University Human Research Ethics Committee (HR 16/2014), written consent was obtained from all participants and all data have been managed as per the *Australian Code for the Responsible Conduct of Research* [45].

Results

Stage 1: Focus group in-vivo results

During the focus groups the participants raised 281 ideas relating to the potential facilitators of transition to adult life for their child with ASD (focus group median number of units = 58, range = 32–133 per group). These were distilled into 132 condensed meaning units (focus group median = 33.5, range = 28–37 per group) highlighting parents' views of the importance of activity participation for their young adults with ASD and the impact of the environment on outcomes (see S2 Table). Across all four focus groups discussions centred on the contrast between the requirements important in a successful transition and parents' perception of the current status. The key discrepancies related to community awareness of focusing on strengths (Focus Group 1—"*importance of people having a positive attitude towards people with ASD*") and equal opportunities (Group 2—"*equal opportunity to embrace ASD*" and the "*need for social supports*"; Group 4 –"*work environment with social interaction*"), along with services to facilitate success (Group 1 –"*access to information through an information centre*"). In contrast, group three overall described good current performance for the three most important condensed meaning units, which were all related to service provision ("*people who create jobs for young adults with ASD*", "*services needed to focus on the individual*" and "*higher education providers that understand our children's needs*"). The condensed meaning units and the summed importance rankings and average current performance ratings for each focus group are provided in S2 Table.

Stage 2: Linkage to the ICF

The condensed meaning units identified in the four focus groups were compiled and distilled to create 22 codes (S3–S5 Tables) that were linked to the ICF, and with 45.2% of the condensed meaning units linking with the Environmental Factors domain (Table 2), 52.0% against the Participation domain (Table 3) and 2.7% against the Body Function domain (Table 4). The focus group discussions focused on the engagement in Participation in learning and applying

Table 2. Absolute frequencies of ICF categories from the environmental factors domain and relative frequencies across all ICF domains.

ICF code	Category code description	N (%)
e430	Individual attitudes of people in positions of authority	3 (4.1%)
e355	Health professionals	3 (4.1%)
e360	Other professionals	3 (4.1%)
e325	Acquaintances, peers, colleagues, neighbours and community members	3 (4.1%)
d815	Preschool education	2 (2.7%)
e398	Support and relationships, other specified	2 (2.7%)
e590	Labour and employment services, systems and policies	2 (2.7%)
e585	Education and training services, systems and policies	2 (2.7%)
e5902	Labour and employment policies	1 (1.3%)
e585	Education and training services, systems and policies	1 (1.3%)
d820	School education	1 (1.3%)
d825	Vocational training	1 (1.3%)
d830	Higher education	1 (1.3%)
e330	People in positions of authority	1 (1.3%)
e399	Support and relationships, unspecified	1 (1.3%)
e525	Housing services, systems and policies	1 (1.3%)
e310	Immediate family	1 (1.3%)
e315	Extended family	1 (1.3%)
e5	Services, systems and policies	1 (1.3%)
e565	Economic services, systems and policies	1 (1.3%)
e570	Social security services, systems and policies	1 (1.3%)
	Total:	33 (45.2%)

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Table 3. Absolute frequencies of ICF categories from the participation domain and relative frequencies across all ICF domains.

ICF code	Category code description	N (%)
d825	Vocational training	4 (5.4%)
d830	Higher education	4 (5.4%)
d820	School education	3 (4.1%)
d8451	Maintaining a job	3 (4.1%)
d798	Interpersonal interactions and relationships, other specified	3 (4.1%)
d8451	Maintaining a job	2 (2.7%)
d815	Preschool education	2 (2.7%)
d6	Domestic life	2 (2.7%)
d7	Interpersonal interactions and relationships	2 (2.7%)
d810	Informal education	2 (2.7%)
d8	Major life areas	2 (2.7%)
d177	Making decisions	2 (2.7%)
d5	Self-care	1 (1.3%)
d940	Human rights	1 (1.3%)
d770	Intimate relationships	1 (1.3%)
d839	Education, other specified and	1 (1.3%)
d175	Solving problems	1 (1.3%)
d845	Acquiring, keeping and terminating a job	1 (1.3%)
d850	Remunerative employment	1 (1.3%)
	Total:	38 (52.0%)

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Table 4. Absolute frequencies of ICF categories from the body function domain and relative frequencies across all ICF domains.

ICF code	Category code description	N (%)
b1301	Motivation	1 (1.3%)
b1648	Higher-level cognitive functions, other specified	1 (1.3%)
	Total:	2 (2.7%)

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knowledge (d1), self-care (d5), domestic life (d6), interpersonal interactions and relationships (d7), major life areas (d8), and community, social and civic life (d9). The focus group data indicated that engagement in these major life areas could be mediated by contextual factors in the Environment, including support and relationships (e3), attitudes (e4) and services, systems and policies (e5). For example, the attitudes of friends, family, peers and people in authority was described as potentially both an enabler and barrier participation. The most relevant construct in the body function domain was mental functions (b1), which was also described as a potential mediator of participation.

Stage 3: Interpretation of findings

Thematic coding of meaning units from the focus groups data resulted in three main themes: *to be understood*, *to understand the world* and *to succeed*. These themes corresponded with the findings from the linkage of meaning units with the ICF, highlighting the importance of environmental aspects in transition. While the discussions within each focus group were subtly different, thematic coding revealed the data were captured within these three main themes.

To be understood. The theme of *to be understood* centred around parents' wishes for their children *to be understood* by their family, peers, employers, teachers and by society in general. Parents described their wish to have the strengths of their child with ASD recognised without prejudice. Parents desired that their children be afforded equal opportunities, which they believed in part were dependent on remediating environmental barriers, see S3 Table.

The theme of *to be understood* is illustrated by the following quote:

"... *employers having an understanding of autism, that is actually the trickiest bit,*"

To understand the world. The parents aspired for their children *to understand the world*, in terms of the social and institutional worlds in which they lived. Helping their children to understand the world involved preparation and support for independence and social integration are available in S4 Table. Parents referred to the mechanisms that supported their children's understanding including the value of mentors in areas of education and work. Parents reported that mentors were at times able to act as advocates for their young person with ASD, an important role particularly given their children's challenges with self-advocacy. Parents also expressed their hope that a mentor or other support person could help their young person with ASD understand the value of completing self-care tasks, such as teeth cleaning. While parents highly valued mentors they highlighted that they needed to be consistent and reliable, pointing to the negative impact of mentors changing or reneging on their commitments. In absence of a peer mentor, the advocacy role for the young person with ASD fell to parents, which was described as having a negative impact on the parent-child relationship.

Institutional supports were highly valued by parents, specifically those from schools including planning for transition early and building life skills through work experience and life skills

training. However, parents believed that further improvements would result from more individualised tailoring of the curriculum to meet the needs of their young adults, specifically through the inclusion of more social skills and daily living training.

The theme of **to understand the world** can be illustrated by the following quote:

"... *someone who knew what it was like for them following them around telling them this is what you do.... Not for the job learning, but for the social aspects...*"

To succeed

Parents expressed their desire for their young people with ASD **to succeed** and to reach their potential. The categories and subcategories associated with the theme **to succeed** are described in available in S4 Table. Parents discussed the idea that their children should be given the opportunities and supports to succeed in the areas of work and study. Parents reiterated the importance of their young person being afforded opportunities to experience success by leveraging their special interests and strengths, potentially fostering their motivation, resulting in positive experiences and building self-confidence. Parents discussed the possibility that some aspects of ASD, given the right environment and opportunities, could be harnessed and help their children to succeed.

Living arrangements were discussed at length by parents, but their definitions of 'successful' living arrangements were highly individualised. Many preferred semi-detached living arrangements, such as a "granny flat" or a self-contained studio within the family home, preferences linked with the realisation that their young person was likely to need ongoing support in their daily lives. Others described their aspirations for their child to live independently in their own homes, see S5 Table.

The theme of **to succeed** can be illustrated by the following quote:

"... *they need self-belief, self-efficacy. They are so often told what they can't do and when they get some positive feedback they feel great.*"

Relationships with the ICF.   In relation to the ICF the theme **to be understood** contributes to several areas. The majority of subcategories within this theme mapped against the domain of the *environment*. However, it also links to constructs within *body functions* and *personal factors*. The theme **to understand the world** can be mapped predominantly to the ICF domain of the *environment*. However, it also links to the ICF domains of *body function* and *personal factors*. **To succeed** links to several domains of the ICF, with the majority of the subcategories in this theme linking to constructs within the *environment* domain. It also mapped to constructs within the domains of *body functions* and *personal factors*. S3–S5 Tables outline the themes, categories and subcategories mapped according to the ICF.

Discussion

Young people with ASD predominantly live in the family home and parents continue to play a vital role in the transition to adulthood [9, 46, 47], giving credence to their perspective in understanding the transition to adulthood of young people with ASD within the normative IQ range. The perspectives of parents and adolescents' perceptions may diverge during this period, and future research should explore the views of young adults with ASD. However, it is unlikely that focus groups or interviews enable optimal qualitative data collection in this group

given their communication difficulties, as such alternative techniques such as Q-methodology should be considered [48–50]. While representative sampling and generalisation is not the goal of qualitative research, findings from this study are potentially transferable [51], as they provide an in-depth description of the perspective or parents of young adults with ASD in the normative IQ range. The authors identified three themes from the data: *to be understood*, to *understand the world* and *to succeed*. These themes have the potential to influence service design and provision for young people and parents alike.

To be understood

The theme *to be understood* highlights the belief of parents that young people with ASD are marginalised because of their diagnostic characteristics, and particularly because of their social deficits [52]. The parents suggested that this was especially problematic given that ASD does not have any physical markers, and in the absence of an intellectual disability, there was an assumption that their children required little or no assistance. The social deficits of ASD continue to have implications for an individual even if they have an average or above average IQ [53], and they require understanding from employers [54], education providers, and service providers to facilitate their full participation in society.

 To be understood encompassed participants' belief that aspects of ASD could be harnessed in a strengths-based approach, suggesting a move beyond equal opportunity to approaches which recognise the specialised skills and abilities of people with ASD. This shift in paradigm to a strengths-based approach, rather than the historical deficit viewpoint, was reiterated across the focus groups [55]. Data analysis revealed that this idea was also linked with the importance of person-centred approaches in improving outcomes for young people with ASD [56].

 To be understood highlighted the importance of maximising the person-environment fit of these young people. Flexible work practices tailored to the needs of the individual with ASD can facilitate workplace success and fit [50]. Maximising this fit includes ensuring employers and colleagues are knowledgeable of the characteristics of people with ASD, who may require accommodations such as minimising external stimuli and a workplace that is predictable and supportive [50]. The role that being understood plays in facilitating workplace success for people with ASD [50, 57, 58] is evident in the finding that while employees with ASD still require support in ASD specific workplaces it is substantially less than in open employment [57]. A holistic understanding of people with ASD should encompass the notion that many possess strengths and abilities that are advantageous in the workplace and that can be utilised in society [58, 59]. Fundamental to this understanding is recognition of individuality of people with ASD [55, 60], and the role of tailored services and supports in meeting their needs and capitalising on their strengths. While participants in this study recognised that a person-centred approach is already evident in some services [56], there is significant room for improvement.

To understand the world

The parents also recognised the bidirectional relationship between their young person with ASD and society, recognising the need for their young person with ASD *to understand the world*. This theme highlighted the challenges that young people with ASD experience with some aspects of social interaction, such as emotion recognition and symbolic communication [59]. While there has been hope that these difficulties would be in part be remediated by early intervention [61], the experience of the parents in these focus groups suggest that there is a need for life-long treatment options [62]. Peer mentoring is one possible life-long approach that provides an opportunity for a young person with ASD to learn in vivo about their

environment, avoiding the need to translate skills from training contexts to real-life [63]. Peer mentoring could potentially reduce the requirement for parents' to support their young person with ASD in some situations, positively impacting on the relationship between parents and their young person with ASD [64].

To succeed

The final theme *to succeed* was characterised by parents expressing their desire for their young person to become a successful adult, however, parents' definitions of success varied greatly. For an individual with ASD success as an adult is facilitated by finding their niche [65] and building self-efficacy through performance mastery [58, 66]. Matching the strengths and skills of adults with ASD to employment environments and tasks fosters success [57] and reduces the need for support [57], contributing to a positive employment relationship likely to perpetuate success in other life areas [50, 67].

The use of the ICF

This study demonstrated the utility of the ICF in research, providing a framework which facilitated data analysis. By elucidating the areas of greatest potential need, the ICF provides important information to researchers and clinicians on the directions for future research and intervention targets [55]. The use of the universal taxonomy of the ICF enables the data to be interpreted and utilised by various professionals and sectors. Overall, the findings from this research highlight the environment as a potential mediating factor in supporting young people with ASD in their transition to adulthood and their participation in major life areas. The holistic examination of ASD using the ICF in this study and in other projects such as the ASD core sets (53, 58, 66, 67), highlight the strengths of people with ASD. Individualised and strengths-based approaches that utilise environmental adaptation could ultimately, improve outcomes for adults with ASD (58).

The findings of this study should be interpreted with the following limitations in mind. The majority of participants were members of various Autism associations, which may have shaped their experiences. Participants were from relatively high socioeconomic backgrounds and likely to have had access to significant financial resources. Their experiences may not represent those with fewer economic resources. It should also be noted that this study did not describe the experiences of parents of people with ASD who had an intellectual disability, but rather provided an in-depth description of those in the normative range. The results also need to be interpreted with some caution as the study did not explore the viewpoints of young people with ASD. While the study sample was small, purposive sampling enabled a rich exploration of the phenomenon serving to enhance the trustworthiness of the data, specifically the transferability of the findings [68].

There is a paucity of evidence addressing the transition to adulthood for young people with ASD. Findings from this research highlight that the environment as an important factor in influencing transition outcomes. Future research should examine how the environment can be modified to facilitate success and how individuals can be guided to seek out a future which meets their aspirations. It would also be of interest to further examine how gaining employment for people with ASD can be fostered and maintained. While this study provided an in-depth description of the viewpoints of parents of young adults with ASD, a similar study should be undertaken with young people with ASD themselves and parents of youth with ASD and an intellectual disability.

Conclusion

The findings from these focus groups highlight the potential of modifying the environment as an approach in working with young people with ASD [69, 70]. Such environmental adaptations could augment other interventions for young people with ASD and ultimately serve to support their participation in major life areas. Transition to adulthood represents a critical period for young people with ASD and their families, a time when supports are needed to maximise the opportunities for young people with ASD to achieve their ambitions and participate fully in society [71].

Supporting information

S1 Table. Clinical description using the SRS-2 and age of diagnosis of young adults discussed in the focus groups.
(DOCX)

S2 Table. Focus group participant's responses to the stimulus question "Thinking about your child with ASD what would help them move into adult life?".
(DOCX)

S3 Table. The distilled quotes, condensed meaning units, codes, sub-categories and categories within the theme of *to be understood*.
(DOCX)

S4 Table. The distilled quotes, condensed meaning units, codes, sub-categories and categories within the theme of *to understand the world*.
(DOCX)

S5 Table. The distilled quotes, condensed meaning units, codes, sub-categories and categories within the theme of *to succeed*.
(DOCX)

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S1 Table. Clinical description using the SRS-2 and age of diagnosis of young adults discussed in the focus groups.

Young person with ASD	Age of diagnosis	Social Responsiveness Scale (SRS) - Second Edition		
		SRS Restricted Interests and Repetitive Behaviour	SRS Social Communication and Interaction	SRS total raw score
1.	2	13	83	96
2.	2	12	68	80
3.	5	23	105	128
4.	5	28	113	141
5.	4	22	75	97
6.	4	23	105	128
7.	6	6	31	37
8.	6	22	95	117
9.	4	20	94	114
10.	4	24	90	114
11.	6	22	74	96
12.	5	14	75	89
13.	5	18	84	102

14.	4	13	41	54
15.	5	25	114	139
16.	4	28	86	114
17.	4	20	73	93
18.	4	20	87	107
19.	4	34	110	144
20.	5	21	91	112
21.	6	21	75	96
22.	5	17	73	90
Range	2-6	6-34	41-114	37-144
Mean (SD)	4.5	20.3 (6.2)	83.7 (20.8)	104.0 (26.0)

S2 Table. Focus group participant's responses to the stimulus question "Thinking about your child with ASD what would help them move into adult life?"

Focus group 1 (n=6)			Focus group 2 (n=4)			Focus group 3 (n=4)			Focus group 4 (n=5)		
Condensed meaning unit[a]	Total importance[b]	Average performance[c]	Condensed meaning unit [a]	Total importance[b]	Average performance[c]	Condensed meaning unit[a]	Total importance[b]	Average performance[c]	Condensed meaning unit[a]	Total importance[b]	Average performance[c]
Mentors in school	2.0	1.2	Future planning		2.3	Work experience		0.0	'Granny flat' living at the family home	3.0	2.4
Mentors in life	1.0	1.5	Information about services	1.0	1.2	Supported employment services		2.2	Supported living budget		2.6
Mentors in health	1.0	1.7	Family network		3.0	Matching strengths and capabilities		3.25	Advocate	1.0	2.6
Understanding in the community	1.0	1.2	Family belief and trust		2.5	Using personal contacts and networks	4.0	1.5	Self-advocacy		2.0
Understanding in the near family	2.0	2.7	Acceptance of differences	1.0	0.8	Life skills training		2.5	Developing self-confidence	2.0	2.6
Disclosure of ASD	1.0	2.8	Social support systems	6.0	1.7	Social skills training		3.5	Understanding employer		2.6
Apprenticeships	1.0	1.5	Understanding from the employers		1.2	Specialist school environments		2.5	Mentors in life	3.0	3.0
Forward planning	1.0	2.0	Understanding from educators		1.0	Mainstream school environments		3.2	Developing independence		2.2
Ongoing planning	1.0	1.8	Adaptive job recruitment		1.2	Access to funding		2.2	Opportunity to make own mistakes		2.6
Education options	1.0	1.7	Matching interest to occupation		1.7	Access to information	2.0	2.8	Gradual independence	3.0	2.8

Tailored Government support	1.0	1.3	ASD adapted recruitment processes		1.2	Consistency is important		3.0	Foster daily living skills		2.6
Gentle staged transition	2.0	1.5	Focus on work performance		1.2	Services need to focus on the individual		2.2	Transition planning early		3.0
Information centre	1.0	1.7	Social stories for employees		1.3	Supported transition programs	6.0	3.0	Individualised services/strategies		2.4
Better knowledge in the health service	1.0	1.5	Recognizing contribution from employees with ASD	2.0	1.2	Higher education providers that understand ASD		2.2	Sex education, especially for girls		2.4
'Buddy' mentoring	1.0	2.0	Non-traditional job framing		1.3	Being proactive	3.0	3.2	Ownership of ASD		2.6
Respite	2.0	1.7	Bosses with 'no ego'		0.8	Planning for adult life early		4.5	Disclosure of ASD		2.8
Family support	1.0	2.2	Employment agencies supporting people with ASD		2.0	Inclusive planning processes	1.0	3.0	Understanding employers		2.2
Employment co-ordinator	1.0	1.8	Support person for job retention		1.7	Knowing other parents		1.8	Understanding from education providers		2.6
School involvement in the transition	1.0	1.0	Mentoring study		1.8	Having access to supports at school		3.2	Strategies to encourage emotional regulation		3.4
Role model with ASD	1.0	1.0	Mentoring work	1.0	1.3	Having access to supports at university		3.5	Contact point schools, employers		2.6

Mentor at work	1.0	1.5	Employment agencies supporting people with ASD		1.5	Having access to supports at work		2.5	Consistent services		2.0
Supervisors need to know what the problems are	1.0	1.3	'Peer-like' mentor		2.2	Information about adult services		3.2	Ongoing support/services	3.0	2.2
Be treated with respect	1.0	1.8	Not being singled out from others		1.2	Tapping into their interests	2.0	3.0	Provide hope		3.0
Government employing people with disabilities	1.0	1.2	'Equal opportunity' to embrace ASD	7.0	1.0	Employers having and understanding of Autism		3.0	Assistance to find work	1.0	2.6
Employers aware of potential of people with ASD	1.0	1.3	Targeted curriculum for ASD		1.2	Opportunities for open employment		2.8	Support in the workplace		3.0
Matching jobs with interests and skills	1.0	1.2	Matching interest to education		2.0	Consistency in service providers is important		3.5	Finding a niche to foster confidence	1.0	2.8
Positive attitudes towards people with ASD	1.0	1.3	Lifelong support for the person with ASD	3.0	1.8	Sharing the transition plan		3.2	Teaching life skills	3.0	3.0
Training for independence	1.0	1.3	Housing transition 'duplex concept'		2.0	Jobs for young adults with ASD		3.0	Support and supervision in employment	2.0	2.6

Option to live independently	1.0	1.5	Sensitivity to vulnerability from peers		1.2				Open to ideas for training – using abilities		2.6
Meeting housing/accommodation needs	1.0	1.5	Stepwise independence program	3.0	2.2				A social work environment	6.0	2.8
Support applying daily living skills	1.0	1.3	Identify motivational drives		2.7				Mentors and services		2.2
'Granny flat solution'	1.0	1.5	Facilitating decision making		2.0				A 'friend' or buddy system	2.0	2.6
Personal assistant explaining to others	1.0	1.3	Find social groups through the internet		2.0						
Full time support Government recognition	1.0	1.3	Intimate relationship information		1.2						
Centre for young adults	1.0	1.2	Financial implications		0.0						
Respite	2.0	1.7									
Support also for those outside school	1.0	1.3									

Note:

[a] Responses to the stimulus question were analysed in-vivo into condensed meaning units.

[b] Participants in each focus group were instructed to rank the three most important (3=most important) condensed meaning units or requirement for a person with ASD to transition to adult life, therefore higher ranks equate with greater importance.

[c] Participants were asked to rate each condensed meaning unit or requirement according to current performance (on a 5 point scale, where 1=poor performance and 5=excellent performance) and this was averaged to ascertain the current performance.

S3 Table. The distilled quotes, condensed meaning units, codes, sub-categories and categories within the theme of *To Be Understood.*

Theme 1: To Be Understood				
Illustrative quotes	**Condensed Meaning Unit (Focus Group Number)**	**Code** **ICF Constructs**	**Sub-category** **ICF Single Level Constructs**	**Category**
He wants to – know he can be normal. Because he is not in school. So in high school it is difficult. They don't want to be singled out.	• Not being singled out from others (2) • Sensitivity to vulnerability from peers (2) • Acceptance of difference (2)	**Not being singled out by others** • Individual attitudes of: - Friends (e420) - Acquaintances, peers, colleagues, neighbours and community members (e425)	• Attitudes (e4)	Inclusive communities
We are on the verge of something big, in the same way that equal opportunity and affirmative action and – of which they have made use of affirmative action to meet some targets. But – equal opportunity, and all the things that have surrounded that over the last 50 or 60 years or whatever – what year is it? 2014?	• Understanding in the community (1) • Understanding in the near family (1) • Disclosure of autism (1) • Equal opportunity' to embrace ASD (2) • Understanding from educators (2) • Understanding from education providers (3) • Disclosure of ASD (3) • Ownership of ASD (3)	**Equal opportunities to embrace ASD** • Human rights (d940) • Individual attitudes of: - Friends (e420) - Acquaintances, peers, colleagues, neighbours and community members (e425) - People in positions of authority (e430)	• Community, social and civic life (d9) • Attitudes (e4)	
He's been linked up to a disability employment provider… I mean he's in his second year there now, and	• Family support (1) • Personal assistant explain to others (1)	**Social support systems** • General social support services (e5750)	• Services, systems and policies (e5)	

[they] still come in because it's not just the getting of the job, it's also the maintenance over time	• Social support systems (2) • Find social groups through the Internet (2) • Social stories for employees (2) • Family network (2) • Family belief and trust (2) • Work environment with social interaction, not working alone and isolated (3) • Someone to advocate for person with ASD (3) • Self-advocacy (3) • Use personal contacts / networks (4)			
There have been mechanisms for accommodating people. Hopefully that is not being lost. I fear perhaps the university system has been driven to a profit-centred frame where even accommodating people with what might have been	• Having higher education providers that understand our children's needs (3)	**Understanding from educators** • School education (d820) • Vocational training (d825) • Higher education (d830) • Individual attitudes of people in positions of authority (e430)	• Major life areas (d8) • Attitudes (e4)	Supportive study and work environments

traditionally found some solace, can't.				
There's a lot of bosses out there that have got egos so there's a lot of bosses that feel like if somebody is "weird", it is the same as school. They don't want you. So my brother's boss is just an example – he's just a genuine, great guy. Who doesn't have an ego. He's just noticing the valuable – you know.	• Be treated with respect (1) • Bosses with no ego (2) • Employer to support self-belief (3)	**Bosses with no egos** • Individual attitudes of people in positions of authority (e430)	• Attitudes (e4)	
His boss is amazing. He recognises this and he's got an approach to managing him.	• Supervisors need to know what the problems are (1) • Focus on work performance (2) • Acceptance of difference (2) • Understanding from the employers (2) • Understanding employers (3) • Employers have an understanding of Autism (4)	**Focus on work performance** • Maintaining a job (d8451) • Individual attitudes of people in positions of authority (e430)	• Major life areas (d8) • Attitudes (e4)	

He's in a job now where the – his boss actually recognises that this guy's got some incredible memory skills.	• Employer realise the potential of people with autism (1) • Positive attitudes towards people with autism (1) • Recognising special contribution from employees with ASD (2) • Better knowledge in the health service (4)	**Recognition of special contribution of employees with ASD** • Maintaining a job (d8451) • Labour and employment policies (e5902)	• Major life areas (d8) • Services, systems and policies (e5)	Strengths focus

S4 Table. The distilled quotes, condensed meaning units, codes, sub-categories and categories within the theme of *To Understand the World.*

Theme 2: To Understand the World				
Illustrative quotes	**Condensed Meaning Unit (Focus Group Number)**	**Code** **ICF Constructs**	**Sub-category** **ICF Single Level Constructs**	**Category**
So at school, if they need to be educated, and they really want an education, and they really want to learn – but the school environment, and the education system – just chews our kids up and spits them out, and I don't think very many of them actually succeed and get through.	• Education options (1) • Targeted curriculum for ASD (2)	**Targeted ASD curriculum** • Preschool education (d815) • School education (d820) • Vocational training (d825) • Higher education (d830) • Education and training services, systems and policies (e585)	• Major life areas (d8) Services, systems and policies (e5)	Preparation for independence and social integration
We were just so impressed because of the life skill training that they [the employment agency] did with him catching buses, and taking cash from home and our accounts in order to you know, pay them at post offices and that sort of thing. Learning to catch public transport, over and over again, different routes around Perth. How to look up timetables, and I think	• Training for independence (1) • Support applying daily living skills (1) • Social Skills training/Structured social groups (1) • Intimate relationship information (2) • Teaching life skills and start early (3) • Foster practical skills - for the day to day (3) • Try for adult children to be independent in dressing, paying bills,	**Skills for adult life** • Self-care (d5) • Domestic life (d6) • Interpersonal interactions and relationships (d7) • Intimate relationships (d770) • Informal education (d810)	• Self-care (d5) • Domestic life (d6) • Interpersonal interactions and relationships (d7) • Major life areas (d8)	

that is all been very valuable for him in terms of moving into adult life, and we now work with an agency called "Interchange" and on Wednesdays they specifically still keep looking at life skills, in terms of even cooking and cleaning at home.	cleaning, washing sheets, changing clothes (3) • Teaching strategies to deal with emotional and encourage self and emotional regulation (3) • Sexual education. Need to protect our young adults, especially girls (3) • Life skills training (4)			
I've always wanted to get – have a mentor for my son… You know, had the same interests… Yeah, someone who can say 'I've been there, done that'.	• Role model with autism (1)	**Social stories for employees with ASD** • Interpersonal interactions and relationships (d7) • Informal education (d810) • Maintaining a job (d8451)	• Interpersonal interactions and relationships (d7) • Major life areas (d8)	
You are doing it right now without help so it won't work, but it is important to have other people coming in and if – and if you imagine that it should be recognised as needing lifelong support	• Lifelong support for person with ASD (2) • Ongoing support / services (3) • Communication is important for schools, employers. need to have a contact point (3)	**Lifelong support for the person with ASD** • Acquaintances, peers, colleagues, neighbours and community members (e325) • People in positions of authority (e330) • Health professionals (e355)	• Support and relationships (e3)	Supporting independence and social integration

that you need for a boy with autism, even if he is an adult		• Other professionals (e360) • Support and relationships, other specified (e398)		
I've always wanted a mentor for my son, someone to help them feel confident.	• Support also for those outside school (1) • Mentor at work (1) • Mentoring study (2) • Mentoring work (2) • Mentor in school (3) • Mentor in life (3) • Mentor in health (3) • Services / mentorship must be available (3) • Mentors at university, school, work (4) • Access to supports at school (4) • Access to supports at university (4) • Having access to supports at work (4)	**Mentoring at work or study** • Interpersonal interactions and relationships, other specified (d798) • Vocational training (d825) • Higher education (d830) • Education, other specified and unspecified (d839) • Maintaining a job (d8451) • Acquaintances, peers, colleagues, neighbours and community members (e325) • Support and relationships, other specified (e398)	• Interpersonal interactions and relationships (d7) • Major life areas (d8) • Support and relationships (e3)	
I wish there was a buddy, someone to go for a coffee with… that would build him up	• "Buddy" mentoring (1) • Peer like - cool mentor (2) • People of their own age, having a 'friend' or buddy system (3)	**Peer like - cool mentor** • Interpersonal interactions and relationships, other specified (d798)	• Interpersonal interactions and relationships (d7) • Support and relationships (e3)	

		• Acquaintances, peers, colleagues, neighbours and community members (e325)	
The school based apprenticeship with a support of an employment coordinator was working really well, it was a really gentle transition. She had the social trainers from school and an employment coordinator that checked on her.	• Employment co-ordinator (1) • Employment agencies supporting people with ASD (2) • Support person for job retention (2) • Must be supported and supervised in the employment setting (3) • Support in the workplace (3)	**Support for job retention** • Interpersonal interactions and relationships, other specified (d798) • Maintaining a job (d8451) • Health professionals (e355) • Other professionals (e360) • Labour and employment services, systems and policies (e590)	• Major life areas (d8) • Support and relationships (e3) • Services, systems and policies (e5)	

S5 Table. The distilled quotes, condensed meaning units, codes, sub-categories and categories within the theme of *To Succeed.*

Theme 3: To Succeed				
Illustrative quotes	**Condensed Meaning Unit (Focus Group Number)**	**Code ICF Constructs**	**Sub-category ICF Single Level Constructs**	**Category**
You know, her narrow interests. Very specialised, very good, very good – you know. It would be great if someone paid her to do all that.	• Job matching with interest and skills (1) • Matching interest to occupation (2) • Matching interest to education (2) • Identify motivational drives (2) • Open to ideas for training - using abilities (3) • Finding their niche and using it to foster involvement + confidence (3) • Focus and matching strengths and capabilities to environments (4) • Tapping into their interests (4)	**Identifying motivational drives** • Motivation (b1301) • Higher-level cognitive functions, other specified (b1648) • Major life areas (d8) • Preschool education (d815) • School education (d820) • Vocational training (d825) • Higher education (d830)	• Mental functions (b1) Major life areas (d8) • Services, systems and policies (e5) • Learning and applying knowledge (d1) • Support and relationships (e3) • Major life areas (d8) Services, systems and policies (e5) • Domestic life (d6) • Support and relationships (e3) • Major life areas (d8) Support and relationships (e3) • Services, systems and policies (e5) • Services, systems and policies (e5)	Planning for success
Schools need to get more involved in the students transition	• Forward planning (1) • Ongoing planning (1) • Future planning (2) • Provide hope (3) • Supported living - having a budget (3)	**Planning for adult life** • Solving problems (d175) • Making decisions (d177)	• Services, systems and policies (e5)	

	• Being proactive is important (4) • Inclusive planning processes which included people outside of the disability sector (4) • Planning for adult life early (4)	• Education and training services, systems and policies (e585)		
I certainly need to think differently about how she can make her own decisions and come to her own conclusions, and perhaps facilitate it rather than direct. So facilitating is as – there's a temptation to jump straight to this direction.	• Facilitating decision making (2)	**Facilitating decision making** • Making decisions (d177) • Support and relationships, unspecified (e399)		
The school based apprenticeship with a support of an employment coordinator was working really well, it was a really gentle transition. She had the social trainers from school and an employment coordinator that checked on her.	• Gentle staged transition (1) • School involvement in the transition (1) • Specialist School Environments (1) • Stepwise independence program (2) • Start the transition as early as possible (3) • Let them make their own mistakes up to some point - it is part of	**Stepwise independences programs** • Major life areas (d8) • Education and training services, systems and policies (e585)		Gradual progress towards success

	- learning. To their own level and steady increments (3) - Gradual independence. Foster practical skills - For the day to day (3) - Self-confidence - giving him the confidence to do it again (3) - Everyone involved knowing the transition plan (4) - Mainstream School Environments (4) - Supported transition programs that gradually withdraw (4)		
A couple of years ago, I thought the best thing we could do maybe is have [build] a duplex.	- Option to live independently (1) - Matching housing/accommodation to needs (1) 'Granny flat solution'(1) - Housing transition 'duplex concept' (2) - Granny flat living - cottage on the side. Adult children are living at home but they should live alone (3)	**Housing transitions** - Domestic life (d6) - Housing services, systems and policies (e525) - Immediate family (e310) - Extended family (e315)	

I would say, you know, you have got to have roles that can accommodate people, and as a process of selection, that doesn't rely on traditional mechanisms, because selecting someone based on interview – you are not selecting them because they are good at interviewing, you are selecting them because they are good at whatever the job is.	• Government decision to employ people with disabilities (1) • Supported employment services (1) • Opportunities for open employment (1) • Centre for young adults (1) • Assistance to find work (3) • Adaptive job recruitment (3) • ASD adapted recruitment processes (3) • Untraditional framing of job (3) • Apprenticeship (3) • Work / practical experience (4) • Having people who will create jobs for young adults with Autism (4)	**Specialised employment services** • Acquiring, keeping and terminating a job (d845) • Remunerative employment (d850) • Health professionals (e355) • Other professionals (e360) • Labour and employment services, systems and policies (e590)		
I am learning all the time as to what is available and what isn't available, because it is – it is very changeable, and – you know, it is good to have current information.	• Information centre (1) • Information about service (2) • Opportunities to gain knowledge about services for adult life (4) • Access to information (4)	**Access to information** • Services, systems and policies (e5)		Services to maintain success

[Services] meeting the individual needs of the person. *There was no funding, and I – with an Asperger's diagnosis*	• Tailored government support (1) • Full time support - government recognition (1) • Respite (3) • Consistency is important (3) • Consistency in service providers is important (3) • Consistent Services (3) • Services need to focus on the individual (3) • Tailor services/strategies to the person (3) • Access to Funding (4) • Knowing other parents (4)	**Financial implications** • Economic services, systems and policies (e565) • Social security services, systems and policies (e570)		

Parents preferred strength-based supports for the young autistic adults in their family. They also outlined that they wanted their adult autistic children to succeed in work and education. Successful completion of post-secondary education could lead to increased employment choices and opportunities to find a place in society. Given that post-secondary education could target strengths and preferences of students, it was therefore necessary to explore how autistic students best navigate and manage post-secondary education, as a next step.

Chapter 3: Paper II-Viewpoints on how students with autism can best navigate university

This chapter presents a Q-method study exploring what best assists autistic students to navigate university successfully. The aim is to identify existing viewpoints of autistic university students, their parents, and their supporters on what best supports the process of successfully managing university for autistic students.

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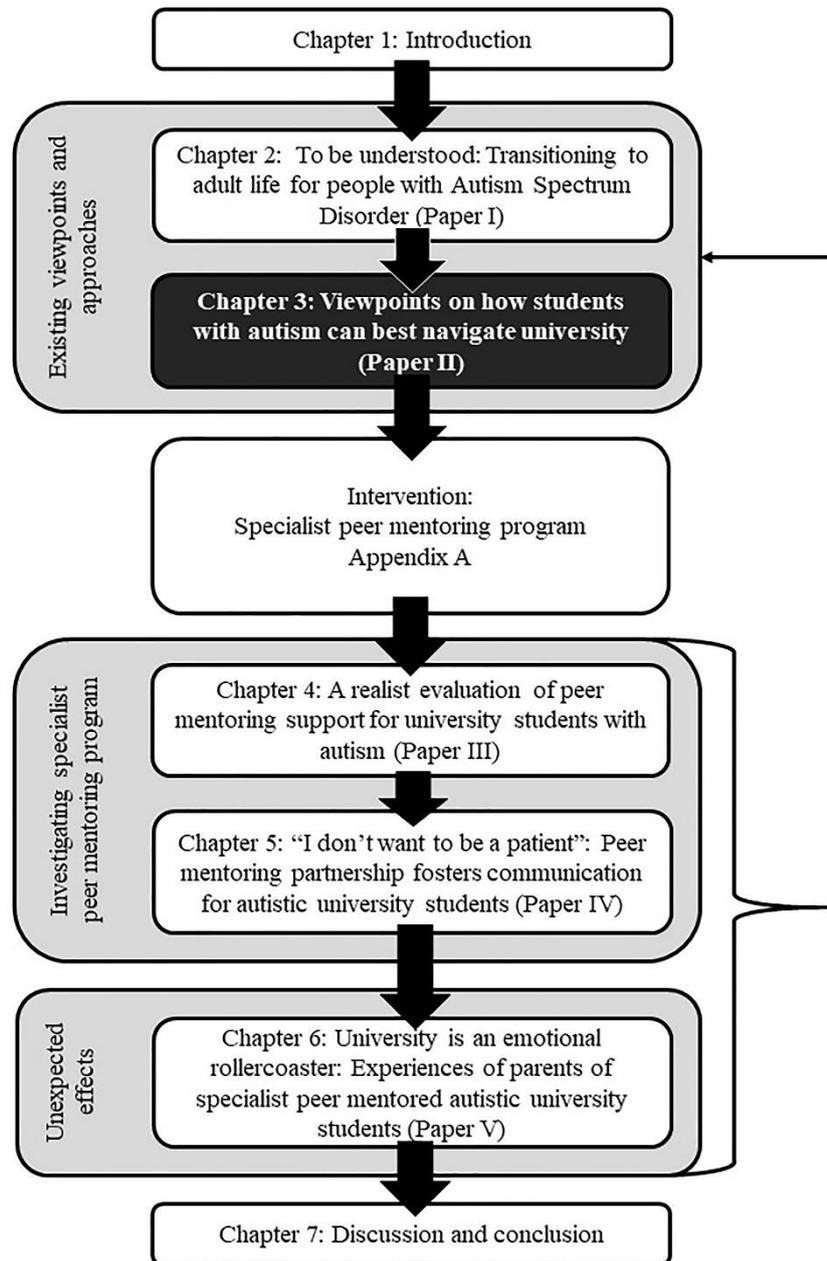
Viewpoints on how students with autism can best navigate university

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ABSTRACT

Background: Despite recognition of the challenges faced by students with autism spectrum disorders (ASD) there is limited understanding of the barriers and facilitators to participation in major life areas, such as being a university student.

Aim/Objective: This research aimed to examine viewpoints on what affects the success of Australian university students with ASD.

Material and Method: Q-methodology was used to describe the viewpoints of university students with ASD, their parents and their mentors, on success at university for students with ASD. A total of 57 participants completed the Q-sort.

Results/Findings: Three viewpoints emerged; *Individualised Support*, *Contextual Support* and *Social Support*.

Conclusions: This study highlighted that supports need to be individualized to the barriers and facilitators faced by Australian students with ASD. Supports also need to be contextualized to the built and social environments of universities.

Significance: This study supports the premise that environmental interventions can be effective in facilitating participation in major life areas, such as university education. Peer mentoring for students with ASD may have utility for this group, but should be extended to include social, emotional and psychological support.

Introduction

Students with Autism Spectrum Disorder (ASD) experience many challenges with social communication and interaction, with routinized, repetitive and restricted patterns of behavior [1] impacting negatively on quality of life [2]. These challenges are reflected in the consistently poor outcomes of this group in important life areas, such as education, employment [3] and social relationships [4]. Research in North America, UK and Sweden has demonstrated that individuals with ASD have low participation rates in further education and employment [3–8]. It is estimated that in Australia only 40% of people with ASD participate in the labor market compared to 53% of all people with other disabilities and 83% of those without disabilities [9]. Similarly, 77% of people with ASD have no post-secondary school qualifications

compared to 54% with all other disabilities and 44% without disabilities [9]. It has also been observed that few individuals with ASD live independently [6,10], with most having few friendships [6,11]. Despite wide recognition of the challenges they face there are few support services [12] and evidence based interventions targeting the needs of young adults with ASD [13]. This is particularly concerning given the unprecedented number of individuals with ASD transitioning to adulthood [14].

While post-secondary education is an effective strategy in improving outcomes for this group [15,16] university students with ASD, including those with average to high intellectual capacities, are at increased risk of not completing their course [17]. Impairments in social communication [18] and executive functioning [19] complicate adaptation to university life for these students. Universities are inherently

unstructured, with navigation relying heavily on self-management and self-advocacy skills [20,21]. When combined with limited support services [22] these stressors can contribute to poor mental health and all too frequently result in students with ASD withdrawing from university [23].

The post-school transition period is a stressful time for families as they attempt to support their family member with ASD transitioning into adulthood in an environment characterized by limited supports and opportunities [24,25]. Rigorous qualitative research enables an understanding of the lived experience of people living with ASD, with particular utility in informing the development of theory and evidence-based interventions [26]. As such the aim of the present study was to explore the viewpoints on successful navigation of university for students with ASD, from the perspectives of the students and those that support them.

Methods

Design

Due to the inherent communication challenges experienced by young adults with ASD traditional qualitative approaches to data collection, such as interviews and focus groups, can be challenging. Q-methodology employs both inductive and deductive approaches, enabling exploration of a target group's viewpoints in relation to a specific topic while minimizing the need for verbal communication [27,28]. Q-methodology has demonstrated particular utility in ASD in examining viewpoints in relation to driving [29], public transport [30] and employment [31]. This method enables the description and prioritization of viewpoints with relatively small numbers of participants [27].

Sample

Adults who self-reported to meeting one of the following criteria were invited to participate in the study: i) having met the diagnostic criteria for ASD and at some time enrolled in a course in an Australian university, or ii) experience working with a student with ASD either as a disability support worker or student mentor, or iii) being a parent of a student with ASD who had attempted university education in Australia. Purposive and snowball sampling through specialist student mentoring programs, universities, autism associations and social media recruited 57 participants from across Australia. Eight of the participants were mothers and four were fathers of university students with ASD (mean age was 53.7 years, SD =8.9). There were four male and 15 female graduate student mentors of university students with ASD (mean age was 28.3 years, SD =6.0). There were three disability services staff members (one male and two female; mean age 55.7 years; SD =2.1), and 23 students with ASD participated in the study (17 male and six female; mean age 24.6 years; SD =7.2). All participants had sufficient proficiency in English to read Q-sort statements. Table 1 outlines the participants' characteristics.

Procedure

Q-methodology follows five steps: i) developing a concourse reflecting the area of inquiry, ii) identifying the salient Q-sort statements, iii) administering the Q-sort (Figure 1), iv) by-person factor analysis and, v) interpreting the factors (viewpoints). Q-methodology studies aim to select participants in order to describe the variation between known groups [28]. In this study Q-methodology identified, categorized and revealed the viewpoints of students with ASD and their parents, mentors and support workers in relation to university environments for students with ASD.

i. Developing the 'concourse'. The concourse relating to 'the barriers and facilitators to participating in university environments for students with ASD was developed drawing from the following sources: the recent systematic review by Gelbar, Smith and Reichow (2014) on supporting students with ASD at university; an educational specialist and a psychologist with two years' experience in coordinating student mentoring programs for students with ASD; informal meetings with individuals who supported university students with ASD; and, a focus group study conducted by the authors with parents of young adults with ASD [32]. Candidate statements were reviewed by various stakeholders, resulting in the final concourse.

ii. Identifying the Q-sort statements. Employing the above concourse as a reference, statements relating to barriers and facilitators on the success at university for students with ASD were reviewed by eight neurotypical adults (all with experience in working with people with ASD) to ensure readability, interpretability and potential suitability. Following feedback these statements were again refined, and then reviewed by two adults with ASD who had

Table 1. Participants characteristics and viewpoint loading on the three viewpoints from defining Q-sorts.

	Viewpoints		
Characteristics with respect to age, gender and ASD group	1	2	3
Male, 19, student with ASD	0.6429*	−0.1277	0.1565
Male, 20, student with ASD	0.7254*	0.2897	0.2286
Male, 22, peer mentor	0.7877*	0.1306	0.2430
Female, 19, peer mentor	0.5988*	0.2939	0.1762
Male, 18, student with ASD	0.8001*	0.0911	0.0891
Female, 50, parent of a student with ASD	0.7293*	0.3247	0.3501
Female, 40, peer mentor	0.7099*	0.4358	0.0355
Male, 23, student with ASD	0.6465*	0.3391	−0.0354
Female, 42, parent of a student with ASD	0.6626*	0.3728	0.3302
Female, 51, parent of a student with ASD	0.1939	0.8395*	−0.0046
Male, 36, student with ASD	0.3805	0.6119*	0.0297
Female, 24, peer mentor	0.3232	0.7095*	0.2959
Female, 55, disability services staff member	0.3094	0.6748*	0.4068
Male, 19, student with ASD	0.4726	0.6322*	0.2348
Female. 22, student with ASD	0.1397	0.8150*	0.1313
Male, 29, peer mentor	0.2067	0.0868	0.7306*
Female, 25, peer mentor	0.3463	0.1476	0.6877*
Male, 18, student with ASD	0.3251	0.0469	0.2948
Female, 41, peer mentor	0.3241	0.2361	0.0493
Female, 54, parent of a student with ASD	0.2946	0.4371	0.2029
Female, 20, student with ASD	0.6135	0.3751	0.1804
Female, 57, parent of a student with ASD	0.4773	0.3864	0.1587
Male, 65, parent of a student with ASD	0.3805	0.3959	0.3970
Female, 28, peer mentor	0.6424	0.4466	0.2334
Male, 28, student with ASD	0.3728	0.1177	0.4859
Female. 50, student with ASD	0.0543	0.1279	0.2709
Female, 25, peer mentor	0.2433	0.4910	0.2683
Male, 48, parent of a student with ASD	0.5268	0.3502	0.4012
Male, 23, student with ASD	0.2078	0.3041	0.0821
Female, 45, parent of a student with ASD	0.5858	0.4310	2708
Female, 31, peer mentor	0.4645	0.3032	0.2625
Male, 29, peer mentor	0.4731	0.4584	0.2209
Male, 30, student with ASD	0.5205	0.2731	0.2012
Male, 25, student with ASD	0.4893	0.4706	−0.0023
Female, 22, peer mentor	0.4923	0.4570	0.3364
Female, 39, student with ASD	0.2114	0.2589	0.2324
Female, 20, student with ASD	0.0380	0.0807	0.2152
Female, 26, peer mentor	0.3276	0.3749	0.0453
Female, 23, peer mentor	0.6616	0.3220	−0.0348
Male. 23, student with ASD	0.2751	0.2806	−0.0424
Male, 24, student with ASD	0.4978	0.4285	0.0835
Male, 63, parent of a student with ASD	0.5683	0.1799	0.1601
Female, 35, peer mentor	0.5925	0.4980	0.2212
Female, 23, student with ASD	0.2273	0.3155	0.1262
Female, 72, parent of a student with ASD	0.5840	0.2945	0.2605
Female, 58, disability services staff member	0.6617	0.4234	0.4000
Male, 21, student with ASD	0.1729	0.1193	0.2474
Male, 27, peer mentor	0.4791	0.3175	0.2036
Female, 47, parent of a student with ASD	0.3373	0.4216	0.4295
Male, 28, student with ASD	0.4337	0.5817	−0.2251
Female, 20, student with ASD	0.5005	−0.0457	0.4493
Female, 25, peer mentor	0.5397	0.3522	0.2157
Female, 50, parent of a student with ASD	0.2214	0.4754	0.1711
Female, 31, peer mentor	0.1658	0.4012	0.5441
Male, 54, disability services staff member	0.6126	0.3583	0.4138
Female, 35, peer mentor	0.4635	0.1752	0.3913
Male, 22, student with ASD	0.0442	−0.1056	−0.2776

*Indicates sorts loading highly on each factor.

attended university. In order to establish content validity, all pilot participants were questioned as to whether or not they thought that any statements were missing, and if so what should be added. Following this process a set of 37 statements were identified, comprising the final Q-sort pack used in this study (Supplementary Appendix 1).

iii. Administering the Q-sort. All participants completed the Q-sort on-line (Figure 1). The participants were asked to carefully read all 37 statements, considering how much they agreed or disagreed with each statement in relation to its impact on success at university for students with ASD. Participants sorted the statements
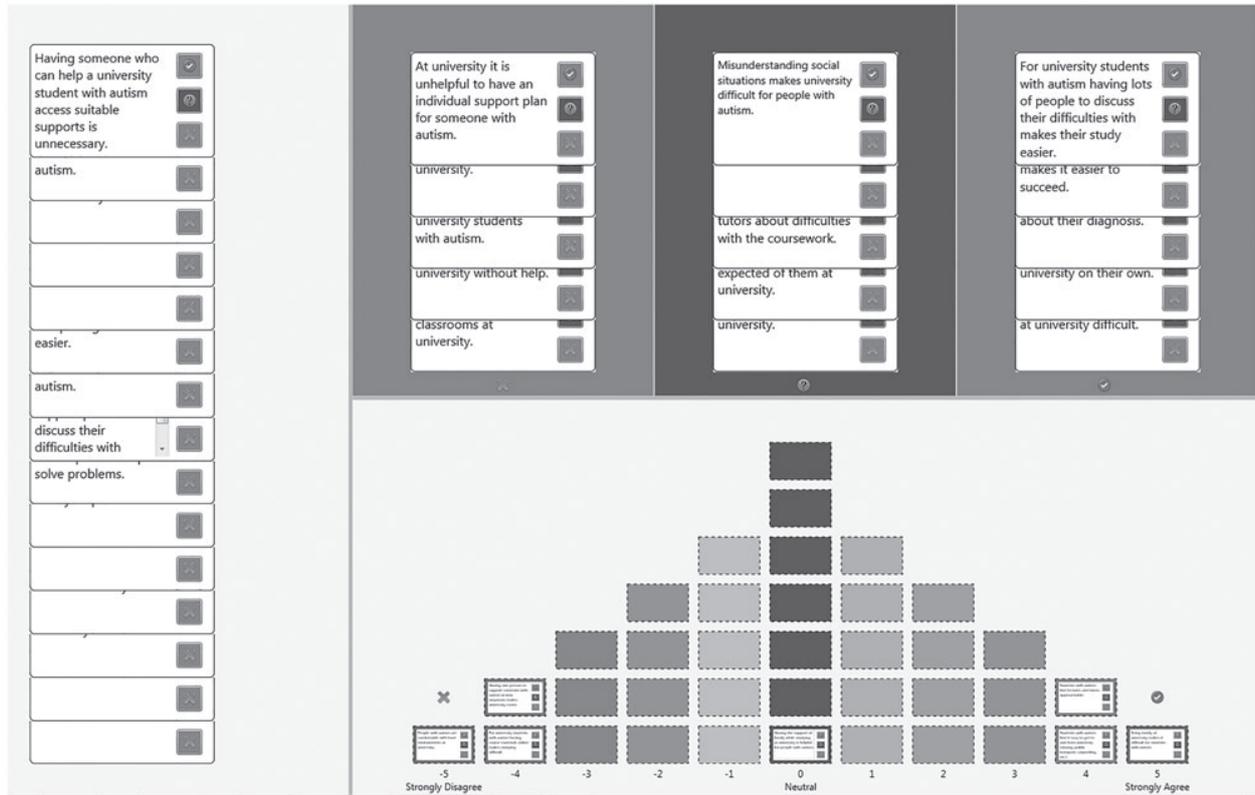
Figure 1. Illustration of how sorting the 'cards' appeared to a participant using the on-line Q-sort program, developed by Curtin Autism Research Group.

onto a normally distributed sorting grid on a continuum of 'strongly disagree' to 'strongly agree', with ranking values of -5 (strongly disagree) 0 to (neutral) to $+5$ (strongly agree). The sorting grid delineated the maximum number of statements for each rank as indicated in Figure 1. Participants were only able to place one statement in each square, with all squares needing to be filled to complete the Q-sort. It was also highlighted to participants that there were no right or wrong answers, and that they were able to move statements until they were satisfied that the Q-sort accurately represented their viewpoints. Participants were invited to propose any statement not included in the original concourse. Seven suggestions were offered.

iv. Data analysis. Q-sorts from each of the 57 participants, were analyzed using varimax by-person centroid factor analysis in the PQ Method software package [33]. The factor analysis grouped individuals, correlating individual participant's responses with those of others. Varimax rotation maximized the number of participant Q-sorts included within each factor, with resulting factors, i.e. viewpoints optimally accounting for and

representing the variance. PQ Method software detects those individual Q-sorts that significantly ($p < 0.05$) define a particular viewpoint, identifying participants who sorted the statements in a similar manner, along the agreement and disagreement continuum. It also pinpoints consensus statements, or statements which do not differ significantly across all viewpoints.

The process of selecting the statements forming the viewpoints followed a step-wise criteria, organized hierarchically in descending order of importance. The first criterion, known as the 'magic number 7', indicates that seven factors is the default number for extraction within the PQ Method [33], and the suggested starting point for analysis [28]. This approach ultimately facilitates the identification of a final set of factors that account for a substantial portion of the variance [28]. The second criterion, the Kaiser-Guttman criterion measured in eigenvalues, adheres to the rule that only those factors with an eigenvalue greater than 1.00 should be considered for inclusion [34]. In this study, five factors met this criterion. The third criterion is the acceptance of only those factors that have two or more significantly loading Q-sorts. In this study only factors one, two and three fulfilled
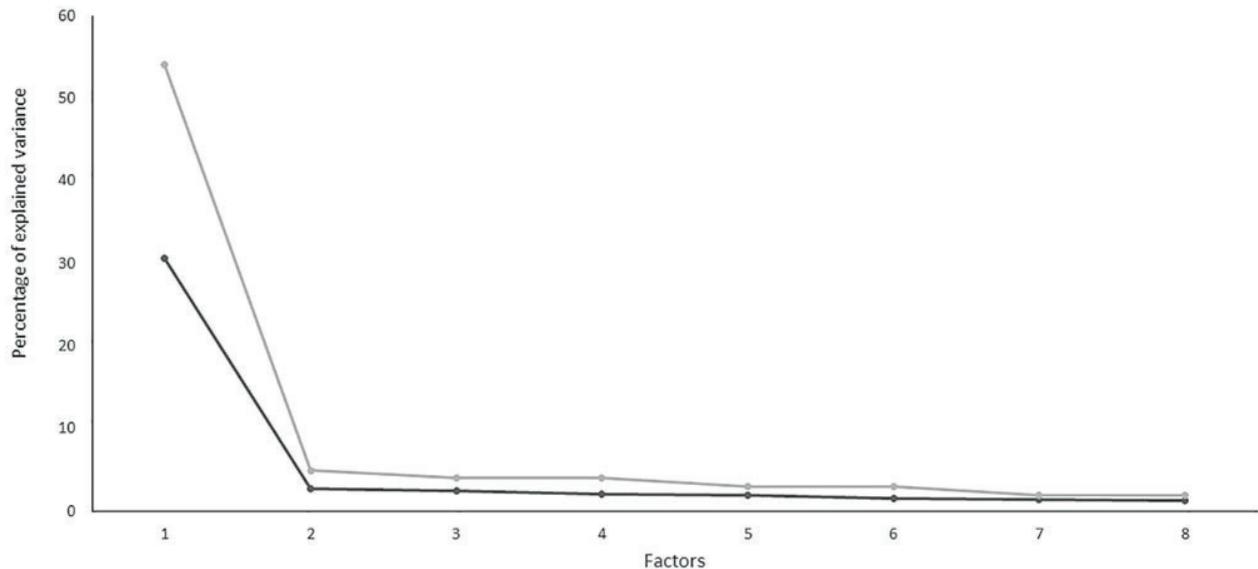
Figure 2. Screen plot of explained variance.

this criterion. As a result, viewpoints four and five were borderline and ultimately omitted. The next criteria to be fulfilled, Humphrey's rule, specifies that a factor is only significant if multiplication of the two highest absolute loadings is greater than twice the standard error [27]. In this study the standard error was 0.16, with viewpoints one, two and three meeting this criterion. Lastly, a scree plot of viewpoints was generated and evaluated in relation to the assumption that all factors displayed prior to plateauing should be retained as a viewpoint (Figure 2). While the scree plot clearly plateaued after two viewpoints, three of the viewpoints fulfilled all other criteria for inclusion, with viewpoints two and three correlating with viewpoint one at 0.6 and 0.5, respectively, essentially removing any risk of collinearity between them. Collectively these results supported the acceptance of three viewpoints, as the stepwise progression through the seven criteria determined that three viewpoints should be considered.

Factor interpretation. In interpreting the factors, each researcher independently examined the statements defining each particular viewpoint with consensus achieved through discussion regarding the naming and identification of the viewpoints.

Ethics

Informed consent was obtained from all participants prior to data collection, and all data were de-identified to ensure confidentiality. Data were securely stored on a password-protected computer at Curtin University, Western Australia. The study was approved through Curtin University Human Research Ethics committee (HR16/2014) in Perth, Western Australia. The research also conformed to the Declaration of Helsinki.

Results

Viewpoint 1: Individualised support

The *Individualised support* viewpoint was defined by nine participants representing all three groups (Table 1) and characterized by its reference to the importance of tailored supports facilitating success at university for students with ASD. Participants loading on this viewpoint indicated that working with a mentor made studying at university easier for students with ASD (statement 14: rating +5) and that it was helpful to have a support person to discuss difficulties with in relation to their coursework, or lecturers or tutors (statement 8: +4). For these participants having a single person supporting a student with ASD made university easier (statement 15: +4), including having one person to assist in accessing suitable supports at university (statement 15: −5). These participants indicated that it was important for students with ASD to meet their peers with ASD at university (statement 13: −4) and to have an individual support plan (statement 20: −4). Table 2 presents the full details.

Viewpoint 2: Contextual support

The *Contextual support* viewpoint was defined by six participants from across all participant groups (Table 1). This viewpoint was distinguishable by its

Table 2. Mean rating across participants for defining statements in viewpoint one Individualised Support (5 = strongly agree to −5 = strongly disagree).

Statements	Viewpoints		
	1	2	3
Working with a mentor at university makes studying at university easier for students with autism	5	3	3
University students with autism find it helpful to have a support person to discuss their difficulties with coursework, or lecturer or tutor	4	4	2
Having one person to support someone with autism in new situations makes university easier	4	2	2
Meeting other people with autism at university is unnecessary	−4	−1	−4
At university it is unhelpful to have an individual support plan for someone with autism	−4	−1	−1
Having someone who can help a university student with autism access suitable supports is unnecessary	−5	−1	2

Table 3. Mean rating across participants for defining statements in viewpoint two Contextual Support, strongly agree (5 = strongly agree to −5 = strongly disagree).

Statements	Viewpoints		
	1	2	3
Having the support of family while studying at university is helpful for people with autism.	3	5	1
University students with autism find it helpful to have a support person to discuss their difficulties with coursework, or lecturer or tutor.	4	4	2
Disability services at university are helpful for people with autism	3	4	−3
Students with autism find it easy to get to and from university (driving, public transport, carpooling, etc.)	0	−4	1
It is easy for students with autism to find their way to their classrooms at university	1	−4	1
People with autism are comfortable with loud environments at university	0	−5	2

emphasis on the supports that students with ASD needed to manage the university environment. Participants indicated that having the support of family while studying at university was helpful (statement 16: +5). A support person to discuss their difficulties with coursework, or lecturer or tutor (statement 8: +4), and the assistance of disability services at university (statement 2: +4) were also helpful for students with ASD. Noisy environments at university were problematic for students with ASD (statement 19: −5). The participants indicated that it could be challenging for students with ASD to locate their classrooms (statement 16: −4) and that transportation to and from university could also be a barrier (statement 24: −4). Table 3 presents the full details.

Viewpoint 3: Social support

The *Social support* viewpoint was defined by two peer mentors. This viewpoint was characterized by the supports students with ASD needed to manage relationships with staff and other students in facilitating success at university. Participants recognized that day-to-day support made studying at university easier for students with ASD (statement 9: 4), noting that peer support of students with ASD at university made completing studies easier (statement 10: 4). Participants highlighted that bullying at university potentially make studying more challenging for students with ASD (statement 4: 5). The participants indicated that meeting other students with ASD at university was necessary (statement 13: −4). Working

with other students on assignments was also seen as difficult for university students with ASD (statement 27: −4), and similarly solving problems without assistance (statement 28: −5). Participants also noted that central student services at university were not helpful for students with ASD (statement 1: −4). Table 4 presents the full details.

Consensus and contended statements

Sixteen consensus statements were identified, with no statistically significant difference in the scores across the viewpoints. Some of these statements made reference to the impact of university services such as the library, online course material and the Student Guild on the potential success of students with ASD at university. Another area of consensus related to the impact of friendships and loneliness. Statements regarding the communication skills of students with ASD were ranked negatively across all three viewpoints. Statements relating to the need for individualized support for students with ASD scored equally positively across all three viewpoints. Table 5 presents the full details.

Contended statements are those that differed the most in their scoring across the viewpoints. The contended statements for *viewpoint 1* were the statements "at university it is unhelpful to have an individual support plan for someone with autism" (−4 to −1) and "having someone who can help a university student with autism access suitable supports is unnecessary" (−5 to 2). Contended statements for *viewpoint 1* also

Table 4. Mean rating across participants for defining statements in viewpoint three Social Support, strongly agree (5 = strongly agree to −5 = strongly disagree).

	Viewpoints		
Statements	1	2	3
For people with autism being bullied at university makes it difficult to study	2	1	5
Having day-to-day support makes studying at university easier for students with autism	3	2	4
Peer support of people with autism at university makes completing studies easier	3	2	4
Central student services at university are helpful for people with autism	0	1	−4[a]
Meeting other people with autism at university is unnecessary	−4	−1	−4[a]
Working with other students on assignments is easy for university students with autism	−1	−3	−4[a]
Students with autism are able to solve difficulties that arise at university without help	−1	−2	−5

aindicates that these statements tied for the two '−4' places in the Q-sort grid.

Table 5. Mean rating across participants for consensus statements, strongly agree (5) to strongly disagree (−5).

	Viewpoints		
Statements	1	2	3
The library is easy to use for students with autism	2	1	2
University students with autism find the quiet study areas in the library helpful	2	2	2
At university it is unnecessary for students with autism to have a peer to help solve problems	−3	−2	−2
University students with autism find it helpful to have a support person to discuss their difficulties with coursework, or lecturer or tutor	4	4	2
Having day-to-day support makes studying at university easier for students with autism	2	3	4
Peer support of people with autism at university makes completing studies easier	3	2	4
The student guild at university is helpful for people with autism	0	0	0
Having one person to support someone with autism in new situations makes university easier	4	2	2
For university students with autism having course materials online makes studying difficult	−3	−2	−2
Interacting with university staff is easy for people with autism	−1	0	−1
Being lonely at university makes it difficult for students with autism	0	1	0
The communication skills of students with autism are effective for university	−1	−2	−1
University students with autism find it easy to speak to lecturers or tutors about difficulties with the coursework	−2	0	−2
It is easy for students with autism to form friendships at university	−2	−1	−1
For university students with autism having lots of people to discuss their difficulties with makes their study easier	1	0	0
For students with autism at university it helps to tell people about their diagnosis	1	0	1

pertained to social situations including "misunderstanding social situations makes university difficult for people with autism" (−2 to 3) and "for students with autism not having friends at university makes it easier to succeed" (−2 to 0). Another contended statement relating to social interaction in this viewpoint was "working with other students on assignments is easy for university students with autism" (−1 to −4). The final set of contended statements for *viewpoint 1* related to the university environment, including the statements that "central student services at university are helpful for people with autism" (0 to −4) and "people with autism are comfortable with loud environments at university" (0 to −5).

For *viewpoint 2* contended statements related to social skills and situations as indicated by the scoring of the statements that "meeting similar people at university is unhelpful for people with autism" (0 to −3) and "meeting other people with Autism at university is unnecessary" (−1 to −4). Interacting with university staff also featured in the contended statements of *viewpoint 2*, including that "students with autism find lectures and tutors approachable" (1 to −1) and "central student services at university are helpful for people with autism" (1 to −4). University study skills

were also highlighted as contended statements for *viewpoint 2* including "the time management skills of someone with autism makes studying at university difficult" (3 to 0) and "it is easy for students with autism to make decisions about university on their own" (−3 to 0). The logistical issues associated with attending university were also present in the contended statements of *viewpoint 2* including "people with autism know what to do between classes at university" (−3 to 1), "it is easy for students with autism to find their way to their classrooms at university" (−4 to 1) and "students with autism find it easy to get to and from university (driving, public transport, carpooling, etc.)" (−4 to 1). Support at university was another contended statement within this viewpoint represented by the contended statements "having someone who can help a university student with autism access suitable supports is unnecessary" (−1 to 2) and "peer support of people with autism at university makes completing studies easier" (2 to 4).

The contended statements for *viewpoint 3* referred to the available supports both on and off university campuses in the statements "having someone who can help a university student with autism access suitable supports is unnecessary" (2 to −5) and "having the

support of family while studying at university is helpful for people with autism" (1 to 5). Another area of contended statements related to university services in the items "central student services at university are helpful for people with autism" (−4 to 0) and "disability services at university are helpful for people with autism" (−3 to 4). The range of social challenges experienced by students with autism at university was also evident in the contended statements related to viewpoint 3 in the item "for people with autism being bullied at university makes it difficult to study" (5 to 1).

Discussion

The viewpoints, *individualized support*; *contextual support*; and *social support* illustrate the participants' perspectives of what is required to facilitate participation and success at university for students with ASD. All three groups defined and loaded proportionally on all three viewpoints. These results support previous research that has proposed that university students with ASD have unmet needs which if met would facilitate their completion of university [35].

Viewpoint 1, relating to individualized support, corresponds with recognition that university students with ASD require support to be successful [21]. While ASD can be recognized by a constellation of core symptoms, diagnosed individuals vary greatly with regards to their difficulties, strengths and skills. This heterogeneity means that effective support needs to be tailored and individualized [36], and while there are instances where the support needs of students with ASD align with those of other students, this viewpoint extends the concept of support to include both the academic and social aspects of university life [37]. It is likely that an individualized approach to support could capitalize on the strengths and abilities of young people with ASD.

Viewpoint 2 reflects the importance of contextual support and focuses on the uniqueness of higher education environments. While post-secondary qualifications have been promoted as a means of improving outcomes for adults with ASD, achieving these has not been realized for many [4,23]. There is a clear need for models of support specifically aimed at meeting the needs of individuals and their families transitioning from secondary school to university [3], a transition reported to be particularly challenging for those with ASD [17]. Recent research suggests that autism specific transition tools, such as the BOOST-A [38,39], if used early on during secondary school can

mitigate this challenge. While university based disability services are available and able to provide a range of supports to students with ASD, they largely rely on students instigating contact and self-advocating, behaviors which students with ASD likely find difficult [35,40].

The core social impairments associated with ASD point to the need to broaden the standard support services available to these students to include social and communication supports [21]. Attending university presents many environmental challenges for students with ASD including, in the first instance, navigating to and from university [41]. The impact of transportation as a barrier to community access for students with ASD should not be underestimated [29,30]. Once at university and in class, students with ASD are likely to encounter many sensory challenges, including loud or crowded environments, and may require assistance in managing these effectively [42].

The social communication difficulties experienced by university students with ASD highlighted in *viewpoints 1* and *2* of this study, serve to remind researchers, supporters and health professionals that people with ASD continue to be challenged by social communication into adulthood. This finding points to the need for adult services which provide individualized and contextualized support targeting these social difficulties. An approach likely to ameliorate these challenges within universities is coordinated and strengths-focused peer mentoring. As universities broadly allow students to select subject areas based on personal interests it is an environment which potentially enables students with ASD to capitalize on their strengths and special interests [43], providing opportunities for the development of greater self-efficacy [44]. Social skills training is another approach demonstrating promising results in adolescents [45,46] and adults with ASD [47], and may be effective in helping young adults with ASD to manage at university.

Viewpoint 3 highlights the challenges that students with ASD experience in negotiating complex social interactions with university students, academic and administrative staff. This is not surprising given the core deficit of social communication in ASD makes social interactions challenging, with viewpoint three highlighting that at least some of these students experience bullying at university [21]. Negative social experiences, such as bullying, may have long lasting deleterious effects on people with ASD and young adults with ASD do report high levels of dissatisfaction with their social interactions [23]. Perhaps individualized social modeling and coaching could be

utilized as a means of managing the social milieu of university, supporting improved social engagement [21,35].

The higher education sector has for many years been making 'reasonable adjustments' and implementing strategies to assist students with disabilities to manage in university environments [48,49]. While these adjustments are often available for students with ASD in response to their self-advocacy and requests for assistance [50], there is a need for supports which are proactive in encouraging students to ask for support.

Difficulties with executive functioning experienced by university students with ASD have been well documented in childhood [51,52] with recent evidence demonstrating these persist into adulthood [19]. *Viewpoints 1, 2* and *3* all point to the benefit of support from one person who has empathy and understanding of the experiences of someone with ASD [53]. This is congruent with a recent finding that 62% of parents of young adults with ASD identify mentoring as the most important unmet service need [54]. Assisting or mentoring someone with ASD to improve their social interactions is challenging [55], with support people themselves requiring opportunities for debriefing [53]. A coordinated peer mentoring program has the potential to engender a supportive environment and facilitate participation in major life areas, including being a university student [56–58]. While peer mentoring has been proposed as potentially effective in supporting students with ASD [59,60] research in this field has been hampered by poor definition of peer mentoring in higher education [61] and limited theoretical frameworks [61]. The role of a peer mentor has been proposed as a 'connecting link, peer leader, learning coach, student advocate, and trusted friend' [62,p. 130–131]. While initial peer mentoring programs have offered promise, further research is needed to understand its effectiveness in promoting greater success at university for students with ASD [63,64].

The nature of the Q-sort methodology introduces a possible limitation to this study. When conducting a Q-sort study great care is taken to ensure the concourse comprises a thorough representation of potential viewpoints, but these are inherently limited to the chosen statements [28]. In this study this was mitigated by the rigorous approach to developing the concourse and participants were encouraged to suggest any viewpoint not included in the original concourse [65]. Q-methodology operates with by-person factor analysis, not by-item, so the need for large samples is not warranted [28]. Rather, the guiding principle that the number of participants should be equal to the number of statements is adopted, with the present study far exceeding this expectation. The Q-methodology has limited ability to contrast between different groups of participants, therefore, this study cannot compare and/or contrast the views of the stakeholders. The different viewpoints that resulted from the Q-methodology are defined by participants and considering *viewpoint 3* was defined by two participants there was a potential for error. The nature of this study being conducted using the on-line Q-sort resulted in the sample self-selected students with ASD or as one of the other groups, and the results must be interpreted with this in mind.

The development of evidence-based interventions and strategies aimed at assisting university students with ASD is a clear research priority, specifically the potential efficacy of environmental interventions such as peer mentoring warrant further investigation. The approach of peer mentoring itself requires more definition in terms of theoretical underpinnings and active ingredients [61]. Future research would benefit from more a greater involvement of individuals with ASD to ensure the focus of research has increased meaning and validity for the people in question.

Conclusions

Findings from this study suggest that it would be beneficial for universities to employ individualized and strength-based approaches in supporting students with ASD, with support best provided by one person with understanding of the nuances of each individual, and extending to contextual and social supports. Interventions guided by these principles could potentially facilitate the success of students with ASD at university, ultimately improving lifelong outcomes.

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Appendix 1: Concourse statements for the Q-sort.

1. Central student services at university are helpful for people with autism

2. Disability services at university are helpful for people with autism

3. People with autism know what to do between classes at university

4. For people with autism being bullied at university makes it difficult to study

5. The library is easy to use for students with autism

6. Students with autism find the quiet study areas in the library helpful

7. At university it is unnecessary for students with autism to have a peer to help solve problems

8. University students with autism find it helpful to have a support person to discuss their difficulties with coursework, or lecturer or tutor

9. Having day-to-day support makes studying at university easier for students with autism

10. Peer support of people with autism at university makes completing studies easier

11. Meeting similar people at university is unhelpful for people with autism

12. The student guild at university is helpful for people with autism

13. Meeting other people with autism at university is unnecessary

14. Working with a mentor at university makes studying at university easier for students with autism

15. Having someone who can help a university student with autism access suitable supports is unnecessary

16. Having the support of family while studying at university is helpful for people with autism

17. Having one person to support someone with autism in new situations makes university easier

18. For university students with autism having course materials online makes studying difficult

19. People with autism are comfortable with loud environments at university

20. At university it is unhelpful to have an individual support plan for someone with autism.

21. Misunderstanding social situations makes university difficult for people with autism

22. Interacting with university staff is easy for people with autism

23. Students with autism find lectures and tutors approachable

24. Students with autism find it easy to get to and from university (driving, public transport, carpooling, etc.)

25. Being lonely at university makes it difficult for students with autism

26. The communication skills of students with autism are effective for university

27. Working with other students on assignments is easy for university students with autism

28. Students with autism are able to solve difficulties that arise at university without help

29. It is easy for students with autism to find their way to their classrooms at university

30. University students with autism find it easy to speak to lecturers or tutors about difficulties with the coursework

31. A university student with autism easily understands what is expected of them at university

32. It is easy for students with autism to form friendships at university

33. For university students with autism having lots of people to discuss their difficulties with makes their study easier

34. For students with autism not having friends at university makes it easier to succeed

35. For students with autism at university it helps to tell people about their diagnosis

36. It is easy for students with autism to make decisions about university on their own

37. The time management skills of someone with autism makes studying at university difficult

The results of this chapter indicated that autistic university students benefitted from supports that were individualised and targeted at the university context. The study also indicated that social supports were also necessary to facilitate the successful navigation of university for these autistic university students. One possible strategy that could deliver an individualised and contextualised intervention, which may also socially support these students, is a SPMP. Indeed, SPMP has increasingly been offered to support autistic university students, but it was necessary to explore how these programs work, through the lenses of autistic students and their specialist peer mentors.

Chapter 4: Paper III-A realist evaluation of peer mentoring support for university students with autism

This chapter presents a realist evaluation that examines the SPMP in university environments. This study is conducted from the perspectives of the autistic university students and their neurotypical peer mentors. It explores the contexts required for peer mentoring of autistic university students, the mechanisms that occur in peer mentoring and the outcomes of peer mentoring both for mentees and their mentors. The study also aims to inform the development of a refined program model describing the relationships between context, mechanism and outcomes, potentially informing future SPMPs for autistic university students. The study adds to the emerging evidence of the importance of the relationship in SPM.
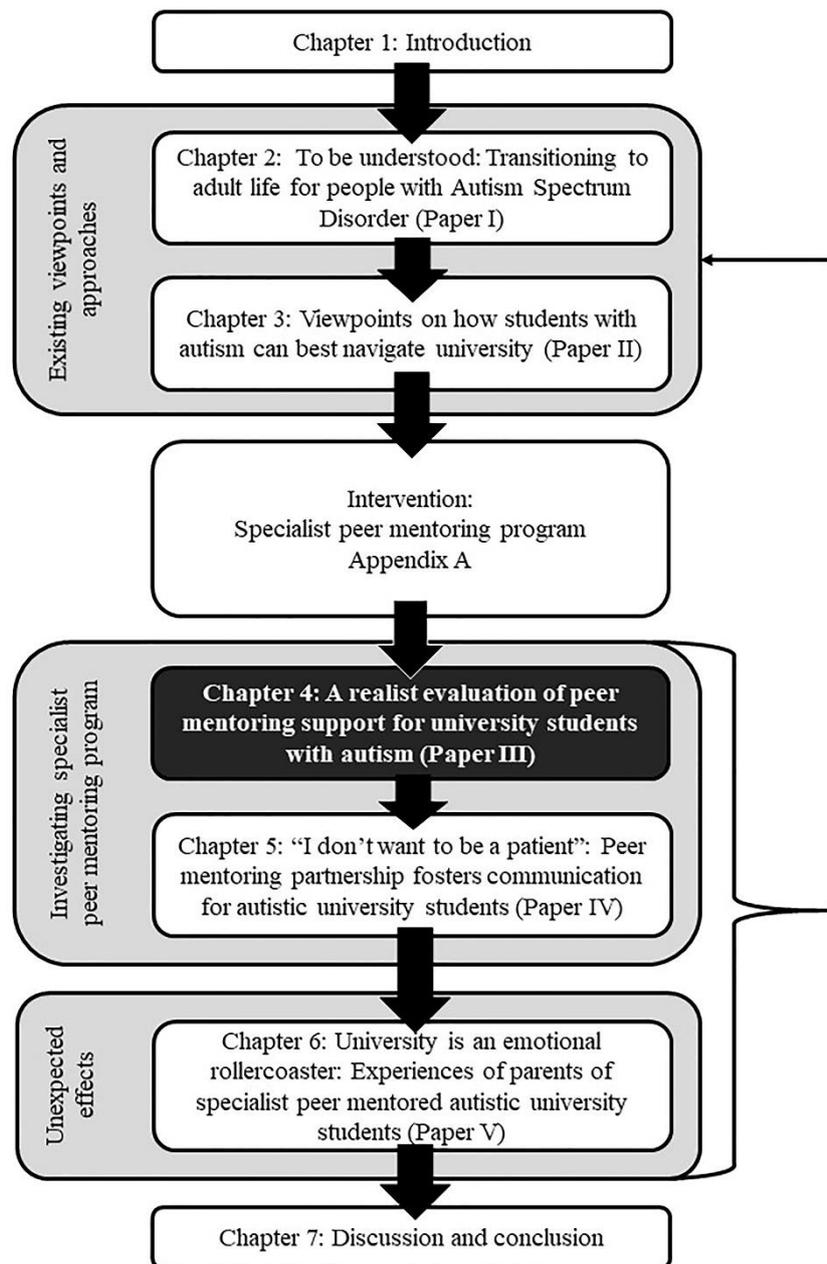
A realist evaluation of peer mentoring support for university students with autism

Craig Thompson (iD) *, Torbjörn Falkmer* (iD) *, Kiah Evans* (iD) *, Sven Bölte* (iD) *and Sonya Girdler* (iD)

Education is effective in improving outcomes in autism spectrum disorder (ASD). While peer mentoring has demonstrated preliminary promise in supporting university students with ASD, the effective mechanisms remain unclear. The aims of this study were to explore the required contexts, mechanisms and outcomes of peer mentoring for university students with ASD. Semi-structured interviews based on a Realist Evaluation framework were conducted with 23 peer mentors and 24 university students with ASD. Thematic analysis identified three context themes: 'environmental conditions', 'university course demands' and 'aspects of ASD'; four mechanism themes: 'mentor', 'communication and social interaction', 'problem solving' and 'training and supervision'; and five outcome themes: 'identifying personal strengths', 'increased autonomy', 'achieving goals', 'relationships' and 'positive mentor outcomes'. Standard peer mentoring approaches can be enhanced to meet the needs of students with ASD by including training for mentors on ASD, and approaches that support mentees' social interaction and communication needs.

Key words: **autism, mentoring, peer mentoring, university**

Education is recognised almost universally as an effective strategy for improving the quality of life of adults with autism spectrum disorder (ASD) (Howlin & Moss, 2012). ASD is a life-long neurodevelopmental condition, characterised by deficits in social communication, social interaction and

restricted or repetitive behaviours (APA, 2013). The estimated prevalence of ASD has steadily increased in recent years, largely as a result of changing diagnostic criteria (Leonard et al., 2010), such that it is now estimated to impact on one in 68 persons (Christensen et al., 2016). Paralleling the increasing completion rates of secondary or high school education (Alcorn MacKay, 2009; Autism Spectrum Australia, 2012), there is an increasing number of students with ASD enrolling in university courses (MacLeod & Green, 2009). However, while there are unprecedented university enrolments, completion rates remain low, with approximately a quarter of students with ASD withdrawing from Australian universities prior to graduation (Autism Spectrum Australia, 2012). The poor completion rates of post-secondary or university education for students with ASD is an international phenomenon, observed in North America (Eaves & Ho, 2008; Shattuck et al., 2012a) and Sweden (Cederlund et al., 2008). The lack of translation of improvements in secondary contexts to adult education outcomes is at least partly the result of a paucity of support for students with ASD in post-secondary education environments (Shattuck et al., 2012b). Standard supports at university are neither effective nor efficient in meeting the needs of students with ASD, and if completion rates are to improve this issue needs to be addressed on a systemic basis (Gelbar et al., 2014; van Hees et al., 2014).

Peer mentoring is one approach that has shown some promise in supporting university students with ASD (Ames et al., 2016; Hastwell et al., 2013; Roberts & Birmingham, 2017; Siew et al., 2017). Peer mentoring is mutually beneficial for both mentors and mentees (Jacobi, 1991). The Cooperative Research Centre for Living with Autism (Autism CRC) Specialist Peer Mentoring Program (SPMP) (McDonald et al., 2016a, 2016b, 2016c) commenced at Curtin University in Western Australia in 2014. The initial iteration of the SPMP resulted in university students with ASD experiencing high levels of satisfaction, increased levels of perceived support and a decrease in apprehension of communication (Siew et al., 2017). Following feedback from the pilot, the SPMP was manualised (Figure 1), providing a standardised approach to peer mentoring for students with ASD, with manuals now freely available from the Autism CRC website (https://www.autismcrc.com.au/). The SPMP model was underpinned by a programme co-ordinator, mentors, mentor supervision and a mentee social group (McDonald et al., 2016b). The programme co-ordinators screened mentees (students with ASD) as they entered the programme, matching them to appropriate mentors

Figure 1: Model of peer mentoring
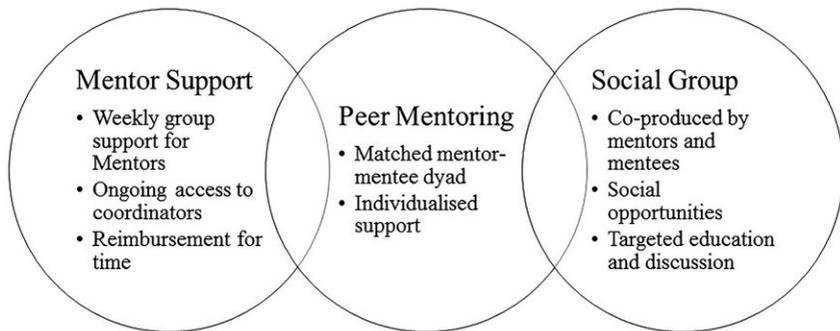
(McDonald et al., 2016a). Potential mentors were invited to apply from graduate health science courses. Potential mentors were interviewed by the programme co-ordinator, with selection focusing on academic history, communication skills, emotional intelligence and motivation to mentor students with ASD. The mentors in the SPMP were postgraduate students in the areas of psychology, speech pathology, nursing and occupational therapy (McDonald et al., 2016b, 2016c). Prior to commencing mentoring, all mentors completed a standardised training programme aimed at increasing their knowledge of ASD, building an understanding of the mentor role, understanding the mentor–mentee boundaries and exploring communication strategies (Hamilton et al., 2016; McDonald et al., 2016b, 2016c). Peer mentors received ongoing support from the programme co-ordinators in the form of one-hour weekly group supervision, providing an opportunity to debrief about mentoring, seek advice and connect with other mentors (Hamilton et al., 2016; Mavropoulou & Avramidis 2012; McDonald et al., 2016b). Mentors adopted a person-centred approach when working with their mentees (McDonald et al., 2016c; Siew et al., 2017). The programme was complemented by a weekly two-hour social group for students with ASD, facilitated by the mentors and guided by feedback from the mentees (McDonald et al., 2016a, 2016b, 2016c). The SPMP was more broadly supported by Curtin University Disability Services, providing students with access to individual counselling and individualised disability action plans, which outlined reasonable adjustments to their study programme, enabling fair and equitable access to the university (Curtin University, n.d.). A pilot

SPMP was also conducted at the University of Western Australia with the equivalent support of the University of Western Australia Disability Services (University of Western Australia, n.d.).

Understanding peer mentoring is, however, hindered by the lack of consensus on the topic in the literature (Crisp & Cruz, 2009; Jacobi, 1991). One framework suggests that peer mentoring has four key components: goal setting support, psychological support, academic support and the provision of a role model (Nora & Crisp, 2007). When incorporated within university disability services, specialist peer mentoring can be holistic, collaborative and proactive for university students with ASD, and this has been proposed as a model of best practice (MacLeod & Green, 2009). Despite peer mentoring being utilised as an on-going intervention strategy to assist students with ASD at university (Ames et al., 2016; McDonald et al., 2016b; Roberts & Birmingham, 2017); it is unclear as to what environmental contexts are required, or the mechanisms that occur within the peer mentoring relationship. As such, this study aimed to explore the contexts required for peer mentoring of university students with ASD, the mechanisms that occur in peer mentoring and the outcomes of peer mentoring both for mentees and their mentors. The study also aimed to inform the development of a refined programme model describing the relationships between context, mechanism and outcomes, potentially informing future peer mentoring programmes for students with ASD.

Methods
Design
Realist Evaluation provides a structured method of exploring the context, mechanisms and outcomes of programmes (Pawson & Tilley, 1997), facilitating the exploration of existing programmes, determining what works for whom and under what conditions, and what outcomes occur (Jagosh et al., 2016; Pawson, 2013; Pawson & Tilley, 1997). Realist Evaluation has been utilised to examine programmes working with a variety of fields such as mental health (Wand et al., 2010), addiction (Davey et al., 2014) and medicine (Williams et al., 2016). Within the Realist Evaluation framework, semi-structured interviews explored the SPMP from the perspectives of the mentees and mentors across two universities in Western Australia: Curtin University and the University of Western Australia.

Participants

A total of 47 semi-structured interviews were completed, with 24 (19 female and five male; mean age = 23.1; SD = 7.4) neurotypical peer mentors supporting university students with ASD and 23 (six female and 17 male; mean age = 28.1; SD = 5.1) university students with ASD. These interviews included 21 mentor–mentee dyads, as shown in Table 1. The university students with ASD were required to identify as being diagnosed with ASD to the respective university disability services to receive support from the SPMP. Autism symptomatology was assessed using the Social Responsiveness Scale-2 (SRS-2), with three participants scoring in the severe range, 10 in the moderate range, five in the mild range, and four below the clinical threshold (mean SRS-2 total score = 84.9; SD = 26.8). Two participants did not have useable data on the SRS-2.

Participants were recruited purposively from the SPMPs. Prior to participating in the SPMP, only eight mentors had previously worked with university students with ASD, but 12 of the mentors had previous experience of working with individuals with ASD. All of the mentors who participated in the present study were postgraduate students of occupational therapy, psychology or speech pathology. None of the mentors were diagnosed with ASD.

Procedures

Interviews explored the context, mechanisms and outcomes of the SPMP (Table 2). The interviews were recorded using a digital audio recorder and completed by two of the authors.

The interviewers were independent of the SPMP and participants were explicitly advised that participation in the interview would in no way impact on their position in the programme. Prior to data collection, all participants provided informed consent, and all data were de-identified to ensure confidentiality. Ethical approval was obtained from Curtin University Human Research Ethics committee (HR16/2014) in Perth, Western Australia. The Human Ethics office at the University of Western Australia provided reciprocal ethics approval (RA/4/1/7606).

Table 1: Description of mentors and mentees

Mentee	Gender	Age	Study-load	Mentee faculty	Mentor	Gender	Age	Previously mentored students	Previous experience working with ASD	No. of monthly meetings	University
&A1	Male	21	Full-time	S&E	&M1	Female	22	No	No	1–5	CU
&A2	Male	24	Part-time	S&E	&M2	Female	23	Yes	Yes	1–5	UWA
&A3	Male	19	Part-time	S&E	&M3	Male	29	No	No	1–5	CU
&A4	Male	19	Full-time	S&E	&M4	Female	32	No	No	1–5	CU
&A5	Female	23	Full-time	Hum.	&M5	Female	35	No	No	1–5	CU
&A6	Male	21	Full-time	S&E	&M6	Female	31	No	Yes	1–5	CU
&A7	Male	23	Part-time	S&E	&M7	Male	28	No	Yes	1–5	CU
&A8	Male	19	Part-time	S&E	&M8	Male	27	No	Yes	11–20	CU
&A9	Male	26	Full-time	S&E	&M9	Female	22	No	Yes	1–5	UWA
&A10	Male	19	Full-time	B	&M10	Female	26	No	Yes	6–10	CU
&A11	Female	22	Part-time	S&E	&M11	Female	29	Yes	No	1–5	CU
&A12	Male	21	Full-time	Hum.	&M12	Female	31	No	No	1–5	CU
&A13	Female	20	Part-time	S&E	&M13	Female	24	No	No	1–5	CU
&A14	Male	18	Full-time	S&E	&M14	Female	40	No	No	1–5	CU
&A15	Male	39	Part time	S&E	&M15	Female	26	No	No	1–5	UWA
&A16	Male	21	Full-time	Hum.	&M16	Male	26	No	No	1–5	CU
&A17	Male	18	Part-time	S&E	&M17	Female	23	No	Yes	6–10	CU

(*Continued*)

Mentee	Gender	Age	Study-load	Mentee faculty	Mentor	Gender	Age	Previously mentored students	Previous experience working with ASD	No. of monthly meetings	University
&A18	Female	20	Full-time	Hum.	&M18	Female	23	No	No	1–5	CU
&A19	Male	26	Full-time	S&E	&M19	Female	32	No	No	1–5	CU
&A20	Male	18	Full-time	S&E	&M20	Male	22	No	No	1–5	CU
&A21	Male	18	Part-time	S&E	&M21	Female	24	Yes	No	1–5	CU
					^M22	Female	23	Yes	Yes	1–5	CU
					^M23	Female	26	Yes	No	6–10	UWA
					^M24	Female	35	Yes	No	1–5	UWA
#A22	Female	26	Part-time	Hum.							CU
#A23	Female	50	Part-time	HS							CU

Notes: &=matched mentor–mentee dyad, #=unmatched mentee, ^=unmatched mentor. B = Business, HS = Health Science, Hum. = Humanities, S&E = Science and Engineering, CU = Curtin University, UWA = University of Western Australia

Table 2: Topics included in the semi-structured interview

Interview topics
Expectations of being involved in the Specialist Peer Mentor Program (SPMP)
Logistics of mentor–mentees working together
What issues or topics were discussed during the mentor–mentee meetings?
What role did the social group play in the SPMP?
How did the meetings change over time?
What were the outcomes of being involved in the SPMP?
Performance rating of the SPMP

Data analysis

Interviews were transcribed verbatim and imported into NVivo 11 (QSR International Pty. Ltd., 2017) for systematic coding, with data initially coded into broad categories based on the Realist Evaluation framework (Vaismoradi et al., 2013). The context of the programme was considered anything that was present prior to the programme's commencement, including aspects of the person, available services and the environment (Pawson, 2013; Pawson & Tilley, 1997). The mechanisms considered all aspects of the programme that acted upon the mentees; and the outcomes were the expected or unexpected consequences of mechanisms in a particular context (Pawson, 2013; Pawson & Tilley, 1997). Thematic coding was completed in relation to each of the context, mechanism and outcome categories. The relationship between the contexts, mechanisms and outcomes were subsequently identified and organised, capturing the themes of the programme. The coding was completed by one of the authors and a researcher independent of the research team, with discrepancies resolved via discussion. An example of the coding procedures is presented in Table 3.

Results

Data analysis generated 10 context codes, 18 mechanism codes and 10 outcome codes. Thematic analysis resulted in the three context themes, four mechanism themes and five outcome themes depicted in Figure 2. The presentation of results first outlines the contexts relevant to the mechanisms within the programme; second, the mechanisms that were utilised within the context; and finally, the resulting outcomes.

Table 3: Procedure of distilling quotations into themes

Quotation	Realist evaluation component	Theme
'He started to become more independent, some of the things that he was doing like assignments for instance, I didn't have to check what assignments he had due. *I just needed to ask him, "What have you got due in the next week or so, or next week or two?"* And he would tell me like, he's got a six-page report to do or he's got a two-page essay to do and things like that. So that kind of gave me the idea that he was starting to be **more independent and taking sort of ownership of what he needed to do**'. (Mentor)	Context • assignments	University course demands
	Mechanism • *I just needed to ask him, 'What have you got due in the next week or so, or next week or two?'*	Problem solving
	Outcome • **He started to become more independent**	Increased autonomy

Contexts

Contexts were comprised of three themes: 'environmental conditions', 'university course demands' and 'aspects of ASD'.

The 'environmental conditions' of universities are designed to meet the needs of and engage the majority of students with design features that promote social opportunities. Consequently, environments such as *'[the student] Guild area [is] busy… [with] big crowds of people'* and *'the library is loud'*. These environments are inherently challenging for students with ASD. Curtin University has an enrolment of approximately 60,000 students and the University of Western Australia 24,000 students. The physical size of these campuses and the sheer number of students represent a significant challenge for mentees. Managing change and coping with new 'environmental conditions' challenged mentees, who reported *'new things'* as *'freaking [them] out'*. A mentor commented, *'He doesn't like too much noise around him, so the library and everything is a bit too much, and there's too much going on'*.

The context of 'university course demands' referred to the impact of the demands of education activities on students with ASD related to the range,

Figure 2: The configuration of contexts, mechanisms and outcomes in the Realist Evaluation of the Specialist Peer Mentor Programme
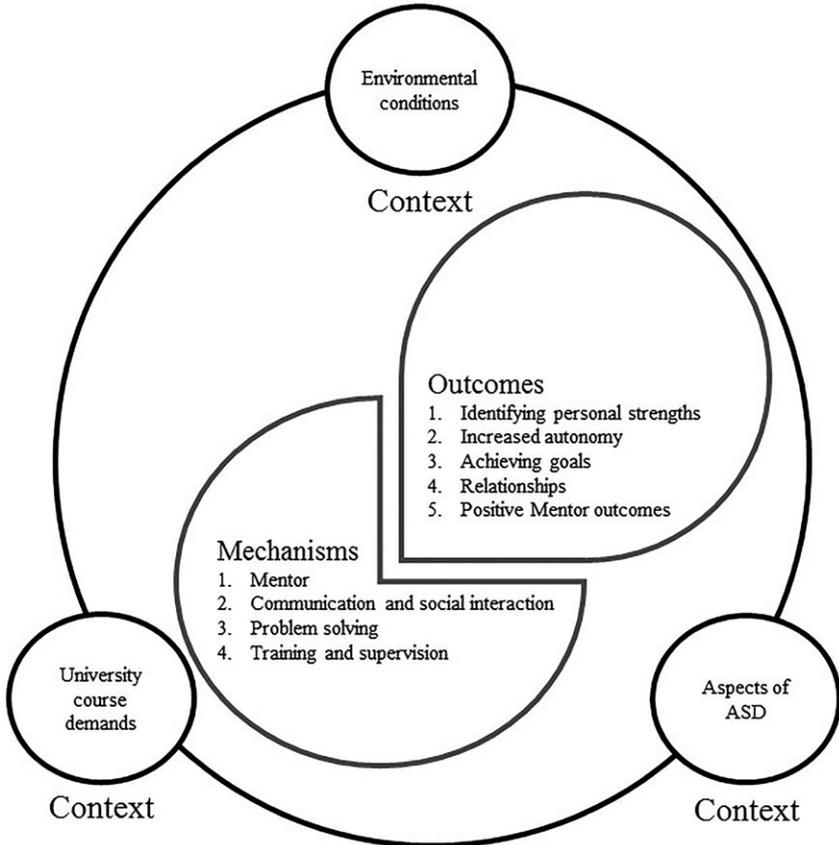
volume and level of difficulty of tasks. The mentees and mentors described students with ASD as having *'difficulty managing the assignment load'* of their courses. Mentees expressed difficulties in *'adapting to university'* teaching styles and processes, which did not match their *'learning abilities'*. The relatively high number of *'group assignments'* at university created particular challenges for mentees, including difficulties communicating with other students, and peers *'taking advantage of mentees'*, with peers pressuring them to do the *'lion's share'* of the assignment:

> *'In terms of groups … one mentee was being taken advantage of [with workload], this happens quite often and it's about trying to manage them wanting to be accepted in a group with what's fair.'*
>
> (mentor)

The *'aspects of ASD'* context referred to the common challenges experienced by the students with ASD. Many of these were individualised and associated with *'family relationships'*, *'loneliness'*, a *'family history of anxiety'*, *'transportation to university'* and *'planning [university] work'*. Family was reported by the participants as either being *'supportive'*, or as putting *'extra pressure on [mentees]'* through *'expectations'*. The mentees talked of their hopes to manage their academic and social anxiety *'concerning university'*. Mentees reported feeling lonely, describing their previous difficulties in forming friendships and feeling alone, resulting in them wanting to avoid attending university. In the words of one mentee, *'I didn't really want to be a part of the university community'*.

Transportation to and from university was a barrier to attending university. While some mentees circumvented this by living on or near campus, others struggled with the challenge of travelling long distances to campus. Transportation challenges related to executive functioning, including *'planning bus routes'* on public transport and *'the anxiety of driving alone'*. For many mentees the challenge of *'planning'* and *'organising'* their studies was overwhelming. One mentor stated, *'[H]e did have good organisational skills, and had the strategies in place, but he had trouble executing them, because of his anxiety'*.

Mechanisms
Mechanisms were comprised of four themes: 'mentor', 'communication and social interaction', 'problem solving' and 'training and supervision'.

The 'mentor' was identified as a core mechanism facilitating engagement in the SPMP. The mentors described a deliberate process of developing a relationship and rapport with their mentee. They described altering their communication style by being more *'concrete'* and literal, especially at the beginning of their relationship with their mentee. Mentors also used the strategy of focusing on special interests of their mentee and this was recognised by the mentees:

*'We used to talk about [my special interest of] art in the beginning.
We talked about a bunch of things, like food – we talked about family.
Yeah, we just talked about life.'*

(mentee)

'Communication and social interaction' was a mechanism identified by mentors and mentees, facilitating the development of the social skills necessary for university, such as *'how to start conversations'* and how make *'small talk'*. The SPMP social group provided a safe space for mentees to experiment with social skills in a *'safe'* and *'non-judgemental'* environment. These social skills could then be tested and generalised within the broader university environment.

'Problem solving' was discussed by mentors and mentees alike as a strategy facilitating participation in university studies and in overcoming organisational barriers. 'Problem solving' was underpinned by the executive functioning of mentees and included planning and prioritisation strategies, such as *'timetables'* and *'calendars on their laptop or phones'*. Strategies translated to other aspects of the mentees' life:

'[W]e spent two sessions programming events into his phone and teaching [mentee] how to do that, so we did every regular event like a lecture. … so that he had time to organise himself and then come to the lecture and since we did that … [and then] for irregular meetings, like doctor's appointments … he really liked that, and said it was working.'

(mentor)

'Problem solving' executive functioning challenges, such as time management, also reduced the mentees' stress levels at university. Mentors and mentees developed specific stress management strategies within the mechanism of 'problem solving' to manage anxiety. Mentees described working with their mentors on *'coping strategies'*, including *'deep breathing'* exercises and other psychological strategies. Some mentees also described how their mentors helped them to develop skills to make tasks more manageable, such as *'break[ing] it down into easier parts'*.

'Problem solving' options were sought beyond the mentor–mentee partnership, decreasing reliance on mentors. Mentors and mentees noted the

value of accessing carefully selected services within the broader university to manage some of the barriers to participation:

> *'We are forever looking up different things that Counselling and Disability Services offer, all the different courses and things like that. [The mentee] has done [the] time management workshops … every now and then we have a look and see what's going on and see what might be relevant to him and tell him about it.'*
>
> (mentor)

Mentors and mentees recognised that environmental challenges also required 'problem solving'. Mentors reported tailoring suggestions to manage the study environment to the individual mentee, such as *'if [they] are used to working in a group, to work together to study'* or *'studying in a quiet place, where [they were] not getting distracted'*. Mentors and mentees recognised that busy environments could not always be avoided on campus, and that mentees needed to learn to manage. 'Problem solving' was also utilised to help desensitise students with ASD to *'big crowds of people'*.

The mechanism of 'training and supervision' was identified solely by the mentors with reference to the structure and support within the SPMP. The mentors reported that the initial training was essential in helping to *'set [their] mind at ease'* in working with their mentees. The mentors also indicated that the ongoing support and supervision from the programme was valuable:

> *'heaps of supervision and help, [the co-ordinators] could not be more supportive if they tried. I can't think really what else they could possibly do'*
>
> (mentor)

Outcomes
Outcomes were comprised of five themes: 'identifying personal strengths', 'increased autonomy', 'achieving goals', 'relationships' and 'positive mentor outcomes'.

Mentors noted that as the SPMP progressed, the mentees were 'identifying personal strengths'. This was a powerful outcome, contributing to all other

outcomes relevant to the mentees. This outcome resulted in mentees developing self-confidence, potentially impacting of major areas of life beyond university. In the words of one mentee, *I finally managed to feel comfortable and I've really come to terms with what my current capabilities are'*.

As mentees grew in confidence, they developed 'increased autonomy' and decreased reliance on their mentors. Mentors described how mentees developed *'independence'* in managing the challenges related to their studies and reported that mentees increasingly provided their own suggestions for managing problematic assignments or other issues.

'Achieving goals' referred to individuals' mastery experiences, which occurred for mentors and mentees as a result of their participation in the SPMP. These achievements included improved study outcomes, improved results and the completion of studies.

> *'Improved time management has helped with my academic performance. I've been able to get in several assignments I feel I wouldn't have handed in if I hadn't been helped with time management [by my mentor].'*
>
> <div align="right">(mentee)</div>

The development of 'relationships' was a particularly positive outcome. Mentees described how they developed relationships with their peers at university as a result of the SPMP.

> *'I always used to arrive ten or fifteen minutes early for class ... So there was always a good chance that someone else [would be] arriving early for a class, so if I could hold a conversation with them for ten minutes, and then participate with them in an activity during my tutorials, then – I was improving. I would make friends … last year, I added … about six friends to my Facebook.'*
>
> <div align="right">(mentee)</div>

> *'Relationships' also developed between the mentors and mentees. Mentees recognised this relationship as a working friendship, which over time became more relaxed and natural. The mentors also recognised that this relationship developed as an outcome of the SPMP and they 'enjoyed their [the mentees'] company'.*

The 'positive mentor outcomes' were identified solely by the mentors. Mentors noted that being involved in the SPMP added to their study demands, but their involvement in the programme was positive. Mentors grew personally and became more *'empathetic'*. Mentors described gaining experience working with *'other health professionals'*, experiences seen as invaluable to their professional development. Finally, mentors recognised that involvement with the SPMP resulted in greater *'insights into autism'*.

Discussion

The voices of the mentors and mentees examined through the Realist Evaluation clearly identified the 'environmental conditions' as a key context for the SPMP. Post-secondary students with ASD continue to experience barriers to their participation in many major areas of life, including education (Shattuck et al., 2012a). These barriers continue even though universities offer supports to students who require them. Parents of young people with ASD believe they need to understand the world better in order to succeed (Thompson et al., 2018a). The results of the present study suggest that this is difficult in the university context, a complex environment with many social and environmental challenges for young people with ASD (Knott & Taylor, 2014). Barriers including the demands of studies, the need to self-advocate (van Hees et al., 2014), negative societal attitudes and the complex social environment of university result in universities being particularly challenging for students with ASD. This, coupled with universities' inherent reliance on autonomy and self-advocacy, undoubtedly contributes to the high rates of withdrawal observed among university students with ASD (Costley et al., 2017). However, this study suggests that interventions such as peer mentoring, which help in developing 'soft skills' for university and work, help to improve outcomes for these students (Siew et al., 2017).

Parents have indicated that a lack of understanding of the abilities of and challenges facing their young people with ASD has a detrimental impact on their opportunities to participate in major areas of life, such as education (Thompson et al., 2018a). The present study suggests that when these abilities and challenges are recognised, and interventions are targeted towards individual needs, education outcomes can be improved. 'Training and supervision' within the SPMP enabled the mentors to understand the mentees more effectively (Hamilton et al., 2016), facilitating the mechanisms of individualised 'problem solving', including recognition of the difficulties associated with executive functioning. The inherent social communication challenges experienced by students with ASD can be a barrier to

being understood in education settings (van Hees et al., 2014). However, within the SPMP the mechanism of the mentor facilitated this understanding as a consequence of training and their willingness to engage with their mentee (Cai & Richdale, 2016; Hamilton et al., 2016). The 'communication and social interaction' mechanism further contributed to students with ASD being understood, resulting in the outcome of 'relationships' within the mentor–mentee dyad. This also enabled the successful management of the university environment. Students with ASD benefit from being understood as individuals and from strategies tailored to their individual needs (Thompson et al., 2018a). As demonstrated in previous studies, the strategies used within the SPMP assisted university students with ASD to develop social competence within the education setting (Bradley, 2016).

Just like their peers, university students with ASD aspire to succeed and complete their university studies (Costley et al., 2017). This desire to succeed in major areas of life, such as education, is also voiced by parents of young people with ASD (Autism Spectrum Australia, 2012). The university system presumes that students are able to navigate the university environment autonomously, relying on students to disclose their diagnosis of ASD to university services. However, self-advocacy is particularly challenging for students with ASD (van Hees et al., 2014), who may be confronting disclosing their diagnoses for the first time themselves (Cai & Richdale, 2016). University students with ASD may be reluctant to disclose their diagnosis as a consequence of the fear associated with previous experiences of bullying in education settings (Costley et al., 2017; van Hees et al., 2014). While students with ASD might be pragmatic, disclosing their diagnosis to qualify for supports, they are unlikely to do so with their peers (Cox et al., 2017). The SPMP has demonstrated that students with ASD are indeed able to participate in university studies with increased autonomy, with the appropriate individualised supports. While further research is required, it is likely that these positive experiences will underpin the achievement of academic and social goals, resulting in more students completing university degrees (Thompson et al., 2018a).

Further scrutiny of the mechanisms utilised in the SPMP highlights the importance of individualised supports. The SPMP intervention has the potential to provide strategies that are tailored to the specific needs of students with ASD, aligned to their course demands and their unique constellation of symptoms of ASD (van Hees et al., 2014). The present study has demonstrated that peer mentoring should also be tailored to the specific contextual

demands of university (Thompson et al., 2018b). Peer mentoring is inherently a social support, which assists students with ASD to develop their social communication skills (Bradley, 2016). Findings align closely with results of previous research in which young people with ASD, their parents and supporters of autistic university students provided their viewpoints on how university students with ASD can navigate university most effectively; it was suggested that supports should be individualised and contextualised to university, and should include social supports (Thompson et al., 2018b).

While peer mentoring has been widely employed within the university sector to support new students (Cornelius et al., 2016) and students from minority backgrounds (Vickers et al., 2017), research has failed to keep pace with these evolving approaches (Gershenfeld, 2014). The development of peer mentoring programmes for students with ASD is underpinned by dual issues of the paucity of research aimed at understanding the most effective approaches to peer mentoring, and understanding of how best to support students with ASD in university environments. While the SPMP had all of the components of a 'standard' peer mentoring programme, it also had unique mechanisms that fostered the participation of students with ASD, as presented in Figure 3. The mechanism of 'communication and social interaction' in the SPMP is unique when compared to 'standard' peer mentoring, and this can effectively facilitate the outcome of developing relationships for students with ASD. The mechanism of 'training and supervision' is also unique, allowing for individualised problem-solving mechanisms and fostering communication and the social interaction of university students with ASD (Hamilton et al., 2016). The unique outcomes for the SPMP compared to 'standard' peer mentoring are the development of relationships both within the university context and beyond. These unique mechanisms resulted in students with ASD identifying their personal strengths. The final unique outcome was the positive experiences for the mentors, as they developed skills applicable to their future careers in health services (Hamilton et al., 2016). Collectively, these elements, outlined in Figure 3, underpin an ASD-specific peer mentoring programme.

This study had a number of limitations. While this study explored the SPMP in a purposeful fashion, it did not empirically quantify the outcomes for the students with ASD. Future research should evaluate the empirical changes that paralleled the positive experience of the SPMP by students with ASD at university. Further exploration of the environmental factors, particularly support and other relationships beyond those of the peer

Figure 3: Delineation of standard peer mentoring and specialist peer mentoring for students with ASD
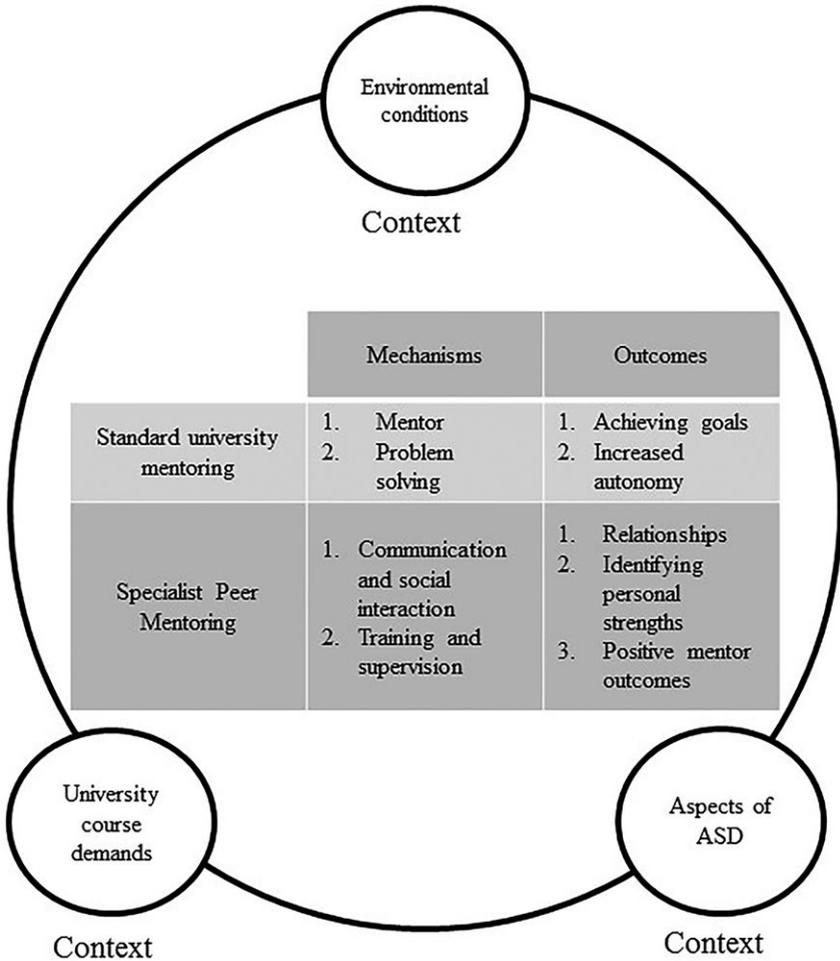
mentor, which facilitate the participation of university students with ASD, is also required. Given that parents are a major source of ongoing support for students with ASD it would also be beneficial to understand their experience of their young person's involvement in the SPMP.

Conclusions

This study has effectively demonstrated the links between the contexts, mechanisms and outcomes associated with the SPMP. The contexts that suggest a SPMP would be required were 'environmental conditions', 'university course demands' and 'aspects of ASD'. The mechanisms required for an effective SPMP were the 'mentor', 'communication and social interaction', 'problem solving' and 'training and supervision'. These mechanisms led to the outcomes of 'identifying personal strengths', 'increased autonomy', 'achieving goals', 'relationships' and 'positive mentor outcomes'. Programmes such as the SPMP have the potential to improve the outcomes of young people with ASD, supporting them in achieving their goals in major areas of life, such as education.

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Conflicts of interest

Sven Bölte discloses no financial or conflict of interest related to this article. Sven Bölte discloses that he has in the last five years acted as an author, consultant or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Ability Partner, Kompetento, Expo Medica and Prophase. He receives royalties for text books and diagnostic tools from Huber/Hogrefe, Kohlhammer and UTB. All authors declare that they have no potential or competing conflicts of interest.

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This chapter highlighted that SPMPs need to be designed to be congruent with the environmental conditions of university, university course demands, and the different facets of ASD. This chapter also identified that the mentor, communication and social interaction, problem-solving, and training and supervision, were all key to effective SPMPs. It outlined the outcomes for the autistic students associated with SPM as identifying their personal strengths, increased autonomy, achieving goals, and relationships. The chapter identified the positive mentor outcomes associated with the SPMP. However, this chapter did not quantify the outcomes and impact of SPM on the social communication deficits of autistic university students. It is also did not fully explore what the specific active ingredients driving the outcomes of SPM were.

Chapter 5: Paper IV-"I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students

This chapter presents a multiple methods study that examines the effects of SPM on the social communication deficits of autistic university students. This chapter also seeks to identify the active ingredients of SPM. Therefore, the aim of this study is to explore the experiences of undergraduate autistic university students participating in SPM, to identify active ingredients in the peer mentoring process and to examine the impact of SPM on social communication. The chapter identifies preliminary evidence indicating the efficacy of SPM on improving social communication for autistic university students. The results provide a deeper understanding of how SPM improves outcomes for autistic university students.
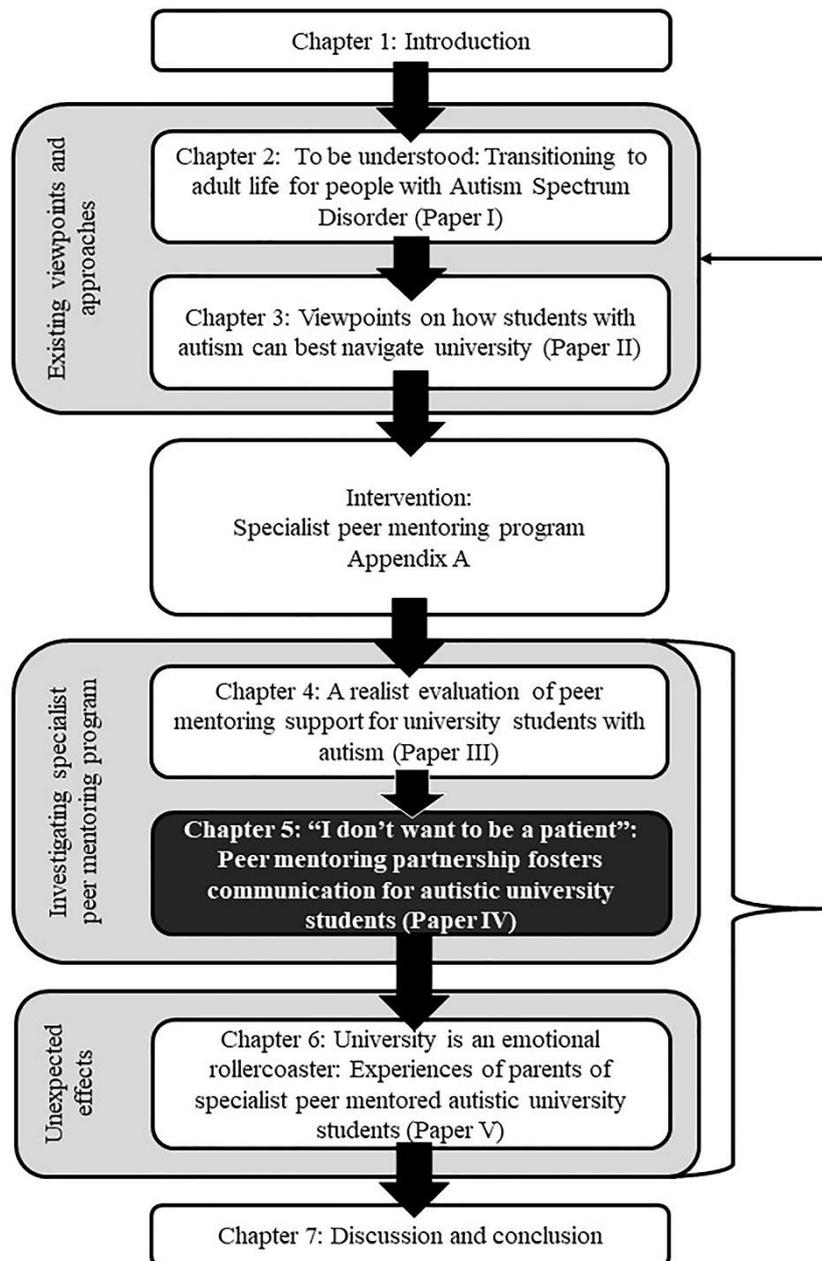
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ORIGINAL ARTICLE

"I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students

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ABSTRACT

Background: Despite recognition of the benefits of post-school education in improving life outcomes for autistic adults their university completion rates remain low.
Aim: To explore the experiences of undergraduate autistic university students participating in specialist peer mentoring (SPM) to identify active ingredients in the peer mentoring process and to examine the impact of SPM on social communication.
Material and method: A total of 30 (8 female; M age $= 22.3$; $SD = 6.7$) undergraduate autistic university students engaged in SPM participated in this study. A quantitative pre-test post-test design examined changes in autistic traits. In parallel, the experiences of participating in SPM were explored through semi-structured interviews.
Results: Improvements were noted at post-test on the Social Responsiveness Scale-2 total score $p = 0.02$), and its Social Communication, ($p = 0.03$) and Social Motivation ($p = 0.03$) sub-scales. Four themes emerged from the interviews: *Developing Partnership and Understanding*, *Modelling and Practising Communication*, *Psychological Support* and *Grading and Planning Skills*.
Conclusions: These results indicated that the mentor-mentee partnership was a crucial active ingredient of SPM. This partnership appeared to modify social cognition and motivation for autistic university students through modelling and practising communication.
Significance: These results demonstrate that SPM can support participation at university for autistic university students.

Introduction

Autism spectrum disorder (ASD) is a lifelong neuro-developmental condition, characterised by the constellation of social communication deficits and restricted, repetitive behaviours or interests [1]. Traditionally, the diagnostic terminology of ASD has been used as part of person-first language. However, there is emerging evidence that this traditional person-first language is no longer the preference of adults with the diagnosis of ASD [2,3]. The community involved in the present research mirrored this language preference. Therefore, participants will be referred to by using identity-first language, such as autistic adults or autistic students.

Internationally, gains in the number of autistic students completing high school education [4,5] and an upward trajectory in the diagnostic rates of ASD [6,7], have led to an unprecedented number of diagnosed autistic individuals graduating from high school aiming to participate in university [8]. However, the increase in high school completion rate has not been mirrored in post-secondary education settings [9–11]. It has been suggested that the transition to university for autistic students is especially challenging [12].

Post-secondary education environments pose many challenges to autistic students given their demands [13,14]. The university environment is socially challenging, loud, crowded [15,16], and the inherent lack of predictability [16] exacerbates autistic students'

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problem solving and executive functioning challenges [17,18]. Conversely, universities present opportunities for autistic students given the variety of available courses and the possibilities to engage in study aligned with special interests [19]. Paradoxically, large universities may be the preferred destination for autistic students, given they offer a wider range of courses and the anonymity afforded by a large student body [20].

Increasing student numbers have required universities to develop support systems to facilitate participation. Accessing these supports largely depends on students' self-advocacy skills, which is something many autistic individuals find problematic [16]. Enrolling in a university course or programme and gaining access to available supports and accommodations is possibly the first time young autistic adults have needed to disclose their diagnosis themselves [21]. For many young autistic adults disclosing their diagnosis can be difficult, given previous negative experiences such as bullying [22]. Another common co-occurring difficulty experienced by autistic individuals is anxiety, and this can present an extra barrier to participation [23,24]. This nexus between the experienced difficulties and the potential unwillingness to disclose may result in many autistic students failing to reveal their diagnosis and resulting in high levels of unmet needs [25,26].

Executive functioning and self-efficacy underpin self-advocacy skills, requiring university students to both recognise a problem and believe they can solve it. Students who experience challenges in learning contexts have significantly lower levels of self-efficacy than their typically developing peers [27]. The development of self-efficacy is facilitated when students have the opportunity and support to influence their learning experience [28,29]. Self-efficacy can be promoted by successful completions of tasks that can result in a sense of mastery [30]. Self-efficacy is further developed by observing others completing activities, verbal support and constructive feedback, and cognitively re-evaluating physiological experiences associated with performance anxiety [30]. Self-efficacy can therefore be enhanced through individualised and activity focussed supports [31].

Impairments in social skills are core challenges experienced by autistic individuals [1] which may hinder the development of self-efficacy, given they result in misunderstandings and limit social opportunities [32]. Social skills training has been employed as one approach in remediating the social communication impairments of people on the autism spectrum [33,34]. Social skills interventions aim to develop discrete skills that can be reproduced and enacted in specific contexts [35]. Social competence is a broader multidimensional concept encompassing social, emotional, cognitive skills and behaviours [35,36]. While several interventions have been developed targeting the social skills of autistic adults [37], there is limited evidence for their effectiveness in improving their social competence [38,39]. To date, only moderate improvements in social competence have been observed from social skills training of autistic adults [40]. It has been proposed that peer-mediated interventions may be more effective in improving the social competence of autistic adults [35,36]. Peer mediated interventions may be particularly effective in generalising social competence when they are embedded within the environment in which they aimed at, such as university [36,41].

The benefits of peer mentoring among typically developing university students is widely recognised [42], but there is limited evidence examining these approaches specialising in meeting the support needs of autistic university students [43]. In recent years, a number of institutions have piloted specialist peer mentoring (SPM) for autistic students with some success (Table 1). Specialist peer mentoring provides an opportunity to deliver tailored support with communication and social interactions, and practical information in relation to university studies for autistic students [43–45]. Embedding SPM in the university context provides an opportunity to support autistic students in developing mastery with the support of observing other students. This, in turn, could assist in developing their self-efficacy. A realist evaluation of the mechanisms of a SPM highlighted the instrumental role of the mentor, communication and social interaction, problem-solving, and training and supervision in supporting positive outcomes for autistic university students [15]. Ultimately, SPM supported autistic university students in identifying their personal strengths, increasing their autonomy, achieving their goals, and developing their relationships [15]. A recent study exploring SPM for university students with disabilities indicated that the provisions of a supportive relationship, support with academic skills, and social support were key aspects in successful mentoring [46]. The emerging theme from the examination of SPM for autistic university students is that a personalised and tailored approach that is fostered by the mentor-mentee relationship is important in the success of such programmes [15,43,47,48]. The active ingredients utilised to develop the strong

Table 1. Published studies exploring outcomes of specialist peer mentoring for autistic university students.

Author, year and country	Description of study	Participants	Outcomes
Ness [43] USA	Qualitative study. A pilot study of peer mentoring of autistic college students over two semesters. Peer mentoring focussed on goal setting and self-regulated learning strategies.	$N = 3$ 2 males (19 and 25 years old) 1 female (21 years old)	Met on 10–11 occasions over the two semesters. All three participants learned and demonstrated new strategies. One participant showed improved grades, one passed a previously failed course and one had minimal change.
Ames et al. [40] Canada	Qualitative study. Peer mentoring programme aiming to aid autistic students in developing social networks and to provide a supportive environment. Specialised mentor training. The programme started in 2008 and support is provided on an ongoing basis.	$N = 15$ 9 male 6 female Aged 18–27 years (12 completed the evaluation)	Seven met weekly, 4 met bi-weekly and 1 monthly. Mean satisfaction 4.25 ($max = 5$). Mentees achieved a high number of goals.
Siew et al. [39] Australia	Qualitative and quantitative study. Pilot peer mentoring programme, aiming to utilise experienced neurotypical students to support autistic university students. Specialised training and supervision were provided to support mentors work with autistic university students. The programme started in 2013 and support is provided on an ongoing basis.	$N = 10$ 7 male 3 female Aged 19–20 years old	Significant improvements observed in levels of social support and perceived apprehension of communication. Mentees were supported through coaching, increased motivation, provision of practical support, group support and emotional support. Mentees reported positive outcomes in transition to university, managing academic work, communication for support, emotions and socialisation.
Roberts and Birmingham [44] Canada	Qualitative study. Volunteer mentors support autistic university students. Specialised mentor training. Mentor supervision. Support was provided over two semesters.	$N = 18$ 9 mentees (2 female; age $M = 21$) 9 mentors	A core theme of 'A mentee-centred approach' was identified with sub-themes of natural progression, the supportive mentor, the meeting process, goals and learning together.
Ashbaugh et al. [45] USA	Case series study. Mentees received support from peer mentors and guidance in organisational skills, targeted social skills and planning social activities. 10-week peer mentoring intervention.	$N = 3$ 1 male (19 years old) 2 females (21 and 24 years old)	Sessions were conducted weekly. The number of peer interactions increased for all mentees and an increase in social activities was also observed. This suggested that interventions targeting social activities could improve satisfaction with university experience.
Lucas and James [46] UK	Quantitative and qualitative study. Specialist (paid) mentors supporting autistic students and/or students with mental health conditions. Specialist mentor training. Support was provided over three academic terms.	$N = 15$ 8 autistic mentees (2 female; age $M = 18.98$) 7 mentees with mental health conditions (6 female; age $M = 22.06$)	Autistic mentees attended on average 8 mentoring sessions. All mentees reported high levels of satisfaction. All mentees indicated mentoring improved academic skills and university life. Autistic mentees reported improved well-being. The central theme identified was 'tailored partnerships'.
Thompson et al. [12] Australia	Qualitative study. Utilised experienced neurotypical students to support autistic university students. Specialised training and supervision were provided to support mentors' work with autistic university students. Support provided on an ongoing basis.	$N = 47$ 24 neurotypical mentors (17 female; mean age $M = 23.1$) 23 autistic mentees (6 female; age $M = 28.1$)	The identified contexts that required a specialist peer mentoring programme included Environmental Conditions, University Course Demands and Aspects of ASD. The identified mechanisms of the programme included Mentor, Communication and Social Interaction, Problem Solving and Training and Supervision. The outcomes identified were Identifying Personal Strengths, Increased Autonomy, Achieving Goals, Relationships and Positive Mentor Outcomes.

mentor-mentee relationship, however, need further examination.

There is emerging evidence supporting the role of SPMs in the retention of autistic university students [49], but there is limited evidence of the impact of these programmes on social communication [43]. The aim of the present study was therefore to explore the experiences of undergraduate autistic university students participating in SPM to identify active ingredients in the peer mentoring process

Semi-structured interview questions for Interpretative phenomenological analysis
What had you hoped you might to achieve by becoming a mentee in the specialist peer mentoring program?
Where did you meet your mentor?
How often did you meet or contact your mentor?
What issues / problems did you discuss?
What worked / what did not work?
How did the mentoring sessions change over time?
How did your relationship with your mentor change over time?
Thinking about the work you have done with your mentor, how has this impacted on your university experience?
What do you think about working with your mentor?
What would change to improve the program?
Are there any other issues you would like to discuss?

Pre and post test Assessment battery
Social Responsiveness Scale, second edition.
Adult Manifest Anxiety Scale-College.
Social Provisions Scale.
Situational Communication Apprehension Measure.
Self-Perceived Communication Competence Scale.
Personal Report of Communication Apprehension.
Generalised Self-efficacy Scale.

Thematic analysis
Interpretative phenomenological analysis

Quantitative analysis
Paired *t*-test

Results merged

Overall interpretation

Figure 1. The study design outlining the use of quantitative pre-post-test assessment battery and semi-structured interviews that when combined provided an enriched understanding of specialist peer mentoring.

and to examine the impact of SPM on social communication.

Methods

Study design

This study employed both quantitative and qualitative components (Figure 1). The quantitative component of the study involved pre-test post-test assessment examining the changes in social responsiveness experienced by university students with ASD engaging in SPM.

The qualitative aspect of the study employed an interpretative phenomenological analysis (IPA) approach to data collection and analysis. IPA focuses on examining the personal reflections on key

experiences in an individual's life [50]. This process is referred to as double hermeneutics, with the researcher attempting to understand a participant's reflections on an experience. In the field of autism research IPA has been in used to examine a wide range of experiences of autistic individuals and their families across the lifespan; including autistic adolescent boys' experience of sexuality [51], the benefits of drama therapy from the perspectives of parents and teachers [52], exploring the experience of supports for adults with Asperger syndrome [53], the experience of disclosure of diagnosis for young autistic adults [54], the experience of acute mental health facilities for autistic adults [55], and masking as a coping strategy for young autistic girls [56].

Participants

Undergraduate university students self-reporting a diagnosis of ASD participating in specialist peer mentoring programmes at Curtin University (CU) in Western Australia and the University of Western Australia (UWA) were invited to participate in this study. Participants were eligible for the study if they were participating is either of these mentoring programmes, which required their discloser of diagnosis at the respective university's disability service to receive this support. Participants were also required to be able to engage in an interview. The UWA pilot programme was based on a manualised generic version of the Curtin University Specialist Peer Mentoring (CSPM) [57,58]. A total of 30 (8 female; age $M = 22.3$; $SD = 6.7$) university students with self-reported ASD participated in this study; with 18 (5 female; age $M = 22.5$; $SD = 9.9$) completing both aspects of the study. Seven (2 female; age $M = 22.3$; $SD = 3.5$) completed the questionnaires only and 5 (1 female; age $M = 21.0$; $SD = 8.9$) participated in the interview only. A total of 26 participants were studying full-time, four studied part-time, and 11 were employed part-time. Several participants had co-morbidities, including ADHD ($n = 2$), depression ($n = 1$), anxiety ($n = 1$), dysgraphia ($n = 1$), and dyspraxia ($n = 1$). The participants predominantly lived in the family home ($n = 27$), with two living independently and one living in shared accommodation. At post-test, or the end of the academic year, participants reported their future plans for their university studies; two reported that they had graduated from their undergraduate studies and two withdrew from their current course. The remaining 26 participants planned to continue their studies.

Intervention

SPM [57] was implemented according to a manualised programme [57,58] across two universities in Western Australia, CU (approximately 60,000 students) and UWA (approximately 24,000 students). At both sites the student mentors were recruited from graduate health sciences programmes of occupational therapy, speech pathology and psychology (17 female and 6 male; age $M = 28.1$; $SD = 5.1$), with eight having previous experience working with autistic individuals. After reviewing expressions of interest programme coordinators interviewed prospective mentors determining their fit for their prospective role [57]. Across both sites coordinators screened mentees for their suitability to participate in the programme, matching them with mentors with similar interests where possible to form dyads [57]. All mentors were provided with training to equip them with skills to better understand and communicate with autistic students [58]. Programme coordinators provided weekly group supervision in supporting the mentors. Mentoring was delivered during the university semesters with four dyads meeting twice weekly and the remainder meeting on a weekly basis. The one-on-one meetings between mentors and mentees lasted between one and two hours. In the CSPM programme this was augmented by a weekly social group facilitated by mentors with input from the coordinators and the mentees [57]. The social group provided an opportunity to form friendships between autistic students, and opportunities to hear from external presenters and practise social skills [57].

Procedure

Autistic university students participating in the SPM programmes were invited to participate in the study. Following recruitment from the SPM programmes, the participants completed a battery of questionnaires at the beginning of the academic year (time-point 1) and at the end of the same academic year (time-point 2). Demographic data were collected at time-point 1. At both time-points, participants completed all questionnaires in one sitting online, except for the SRS-2, which was completed at the same time as a paper-based assessment. At time-point 1 the online questionnaires took on average 28 min and at time-point 2, 20 min to complete.

The experiences of engaging in a SPM programme for autistic university students were explored through semi-structured interviews undertaken with mentees at the end of the academic year. Participants were

provided with the topics prior to the interview being conducted and recorded. In an attempt to maximise consistency across interviews and support the communication of autistic students, prior to commencing the interviews the two interviewers (CT and an independent researcher) discussed potential strategies for re-phrasing questions and prompting participants. As a strategy to minimise the risk of social desirability bias the interviewers were not involved in the delivery of the SPM programmes. This process provided rich data, enabling a comprehensive understanding of the experience of autistic university students [59].

The results of the quantitative assessments were examined in relation to the qualitative data to validate and explain the results. Combining the results of the quantitative assessments and the semi-structured interviews in this study provided an understanding of the effect of it and the experiences autistic university students in the SPM programme had [60]. This process served to triangulate and add credibility to the results [61].

Interview guide

Semi-structured interviews were conducted at the end of the academic year, aiming to explore the expectations, experiences and outcomes of SPM of autistic university students. The interview guide (Figure 1) considered the needs of autistic students, utilising focussed language, with questions provided to participants prior to the interview. Interview questions were developed with reference to International Classification of Functioning, Disability and Health (ICF) [62], a holistic biopsychosocial model, which in the present study provided a framework for exploring the enablers and barriers to participation in the major life area of education [63,64]. The ICF includes domains related to body functions, body structures, activities and participation [62], which can be explored within the contextual aspects of environmental and personal factors [63]. The inherent structure of the ICF facilitates discussion of the impact of personal strengths and barriers on participation or functioning [63]. The use of the ICF ensured that the interview guide was holistic and that it focussed on participation in the major life area of education.

Questionnaires

The questionnaires designed to examine the impact of SPM on social communication, anxiety and core autistic symptoms are outlined below:

Autistic traits, specifically social communication and motivation, were measured via the self-report version of the Social Responsiveness Scale, second edition (SRS-2) [65]. The SRS-2 is a 65 item scale using a 4-point Likert scale, ranging from 'not true' to 'almost always true' to quantify the severity of autistic traits [65]. The SRS-2 has established reliability including test-retest reliability ($r_{tt} = 0.84$–0.97), inter-rater reliability ($r_{rr} = 0.76$ and 0.95) [66], with evidential content, construct, criterion and predictive validity [67]. The SRS-2 also served to confirm the self-disclosed ASD diagnosis of the participants. Higher scores represent greater autistic traits.

Domain specific anxiety was measured using the Adult Manifest Anxiety Scale-College (AMAS-C) [68]. The AMAS-C was designed to evaluate anxiety for a university population. The AMAS-C consists of 49 yes/no questions and provides a score of overall anxiety, including five sub-scales (physiological anxiety, social concern/stress, test anxiety, worry/oversensitivity and lie/validity) [68]. The AMAS-C's internal consistency has been estimated to be between $r_\alpha = 0.72$–0.95 and construct, convergent, and discriminant validity has been demonstrated [69]. Higher scores on the AMAS-C indicate higher levels of anxiety.

Personal Report of Communication Apprehension (PRCA) [70] is a scale that measures perceived levels of communication apprehension within four communication domains. The 24-items of the PRCA are rated on a 5-point Likert scale [70]. Test-retest reliability of the PRCA is estimated to be $r_{tt} = 0.82$, internal consistency has been estimated to be $r_\alpha = 0.92$ and has high levels of predictive validity [71]. Higher scores are indicative of greater communication apprehension.

Situational Communication Apprehension Measure (SCAM) [72]. The SCAM measures state communication apprehension in a specific context and is a 20-item measure requiring participants to rate each item on a 7-point Likert scale [72]. The SCAM requires participants to rate how they felt when they interacted with someone offering a supervisory capacity. The SCAM was modified to fit the university setting. The SCAM has an estimated internal consistency of $r_{tt} = 0.85$–0.90 [73]. The SCAM has demonstrated construct and criterion validity [73]. Higher scores indicate increasing levels of communication apprehension.

Self-Perceived Communication Competence Scale (SPCC) [71] is a 12-item scale exploring an individual's perceived communication competence [71]. Participants rate their perceived competence on a

scale between 0 (completely incompetent) and 100 (completely competent) [71]. The SPCC has reliability estimates above $r_{tt} = 0.85$ and has demonstrated considerable predictive validity. Higher scores indicate greater levels of perceived communication competence.

Social Provisions Scale (SPS) [74] is a 24-item scale using a 4-point Likert scale examining the social relationships that provide social support of the participants. The SPS examines attachment, social integration, reassurance of worth, reliable alliance, guidance and opportunity for nurturance. The validity of the SPS has been demonstrated by the reported internal consistency of $r = 0.92$ [74]. Higher scores indicate greater levels of perceived support.

Generalised Self-efficacy Scale (GSE) [75] is a 10-item scale measuring perceived levels of self-belief. The GSE is scored on a 4-point Likert scale from 'not at all true' to 'exactly true'. The reliability of the GSE is estimated of 0.76–0.90 [75]. Positive predictive validity has been demonstrated with constructs such as optimism and work satisfaction [75]. Negative predictive validity has been observed with constructs such as anxiety, depression and stress [75]. Higher scores reflect higher levels of self-efficacy.

Data analysis

The semi-structured interviews were transcribed verbatim and analysed using NVivo 12 [76]. The transcripts were analysed using the IPA six-step process utilising iterative and inductive cycle [50]. Stages one to five were conducted by CT and all authors worked together on stage six of the IPA analysis. The first stage of the analysis involved becoming familiar with the interview data by reading and re-reading an individual transcript from one participant. This process facilitated a deep exploration of the participant's experience. The second stage was to make initial comments or notes regarding the experience of the participant. This allowed for a deep exploration and recognition of key aspects of the interview. The third stage identified emerging themes from the transcript by noting similarities in the observed notes or comments. Stage four identified links between the emerging themes. This stage allowed the authors to distil the emerging themes into a structure that illustrated the experience of the participant. Stage five of the analysis was the replication of the previous steps to examine the remaining transcripts in turn. In stage six the authors searched for patterns across the themes from the individual participant's data. This

entire process facilitated a deep exploration of each individual case and ultimately a thorough exploration of all participants' experiences. To ensure credibility and trustworthiness of the emerging and subsequent themes they were reviewed by all authors with thematic disagreements explored until consensus was achieved. Member checking of the themes was used to further enhance their credibility [61].

SPSS version 25.0 [77] was used for quantitative data analyses. The data were analysed using repeated measures t-tests to compare pre-test and post-test questionnaire scores from all of the scales. Alpha value was set at $p = 0.05$. The data were also analysed using the Wilcoxon Signed Ranks test and the results were identical. Therefore, the repeated measures t-tests were used to gain increased information this can convey.

Ethical considerations

The interviewers were independent of the SPMs operating at CU and UWA and participants were explicitly advised their decision to participate in the study would not impact on their position in the programme. Prior to data collection, all participants provided informed consent, and all data were de-identified on transcription, ensuring confidentiality. Ethical approval was obtained from Curtin University Human Research Ethics Committee (HR16/2014) in Perth, Western Australia. The Human Ethics office at the University of Western Australia granted reciprocal ethics approval (RA/4/1/7606).

Results

Semi-structured interview results

Thematic analysis of the interviews revealed four overall themes: *Developing Partnership and Understanding, Modelling and Practising Communication, Psychological Support* and *Grading and Planning Skills*.

The theme *Developing Partnership and Understanding* describes the gradual, developing relationship between mentor and mentee. Autistic university students noted that initially their mentors took a leading role in the relationship, but with the progress of time the relationship became more equal, eventually evolving into a partnership. Mentees described their relationships with their mentors as progressing from a 'formal mentor/mentee relationship' to more of a 'friendship [type] of relationship' with 'conversations [no-longer] one-sided'. The autistic

university students noted that the relationship with their mentors was different to a formal therapeutic relationship, seeing themselves as equals, valuing it as a partnership:

> I'm not a patient. I'm very willing to take advice, and I'm very willing to tell you my experiences and help you as much as you are helping me, but I want to be friends. I don't want to be a patient and you are the doctor.

The *Modelling and Practising Communication* theme captured the autistic university students' description of their developing social competence in the context of their partnership with their mentors. Correspondence with their mentors through emails provided an opportunity to model appropriate communication, with mentees transferring these skills to their communication with university staff members, including 'how to get feedback on assignments from lecturers'. This theme also described the process of practising and problem-solving issues related to verbal communication. Some autistic university students described 'role-play[ing] conversations' with their mentors, others discussed 'how to start conversations with other students', 'mak[ing] new friendships', or 'work[ing] with other students'. Overall, mentees recognised the value of SPM in providing them with opportunities to develop their social skills:

> …[the social group is] a place where I can give advice and practise my social interaction skills and by doing it with people who are more likely to understand if I get it wrong regardless …I can [also] practise on the other mentors who don't know me as well.

The social group was described as a key component of SPM in extending the practise of communication skills beyond the mentor-mentee dyad.

> …[the social group is] a prototype testing room. You test all your prototype [communication] strategies on the people who are most likely to tell you whether you are wrong or you are right.

The theme *Psychological Support* recognised the provision of the broad general support provided by SPM and mentors. The participants described how they received support with managing their anxieties related to the university environment and their studies. This support was individualised to the autistic university student, with one describing restricting negative thinking:

> She just suggests what I can say to someone, and suggests – she makes sure that I don't stress too much about talking with people.

Another autistic student indicated how their mentor encouraged them to access existing support structures:

> So that was another strategy that we had – being able to open up to people, and the minute I was able to open up. Involving [my partner] in the more stressful side of my life – it strengthened our relationship as a couple. … I've been able to 'open up' to my other friends, and get their perspectives on my stress – to get ideas about their ways of dealing with stress.

The autistic university students worked with their mentors on strategies to 'cope with the study load and other expectations of university.' Mentors facilitated the identification of available practical and psychological supports, enabling participants to negotiate the bureaucracy of university, including obtaining an 'assessment extension' or 'support plans from disability services'. The support provided by SPM was critical for their university studies:

> Knowing that there is genuine support is the greatest asset. Having the specialist peer mentor offers such a support in a semi-structured way.

The theme *Grading and Planning Skills* outlines how the autistic university students worked with their mentors to create bespoke plans to manage their studies. The participants talked at length about how they worked with their mentors to overcome challenges in relation to their planning and time management skills. In this theme, the autistic university students discussed how they worked with their mentors to grade their academic studies:

> If I'm stressing about an assignment, [my mentor] helps me set it up – helps break it down into easier parts.

The autistic university students noted that working with their mentors helped them to manage their lives more effectively:

> Just improving my organisation skills overall and just becoming a better adult so I can organise my day and my week and my time at a much better level.

This grading process expanded beyond academic studies to learning social skills with the participants noting that they needed to work beyond their mentor-mentee dyad to improve their social competence:

> How can you learn social activities with just your mentor? You've got to come to the social group. It's so important. I sound so – I know 'dreary' to them, probably – and phrasing socialisation – who do I think I am? But it is – it's invaluable and I think some of the mentors don't mentally understand how important the social group is.

Active ingredients

As presented, the autistic university students indicated four themes, i.e., active ingredients, in specialist peer mentoring. These active ingredients are outlined and explored more in detail in Table 2.

Quantitative results

Mean scores and standard deviations for all scales are in presented Table 3. Participants showed a significant decrease in autistic trait behaviours on the total SRS-2 from time-point 1 and time-point 2, demonstrating a moderate effect size ($t = 2.52$, $p = 0.02$, $d = 0.40$). The change was mostly driven by improvements on the SRS-2 social communication sub-scale, demonstrating

a moderate effect size ($t = 2.24$, $p = 0.03$, $d = 0.45$) and in the social motivation sub-scale between time-point 1 and time-point 2, demonstrating a moderate effect size ($t = 2.27$, $p = 0.03$, $d = 0.38$). The differences between time-point 1 and time-point 2 on all remaining sub-scales were non-significant.

A trend towards improvement was observed in the physical anxiety sub-scale of the AMAC-C ($M1 = 3.66$, $SD1 = 2.35$; $M2 = 3.00$, $SD2 = 2.19$; $t(17) = 2.06$, $p = 0.05$). Changes observed in social communication and interaction on the SPS and SCAM were not significant. No significant change was noted in communication anxiety in the PRCA or self-rated communication competence. The dyad sub-scale of the SPCCS showed non-significant trend in perceived dyadic communication ($M1 = 56.47$, $SD1 = 20.66$;

Table 2. Identification and exploration of the active ingredients of specialist peer mentoring.

Active ingredients	
Operational definitions and outcome	Sample quote(s)
1. Developing partnerships and understanding Mentors and mentees developed a working relationship to achieve goals together. • Relationships are fostered by mentors utilising person-centred counselling skills such as unconditional positive regard and active listening [73].	'It's not formal. It's a lot more relaxed – relational.'
Mutual respect was developed through mentors using therapeutic use of self, which became the foundation for other interventions [74]. Mentors utilised advocacy skills in collaboration with mentees to support them to manage the university system.	
2. Modelling and practising communication Mentees work closely with the same mentor for prolonged periods, which allows autistic students to observe communication skills. The demonstration of social skills from the mentor provides a 'template' for the autistic student to utilise at university. • The observation of social skills assists in the development of communication self-efficacy.	'She's made my horizons, I suppose, open up. So that's allowed me to open up as a person, I'm still hesitant at first as anyone would be in a new group or environment or people you didn't know, but its allowed me to definitely be more self-confident.' '[They] help me with planning with what to say to [lecturers] and what to say in an email.'
Regular communication as a dyad encouraged the development of self-confidence. Regular dyadic communication reduced anxiety regarding social skills. Practising and problem solving written communication at university developed context specific social skills. Context specific communication challenges were problem solved to focus on working with peers in classrooms and on assignments.	'[We] mainly focussing on social aspects when it comes to our meetings, so what we try to do is develop skills that will help me to approach people or in things that I'm not confident in, and help me make new friends.'
3. Psychological support Using their relationship, mentors listen to university autistic students to offer support for individualised distress. • Within the boundaries of the mentoring relationship, mentors provide suggestions to manage stress, anxiety, low mood and other similar experiences.	'She's always understanding of my problems and she always helped me get meetings with [the course coordinator] on a tight schedule or going to meet me straight after talking with you or anybody else. After her classes she would come and meet me and then she'd basically be able to calm me down and work it out and be able to call, since I wasn't very comfortable with calling my lecturer on the phone, she would do the calls then I would talk to them from there or something.'
Mentors used verbal persuasion to support mentees to develop self-efficacy. Mentors encouraged autistic university students to seek assistance from other health professionals as necessary.	'I think maybe just being able to talk about it is quite helpful.'
4. Grading and planning skills Mentors work to plan, prioritise and grade tasks by breaking them into manageable components. • University assessments are often complicated and it is often necessary to separate discreet parts so that the full task can be completed more easily.	'She helps me towards the start of semester, she helps me set out what to do, and when I have to do it, and stuff like that. If I'm stressing about an assignment, she helps me set it up – helps break it down into easier kind of parts.'
Difficulties with time management were overcome using high and low tech solutions. Mentors collaborated with mentees to prioritise university tasks to ensure assessments were completed appropriately.	' … just making sure to point out how much time I have for each part. Because it's easy to look at that information and just think, 'How am I gonna get this done?' You know, so, to get instructions and someone point out, 'No, you've got this much time for that, and there's weeks between these assignments'. It makes it easier to get my head around.'

Table 3. Results of the paired *t*-tests between time-point 1 and 2 on all questionnaires in the assessment battery.

	time-point 1		time-point 2				
	M	*SD*	*M*	*SD*	*t*	*p*	*Effect size*
SRS-2 – Total[++]	89.72	24.00	79.66	26.66	2.52	**0.02**	0.40
Social Awareness[++]	9.50	3.14	9.11	3.06	0.67	0.51	0.12
Social Cognition[++]	15.27	5.88	14.05	5.39	1.20	0.24	0.23
Social Communication[++]	29.94	7.89	25.50	11.29	2.24	**0.03**	0.45
Social Motivation[++]	18.22	5.88	16.00	5.91	2.27	**0.03**	0.38
Restricted Interests and Repetitive Behaviour[++]	16.88	7.50	14.94	6.05	1.65	0.11	0.28
AMAS-C[++] Total	24.33	8.30	21.88	8.77	1.60	0.12	0.28
PRCA[++] Total	71.37	4.60	73.25	9.29	−0.64	0.53	−0.25
SCAM[++]	78.61	4.91	77.72	8.18	0.54	0.59	0.13
SPCCS[++] Total	51.77	17.48	54.05	14.22	−0.63	0.54	−0.31
SPS[+] Total	70.22	15.64	69.38	13.27	0.40	0.69	0.05
GSE[+]	27.50	5.11	29.05	4.34	−1.19	0.25	−0.33

Note. [+]increasing scores: improvement; [++]decreasing scores: improvement; SRS-2: Social Responsiveness Scale, second edition; AMAS-C: Adult Manifest Anxiety Scale-College; PRCA: Personal Report of Communication Apprehension; SCAM: Situational Communication Apprehension Measure; SPS: Social Provisions Scale; SPCCS: Self-Perceived Communication Competence Scale; GSE: Generalised Self-efficacy Scale. *p*-value in bold indicates significant difference.

$M2 = 63.61$, $SD2 = 15.98$; $t(17) = -1.85$, $p = 0.09$). No significant change was observed in generalised self-efficacy as measured by GSE.

Discussion

The merged qualitative and quantitative results of this study (Figure 2) suggest that the mentor-mentee partnership assists in improving the social communication of autistic university students, with the relationship underpinning the success of SPM at university. As with previous research, the mentor-mentee relationship has been identified as being central to the success of SPM for autistic university students [15,43,46,48] and those with other disabilities [46]. The mentoring partnership appears to modify social cognition and motivation of autistic students [15], with benefits beyond improving socialisation, to encouraging autistic students to develop strategies to manage their studies and the university environment. The inherent individuality of the mentor-mentee partnership enables the development of bespoke strategies, maximising social competence [41,43,48], fostering participation in post-secondary education and the transition to adult life. This process of active inclusion at university can assist the development of self-belief, contributing to the fulfilment of the student's potential [78]. It could have been expected that autistic university students would have experienced less anxiety, but no significant improvements were noted. Furthermore, no significant changes were observed in restricted and repetitive behaviours of the autistic university students. However, participants were able to maintain their participation at university, which may suggest that they have developed improved coping mechanisms.

Mentor-mentee partnership

The mentor-mentee partnership is an intense and initially challenging relationship for autistic students. However, the purposeful and supportive nature of this relationship encourages them to continue to develop the partnership, with autistic students becoming increasingly comfortable within the dyadic relationship as they learn from their mentor's experience [79]. An equal partnership in the mentor-mentee relationship provides opportunities for autistic students to further their self-advocacy. This dyad becomes a vehicle for developing strategies to manage the university environment. Some autistic students used this dyad to mainly practise social skills, while others focussed on using it as a mechanism to develop study skills.

Embedding the peer mentor relationship within the university setting appears to provide unique opportunities to address the individualised challenges of autistic students. Practising context-specific social skills within the mentor-mentee dyad can facilitate more effective communication with university staff and other students [43], fostering social competence within autistic students so they can more readily adapt to the university setting [35]. Similar to previous research, the present study has demonstrated that SPM can improve social interactions [15,43,80]. The present study demonstrated that this can be achieved by modelling skills from their mentor. The naturalistic approach of using this relationship to improve social competence and interaction appeared to be

Themes
Developing Partnership and Understanding,
Modelling and Practising Communication,
Psychological Support,
Grading and Planning skills.

Significant changes
Social Responsiveness Scale, second edition
(SRS-2) Total Score ↓
SRS-2 Social Cognition sub-scale ↓
SRS-2 Social Motivation sub-scale ↓

Non-significant results
Adult Manifest Anxiety Scale-College ↓
Generalised Self-efficacy Scale ↑

Results merged
Engagement in the mentoring partnership → impacts on social
cognition and motivation
Communication practise → impacts on social cognition and
motivation
Psychological support → mediates experience of anxiety
Grading and planning studies → impacts upon self-efficacy.

Overall interpretation
Commitment to partnership development and one-on-one social
skills practise can improve social skills and competence
Psychological support provided by a mentor can facilitate
participation at university regardless of experience of anxiety
The process of grading and planning university study facilitates
participation in university studies developing self-efficacy

Figure 2. Merging and interpretation of the results from the semi-structured interviews and the quantitative assessment battery.

effective as demonstrated by the changes observed in the social cognition and social motivation sub-scales. The improvements in the social communication of autistic individuals has previously been observed in more traditional social skills training [33,81,82], video modelling [83,84] and in communication coaching [85]. The dyadic partnership in SPM is underpinned by social communication, affording all participants

the opportunity to improve their social skills through modelling. The development of such partnerships has been shown in this and other studies to have a positive impact on the social outcomes for university autistic students [79].

The mentor-mentee partnership within the university environment

SPM aims to increase participation at university and improvements have been observed in this setting [15,43]. The SPM also appears to assist autistic students in strengthening their connection with university [44]. However, students continue to require emotional and psychological support to moderate the challenges they experience in managing the social, emotional and study demands of university [15]. If allowed to develop, the mentor-mentee partnership can provide the autistic university students with an avenue for psychological support. It is likely that without this support autistic students would continue to rely on their families as the primary, and often only, source of support. Other forms of appropriate support is therefore critical to people with autism and is likely to be key in improving mental health outcomes [86]. There is growing concern that services lack sufficient knowledge of ASD to consistently recognise mental health challenges in this population [87]. This is compounded by the difficulties with social communication and camouflaging of symptoms [88]. Through the peer-mentoring relationship the student mentor could be uniquely placed to offer early support [43]. The student mentor is in an ideal position to encourage the autistic university student seek further support when necessary [15].

Specialist peer mentoring is embedded within the university environment and the nature of the peer relationship moves the focus from traditional intervention approaches to a strengths-based approach. Indeed, the relationship developed between the mentor and mentee leads to strategies that utilise the unique strengths of autistic individuals and modifies the environment to maximise participation at university [43,89,90]. Autistic university students develop strategies in partnership with their mentors to overcome barriers to their studies, such as breaking assessment tasks down into manageable components and time management [15,43]. This process of grading facilitated the management of executive function difficulties that otherwise may limit autistic students' ability to organise their studies [15]. Previous studies have demonstrated that SPM can improve academic

results [44,89]. The results from the current study have identified the active ingredient of grading and adapting assessments, similar to the results of the realist evaluation [15]. The use of the individual meetings between mentors and mentees ensured that the autistic university students were provided with regular opportunities to practise and develop social skills within the university context. The mentoring partnership provides an explicit reason for the interaction, maximising motivation for communication. With the support of mentors, autistic university students could develop improved self-advocacy and through modelling, the mentors demonstrate when and how the autistic university student should seek assistance. In the long-term, the skills developed in the mentor-mentee partnership could foster sufficient self-advocacy of autistic university students. A potential barrier to this form of partnership learning is, however, the tendency of autistic university students to be inflexible as part of the core characteristics of repetitive and restricted behaviour. This inflexibility can lead to hyper-focus on the academic task, which in some circumstances can be academically beneficial, but in other situations, be detrimental. While the mentors in the SPM programme do not directly address this inflexibility, by developing other skills they may mediate this difficulty. SPM is uniquely placed as an intervention to meet the preferences of autistic young people and their families for interventions that aim to utilise their abilities and modify the environment to maximise success [49,90].

Limitations and future directions

It is currently unclear as to the broader impact of SPM on participation in other key life areas, such as employment or independent living. Considering that SPM appears to assist autistic university students to participate at university, future research should consider the potential of this approach to support autistic individuals in the transition from higher education into employment, and more broadly across adult life. It would be of interest to explore the impact of SPM on restricted and repetitive behaviours, as this could influence studies and employment, something future research could focus on. Future research should also expand consideration of the impact of mentoring on relationships and outcomes beyond the mentor-mentee dyad, including examining the experiences of parents whose young adults participate in specialist peer mentoring. Furthermore, future research could

expand on the limited understanding of the impact of SPM on mentors.

The results of this study must be interpreted with its limitations in mind. Firstly, the lack of a control group makes it more challenging to disentangle improvements that result from SPM from maturation and/or general adaptation to university. Secondly, the small sample size limited the ability to identify quantifiable changes over time, due to type II error. For that reason, non-significant trends are pointed out in the results section. It should also be pointed out that should Bonferroni correction of the critical alpha value have been applied, only SRS-2 – Total score would have indicated a significant change over time. However, the detailed analysis was presented in order to guide the reader towards measure components where the changes occurred the most. This study utilised the SRS-2 to gauge levels of repetitive and restricted behaviours, but their impact on academic success was not measured. It should be pointed out that the questionnaires utilised in this study were selected pre-hoc and the 'world view' of the researchers influenced these choices. It could also have influenced the interpretation of interview data and to account for this member checking was conducted [91].

Conclusion

This study demonstrated that social communication and social motivation can improve for university autistic students participating in SPM. They can develop a working partnership to manage the social and study challenges at university. Finally, this study demonstrated that the engagement in a mentor-mentee partnership in a SPM programme can influence social competence for autistic university students participating in SPM.

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Disclosure statement

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The results of this chapter indicated that SPM could have a positive impact on social communication and motivation for communication in autistic university students. Moreover, a key active ingredient for the success of SPM was the partnership that developed between the mentor and the autistic mentee. The latter indicated that modelling and practising communication with their mentor was a key active ingredient of SPM. The provision of psychological support and assistance in planning for assessments were also key active ingredients identified by autistic university students. Considering that SPM could provide effective supports for these students it would be important to explore how this affects them outside of university, especially within their own families. Consequently, the impact of SPM on parents of autistic university students should come in focus.

Chapter 6: Paper V-University is an emotional rollercoaster: Experiences of parents of specialist peer mentored autistic university students

This chapter presents the results of an interview study with of parents of autistic university students participating in SPM. More specifically, the aim of this chapter is to explore the experiences of parents of specialist peer mentored autistic university students, revealing unintended consequences of SPM. The ICF is employed as an analysis framework, allowing the recognition that the SPM mainly focuses on mediating the environment to assist autistic university students develop study skills and self-reliance.
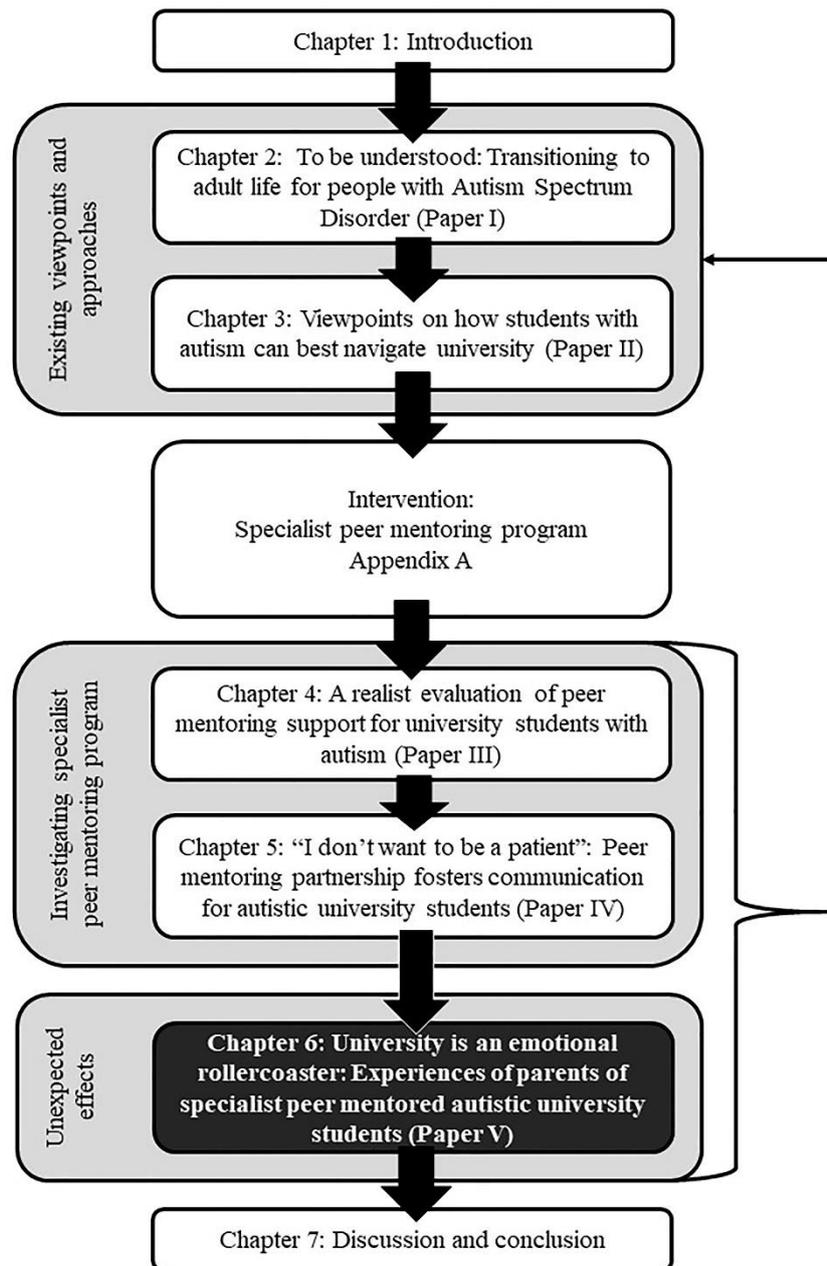
University is an emotional rollercoaster: Experiences of parents of specialist peer mentored autistic university students.

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University is an emotional rollercoaster: Experiences of parents of specialist peer mentored autistic university students.

Most parents continue to provide invaluable support for autistic students at university and they may experience considerable levels of stress in doing so, this might be mitigated by specialist peer mentoring (SPM). This study explored the experiences of parents of autistic university students in SPM programmes. A total of 13 semi-structured interviews (11 mothers and two fathers) were completed. Thematic analysis was identified five interrelated themes: *The mentoring relationship is a facilitator*, *Developing skills for university*, *Mentoring changes lives*, *Mentoring is not a substitute for other supports,* and *'University' is an emotional rollercoaster*. Directive content analysis linked the data to the Comprehensive International Classification of Functioning, Disability and Health core set for autism spectrum disorder. Parents described how SPM improved their experience of parenting and their child's study skills and self-reliance.

Keywords
Autism spectrum disorder; Parents; Parent–child relationship; Mentoring; Supports; University

Access to successful education is a key strategy for improving employment outcomes, further learning, independent living, and promoting autonomy in autistic adults [1]. Given improvements in rates of young people with autism completing secondary education [2-4], there is an expectation that there will be an increasing number of these students participating in tertiary education settings [5]. However, despite continuing growth in the number of autistic youth successfully completing high school, there is no evidence that this success has translated to an increase in those completing post-school qualifications [6, 7].

Parents continue to offer social, emotional and general supports to autistic individuals through secondary school and into university [8]. In childhood, parental support complements that provided by services and therapy providers. However, there is a sudden and dramatic decrease in formal supports during adolescence and into adult life [9], which means many young adults often turn to their parents as their primary source of support. Parents indicate that their autistic children entering early adulthood are concerned that their peers and people in authority do not understand the challenges or strengths associated with the condition [10]. The challenge of being understood is perhaps exacerbated by the autistic difficulty of understanding the world [10]. Parents highlight that approaches aiming to support autistic university students should be person-centred and tailored to meet an individual's needs and context [11]. It is likely that interventions and support strategies targeting the environment will be central in managing the challenges experienced by autistic university students [10, 11].

A young person's transition to adult life impacts on family dynamics and relationships [8], with adolescents striving to form their own identity, separate from that of their parents. This can increase tension within a family, which likely contributes to the observed decrease in the quality of the relationship between parents and autistic young adults during this time [12]. The paucity of available therapeutic and support services available to autistic young adults likely increase the need for parental support at a time when autistic young adults are searching for autonomy [13]. The demands of universities tax the executive functioning of autistic university students who draw on their parents for guidance and support from their parents in the form of advocacy and management of study demands [14].

Peer mentoring has emerged as a common approach to supporting individuals in education and employment contexts, and yet there is a lack of a clear definition of the intervention [15]. Often, peer mentoring is characterised by cross-age mentoring whereby more

experienced peers support or coach younger or less experienced individuals [16]. Traditional peer mentoring approaches utilise subject matter experts to support younger less experienced peers. However, in specialist peer mentoring (SPM) university peers offer their expertise to autistic students on the social skills and rules underpinning communication for the university environment [17, 18]. SPM programmes at Curtin University in Western Australia and the University of Western Australia (UWA) involve programme coordinators, mentors, mentees and a social group [18-20]. The programme coordinators recruit and screen potential mentors from graduate health science programmes [21], with mentors matched to mentees by the programme coordinators [18, 21]. Mentors receive ongoing weekly supervision and specialist training on autism, guidance on effectively communicating and strategies for problem-solving with autistic students prior to commencing mentoring [18, 21]. The autistic mentees and their assigned mentors meet weekly, working on individualised goals and needs relating to managing communication, study, and executive functioning challenges [20].

It is estimated that approximately 34% of autistic individuals graduating from high-school now attend universities [6], but they remain at high risk of withdrawing prior to completing their studies [22-24]. Universities have begun to employ SPM as an approach to support the participation and engagement of autistic university students within this context, with evidence emerging of its value to both autistic students and their mentors [17-20, 25-27]. Autistic university students report a need for support in engaging with lecturers and other students [28]. Given their knowledge of the university environment and its social systems, peer mentors are ideally positioned to provide this contextualised assistance [18]. Small-scale pilot studies of SPM have demonstrated that SPM is feasible, demonstrating preliminary efficacy in improving the academic performance of autistic university students [18, 19, 26]. Participating in SPM has also been associated with improved social and problem-solving skills [17-19, 25, 27, 29].

The International Classification of Functioning, Disability and Health (ICF; World Health Organisation 2001) outlines a biopsychosocial framework, conceptualising functioning and disability as resulting from a dynamic interaction between a health condition, in this case autism, and relevant environmental and personal factors [30]. The ICF's four components are Body Functions and Structures, Activities and Participation, Environmental and Personal Factors [30]. The Body Function and Structures component refers to aspects of the body that are important for functioning, such as anatomy and mental functions [31]. The Activities and Participation component refers to all aspects of peoples' lives, including basic activities such

as speaking and complex tasks such as various levels of education [31]. The Environment and Personal Factors are the contextual components of the ICF [30]. The Environment component of the ICF is compromised of the categories of the physical, social and institutional context and impact on performance [30]. As a supplement to the original ICF definitions of categories of Personal Factors have been recently developed and include aspects such as age, genetics, memory, and personal attitudes [32]. Categories within the environmental component of the ICF can act as either facilitators or barriers to performance. The ICF provides a framework for structuring and evaluating interventions, such as SPM, and a means of objectively understanding the focus of strategies by targeting barriers or facilitators as defined by the ICF [33]. The structure of the ICF encourages researchers and clinicians to consider intervention targets beyond impairment, directing their attention towards contextual factors external to an individual living with a health condition, including aspects of the environment or an activity. Providing a framework to holistically understand a person on the autism spectrum (figure 1) the ICF fosters a more balanced approach to both identifying the challenges and strengths of autistic individuals, and is advocated as an approach likely to improve outcomes for these individuals [34, 35].
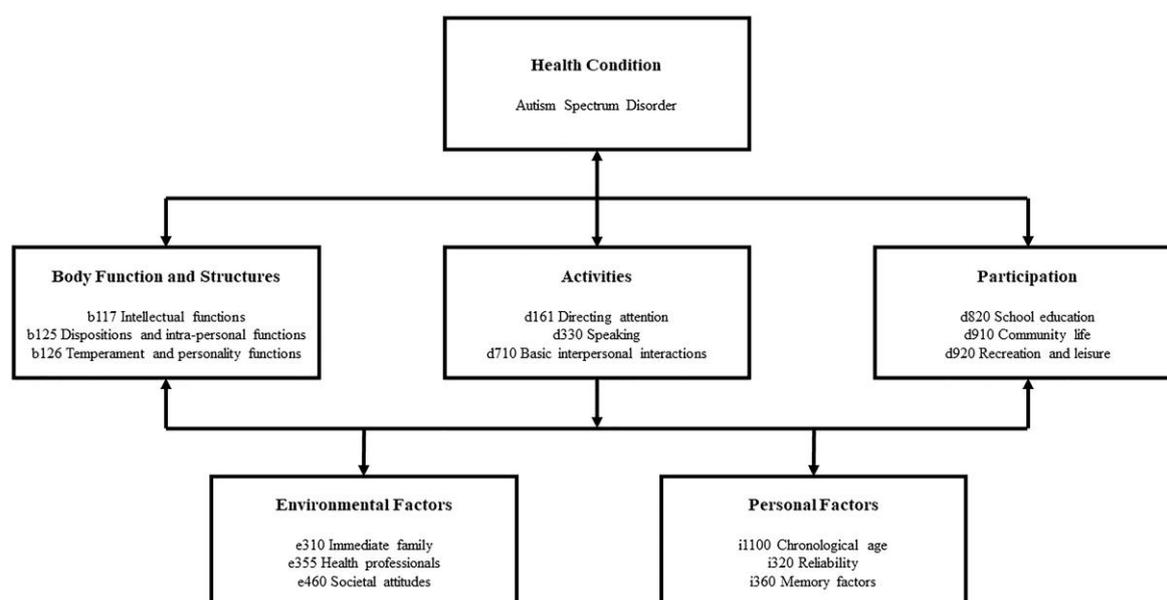

Figure 1: The International Classification of Functioning, Disability and Health (ICF; (World Health Organisation 2001). Illustrative ICF categories selected from the Comprehensive International Classification of Functioning, Disability and Health core set for Autism.

The utility of the ICF for researchers and clinicians in the area of autism has been improved by the development of the ICF core sets for Autism Spectrum Disorder (ASD) which through a rigorous process identified those categories most relevant to understanding functioning in autism [36]. Previous research examining the active ingredients of SPM, or those mechanisms supporting outcomes, and their alignment with the ICF core set for ASD revealed that SPM was strongly aligned with the ICF domains of participation and the environment [18]. The active ingredients of SPM, operating within these domains, assist autistic university students in maximising the fit between themselves, participating in major life areas, such as higher education [18]. While research aimed at understanding the appropriateness of SPM for autistic university students has explored, in-depth, the experiences of autistic university students [19] and their peer mentors [18], the experiences of parents of autistic students involved in the SPM remain unknown. Considering parents often continue to provide advocacy and support to young adults with autistic university students, and SPM aims to meet these needs it is important to examine the impact it has on them. Thus, the aim of this study was to explore the experiences of parents of specialist peer mentored autistic university students.

Method

Study design

An inductive design underpinned the selection of a semi-structured interview approach as the most appropriate method for eliciting the rich experiences of parents of autistic university students participating in SPM. This in-depth approach allowed the exploration of parents' expectations, perceptions, opinions, beliefs, and attitudes about SPM and its impact on autistic university students and their families.

Participants

Purposive sampling sought parents of autistic university students participating in SPM by seeking permission from autistic university students participating in two specialist peer mentor programmes based on the Autism CRC Specialist Peer Mentoring Programme outlined earlier [21]; the Curtin Specialist Mentor Programme (https://students.curtin.edu.au/experience/mentoring/autism-related-conditions/), and the Specialist Peer Mentor Programme at the University of Western Australia (https://www.student.uwa.edu.au/experience/health/uniaccess/Mentoring).

A total of 13 parents (2 fathers and 11 mothers) participated in the interviews (Table 1). One of the parents identified themselves as being on the autism spectrum. Parents discussed the experiences of 12 specialist peer mentored autistic university students (average student age=21.2; SD=1.94; 2 female).

Table 1. Demographic details of the parents of autistic university students engaged in SPM.

Demographic data		
Employment status of participants	1	volunteering
	1	studying full-time
	3	unemployed
	5	employed part-time
	3	employed full-time
Marital status of participant	3	divorced
	10	married
Income level of participant	3	$0 - $20,000
	3	$20,001 - $40,000
	2	$40,001 - $60,000
	4	$80,001 - $100,000
	1	$100,000 +
Income level of spouse (where applicable)	1	$0 - $20,000
	1	$20,001 - $40,000
	1	$40,001 - $60,000
	3	$80,001 - $100,000
	4	$100,000 +
Highest education level of participant	1	High School
	1	Trade/technical qualification
	1	Graduate diploma or certificate
	1	Advanced diploma
	8	Bachelor degree
	1	Postgraduate degree (Masters or PhD)
Highest education level of spouse (where applicable)	2	Trade/technical qualification
	2	Graduate diploma or certificate
	2	Advanced diploma

	3	Bachelor degree
	1	Postgraduate degree (Masters or PhD)
Age of diagnosis of their child	4	2-6 years
	2	7-12 years
	6	13-18 years
	1	18+ years
Living arrangements autistic university student	12	living in family home
	1	Living in shared accommodation without support
Number of siblings of the autistic university student	2	none
	6	one
	5	two siblings

Procedures

Prior to commencing the interviews, two of the authors (CT and KE) developed an interview guide (Table 2), inclusive of appropriate prompts. The context to be explored with participants was clear from the outset; namely, the expectations and experiences of parents of university students with ASD participating in SPM programmes. The interviews were conducted either face-to-face or over the phone, according to the preferences of the interviewees. The interviews were recorded using a digital audio recorder and transcribed verbatim.

Table 2. Parent interview topics.

Interview topics
What were your expectations and goals for education for your autistic university student?
What were your expectations of SPM for your autistic university student?
What was the impact of SPM on your autistic university students?
What was the impact of SPM on families?
How would you evaluate the SPM program?

Data Analysis

Transcribed interviews were checked for accuracy by the interviewers prior being important into NVivo 12 [37] which supported the analysis process. Data analysis was completed in three stages; 1) the identification of meaningful concepts as outlined in the standard ICF linking rules [38, 39], 2) thematic analysis to identify themes, and 3) directive content analysis, linking meaningful concepts to the ICF core set for ASD [36]. Meaningful concepts were extracted from the data by an inductive approach, examining the text for changes in meaning within the data [38, 39]. The process of extracting meaningful concepts was completed by two authors (CT and BM) who met regularly discussing the process and sections of text to ensure consistency.

Thematic analysis was conducted by the same authors, employing an inductive approach in generating themes and a deductive approach in mapping meaningful concepts to the comprehensive ICF core set for ASD [36]. The process of identifying the meaningful concepts ensured that these two authors were familiar with the data prior to commencing thematic analysis. Meaningful concepts were explored thematically and grouped accordingly, underpinning potential themes. The potential themes were mapped inductively in a collaborative process between the two authors. These mapped themes were defined and named, with any disagreements resolved via discussion until consensus was achieved. The credibility of the results from the thematic analysis was explored with the remaining authors and any disagreements were resolved following group discussions. The resultant themes were provided to the participants for member checking [40].

Directive content analysis [41] was used to deductively analyse meaningful concepts identified in the data. The ICF linking rules [38] were employed to map the meaningful concepts against the ICF core set for ASD [36] and the proposed Personal Factors [32]. Meaningful concepts that were not captured in the linking process were coded as 'not-coded'. Two authors (CT and BM) initially independently coded meaningful concepts, according to the linking rules, subsequently comparing their results, resolving any discrepancies via discussion until a consensus was reached for every meaningful concept.

Ethical considerations

This study was approved by Curtin University Human Research Ethics committee (HR16/2014) in Western Australia, with the Human Ethics office at the University of Western

Australia providing reciprocal approval (RA/4/1/7606). Parents were contacted only when the autistic university student provided written consent for the researchers to do so. Informed written consent was obtained from all participants prior to commencing the semi-structured interview.

Results

Interview themes

A total of 284 meaning concepts emerged from the data, which were largely encompassed by five inter-related themes: *1) The mentoring relationship is a facilitator; 2) Developing skills for university; 3) Mentoring changes lives; 4) Mentoring is not a substitute for other supports; and, 5) 'University' is an emotional rollercoaster*. This thematic framework (Figure 2) indicated that from the parents' perspectives the mentoring relationship facilitated the development of skills for university, which impacted on the lives and experiences of autistic university students. Overall, parents described the experience of their autistic young adult attending university as an *"emotional rollercoaster"* and while SPM was important in support their young adults, it could not provide all of the necessary supports.
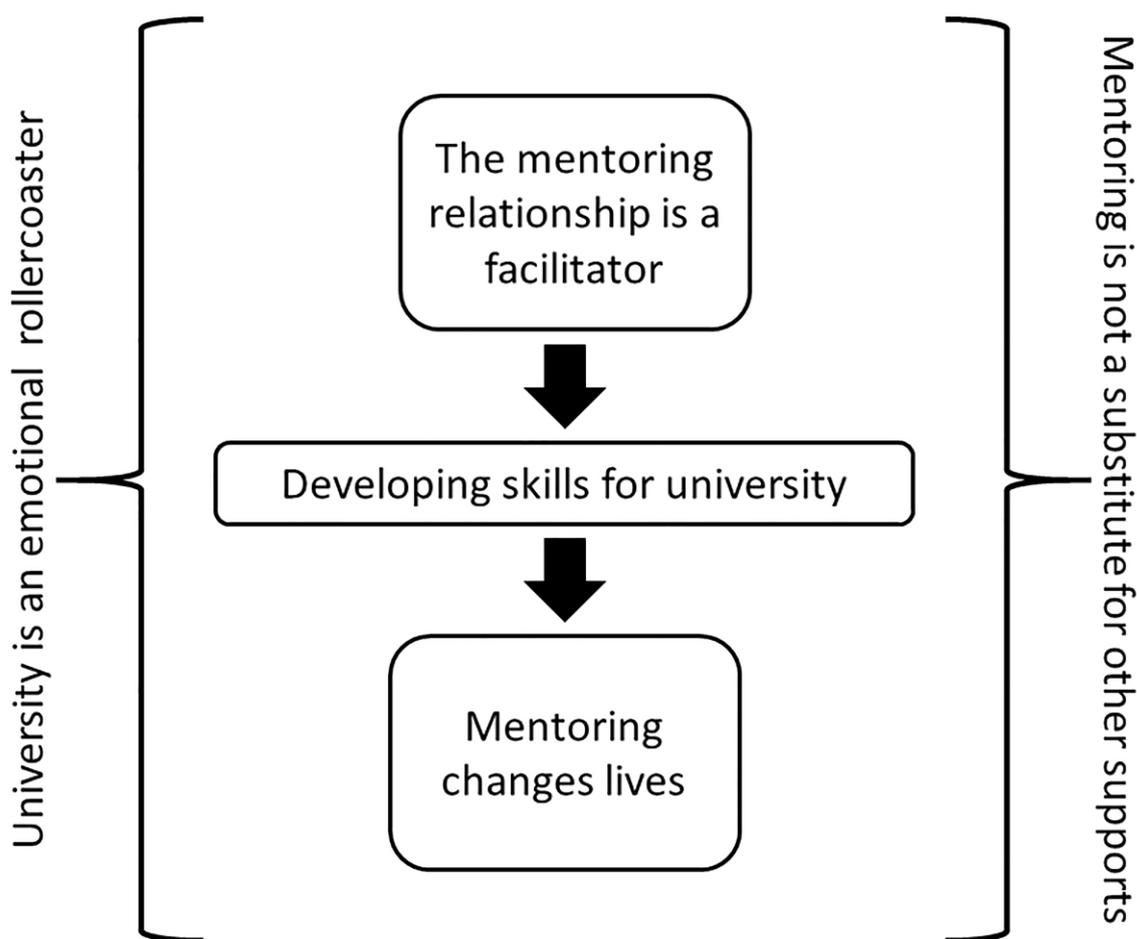
Figure 2: The five inter-related themes from interviews with parents of autistic university students.

The mentoring relationship is a facilitator

This theme captured the interaction within the mentor-mentee dyad that served as a key mechanism in supporting outcomes for autistic university students. Parents observed that autistic university students initially found university challenging. These challenges included difficulty interacting with lecturers and peers, organising their studies and navigating the university campus:

> " … [they have] very little organisational skills … [peer mentoring] gave him someone from a higher standing from a higher level to teach him how things perhaps should be done and how to navigate things."

Parents noted that the mentor relationship helped autistic university students in "finding [their] feet" in their early university days. As the mentee-mentor relationship evolved across the semester mentees began to admire their mentor, seeking to emulate their skills in managing

university life, and their relationships peers and their parents. Having the relationship at the core of peer mentoring enabled support to be tailored to each autistic university student.

Developing skills for university

This theme captured those aspects of SPM that enhanced autistic students' academic and life skills within the university context. Parents reflected that prior to attending university they supported their autistic children in planning and prioritising their learning experiences. Parents noted that as a result of working with their peer mentor, their autistic young adults had improved in their planning and execution of academic tasks. Peer mentors supported mentees by modelling problem solving of university-related challenges, with the result that they were able to engage more effectively in classes and in the broader university environment:

> " … all that stress and anxiety about being in this environment all these 'strange faces' that he has to talk to, all that is alleviated a bit by [SPM]…"

Parents perceived mentors as assisting autistic university students in breaking down, planning and managing their university assessments:

> "[His mentor] could break it down, and just to the points that [they] had to do."

Parents reported that group-based assignments were a cause of significant stress for autistic students, and they commented on the value of the support that mentors provided in helping their young adult in negotiating the expectations and interactions with their peers.

Parents described instances of mentors assisting autistic university students in navigating the process of obtaining assessment extensions, to the point where they were eventually able to negotiate this process independently, without external help either from their mentors of parents.

> "[My daughter] hasn't needed me to come on to campus and talk to her lecturers. She's done that herself, and she feels that she can do it herself, and if she can't do it by herself, she knows that she can talk it over with her mentor."

In working with their autistic university student SPM developed study plans, with the goal of completing their course work, with the consequence that they were able to manage their anxieties and apprehension more effectively:

> "For me the main thing was to have someone oversee his organisation and someone that he could go to. If he had a specific person that he could go to, if he had a problem and didn't know which way to approach it."

Parents observed that autistic university students "stress when it comes to exam time", but as a result of participating in SPM they had noted improved outcomes, including improvements in academic performance:

> "I know he says he's passed every assignment he's done so, which is very good!"

Mentoring changes lives

The theme describes the impact of SPM on the lives of parents of autistic university students and that of autistic students themselves. Parents reflected prior to SPM it had been their role to manage their children's educational experiences and they had to understand "…what they were studying." However, parents were acutely aware that now their children were young adults and at university high levels of involvement from them was not appropriate nor welcomed. Parents saw SPM as providing a much more age-appropriate support mechanism, enabling parents to take a step back, as they no longer needed to "rescue" or tutor their autistic university student:

> "[My daughter] knew what to expect. [She was] meeting with [her mentor] and telling [her] about the different problems that [she] had, [her mentor] was giving her ideas, like how to access the help with writing reports."

The support and assistance provided by mentors mitigated the need for parents to provide support:

> "Things have definitely improved. As I said, I sort of feel that I have taken that step back, and I'm, sort of, like, on the periphery at the moment."

Parents perceived their participation in SPM as improving their relationship with their adult child, attributing their involvement in mentoring as reducing the friction and arguments in the parent-child relationship. Parents were relieved that they were able to delegate their child's advocacy and support needs at university to a specialist mentor, allowing their relationship to "mature and develop." Many parents described SPM as allowing them the freedom to pursue their own life goals:

> "I delayed my [own] studies until next year, because I know that [Mentee]'s got the mentoring programme here, I've still got to be 'aware' of things and everything like that, but I will be studying."

The support of SPM also impacted on parents' time resources, increasing their available time, enabling them to spend more time with other family members:

> "I've got two other children, and I can spread myself around a little bit more. … So, I
> think, [SPM], it's balanced us all. It's been a bit of a levelling"

Ultimately, parents believed that mentoring "makes life easier" and they had "improved peace of mind":

> "I don't have to worry. … it's not up to me to 'fix' things … there is someone that I
> can go to, to say, 'What should we – what can be done here?' … if there wasn't the
> mentoring thing, it would have been 'me' having to contact the university."

This theme also referred to parents' observations of autistic university students developing relationships as a result of specialist peer mentoring:

> "It was the mentoring that gave him a connection with an individual, that he could go
> to and that individual could then help him, encourage him."

As a consequence, parents were "…confident that [their children] now know how to navigate and follow the university programme." Working with mentors enable autistic university students to take more "ownership" and "responsibility" of their university journey, which will continue to develop and change their lives.

This journey was also observed in the ongoing development of friendships and confidence in communicating with peers:

> "…having support. Having someone that would support her and to – that she might
> make some friends."

Parents believed that mentoring fostered their child's "sense of connectedness" to university, particularly through their involvement in the "social group", given it required autistic university students to expend spend less effort in socializing, helping them to focus on their studies:

> "… [SPM] makes them able to cope with university, and therefore concentrate on
> studies and therefore get out and change the world."

From the perspective of the parents participating in SPM meant that autistic university students were less isolated at university and not as anxious about their studies:

> "It's not just anxiety about going to your class, it's anxiety about having to get there in
> the first place, and then finding your way around the campus, and learn what the rules
> are, both the written, and the unwritten rules, of life at university."

Parents perceived SPM as a catalyst in helping autistic university students develop confidence in their own ability to organise and plan their studies, enabling them to take "responsibility of their studies" while having the opportunity "approach and ask advice" from their mentor as needed:

>"But then the second semester, she knew what to expect, she was meeting with [her Mentor], she was telling [her Mentor] about different problems that she had. [Her Mentor] was giving her ideas, like, she helped [my daughter] access the help that you can get with writing reports, and things like that."

Mentoring is not a substitute for other supports

Parents readily recognise the powerful support the SPM provided autistic university students, they also noted that supports were required in addition to mentoring, hence the theme *Mentoring is not a substitute for other supports* emerged. Parents noted that autistic university students continued to receive support from General Practitioners, Counsellors and Psychologists. Parents continued to support their autistic young adults, encouraging them to stay focused on university tasks, and providing psychological support as needed:

>"I have to keep [my son] on track when [he is at] home. [He is] quite easily distracted…"

While parents appreciated the independence that peer mentoring fostered they also expressed a desire for greater communication and feedback on their child's progress and even more involvement in the SPM process:

>"Parental involvement [would be good] and feedback in general, if the student approves and agrees. As I have always been a proactive parent, it is nice to get more feedback from mentors and [university] staff in general."

University is an emotional rollercoaster

This theme captures parents' perception that while university was a challenging journey, for their autistic young adults, it could be navigated with appropriate supports. Parents talked about the wide range of emotions they had experienced while attempting to support their child through their university studies. While the journey began with pride and excitement as their autistic young adult commenced their university studies, it was quickly followed by feelings of apprehension and anxiety, as young adults encountered challenges navigating university:

>"Extremely nerve-wracking, but also exciting. I initially needed to help him a lot with being organised and keeping on top of things, as everything was very overwhelming. He was presented with so many new situations and people to deal with all at once, which was very stressful."

The parents reported an experiencing a range of emotions when SPM commenced, including relief, happiness and pride:

"Very proud, but determined to be well prepared to make the experience as smooth and as positive as possible."

Linking to the ICF

The data from the 13 interviews relating to the SPM intervention and associated experiences resulted in 284 meaningful concepts. These meaningful concepts were linked to the second-level of the ICF and the sub-set of the ICF core set for ASD; *Body Functions and Structures* (14*%), Activities and Participation* (44%), *Environmental factors* (32%) and *Personal Factors* (7%) within the comprehensive ICF core set for ASD (3% not coded).

The meaningful concepts were linked to the *Mental functions* chapter of the *Body functions* of ICF only, and the most frequently associated category being *e152 Emotional functions* and the second-highest category *b114 Orientation functions*. The *Emotional functions* identified by parents of autistic university students highlighted their importance of managing the psychological impact of attending university and their relationships with others at university.

Table 3. Absolute frequencies of ICF categories from the Body Functions component linked to meaningful concepts identified from interviews with parents (N=13) of autistic university students

Second level category code	Category code description	N
b152	Emotional functions	21
b114	Orientation functions	8
b125	Dispositions and intra-personal functions	4
b126	Temperament and personality functions	2
b164	Higher-level cognitive functions	2
b140	Attention functions	1
b160	Thought functions	1

The *Activity and Participation* component of the ICF was linked to 44% of the meaningful concepts, as shown in Table 4. The meaningful units were linked to six of the nine chapters of the *Activity and Participation* component of the ICF and most frequently to the

Major Life Areas chapter. The *General tasks and demands* chapter was the second most linked chapter. The category most highly linked to the meaningful units was *d830 Higher Education*, highlighting the focus of the discussion with parents. The second most frequently linked category was *d240 Handling stress and other psychological demands*, corresponding with parents' view that the autistic university students needed to manage the psychological challenges of their studies.

Table 4. Absolute frequencies of ICF categories from the Activity and Participation component linked to meaningful concepts identified from interviews with parents (N=13) of autistic university students.

Second level category code	Category code description	N
d830	Higher education	57
d240	Handling stress and other psychological demands	18
d177	Making decisions	13
d720	Complex interpersonal interactions	7
d175	Solving problems	3
d161	Directing attention	3
d160	Focusing attention	2
d710	Basic interpersonal interactions	2
d910	Community life	2
d870	Economic self-sufficiency	2
d750	Informal social relationships	2
d760	Family relationships	2
d820	School education	2
d470	Using transportation	2
d250	Managing one's own behaviour	1
d475	Driving	1
d740	Formal relationships	1
d155	Acquiring skills	1

The *Environment* component of the ICF was linked to 32% of the meaningful units of the interviews as shown in Table 5. The meaningful units were linked to three of the five chapters of *Environment* components of the ICF. The most highly linked chapter was *Chapter 5 Services, systems and policies*. The most highly linked category was *e585 Education and training services, systems and policies*, corresponding with the parents' discussion of the policies and services relevant to supporting autistic university students.

Table 5. Absolute frequencies of ICF categories from the Environment component linked to meaningful concepts identified from interviews with parents (N=13) of autistic university students.

Second level category code	Category code description	N
e585	Education and training services, systems and policies	43
e310	Immediate family	18
e325	Acquaintances, peers, colleagues, neighbours and community members	16
e460	Health professionals	3
e330	People in positions of authority	3
e320	Friends	2
e575	General social support services, systems and policies	1
e580	Health services, systems and policies	1
e355	Health professionals	1

The *Personal Factors* component of the ICF was linked to 7% of the meaningful concepts identified from the interviews, as shown in Table 6. The meaningful concepts were linked to three of the five chapters of the *Personal Factors* of the ICF. The categories most linked to the meaningful units was *i335 Self-confidence* and *i430 Social skills*, referring to parents' discussion of the need for their children to develop confidence and social skills supporting their navigation of the university environment.

Table 6. Absolute frequencies of ICF categories from the Personal Factor component linked to meaningful concepts identified from interviews with parents (N=13) of autistic university students.

Second level category code	Category code description	N
i335	Self-confidence	4
i430	Social skills	4
i433	Methodical skills	3
i436	Empowerment	2
i439	Proaction	2
i428	Attitude toward help	1
i540	Belonging to groups in society	1
i550	Educational status	1

Discussion

The findings of this study indicate that overall parents' experience of SPM was positive. Themes emerging from discussions with parents suggest that SPM largely addresses the concerns, while simultaneously meeting the hopes and aspirations of parents for their autistic young adults. Autistic university students participation in SPM reduces the need for parents to provide academic, organisational, or psychological supports [42]. In previous studies, the authors examined the impact of SPM on mentors and autistic university students from their perspectives and the results are broadly congruent with the results of this study [18, 20]. Indeed, it appears that SPM makes a positive impact on both the lives of autistic university students and their parents.

The relationship between the autistic student and their mentor was key to the success of SPM at university. Parents described the mentoring relationship as a catalyst in changing their child's behaviour and fostering their success at university. The quality of the relationship between the mentor and the autistic university students has previously been noted as key in the mentoring process and as providing both emotional support and academic performance [27]. Through the advocacy and support of the mentor relationship, the challenges experienced by autistic university students could be overcome. As the mentors can assist to improve communication with university lecturers this same process can assist them to understand the

challenges and strengths of autistic university students [10]. The advocacy demonstrated by mentors assisted the autistic students to develop self-advocacy skills [27]. Traditionally, parents are confused as to how they should organise the necessary supports for their autistic university students as they move into adulthood [8, 42, 43] but SPM removes this confusion.

The dyadic relationship between mentor and mentee supports autistic students in understanding their university peers [10]. In the intense dyadic interaction, the autistic university students and their mentors problem-solved issues relating to social interactions. This was achieved through the individualised and contextualised ingredients of the mentoring relationship within a broader plan including any necessary supports outside of the SPM relationship [11]. Parents interviewed in this study observed that as a result of participating in SPM their young adults improved their study skills, with parallel improvements in their executive functioning, addressing parents desire for their autistic university student to succeed in the university environment [10, 14]. Interventions which focus on modifying the relationship between the university environment and an autistic individual has been prioritised as an intervention target by autistic students and their families [10, 14].

The dyadic partnership formed in SPM had impacts beyond the university setting and specifically on families and their relationships. In the absence of SPM, the support vacuum experienced by autistic university students is often filled by parents, which can have a detrimental effect on the changing relationship into adulthood [44, 45]. The specialist mentor provided study support and advocacy, which had the effect of reducing the need for parental involvement in university studies [46]. The parents in the present study indicated that when they decreased their involvement the studies of the autistic students, they noted improvements in their relationship. During the transition into adulthood, parent-child relationships invariably change and the specialist mentor provided space for this development to occur. Ultimately, mentoring in this form can provide a catalyst for the development of autonomy for young autistic adults [15].

The unmet needs of young autistic adults have detrimental impacts across the entire family [8, 12, 13, 43, 47]. The individualised and contextualised supports of SPM at university aided in the reduction of these unmet needs, positively affecting the lives of the autistic university students and their families. SPM had the effect of providing parents of autistic university students with increased opportunity to explore their own leisure, work or study options. This,

in turn, may have positive implications for the mental health of parents [48]. For autistic university students, the specialist mentor served to assist in working within environmental factors, as classified by ICF, increasing the fit between the individual and their situation [14, 18]. This SPM process aided the successful navigation of the university environment enabling autistic university students to succeed in their studies [11]. Simultaneously, the autistic university student may also develop further life and social skills that will aid in finding their place in society [18].

The use of the ICF core set for ASD [36] to objectively define the intervention from the perspective of the parents helped to demonstrate that the SPM intervention actually focused on maximising the person-environment fit. While there has been some criticism regarding the definitions of the participation, activity and the relation to the environment [49], this study has followed the traditional tripartite of the ICF model. Linking the findings of this study to the ICF core sets of ASD demonstrated that the SPM intervention, from the perspective of parents, matched the preferred approach identified in previous research as it does not focus on deficits [14]. This demonstrates the utility of the ICF core set for ASD in guiding both the development of interventions and in reviewing support services to ensure they achieve their objectives. Considering that the ICF core set for ASD can facilitate the examination of challenges and strengths it can assist service providers to utilise a strength-based approach when working with autistic individuals [50]. Finally, this study has demonstrated that the holistic nature of the comprehensive ICF core set for ASD could be used effectively from the parents' perspective to identify unmet needs of autistic adults and their families.

The results of this and other studies indicate that when developing supports, such as SPM, the relationship between the environment and the autistic students' needs to be carefully examined. The services should maximise the fit between the strengths of the autistic students, while at the same time modifying environmental interactions. This should include individualised strategies to minimise the impact of the executive functioning challenges experienced by autistic university students. The ICF core set for ASD should be utilised to review the design and implementation of services and supports for autistic students to ensure focus is on participation, rather than symptom change at the body function and structure level [36].

This study was limited to exploring the perceptions of parents of autistic university students within the context of Curtin University and UWA SPM programmes. The associated experiences of the autistic university students have were explored in other studies [18, 20]. A strength of the study was that the methodological approach allowed the rich voices of the participants to be heard. This methodological strength may also be viewed as a weakness, as transferability of the results is limited. However, the findings may also reflect the experiences of parents' of young autistic adults in other post-school education contexts such as vocational education or entry-level employment.

The present study indicated that as a result of their young adult's participation in SPM at university, parents broadened their own participation in important activities. This suggests that SPM benefits mot only young autistic adults, but also their parents. Future research should further quantify the impact of programmes such as SPM on the parents of young autistic adults. It is also likely that SPM economic benefits to autistic students, their families and universities, but this should be further examined in a comprehensive cost-benefit study of both short and long-term impacts of SPM.

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Conflicts of interest

Sven Bölte discloses no financial or conflict of interest related to this article. Sven Bölte discloses that he has in the last 5 years acted as an author, consultant or lecturer for Shire, Medice, Roche, Eli Lilly, Prima Psychiatry, GLGroup, System Analytic, Ability Partner, Kompetento, Expo Medica, and Prophase. He receives royalties for textbooks and diagnostic tools from Huber/Hogrefe, Kohlhammer and UTB.

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The results of this chapter outlined that the mentoring relationship is a facilitator of the development of autistic university students and their skill sets. Furthermore, SPM facilitated change in the lives of parents and their autistic university students. However, these results indicated that SPM is not a substitute for other supports of autistic university students and participating in post-secondary education is an emotional rollercoaster for families. The ICF analysis indicated that the SPM intervention did indeed focus on managing the environment to facilitate participation in university.

This chapter concludes the empirical part of the thesis.

Chapter 7: Thesis Discussion

Thesis Discussion

Everyone should have the opportunity to follow their dreams. Studying at university is one strategy allowing people to achieve their dreams [132, 249]. However, it has been proven difficult for autistic individuals who often have numerous obstacles to overcome when achieving their dreams and struggle to reach their potential because of their difficulties with, for example, social communication [123]. So, a key question is how can young autistic people work through these challenges as they move into adult life [132]? Addressing the knowledge gap of young adulthood in autism could have broad ranging impacts, such as improved education, employment, relationship, and autonomous living outcomes. These impacts could improve adult life outcomes for autistic adults.

Post-secondary education is an important avenue for improving participation and opportunities for young autistic people [118]. Inclusive education has been a mechanism utilised extensively to improve outcomes for people with disabilities in general [93, 154, 206], as levels of educational attainment have implications for independent living, employment and autonomy. Historically, when compared to their peers, autistic adults have been noted as having poorer overall outcomes in the area of education [215], employment [235] and independent living [58], areas essential for autonomy in adulthood [79]. Regardless of the research perspective, there has been a lag in the examination of the autistic adult experiences when compared to that of autistic children [134]. The predominant focus on the childhood experience has resulted in a lack of evidence for supporting autistic adults, particularly as they begin to transition into adult life [132]. The limited research in the area of autistic adulthood has primarily focused on ameliorating deficits [127, 168]. Consequently, there has not been a coherent method that utilises strengths while mitigating the challenges faced by autistic adults.

An opportunity to meet the unmet needs of autistic adults to improve participation in major life areas is to utilise a strengths-based approach [199, 208]. However, to be successful strengths-based approaches need to be contextually specific and environmental in their design [239], focusing on the abilities of autistic individuals rather than impairment [14, 237-239], as demonstrated in the present thesis. Approaches that are individualised and strength-based do increase the possibility of success [115], by recognising the talents, abilities, capacities, resources, and potential for growth of people [208]. Another essential component of strengths-based approaches involves matching the demands of the activity to the abilities and/or interests of young autistic adults

[143]. In the post-secondary context, large universities with diverse course options provide opportunities for autistic students to match their interests with their studies [249]. However, it is not clear if higher education institutions are facilitating this process effectively [11, 237].

When promoting strength-based approaches, it is necessary to holistically understand autistic adults [199]. This understanding provides the basis of the identification and recognition of strengths, and potentially leads to the development of facilitators for positive experiences [178]. Some of the key strengths of autistic individuals include attention to detail, preference for repetitive/predictable tasks, computer skills, trustworthiness, and strong memory skills [85]. Parents have recognised that when young autistic adults' strengths are not clearly understood by others, they can instead become a barrier to their participation in major life areas, such as employment or education [239]. Therefore, it is critical to promote an understanding of strengths to provide an opportunity to improve the fit between the autistic person and the environment [237]. While universities and employers can optimise the fit between the individual and the environmental demands, some 'gifted' autistic students' strengths can actually mask their challenges in education and employment settings, unless an holistic understanding approach is taken [12]. Perhaps due to masking of their challenges, autistic adults without a co-occurring intellectual disability paradoxically often have poorer employment outcomes than their counterparts [235]. In order to identify the needs of those young 'gifted' autistic adults, a holistic understanding of their strengths and challenges is required to provide an environment where autistic people feel comfortable in sharing and demonstrating their abilities.

Strategies to improve social communication are necessary to facilitate individualised strength-based approaches. Indeed, parents have recognised that the social communication skills of young autistic adults need to be addressed to assist in understanding their strengths, so that they also can understand the world in which they live (chapter 2) [237]. It is a bidirectional relationship, in which strengths-based approaches allow opportunities to problem-solve communication difficulties that utilise the abilities of autistic adults (chapter 4 and 5) [239, 240]. Consequently, addressing the communication challenges within the university context can facilitate the development of social competence in autistic adults [47, 239]. Modelling communication within the environment using peers can thus promote social skills for autistic students [239]. These context-specific social skills are by nature effective in facilitating participation in specific major life areas, such as employment or education [24, 239, 240, 255]. The resultant increase in participation provides further opportunities for task mastery, which , in turn, may develop task-

specific self-efficacy [223]. In chapter 5 [240] of this thesis, autistic university students participating in SPM made small, but non-significant, improvements on the Generalised Self-Efficacy measure [213]. While developing social communication skills will assist young autistic adults to communicate their abilities more effectively [239] and provide learning opportunities and mastery skills, without effective executive functioning, the uptake of these opportunities will continue to be limited.

Executive functioning of autistic individuals can either hinder or support the completion of tasks. There is evidence that some autistic adults have executive functioning strength, such as working memory [166] and attention to detail [85]. However, there are common aspects of executive functioning that are challenging for young autistic adults, such as task planning, completion, and transitioning between activities [254]. Executive functioning skills mediate participation in major life areas and the development of individualised strategies to manage the completion of tasks is key to ongoing success [239]. Chapter 4 and 5 of this thesis has identified that appropriate environmental approaches may assist in the development of executive functioning skills for autistic adults [238-240]. Indeed, the contextual problem-solving support, as provided by mentors in the SPMP, is one opportunity to develop effective individualised executive functions strategies for autistic adults [239, 240]. As autistic individuals move into adulthood, the reduction of available services and supports makes the task of developing these skills more challenging [12]. In adulthood, this issue is exacerbated further, as accessing services relies on self-advocacy it is necessary to self-advocate to access any service, which commonly is a difficult task for autistic individuals [251].

As demonstrated in this thesis, students are expected to self-advocate when they need assistance and this provides a platform for the use of SPM with autistic university students [238-240]. The mentor is a crucial mechanism of SPM, as they interact with the autistic student to facilitate their participation [239]. However, for this process to be successful, the mentor needs the skills and knowledge to foster a partnership with their autistic mentee [240]. The results of chapter 4 of this thesis have indicated that an essential mechanism in promoting this mentor-mentee relationship is the specialised training provided to mentors, which aims to develop an understanding of autism along with strategies for working together [240]. This targeted education is only the first step in developing the mentor-mentee relationship. Mentors require ongoing supervision and support to ensure the partnership continues to evolve, so that they can work effectively with the autistic university student to help problem-solve challenges as they arise

[111, 224, 239]. The communication strategies of the mentors, including person-centred counselling and demonstrating mutual respect, were critical in the development of this relationship and are considered vital active ingredients of SPM. Through the mentor-mentee relationship developing into a partnership, the autistic university students observe and learn social skills that were specific to the university environment. Chapter 4 and 5 of this thesis demonstrated that the mentor also provided psychological support and assistance in setting goals to facilitate academic success [81]. This active ingredient of modelling communication identified in chapter 5 fosters the development of social skills in a naturalistic fashion. Individualised problem-solving is another mechanism of SPM identified in chapter 4 of this thesis, whereby the mentor-mentee partnership facilitated bespoke approaches to be utilised in addressing challenges experienced by the autistic university student. This thesis (chapter 4 and 5) examined the impact of these mechanisms and active ingredients, which appeared to positively affect the experience of autistic students at university. Consequently, the mentor-mentee relationship was critical to success.

To examine how the mentor-mentee relationship influences the interaction between the autistic university student and the environment, chapter 6 of this thesis used the ICF as a framework. From an ICF perspective, the environment can be either a facilitator or a barrier to participation for autistic adults. The autistic individual with all of their strengths and challenges interact with the environment to complete their activities and participate in major life areas [9]. In this conceptualisation, the environment encompasses everything external to the person, including the physical surroundings, institutional context and other individuals [267, 269]. Maximising the person-environment fit promotes the effectiveness of strengths-based approaches [14, 239, 240], which can minimise potential barriers to participation [167]. The results of this thesis suggest that promoting a successful environmental approach requires institutions and governments to have policies and systems in place that allow for reasonable adjustments to be made for autistic adults and the development of services to facilitate these process [238, 239]. While not always apparent, some effective legislative approaches have been implemented, such as the Disability and Discrimination Education Act [1] (DDA, Australia), the Equality Act [3] (UK), and the Individual with Disabilities Act [2] (USA). These government policies and other similar ones are providing the institutional environment imperative to develop services to facilitate participation in post-secondary education and employment. Based on these policies peer mentoring programs, such as ACSPMP (Appendix A), Horizons (https://www.uml.edu/research/autism/services/horizons.aspx), and the Autism Mentorship

Initiative https://www.sfu.ca/students/accessible-learning/programs-and-services/autism-mentorship-program.html) have increasingly been used in Australia [224, 240], Canada [8, 204], the USA[124] and the UK [170]. There is emerging evidence that these programs should be individualised and the programs should be underpinned by an effective relationship between the mentor and mentee, but the mechanisms behind them in general, and SPM in particular, were not well understood. Similarly, a mentoring program for university students with other disabilities may benefit from individualised approaches that are facilitated by the mentor-mentee relationship.
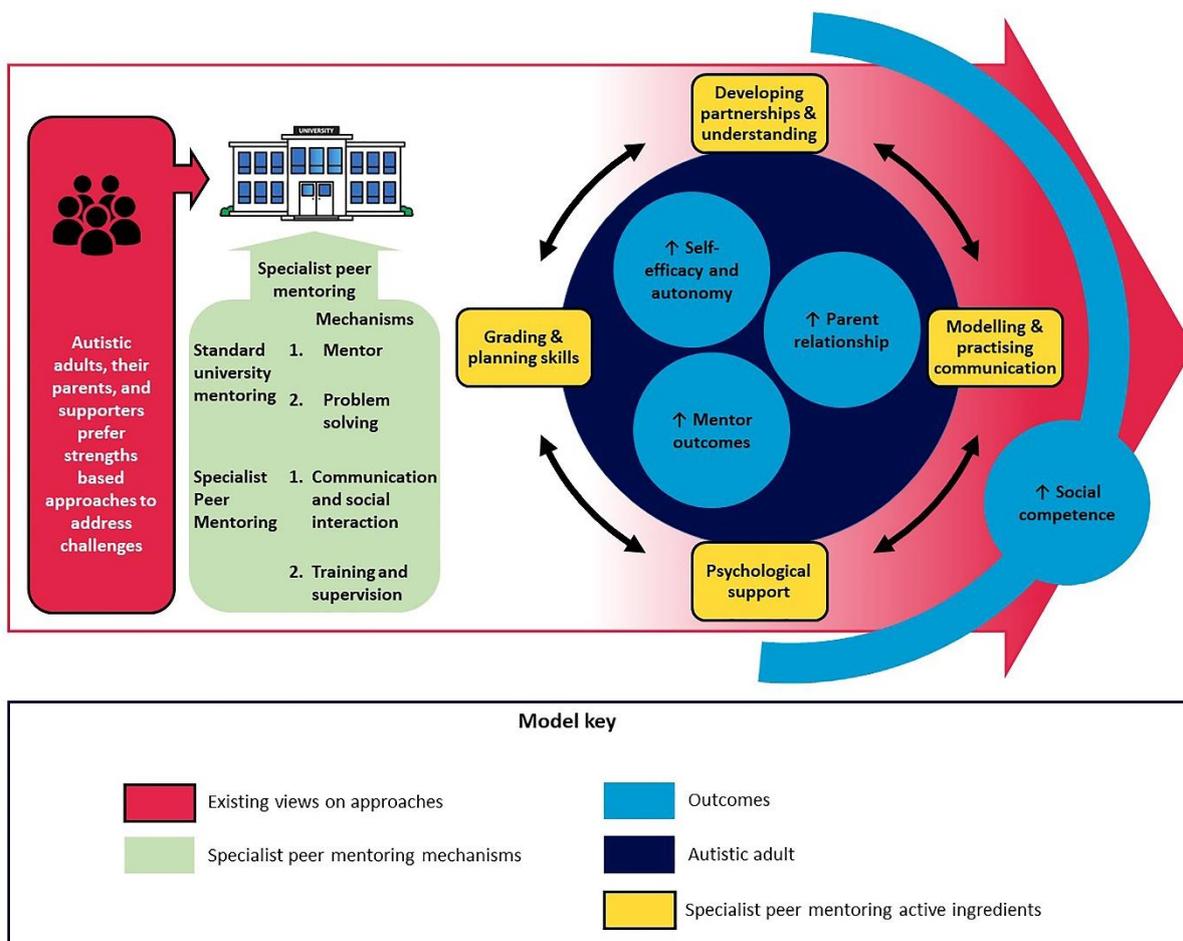
Figure 7.1: Conceptual model of thesis approach, the mechanisms and active ingredients of specialist peer mentoring and the resultant outcomes.

The conceptual model in Figure 7.1 has been produced as an illustration of the investigations and findings of the present thesis. The overall arrow of the model symbolically represents the progression of autistic adults through life, with the context of this thesis being university. Using the strength-based approach, the mechanisms and the active ingredients of SPM drove the outcomes that may continue to develop and affect their lives post university studies. These

outcomes are represented in the model in light blue. It should be noted that relationships between the active ingredients of SPM are illustrated by the bidirectional arrows, as they will inherently vary depending on individual dyadic needs.

More specifically, the model illustrates that the broad mechanisms of the SPM program, while the active ingredients are specific strategies of the intervention. The design of SPM programs are context-specific, and the mechanisms required are dependent on the demands of the environment and the core tasks of the situation in question [239]. One contribution of the present thesis in (chapter 4) is the demonstration that mechanisms of SPM can improve experiences of autistic university students and mitigate their autistic challenges, while continuing to being goal-focused [8, 204, 224, 239, 240]. Chapter 5 of this thesis has also shown that mentors who work on study goals allow the autistic university students to manage their executive functioning challenges more effectively [239]. The results of this thesis demonstrated that through the goal-directed relationship and the context specific strategies employed, the autistic university students can develop social competence and manage their challenges in this environment [239, 240]. For example, the autistic university students reported a statistically significant decrease in autistic traits, specifically on the Social Responsiveness Scale-2 total score ($d=0.40$), its Social Communication, ($d=0.45$) and Social Motivation ($d=0.38$) sub-scales, all with moderate standardised differences [240]. The results also demonstrated that SPM can facilitate autistic university students to improve the management of their own physical and social environment [239]. These improvements illustrate how strengths-based approaches can leverage contextual factors, such as the environment and personal factors, to facilitate positive changes for autistic students. Personal strengths, such as loyalty and honesty can be particularly useful in environmental support interventions, such as SPM [85]. Indeed, chapters 4 and 5 of this thesis does suggest that personal factors of loyalty and honesty are effective in the formation of the dyadic relationship that is crucial for SPM [239, 240].

Finally, chapter 6 of this thesis has shown that SPM can have positive benefits also in broader environmental contexts, such as for the family of autistic university students. Parents in chapter 6 noted that before the involvement of their autistic son or daughter in the SPM program, they were involved in all facets of their study life [241]. In the absence of SPM, this parental involvement is continuingly necessary, due to the aforementioned limited adult services [89]. Consequently, parents of autistic university students who engaged in SPM can decrease their

involvement in their son's or daughter's studies and focus on, for example, their own relationship [241]. While the journey of parents of autistic university students is a 'roller-coaster', involvement in SPM decreased the stressors experienced as a parent and family [241]. The involvement in SPM allowed parents to balance their contributions, promoting their ability to attend to some of their other life goals [152, 241]. They were also able to focus their attention across their whole family, which may have positive impacts on their quality of life [241]. Consequently, SPM may have broad benefits for everyone involved, including the autistic student, their family and, importantly, their mentors, as they gained experience in working in partnerships, which - as mentioned - may be beneficial for their future career development [111, 239]. In fact, the mentors gained crucial experience that could fast-track their career development [239]. While not studied in particular, being a mentor may also promote the value of life-long learning and continuous professional development among the mentors [111, 239]. A more pervasive effect of SPM is that it provides non-autistic university students with opportunities to interact on a one-on-one basis with autistic university students in a supportive environment [204, 239, 240].

Limitations

The present thesis applied multiple methods in response to the thesis aims and objectives. When interpreting the results, there are limitations to consider in relation to recruitment bias, response bias, methodological issues with regard to research design and, finally, proxy reporting.

Recruitment bias

The potential impact of recruitment bias must be considered when interpreting the results of this thesis. The results outlined in chapter 2 could have been affected by the relatively high socioeconomic status of the participants. These parents were also engaged with autism support groups possibly affecting the discussions in the focus groups to be more expansive and more positive about autistic adult outcomes in their responses. The results of chapters 3, 4, 5, and 6 were limited by the purposive and snowball sampling methods utilised. The participants were all of relatively high socioeconomic and educational status and therefore would respond differently to those who are not. It may for example have generated responses that were more focused on educational attainment that other groups. A broader recruitment approach may facilitate inclusion of participants from a larger range of socioeconomic status backgrounds. However, this may be more challenging than it may initially appear, as research from the USA has highlighted a general bias in diagnosing ASD towards individuals with higher

socioeconomic status [90, 186]. In contrast, research from Europe [86] and Australia [16] suggests that broader recruitment may indeed be achievable, with ASD being equally prevalent in populations with lower socioeconomic status in these locations.

Response bias

When interpreting the results of throughout this thesis, it is also necessary to consider response bias, as the participants in research may respond inaccurately or falsely, particularly in research involving interviews or focus groups where they might acquiesce with the researcher and agree with their presumed viewpoints. Moreover, the social communication difficulties inherent to the diagnosis of ASD, which may influence their responses when engaged in interviews, may result in short and simplified responses to questions. These communication deficits could indeed result in data lacking richness, limiting the depth of the understanding of the topic. In an attempt to mitigate the impact of these limitations, interview questions were carefully constructed to avoid closed questions and to include extra prompts to expand the responses where needed. In contrast, parents in chapters 2 and 6 were interviewed and when compared with their autistic children, they were not limited by communication difficulties and therefore able to actually provide expansive answers. However, the parents' data could have been limited by response bias as they may have provided comments that were deemed socially appropriate or those they anticipated were sought by the researcher. This potential response bias of the parents may generate an inaccurate understanding of SPM and the experiences participating in the program. The results in chapter 4 from the interviews with the mentors could also have been limited in this fashion. Member checking was conducted in chapters 2 and 6 in an attempt to minimise this bias, providing an opportunity for all participants to review and correct any bias that they had observed. In chapter 4, the potential for response bias was limited by combining the information gathered from the interviews with autistic university students and their mentors. Response bias could be mitigated in future research by using participatory action research or through other means of co-producing research. In Chapter 3, response bias was minimised through the Q-method, as the number of statements that are sorted by the participants are pre-defined. In Q-method researchers provide each participant with a large number of responses to the research question, in Chapter 3 there were 38 statements, and the participants rate their agreement with these statements. The large number of statements means that the participant has limited opportunity for response bias. However, the total effect of response bias is hard to determine.

Methodological issues with regard to research design

Cognisant of the social communication difficulties in autistic people, the Q-method was employed. In chapter 3, this method was used to explore the viewpoints of autistic adults who studied or were studying at university, their parents and those who support this population in their studies. A limitation of the Q-method is the concourse underpinning the development of statements to address the research question, as it can hinder demonstrating the participants' full viewpoint using only these statements. In an attempt to curtail this limitation, the concourse was developed from the literature with the support of an autistic reference group. In addition, participants were asked to add any missing statements or comments on completion of the Q-sort. To ensure that the concourse is representative in future research a broader co-production approach could be utilised. A further possible limitation of the Q-methos is that researchers interpret the meaning of the factors in a similar process used by qualitative researchers interpreting themes, which could introduce bias.

A possible limitation in chapter 5 is that a Bonferroni correction was not completed when seven tests were performed. The Bonferroni correction was not utilised because it would have provided a very conservative evaluation of the data therefore increasing the possibility of a type II error [192], which was not warranted because these results were supported by qualitative data. Furthermore, the Bonferroni correction assumes equal weighting among the tests and the varied results in chapter 5 do not support this assumption [15].

Research methods such as interviews can provide rich data, but they do have inherent limitations, present in chapters 4 and 6. The data in the interviews are limited in breadth because the participants were purposively recruited, and therefore the results of the interview studies were not generalisable, but may be transferable to the broader population. In this thesis, it may be possible to transfer results to similar post-secondary education environments in Australia. The results of interviews with parents and mentors in chapters 4 and 6 may have been affected by the social interaction created by the interviewers with the mentors, as the participants might respond in a way that supports the SPM program. All of the parents interviewed in chapter 6 still had adult autistic children involved in the SPM program and this may have resulted in a more favourable interview response. The potential of biased responses was, however, mitigated

by interviewing almost all of the mentors and by utilising researchers external to the SPM program. The semi-structured interview guides utilised in chapters 4 and 6 to facilitate the interviewer-participant conversation may have served to limit the topics discussed, but this could also have ensured that a holistic exploration of the SPM program was completed.

Proxy reporting

The studies in chapter 2 and 6 are limited by the use of proxy report data from parents. The parents provided data regarding what they had observed of their autistic son or daughter moving into adult life. Parents cannot know the exact feelings or experiences of their children, but they can provide information on their observations. These observations could be limited by recall bias associated with their experiences, but can provide some insight into what strategies were successful and what they consider barriers to their children's participation. These limitations may decrease the accuracy of these results. In the focus groups discussed in chapter 2, some participants could have been reticent to provide their full and frank views for fear of judgement by other participants. This limitation could be addressed by using strategies to include autistic adults in future research, and by for example experience sampling method using mobile applications to explore SPM in the moment [63, 64, 265].

In chapter 5, the SPMP was evaluated using a multiple methods approach. Due to the paucity of literature examining SPM, a power calculation was not completed before conducting the study in chapter 5. This increased the potential of a type II error. The observed effect size of SPM in chapter 5 on social communication and motivation was approximately d=0.4, and therefore the approximate sample required to obtain significant results would be 150. However, only 17 participants of the 30-40 mentees were recruited; therefore, this limits the generalisability of these results. The results of this multiple methods study must be interpreted with caution, due to the small number of participants who completed all of the measures. Recruitment may have been limited by the large volume of questionnaires employed, possibly reducing the accuracy of the results of those that did participate. As a consequence of the limited sample size, data were not normally distributed, but paired t-tests were used. It was decided to use the parametric statistical test as the results mirrored the equivalent non-parametric test and Cohen's d effect size can be calculated when using the t-test. The results of the evaluation also needed to be interpreted carefully as a Bonferonni correction was not

completed. This could be minimised by repeating the study with an increased sample and either reducing the questionnaires or by applying a Bonferonni correction.

An effective strategy to help understand the broad impacts of SPM is to utilise the ICF. Chapters 2 and 4 of this thesis demonstrated that the ICF, especially the ICF core set for ASD, can be used in conjunction with the standardised linking rules [70, 71] to objectively examine experiences of participants [237, 241]. The ICF is a holistic model that employs a biopsychosocial approach and has the breadth to capture the impact of SPM across all aspects of life. The ICF also provides a uniform and non-discipline specific language to discuss SPM. The use of the ICF, however, may have limited the understanding of the influences of the environmental factors on behaviours and learning. This may have been mitigated by employing the Social Learning Theory [26] as a means of examining the process and impact of SPM and could have explained the process of developing self-efficacy at university for autistic university students. However, the Social Learning Theory is not equipped with the same uniform and objective descriptors that are in the ICF. A further limitation of this thesis is that the ICF was not utilised in all chapters. These limitations could be minimised by utilising the ICF more broadly or by supplementing this with the Social Learning Theory.

Lastly, the long-term effects of SPM were not examined in this thesis. Due to the short-term nature of the outcome measurements, the impact on the grades of autistic students were not considered and this is a further limitation. Furthermore, in chapter 5 of this thesis did not employ a control group. Consequently, this thesis is unable to directly ascertain that the observed changes are a consequence of SPM. To mitigate these limitations future research could be conducted over a longer period and employ a control group.

Recommendations and future research

Given the holistic approach of the ICF, it could be employed in the assessment of autistic university students to identify the strengths and challenges [41]. This process could also be utilised to enhance a strength-based approach, such as SPM. The identification of the strengths of autistic university students would allow mentors to more appropriately use strengths in the strategies they employ. Furthermore, with the results of this thesis universities can develop SPM programs to improve the service for autistic university students. The ICF can be used to

examine, guide and develop interventions to ensure they balance the strengths with the challenges of autistic individuals.

The results of this thesis suggest that SPM can help autistic adults participate in university studies. The ACSPMP [181, 182] could be implemented at universities that have adequate policies and services to assist students with disabilities and other challenges. The SPM program can be used at these institutions to complement the general support programs with the autism-specific strategies it offers. The results of chapters 4, 5, and 6 demonstrate that to facilitate an effective ACSPMP, the mentors and coordinators must have the appropriate skills to work with autistic adults. They can be developed by providing the mentors and program coordinators specialist training on autism, communication, goal setting, and problem-solving strategies. This thesis (chapters 4 and 5) demonstrated that training and education would facilitate the program to be individualised, strength-based, and goal-oriented. Since working in a individualised, goal-oriented. Since working in an individualised, goal-oriented partnership is an essential mechanism to success, this could be enhanced by providing the mentor with tools to assist the process. Furthermore, considering that the partnership provides opportunities to observe and practise contextual social skills it is recommended that face-to-face verbal communication should be prioritised in the mentor-mentee partnership. To provide the best opportunity for the SPM program to promote development of communication skills, the program should involve the use of a Social Group facilitated by mentors with input from the autistic university students. The program will provide the autistic university student the opportunity to meet others on the autism spectrum, practise their communication skills with other mentors, and to facilitate social events.

There are many opportunities to further develop an understanding of SPM for autistic university students. It is important to repeat the evaluation in chapter 5 with a control group, larger sample and conduct the study over several years. The longer-term study would provide evidence on the efficacy and causality of the program. An effective examination of the long-term effects could be achieved through employing a longitudinal multi-site randomised controlled trial with an active control. Another area that could be explored is the efficacy of delivering the SPM program using an online or App-based platform utilising video communication technology rather facilitating the program face-to-face. Larger scale studies could also be used to examine the impact of SPM on self-efficacy and self-advocacy of autistic

university students. These large scale studies could examine the impact of SPM on the the skill and personal development of mentors.

Table 0.1. Key strategies for successful SPM for autistic university students.

Best current evidence for SPM Programs
1. Program co-ordinators and mentors must have appropriate skills for working with autistic adults.

2. Mentors should receive specialist training on;
    a. Understanding autism,
    b. Communication with autistic adults,
    c. Goal setting strategies,
    d. Problem-solving strategies.

3. SPM Programs should be;
    a. Individualised,
    b. Strength-based,
    c. Goal-oriented.

4. A Social Group co-facilitated by mentors and autistic students should be incorporated in SPM Programs.

Future research on SPM could explore what other areas the program could be utilised within. An area of interest is whether the SPM can be used across the lifespan for example in workplaces. High school is another possible period of the lifespan where the use of SPM program could be explored. The program would require adaptions to align with the needs of younger students and mentees. This adaption would result in a modification of the training program and supports for mentors. The Self-Determination Learning Model of Instruction [222] could be embedded in the training program to add structure to mentoring for younger students. This process would also open up the opportunity to examine whether the SPM influences self-determination for autistic students.

Further research could explore the impact of SPM on people other than the mentees. Considering that the mentors participating in this thesis were all from health sciences backgrounds it would be of interest to see if similar results could be achieved with students

from other backgrounds. Future research could also examine what makes an effective mentor in a SPM program. It would also be of interest to examine the long-term impact of SPM on a mentor's career and attitudes towards mentorship and ongoing learning and professoional development. In addition, it is of interest to explore whether autistic students or graduates could participate in the program as a mentor. Finally, future research could explore the impact of the SPM program on students with other disabilities.

Conclusions

This thesis (chapters 4, 5, and 6) has demonstrated that SPM can assist autistic university students' successful participation at university. Post-secondary education facilitated by SPM supports autistic university students to successfully navigate university and promotes their transition to adult life. This may facilitate opportunities for employment, which could then provide an opportunity to succeed in adult life. Overall, the results indicate that the relationships developed between the autistic student and mentor is a critical aspect of SPM. The development of this relationship is purposeful, with mentors using communication strategies to create this partnership. The dyadic nature of this relationship assists autistic university students in developing social competence. Autistic university students can also develop executive functioning strategies through their participation in the SPM program, which can facilitate participation at university. Chapter 6 of this thesis also demonstrated the unexpected effects that SPM can have on others associated with the autistic university students, such as their parents, whereby parents noted improvements in their relationship with their adult autistic child and mentors gained invaluable experience for their future career.

> "The mentor program was extremely valuable and my mentor was an approachable and relaxing source of advice and helped with university learning. I was able to address my problems effectively and the program has definitely provided me with valuable experiences. I found the program extremely helpful and a great source of advice and connections." Autistic university student (mentee).

Given the increasing number of autistic individuals attending post-secondary education, there is a strong need for individualised and strength-based approaches, such as SPM support to promote successful participation at university [8, 124, 203, 224]. As suggested by research conducted by Ames, McMorris, Alli, and Bebko [8], Hillier, Goldstein, Tornatore, Byrne, and Johnson [124], Roberts and Birmingham [203], and Siew, Mazzucchelli, Rooney, and Girdler [224] and given the

increasing numbers of autistic adults SPM plays a critical role in facilitating this participation and it is a key asset in university education for autistic students, because as Malcom X pointed out *"Without education [we] are not going anywhere in this world"*.

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Appendices

Appendix A: Autism CRC Specialist Peer Mentoring Program Manuals

Specialist Peer Mentoring Module

Providing Support to Tertiary Students on the Autism Spectrum and Related Conditions

Program Coordinator Manual

JUNE 2016

Curtin University

THE UNIVERSITY OF WESTERN AUSTRALIA

Australian Government
Department of Industry, Innovation and Science

Business Cooperative Research Centres Programme

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole of life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people with autism.

autismcrc.com.au

Dedication and Acknowledgements

I dedicate this work to all tertiary students on the autism spectrum (and related conditions) who continually strive to realise their educational and life potential.

> *"My son is a first year Curtin University student studying Physics and Engineering. Being autistic, he finds it difficult to fit into general social environments, and consequently to make friends and feel accepted. However, the mentoring program has been instrumental in helping him settle into university life, alleviating the enormous stress he had initially been suffering. He has found guidance, support, friendship and understanding. The weekly social group meetings have also been a wonderful part of the program. They have been fun and informative and allowed my son to make friends and meet people who understand him, in a safe and supportive environment. Without this fantastic program he would still be feeling anxious and isolated."*
>
> *(Parent of 1st year CSMP Mentee)*

Table of Contents

Autism CRC Specialist Peer Mentoring Module

MODULE ORGANISATION

The Autism CRC Specialist Mentoring Module is based on the Curtin University Specialist Mentoring Program (CSMP) - http://life.curtin.edu.au/health-and-wellbeing/autism-related-conditions-peer-mentoring.htm) and is broken into the following five separate sections:

1. The *Program Coordinator Manual* for the Coordinator (PDF).

2. The *Specialist Mentor Toolkit* for the Mentors (inclusive of the National Autistic Society [NAS] *Student Mentor Guidelines* and the National Disability Coordination Officer Programme [NDCO] of Australia *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder*) (PDF).

3. The *Mentee Information Booklet* for the Mentees and their Support Persons (inclusive of the National Disability Coordination Officer Programme [NDCO] of Australia *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder*) (PDF).

4. The *Specialist Peer Mentor Training Program* for the Coordinator *(PowerPoint*).

5. The *Mentoring Module Forms, Samples & Templates* for the Coordinator reproduces what is found in Appendix A, B, C, of the *Program Coordinator's Manual.* It is reproduced in Word Document form to allow modifications to be made easily according to individual institution's requirements (Word Document).

The Coordinator will need to be familiar with all five sections of the module so that each part can be used separately, modified, integrated and executed successfully according to the individual needs of their tertiary institution.

MODULE RATIONALE

The Cooperative Research Centre for Living with Autism (Autism CRC) Specialist Peer-to-Peer Mentoring Module has been designed to respond to the growing number of students on the Autism Spectrum and related conditions now enrolling in tertiary education courses worldwide (Bebko, Schroeder, & Ames, 2011; Hastwell, Harding, Baron Cohen & Martin, 2012; Hastwell, Harding, Martin, & Baron-Cohen, 2013). Preliminary research indicates that the prevalence of tertiary students on the Autism Spectrum is approximately 1% of the overall student population as high as prevalence rates of individuals on the Autism Spectrum for the general population (White, Ollendick, & Bray, 2011).

The reported increases in the number of tertiary students on the Autism Spectrum range between two to as much as eight-fold over five years (Bebko, et al., 2011; Hastwell, et al., 2012). International research indicates that these individuals are not

performing to their full academic potential (Equality Challenge Unit, 2011). Researchers in the United Kingdom have found that those with an Autism Spectrum diagnosis have the lowest percentage of first or upper second degree classifications achievement of any disability groups who are engaged in higher education (Equality Challenge Unit, 2011).

Research into life outcomes for adults on the autism spectrum indicates they are a significantly disadvantaged group. A recent international research review investigating the prognosis, outcomes and effective interventions for adults on the autism spectrum found that they are significantly disadvantaged in the areas of employment, social relationships, physical / mental health and quality of life (Howlin & Moss, 2012). More recent United Kingdom (UK) research of 374 adults on the autism spectrum (specifically Asperger Syndrome [AS]) indicates that 66% experienced suicidal ideation, 35% experienced planned or attempted suicide with rates that are more than nine times higher than that found in the normal UK population (Cassidy, Bradley, Robinson, Allison, McHugh & Baron-Cohen, 2014). Support to facilitate this population's inclusion into mainstream society has been lacking with little research investigating the most effective ways to intervene and improve outcomes for these adults (Howlin & Moss, 2012).

According to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (American Psychiatric Association, 2013), individuals on the autism spectrum experience impairment in the two domains of social communication and restricted interests/repetitive behaviour. Beyond these impairments there are often more cognitive characteristics to consider including deficits in 'theory of mind' skills, difficulties with executive functioning, weak central coherence, difficulties with sensory processing and motor functioning problems (Australian Autism Education and Training Consortium (AAETC), 2008). Such students may also have a number of relative cognitive strengths in the areas of rote memory, visual spatial abilities, compartmentalized learning, preference for routine and rules, intense interests, savant skills and being logical (AAETC, 2008).

Students on the Autism Spectrum have been increasingly included in mainstream education settings (Frederickson, Jones & Lang, 2010; Jordan, 2005; Leach & Duffy, 2009; Ravet, 2011). However, research has shown that students with intellectual disabilities, including those on the Autism Spectrum, often experience many challenges in accessing the necessary supports in these environments (Ford, 2007; Forlin, Keen & Barrett, 2008; Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2010; Kidd & Kaczmarek, 2010; MacDermott, 2008; McDonald, 2010, 2014; Shaddock, 2005; Shaddock, Smyth King & Giorcelli, 2007; Wing, 2007).

Concerns have been raised about the lack of appropriate, individualized attention and support available, the high attrition rates and the inordinate degree of bullying experienced by such students in mainstream educational settings (Attwood, 2007; Humphrey & Lewis, 2008b; Humphrey & Symes, 2010; Lynch & Irvine, 2009). Additionally, such students often experience social isolation, anxiety and sensory difficulties in mainstream settings where their need for routine and predictability is often at odds with the chaotic, noisy happenings of mainstream education (Humphrey & Lewis, 2008a; Knott & Taylor, 2014; Symes & Humphrey, 2010; Trembath, Germano, Johanson & Dissanayake, 2012; Wing, 2007).

Prior research has also shown that students on the autism spectrum have high dropout rates from secondary school, low rates of post-secondary education, poor post compulsory school integration, reduced independent living and community participation outcomes (Attwood, 2007; AAETC, 2008). Students on the Autism Spectrum are a particularly vulnerable group whose academic success is highly dependent on the quality of inclusiveness that they experience in an educational environment (Kidd & Kaczmarek, 2010; Leach & Duffey, 2009; McDonald, 2010, 2014; Van Hees, Moyson & Roeyers, 2014).

In the Australian context, one recent survey by Autism Spectrum Australia (Aspect), 2012) investigating the experiences, aspirations and needs of 300 adults with AS and High Functioning Autism (HFA) from every state and territory in Australia confirmed that, despite this group's aptitude for study, they experience significant struggles to reach their full potential in education. At the time of the survey more than 80% of the 300 respondents with AS and HFA had commenced or completed a tertiary qualification. Of this group, almost 75% identified that they needed support to help them study. Almost 50% of the 300 respondents reported that they received no, or insufficient, additional support for their learning needs during their time in education.

In the same survey, tertiary education disability officers reported that students on the Autism Spectrum experienced difficulties in verbal comprehension, planning, organisation, social awareness and group work. Disability officers also perceived a lack of awareness and understanding of ASCs among tertiary educators. Over 66% of parents surveyed stated that educators in Australia are not well-informed about ASCs. Approximately 50% of the parents surveyed indicated that their child had not performed to his or her full potential while in education. The same survey found that in contrast to an Australian national employment rate of 95%, just 54% of adults with AS and HFA had a paid job at the time of completing the survey - and of those 54% in employment, 33% were found to be working in casual employment (Aspect, 2012).

Current preliminary research indicates that successful inclusion of students on the Autism Spectrum in tertiary education environments incorporates a community of practice where a number of supports and initiatives are available (Barnhill, 2014; Gelbar, Smith & Reichow, 2014; Hastwell, et al., 2012; Hastwell, et al., 2013; Van Hees, Moyson & Roeyers, 2014; Wolf, Brown & Bork, 2009). Promising programs at the tertiary level include many different types of support with the student voice often being given increased importance to ensure that programs remain of greatest, practical benefit to this population of students (Bebko, et al., 2011; Hastwell et al., 2012; Hastwell et al., 2013; Wolf et al., 2009). Peer-to-peer mentoring where tertiary students on the autism spectrum are provided with trained, specialist student mentors to help them navigate university life has been highlighted as an effective means of providing support to these students (Bebko, et al., 2011; Hastwell et al., 2013; Wolf et al., 2009).

MODULE BACKGROUND

In 2014, inspired by the success of a small number of recent, promising peer-to-peer tertiary mentoring programs operating in Canada (Bebko, et al., 2011), the United Kingdom (Hastwell, et al., 2012; Hastwell, et al., 2013; Mowat, Cooper, & Gilson, 2011) and the United States (Wolf, et al., 2009), Curtin University and Autism West funded Dr Jasmine McDonald and Theresa Kidd to develop and implement one of the first specialist mentoring programs for students on the Autism Spectrum in Australia – the

Curtin Specialist Mentoring Program (CSMP). This was in line with federal Disability Discrimination legislation (Disability Discrimination Act, 1992, Disability Standards for Education 2005) and Curtin's Disability, Access and Inclusion Plan (2012-2017) which states a commitment to provide "equitable and inclusive access for people with a disability to its facilities, services, events and academic programs" (p.7).

In its inaugural year CSMP provided specialist mentoring to 17 students over the 2014 academic year, with most mentees electing to retain a specialist mentor for the 2015 academic year. In its second year CSMP provided specialist mentoring to 32 students during the 2015 academic year with most mentees electing to retain a specialist mentor for the 2016 academic year. CSMP also initiated a social group that has become an integral part of the mentoring program.

CSMP is presently jointly funded through Curtin University Counselling and Disability Services (CDS) and the Additional Support for Students with Disabilities (ASSD) Fund, Higher Education Disability Support Programme. The objectives of the ASSD component are to provide funding to eligible higher education providers to assist with the high costs incurred in providing educational support and/or equipment to students with disability to enable them to participate in higher education; and encourage efficient and effective use of equipment and education resources to support students with disability.

The following module outlines a modified, generic version of the Curtin University Specialist Mentoring Program (CSMP). Two independent evaluations of CSMP were conducted during its first semester of operation in 2014 (Hamilton, 2015; Hamilton, Stevens & Girdler, 2016; Siew, 2014). Additionally, a comparative, replication study of the CSMP program, based on the draft CRC module, was conducted at the University of Western Australia (UWA) during semester two, 2015.

Evaluation results of the 2014 CSMP program from the mentee perspective indicate that there was a significant improvement in mentee participants' sense of support and a significant decrease in their apprehension in communicating with others over the course of the program. Mentee participants also reported being highly satisfied with the program with a mean satisfaction score of 4.31 out of 5 (Siew, 2014). Evaluation results of the CSMP 2014 mentor training and program from the mentor perspective indicate that the training was well received with an overall mean satisfaction score of 4.7 out of 5 (Hamilton, 2015; Hamilton, Stevens & Girdler, 2016). Final results from the UWA comparative, replication study are yet to be released. Research papers based on these studies are in development.

Preliminary feedback from the mentees involved with the UWA 2015 Specialist Peer Mentoring Program indicates they valued the program and would like to continue to be involved if the program remained available. UWA are presently investigating an alternative, potentially more affordable model of service delivery where the program would source voluntary Psychology undergraduate mentors in their honours year or last year of a double degree to help provide them with extra professional practice opportunities. It is proposed that supervision of these mentees would be undertaken by a postgraduate, clinical Psychology placement student within Disability Services with their time divided between their mentoring coordinator and counselling roles. Such a service delivery model may be more appealing to some tertiary institutions where the potential cost of delivering such mentoring services may be a prohibitive factor. However, such a service delivery model will need to ensure that student coordinators

and mentors have informed and regular supervision from experienced staff when dealing with such a potentially complicated population of students to ensure duty of care requirements are met.

The module is provided with the intention that other tertiary institutions may use the experience and resources developed by CSMP, UWA and the Autism CRC to adapt to their own circumstances so that tertiary students on the autism spectrum and those with related conditions will have a greater chance to realise their educational potential in tertiary environments.

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Program Coordinator Role

> *"I have found the Program Coordinator Role to be both rewarding and challenging. It has been highly instructive to get to know both the mentors and the mentees. The mentors have continually shown great dedication toward their mentees and have been instrumental in providing tailored, individualised support to them. The mentors have found that the mentees are all different in their needs and their ability to progress toward their own educational and life goals. The regular supervision meetings help the mentees gain much needed understanding, support and guidance for their role from both the Coordinator and the other mentors – essential when inevitable difficulties arise."*
>
> *(CSMP Coordinator)*

The role of the Program Coordinator is crucial to the success of the program and should be filled by a professional in the field who has had substantial experience dealing with individuals on the Autism Spectrum and their families (Hamilton, 2015). The Coordinator should be allocated adequate time to fulfil the role so that they may deal effectively with the ever growing number of students on the autism spectrum now entering the tertiary system. Recent research confirms that individuals on the Autism Spectrum have particularly complex profiles with some experiencing serious comorbid conditions and high suicidal ideation (Cassidy et al., 2014). The CSMP experience has shown that critical issues arise on a regular basis that need to be addressed appropriately and in a timely and proactive manner before serious consequences occur. Mentors need ongoing support and guidance regarding their often difficult and demanding role. The Program Coordinator should therefore, work closely with the mentors (Disability Advisors and the Counselling team – if available) to ensure the best possible coordinated service to mentees (Hamilton, Stevens & Girdler, 2016).

MANUAL ORGANISATION

The Program Coordinator Manual is broken into four sections:

1. Program Duties.

2. Mentor Information.

3. Mentee Information.

4. Appendices: A (Mentor Information) / B (Mentee Information) / C (Crisis Management Information). All forms in the Appendices are generic in nature or samples from Curtin University or the University of WA.

Program Duties

The following list of duties is provided as a recommended framework only and should be amended according to the resources available to the program in each tertiary site.

The Program Coordinator's role involves the following duties:

- Overseeing specific duties in relation to mentors and mentees as detailed in the following two sections of this document.

- Advertising and distributing information about the program through various channels throughout the year (website, social media, secondary school networks, conferences, Autism community networks etc.) (See Appendix A – *General Program Information, Mentor Induction Flyer* and Appendix B – *Mentee Induction Flyer*).

- Creating and adapting appropriate documentation to support the program (See Appendices).

- Generating a Mentee/Mentor Composite List (See Appendix A - *Mentee/Mentor Composite List*).

- Reading, processing and storing of documentation for weekly time-sheets, social group, mentor weekly reports and other documentation (See Appendix A).

- Developing a working, collegial relationship with the Disability and Counselling Team (if available).

- Receiving supervision and support for the coordination role from a senior member of the Disability / Counselling Team (if available).

- Consulting with the Counselling and Disability Team and other relevant departments / agencies when problematic / crisis situations arise.

- Receiving referrals for the program from the Disability / Counselling Team *(See* Appendix B – *Specialist Peer Mentoring Program Referral Form).*

- Organising meetings with interested parties to educate the campus community about the Specialist Peer Mentoring Program and the nature of Autism Spectrum Conditions (ASC).

- Organising and undertaking recurrent evaluations to include key stakeholder feedback (mentor, mentee, relevant tertiary staff members etc.) to continually inform practice.

- Keeping up-to-date with current research in the area to continually inform practice.

Duties (in relation to Mentors)

- Creating links with faculties / departments on campus (Psychology, Occupational Therapy, Education, Speech Pathology, Engineering, Computer Science and so on) to source appropriate mentors (See Appendix A – *General Program Information* and *Mentor Induction Flyer*).

- Providing induction materials to potential mentors of the program (See Appendix A – *Mentor Induction Flyer, General Program Information*).

- Conducting referee checks and interviewing potential mentors to determine suitability to their role in terms of their motivation, education, training, experience and social competence.

- Choosing and pairing of suitable mentors with mentees (See Appendix B – *Mentee/Mentor Composite List).*

- Providing transition support to mentees when a change of mentor is needed (See Appendix A – *Mentor Handover Form).*

- Conducting the initial Mentor Induction Meeting and providing intake materials (See section *Mentor Information - Mentor Induction Meeting*).

- Ensuring Mentors have the necessary current National Police Clearance and Working with Children Checks as per requirements of the tertiary site.

- Providing training and regular group supervision meetings to mentors (See separate *Autism CRC PowerPoint* & *Specialist Mentor Toolkit* Documents).

- Collecting completed Mentor Confidentiality Agreement, Mentor/Mentee Responsibilities Contract from mentors (See Appendix A – *Mentor Confidentiality Agreement, Mentor/Mentee Responsibilities Contract*).

- Chairing weekly mentor supervision meetings during the teaching weeks of the semester.

- Overseeing the mentors' work with their mentees inclusive of providing support during crisis situations that may develop (See Appendix C – *Crisis Management Information*).

- Reviewing and checking receipt of weekly report, attendance at supervision meeting and time-sheet submission (See Appendix A - *Weekly Checklist for Report, Meeting & Time-sheet*).

- Overseeing mentors (and mentees if applicable) charged with running the social group (See Appendix A – *Social Group Weekly Report Form* and *Sample*).

- Meeting with individual mentors (and their mentees if required) on an as-needs-basis.

- Helping to organise appropriate guest speakers and materials for the social group.

- Providing recognition of the mentor role in the form of a reference, certificate or documentation on a student's academic record.

Duties (in relation to Mentees)

- Liaising with parents, support persons, students on the Autism Spectrum etc. about the program and distributing program materials (See Appendix A – *General Program Information* and Appendix B – *Mentee Induction Flyer*).

- Assessing applications and student referrals from Counselling / Disability Services as to a student's suitability to be part of the Specialist Peer Mentoring Program. (See Appendix B – *Specialist Peer Mentoring Program Referral Form*).

  Please Note: Potential mentees cannot be accepted into the program if they have significant behavioural issues that would breach a duty of care to student mentors.

- Providing induction materials for new mentees to the program (See Appendix A – *General Program Information* and Appendix B – *Mentee Induction Flyer* and separate *Mentee Information Booklet*).

- Conducting intake interviews with mentees (and their families / support persons).

- Collecting completed necessary intake / permission / safety plan forms and issuing necessary mentee program information (See Appendix B – *Mentee Intake Form, Mentee Release of Information Form*, *Mentee Consent Form,* Appendix C – *UWA Safety Plan Sample* and separate *Mentee Information Booklet*).

- Liaising with parents / support persons / Counselling / Disability Services (with mentee's permission) about the ongoing support needed by the mentee over time.

- Meeting with individual mentees (and their mentors if required) on an as-needs-basis.

- Helping to link mentees with support and work experience opportunities both on and off campus (See Appendix B – *Brief Information Sheet for Work Experience / Employment Sample* – Completed with mentee's input and permission regarding disclosure of details).

- Organising the handover of mentees from one mentor to another as needed (See Appendix A - *Mentor Handover Form*).

Research / Evaluation Duties

- Conducting ongoing evaluations to continually improve the program based on key stakeholder feedback (with the student mentee perspective being given precedence).

Crisis Management Duties

During mentor training, mentors will be made aware of their respective institution's Crisis Response Plan (See Appendix C – *Crisis Management Response Information and Samples*). They will be instructed that if they find themselves in a crisis situation they should follow their own institution's Crisis Response Plan and contact their Coordinator as soon as possible.

Please Note: Coordinators should ensure that they insert the correct Crisis Management Information in the Specialist Mentor Toolkit (Appendix B – *Crisis Management Information)* according to their own institution policies **prior to issuing the Toolkit to mentors and prior to the training (where direct reference to the Crisis Management Information is made).**

Based on the recent experience of CSMP, some of these crisis situations may involve:

- Serious mental health problems (depression / anxiety / suicidal ideation).

- Harm to self or others.

- Substance abuse (Drug & Alcohol).

- Emotional, Physical and/or Sexual Abuse.

- Lesbian/Gay/Bisexual/Transgender/Intersex (LGBTI) Issues.

In these circumstances a Coordinator should remind the mentor that their task is to:

- Stay calm, be non-judgmental and use active listening skills to understand their mentee's difficulties.

- Reassure their mentee that any information given will be treated as confidential (unless there is risk of harm to self or others).

- Remind their mentee to use recommended calming strategies noted in their mentee's initial intake form and Safety Plan (See Appendix B – *Mentee Intake Form* and Appendix C – *UWA Specialist Mentoring Safety Plan Sample*).

- Find out the location of their mentee especially if they threaten self-harm or harm to others.

- Note down any important information about their mentee's situation ready to report to other relevant personnel if the need should arise – Security / Police / Coordinator / Disability Services / Counselling etc.

- Remind their mentee of the boundaries of their mentoring role (they are not their mentee's parent, therapist or counsellor).

- Refer their mentee onto appropriate campus personnel and services ASAP to receive professional help especially if suicidal thoughts have been expressed.

- Follow their institution's Crisis Response Plan and ring emergency personnel if needed (see Appendix C – *Curtin Crisis Management Response Chart Sample & UWA Specialist Mentoring Safety Plan Sample*).

- Contact their Program Coordinator ASAP by phone or email about the situation to receive further help.

- Debrief individually with their Coordinator or during the supervision meetings to gain personal support and feedback.

- Seek counselling for themselves if they need ongoing support.

- Discuss mentee's inclusion in program with Coordinator if ongoing issues continually breach the defined role and responsibility of a student mentor.

According to Wolf et al. (2009 pp. 150-152), Myles (2005 pp. 59-73) and the CSMP experience, after a critical incident has occurred it is important that a functional assessment of the behaviour be conducted as most mentee behaviour will be associated with a reason, cause or condition under which the behaviour occurs.

After a mentee has experienced a crisis, the mentor should notify the Coordinator as soon as possible and provide details about the crisis situation. Depending on the situation the coordinator may contact other appropriate personnel, disability and counselling staff who can provide ongoing support and investigate the situation more fully. Parents or support persons (nominated on the initial intake form) may also be contacted to help provide support and background information regarding the mentee's behaviour. Where possible, a team approach to assist the mentee is advised. A review of the mentee's inclusion in the program may also be needed if ongoing issues breach duty of care requirements of a student mentor.

Wolf et al. (2009) recommend the following stress management techniques for this population of students:

- Identify potentially stressful situations.

- Determine what precipitates crises.

- Identify how stress manifests itself (e.g., what behaviours are demonstrated).

- Identify calming methods.

- Determine medications used in past with medical/clinical support. (p.151)

Wolf et al. (2009) also nominate the following stress-relieving activities on campus:

- Regular exercise.

- Outings with peers, friends, or family.

- Maintaining a healthy eating and sleeping schedule.

- Scheduled downtime every day and during each study period.

- Structured time for TV, movies, or video games (with an alarm to end time).

- Yoga or meditation (also a good group activity).

- Listening to music. (p.152)

If further information is sought on functional assessments and stress management techniques, please refer to Wolf et al. (2009, pp. 150-152) and Myles (2005, pp. 59-73).

Please Note: Coordinators will need to insert their own appropriate institution Crisis Response information into Appendix C – *Crisis Management Response Information* of this document and into the separate *Mentor Toolkit* (See Appendix B).

MENTOR INFORMATION

Specialist Peer Mentoring Program Model

The Specialist Peer Mentoring Program Model draws on the CSMP experience and research (Hamilton, 2015; Hamilton, Stevens & Girdler; 2016; Siew, 2014) that indicates the quality of mentoring is impacted by such factors as:

- Specialised mentor training (prior to meeting mentees)

- Mentor's approach and self-efficacy (based on training / mentor experience)

- Mentor-mentee relationship (supported by experienced Coordinator)

- Group mentor supervision (on a regular basis)

- Structural supports (Coordinator, Disability / Counselling Support)

- Social group (inclusive of mentors / mentees on a regular basis)

Supervision

Access to coordinator

Training

Mentor Support   Peer Mentoring   Social Group

Mentor Role

> *"Being a part of CSMP has been an incredibly rewarding, memorable and an invaluable learning experience. As a mentor, I had the honour of working with C., a first year student on the Autism Spectrum. Prior to working with the program, I knew little about the daily challenges and anxieties that those on the Autism Spectrum faced. However, working with C. has made me profoundly aware of how courageous these mentees are in confronting the challenge of university life. The program means that the mentees do not have to do it alone. I saw how the mentoring program provided the scaffolding and support needed for the mentees to adjust to university and develop meaningful friendships. I feel very proud and honoured to be involved in such a worthwhile project that makes such a difference in these students' lives."*
>
> *(CSMP Mentor)*

Roberts (2000) defined mentoring as a:

> Formalised process whereby a more knowledgeable and experienced person actuates a supportive role of overseeing and encouraging reflection and learning within a less experienced and knowledgeable person, so as to facilitate that persons' career and development. (p.162)

According to Bebko, Schroeder and Ames, (2011) who developed the York University Asperger Mentorship Program (AMP) in Canada:

> The role of the mentor is akin to that of a "coach", … A coach helps you practice skills, they help you prepare for the game, they cheer you along, and work with you after the game to talk about what went well and how to practise for the next game – but a coach does not play the game for or with you. This analogy is used to clarify that the role of the mentor is different from a counsellor or a friend. (p.5)

The CSMP experience has found this notion of a mentor very useful in clarifying the boundaries of the mentor role. Mentors essentially help 'coach' their mentees by communicating and/or meeting with their mentees for one or more hours per week during the teaching weeks of the semester. The communication channels used are determined by both parties and may also depend upon whether the student is internal (on campus) or external (off campus) to the university.

Key Duties of a Specialist Mentor

Participate in specialist training / weekly reporting & supervision	Communicate / meet weekly with their mentee during semester	Understand their mentee's profile from intake form and safety plan
Provide flexible and individualised support	Ensure mentee registered with Disability Services to gain accommodations.	Build on the mentee's short and long term life goals including employment
Link mentee to appropriate university services and clubs	Encourage mentee to attend Social Group	Increase mentee's independence, self-advocacy and confidence over time.

Please Note: The CSMP experience has found that Facebook should not be used by a mentor as a preferred, individual communication method with their mentee as this does not establish appropriate professional boundaries between the mentor and mentee and problems of over-familiarity have arisen because of this.

The mentor role involves the following duties:

- Reading preparatory training material in preparation for specialist mentor training.

- Attending half-day specialist mentor training.

- Familiarising themselves with the profile and needs of their mentee (See Appendix A, B & C – *Mentee Intake Form*, *Mentor Handover Form [if applicable], Safety Plan* and other relevant weekly and medical reports etc. held in their mentee's record/file).

- Establishing boundaries and responsibilities of the mentee/mentor role with their mentee and signing off on Mentor/Mentee Responsibilities Form early in the relationship (See Appendix A – *Mentor/Mentee Responsibilities Contract*).

- Being available to work as a specialist mentor for one or more hours during the teaching weeks of the semester.

- Being available to attend regular, group supervision meetings during the teaching weeks of the semester.

- Completing and submitting a short weekly report detailing meeting times, issues arising and referrals by the specified time and date during the teaching weeks of the semester (See Appendix A – *Mentor Reporting Form* and *Sample*).

- Completing and submitting a fortnightly time-sheet detailing working hours if applicable (See Appendix A – *Mentor Time Form*).

- Encouraging their mentee to indicate what difficulties (social, academic, etc.) they may be experiencing with university life.

- Giving advice to their mentee about how to handle these difficulties or where to gain appropriate support/advice.

  Please Note: the mentor may need to accompany the mentee initially to a support service or on-campus group.

- Ensuring their mentee has registered with their institution's Disability Services and has investigated whether he/she is eligible for accommodations/ modifications.

- Participating in the Social Group Coordinating Committee (if possible) and submitting social group reports during supervision meetings (See Appendix A – *Social Group Report Form* and *Sample*).

- Encouraging their mentee to attend the Social Group during the teaching weeks of the semester and attending the group with them as required.

- Encouraging and supporting their mentees to prepare their resumes by connecting them with their Careers Department and to help them seek out work experience/work preferably in their respective fields of study (See Appendix B – *Brief Information Sheet for Work Experience/Employment*).

- Working toward the long term goal of trying to help their mentee gain as much confidence, independence, agency and self-advocacy as possible in preparation for a more successful adult life.

- Completing a handover form summarising the strengths, difficulties etc. of their mentee (See Appendix A – *Mentor Handover Form*) at the conclusion of their mentoring role.

- Participating in an evaluation process as required.

- Developing appropriate self-care and crisis management skills.

CSMP evaluation results regarding the training and the program from the mentor perspective indicate that mentors:

- Found the specialist training and weekly supervision received during the program imperative because of the individual and complicated nature of each mentee's profile.

- Found the weekly supervision meetings allowed them to acquire support, advice and to debrief – nominated as essential for their role.

- Developed a strong, collegial relationship with their program coordinators that was vital to the success of their role as a mentor (Hamilton, 2015).

Mentor Selection

It is recommended that specialist mentors be carefully selected from a pool of successful, experienced undergraduate and/or postgraduate students (e.g. Schools of Occupational Therapy, Psychology, Speech Pathology, Nursing, Education, Computer Science, Engineering etc.). Organising a pool of trained specialist peer mentors by the beginning of the academic year ensures that irrespective of demand, appropriately trained mentors will be available throughout the academic year. If demand is high, some mentors may also be available to mentor two or more mentees. These students will gain valuable training and professional practice experience working with mentees on the Autism Spectrum in a supervised, supportive setting prior to them embarking on careers in their respective fields. Additionally, these experienced students potentially provide a high level of dedication, understanding and expertise when dealing with mentees given their background and success in tertiary education.

Prospective mentors should demonstrate in their application and interview:

- A proven academic track record.

- Suitability to be a mentor.

- Appropriate communication skills.

- Emotional intelligence.

- Good references.

- Relevant experience (if any).

The canvassing and selection process for mentors should occur early in the semester before the mentors are needed so that there is ample time available for selection, induction and training.

Hence, relationships need to be established with the respective Schools / Departments in the tertiary environment concerned. Prospective mentors are contacted via their respective Schools / Departments through use of the *Mentor Induction Flyer* (See Appendix A). The flyer requests that they provide a current resume, reasons for their interest in the program and to nominate an academic staff member who can attest to their suitability for the program. If selected to be interviewed by the Coordinator, prospective mentors should then be emailed a *General Program Information sheet* (See Appendix A) and be invited to attend an interview process where their suitability for the role will be determined.

If successful, mentors should then be given the details of an induction meeting (See next section – *Mentor Induction Meeting* for details) and details of the half-day specialist mentor training (See separate PowerPoint - *Specialist Peer Mentor Training Program*) that they will be required to attend prior to the beginning of the semester. Mentor details should be recorded by the Coordinator on the *Mentee/Mentor Composite List* (See Appendix A).

Mentor Induction Meeting

The Mentor Induction Meeting takes approximately 90 minutes to conduct. At the introductory induction meeting mentors will (See Appendix A – *Mentor Induction Meeting Checklist*):

- Meet their fellow mentors to begin the process of team building and collegiality.

- Be issued the *Specialist Mentor Toolkit*, the National Autistic Society (NAS) *Student Mentor Guidelines (UK)* and the National Disability Coordination Officer Programme (NDCO) of Australia, *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* (see below for links to access NAS and NDCO documents).

- Be instructed to read and digest the Toolkit and the other two documents prior to their Specialist Mentor Training.

- Be given details of the training day and have their queries about the program addressed.

- Have the importance and the workings of the social group explained (*See Social Group* Section in this document).

- Be informed of the details of the Social Group and asked to volunteer to be on a Social Group Coordinating Committee (3-5 students needed). (See Appendix A - *Social Group Report Form* and *Sample* and Appendix B – *Mentee Social Group Flyer*).

- Be issued and asked to sign a *Mentor Confidentiality Agreement* (See Appendix A) ensuring any mentee details discussed remain confidential.

- Be issued and asked to get joint signatures (mentee/mentor) on the *Mentor/Mentee Responsibilities Contract* form and return ASAP to Coordinator (See Appendix A - *Mentor/Mentee Responsibilities Contract*).

- Be informed of their contract and payment requirements and dates (if mentors are to be paid).

- Be informed of the need for a current National Police Clearance and Working with Children Check to be gained by them prior to them working with their mentees.

- Be informed of the mentee/mentor pairings (organised to ensure a positive relationship based on the interests and/or backgrounds of both parties).

- Be issued their mentee's file (hard copy) to view and return to the Program Coordinator at the conclusion of the meeting (consisting of their mentee's intake form, Safety Plan and any other relevant information provided).

- Be asked to note down important details of their mentee's file using their mentee's first name only to ensure anonymity (contact details, interests of mentee, specific problem areas, Safety Plan details etc.).

- Be informed that they can set up a private meeting with the Coordinator if they need further time to review their mentee's file or if the file is not yet available.

- Be informed that they will either be responsible for contacting their mentee individually after their training or that a 'Meet and Greet Meeting' will be organised by the Coordinator.

  Please Note: Based on the CSMP experience, it is recommended that the 'Meet and Greet Meeting' be conducted in a group format immediately following the mentor training. This meeting has included the mentees (their support persons) and the mentors and begins the process of developing relationships among the group in preparation for the formation of a social group.

- Be informed of the supervision meeting dates, times and deadlines for weekly reports during the teaching weeks of the semester (See Appendix A - *Mentor Reporting Form and Sample)*.

- Be asked to highlight (bold type) any pressing issues and positive breakthroughs in their weekly reports that may need to be discussed at the supervision meeting.

Please Note: Student mentors are expected to have read through the Toolkit, the NAS and the NDCO booklets prior to training to supplement the mentor training given.

The National Autistic Society (NAS) of the United Kingdom *Student Mentor Guidelines* booklet (PDF format) can be downloaded through the NAS website: http://www.autism.org.uk/studentmentors. The NAS *Student Mentor Guidelines* booklet covers the following areas:

- o Understanding the Autism Spectrum.

- o The role of a student mentor.

- o Getting started.

- o Supporting a student with Asperger Syndrome.

- o Useful resources.

- o Further reading.

Additionally, the National Disability Coordination Officer Programme (NDCO) of Australia *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder (Transition to Tertiary - Short Version PRINT)* can be downloaded through www.adcet.edu.au/autism-transition.

The NDCO booklet is also issued to the mentees as part of the Mentee Information Booklet (Section 3 of the Manual) they receive when they become a mentee with the program. The NDCO booklet is an excellent resource for both mentees and mentors in relation to understanding some of the challenges faced by tertiary students on the Autism Spectrum. The NDCO booklet covers the following areas:

- o Awareness of yourself and others.

- o Knowing your strengths.

- o Familiarising yourself with the campus.

- o Studying at university or TAFE.

- o Organising your study.

- o What support could be helpful.

- o Finding key people who can help you.

- o Communication tips.

- o Managing stress and anxiety.

Mentor Training

CSMP evaluation results of the 2014 mentor training and program from the mentor perspective indicate that the training was well received with an overall mean satisfaction score of 4.7 out of 5. Results indicate that the training increased mentors' knowledge and insight into the mentee experience (Hamilton, 2015; Hamilton, Stevens & Girdler, 2016).

The goals of the training are for the mentor to:

- Increase their understanding of the different ways an Autism Spectrum Condition (ASC) can impact on a student in a tertiary education setting.

- Understand their role and develop skills to establish a sound working relationship with their mentee.

- Increase their capacity to provide appropriate, individualised support and guidance to their mentee.

- Understand the importance of interpersonal boundaries, crisis management, confidentiality and self-care.

- Understand the policies, practices and procedures of their Specialist Peer Mentoring Program.

It is recommended that mentor training occurs prior to the beginning of the semester or academic year. The training is timed to take place over a half day and is made up of approximately two 90 minute sessions. To conduct specialist mentor training, the Coordinator should be familiar with the other module documents:

- The *Specialist Mentor Toolkit* for the Mentors (inclusive of the NAS *Student Mentor Guidelines* and the NDCO *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder*).

- The *Mentee Information Booklet* for the Mentees (and their Support Persons).

- The *Specialist Peer Mentor Training Program (PowerPoint)* for the Coordinator.

Please Note: Mentors should be given a copy of the *Specialist Mentor Toolkit* Booklet inclusive of the *NAS Student Mentor Guidelines* and the NDCO *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* at the Mentor Induction Meeting (see *Mentor Induction Meeting* Section of this document) at least one week prior to training so that mentors have time to familiarise themselves with the contents of these documents **before the training day takes place**.

Mentor Supervision

After specialist training and mentors have had the chance to meet their mentees, regular weekly group mentor supervision meetings should be held for approximately one hour during the teaching weeks of the semester. The CSMP experience has shown that this allows mentors the ability to have the necessary support and to debrief, share ideas and receive feedback from the Coordinator and fellow mentors about the

sometimes difficult situations they may be facing with their mentee. Evaluation research of the original CSMP program indicates that mentees found such supervision vital because it gave them the chance to debrief; brainstorm; share resources; receive support; alleviate isolation; and reflect on their work and the progress of their mentee(s) (Hamilton, 2015, Hamilton, Stevens & Girdler, 2016).

Prior to the weekly supervision meetings, the Coordinator should:

- Remind mentors to highlight (bold type) any pressing issues and/or positive improvements in their weekly reports that may need to be discussed at the supervision meetings (See Appendix A - *Mentor Reporting Form and Sample)*.

- Receive electronically completed *Social Group Report Forms*, *Mentor Reporting Forms* and *Mentor Time Forms* (See Appendix A) from the mentors before the supervision meeting is scheduled so that the Coordinator can be familiar with the relevant details of the weekly events and any pressing issues/ improvements that need to be discussed at the meeting. Use the checklist to help track report, meeting attendance and timesheet submission (See Appendix A – *Weekly Checklist for Report, Meeting & Timesheet*).

- Make hard copies of the completed reporting forms to file in securely stored, paper-based mentee files so that mentors (and permitted others) can view the files individually as needed.

- Store both soft and hard copies of the forms securely in the relevant electronic and hard copy files and folders according to institution policies.

- Check and sign off on *Mentor Time Forms* for approval and submit to relevant departments within the institution so that mentors can be paid for their time (if applicable).

At the weekly supervision meetings, the Coordinator should:

- Chair the meeting and complete *Weekly Checklist for Report, Meeting & Timesheet* to track report and time sheet submission and mentor attendance (See Appendix A).

- Disseminate any relevant program information.

- Receive a brief verbal summary of any pressing issues and/or positive improvements of each mentor's interactions with their mentee based on their completed *Mentor Reporting Form* (See Appendix A - *Mentor Reporting Form and Sample*).

- Give feedback/suggestions to the mentors about any challenges they may be experiencing with their mentee.

- Encourage other mentors to give input regarding how these challenges could also be dealt with more successfully based on their own experiences with their mentee.

- Receive a brief weekly report from the Social Group from one of the Coordinating Committee (See Appendix A for *Social Group Weekly Report Form* and *Sample*).

- Encourage other mentors to give feedback about the Social Group to help improve its appeal and relevance to the mentees who may not be attending.

After the weekly supervision meetings, the Coordinator should:

- Follow up on referrals that need to be made.

- Contact support persons about mentee difficulties that need further investigation.

- Continue with other duties detailed in the *Program Coordinator Role* Section of this document.

Social Group

> *"The mentoring program offers the mentees a rare opportunity to meet like-minded people their age and fosters the development of interpersonal relationships. There is a scarcity of such opportunities for adults on the Autism Spectrum. My mentee has been at Curtin University for 3 years and had never made any friends. He now attends the weekly social club meetings as well as plays cards with another mentee weekly. These social gatherings mean a lot to my mentee, he continually indicates that he wants to improve his social skills. I believe the mentoring program provides him with an opportunity to reach this goal."*
>
> *(CSMP Mentor)*

CSMP evaluation research indicates that the group nature of the Social Group facilitated valuable opportunities for socialisation and created a sense of belonging on campus (Siew, 2014). Both mentors and mentees should therefore be encouraged and invited to be part of the Social Group Coordinating Committee and attend the social group when possible. The Coordinating Committee should provide a regular report (See Appendix A - *Social Group Weekly Report Form* and *Sample*) during the weekly supervision meeting so that they may inform the larger group of activities and gain valuable feedback regarding the success of the social group.

Based on the CSMP experience, it is recommended that the Social Group:

- Be coordinated by a group of mentors and mentees so that responsibility for and running of the group can be shared.

- Be held weekly in an appropriate campus venue during the teaching weeks of the semester (preferably during a non-teaching time on campus).

- Be advertised through email and a specific, closed Social Group Facebook page created by the Social Group Coordinating Committee where relevant information and social events can be posted by both mentors and mentees.

- Have extra social events organised by both mentees and mentors to occur during the non-teaching weeks of the year.

- Be a safe, welcoming social space for mentees (and mentors) to commune / make friends / practise social skills, presentations etc. / experience belonging/ decrease isolation.

- Be approximately 60 to 90 minutes in length and be held in a regular venue with internet access and a large screen. Have a pre-organised program informed by both mentee and mentor feedback and be organised in two parts:

  - A short (approx. 15 - 30 minutes) formal aspect delivered/organised by the social group committee (e.g. social skills, guest speakers, dating advice, careers etc. based on mentee needs and wants).

  - A longer (approx. 45 - 60 mins) informal aspect (e.g. electronic and board game playing – CSMP favourites Jenga, Fibbage and Pandemic).

- Have a regular report written by a member of the Social Group Committee and delivered at the supervision meeting (See Appendix A – *Social Group Weekly Report Form* and *Sample)*.

- Be given regular feedback by both mentors and mentees to ensure the ongoing relevance and appeal of the group.

MENTEE INFORMATION

"Going into university for the first time was challenging and scary yet exciting, all on its own. Struggling with new situations, structure and community made the mentoring program such a vital safety net and building bridge in becoming my own person and making a name for myself. The program gave me a mentor that helped me make and keep friends in my degree and yet support me with regular conversations, meetings and information. I've been a part of programs like this before and nothing compares to the support, care and thrive for my success, it offers."

(CSMP Mentee)

Pre-Mentee Intake Meeting

Ideally the mentee entry process should occur over many months prior to the beginning of the academic year or semester. Potential mentees (and their families) can be informed of the Specialist Peer Mentoring Program through use of a *General Program Information* sheet and *Mentee Induction Flyer* (See Appendix A and B respectively) and recruited through:

- Various advertising means (internal and external to the tertiary institution including social media, Autism Associations, Autism Community Groups, conferences, secondary schools, Education Departments, radio stations, television, newspaper articles and so on).

- The tertiary institution's website.

- The tertiary institution's Disability Advisors (see Appendix B, *Specialist Peer Mentoring Program Referral Form*).

Please Note: Once registered with an institution's Disability Service, mentees can also be informed of the Specialist Peer Mentoring Program and the accommodations and modifications potentially available to them based on their profile and documentation (e.g. use of a laptop in exams, extended time in exams, separate room for exams, a scribe, extensions etc.). Based on the CSMP experience, it is recommended that all mentees be registered with both their Disability Service and the Specialist Peer Mentoring Program to ensure that best conditions for success are made available at the earliest time.

After potential mentees (or their representatives) make initial contact with the Program Coordinator and indicate they want to be part of the program, mentees (and their support persons) should be:

- Emailed relevant general program information before they attend an intake meeting (See Appendix A – *General Program Information)*.

- Asked to attend an intake meeting with the Coordinator where they will be issued a booklet containing necessary program information and forms (see next section) - ideally conducted prior to the beginning of the academic year or semester and prior to the Mentor Induction Meeting.

Please Note: Potential mentees are encouraged to bring a support person / parent if needed to the intake meeting (especially 1st year students). Previous CSMP experience has found that support persons / parents often have different perspectives regarding the relative strengths and difficulties experienced by the individual on the Autism Spectrum. Both perspectives are potentially very valuable as every individual on the Autism Spectrum is highly idiosyncratic in their presentation. Additionally, some students on the Autism Spectrum may have difficulty communicating the details of their situation.

Mentee Intake Meeting

At the meeting the mentee should be (see Appendix B – *Mentee Intake Meeting Checklist)*:

- Issued a booklet containing the:

  - *Mentee Information Booklet* (See separate document).

  - NDCO *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* (See reference to separate document).

  - *Mentee Intake Form* (See Appendix B).

  - *Mentee Release of Information Form* (See Appendix B)*.

  - *Mentee Consent Form* (See Appendix B).

  - *Mentee Safety Plan (*Appendix C).

  - *Mentee Social Group Flyer* (Appendix B)

Please Note: The permission forms allow the Program Coordinator to seek and share information with nominated persons (including parents/support persons, Course Coordinators, Disability and Counselling Services on an as-needs-basis). CSMP has found the ability to discuss matters with other informed parties to be an invaluable resource when trying to support mentors and their mentees through difficult situations.

- Given an explanation of the contents of the booklet.

- Asked to complete and return the relevant forms to the Coordinator ASAP (See Appendix B - *Mentee Intake Form, Mentee Release of Information Form, Mentee Consent Form* and Appendix C – *Mentee Safety Plan*).

Please Note: Mentees may need the assistance of a trusted support person/parent or the Coordinator to complete the intake form.

- Encouraged to ask any questions they may have about the program.

- Informed as to how the first point of contact between mentor and mentee will be made during the initial interview.

Please Note: This may take the form of a separate individual meeting or a 'Meet and Greet' Group Meeting including all mentors and mentees in the program directly after the Mentee Training Day as a forerunner to the Social Group.

- Issued a 'Meet & Greet' flyer if needed (See Appendix B - *Meet & Greet Flyer).*

- Encouraged to contact the Coordinators should they experience difficulties with their mentor.

Post-Mentee Intake Meeting

After the meeting the Coordinator should:

- Take receipt of the completed mentee forms.

- Scan and place the completed intake form, permission forms and safety plan into secure electronic files to satisfy institution record keeping requirements.

- Establish a hard copy mentee file in a secure site to house the documents (intake / permission forms, safety plan, other documentation and weekly reports) for use by the Coordinator and mentors who will need to access the files at different points in time (see Mentor Role Information).

- Record relevant mentee details on the *Mentee/Mentor Composite List* (See Appendix A – *Mentee/Mentor Composite List*).

  Please Note: The composite list allows the Coordinator to access important details quickly and is especially valuable when crisis situations occur and emergency contact details need to be accessed immediately.

- Email the mentee confirming mentee/mentor initial meeting details ('Meet & Greet' group meeting or individual organised meetings).

- Collect and file completed *Mentor/Mentee Responsibilities Contract* at 'Meet and Greet' Meeting or at first supervision meetings.

Useful Resources

Publications (many authored by those on the Autism Spectrum)

Attwood, S. (2008). *Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome*. London: Jessica Kingsley.

Attwood, T. (2007). *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley.

Attwood, T., Evans, C.R. & Lesko, A. (2014). *Been There. Done That. Try This!: An Aspie's Guide to Life on Earth.* London: Jessica Kingsley.

Attwood, T. & Grandin, T. (2006). *Asperger's and Girls.* Arlington, Texas: Future Horizons.

Autism Association of WA. (2007). *Beyond Behaviour Management*. Perth, WA: Autism Association of WA.

Baker, J. (2006). *The Social Skills Picture Book for High School and Beyond*. Arlington, Texas: Future Horizons.

Bebko, J.M., Schroeder, J.H., & Schroeder, & Ames, M.E. (2011). *A mentoring program for students with Asperger and ASDs.* Retrieved from: http://www.counselling.net/jnew/pdfs/handbooksmunualsguides/YORK%20UNIVERSITY,%20A%20Mentoring%20Program%20for%20Students%20with%20Asperger%20and%20ASDs.pdf

Brown, D. (2013). *The Aspie Girl's Guide to Being Safe with Men.* London: Jessica Kingsley.

Dubin, N. (2009). *Asperger Syndrome and Anxiety: A Guide to Successful Stress Management.* London: Jessica Kingsley.

Edmonds, G. & Worton, D. (2006). *The Asperger Social Guide.* London: Sage Publications.

Goodall, E. (2016) *The Autism Spectrum Guide to Sexuality and Relationships: Understand Yourself and Make Choices that are Right for You.* London: Jessica Kingsley.

Grandin, T. (2006) *Thinking in Pictures and Other Reports from my Life with Autism.* New York: Vintage Books.

Grandin, T & Duffy, K. (2004). *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

Lawson, W. (2003). *Build Your Own Life: A Self-Help Guide For Individuals with Asperger Syndrome.* Philadelphia, PA: Jessica Kingsley.

Lawson, W. (2001). *Understanding and Working with the Spectrum of Autism: An Insider's View.* Philadelphia, PA: Jessica Kingsley.

Myles, B. S. (2005). *Children and Youth with Asperger Syndrome.* California: Corwin Press.

Myles, B. S., & Adreon, D. (2001). *Asperger Syndrome and Adolescence. Practical Solutions for School Success.* Kansas: AAPC.

Myles, B.S., Trautman, M.L. & Schelvan, R.L. (2004). *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

Palmer, A. (2006) *Realizing the College Dream with Autism or Asperger Syndrome: A Parent's Guide to Student Success.* Philadelphia, PA: Jessica Kingsley.

Prince-Hughes, D. (2002). *Aquamarine Blue Five: Personal Stories of College Students with Autism.* Athens, Ohio: Swallow Press.

Purkis, J. (2006). *Finding a Different Kind of Normal: Misadventures with Asperger Syndrome.* London: Jessica Kingsley.

Purkis, J. (2014). *The Wonderful World of Work: A Workbook for Asperteens.* London: Jessica Kingsley.

Purkis, J., Goodall, E. & Nugent, J. (2016) *Guide to Good Mental Health on the Autism Spectrum.* London: Jessica Kingsley.

Santomauro, J. (2011). *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life.* London: Jessica Kingsley.

Shore, S.M. & Rastelli, L.G. (2006). *Understanding Autism for Dummies.* Hoboken, NJ; Wiley Publishing.

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Simone, R. (2010). *Asperger's on the Job.* Arlington, Texas: Future Horizons.

Willey L.H. (1999). *Pretending to be Normal.* London: Jessica Kingsley.

Willey L.H. (2012). *Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life.* London: Jessica Kingsley.

Wolf, L.,Thierfeld Brown, J. & Kukiela Bork, G. (2009). *Students with Asperger Syndrome: A Guide for College Personnel.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

DVDs

Radtke, M. (2012). *A 9th Planet Video Behavior Modeling Course*. USA: 9th Planet.

Saines, G. & Jackson, J. (2010). *Temple Grandin*. USA: HBO Films.

Websites

http://www.autismcrc.com.au/

http://www.tonyattwood.com.au/

www.templegrandin.com/

www.facebook.com/autismdiscussionpage

www.suelarkey.com.au/

http://www.latrobe.edu.au/otarc/

http://www.autismresearchcentre.com/

http://www.cci.health.wa.gov.au/resources/consumers.cfm

http://www.autism.org.uk/

http://www.autism-uni.org/

https://www.autismspeaks.org/

http://www.autism.com/

Please Note:

http://www.cci.health.wa.gov.au/resources/consumers.cfm

Centre for Clinical Interventions (CCI) WA website (Consumer Resources Section) – provides excellent online consumer modules for the general public to use on Social Anxiety, Worrying, Assertiveness, Depression and many more that may be helpful to a mentee depending upon their individual needs. CSMP has found these modules to be very helpful to mentees who wish to address the specific psychological difficulties

that affect their ability to maintain good mental health. Mentors may need to help their mentee access and complete appropriate modules during their sessions.

http://www.latrobe.edu.au/otarc/

Olga Tennison Autism Research Centre (OTARC) provides information on supporting tertiary university and TAFE students diagnosed with an Autism Spectrum Condition (ASC), their parents, and tertiary staff interested in learning more about ASCs. This information pertains to supporting students with an ASC in academic settings and comes from a variety of sources including local and international information, peer reviewed research and research conducted at OTARC (funded by DHS, Victoria). The information provided is general and not targeted for specific tertiary institutions.

http://www.autism-uni.org/

Autism & Uni is a multinational EU-funded project that helps greater numbers of young adults on the Autism Spectrum to gain access to Higher Education (HE) and to navigate the transition successfully. They have created FREE resources that HE Institutions across Europe can adopt. These include a set of Best Practice Guides for HE managers, academics and support staff. There is also an Online Toolkit for students to give them the information and strategies needed to manage the transition to university.

Computer Applications (as recommended by CSMP mentors and mentees)

- **Lost on Campus** (Free App. - Australia's biggest campus mapping app, with 42 campuses and over 36,000 locations).

- **Smiling Mind** (Free App. - Modern mediation program developed by psychologists for young people).

- **Anti-Social** (Small cost to buy App. - Makes it easy to target and block any distracting websites).

- **Procrastination** (Free App. - for all procrastinators).

- **SafeZone** (Free App. - for all students and staff that connects directly to the university security team while on campus.)

- **MindShift** (Free App. for young adults to help learn ways to relax, develop more helpful ways of thinking, and identify active steps that will help take charge of anxiety. This app includes strategies to deal with everyday anxiety, as well as specific tools to tackle: Test Anxiety, Perfectionism, Social Anxiety, Performance Anxiety, Worry, Panic, Conflict).

- **Friendmaker** (Small cost to buy App. - companion to Dr E. Laugeson's book, *The Science of Making Friends*, and contains important skills, strategies, role-play videos, and tools for making and keeping friends based on guidance from the UCLA Peers program).

Appendix A – Mentor Information

MENTOR INDUCTION MEETING CHECKLIST

Tick Completed Items:

☐ Instruct mentors to briefly introduce themselves to group.

☐ Issue *Specialist Mentor Toolkit,* National Autistic Society (NAS) *Student Mentor Guidelines (UK)*, National Disability Coordination Officer Programme (NDCO) of Australia *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* and *Mentor Confidentiality Agreement* (See Appendix A).

☐ Ask mentors to sign and return the *Mentor Confidentiality Agreement.*

☐ Be issued and asked to get joint signatures (mentee/mentor) on the *Mentor/Mentee Responsibilities Contract* form to be returned ASAP to Coordinator.

☐ Instruct to read and digest three documents (Toolkit, NAS Guidelines & NDCO Helpful Hints) prior to their Specialist Mentor Training.

☐ Give details of the training day and have any queries addressed.

☐ Explain importance and the workings of the social group.

☐ Ask for and note down names of volunteers to be on a Social Group Coordinating Committee (3-5 students needed so responsibilities can be shared).

☐ Give details of contract and payment requirements (if mentors are to be paid).

☐ Inform regarding National Police Clearance and Working with Children Check requirements.

☐ Issue mentee/mentor pairings list.

☐ Inform of details of mentor/mentee meeting requirements ('Meet and Greet' Meeting or individual meetings to be organised).

☐ Issue details of supervision meeting dates, times and deadlines for weekly reports during the teaching weeks of the semester.

☐ Remind to highlight (bold type) any pressing issues and positive breakthroughs in their weekly reports that need discussion at the supervision meetings.

☐ Issue their mentee's file (hard copy) to briefly view, note important details (such as contact details, mentee interests, Safety Plan) and return to the Program Coordinator at the conclusion of the meeting (10 minutes approx.).

☐ Collect mentee files from mentors and indicate they can revisit or gain access to files at another prearranged time if needed.

GENERAL PROGRAM INFORMATION

Specialist Peer Mentoring Program Information

(Supporting students on the Autism Spectrum and related conditions)

The Specialist Peer Mentoring Program is designed to support students on the Autism Spectrum and related conditions to improve their retention, academic success and well-being at university through the employment of a peer-mentoring program.

Research has shown that tertiary students on the Autism Spectrum may experience difficulties with:

- Planning and organising.

- Verbal comprehension.

- Group work and oral presentations.

- Forming friendships and joining groups.

- Seeking help / Self-advocacy.

- Anxiety / Depression.

Research has also shown that an experienced specialist peer mentor can help with these difficulties.

What is a Peer Mentor?

A peer mentor is a friendly, successful and experienced student who has received specific training in Autism Spectrum Conditions. Each student mentee is paired with a specialist peer mentor who is available to provide support and guidance according to their mentee's individual needs.

Mentors provide mentees with the opportunity to discuss personally relevant issues and their short, medium and long term academic and life goals. Individual

communications and/or meetings encourage the mentee to develop strategies to work through specific problems and practise target skills. Mentors can also assist students in locating appropriate services or groups on campus.

Mentors work toward the long term goal of trying to help their mentee gain as much confidence, independence and self-advocacy as possible in preparation for a more successful life.

What else can the Specialist Peer Mentoring Program do?

- Facilitate a Social Group to help mentees build a welcoming social network within their campus community.

- Support mentees to gain Work Experience/Employment in their field of interest/study over the course of their studies.

Mentees' key role & responsibilities:

- Respond ASAP to any communications from their mentor during the semester.

- Contact/meet their mentor at agreed times (and locations on campus if applicable).

- Advise their mentor by email/text of any unavoidable changes to arrangements at least 24 hours in advance.

- Communicate any difficulties they may be experiencing to their mentor.

- Be open to try different techniques to improve these difficulties.

- Try to attend Social Group events when possible.

Mentors' key role & responsibilities:

- To listen to their mentee's concerns and provide guidance for overcoming the challenges of studying in a tertiary environment.

- To link their mentee with clubs, services and supports that are on campus to help them succeed socially, emotionally and academically.

- To provide assistance with strategies for organising and planning workloads, working within groups, giving presentations, finding employment and so on.

- Try to attend Social Group events when possible.

Please contact the Program Coordinator below for more information:

(Please insert Program Coordinator contact details here)

Wanted: Specialist Peer Mentors

(Supporting students on the Autism Spectrum and related conditions)

- Are you a successful, experienced tertiary student who would like to gain valuable experience mentoring a student on the Autism Spectrum?

- Are you available to work on campus one or more hours per week during semester?

- Would you like to work in a team environment, receive specialist training and support for your role?

- If your answer is YES to all of these questions, please *email (fill in appropriate Coordinator name and contact details)* ASAP and include the following details:

    1. A current resume.

    2. Reasons for your interest in the specialist mentoring role.

    3. The name / contact details of an academic staff member who can attest to your suitability for the role of a specialist mentor.

Specialist Peer Mentoring Program Time Sheet

Mentor Name: ………………………..……………………………………………..

Student ID: ……………………..………………………………………………….

Staff ID: ………………..……………………………………………………………

School: …………………..………………………………………………………….

I have undertaken the following support services for:

Mentee Name: ……………………..…………………………………..…………

Student ID: ……………………..…………………………………………………

School: ………………..…………………………………………………………

SEMESTER   1   2   Year: 20_ _

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Date: …………………….   Hours Worked: ……………………..

Mentor Signature: …………………………………….Date: …………………………

Mentee Signature: …………………………………..Date: …………………………

Coordinator Signature: ……………………………….Date: ………………………….

Specialist Peer Mentor Weekly Reporting Form

Mentor Name: _____

Mentee Name: _____

For Week Ending Friday | | | |
---|---|---|

Times, Types and Place of Contact:-

-
-
-
-
-

Session Content:-

Strengths:-

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Difficulties:-

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Possible Solutions:-

```

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Referrals (Where, Reason for referral):-

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MENTOR REPORTING FORM (SAMPLE)

Mentor Name: _____G _____

Mentee Name: _____W_____

For Week Ending Friday	14	03	20xx

Times, Types and Place of Contact:-

- 12/3 Meeting with mentee – waited didn't turn up
- 12/3 emailed mentee
- 13/3 emailed mentee and text
- 14/3 reminder text
- 14/3 meeting with mentee

Session Content:-

Emailed W after I waited on Wed and he didn't show up just enquired about how he was and let him know that I waited and that I could meet either Thurs or Fri.
Received email from W, had a busy day and remembered Wed night after it was too late. Was happy to rearrange and scheduled time for Fri afternoon to catch up.

Was early for meeting on Fri, explained the situation on wed needed to do shopping and had phoned a friend, didn't expect him to say he was going right then. Has transport issues, is able to drive but doesn't have a car, relies on friends in order to do shopping. Does use public transport and is competent. Asked if he had a diary has never liked using them, showed him the semester planner and explained how he could map out his assignments felt this might be quite useful.

He advised until today did not have internet access in his room, showed me that he had purchased wireless internet, had also arranged with other students in student housing to share and had advised them that he wouldn't purchase until everyone paid the first month in advance (Check at supervision meeting how others in student housing organise this). Let him know that was good and suggested he use the same strategy if they were cooking for each other so he wasn't always paying.

Doesn't have any goals at the moment is happy with the way things are going, and is finding the work easy. Finds the catch up's helpful, he advised his major problem is usually around exam time, which I suggested it may be good to book in with the counselling service early so he has that added support. He did feel that knowing I would be around e.g. our catch up's would be helpful.

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Looked at his timetable and suggested that maybe Tuesday would be a better day for meeting as he had fewer classes, so would possibly feel less overwhelmed, he agreed and we arranged to meet Tuesday's 12pm from now on suggested he put a reminder in his phone, as I didn't want to be reminding him every week as I felt like I was nagging him, felt this was a good idea.

Spoke about the Social Group and advised him that J. was now studying her Masters at Curtin too and was keen to go along, he thought he might attend next week as we had also moved our catch up which would free him up to attend.

He told me he has also made a friend in Physics, someone who doesn't like being around people, prefers his own company. His house mates were surprised as this was the first person he had brought home.

Also spoke about being safety conscious when catching public transport late at night, keeping to well-lit areas. He felt comfortable with this as where he lived in UK was rural and was a rough area.

Strengths:-

Planning and Organising.

Difficulties:-

Time management.
Transport – more around relying on other people or public transport.
Stress around exam time.

Possible Solutions:-

Continue seeking out appropriate help re time management on campus and alert W to what is available. Check at supervision meeting how others in student housing organise internet access and payment.

Referrals (Where, Reason for referral):-

Refer W to Counselling so he can start to get some help for anxiety prior to the exam period.

MENTOR/MENTEE RESPONSIBILITIES CONTRACT

Responsibilities of a CSMP Mentor

I agree to:

- Respect the professional boundaries between the mentor and the mentee.
- Respond ASAP to any communications from my mentee during the semester.
- Contact or meet my mentee at agreed times (and locations if applicable).
- Advise my mentee by email/text of any unavoidable changes to arrangements at least 24 hours in advance.
- Lodge a regular report documenting issues arising for supervision purposes.
- Communicate with my mentee in clear and specific terms providing a written and/or diagrammatic representation of the communication (if needed).
- Attend the Social Group (when possible) and regular supervision meetings to gain advice and guidance.
- Support my mentee to prepare their resume and seek out relevant work experience / work over time.
- Provide guidance consistent with the defined role of a specialist student mentor.
- Provide feedback about the program through participation in evaluation research.

Responsibilities of a CSMP Mentee

I agree to:

- Respect the professional boundaries between the mentor and the mentee.
- Respond ASAP to any communications from my mentor during the semester.
- Contact or meet my mentor at agreed times (and locations if applicable).
- Advise my mentor by email/text of any unavoidable changes to arrangements at least 24 hours in advance.
- Try to attend any meetings requested by the Specialist Peer Mentoring Program including the Social Group.
- Work toward my own short, medium and long term life goals including employment.
- Communicate any difficulties I may be experiencing to my mentor (or the Coordinators should the need arise).
- Be open to try different techniques to improve difficulties I may be experiencing.
- Provide feedback about the program through participation in evaluation research.
- Contact the Coordinator if I am experiencing concerns / difficulties working with my mentor.

We, (print mentor name) _____and

   (print mentee name) _____have

read and understood the above Mentor/Mentee Responsibilities Form. We agree to these conditions for the mentoring service provided by CSMP.

Mentor Signature_____ Date_____

Mentee Signature_____ Date_____

MENTOR CONFIDENTIALITY AGREEMENT

I (name)..

OF (address) ....

understand that maintenance of confidentiality is an express condition of my role as a specialist mentor.

I undertake to treat as confidential any information to which I may have access in the course of my mentoring role. I shall only access clinical records that are relevant to my duties as a mentor and refrain from accessing any other clinical records of the service. I am aware that unauthorised access to electronic records may be tracked.

If a conflict of interest exists between a presenting mentee and myself, I shall immediately inform my Coordinator. I shall not use such information other than as required in the course of my duties as a mentor within the Service.

I shall not divulge such information to any party outside of the Specialist Peer Mentoring Program either during or subsequent to my role as a mentor except as may be required by a competent court of law or as authorised in writing by the Coordinator.

Signed: ……………….. Date...............................

Witness: ……………... Date...............................

SOCIAL GROUP REPORT FORM

Report for Weekly Social Group

Date:

Mentees in Attendance:

Mentors in Attendance:

What happened at the social group?

What areas could be improved?

What is planned for future weeks?

SOCIAL GROUP REPORT FORM (SAMPLE)

Report for Weekly Social Group

Date: Wednesday 4th of March 20xx

Attendance:

Mentees:

Mentors:

What happened at the social group?

- The session started on time at 12.15pm.
- Firstly K. facilitated an icebreaking activity "If's & What's" and "Candy Confessions"
- Everyone participated in the activity, all were engaged
- We then played board and table games in groups such an Jenga, Poker, Zombie card game
- E. performed a song she has written herself
- The meeting finished on time at 1.45pm.

What areas could be improved?

- Make sure that any important information about the next meeting is announced before the social group ends e.g. Next week M. is facilitating a session where participants bring something meaningful along with them to talk about – but we didn't manage to tell the attendee's to bring something along with them next week. We will have to ask Mentors to remind mentee's and post it on the social group Facebook page instead.

What is planned for future weeks?

- M. will be running a social activity session focusing on Mentee's interests and passions
- Working on listening and talking – asking questions to find out more about others, starting conversations about other people's interests etc.

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MENTOR HANDOVER FORM

To help with the handover process, please complete the form below and return to your Specialist Mentoring Coordinator:

Mentor Name:

Mentee Name:

1. My mentee's main strengths are:

2. My mentee's main difficulties are:

3. The goals that I see as being useful and achievable for my mentee are:

a) Short term:

Have you discussed these with your mentee? Yes/ No

b) Long term:

Have you discussed these with your mentee? Yes/ No

4. Please provide any additional information that the new mentor may find useful.

MENTEE/MENTOR COMPOSITE LIST (SAMPLE)

Mentee List						
Name & School / Faculty	Student No.	Email	Phone	Entry Date	Parent/Support Person Contact Details	Mentor Name

Mentor List						
Name & School / Faculty	Student No.	Email	Phone	Entry Date	Attended Training	Mentee Name/s

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WEEKLY CHECKLIST FOR REPORT (R), MEETING (M) & TIME-SHEET (T) (SAMPLE)

Date	Wk1		Wk2			Wk3		Wk4			Tuition Free	Wk5			Wk6	
MENTOR	R	M	R	M	T	R	M	R	M	T		R	M	T	R	M

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Appendix B – Mentee Information

Specialist Peer Mentoring Program

- Are you a student who is on the Autism Spectrum or has a related condition?

- Would you like an experienced, successful peer mentor to help you navigate university life during the academic year?

- Would you prefer a peer mentor specifically trained to support your individual strengths and needs?

If your answer is YES to all of these questions then please contact (Fill in name/s and contact details of appropriate person/s) ASAP for more details as mentee places are limited.

MENTEE INTAKE MEETING CHECKLIST

Mentee Name:

Tick completed items:

Meeting:

☐ Issue booklet containing:

- o *Mentee Information Booklet* (See separate document).

- o NDCO *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* (See reference to separate document).

- o *Mentee Intake Form* (See Appendix B).

- o *Mentee Release of Information Form* (See Appendix B)*.*

- o *Mentee Consent Form* (See Appendix B).

- o *Mentee Safety Plan (*Appendix C).

- o *Mentee Social Group Flyer* (Appendix B)

☐ Explain contents of booklet.

☐ Ask mentee to complete and return the relevant forms to the Coordinator ASAP (See Appendix B - *Mentee Intake Form, Mentee Release of Information Form, Mentee Consent Form* and Appendix C – *Mentee Safety Plan*).

☐ Encourage mentee to ask any questions they may have about the program.

☐ Inform mentee as to how the first point of contact between mentor and mentee will be made.

☐ Issue a 'Meet & Greet' flyer if needed. (See Appendix B - *Meet & Greet Flyer).*

☐ Encourage mentee to contact the Coordinators should they experience difficulties with their mentor.

Post Meeting:

☐ Scan and place completed forms in mentee file (soft and hard copy).

☐ Record relevant details on composite list.

☐ Send a reminder 'Meet and Greet' meeting email or set up a meeting with their allocated mentor.

Social Group

(Fill in times, day, dates and location)

The Social Group is a fun, social space that occurs each week throughout the teaching weeks of semester. All are welcome! Please bring any board, card or electronic games you'd like to play. Our emails are below if you wish to contact us. We hope to see you there!

(Fill in email contact details of Social Group Coordinators and provide details of the Social Group Facebook page if one has been created)

'MEET & GREET' MEETING
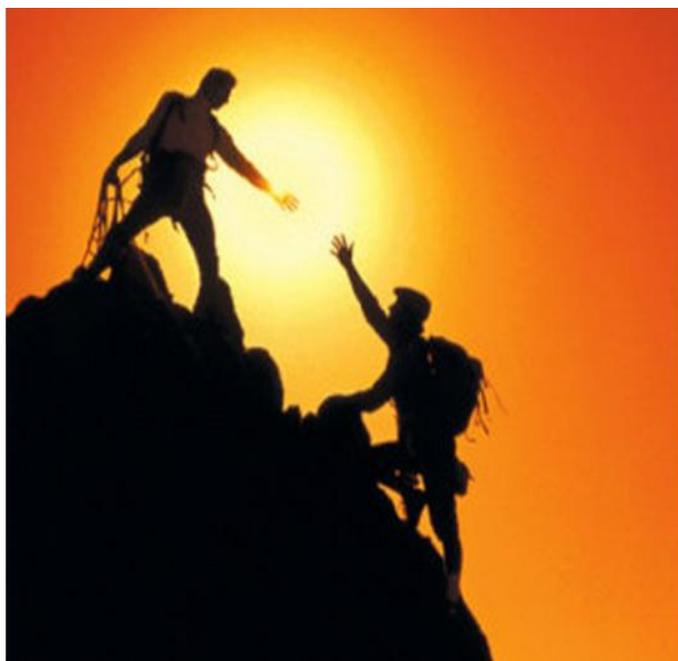
You (and a support person) are invited to meet your mentor and others involved in the Specialist Peer Mentoring Program.

Where?

When?

RSVP?

Coordinator:

(Fill in contact details of Coordinator)

MENTEE INTAKE FORM

SPECIALIST PEER MENTORING PROGRAM

Information provided on this form will be kept confidential. Mentees have very valuable knowledge about what works and doesn't work for them. By providing detailed information mentees will help their mentor understand their individual profile and specific needs more quickly. Not all sections of this form will be relevant to all mentees, please fill out all relevant areas to your situation.

(*It is highly recommended that mentees gain the assistance of a support person / parent when filling out this form because they can often provide additional information that will be useful to their mentor.)

General Information:

Today's date: _____

Your full name: _____

Your preferred name: _____

Your age: _____

Your birth date: _____

Your home address: _____

Your phone number/s: _____

Your preferred email: _____

Your preferred contact method: _____

Your student number: _____

Parent / support person contact information (name, address, phone, email):
_____
_____
_____
_____

(To be part of the Specialist Peer Mentoring Program you will need to give permission for us to contact your parent/support person should an emergency arise or more details about your situation need to be known. Please tick appropriate box on the attached Release of Information Form).

Prior Educational Background:

Where did you receive your high school education (this includes home school education)?

_____

What year did you finish your high school education?

_____

Were you provided with appropriate educational support in your high school setting? (tick one)

- o No.

- o Yes. (give details)

_____
_____

Have you attended TAFE or any other tertiary education institutions? (tick one)

- o No.

- o Yes.

If yes, what degrees, diplomas or certificates did you attempt and what were your results?

_____
_____
_____

Did you receive extra support at these other tertiary education institutions? (tick one)

- o No.

- o Yes.

If yes, what supports were put in place that were helpful?

_____
_____
_____

Current University Information:

Course enrolled in:

_____

Current major:

_____

Year (circle one or more):   First   Second   Third   Fourth   Fifth   Sixth

Academic standing at the moment (circle one):   Good

Conditional

Course coordinator's name and contact details (if known):

_____

Do we have permission to speak with this person? (tick one)

- o   No.

- o   Yes.

(If yes, please tick appropriate box on the attached Release of Information Form)

Academic & Scholarship Services:

Do you currently receive any assistance to help you with your studies (tick one)?

- o   No. Why not? (give details)

_____
_____

- o   Yes. (give details)

_____
_____
_____

University Disability Service:

Are you registered with the University Disability Service? (tick one)

- o   No. *

- o   Yes.

(If yes, please tick appropriate box on the attached Release of Information Form so that we can access any other relevant background information from your Disability Advisor.)

(*Please Note: All mentees need to be registered with the University Disability Service to gain the services of a specialist mentor and any other accommodations / modifications for which they may be eligible).

Housing Information:

Where do you live? (tick one)

- o On campus.
- o With parents at home.
- o With other family member/s.
- o Off campus: Shared or Alone. (please circle)
- o Other. (provide details)

Please tell us about any difficulties you may be experiencing with your living arrangements?

_____

_____

Student Activities:

Are you a member of any groups on campus? (tick one)

- o No. (why not? give details)

_____

_____

- o Yes. (give details)

_____

_____

Transportation:

Are there any difficulties with transportation to and from university? (tick one)

- o No.

- o Yes. (give details)

_____

_____

Health Information:

Please indicate your main disability/diagnosis/condition?

_____

_____

When were you first diagnosed with this condition?

_____

Please describe how your condition affects you in relation to the following areas and if known, what helps you to overcome these difficulties. (Fill in areas relevant to you only):

Communication (difficulties and what helps):

_____
_____
_____

Social Relatedness (difficulties and what helps):

_____
_____
_____

Rigidity/Obsessiveness/Resistance to Change (difficulties and what helps):

_____
_____
_____

Sensory Function (difficulties and what helps):

_____
_____
_____

Learning and Memory (difficulties and what helps):

_____
_____
_____

Attention and Organisation (difficulties and what helps):

_____
_____
_____

Behaviour (difficulties and what helps):

_____
_____
_____

Emotions (difficulties and what helps):

_____
_____
_____

Self-Care (difficulties and what helps):

_____
_____
_____

Do you have other important health issues or medical conditions others should know about? (tick one)

- o   No.

- o   Yes. (give details)

_____
_____

Have you been treated for a psychological disorder such as anxiety or depression? (tick one)

- o   No.

- o   Yes. (give details about difficulties and treatments)

_____
_____

How would someone know that you are becoming anxious, stressed, depressed or annoyed?

_____
_____

What should others do to help you when you are highly stressed?

_____
_____

What are the methods that you use to calm yourself when you are highly stressed?

_____
_____

Medication Information:

Are you currently taking any medication? (tick one)

- o   No.

- o   Yes. (If yes, give details)

_____
_____

Are there any side effects to the medication that others should know about? (tick one)

- o No.

- o Yes. (If yes, give details)

_____
_____

Personal Strengths and Goals

My areas of special interest are:

_____
_____
_____

My best skills are:

_____
_____
_____

My short term goals are:

_____
_____
_____

My long goals are:

_____
_____
_____

Work and Work Experience

Have you been able to gain any work or work experience? (tick one)

- o Yes. Where and When? (give details)

_____
_____

- o No. Is this something you would like help with? (give details)

_____
_____

Thank you for completing this form. Please provide copies of any documentation about yourself that could be helpful to your mentor and the Program Coordinator. Please complete intake forms, scan and email/deliver them back to the Specialist Peer Mentoring Program Coordinator ASAP. If you experience any difficulties please do not hesitate to contact the Program Coordinator for some assistance. *(Program Coordinator's contact details here)*

MENTEE RELEASE OF INFORMATION FORM

I, _____ *(insert your name and student number)* am currently receiving services from the Specialist Peer Mentoring Program. I give permission for you to release information about me to the following persons:

Please tick appropriate boxes:

- o   Parent/Support Person.

- o   Course Coordinator.

- o   Disability Service Staff.

- o   Counselling Service Staff.

_____   _____

(Student Signature)   (Coordinator Signature)

_____   _____

(Print Name)   (Print Name)

_____   _____

(Date)   (Date)

AutismCRC

MENTEE CONSENT FORM

As part of providing a peer mentoring service to you, the Program Coordinator and your assigned mentor will need to collect and record personal information from you that is relevant to your current situation. This information will be a necessary part of assessing the areas that you may need support with while at university.

Access

You may access the material recorded in your file upon request, subject to the exceptions in National Privacy Principle 6. If you wish to see your file, you may make a request to your Program Coordinator to help you with this.

Confidentiality

All personal information gathered by the Program Coordinators and mentors during the provision of mentoring services will remain confidential and secure except when:

1. It is subpoenaed by a court, or
2. Failure to disclose the information would place you or another person at risk; or
3. Your prior approval has been obtained to
   a) provide a written report to another professional agency e.g. a GP or another professional, or
   b) discuss the material with another person e.g. a parent or employer

Generally files are kept for a minimum of five years and are then destroyed.

I, (*print name/student number*) _____have read and understood the above Consent Form. I agree to these conditions for the mentoring service provided by the Specialist Peer Mentoring Program.

Signature _____Date_____

SPECIALIST PEER MENTORING PROGRAM REFERRAL FORM

The aim of mentoring support is to help students navigate tertiary study and to achieve their academic and personal goals.

Any student who has been diagnosed to be on the Autism Spectrum or has a related condition that affects their ability to study successfully is eligible for support through the program.

* Please Note: It is not recommended that peer mentoring be provided to students with significant behavioural issues that would potentially put their student mentor at undue risk.

Date:

Name:

Student Number:

Phone Number:

Email:

Course of study:

Name and position of Staff Member providing referral:

Reason for Referral:

Contact Details of Staff Member providing referral:

Office use only	
Name of mentor	
Mentor student ID	
Date forwarded	

INFORMATION SHEET FOR WORK EXPERIENCE/EMPLOYMENT (SAMPLE)

Brief Information Sheet on J.

Individuals on the Autism Spectrum can experience difficulties in four key areas:
- Social Understanding.
- Communication.
- Change/Limited Interests.
- Sensory Hyper/Hypo sensitivity.

They can also offer strengths in the following ways:
- Honesty / loyalty.
- Excellent rote memory for areas of interest.
- Visual spatial abilities.
- Detail focused.
- Preference for organised procedures.
- Intense interests / savant skills.
- Being logical.

J. is a highly intelligent young woman who has worked hard to build on her strengths, however, at times she will need support and guidance with her difficulties. It is recommended that J. be assigned a work mentor who can help J. if the need arises.

J.'s Specific Profile

- Social Understanding
    1. May not always understand sarcasm/figurative language etc.
    2. May not fully understand the social nuances of situations.
    3. May have difficulty navigating office politics.
    4. May become shy in large crowds of peers of similar ages.
    (Solution - Provide a Supportive Mentor / Encourage J. to communicate difficulties to Mentor).

- Communication
    1. May not always seek help when needed.
    2. Prefers to have visual information to support verbal instructions.
    3. Needs to have feedback sought regarding her understanding of requirements.
    4. Needs to be encouraged to advocate on her own behalf.
    5. Needs clear list of instructions and tasks.
    (Solution - Have written information to support verbal instructions / Check J.'s understanding of tasks to be undertaken / Use of Mentor).

- Change/Limited Interests
    1. Prefers order, timelines and logicality.
    2. Appreciates being informed of change prior to situations occurring.
    3. Appreciates knowledge and use of established work procedures and practices.
    4. Enjoys playing video games/ board games/cards/dancing/ astronomy/drawing/and watching fantasy or action movies.

(Solution - Have an ordered, organised workplace where change is communicated as early as possible / Communicate J.'s interests to other staff members so that a common bond can be established / Use of Mentor).

- Sensory Hyper/Hypo sensitivity
  1. Limited Food Preferences.
  2. Difficulty with loud sounds.
 3. Difficulty with strong smells.
  (Solution - Allow J. to order/have her own food preferences when social events arise /Seat J. in a quiet area in the workplace/Use of Mentor).

Appendix C – Crisis Management Information (Samples)

CURTIN CRISIS RESPONSE CHART (SAMPLE)

Please Note: Coordinators will need to source/adapt their own appropriate institution crisis management information (i.e. Crisis Response Chart & Safety Plan) and attach it to Specialist Mentor Toolkit (Appendix B):
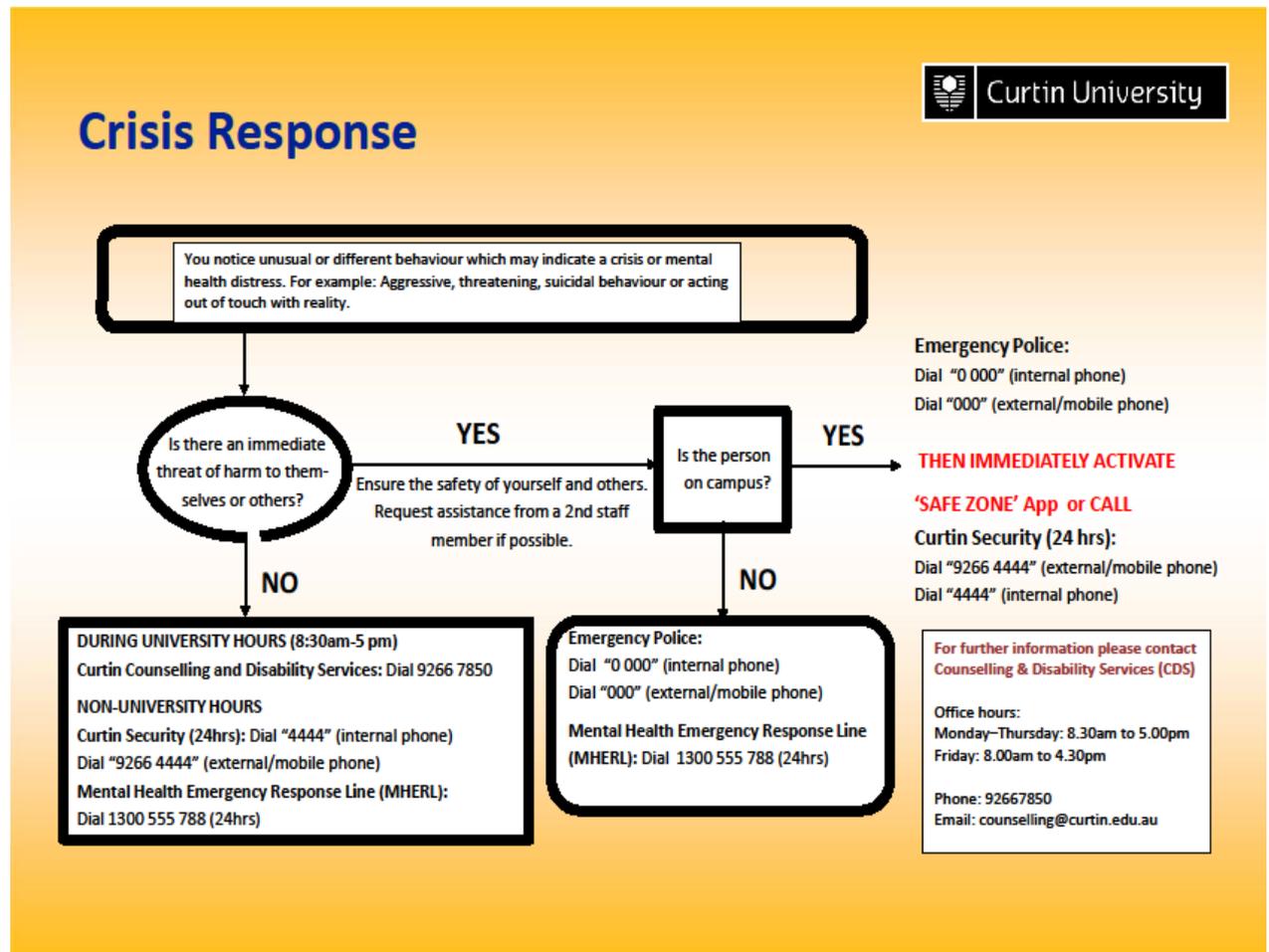
THE UNIVERSITY OF
WESTERN AUSTRALIA
Achieving International Excellence

UWA Specialist Mentoring Safety Plan

Date: __ / __ /_____ Having a plan in place that can help guide you through difficult moments can make a difference and keep you safe. A safety plan is designed so that you can start at step one and continue through the steps until you feel safe. You should keep your plan in a place where you can easily access it.

Things I can do to keep me well: (e.g., keep up my self-care activities like exercise, relaxation, seeing friends and family, attend my one-on-one meetings with my mentor).

Step 1 Recognise My Warning Signs: What sorts of thoughts, images, moods, situations, and behaviours indicate to you that a crisis may be developing? Write these down in your own words.

Step 2 Coping Strategies: Things I can do to improve my mood and keep me safe (relaxation, physical activity, music, deep breaths, positive self-talk, making the environment safe).

Step 3 People I Can Contact For Help: List of family members or friends who are supportive and who you feel you can talk to when under stress.

First Person I can Call

AutismCRC

Name:	Relationship:	Phone:

Other People I Can Call:

Name:	Relationship:	Phone:

Step 4: Professionals Or Agencies I Can Contact		
Professional or Agency:	**Phone:**	**Comments**
GP:	Ph:	During Office Hours
Lifeline Suicide Call Back Service	Ph: 1311 14 Ph: 1300 659 467	24/7 Crisis Telephone Lines
Mental Health Emergency Response Line (MHERL)	Metro callers 1300 555 788 Peel callers 1800 676 822	24/7 assessment, support and referral if required.
If you are at immediate risk of harm to yourself or others, contact emergency services on 000.		

I understand the above Safety Plan and agree to follow it to help me keep safe
Mentee Signature: Coordinator Signature: Mentor Signature:

Wilson, McMillan & French (2013). Royal Perth Hospital, Department of Psychiatry WA

Specialist Peer Mentoring Module

Providing Support to Tertiary Students on the Autism spectrum and Related Conditions

Specialist Mentor Toolkit

June 2016

Curtin University

THE UNIVERSITY OF WESTERN AUSTRALIA

Australian Government
Department of Industry,
Innovation and Science

Business
Cooperative Research
Centres Programme

Copies of this executive summary report, the associated mentoring modules and resources can be downloaded from the Autism CRC website autism crc.com.au

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism . Taking a whole of life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people with autism .

autism crc.com.au

> *"For weeks you see what you think is little or no improvement. What you don't realize is that it is happening without you knowing and all of a sudden you see them taking on board what you have said, encouraging fellow mentees to go out and try things and inviting them along to study groups. Without the program they wouldn't have this, it's fantastic to see and very rewarding that you can make a difference."*
>
> *(CSMP Mentor)*

Table of Contents

Specialist Mentor Toolkit

Congratulations on your new role as a specialist mentor for a tertiary student on the autism spectrum and related conditions. The Specialist Peer Mentoring Program is based on the successful Curtin University Specialist Mentoring Program (CSMP) situated in Perth, Western Australia – (http://life.curtin.edu.au/health-and-wellbeing/autism_-related-conditions-peer-mentoring.htm), and is designed to specifically support students on the autism spectrum and related conditions in a tertiary education setting. The following Toolkit provides some valuable background information and tools that you may find assist in your role as a specialist mentor.*

*Please Note: Mentors should be familiar with the contents of this Toolkit, the National Autistic Society (NAS) *Student Mentor Guidelines* http://www.autism .org.uk/studentmentors and the National Disability Coordination Officer Programme (NDCO) *Transition to Tertiary Education*: *Helpful Hints for People with Autism spectrum Disorder* www.adcet.edu.au/autism -transition booklet before they undertake their Specialist Mentor Training. Along with the Specialist Mentor Toolkit, these documents will be distributed by your Coordinator at the initial Mentor Induction Meeting. Mentors should be aware that their mentee will also be issued with a copy of the NDCO booklet and a Mentee Information Booklet when they join the Specialist Peer Mentoring Program.

PROGRAM RATIONALE

The Specialist Peer Mentoring Module has been designed to respond to the growing number of students on the Autism spectrum and related conditions now enrolling in tertiary education courses worldwide (Bebko, Schroeder, & Ames, 2011; Hastwell, Harding, Baron Cohen & Martin, 2012; Hastwell, Harding, Martin, & Baron-Cohen, 2013). Preliminary research indicates that the prevalence of tertiary students on the autism spectrum is approximately 1% of the overall student population, as high as prevalence rates of individuals on the autism spectrum for the general population (White, Ollendick, & Bray, 2011).

The reported increases in the number of tertiary students on the autism spectrum range between two to as much as eight-fold over five years (Bebko, et al., 2011; Hastwell, et al., 2012). International research indicates that these individuals are not performing to their full academic potential (Equality Challenge Unit, 2011). Researchers in the United Kingdom (UK) have found that those with an autism spectrum diagnosis have the lowest percentage of first or upper second degree classifications achievement of any disability groups who are engaged in higher education (Equality Challenge Unit, 2011).

Research into life outcomes for adults on the autism spectrum indicates they are a significantly disadvantaged group. A recent international research review investigating the prognosis, outcomes and effective interventions for adults on the autism spectrum found that they are significantly disadvantaged in the areas of employment, social relationships, physical/mental health and quality of life (Howlin & Moss, 2012). More recent UK research of 374 adults on the Autism spectrum (specifically Asperger Syndrome [AS]) indicates that 66% experienced suicidal ideation, 35% experienced planned or attempted suicide with rates that are more than nine times higher than that found in the normal UK population (Cassidy, Bradley, Robinson, Allison, McHugh &

Baron-Cohen, 2014). Support to facilitate this population's inclusion into mainstream society has been lacking with little research investigating the most effective ways to intervene and improve outcomes for these adults (Howlin & Moss, 2012).

According to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (American Psychiatric Association, 2013), individuals on the autism spectrum experience impairment in the two domains of social communication and restricted interests/repetitive behaviour. Beyond these impairments there are often more cognitive characteristics to consider including deficits in 'theory of mind' skills, difficulties with executive functioning, weak central coherence, difficulties with sensory processing and motor functioning problems (Australian Autism Education and Training Consortium (AAETC), 2008). Such students may also have a number of relative cognitive strengths in the areas of rote memory, visual spatial abilities, compartmentalized learning, preference for routine and rules, intense interests, savant skills and being logical (AAETC, 2008).

Students on the autism spectrum have been increasingly included in mainstream education settings (Frederickson, Jones & Lang, 2010; Jordan, 2005; Leach & Duffy, 2009; Ravet, 2011). However, research has shown that students with intellectual disabilities, including those on the Autism spectrum, often experience many challenges in accessing the necessary supports in these environments (Ford, 2007; Forlin, Keen & Barrett, 2008; Humphrey & Lewis, 2008a, 2008b; Humphrey & Symes, 2010; Kidd & Kaczmarek, 2010; MacDermott, 2008; McDonald, 2010, 2014; Shaddock, 2005; Shaddock, Smyth King & Giorcelli, 2007; Wing, 2007).

Concerns have been raised about the lack of appropriate, individualized attention and support available, the high attrition rates and the inordinate degree of bullying experienced by such students in mainstream educational settings (Attwood, 2007; Humphrey & Lewis, 2008b; Humphrey & Symes, 2010; Lynch & Irvine, 2009). Additionally, such students often experience social isolation, anxiety and sensory difficulties in mainstream settings where their need for routine and predictability is often at odds with the chaotic, noisy happenings of mainstream education (Humphrey & Lewis, 2008a; Knott & Taylor, 2014; Symes & Humphrey, 2010; Trembath, Germano, Johanson & Dissanayake, 2012; Wing, 2007).

Prior research has also shown that students on the autism spectrum have high dropout rates from secondary school, low rates of post-secondary education, poor post compulsory school integration, reduced independent living and community participation outcomes (Attwood, 2007; AAETC, 2008). Students on the autism spectrum are a particularly vulnerable group whose academic success is highly dependent on the quality of inclusiveness that they experience in an educational environment (Kidd & Kaczmarek, 2010; Leach & Duffey, 2009; McDonald, 2010, 2014; Van Hees, Moyson & Roeyers, 2014).

In the Australian context, one recent survey (Autism Spectrum Australia or Aspect, 2012) investigating the experiences, aspirations and needs of 300 adults with AS and High Functioning Autism (HFA) from every state and territory in Australia confirmed that, despite this group's aptitude for study, they experience significant struggles to reach their full potential in education. At the time of the survey more than 80% of the 300 respondents with AS and HFA had commenced or completed a tertiary qualification. Of this group, almost 75% identified that they needed support to help

them study. Almost 50% of the 300 respondents reported that they received no, or insufficient, additional support for their learning needs during their time in education.

In the same survey, tertiary education disability officers reported that students on the autism spectrum experienced difficulties in verbal comprehension, planning, organisation, social awareness and group work. Disability officers also perceived a lack of awareness and understanding of autism spectrum Conditions among tertiary educators. Over 66% of parents surveyed stated that educators in Australia are not well-informed about autism spectrum Conditions. Approximately 50% of the parents surveyed indicated that their child had not performed to his or her full potential while in education. The same survey found that in contrast to an Australian national employment rate of 95%, just 54% of adults with AS and HFA had a paid job at the time of completing the survey - and of those 54% in employment, 33% were found to be working in casual employment (Aspect, 2012).

Current preliminary research indicates that successful inclusion of students on the Autism spectrum in tertiary education environments incorporates a community of practice where a number of supports and initiatives are available (Barnhill, 2014; Gelbar, Smith & Reichow, 2014; Hastwell, et al., 2012; Hastwell, et al., 2013; Van Hees, Moyson & Roeyers, 2014; Wolf, Brown & Bork, 2009). Promising programs at the tertiary level include many different types of support with the student voice often being given increased importance to ensure that programs remain of greatest, practical benefit to this population of students (Bebko, et al., 2011; Hastwell et al., 2012; Hastwell et al., 2013; Wolf et al., 2009). Peer-to-peer mentoring where tertiary students on the autism spectrum are provided with trained, specialist student mentors to help them navigate university life has been highlighted as an effective means of providing support to these students (Bebko, et al., 2011; Hastwell et al., 2013; Wolf et al., 2009).

PROGRAM BACKGROUND

In 2014, inspired by the success of a small number of recent, promising peer-to-peer tertiary mentoring programs operating in Canada (Bebko, et al., 2011), the United Kingdom (Hastwell, et al., 2012; Hastwell, et al., 2013; Mowat, Cooper, & Gilson, 2011) and the United States (Wolf, et al., 2009), Curtin University and Autism West funded Dr Jasmine McDonald and Theresa Kidd to develop and implement one of the first Specialist Peer Mentoring Programs for students on the Autism spectrum in Australia – the Curtin Specialist Mentoring Program (CSMP). This was in line with federal Disability Discrimination legislation (Disability Discrimination Act, 1992, Disability Standards for Education 2005) and Curtin's Disability, Access and Inclusion Plan (2012-2017) which states a commitment to provide "equitable and inclusive access for people with a disability to its facilities, services, events and academic programs" (p.7).

In its inaugural year CSMP provided specialist mentoring to 17 students over the 2014 academic year, with most mentees electing to retain a specialist mentor for the 2015 academic year. In its second year CSMP provided specialist mentoring to 32 students during the 2015 academic year with most mentees electing to retain a specialist mentor for the 2016 academic year. CSMP also initiated a social group that has become an integral part of the Specialist Peer Mentoring Program.

The Toolkit is part of a modified, generic version of the Curtin University Specialist Mentoring Program (CSMP). Two independent evaluations of CSMP were conducted

during its first semester of operation in 2014 (Hamilton, 2015; Hamilton, Stevens & Girdler, 2016; Siew, 2014). Additionally, a comparative replication study of the CSMP program, based on the draft CRC module, was conducted at the University of Western Australia (UWA) during semester two, 2015.

Evaluation results of the 2014 CSMP program from the mentee perspective indicate that there was a significant improvement in mentee participants' sense of support and a significant decrease in their apprehension in communicating with others over the course of the program. Mentee participants also reported being highly satisfied with the program with a mean satisfaction score of 4.31 out of 5 (Siew, 2014). Evaluation results of the CSMP 2014 mentor training and program from the mentor perspective indicate that the training was well received with an overall mean satisfaction score of 4.7 out of 5 (Hamilton, 2015; Hamilton, Stevens & Girdler, 2016). Final results from the UWA comparative, replication study are yet to be released. Research papers based on these studies are in development.

The Toolkit is provided with the intention that other tertiary institutions may use the experience and resources developed by CSMP, UWA and the Autism CRC to adapt to their own circumstances so that tertiary students on the Autism spectrum and those with related conditions will have a greater chance to realise their educational potential in tertiary environments.

SPECIALIST PEER MENTORING PROGRAM MODEL

The Specialist Peer Mentoring Program Model draws on the CSMP experience and research (Hamilton, Stevens & Girdler; 2016) that indicates the quality of mentoring is impacted by such factors as:

- Specialised mentor training (prior to meeting mentees).

- Mentor's approach and self-efficacy (based on training / mentor experience).

- Mentor-mentee relationship (supported by an experienced Coordinator).

- Group mentor supervision (on a regular basis).

- Structural supports (Coordinator, Disability / Counselling Support).

- Social group (inclusive of mentors / mentees on a weekly basis).

Mentoring Program Model

Mentor Support — Supervision, Access to coordinator, Training

Peer Mentoring

Social Group

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THE PEER MENTORING ROLE

"Being a part of CSMP has been an incredibly rewarding, memorable and an invaluable learning experience. As a mentor, I had the honour of working with C., a first year student on the Autism spectrum. Prior to working with the program, I knew little about the daily challenges and anxieties that those on the Autism spectrum faced. However, working with C. has made me profoundly aware of how courageous these mentees are in confronting the challenge of university life. The program means that the mentees do not have to do it alone. I saw how CSMP program provided the scaffolding and support needed for the mentees to adjust to university and develop meaningful friendships. I feel very proud and honoured to be involved in such a worthwhile project that makes such a difference in these students' lives."

(CSMP Mentor)

Roberts (2000) defined mentoring as a:

> Formalised process whereby a more knowledgeable and experienced person actuates a supportive role of overseeing and encouraging reflection and learning within a less experienced and knowledgeable person, so as to facilitate that persons' career and development. (p.162)

According to Bebko, Schroeder, & Ames, (2011) who developed the York University Asperger Mentorship Program (AMP) in Canada:

> The role of the mentor is akin to that of a "coach,"… A coach helps you practice skills, they help you prepare for the game, they cheer you along, and work with you after the game to talk about what went well and how to practice for the next game – but a coach does not play the game for or with you. This analogy is used to clarify that the role of the mentor is different from a counsellor or a friend. (p.5)

Mentors help 'coach' their mentees by communicating and/or meeting with their mentees for one or more hours per week generally during the teaching weeks of the semester. The communication channels used are determined by both parties and may also depend upon whether the student is internal (on campus) or external (off campus) to the university.

Some mentees may need more mentoring than others depending upon the complexity of their profiles. No two mentees will be alike in their needs. Mentors should not take

on the role of counsellor, tutor or parent but encourage their mentee to make contact with appropriate staff and services on campus to meet their needs.

Please Note: The CSMP experience has shown that Facebook should not be used by mentors as a preferred, individual communication method with their mentee as this does not establish appropriate professional boundaries between the mentor and mentee and problems of over familiarity have arisen because of this.

Key Duties of a Specialist Mentor

AutismCRC

Participate in specialist training / weekly reporting & supervision	Communicate / meet weekly with their mentee during semester	Understand their mentee's profile from intake form and safety plan
Provide flexible and individualised support	Ensure mentee registered with Disability Services to gain accommodations.	Build on the mentee's short and long term life goals including employment
Link mentee to appropriate university services and clubs	Encourage mentee to attend Social Group	Increase mentee's independence, self-advocacy and confidence over time.

The mentor role involves the following duties:

- Completing appropriate specialist mentor training.

- Familiarising yourself with the profile / needs of your mentee and maintaining confidentiality (See relevant information held in mentee's record/file such as completed *Intake Form / Handover Form / Safety plan* etc.).

- Establishing boundaries and responsibilities of the mentee/mentor role (See Appendix A - *Mentor/Mentee Responsibilities Form*).

- Being available to work as a specialist mentor for one or more hours during the teaching weeks of the semester.

- Being available to attend a regular, group supervision meeting during the teaching weeks of the semester.

AutismCRC

- Providing a short weekly report detailing meeting times, issues arising and referrals by the specified time and date during the teaching weeks of the semester (See Appendix A – *Weekly Reporting Sheet* and *Sample*).

- Providing a fortnightly time sheet detailing working hours if required (See Appendix A – *Mentor Time Sheet*).

- Encouraging your mentee to indicate what difficulties (social, academic, etc.) they may be experiencing with university life.

- Giving advice and guidance to your mentee about how to handle these difficulties or where to gain appropriate support/advice from within the tertiary environment given your own successful tertiary student experience.

- Ensuring your mentee has registered with Disability Services and has investigated whether he/she is eligible for accommodations/modifications.

- Helping coordinate and providing feedback to the social group (See Appendix A – *Social Group Weekly Report Form* and *Sample*).

- Encouraging your mentee to attend the Social Group and attending with them as required.

- Encouraging and supporting your mentee to prepare their resume and seek out suitable work experience/work preferably in their respective fields of study (See Appendix A – *Brief Information Sheet for Work Experience/Employment [Sample]*).

- Working toward the long term goal of trying to help your mentee gain as much confidence, independence and self-advocacy as possible in preparation for a more successful adult life.

- Completing a handover sheet summarising the strengths, difficulties etc. of your mentee (See Appendix A – *Mentor Handover Sheet*) when your mentoring role finishes.

- Participating in an evaluation process as required.

- Developing appropriate self-care and crisis management skills (See Section 4 and Appendix B - *Crisis Management Information*).

- Making individual contact with your Coordinator as needed.

As a mentor you will potentially gain:

- Valuable professional practice experience in a supervised, supportive setting.

- Work experience for future employment.

- Leadership training and experience.

- Improved personal development, confidence and articulation skills.

- Personal satisfaction from giving and sharing knowledge.

- Networking opportunities with people from different cultures, nationalities, ages and backgrounds.

- Experience working as part of a team in a collegial setting.

- Experience as a positive role model for your mentee.

- Experience being part of a social group with students on the autism spectrum.

- Knowledge of autism spectrum Conditions and disability issues.

- Possible payment and official recognition of your role.

SOCIAL GROUP COORDINATING COMMITTEE

"The mentoring program offers the mentees a rare opportunity to meet like-minded people their age and fosters the development of interpersonal relationships. There is a scarcity of such opportunities for adults on the spectrum. My mentee has been at Curtin for 3 years and had never made any friends. He now attends the weekly social club meetings as well as plays cards with another mentee weekly. These social gatherings mean a lot to my mentee, he continually indicates that he wants to improve his social skills. I believe the mentoring program provides him with an opportunity to reach this goal."

(CSMP Mentor)

"It is rewarding to see a group of strangers all become great friends by the end of semester. The social connections formed provide a valuable social support network for the mentees."

(CSMP Social Group Coordinator)

As a mentor you will also be asked to be part of a Social Group Coordinating Committee. The Social Group:

- Is coordinated and attended by mentors and mentees.

- Is held on a regular basis during the teaching weeks of semester.

- Has a Social Group report written and delivered by the relevant coordinating committee mentors at the regular supervision meeting where feedback is given (See Appendix A – *Social Group Report Form* and *Sample*).

- Is a safe, welcoming social space to commune / make friends / practise social skills / experience belonging.

- Is organised in two parts:

  - A short (approx. 15 - 30 minutes) formal aspect delivered/organised by the social group committee (e.g. social skills, guest speakers, dating advice, careers etc. based on mentee needs and wants).

  - A longer (approx. 45 - 60 mins) informal aspect (e.g. electronic and board game playing – CSMP favourites Jenga, Fibbage and Pandemic).

- Is advertised through a specific, private Social Group Facebook page (posting of events etc.) coordinated by the mentors (and mentees when possible).

BOUNDARIES OF THE MENTOR ROLE

It is important that both mentors and mentees understand the boundaries of the mentor/ mentee relationship so that misunderstandings and resultant difficult situations do not arise. At the beginning of involvement with the Specialist Peer Mentoring Program, both mentors and mentees will be issued with information outlining the boundaries of the mentor/mentee relationship. Mentors will be asked to engage in conversation with their mentee about the mentor/mentee role culminating in the signing of the *Mentor/Mentee Responsibilities Contract* (See Appendix A - *Mentor/Mentee Responsibilities Contract).*

The CSMP experience has shown that difficulties can arise when appropriate professional boundaries have not been observed by either the mentor or the mentee. Given the emotional vulnerability of many students on the autism spectrum it is important that a respectful and professional distance be established between you and your mentee. Caution should be exercised regarding self-disclosure of very personal information. While you should be friendly and empathetic when working with your mentee you should not take on the role of a friend who the mentee becomes reliant upon to be part of their permanent social circle. The support and encouragement of other friendships through the social group and other clubs on campus should be the mentor's goal for their mentee.

If you and your mentee choose to become friends after your involvement with the Specialist Peer Mentoring Program finishes then this will need to be negotiated by both parties on a case-by-case basis with no expectation or pressure to be placed on either party.

To help establish and explain boundaries, mentors are asked to sign and request their mentees to sign a *Mentor/Mentee Responsibilities Contract* as soon as possible which outlines the following mentor/mentee responsibilities (see Appendix A).

Responsibilities of a Mentor are to:

- Respect the professional boundaries between the mentor and the mentee.

- Respond ASAP to any communications from their mentee during the semester.

- Contact or meet their mentee at agreed times (and locations if applicable).

- Advise their mentee by email/text of any unavoidable changes to arrangements at least 24 hours in advance.

- Lodge a regular report documenting issues arising for supervision purposes.

- Communicate with their mentee in clear and specific terms providing a written and/or diagrammatic representation of the communication (if needed).

- Attend the Social Group when possible and regular supervision meetings to gain advice and guidance.

- Support their mentee to prepare their resume and seek out relevant work experience / work over time.

- Provide guidance consistent with the defined role of a specialist student mentor.

- Provide feedback about the program through participation in evaluation research.

Responsibilities of a Mentee are to:

- Respect the professional boundaries between the mentor and the mentee.

- Respond ASAP to any communications from their mentor during the semester.

- Contact or meet their mentor at agreed times (and locations if applicable).

- Advise their mentor by email/text of any unavoidable changes to arrangements at least 24 hours in advance.

- Try to attend any meetings requested including the Social Group.

- Be open to try different techniques to improve difficulties they may be experiencing.

- Communicate any difficulties they may be experiencing to their mentor (or the Coordinators should the need arise).

- Provide feedback about the program through participation in evaluation research.

- Contact the Coordinator if they are experiencing concerns / difficulties working with their mentor.

FIRST AND SUBSEQUENT MEETINGS

At your first and subsequent meetings with your mentee it will be helpful to:

- Exchange contact details and establish favoured communication channels (not Facebook).

- Book communication / meeting times and meeting places (encourage face-to-face if possible).

- Discuss your mentee's interests & hobbies to develop trust / rapport (see Appendix C - *NAS Mentor Guidelines* pp. 16 - 18).

- Explain the mentoring role and how it differs from other roles (counsellor, parent etc.).

- Review & sign off 'Mentor / Mentee Responsibilities Contract' with mentee (see Appendix A – *Mentor/Mentee Responsibilities Contract*) and return to your Coordinator.

- Ensure mentee is registered with Disability Services & has appropriate accommodations / modifications in place.

- Encourage them to attend the Social Group.

- Answer any initial queries they may have.

- Establish short, medium & long term goals with your mentee (See *Recommended Methods of Communication* next section of this document).

- Help your mentee review & plan their class, study & assignment schedule & syllabi for the semester (See Appendix C - *NAS Mentor Guidelines* pp. 30 - 33).

- Link them with appropriate academic & social support (other services / clubs on campus) and tailor your support to their individual needs.

RECOMMENDED METHODS OF COMMUNICATION

Apart from the many communication ideas and tips found in the *National Autistic Society (NAS) Student Mentor Guidelines* (See Appendix C), previous CSMP mentors have found the following communication tips to be helpful:

- **Active / Reflective Listening** - Active / reflective listening is a communication technique used in counselling, training and conflict resolution, which requires the listener to feedback what they hear to the speaker, by re-stating or paraphrasing what they have heard in their own words and to confirm the understanding of both parties. Your mentee will appreciate it if you reserve judgement, show empathy and encourage them to speak openly about their situation using active / reflective listening techniques. It is important to help the mentee feel that their words are being respected and validated by asking clarifying reflective, open-ended questions until you more fully understand their situation.

  Example: Your mentee reveals to you that they are very upset about how their brother is treating them at home. You acknowledge their emotion and message by reflecting back to them such statements as: "It sounds like home life is very difficult for you at the moment. From what you have said it seems like it is hard for you to gain the right sort of support from your brother. How do you feel about that situation? What sort of support would you like?"

  And so on … you can offer reflective feedback until you can understand the mentee's situation more clearly. Remember you cannot be your mentee's teacher, therapist or parent but you can listen and offer a range of possible solutions from your own experience and also recommend appropriate support services from different specialist departments on campus (such as Counselling Services etc.).

- **Making use of 'I' Statements, Appropriate Self-Disclosure & Normalising** – It has been found by mentors when giving advice that the use of 'I' statements can be more effective than 'you' statements which may be misinterpreted as personal criticism by some mentees. Additionally, use of 'I' statements often allows your mentee to feel empowered to make their own decisions and choices regarding the advice being given. Appropriate self-disclosure of similar situations experienced or known about by the mentor can also help the mentee realise that many problems that they experience are a normal part of student life and as such can often be solved by seeking out appropriate advice and expertise located on campus.

  Example: Your mentee is pacing up and down when you meet them. They are very distressed about an upcoming assignment. After using active listening techniques to find out about their difficulties more fully, you attempt to discuss possible solutions by framing the advice using 'I' statements in the following way: "I remember that last semester I had a very difficult assignment as well. It felt like I was never going to be able to complete it. I felt very overwhelmed. I

asked one of the other students in my course what they were doing about the assignment and they said they were going to segment their work over a number of weeks so that it did not have to be done all in the final week that it was due. That advice really helped me and I ended doing the same by putting in mini-deadlines for myself".

And so on … you can brainstorm a range of solutions with your mentee as each person on the autism spectrum will be different regarding what solutions suit their situation best.

- **Setting Short, Medium and Long Term Goals** – It is important to ask your mentee about the life dreams they wish to realise. When discussing their dreams it is helpful to explore and set realistic, achievable short, medium and long term goals preferably within a timeframe. These goals will also need to be regularly reviewed and revised together. Each mentee will have their own academic profile and demonstrate very individual rates of progress that will need to be understood and appreciated by their mentor in relation to helping set realistic goals within time-frames. The setting of measurable goals helps both the mentee and mentor see what progress is being made toward the realisation of the mentee's life goals.

  Example – Your mentee is studying Astrophysics and indicates that one of her life dreams is to become a Science Communicator. You decide to translate this dream into a discussion about how to realise her dream by expressing the following: "I have found it helpful to draw up a goal setting plan where realistic short, medium and term goals are organised within suggested time frames to help me see and do what is needed to help me achieve my dreams. I am wondering if you would like to explore this as an option for helping you realise one or more of your life-dreams?"

  And so on … you can then both explore together the things that will need to be done to help realise one or more of your mentee's life goals. This may include such things as your mentee ensuring that their present academic course will lead to such a career. Investigating what demand there is for such a career path. It may also include visiting the careers section on campus to discuss suitable work experience placements and getting a resume completed and so on.

  Please Note: Goal setting sheets are available on the Centre for Clinical Interventions website (See *Useful Resources* section p. 25 - www.cci.health.wa.gov.au/).

- **Respecting the Self-Determination Rights of the Mentee** – Many individuals on the autism spectrum have had much of their lives supported and directed by others and their decision making skills may be limited because of this. When they begin tertiary education it is often a time of transition into adulthood where mentees must begin to make informed choices about their future. It is important to support their own agency and self-determination about their own lives. At

times it may feel easier to make decisions for your mentee based on your own experience but this may disempower them and rob them of the opportunity to grow in this regard. It is important to encourage your mentee to have their own voice in decisions being made about their current life and future. This can be done by asking open-ended questions and encouraging critical thinking when exploring an issue with your mentee.

Example: Your mentee is studying Physiotherapy. He tells you that he can cope with the theoretical side of his studies but the practical side of things is very difficult for him because he has to deal with live clients. You can help your mentee explore the range of options available to him by asking such open-ended questions as: "What would you like to do about this situation? I find investigating the pros and cons of a situation often help me make informed decisions. Would it help if we drew up a visual diagram of the consequences of making such a decision? What areas do you think need to be investigated more fully before any decisions are made?"

And so on … it is important to encourage and allow your mentee the opportunity to make informed choices about their own life. Providing scaffolding to the decision making process is potentially helpful for your mentee and provides a way forward for them that they will be able to re-use when making other difficult decisions about their life.

SENSORY DIFFERENCES

Stress and anxiety can occur for your mentee due to the often unknown aspects of campus life. This may escalate their sensory challenges. Hyper or hypo sensitivity in sensory domains may impact on your mentee's ability to function in the social world and potentially increase their level of anxiety. The CSMP experience has shown that the following strategies may assist if these difficulties arise.

Firstly, review with your mentee how sensory issues are normally handled in other environments. The Mentee Intake Form in your mentee's file may provide some useful information on specific sensory issues. Mentees should also be encouraged to consider using the following strategies/interventions to help with sensory issues:

Auditory Sensitivity

- Encourage use of headphones that muffle/reduce sounds or that provide music.

- Find a quiet study location together, away from the noisiest or busiest areas.

- Minimize background noise by encouraging them to get to lectures early and sit at the front.

- Encourage them to record or download lectures to replay later.

- Use earplugs in noisy areas.

- Arrange a scribe for lectures through Disability Services.

- Seek specific accommodations through their Disability Access Plan.

Smell Sensitivity or Preferences

- Remove or reduce exposure to foods, perfumes, air fresheners, printing inks, markers/ pens etc. with offending odours by noting trouble spots on campus and avoiding them.

- Remind them that some individuals can become more alert with the addition of certain smells such as natural scents.

- Suggest they bring a desired smell with them on a piece of cloth to mask unpleasant smells.

- Seek specific accommodations through their Disability Access Plan.

Visual Organization Needs

- Remind them to remove clutter or visual distractions in their study and assessment areas.

- Advise them how and where on campus they can create an organized workspace.

- Discuss appropriate study organisation techniques e.g. Google Calendar.

- Help them outline their assessment due dates on a visual semester planner.

- Seek specific accommodations through their Disability Access Plan.

Visual-Light Sensitivity

- Remind them to use sunglasses, hats/caps and to investigate Irlin lenses.

- Help them to seek out places on campus with appropriate lighting, such as indirect lighting, low lighting or natural lighting instead of overhead fluorescent lighting if that is the problem.

- Seek specific accommodations through their Disability Access Plan.

Touch Sensitivity/Personal Space

- Remind them to seek appropriate accommodations to gain adequate personal space during assessment and study activities.

- Seek out appropriate, quiet, study work areas on campus.

- Seek specific accommodations through their Disability Access Plan.

MENTOR / MENTEE REAL LIFE SCENARIOS

The following section provides four real life scenarios produced by previous CSMP specialist mentors detailing how they managed difficult situations with their mentees. There are also helpful tips for new mentors.

It should be noted that each mentee's profile, needs and progress were different and the mentors adapted their style of mentoring accordingly.

Scenario 1:

X and his housemates (he lives on campus) were fined $55 each after a failing a random house inspection. It came after a stressful week for X as he had not done as much study or assignment work as he had planned and was starting to fall behind in his units. I met him that afternoon and he looked very worried, stressed and tired.

How did the mentor manage this situation?

We sat down and he told me what had happened with the house. I asked him about his uni work (because I knew it was an ongoing issue) and he said that he was very annoyed and angry at himself for having wasted the previous weekend by not doing any study. After telling me everything he had to do I calmed him down and we made a plan. I said that there was nothing we could do about the weekend just gone, let's not worry about it – we'll learn from it and let's work out what we're going to do from here on in. I said I would compose an email to the housing people for him to send asking about the legitimacy of the $55 fine – so that was that sorted for the time being. Next were his assignments – I asked which were due tomorrow and the next day. I find that he becomes overwhelmed with the amount of work that needs doing and this affects his ability to focus. Rather, I broke his tasks down into more manageable chunks so they didn't seem as big a load. I advised that he work on his assignment due the next day that night and said I would meet him in the library the next night to assist him in concentrating on the one due the day after.

Tips that may be helpful for new mentors:

It takes a while to get to know the mentees, how they tick, what works for them and what doesn't etc. – especially because they don't give much back. For this reason, don't think you aren't assisting them – trust that you are making a difference, even if it is small. I found self-disclosure very useful and posing advice in a round-a-bout way a bit more effective than simply telling them what to do. In the above situation – just being able to meet X when he was stressed was useful for him as I think it was reassuring that there was someone else there. Get used to silences! It took me a while to get used to silences and allow X to speak before jumping in and answering a question for him or providing options.

Scenario 2:

In the beginning of our relationship X would not respond to texts/emails and would frequently be late to our meetings.

How did the mentor manage this situation?

This was managed by directly addressing the situation with X during mentoring sessions. I explained to him that it comes across as rude when he does not respond to my emails or texts, and it makes me feel like he is not paying attention to my advice or is not interested in what I have to say. I asked him if this was true, and he reported it was not. I also explained that according to social norms, X should let people know when he is going to be late for a meeting, interview, date, etc. We practiced (e.g., text role plays) polite/appropriate ways to indicate when one is running late. I emphasized the importance of this in professional or academic settings (e.g., if he was going to be late for work).

I had to follow up on this a few times by reminding him of what we had covered in sessions when he slipped up. For example, if he did not respond to a text message after a few hours, I would text him again and say something like, "Hi X, as we discussed in our meeting, can you let me know that you have received my text messages, that is how I know things are confirmed." I only had to remind him 3 or 4 times and ever since he always responds to my texts/emails and also lets me know when he is running late for a session (usually only when he can't find parking).

Tips that may be helpful for new mentors:

I think it is important to remember that "beating around the bush" in an attempt to be polite when giving advice to the mentees is likely not the best approach. Although it may feel rude or confronting, I think it is best to be as direct and to the point as possible when giving advice or providing information.

Scenario 3:

I was very fortunate with the mentee I worked with this year. He was incredibly intelligent, cooperative, engaging and a total joy to work with. He was very organised and prepared for his classes and academically excelling in all his courses. His mother was also very organised and an incredible support for him. However, this left me wondering: what was my role? After a couple of meetings, I started asking myself was I really necessary? What was left for me to do? At our mentor meetings every week, I would hear how much work the other mentors were doing for their mentees with helping them organize their timetables, scholarships, classes etc. I started to feel superfluous and I noticed that the meetings with my mentee were getting shorter, as the mentee seemed to be just as confused about my role.

How did the mentor manage this situation?

I decided to address this issue by first speaking with the Coordinators. I told them about my concerns. I was surprised and reassured to hear that my role was important and that my mentee could still benefit from working with me.

I looked over the initial documentation we were given at orientation and familiarized myself with areas that he said he found challenging (i.e. initiating conversation, crowded places, speaking to strangers). I decided to speak about these concerns with him, and see if his concerns could be identified as goals to address over the semester. My mentee was very enthusiastic about the idea. We developed a social situation fear hierarchy and agreed upon weekly goals to set each week. We identified skills that we wanted to learn from one other, for example we agreed that he could assist me with me being more organised and I could assist him by developing his social skills. All of a sudden, we both saw me as having a role: To mentor him in developing his social skills. Harrah!

Tips that may be helpful for new mentors:

- Speak to your Coordinators.
- Identify what your strengths are and look at how you could use these to assist your mentee.
- Find out what the mentee needs. He or she might not know or be able to tell you, so be prepared to offer suggestions.
- Mentoring is not just about assisting the mentee with academic and administrative difficulties. My mentee was more knowledgeable than me about these matters. Mentoring is about assisting the students to transition into university life, and all that involves - such as making friends, knowing how to order hot chips from the cafeteria, asking for directions, developing a timetable, asking for extensions etc.
- These students have plenty of needs that you could help them meet. You just have to work out what their needs are and how you can help.

Scenario 4:

Throughout the year, it was difficult to see the impact that I was having on X and his time at university. X is a very quiet and reserved individual, which worried me when one weekend during the second semester, I received a text telling me that he was very anxious and didn't know what to do. Unexpectedly, he opened up to me and was able to discuss very personal stressors that were impacting on his anxiety levels and therefore his overall well-being. He did not want to speak on the phone, so we continued messaging and I was worried that he was a risk to himself as he felt he had no other supports.

How did the mentor manage this situation?

After many text messages I was able to convey my support for X, and organised to meet with him at university on the Sunday to talk over his problems. I was able to get in contact with the Coordinator who was very helpful and reassuring. I then met with X on the Sunday and was able to listen to how he was feeling, and with the help of the Coordinators was able to organise a meeting with his Disability Advisor a couple of days later. I think it made me realize that X had trusted me with a very personal secret, and that over time (without realising) I had developed a good rapport with him. I think it was so important for X to have someone to talk to during such a complicated and stressful time in his life and I was glad that I could be there for him. Over the coming weeks, myself and the Coordinators helped to organize counselling support for X at the University. The amount of support given to me by the Coordinators was very reassuring, and being able to discuss my worries or concerns with others made me more confident in my abilities to help X.

Tips that may be helpful for new mentors:

You may not know the impact that you are having on other peoples' lives, however I think just being there to support someone is crucial. It is important that everyone feels comfortable being himself or herself, and understanding and believing in their own self-worth.

- Don't be afraid to ask for help or seek advice from others. I learnt so much through hearing other mentors' experiences during our meetings.

- At the start I would feel awkward pointing out obvious things such as: appropriate conversation topics; facial expressions; asking questions back to me; trying to keep eye contact etc. however it is important to realise that they may need those prompts, and that you are helping them develop skills that they will use in everyday life.

CRISIS MANAGEMENT INFORMATION

Appendix B provides Crisis Management Information. **In situations of crisis - remember your own self-care and limitations as a specialist student mentor**. Situations may arise where your mentee may confide in you regarding difficulties they may be experiencing. Some of these issues may involve:

- Serious mental health problems (depression / anxiety / suicidal thoughts).

- Substance and Alcohol abuse.

- Emotional, Physical and/or Sexual Abuse.

- Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) issues.

- Harm to self or others.

Your task is to:

- Stay calm, be non-judgmental and use active, reflective listening skills to understand your mentee's difficulties.

- Reassure them that any information given will be treated as confidential (unless there is risk of harm to self or others).

- Remember the boundaries of your role – you are there to listen but you are not your mentee's counsellor, therapist or parent.

- Remind them to use recommended calming strategies noted in their initial intake form and Safety Plan (See Appendix B – Crisis Management Information).

- Find out their location especially if they threaten self-harm or harm to others.

- Note down any important information about their situation ready to pass onto other relevant staff if the need should arise – Police / Campus Security Personnel / Coordinator / Disability/ Counselling staff.

- Follow your institution's Crisis Response Plan and ring emergency personnel if needed ASAP (see Appendix B – Crisis Management Information).

- Contact your program Coordinator ASAP by phone or email about the situation to receive further help.

- Help refer your mentee onto appropriate campus personnel and services ASAP to receive professional help especially if suicidal thoughts have been expressed.

- Debrief during individual meetings with your Coordinator and the supervision meetings to gain personal support and feedback.

- Seek counselling for yourself if your own situation needs ongoing support.

According to Wolf et al. (2009, pp. 150-152), Myles (2005, pp. 59-73) and the CSMP experience, after a critical incident has occurred it is important that a functional assessment of the behaviour be conducted as most mentee behaviour will be associated with a reason, cause or condition under which the behaviour occurs.

After a mentee has experienced a crisis, the mentor should notify the Coordinator as soon as possible and provide details about the crisis situation. The Coordinator will contact other appropriate personnel, disability and counselling staff who can provide ongoing support and investigate the situation more fully. Parents or support persons (nominated on the initial intake form) may also be contacted to help provide background information regarding the mentee's behaviour.

Wolf et al. (2009) recommend the following stress management techniques for this population of students:

- Identify potentially stressful situations.

- Determine what precipitates crises.

- Identify how stress manifests itself (e.g., what behaviours are demonstrated).

- Identify calming methods.

- Determine medications used in past with medical/clinical support. (p.151)

Wolf et al. (2009) also nominate the following stress-relieving activities on campus:

- Regular exercise.

- Outings with peers, friends, or family.

- Maintaining a healthy eating and sleeping schedule.

- Scheduled downtime every day and during each study period.

- Structured time for TV, movies, or video games (with an alarm to end time).

- Yoga or meditation (also a good group activity).

- Listening to music. (p.152)

See Appendix B for Crisis Management Response Plan Information.

USEFUL RESOURCES

Publications (many authored by those on the Autism spectrum)

Attwood, S. (2008). *Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome*. London: Jessica Kingsley.

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Grandin, T. (2006) *Thinking in Pictures and Other Reports from my Life with Autism.* New York: Vintage Books.

Grandin, T & Duffy, K. (2004). *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

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Myles, B. S. (2005). *Children and Youth with Asperger Syndrome.* California: Corwin Press.

Myles, B. S., & Adreon, D. (2001). *Asperger Syndrome and Adolescence. Practical Solutions for School Success.* Kansas: AAPC.

Myles, B.S., Trautman, M.L. & Schelvan, R.L. (2004). *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

Palmer, A. (2006) *Realizing the College Dream with Autism or Asperger Syndrome: A Parent's Guide to Student Success.* Philadelphia, PA: Jessica Kingsley.

Prince-Hughes, D. (2002). *Aquamarine Blue Five: Personal Stories of College Students with Autism.* Athens, Ohio: Swallow Press.

Purkis, J. (2006). *Finding a Different Kind of Normal: Misadventures with Asperger Syndrome.* London: Jessica Kingsley.

Purkis, J. (2014).*The Wonderful World of Work: A Workbook for Asperteens.* London: Jessica Kingsley.

Purkis, J., Goodall, E. & Nugent, J. (2016) *Guide to Good Mental Health on the Autism spectrum.* London: Jessica Kingsley.

Santomauro, J. (2011). *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life.* London: Jessica Kingsley.

Shore, S.M. & Rastelli, L.G. (2006). *Understanding Autism for Dummies.* Hoboken, NJ; Wiley Publishing.

Simone, R. (2010). *Asperger's on the Job.* Arlington, Texas: Future Horizons.

Willey L.H. (1999). *Pretending to be Normal.* London: Jessica Kingsley.

Willey L.H. (2012). *Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life.* London: Jessica Kingsley.

Wolf, L.,Thierfeld Brown, J. & Kukiela Bork, G. (2009). *Students with Asperger Syndrome: A Guide for College Personnel.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

DVDs

Radtke, M. (2012). A 9th Planet Video Behavior Modeling Course. USA: 9th Planet.

Saines, G. & Jackson, J. (2010). *Temple Grandin*. USA: HBO Films.

Websites

http://www.autism crc.com.au/

http://www.tonyattwood.com.au/

www.templegrandin.com/

www.facebook.com/autism discussionpage

www.suelarkey.com.au/

http://www.latrobe.edu.au/otarc/

http://www.cci.health.wa.gov.au/resources/consumers.cfm

http://www.autism .org.uk/

http://www.autism researchcentre.com/

http://www.researchautism .org/resources/AspergerDVDSeries.asp

http://raisingchildren.net.au/children_with_autism /children_with_autism _spectrum_disorder.html

http://www.autism -uni.org/

https://www.autism speaks.org/

http://www.autism .com/

Please Note:

http://www.cci.health.wa.gov.au/resources/consumers.cfm

Centre for Clinical Interventions (CCI) WA website (Consumer Resources Section) – provides online modules on Social Anxiety, Worrying, Assertiveness, Depression etc. that may be useful to a mentee depending upon their individual needs. CSMP has found these modules to be very helpful to mentees who wish to address the specific psychological difficulties that affect their ability to maintain good mental health. Mentors may need to help their mentee access and complete appropriate modules during their sessions.

http://www.latrobe.edu.au/otarc/

Olga Tennison Autism Research Centre (OTARC) provides information on supporting tertiary university and TAFE students diagnosed with an Autism spectrum Condition (ASC), their parents, and tertiary staff interested in learning more about ASCs. This information pertains to supporting students with an ASC in academic settings and comes from a variety of sources including local and international information, peer reviewed research and research conducted at OTARC (funded by DHS, Victoria). The information provided is general and not targeted for specific tertiary institutions.

http://www.autism -uni.org/

Autism & Uni is a multinational EU-funded project that helps greater numbers of young adults on the Autism spectrum to gain access to Higher Education (HE) and to navigate the transition successfully. They have created two FREE resources that HE Institutions across Europe can adopt. These include a set of Best Practice Guides for HE managers, academics and support staff. The guides are written in an accessible way and inform staff about Autism in the HE context, what is considered good practice and what staff can do to support autistic students well. There is also an Online Toolkit for students to give them the information and strategies needed to manage the transition to university.

Computer Applications (as recommended by CSMP mentors and mentees)

- **Lost on Campus** (Free App. - Australia's biggest campus mapping app, with 42 campuses and over 36,000 locations).

- **Smiling Mind** (Free App. - Modern mediation program developed by psychologists for young people).

- **Anti-Social** (Small cost to buy App. - Makes it easy to target and block any distracting websites).

- **Procrastination** (Free App. - for all procrastinators).

- **SafeZone** (Free App. - for all students and staff that connects directly to the university security team while on campus.)

- **MindShift** (Free App. for young adults to help learn ways to relax, develop more helpful ways of thinking, and identify active steps that will help take charge of anxiety. This app includes strategies to deal with everyday anxiety, as well as specific tools to tackle:

  o Test Anxiety.
  o Perfectionism.
  o Social Anxiety.
  o Performance Anxiety.
  o Worry.
  o Panic.
  o Conflict.

- **Friendmaker** (Small cost to buy App. - companion to Dr E. Laugeson's book, *The Science of Making Friends*, and contains important skills, strategies, role-play videos, and tools for making and keeping friends based on guidance from the UCLA Peers program).

NAS MENTOR GUIDELINES & NDCO TRANSITION TO TERTIARY EDUCATION

The National Autistic Society (NAS) of the United Kingdom has produced a very helpful *Student Mentor Guidelines* booklet (see separate document). Prior to training mentors will be issued with this document and should be familiar with its contents.

The NAS booklet covers the following areas:

- Understanding the Autism spectrum.
- Your role as a student mentor.
- Getting started.
- Supporting a student with Asperger Syndrome.
- Useful resources.
- Further reading.

The National Autistic Society (NAS) of the United Kingdom *Student Mentor Guidelines* booklet (PDF format) can be downloaded through the NAS website: http://www.autism .org.uk/studentmentors**.**

Additionally, the National Disability Coordination Officer Programme (NDCO) of Australia has produced another helpful booklet titled *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* (see separate document). Prior to training mentors will be issued with this document and should be familiar with its contents.

The NDCO booklet covers the following areas:

- Awareness of yourself and others.
- Knowing your strengths.
- Familiarising yourself with the campus.
- Studying at university or TAFE.
- Organising your study.
- What support could be helpful.
- Finding key people who can help you.
- Communication tips.
- Managing stress and anxiety.

The NDCO *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder (Transition to Tertiary - Short Version PRINT)* can be downloaded through www.adcet.edu.au/autism -transition.

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Appendix A

MENTOR/MENTEE RESPONSIBILITIES CONTRACT

Responsibilities of a CSMP Mentor

I agree to:

- Respect the professional boundaries between the mentor and the mentee.
- Respond ASAP to any communications from my mentee during the semester.
- Contact or meet my mentee at agreed times (and locations if applicable).
- Advise my mentee by email/text of any unavoidable changes to arrangements at least 24 hours in advance.
- Lodge a regular report documenting issues arising for supervision purposes.
- Communicate with my mentee in clear and specific terms providing a written and/or diagrammatic representation of the communication (if needed).
- Attend the Social Group (when possible) and regular supervision meetings to gain advice and guidance.
- Support my mentee to prepare their resume and seek out relevant work experience / work over time.
- Provide guidance consistent with the defined role of a specialist student mentor.
- Provide feedback about the program through participation in evaluation research.

Responsibilities of a CSMP Mentee

I agree to:

- Respect the professional boundaries between the mentor and the mentee.
- Respond ASAP to any communications from my mentor during the semester.
- Contact or meet my mentor at agreed times (and locations if applicable).
- Advise my mentor by email/text of any unavoidable changes to arrangements at least 24 hours in advance.
- Try to attend any meetings requested by the Mentoring Program including the Social Group.
- Work toward my own short, medium and long term life goals including employment.
- Communicate any difficulties I may be experiencing to my mentor (or the Coordinators should the need arise).
- Be open to try different techniques to improve difficulties I may be experiencing.
- Provide feedback about the program through participation in evaluation research.
- Contact the Coordinator if I am experiencing concerns / difficulties working with my mentor.

We, (print mentor name) _____and

   (print mentee name) _____have

read and understood the above Mentor/Mentee Responsibilities Form. We agree to these conditions for the mentoring service provided by CSMP.

Mentor Signature_____ Date_____

Mentee Signature_____ Date_____

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SPECIALIST PEER MENTOR WEEKLY REPORTING FORM

Mentor Name: _____

Mentee Name: _____

For Week Ending Friday		

Times, Types and Place of Contact:-

-
-
-
-
-

Session Content:-

Strengths:-

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Difficulties:-

[ ]

Possible Solutions:-

[ ]

Referrals (Where, Reason for referral):-

[ ]

MENTOR WEEKLY REPORTING FORM (SAMPLE)

Mentor Name: _____G_____

Mentee Name: _____W_____

For Week Ending Friday

14	03	20xx

Times, Types and Place of Contact:-

- 12/3 Meeting with mentee – waited didn't turn up
- 12/3 emailed mentee
- 13/3 emailed mentee and text
- 14/3 reminder text
- 14/3 meeting with mentee

Session Content:-

Emailed W after I waited on Wed and he didn't show up just enquired about how he was and let him know that I waited and that I could meet either Thurs or Fri. Received email from W, had a busy day and remembered Wed night after it was too late. Was happy to rearrange and scheduled time for Fri afternoon to catch up.

Was early for meeting on Fri, explained the situation on wed needed to do shopping and had phoned a friend, didn't expect him to say he was going right then. Has transport issues, is able to drive but doesn't have a car, relies on friends in order to do shopping. Does use public transport and is competent. Asked if he had a diary has never liked using them, showed him the semester planner and explained how he could map out his assignments felt this might be quite useful.

He advised until today did not have internet access in his room, showed me that he had purchased wireless internet, had also arranged with other students in student housing to share and had advised them that he wouldn't purchase until everyone paid the first month in advance (Check at supervision meeting how others in student housing organise this). Let him know that was good and suggested he use the same strategy if they were cooking for each other so he wasn't always paying.

Doesn't have any goals at the moment is happy with the way things are going, and is finding the work easy. Finds the catch up's helpful, he advised his major problem is usually around exam time, which I suggested it may be good to book in with the counselling service early so he has that added support. He did feel that knowing I would be around e.g. our catch up's would be helpful.

Looked at his timetable and suggested that maybe Tuesday would be a better day for meeting as he had fewer classes, so would possibly feel less overwhelmed, he

agreed and we arranged to meet Tuesday's 12pm from now on suggested he put a reminder in his phone, as I didn't want to be reminding him every week as I felt like I was nagging him, felt this was a good idea.

Spoke about the Social Group and advised him that J. was now studying her Masters at Curtin too and was keen to go along, he thought he might attend next week as we had also moved our catch up which would free him up to attend.

He told me he has also made a friend in Physics, someone who doesn't like being around people, prefers his own company. His house mates were surprised as this was the first person he had brought home.

Also spoke about being safety conscious when catching public transport late at night, keeping to well-lit areas. He felt comfortable with this as where he lived in UK was rural and was a rough area.

Strengths:-

Planning and Organising.

Difficulties:-

Time management.
Transport – more around relying on other people or public transport.
Stress around exam time.

Possible Solutions:-

Continue seeking out appropriate help re time management on campus and alert W to what is available. Check at supervision meeting how others in student housing organise internet access and payment.

Referrals (Where, Reason for referral):-

Refer W to Counselling so he can start to get some help for anxiety prior to the exam period.

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SOCIAL GROUP REPORT FORM

Date:

Mentees in Attendance:

Mentors in Attendance:

What happened at the social group?

What areas could be improved?

What is planned for future weeks?

SOCIAL GROUP REPORT FORM (SAMPLE)

Date: Wednesday 4th of March 20xx

Attendance:

Mentees:

Mentors:

What happened at the social group?

- The session started on time at 12.15pm.
- Firstly K. facilitated an icebreaking activity "If's & What's" and "Candy Confessions"
- Everyone participated in the activity, all were engaged
- We then played board and table games in groups such an Jenga, Poker, Zombie card game
- E. performed a song she has written herself
- The meeting finished on time at 1.45pm.

What areas could be improved?

- Make sure that any important information about the next meeting is announced before the social group ends e.g. Next week M. is facilitating a session where participants bring something meaningful along with them to talk about – but we didn't manage to tell the attendee's to bring something along with them next week. We will have to ask Mentors to remind mentee's and post it on the social group Facebook page instead.

What is planned for future weeks?

- M. will be running a social activity session focusing on Mentee's interests and passions
- Working on listening and talking – asking questions to find out more about others, starting conversations about other people's interests etc.

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MENTOR HANDOVER FORM

To help with the handover process, please complete the form below and return to your Specialist Mentoring Coordinator:

Mentor Name:

Mentee Name:

1. My mentee's main strengths are:

2. My mentee's main difficulties are:

3. The goals that I see as being useful and achievable for my mentee are:

a) Short term:

Have you discussed these with your mentee? Yes/No

b) Long term:

Have you discussed these with your mentee? Yes/No

4. Please provide any additional information that the new mentor may find useful.

MENTOR TIME SHEET

Mentor Name: ……………………...

Student ID: ……………………...

Staff ID: ………………...

School: ……………………..

I have undertaken the following support services for:

Mentee Name: ……………………....................................…………

Student ID: ……………………...

School: ……………………..

SEMESTER   1   2   Year: 20_ _

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Date: ……………………   Hours Worked: ……………………..

Mentor Signature: …………………………………Date: …………………………

Mentee Signature: ………………………………..Date: …………………………

Coordinator Signature: ………………………….Date: ………………………….

INFORMATION SHEET FOR WORK EXPERIENCE/EMPLOYMENT (SAMPLE)

Brief Information Sheet on J.

Individuals on the autism spectrum can experience difficulties in four key areas:
- Social Understanding
- Communication
- Change/Limited Interests
- Sensory Hyper/Hypo sensitivity

They can also offer strengths in the following ways:
- Honesty / loyalty
- Excellent rote memory for areas of interest
- Visual spatial abilities
- Detail focused
- Preference for organized procedures
- Intense interests / savant skills
- Being logical

J. is a highly intelligent young woman who has worked hard to build on her strengths, however, at times she will need support and guidance with her difficulties. It is recommended that J. be assigned a work mentor who can help J. if the need arises.

J.'s Specific Profile

- Social Understanding
  1. May not always understand sarcasm/figurative language etc.
  2. May not fully understand the social nuances of situations
  3. May have difficulty navigating office politics
  4. May become shy in large crowds of peers of similar ages.
  (Solution - Provide a Supportive Mentor / Encourage J. to communicate difficulties to Mentor)

- Communication
  1. May not always seek help when needed
  2. Prefers to have visual information to support verbal instructions
  3. Needs to have feedback sought regarding her understanding of requirements
  4. Needs to be encouraged to advocate on her own behalf
  5. Needs clear list of instructions and tasks
  (Solution - Have written information to support verbal instructions / Check J.'s understanding of tasks to be undertaken / Use of Mentor)

- Change/Limited Interests
  1. Prefers order, timelines and logicality
  2. Appreciates being informed of change prior to situations occurring
  3. Appreciates knowledge and use of established work procedures and practices
  4. Enjoys playing video games / board games / cards / dancing/ astronomy / drawing / and watching fantasy or action movies

(Solution - Have an ordered, organised workplace where change is communicated as early as possible / Communicate J.'s interests to other staff members so that a common bond can be established / Use of Mentor)

- Sensory Hyper/Hypo sensitivity
    1. Limited Food Preferences
    2. Difficulty with loud sounds
    3. Difficulty with strong smells
    (Solution - Allow J. to order/have her own food preferences when social events arise / Seat J. in a quiet area in the workplace / Use of Mentor)

Appendix B

CRISIS MANAGEMENT INFORMATION & SAFETY PLAN

[Program Coordinator to Insert

Institution's Crisis Management Information & Safety Plan]

Specialist Peer Mentoring Module

Providing Support to Tertiary Students on the Autism Spectrum and Related Conditions

Mentee Information Booklet

June 2016

Curtin University

THE UNIVERSITY OF WESTERN AUSTRALIA

Australian Government
Department of Industry, Innovation and Science

Business Cooperative Research Centres Programme

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Jemima D'Abrera Talented CSMP Student Mentee responsible for producing image used on cover and in other parts of the document.

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The Cooperative Research Centre for Living with Autism (Autism CRC)

The Cooperative Research Centre for Living with Autism (Autism CRC) is the world's first national, cooperative research effort focused on autism. Taking a whole of life approach to autism focusing on diagnosis, education and adult life, Autism CRC researchers are working with end-users to provide evidence-based outcomes which can be translated into practical solutions for governments, service providers, education and health professionals, families and people with autism.

autismcrc.com.au

> *"Going into university for the first time was challenging and scary yet exciting, all on its own. Struggling with new situations, structure and community made the mentoring program such a vital safety net and building bridge in becoming my own person and making a name for myself. Although I went into university with outside friends on the other side of campus, the program gave me a mentor that helped me make and keep friends in my degree and yet support me with regular conversations, meetings and information. I've been a part of programs like this before and nothing compares to the support, care and thrive for my success, it offers."*
>
> *(CSMP Mentee)*

> *"The mentor program has given me more confidence in what I want to do when I leave university and has also given me something to look forward to during the week along with some new friends. It also allows me to seek help from those who understand my condition and have the ability to talk to someone when there is no one else to talk to. Plus being able to recognize people around campus makes the place feel less big and full of strangers."*
>
> *(CSMP Mentee)*

WELCOME TO THE SPECIALIST PEER MENTORING PROGRAM

The Specialist Peer Mentoring Program is based on the successful Curtin University Specialist Mentoring Program (CSMP) situated in Perth, Western Australia – (http://life.curtin.edu.au/health-and-wellbeing/autism-related-conditions-peer-mentoring.htm), and is designed to specifically support students on the Autism Spectrum and related conditions in a tertiary education setting.

WHY CHOOSE TO HAVE A MENTOR?

Research has shown that while tertiary students on the Autism Spectrum (and related conditions) can have particular academic strengths in their chosen study fields they may also experience difficulties with such areas as:

- Planning and organisation.

- Comprehension.

- Group work and oral presentations.

- Forming friendships and joining groups/activities.

- Seeking help / self-advocacy.

- Anxiety / depression.

- Gaining work experience / employment.

The Specialist Peer Mentoring Program has been specifically designed to support students on the Autism Spectrum and related conditions to improve their retention, academic success and well-being at university through the employment of a peer-mentoring program.

WHAT IS A PEER MENTOR?

A peer mentor is a friendly, successful and experienced student who has received specific training in Autism Spectrum Conditions. Each student mentee is paired with a successful student peer mentor who is available to provide support and guidance according to their mentee's individual needs. Roberts (2000) defined mentoring as a

> Formalised process whereby a more knowledgeable and experienced person actuates a supportive role of overseeing and encouraging reflection and learning within a less experienced and knowledgeable person, so as to facilitate that persons' career and development. (p.162)

Mentors work towards the long term goal of trying to help their mentee gain as much confidence, independence and self-advocacy as possible during their tertiary education in preparation for a more successful life.

THE PEER MENTORING ROLE

"Being a part of the mentoring program has been an incredibly rewarding, memorable and an invaluable learning experience. As a mentor, I had the honour of working with C., a first year student on the Autism Spectrum. Prior to working with the program, I knew little about the daily challenges and anxieties that those on the Autism Spectrum faced. However, working with C. has made me profoundly aware of how courageous these mentees are in confronting the challenge of university life. The program means that the mentees do not have to do it alone. I saw how the mentoring program provided the scaffolding and support needed for the mentees to adjust to university and develop meaningful friendships. I feel very proud and honoured to be involved in such a worthwhile project that makes such a difference in these students' lives."

(CSMP Mentor)

According to Bebko, Schroeder, & Ames, (2011) who developed the 'Asperger Mentorship Program' for students on the Autism Spectrum in Canada:

> The role of the mentor is akin to that of a "coach,"… A coach helps you practice skills, they help you prepare for the game, they cheer you along, and work with you after the game to talk about what went well and how to practice for the next game – but a coach does not play the game for or with you. This analogy is used to clarify that the role of the mentor is different from a counsellor or a friend. (p.5)

Using their own student success as a basis, your peer mentor will help 'coach' you and share ways to be a successful tertiary student. Your mentor understands that each person on the Autism Spectrum is different and will need support based on their individual strengths, needs and life goals. Before your mentor meets you, they will have had the opportunity to learn more about you from your intake form and other information you have provided to the Specialist Peer Mentoring Program.

Your mentor will communicate and/or meet with you for approximately one hour (or more) per week mainly during the teaching weeks of the semester. Meeting times and communication methods used will be determined by you and your mentor according to your individual circumstances.* If you are an internal student, face-to-face communication is recommended so that your mentor can help familiarise you with campus life and help develop your social skills. Your mentor will also support and encourage you to make contact with appropriate staff, students and services on and

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off campus to meet your individual needs. After the mentee/mentor pairings have been made, you will be notified as to your initial meeting arrangement with your mentor. This may take the form of an individual meeting or a 'Meet and Greet' meeting with other mentees and mentors.

*Please Note: Facebook is not recommended as a personal communication method between the mentor and mentee because it has been found that it does not support professional boundaries to be established or maintained.

References

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Roberts A. (2000) Mentoring Revisited: a phenomenological reading of the literature. *Mentoring and Tutoring,* 8(2), 145-170.

THE RESPONSIBILITIES CONTRACT

At the beginning of your involvement with the Specialist Peer Mentoring Program you and your mentor will be asked to sign a Responsibilities Contract outlining the boundaries of the mentor/mentee relationship. Prior experience has shown that difficulties can arise when appropriate professional boundaries have not been observed. While you will work as a friendly, cooperative team it is important that a respectful, professional distance between you and your mentor be established and maintained. At the end of the mentor/mentee relationship mentee and mentor pairs are free to establish a friendship if they both feel comfortable to do so. The Responsibilities Contract includes the following undertakings:

Your Mentor's Responsibilities are to:

- Respect the professional boundaries between the mentor and the mentee.

- Respond ASAP to any communications from their mentee during the semester.

- Contact or meet their mentee at agreed times (and locations if applicable).

- Advise their mentee by email/text of any unavoidable changes to arrangements at least 24 hours in advance.

- Lodge a regular report documenting issues arising for supervision purposes.

- Communicate with their mentee in clear and specific terms providing a written and/or diagrammatic representation of the communication (if needed).

- Attend the Social Group (when possible) and regular supervision meetings to gain advice and guidance.

- Support their mentee to prepare their resume and seek out relevant work experience / work over time.

- Provide feedback about the program through participation in evaluation research.

- Provide guidance consistent with the defined role of a specialist student mentor.

Your Responsibilities as a Mentee are to:

- Respect the professional boundaries between the mentor and the mentee.

- Respond ASAP to any communications from your mentor during the semester.

- Contact or meet your mentor at agreed times (and locations if applicable).

- Advise your mentor by email/text of any unavoidable changes to arrangements at least 24 hours in advance.

- Try to attend any meetings requested including the Social Group.

- Work toward your own short, medium and long term life goals including employment.

- Communicate any difficulties you may be experiencing to your mentor (or the Coordinator should the need arise).

- Be open to try different techniques to improve difficulties you may be experiencing.

- Provide feedback about the program through participation in evaluation research.

- Contact your Coordinator if you are experiencing concerns / difficulties working with your mentor.

AutismCRC

THE SOCIAL GROUP

> *"The mentoring program offers the mentees a rare opportunity to meet like-minded people their age and fosters the development of interpersonal relationships. There is a scarcity of such opportunities for adults on the spectrum. My mentee has been at University for 3 years and had never made any friends. He now attends the weekly social club meetings as well as plays cards with another mentee weekly. These social gatherings mean a lot to my mentee, he continually indicates that he wants to improve his social skills. I believe the mentoring program provides him with an opportunity to reach this goal."*
>
> *(CSMP Mentor)*

> *"It is rewarding to see a group of strangers all become great friends by the end of semester. The social connections formed provide a valuable social support network for the mentees."*
>
> *(CSMP Social Group Coordinator)*

The Social Group is:

- A safe, welcoming social space for mentees to commune / make friends / practise social skills / experience belonging / decrease isolation.

- Coordinated and attended by mentees and mentors.

- Held regularly during the teaching weeks of the semester (details to follow).

- Advertised through a specific, private Social Group Facebook page (posting of events etc.) created and maintained by the Social Group Coordinating Committee.

- Organised in two parts:
    - A formal aspect (e.g. social skills, guest speakers etc.)
    - An informal aspect (e.g. electronic and board game playing).

The Social Group creates valuable opportunities for socialisation and a sense of belonging on campus. Please feel free to come along and be part of the fun! Please let the Coordinators know if you wish to be part of the Social Group and linked up to

the Social Group Facebook page. All mentees and mentors are welcome to be part of the organising committee.

> *"My son is a first year University student studying Physics and Engineering. Being autistic, he finds it difficult to fit into general social environments, and consequently to make friends and feel accepted. However, the mentoring program has been instrumental in helping him settle into university life, alleviating the enormous stress he had initially been suffering. He has found guidance, support, friendship and understanding. The weekly social group meetings have also been a wonderful part of the program. They have been fun and informative and allowed my son to make friends and meet people who understand him, in a safe and supportive environment. Without this fantastic program he would still be feeling anxious and isolated."*
>
> *(Parent of 1st year CSMP Mentee)*

MENTEES WHO GAIN THE MOST OUT OF THE PROGRAM

The CSMP experience has shown that those mentees who gain the most out of the Specialist Peer Mentoring Program are those who are:

- Committed to engage with the program fully and work with their mentor (and others) on a regular, timely basis during the teaching weeks of the semester.

- Proactive in setting and achieving their own short, medium and long term goals.

- Open to trying and practising different strategies to maximise their strengths and address their difficulties.

The CSMP experience has also shown that mentees can improve their academic results, gain scholarships, work experience, paid work and internships (in their fields of study) and progress along the trajectory of realising their life's goals when they fully engage with the Specialist Peer Mentoring Program.

USEFUL RESOURCES

Publications (many authored by those on the Autism Spectrum)

Attwood, S. (2008). *Making Sense of Sex: A Forthright Guide to Puberty, Sex and Relationships for People with Asperger's Syndrome*. London: Jessica Kingsley.

Attwood, T. (2007). *The Complete Guide to Asperger's Syndrome*. London: Jessica Kingsley.

Attwood, T., Evans, C.R. & Lesko, A. (2014). *Been There. Done That. Try This!: An Aspie's Guide to Life on Earth.* London: Jessica Kingsley.

Attwood, T. & Grandin, T. (2006). *Asperger's and Girls.* Arlington, Texas: Future Horizons.

Baker, J. (2006). *The Social Skills Picture Book for High School and Beyond.* Arlington, Texas: Future Horizons.

Brown, D. (2013). *The Aspie Girl's Guide to Being Safe with Men.* London: Jessica Kingsley.

Dubin, N. (2009). *Asperger Syndrome and Anxiety: A Guide to Successful Stress Management.* London: Jessica Kingsley.

Edmonds, G. & Worton, D. (2006). *The Asperger Social Guide.* London: Sage Publications.

Goodall, E. (2016) *The Autism Spectrum Guide to Sexuality and Relationships: Understand Yourself and Make Choices that are Right for You.* London: Jessica Kingsley.

Grandin, T. (2006) *Thinking in Pictures and Other Reports from my Life with Autism.* New York: Vintage Books.

Grandin, T & Duffy, K. (2004). *Developing Talents: Careers for Individuals with Asperger Syndrome and High-Functioning Autism.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

Lawson, W. (2003). *Build Your Own Life: A Self-Help Guide For Individuals with Asperger Syndrome.* Philadelphia, PA: Jessica Kingsley.

Myles, B.S., Trautman, M.L. & Schelvan, R.L. (2004). *The Hidden Curriculum: Practical Solutions for Understanding Unstated Rules in Social Situations.* Shawnee Mission, Kansas: Autism Asperger Publishing Co.

Palmer, A. (2006) *Realizing the College Dream with Autism or Asperger Syndrome: A Parent's Guide to Student Success.* Philadelphia, PA: Jessica Kingsley.

Prince-Hughes, D. (2002). *Aquamarine Blue Five: Personal Stories of College Students with Autism.* Athens, Ohio: Swallow Press.

Purkis, J. (2006). *Finding a Different Kind of Normal: Misadventures with Asperger Syndrome.* London: Jessica Kingsley.

Purkis, J. (2014).*The Wonderful World of Work: A Workbook for Asperteens.* London: Jessica Kingsley.

Purkis, J., Goodall, E. & Nugent, J. (2016) *Guide to Good Mental Health on the Autism Spectrum.* London: Jessica Kingsley.

Santomauro, J. (2011). *Autism All-Stars: How We Use Our Autism and Asperger Traits to Shine in Life.* London: Jessica Kingsley.

Shore, S.M. & Rastelli, L.G. (2006). *Understanding Autism for Dummies.* Hoboken, NJ; Wiley Publishing.

Simone, R. (2010). *Asperger's on the Job.* Arlington, Texas: Future Horizons.

Willey L.H. (1999). *Pretending to be Normal.* London: Jessica Kingsley.

Willey L.H. (2012). *Safety Skills for Asperger Women: How to Save a Perfectly Good Female Life.* London: Jessica Kingsley.

DVDs

Radtke, M. (2012). A 9th Planet Video Behavior Modeling Course. USA: 9th Planet.

Saines, G. & Jackson, J. (2010). *Temple Grandin*. USA: HBO Films.

Websites

http://www.autismcrc.com.au/

http://www.tonyattwood.com.au/

www.templegrandin.com/

www.facebook.com/autismdiscussionpage

www.suelarkey.com.au/

http://www.latrobe.edu.au/otarc/

http://www.autismresearchcentre.com/

http://www.cci.health.wa.gov.au/resources/consumers.cfm

http://www.autism.org.uk/

http://www.autism-uni.org/

http://www.autism.com/

https://www.autismspeaks.org/

Please Note:

http://www.cci.health.wa.gov.au/resources/consumers.cfm

Centre for Clinical Interventions (CCI) WA website (Consumer Resources Section) – provides online modules on Social Anxiety, Worrying, Assertiveness, Depression etc. that may be useful to a mentee depending upon their individual needs.

http://www.latrobe.edu.au/otarc/

Olga Tennison Autism Research Centre (OTARC) provides information on supporting tertiary students diagnosed with an Autism Spectrum Condition (ASC), their parents, and tertiary staff interested in learning more about ASCs. This information pertains to supporting students on the Autism Spectrum in academic settings and comes from a variety of sources including local and international information, peer reviewed research and research conducted at OTARC. The information provided is general and not targeted for specific tertiary institutions.

http://www.autism-uni.org/

Autism & Uni is a multinational EU-funded project that helps greater numbers of young adults on the Autism Spectrum to gain access to Higher Education (HE) and to navigate the transition successfully. They have created FREE resources that HE Institutions across Europe can adopt. These include a set of Best Practice Guides for HE managers, academics and support staff. The guides are written in an accessible way and inform staff about Autism in the HE context, what is considered good practice and what staff can do to support autistic students well. There is also an Online Toolkit for students to give them the information and strategies needed to manage the transition to university.

Computer Applications (as recommended by CSMP mentors and mentees)

- **Lost on Campus** (Free App. - Australia's biggest campus mapping app, with 42 campuses and over 36,000 locations).

- **Smiling Mind** (Free App. - Modern mediation program developed by psychologists for young people).

- **Anti-Social** (Small cost to buy App. - Makes it easy to target and block any distracting websites).

- **Procrastination** (Free App. - for all procrastinators).

- **SafeZone** (Free App. - for all students and staff that connects directly to the university security team while on campus).

- **MindShift** (Free App. for young adults to help learn ways to relax, develop more helpful ways of thinking, and identify active steps that will help take charge of anxiety. This app includes strategies to deal with everyday anxiety, as well as specific tools to tackle: Test Anxiety, Perfectionism, Social Anxiety, Performance Anxiety, Worry, Panic, Conflict).

- **Friendmaker** (Small cost to buy App. - companion to Dr E. Laugeson's book, *The Science of Making Friends*, and contains important skills, strategies, role-play videos, and tools for making and keeping friends based on guidance from the UCLA Peers program).

Tertiary Education: Helpful Hints for Individuals on the Autism Spectrum

To help with your transition to tertiary study you will be issued with a booklet titled *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder* produced by the National Disability Coordination Officer Programme (NDCO) of Australia. Please take the time to familiarise yourself with the booklet as it covers the following important areas:

- Awareness of yourself and others.

- Knowing your strengths.

- Familiarising yourself with the campus.

- Studying at university or TAFE.

- Organising your study.

- What support could be helpful.

- Finding key people who can help you.

- Communication tips.

- Managing stress and anxiety.

The NDCO *Tertiary Education: Helpful Hints for People with Autism Spectrum Disorder (Transition to Tertiary - Short Version PRINT)* can also be downloaded through www.adcet.edu.au/autism-transition

Appendix B: Human Research Ethics Committee approval

Memorandum

To	Professor Torbjorn Falkmer, Occupational Therapy and Social Work
From	Professor Peter O'Leary, Chair Human Research Ethics Committee
Subject	Protocol Approval **HR 16/2014**
Date	24 February 2014
Copy	Dr Sonya Girdler Occupational Therapy and Social Work Mr Craig Thompson Occupational Therapy and Social Work

Office of Research and Development
Human Research Ethics Committee

TELEPHONE	9266 2784
FACSIMILE	9266 3793
EMAIL	hrec@curtin.edu.au

Thank you for providing the additional information for the project titled *"Transition to adulthood for young people with high functioning autism spectrum disorders"*. The information you have provided has satisfactorily addressed the queries raised by the Committee. Your application is now **approved**.

- You have ethics clearance to undertake the research as stated in your proposal.
- The approval number for your project is **HR 16/2014**. *Please quote this number in any future correspondence.*
- Approval of this project is for a period of four years **25-02-2014** to **25-02-2018**.
- Your approval has the following conditions:
    i) Annual progress reports on the project must be submitted to the Ethics Office.
- **It is your responsibility, as the researcher, to meet the conditions outlined above and to retain the necessary records demonstrating that these have been completed.**

Applicants should note the following:

It is the policy of the HREC to conduct random audits on a percentage of approved projects. These audits may be conducted at any time after the project starts. In cases where the HREC considers that there may be a risk of adverse events, or where participants may be especially vulnerable, the HREC may request the chief investigator to provide an outcomes report, including information on follow-up of participants.

The attached **Progress Report** should be completed and returned to the Secretary, HREC, C/- Office of Research & Development annually.

Our website https://research.curtin.edu.au/guides/ethics/non_low_risk_hrec_forms.cfm contains all other relevant forms including:
- Completion Report (to be completed when a project has ceased)
- Amendment Request (to be completed at any time changes/amendments occur)
- Adverse Event Notification Form (If a serious or unexpected adverse event occurs)

Yours sincerely

Professor Peter O'Leary
Chair Human Research Ethics Committee

Standard conditions of ethics approval

These standard conditions apply to all research approved by the Curtin University Human Research Ethics Committee. It is the responsibility of each researcher named on the application to ensure these conditions are met.

1. **Compliance.** Conduct your research in accordance with the application as it has been approved and keep appropriate records.
   a. **Monitoring** - Assist the Committee to monitor the conduct of the approved research by completing promptly and returning all project review forms that are sent to you.
   b. **Annual report** - Submit an annual report on or before the anniversary of the approval.
   c. **Extensions** - If you are likely to need more time to conduct your research than is already approved, complete a new application six weeks before the current approval expires.
   d. **Changes to protocol** - Any changes to the protocol are to be approved by the Committee before being implemented.
   e. **Changes to researcher details** - Advise the Committee of any changes in the contact details of the researchers involved in the approved study.
   f. **Discontinuation** - You must inform the Committee, giving reasons, if the research is not conducted or is discontinued before the expected completion date.
   g. **Closure** - Submit a final report when the research is completed. Include details of when data will be destroyed, and how, or if any future use is planned for the data.
   h. **Candidacy -** If you are a Higher Degree by Research student, data collection must not begin before your Application for Candidacy is approved by your Faculty Graduate Studies Committee.
2. **Adverse events.** Consider what might constitute an adverse event and what actions may be needed if an adverse event occurs. Follow the procedures for reporting and addressing adverse events (http://research.curtin.edu.au/guides/adverse.cfm).Where appropriate, provide an adverse events protocol. The following are examples of adverse events:
   a. Complaints
   b. Harm to participants. This includes physical, emotional, psychological, economic, legal, social and cultural harm (NS Section 2)
   c. Loss of data or breaches of data security
   d. Legal challenges to the research
3. **Data management plan.** Have a Data Management Plan consistent with the University's recordkeeping policy. This will include such things as how the data are to be stored, for how long, and who has authorised access.
4. **Publication.** Where practicable, ensure the results of the research are made available to participants in a way that is timely and clear (NS 1.5). Unless prohibited from doing so by contractual obligations, ensure the results of the research are published in a manner that will allow public scrutiny (NS 1.3, d). Inform the Committee of any constraints on publication.
5. **Police checks and other clearances.** All necessary clearances, such as Working with Children Checks, first aid certificates and vaccination certificates, must be obtained before entering a site to conduct research.
6. **Participant information.** All information for participants must be approved by the HREC before being given to the participants or made available to the public.
   a. **University logo.** All participant information and consent forms must contain the Curtin University logo and University contact details for the researchers. Private contact details should not be used.
   b. **Standard statement.** All participant information forms must contain the HREC standard statement.

   This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR 16/2014). The Committee is comprised of members of the public, academics, lawyers, doctors and pastoral carers. If needed, verification of approval can be obtained either by writing to the Curtin University Human Research Ethics Committee, c/- Office of Research and Development, Curtin University, GPO Box U1987, Perth, 6845 or by telephoning 9266 2784 or by emailing hrec@curtin.edu.au.

   c. **Plain language.** All participant information must be in plain language that will be easily understood by the participants.

Please direct all communication through the Research Ethics Office

Appendix C: Participant Information Sheets and Consent Forms

Paper I: Participant information sheet and consent form

What is it like becoming an adult if you have autism?

My name is Craig Thompson. I am looking for people to take part in a research project that aims to find out what it is like becoming an adult if you have high functioning autism or Asperger's Syndrome.

Who is this study about?
For this study I am looking for parents of young people (aged 18-30) with high functioning autism spectrum disorder or Asperger's Syndrome, from here on I will simply refer to this as autism.

What is this study about?
Becoming an adult can be an exciting, but challenging time as young people develop their own identity. I would like to find out about your experience as your son or daughter becomes an adult.

I will be asking you questions such as the following:

What has this time of change been like? What has helped the process of change? Do you receive all the support or help you need? Does your son or daughter receive all the support or help they need? What are your feelings about the future for your son or daughter? What are your feelings about the future for yourself and the rest of your family?

What will I be asked to do?
If you decide to take part, I will invite you to meet with me once, for about two hours at a place that is convenient for you (for example, Autism Association of WA, Autism West or Curtin University).

You will be asked to take part in a group discussion with other parents of young people with autism. There will be two parts of the group discussions. The first being an opportunity to raise and discuss issues. While the second being an opportunity to rank the importance of these issues. I will keep size of the group to approximately ten people. These focus groups will be audio recorded so that they results can be confirmed at a later date.

I will also ask you to complete three questionnaires about you, your family and your son/daughter.

This is an opportunity for us to find out your opinions and everyone's viewpoint is valuable.

Are there any risks?
There are no known risks involved in participating in this study. Your involvement is completely voluntary. You are able to withdraw at any time without having to provide a reason.

What might be the benefits?
I hope that finding answers to these questions will help people with autism and their families.

Confidentiality
All data will be stored and used confidentially. Results will be presented so your name and personal details cannot be linked to your opinions. The data gathered will be published as scientific articles, as theses and presented at relevant conferences.

Further information

If you consent to being involved in the study, we will contact you in the near future, either by email or phone. You will be able to find out more information about the study, and I will organise a time and place that that suits you.

As a token of our appreciation for participating in this study we would like to give you two adult cinema tickets and to reimburse your travel expenses.

If you have any questions regarding the study, please feel free to contact me by telephone (9266 3942) or by email craig.thompson@curtin.edu.au . Or, you can contact either of my supervisors, Professor Torbjörn Falkmer or Dr Sonya Girdler by telephone (9266 3600).

Thank you for your time and consideration.

Kind regards,

Craig Thompson
PhD Candidate
Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3942
Email: craig.thompson@curtin.edu.au

Dr Torbjörn Falkmer
Professor/Senior Research Fellow
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: t.falkmer@curtin.edu.au

Dr Sonya Girdler
Senior Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: sonya.girdler@curtin.edu.au

Curtin University

Personal Consent to Participate

What is it like becoming an adult if you have autism?

☐ I agree to participate in the study as outlined to me.

☐ I have been informed of and understand the purpose of the study.

☐ I consent to the focus group being audio recorded.

☐ I have had an opportunity to ask questions.

☐ I understand that there are no known risks involved in the study.

☐ I understand that participation is voluntary and that I can withdraw at any time without consequence.

☐ I have been informed that all personal information will be kept confidential and any identifiable information will not be used in published material.

☐ I agree that the information I provide can be used in other studies and/or publications

☐ I agree to be informed about future studies

Name: _____

Email address: _____

Telephone numbers   Daytime: _____   Evening: _____

Mobile: _____

Signature: _____

Date: _____

Paper II: Participant information sheets and consent forms

What is it like being at university if you have autism?

My name is Craig Thompson. I am looking for people to take part in a research project that aims to find out what it is like becoming an adult if you have high functioning autism or Asperger's Syndrome.

Who is this study about?
For this study, I am looking for people with high functioning autism spectrum disorder or Asperger's Syndrome and their parents, from here on I will simply refer to this as autism.

What is this study about?
I would like to find out about the experiences of being at university for someone with autism. I am also interested in what helps them at university or what makes it more difficult.

What will I be asked to do?
If you decide to take part, I will invite you to meet me once, for about 45 minutes at a place that is convenient for you (for example, your home or Curtin University).

You will be given one sets of cards with statements on them. I will ask you to sort these statements on a grid according to how relevant they are to you, just as the person is doing in this photo. Or, if you chose you can sort these cards on a computer.
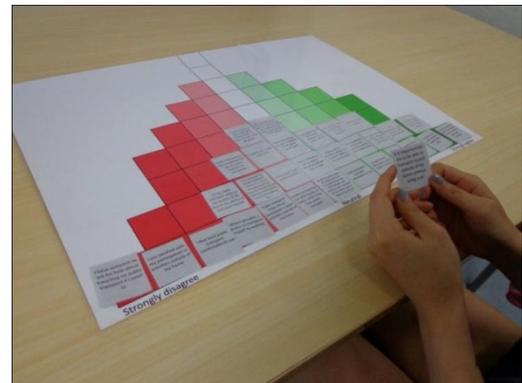
I will also like you to complete some short questionnaires about you and your family.

I will also ask your child to sort the same set of cards.

This is an opportunity for us to find out your opinions and there are no right or wrong answers.

Are there any risk?
There are no known risks involved in participating in this study. Your involvement is completely voluntary. You are able to withdraw at any time without having to provide a reason.

What might be the benefits?
I hope that finding answers to these questions will help people with autism and their families.

Confidentiality
All data will be stored and used confidentially. Results will be presented so your name and personal details will not be linked to your opinions. The data gathered will be published as scientific articles, as theses, and presented at relevant conferences.

Further information

If you consent to being involved in the study, I will contact you in the near future. You will be able to find out more information about the study, and I will organise a time and place that that suits you.

As a token of our appreciation for participating in this study we would like to give you two adult cinema tickets or an equivalent Coles Myer voucher and to reimburse your travel expenses.

If you have any questions regarding the study, please feel free to contact me by telephone (9266 3942) or by email craig.thompson@curtin.edu.au . Or, you can contact either of my supervisors, Professor Torbjörn Falkmer or Dr Sonya Girdler by telephone (9266 3600).

Thank you for your time and consideration.

Kind regards,

Craig Thompson
PhD Candidate
Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3942
Email: craig.thompson@curtin.edu.au

Dr Torbjörn Falkmer
Professor/Senior Research Fellow
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: t.falkmer@curtin.edu.au

Dr Sonya Girdler
Senior Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: sonya.girdler@curtin.edu.au

Paper III and IV: Participant informations sheet and consent forms

What is it like becoming an adult if you have autism?

My name is Craig Thompson. I am looking for people to take part in a research project that aims to find out what it is like becoming an adult if you have high functioning autism or Asperger's Syndrome. This part of the project is focused experiences young people with at university high functioning autism or Asperger's Syndrome.

Who is this study about?
For this study I am looking for young people with high functioning autism spectrum disorder at university participating in a peer mentor program, their mentor and their parent(s). From here on I will simply refer to high functioning autism spectrum disorder as autism.

What is this study about?
Becoming an adult can be an exciting, but challenging time.

I would like to find out about your experience as you became an adult.

What will I be asked to do?
If you decide to participate, you will be invited to participate in a one-on-one interview at a place that is convenient to you (for example, your home or Curtin University). If you prefer you can provide written answers based on the interview questions.

I will ask your mentor the same questions, but <u>I will not discuss any of the answers with any one taking part in the study</u>.

You will be asked describe what you consider a successful transition to university for an adult with Autism or Asperger's Syndrome. You will be asked about your experience and what helped (or did not help) at university.

I will also ask you to complete a short questionnaire about yourself and your mentor.

This is an opportunity for us to find out your opinions and everyone's viewpoint is valuable.

Are there any risk?
There are no known risks involved in participating in this study. Your involvement is completely voluntary. You are able to withdraw at any time without having to provide a reason.

What might be the benefits?
I hope that finding answers to these questions will help people with autism and their families.

Confidentiality
All data will be stored and used confidentially. Results will be presented so your name and personal details will not be linked to your opinions. The data gathered will be published as scientific articles, as theses, and presented at relevant conferences.

Further information

If you consent to being involved in the study, I will contact you in the near future, either by email or phone. You will be able to find out more information about the study, and I will organise a time and place that that suits you. To assist with the study, I may need to contact your Doctor to confirm your diagnosis of autism. I may also ask you to complete a short questionnaire about your current experience of having ASD.

As a token of our appreciation for participating in this study we would like to give you one adult cinema ticket equivalent Coles-Myer voucher

If you have any questions regarding the study, please feel free to contact me by telephone (9266 3942) or by email craig.thompson@curtin.edu.au . Or, you can contact either of my supervisors, Professor Torbjörn Falkmer or Dr Sonya Girdler by telephone (9266 3600).

Thank you for your time and consideration.

Kind regards,

Craig Thompson
PhD Candidate
Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3942
Email: craig.thompson@curtin.edu.au

Dr Torbjörn Falkmer
Professor/Senior Research Fellow
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: t.falkmer@curtin.edu.au

Dr Sonya Girdler
Senior Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: sonya.girdler@curtin.edu.au

Curtin University

Personal Consent to Participate

What is it like becoming an adult if you have autism?

☐ I agree to participate in the study as outlined to me.

☐ I agree to the audio recording of my interview

☐ I have been informed of and understand the purpose of the study.

☐ I agree that you can speak with the following people – please write their name in the space provided.

    ☐ My mother _____   ☐ My father _____

    ☐ My mentor(s) _____

    NB. No one except you and the research team will see these responses.

☐ I have had an opportunity to ask questions.

☐ I understand that there are no known risks involved in the study.

☐ I understand that participation is voluntary and that I can withdraw at any time without consequence.

☐ I agree that you can contact my Doctor in regards to my Autism or Asperger's Syndrome diagnosis.

☐ I have been informed that all personal information will be kept confidential and any identifiable information will not be used in published material.

☐ I agree that the information I provide can be used in other studies and/or publications

☐ I agree to be informed about future studies

Name: _____

Email address: _____

Telephone numbers   Daytime: _____   Evening: _____

                  Mobile: _____

Signature: _____

Date: _____

What is it like becoming an adult if you have autism?

My name is Craig Thompson. I am looking for people to take part in a research project that aims to find out what it is like becoming an adult if you have high functioning autism or Asperger's Syndrome. This part of the project is focused experiences young people with at university high functioning autism or Asperger's Syndrome.

Who is this study about?
For this study I am looking for young people with high functioning autism spectrum disorder at university participating in a peer mentor program, their mentor and their parent(s). From here on I will simply refer to high functioning autism spectrum disorder as autism.

What is this study about?
Becoming an adult can be an exciting, but challenging time. I would like to find out about your experience as your friend, colleague, employee or student became an adult.

I will be asking you questions such as the following:

What has this time of change been like? What has helped the process of change? Do you receive the support or help you need? Does your friend, colleague, employee or student receive the support or help they need? What are your feelings about the future for your friend, colleague, employee or student? What are your feelings about the future for your friend, colleague, employee or student?

I hope that finding answers to these questions will help people with autism and their families.

What will I be asked to do?
If you decide to participate, you will be invited to participate in a one-on-one interview at a place that is convenient to you (for example, your home or Curtin University). If you prefer you can provide written answers based on the interview questions.

I will ask your mentee the same questions, but <u>I will not discuss any of the answers with any one taking part in the study</u>.

You will be asked describe what you consider a successful transition to university for an adult with Autism or Asperger's Syndrome. You will be asked about your experience and what helped (or did not help) your mentee at university.

I will also ask you to complete a short questionnaire about yourself and your mentee.

This is an opportunity for us to find out your opinions and everyone's viewpoint is valuable.

Are there any risk?
There are no known risks involved in participating in this study. Your involvement is completely voluntary. You are able to withdraw at any time without having to provide a reason.

What might be the benefits?
I hope that finding answers to these questions will help people with autism and their families.

Confidentiality
All data will be stored and used confidentially. Results will be presented so your name and personal details will not be linked to your opinions. The data gathered will be published as scientific articles, as theses, and presented at relevant conferences.

Further information
If you consent to being involved in the study, I will contact you in the near future, either by email or phone. You will be able to find out more information about the study, and I will organise a time and place that that suits you.

As a token of our appreciation for participating in this study we would like to give you one adult cinema ticket or equivalent Coles-Myer voucher.

If you have any questions regarding the study, please feel free to contact me by telephone (9266 3942) or by email craig.thompson@curtin.edu.au . Or, you can contact either of my supervisors, Professor Torbjörn Falkmer or Dr Sonya Girdler by telephone (9266 3600).

Thank you for your time and consideration.

Kind regards,

Craig Thompson
PhD Candidate
Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3942
Email: craig.thompson@curtin.edu.au

Dr Torbjörn Falkmer
Professor/Senior Research Fellow
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: t.falkmer@curtin.edu.au

Dr Sonya Girdler
Senior Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: sonya.girdler@curtin.edu.au

Curtin University

Personal Consent to Participate

What is it like becoming an adult if you have autism?

☐   I agree to participate in the study as outlined to me.

☐   I agree to the audio recording of my interview

☐   I have been informed of and understand the purpose of the study.

☐   I have had an opportunity to ask questions.

☐   I understand that there are no known risks involved in the study.

☐   I understand that participation is voluntary and that I can withdraw at any time without consequence.

☐   I have been informed that all personal information will be kept confidential and any identifiable information will not be used in published material.

☐   I agree that the information I provide can be used in other studies and/or publications

☐   I agree to be informed about future studies

Name: _____

Email address: _____

Telephone numbers   Daytime: _____   Evening: _____

                                        Mobile: _____

Signature: _____

Date: _____

Paper V: Participant information sheet and consent form

What is it like becoming an adult if you have autism?

My name is Craig Thompson. I am looking for people to take part in a research project that aims to find out what it is like becoming an adult if you have high functioning autism or Asperger's Syndrome. This part of the project is focused experiences young people with at university high functioning autism or Asperger's Syndrome.

Who is this study about?
For this study I am looking for young people with high functioning autism spectrum disorder at university participating in a peer mentor program, their mentor and their parent(s). From here on I will simply refer to high functioning autism spectrum disorder as autism.

What is this study about?
Becoming an adult can be an exciting, but challenging time. I would like to find out about your experience as your son or daughter became an adult.

I will be asking you to think about questions such as the following:

What has this time of change been like? What has helped the process of change? Do you receive all the support or help you need? Does your son or daughter receive all the support or help they need? What are your feelings about the future for your son or daughter? What are your feelings about the future for yourself and the rest of your family? I hope that finding answers to these questions will help people with autism and their families.

What will I be asked to do?
If you decide to participate, you will be invited to participate in a one-on-one interview at a place that is convenient to you (for example, your home or Curtin University). If you prefer you can provide written answers based on the interview questions.

I will ask your son or daughter similar questions as well, but <u>I will not discuss any of the answers with anyone taking part in the study</u>.

You will be asked describe what you consider a successful transition to becoming an adult. You will be asked about your experience and what helped (or did not help) your son or daughter as they became an adult.

I will also ask you to complete some questionnaires about you, your family and your son/daughter.

This is an opportunity for us to find out your opinions and everyone's viewpoint is valuable.

Are there any risk?
There are no known risks involved in participating in this study. Your involvement is completely voluntary. You are able to withdraw at any time without having to provide a reason.

What might be the benefits?
I hope that finding answers to these questions will help people with autism and their families.

Confidentiality
All data will be stored and used confidentially. Results will be presented so your name and personal details will not be linked to your opinions. The data gathered will be published as scientific articles, as theses, and presented at relevant conferences.

Further information
If you consent to being involved in the study, I will contact you in the near future, either by email or phone. You will be able to find out more information about the study, and I will organise a time and place that that suits you. I may also ask you or your son/daughter to complete a short questionnaire about their current experience of having autism.

As a token of our appreciation for participating in this study we would like to give you one adult cinema ticket equivalent Coles-Myer voucher

If you have any questions regarding the study, please feel free to contact me by telephone (9266 3942) or by email craig.thompson@curtin.edu.au . Or, you can contact either of my supervisors, Professor Torbjörn Falkmer or Dr Sonya Girdler by telephone (9266 3600).

Thank you for your time and consideration.

Kind regards,

Craig Thompson
PhD Candidate
Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3942
Email: craig.thompson@curtin.edu.au

Dr Torbjörn Falkmer
Professor/Senior Research Fellow
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: t.falkmer@curtin.edu.au

Dr Sonya Girdler
Senior Lecturer
School of Occupational Therapy and Social Work
Curtin University
Phone: 9266 3600
Email: sonya.girdler@curtin.edu.au

This research has been reviewed and given approval by the Curtin University Human Research Ethics Committee (approval number HR 16/2014). Should you wish to make a complaint on ethical grounds, please contact the Human Ethics Committee (Secretary), phone: 9266 2784, email: hrec@curtin.edu.au, mail: c/- Office of Research and Development, Curtin University of Technology, GPO Box U1987, Perth WA 6845

Curtin University

Personal Consent to Participate

What is it like becoming an adult if you have autism?

☐ I agree to participate in the study as outlined to me.

☐ I have been informed of and understand the purpose of the study.

☐ I have had an opportunity to ask questions.

☐ I understand that there are no known risks involved in the study.

☐ I understand that participation is voluntary and that I can withdraw at any time without consequence.

☐ I have been informed that all personal information will be kept confidential and any identifiable information will not be used in published material.

☐ I agree that the information I provide can be used in other studies and/or publications

☐ I agree to be informed about future studies

Name: _____

Email address: _____

Telephone numbers   Daytime: _____   Evening: _____

Mobile: _____

Signature: _____

Date: _____

Appendix D: Recruitment Flyers

What is it like becoming an adult if you have autism?

Becoming an adult can be an exciting, but challenging time. This research project aims to find out what it is like becoming an adult if you have high functioning autism or Asperger's Syndrome. We would like to find out about your experience as your son or daughter becomes an adult.

Who is this study about?

For this study we are looking for parents of young people (aged 18-30) with high functioning autism spectrum disorder or Asperger's Syndrome.

What will you be asked to do?

If you decide to take part, you will be asked to take part in a group discussion with other parents of young people with autism.

The groups will run for about two hours at a place that is convenient to you (for example, Autism Association of WA, Autism West or Curtin University).

This is an opportunity for us to find out <u>your opinions and everyone's viewpoint is valuable</u>.

What might be the benefits?

I hope that finding answers to these questions will help people with autism and their families. As well as informing services about what is needed now and into the future.

As a token of our appreciation for participating in this study we would like to give you two adult cinema tickets and to reimburse your travel expenses.

If you are interested or have any questions regarding the study, please feel free to contact Craig Thompson by telephone (9266 3942) or by email (craig.thompson@curtin.edu.au).

Find us on Facebook https://www.facebook.com/curtin.autismresearch

University Experience and Autism

Becoming an adult can be an exciting, but challenging time. I would like to find out about your experiences, of becoming an adult.

Who is this study about?

People who support university students with high functioning autism spectrum disorder.

What will you be asked to do?

You will be asked to sort a sets of statements on your computer, as shown in this picture.

This should take about 20 minutes.

I will also like you to complete one short questionnaire online about you.

What might be the benefits?

This will help inform the continual improvement of the Curtin Specialist Mentor Programme students with Autism Spectrum Conditions. I hope that finding answers to these questions will help people with autism and their families. As well as informing services about what is needed now and into the future.

If you are interested or have any questions regarding the study, please feel free to contact Craig Thompson by telephone (9266 3942 or 0411 618 910) or by email (craig.thompson@curtin.edu.au).

Find us on Facebook https://www.facebook.com/curtin.autismresearch
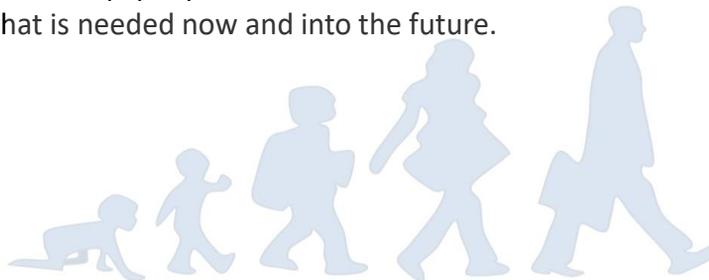
University Experience and Autism

Who is this study about?

Young people with high functioning autism spectrum disorder or Asperger's Syndrome who have studied at university, their parents and their mentors.

What will you be asked to do?

You will be asked if we can complete a short interview with your parent(s) and your mentor. We would also like to ask you some questions and you can decide if you would like to be interviewed or provide written answers to the questions.

What might be the benefits?

This will help inform the continual improvement of the Specialist Mentor Programme students with Autism Spectrum Conditions. I hope that finding answers to these questions will help people with autism and their families. As well as informing services about what is needed now and into the future.

As a token of our appreciation for participating in this study we would like to give you a $20 Coles-Myer voucher or one adult cinema tickets.

If you are interested or have any questions regarding the study, please feel free to contact Craig Thompson by telephone (9266 3942 or 0411 618 910) or by email (craig.thompson@curtin.edu.au).

Find us on Facebook https://www.facebook.com/curtin.autismresearch

Appendix E: Demographic Questionnaires

Please indicate your relationship to the young person with Autism or Asperger's Syndrome.

☐ Mother   ☐ Stepmother

☐ Father   ☐ Stepfather

☐ Foster Mother   ☐ Foster Father

☐ Other (please specify) _____

Unique ID
First 2 letters of your first name:
First 2 letters of your surname:
Street number of your house:
First 2 letters of your suburb:
Your gender (M / F):

1. What is the gender of the young person with Autism or Asperger's Syndrome?

☐ Male   ☐ Female

2. What is the current age of the young person with Autism or Asperger's Syndrome? _____

3. How old was the young person with Autism or Asperger's Syndrome when they were formally diagnosed?

☐	☐	☐	☐	☐	☐	☐
Less than 12 months	12-18 months	19-24 months	2-6 years	7-12 years	13-18 years	18+ years

4. What best describes the young person with Autism or Asperger's Syndrome current employment status? (please tick all relevant boxes)

☐ Employed full-time

☐ Employed part-time (approximate number of hours per week ____)

☐ Unemployed & looking for work

☐ Unemployed & not looking for work

☐ Participating in an alternative to employment programme

☐ Volunteer

☐ Studying full-time

☐ Studying part-time

5. What is the highest level of education achieved by the young person with Autism or Asperger's Syndrome?

☐ Primary school

☐ Some high school

☐ High school (Year 12 or equivalent)

☐ Trade or technical qualification

☐ Graduate diploma or certificate

☐ Advanced diploma

☐ Bachelor degree

☐ Postgraduate degree (Masters or PhD)

6. What best describes the living arrangements of the young person with Autism or Asperger's Syndrome?

☐ Living in the family home

☐ Living in individual accommodation <u>with</u> support

☐ Living in individual accommodation <u>without</u> support

☐ Living in shared accommodation <u>with</u> support

☐ Living in shared accommodation <u>without</u> support

☐ Living with their spouse or partner

7. How many siblings does the young person with Autism or Asperger's Syndrome have?

☐ None →Go to Question 10

☐ 1

☐ 2

☐ 3

☐ 4

☐ More than 4

Please continue over the page

8. Please indicate if any of these siblings has an Autism Spectrum Disorder?

☐ None

☐ 1

☐ 2

☐ 3

☐ 4

☐ Other (please specify) _____

9. Please indicate the birth order of your child/children with Autism or Asperger's Syndrome among their siblings?

☐ First

☐ Second

☐ Third

☐ Fourth

☐ Fifth

☐ Other _____

10. Please indicate your marital status

☐	☐	☐	☐	☐	☐	☐
Single	Married	De facto	Separated	Never married	Widowed	Divorced

Please continue over the page

11. What best describes your current work status?

☐ Not working due to her child's disability

☐ Not working for other reasons

☐ Fulltime homemaker

☐ Volunteer

☐ Looking for work outside the family home

☐ Working full-time

☐ Working part-time (approximate number of hours per week _____)

12. What is the highest level of education you have completed?

☐ Some high school

☐ High school (Year 12 or equivalent)

☐ Trade or technical qualification

☐ Graduate diploma or certificate

☐ Advanced diploma

☐ Bachelor degree

☐ Postgraduate degree (Masters or PhD)

13. What is your approximate annual income?

☐ $0 - $20,000

☐ $20,001 - $40,000

☐ $40,001 - $60,000

☐ $80,001 - $100,000

☐ $100,000 +

The following questions refer to your spouse / partner.

☐ Not applicable → Go to question 17

14. What best describes their current work status?

☐ Not working due to her child's disability

☐ Not working for other reasons

☐ Fulltime homemaker

☐ Volunteer

☐ Looking for work outside the family home

☐ Working full-time

☐ Working part-time (approximate number of hours per week _____)

15. What is the highest level of education he has completed?

☐ Some high school

☐ High school (Year 12 or equivalent)

☐ Trade or technical qualification

☐ Graduate diploma or certificate

☐ Advanced diploma

☐ Bachelor degree

☐ Postgraduate degree (Masters or PhD)

16. What is their approximate annual income?

☐ $0 - $20,000

☐ $20,001 - $40,000

☐ $40,001 - $60,000

☐ $80,001 - $100,000

☐ $100,000 +

17. Please provide your postcode _____

1. What is your gender?

☐ Male   ☐ Female

2. How old are you? _____

3. How long have you known the young person with Autism or Asperger's Syndrome?

☐ Less than 1 week

☐ 1 week - 1 month

☐ 1-3 months

☐ 3-6 months

☐ 6-12 months

☐ Other (please specify) _____

4. On average how frequently do you meet / interact with the young person with Autism or Asperger's Syndrome per month?

☐ Zero

☐ 1-5 times per month

☐ 6-10 times per month

☐ 11-20 times per month

☐ 21+ times per month

5. Where do you meet / interact with the young person with Autism or Asperger's Syndrome?

☐ Work

☐ School, TAFE, University or other education facility

☐ Coffee shop / café

☐ A personal residence

☐ Other (please specify) _____

6. What course are you studying?

_____

7. What year of study are you currently completing?

Undergraduate   Post-graduate

☐ First year   ☐ First year

☐ Second year   ☐ Second year

☐ Third year   ☐ Other (please specify) _____

☐ Fourth year

☐ Other (please specify) _____

8. Have you mentored students previously?

☐ Yes   ☐ No

9. Have you any prior experience working with individuals Autism Spectrum Disorders?

☐ Yes   ☐ No

10. Please provide your postcode _____

1. What is your gender?

☐ Male   ☐ Female

2. How old are you? _____

3. What best describes your current employment status? (please tick all relevant boxes)

☐ Employed full-time

☐ Employed part-time (approximate number of hours per week ____)

☐ Unemployed & looking for work

☐ Unemployed & not looking for work

☐ Participating in an alternative to employment programme

☐ Volunteer

☐ Studying full-time

☐ Studying part-time

4. What is the <u>highest</u> level of education you have achieved?

☐ Primary school

☐ Some high school

☐ High school (Year 12 or equivalent)

☐ Trade or technical qualification

☐ Graduate diploma or certificate

☐ Advanced diploma

☐ Bachelor degree

☐ Postgraduate degree (Masters or PhD)

☐ Other (please describe) _____

5. What best describes where you live?

☐ Living in family home

☐ Living in individual accommodation with support

☐ Living in individual accommodation without support

☐ Living in shared accommodation with support

☐ Living in shared accommodation without support

☐ Living with their spouse or partner

☐ Other (please describe) _____

6. Please indicate your marital status

☐	☐	☐	☐	☐	☐	☐
Single	Married	De facto	Separated	Never married	Widowed	Divorced

7. What is your approximate annual income?

☐ $0 - $20,000

☐ $20,001 - $40,000

☐ $40,001 - $60,000

☐ $80,001 - $100,000

☐ $100,000 +

8. Do you have any other medical conditions?

_____

_____

_____

_____

_____

9. Please provide your postcode _____

Appendix F: Interview Schedules

Mentee interview guide for the peer mentor program

Interviewer to introduce themselves, the project and this study.

Introducing the interview.

- The purpose of this interview is to gain an understanding about the Curtin Specialist Mentor Program and how this effects your son/daughter's experience and achievements at university

  NB. The interviewer need to stress their independence from the Curtin Specialist Peer Mentoring Program

  Mentor prompt: ask for concrete examples where necessary

Why?

Interviewer to introduce this section by stating: I would like to begin by asking you about you about why you were interested in joining the specialist peer mentoring program

1. What had you hoped you might to achieve by becoming a mentor in the specialist peer mentoring program? OR

   What did you want from being involved in the specialist peer mentoring program? OR

   What were your expectations of being involved in the specialist peer mentoring program?

What happened?

Interviewer to introduce this section by stating: I would now like to move on to asking you about what and how you work with your mentor in the specialist peer mentoring program

2. Where did you meet your mentor?

   Library, coffee shop, etc.

   Prompts to interviewer: check if there are any other places they have met their mentor

3. How often did you meet your mentor?

4. What issues / problems did you discuss?

   Prompts to interviewer: ask for concrete examples. Ask what information or guidance the mentor provided. What worked / what did not work?

a. Prompt to interviewer: to ensure all topics covered ask the mentee to explore the checklist below (this can be provided to mentee if they wish)

What university issues do you discuss?

 i. Transition to university

 ii. Accommodation e.g. living on campus, renting alone, living with parents, renting with other people, etc.

 iii. Communication with university

 iv. Knowledge about support and resources available on campus e.g. Guild, Library, counselling service, the health services, various clubs and associations, etc.

 v. Study skills

 vi. Planning and organizing academic work

 vii. Class participation

 viii. Meeting/ Group work commitments

 ix. Interactions with teaching staff

 x. Planning and organizing everyday life

 xi. Interaction with other students

 xii. Anxiety or low moods

 xiii. Sense of support and from whom

b. What other issues do you discuss?

5. As you continued to meet with your mentor did the sessions change how did the mentoring sessions change over time?

Prompts to interviewer: Did you talk about different topics? Did you talk more?

6. How did your relationship with your mentor change over time?

7. Thinking about the work you have done with your mentor… How has this impacted on your university experience?

Provide examples if necessary

Prompts to interviewer: Academic performance, relationships with lecturers/tutors/peers/services on campus

8. Overall, what do you think about working with your mentor?

The Social group

Interviewer to introduce this section by stating: I would now like to move on to asking you about the social group of the specialist peer mentoring program

9. Did you attend the social group?   YES/NO

10. What role has the social group played in your time at university?

    What did you do in the group?

    What was useful / good?

11. How did your mentor sessions change how you participated in the social group?

Evaluation

Interviewer to introduce this section by stating: I would now like to move on to asking you about how you would evaluate the specialist peer mentoring program

12. Is there anything about the mentor program that you would change to improve the program?

13. Are there any other issues you would like to discuss?

14. If you rated the specialist peer mentoring program out of 10 what would you give it?

Mentor interview guide for the Curtin Specialist Mentor Program

Interviewer to introduce themselves, the project and this study.

Introducing the interview.

- The purpose of this interview is to gain an understanding about the Curtin Specialist Mentor Program and how this effects your son/daughter's experience and achievements at university

    NB. The interviewer need to stress their independence from the Curtin Specialist Peer Mentoring Program

    Mentor prompt: ask for concrete examples where necessary

Why?

Interviewer to introduce this section by stating: I would like to begin by asking you about you about why you were interested in joining the specialist peer mentoring program

1. What had you hoped you might to achieve by becoming a mentor in the specialist peer mentoring program? OR

    Why were you interested in becoming a mentor? OR

    What were your expectations of being involved in the peer mentor program?

What happened?

Interviewer to introduce this section by stating: I would now like to move on to asking you about what and how you mentor your mentee in the specialist peer mentoring program

2. Where did you meet your mentee?

    Library, coffee shop, etc.

    Prompts to interviewer: check if there are any other places they have met their mentee

3. How often did you meet your mentee?

4. What issues / problems do you discuss?

    Prompts to interviewer: ask for concrete examples. Ask what information or guidance the mentor provided. What worked / what did not work?

a. Prompt to interviewer: to ensure all topics covered ask the mentor to explore the checklist below (this can be provided to mentor if they wish)

What university issues do you discuss?

   i. Transition to university

   ii. Accommodation

   iii. Communication with university

   iv. Knowledge about support and resources available on campus

   v. Study skills

   vi. Planning and organizing academic work

   vii. Class participation

   viii. Meeting/ Group work commitments

   ix. Interactions with teaching staff

   x. Planning and organizing everyday life

   xi. Interaction with other students

   xii. Anxiety or low moods

   xiii. Sense of support

b. What other issues do you discuss?

5. How did the mentoring sessions change over time?

   Prompts to interviewer: Did your mentee talk about different topics? Did your mentee talk more?

6. How did your relationship with your mentee change over time?

   Prompts to interviewer: ask for concrete examples. Also check whether the mentee has become more open, have they talked more, have topics they discuss changed, what they have asked you, places you have met, your boundaries, etc.

Interviewer to introduce this section by stating: I would now like to move on to asking you about how being a mentor in the specialist peer mentoring program has affected you

7. How has being a mentor impacted on you personally and academically? Explore both positive and negative

   Prompt to interviewer: Ensure the interviewee has explored positives and negatives

   Provide examples if necessary

Possible topics: Academic performance, relationships with lecturers/tutors/peers/services on campus

8. How did your personal experience change over time?

   Prompts to interviewer: Did you feel anxious, over whelmed,

9. Overall, what do you thinking about working with your mentee?

Self-care

Interviewer to introduce this section by stating: I would now like to move on to asking you about what strategies you have used to help you continue as a mentor specialist peer mentoring program and a university student

10. How did you cope with being a mentor?

11. How did your experience change with your changing study load?

12. Describe your boundaries with your mentee? How did you maintain these?

Evaluation

Interviewer to introduce this section by stating: I would now like to move on to asking you about how you would evaluate the specialist peer mentoring program

13. Is there anything about the mentor program that you would change to improve the program?

14. Are there any other issues you would like to discuss?

15. If you rated the specialist peer mentoring program out of 10 what would you give it?

Parent interview guide for the Curtin Specialist Mentor Program

Interviewer to introduce themselves, the project and this study.

Introducing the interview.

- The purpose of this interview is to gain an understanding about the Curtin Specialist Mentor Program and how this effects your son/daughter's experience and achievements at university

  NB. The interviewer need to stress their independence from the Curtin Specialist Peer Mentoring Program

Experience

Interviewer to introduce this section by stating: I would like to begin by asking you about you and your families' experience of "university" and the specialist peer mentoring program

1. How did you feel when your son/daughter was accepted into university?
   How did you feel when they started university?
2. What was it like for you and them when they started university?
3. What is it like for you both now?
4. How did you find about the specialist peer mentor program?

Interviewer to introduce this section by stating: I would now like to move on to asking you about what you expected from specialist peer mentoring program when you son/daughter started in the specialist peer mentoring program

5. What did you want from the specialist peer mentoring program for your son/daughter?
6. What did you expect from the specialist peer mentoring program for your son/daughter and yourself?

Benefits

Interviewer to introduce this section by stating: I would now like to move on to asking you about how the specialist peer mentoring program has changed you son/daughter experience/achievements at university

7. How has being involved in the peer mentor program affected your son/daughter?
   Prompt to interviewer: Ensure the interviewee has explored positives and negatives

8. How has being involved in the peer mentor program affected you and your family?

   Prompt to interviewer: Has the specialist peer mentoring program changed how the family or parents have to support their son/daughter. Ensure the interviewee has explored positives and negatives.

Evaluation

Interviewer to introduce this section by stating: I would now like to move on to asking you about how you would evaluate the specialist peer mentoring program that supports your son/daughter at university

9. What is your overall view of the peer mentor program?
10. Is there anything that you would suggest to change the program to improve it into the future?
11. Are there any other issues you would like to discuss?
12. If you rated the specialist peer mentoring program out of 10 what would you give it?

Appendix G: Author contribution statements

Author Contribution Statement: Chapter 2

As co-authors of the paper entitled, "To be understood: Transitioning to adult life for people with Autism Spectrum Disorder." we confirm that Craig Thompson has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings;
- Corresponding author for communication with the journal

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed _____ Torbjörn Falkmer   Date 11/3/2020

Signed _____ Sonya Girdler   Date 13/3/2020

Signed _____ Sven Bölte   Date 13/3/2020

Author Contribution Statement: Chapter 3

As co-authors of the paper entitled, "Viewpoints on how students with autism can best navigate university." we confirm that Craig Thompson has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings;
- Corresponding author for communication with the journal

Our contribution to the paper was consistent with the role of supervisors and involved the following contributions:

- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed   Torbjörn Falkmer   Date 11/3/2020

Signed   Sonya Girdler   Date 13/3/2020

Signed   Sven Bölte   Date 13/3/2020

Author Contribution Statement: Chapter 4

As co-authors of the paper entitled, "A realist evaluation of peer mentoring support for university students with autism." we confirm that Craig Thompson has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings;
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- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

Signed   Torbjörn Falkmer   Date 11/3/2020

Signed   Sonya Girdler   Date 13/3/2020

Signed   Sven Bölte   Date 13/3/2020

Signed   Kiah Evans   Date 12/3/2020

Author Contribution Statement: Chapter 5

As co-authors of the paper entitled, "I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students." we confirm that Craig Thompson has been the principal researcher and has made the following contributions:

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- Data collection, analysis and interpretation;
- Writing the manuscript and critical appraisal of the findings;
- Corresponding author for communication with the journal

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| Signed		Torbjörn Falkmer	Date 11/3/2020
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Signed		Sven Bölte	Date 13/3/2020
Signed		Jasmine McDonald	Date 11/3/2020
Signed		Theresa Kidd	Date 11/3/2020

Author Contribution Statement: Chapter 6

As co-authors of the paper entitled, "University is an emotional rollercoaster: Experiences of parents of specialist peer mentored autistic university students." we confirm that Craig Thompson has been the principal researcher and has made the following contributions:

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- Writing the manuscript and critical appraisal of the findings;
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- Assistance with conceptualisation and design of the research;
- Assistance with data analysis and interpretation; and
- Review and editing of the manuscript.

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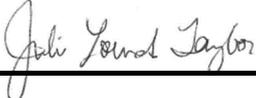
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kind regards

Craig

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Viewpoints on how students with autism can best navigate university

Author: Craig Thompson, , , et al

Publication: Scandinavian Journal of Occupational Therapy

Publisher: Taylor & Francis

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Sent: Tuesday, 17 March 2020 9:55 PM
To: Craig Thompson
Subject: RE: iocc20:"I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students

17 March 2020

Dear Craig Thompson,

C. Thompson, J. McDonald, T. Kidd, T. Falkmer, S. Bölte & S. Girdler (2020): "I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students, Scandinavian Journal of Occupational Therapy, DOI: 10.1080/11038128.2020.1738545

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Subject: iocc20:"I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students

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Contact name: Craig Thompson

Street address: 8 Holmes Place
Town: Hilton
Postcode/ZIP code: 6163
Country: Australia
Contact telephone number: 0411618910
Contact email address: craig.thompson@curtin.edu.au

Article title: "I don't want to be a patient": Peer mentoring partnership fosters communication for autistic university students
Article DOI: 10.1080/11038128.2020.1738545
Author name: C. Thompson, J. McDonald, T. Kidd, T. Falkmer, S. Bölte & S. Girdler
Journal title: Scandinavian Journal of Occupational Therapy
Volume number: *
Issue number: *
Year of publication: *
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