

**School of Occupational Therapy and Social Work**

**Boosting Post-School Outcomes:  
Development and Evaluation of an Online  
Transition Planning Program for  
Adolescents on the Autism Spectrum**

**Megan Kelly Hatfield**

**This thesis is presented for the Degree of  
Doctor of Philosophy  
of  
Curtin University**

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# Author's Declaration

I declare that this thesis is my own account of my research and contains as its main content work which has not previously been submitted for a degree at any tertiary education institution.

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 HR110/2014.

Megan Hatfield

Date: 07 June 2017

# Statement of Contributors

## **Supervisors:**

- Professor Torbjörn Falkmer
- Associate Professor Marina Ciccarelli
- Dr Marita Falkmer
- Emeritus Professor Sylvia Rodger

**Statistician:** Richard Parsons

**Honours student:** Nina Murray

## **Research Assistants:**

- Gal Rose, Timothy Parkin and Greg Lynn who completed data transcription.
- Paula Jops who conducted the interviews in the process evaluation.

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<http://www.autismcrc.com.au/>



# Abstract

Despite the numerous strengths that adolescents on the autism spectrum possess, they experience inferior post-school outcomes in comparison to adolescents with other disabilities and adolescents without a disability. Transition planning has been found to enhance post-school outcomes in adolescents with disabilities.

Unfortunately, most existing transition planning programs are not autism-specific and therefore may not meet the needs of adolescents on the autism spectrum.

The aim of this thesis was to develop and evaluate an online transition planning program to support adolescents on the autism spectrum to prepare for leaving school. The program was developed using the PRECEDE-PROCEED model.

The thesis is comprised of three phases. Phase 1 was a needs assessment to determine autism-specific needs in transition planning. A survey was completed by adolescents on the autism spectrum, as well as parents and professionals (N=162) that explored predisposing, reinforcing, and enabling factors that supported transition planning. Results identified various factors: adolescents' motivation, anxiety, and insight as predisposing factors; providing flexibility and choice as reinforcing factors; and having a plan as an enabling factor. In addition, interviews were conducted with parents (n=9) and professionals (n=4) to identify their viewpoints related to the transition planning needs of adolescents on the autism spectrum. Findings emphasised the importance of supporting the adolescents on the autism spectrum to grasp the big picture, to understand the purpose of transition planning to enhance motivation and empower their participation in transition planning.

Phase 2 involved the development of an autism-specific transition planning program, the Better Outcomes & Successful Transitions for Autism (BOOST-A™). The program was developed based on three frameworks: self-determination theory, strengths-based approach, and technology-based approach. Two pilot studies were conducted. In Pilot A, the BOOST-A™ was trialled with six adolescents on the autism spectrum along with their parents and the professionals who supported them. In

Pilot B, feedback on the BOOST-A™ was obtained from 88 allied health professionals via an online survey. Results indicated that the BOOST-A™ was a viable and feasible program, and modifications were made to improve the program based on feedback from participants.

The effectiveness of the BOOST-A™ was determined in Phase 3. A quasi-randomised controlled trial was conducted with adolescents on the autism spectrum across Australia (N=94) over one year, with participants allocated to the intervention group (n=49) receiving the BOOST-A™, and the control group (n=45) participating in regular practice. Results indicated significant differences from pre- to post-test in favour of the intervention group for opportunity for self-determination at home, domain-specific self-determination, and career exploration. A process evaluation determined the barriers and enablers to using the BOOST-A™ by collecting qualitative and quantitative feedback from participants in the intervention group. Findings of the process evaluation indicated that the BOOST-A™ supported adolescents to feel empowered through the strengths-focus, and to overcome inertia by providing a structured transition planning process. Some participants did not benefit from the program because they did not have a 'champion' to support the process, or due to difficulty engaging the adolescent in transition planning.

Overall, the BOOST-A™ was determined to be feasible, and user-friendly transition planning program, with preliminary evidence for effectiveness. Further research is needed to determine the effectiveness of the BOOST-A™ in enhancing post-school outcomes, and to identify strategies to encourage collaboration between professionals and parents in transition planning. It is recommended that the BOOST-A™ be developed further to integrate peer-mediated interventions, video modelling, and the serious game framework to further enhance participation in transition planning of adolescents on the autism spectrum.

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I would like to thank Dr Richard Parsons for his assistance with the analyses, and teaching me so much about statistics. Thank you to my PhD friends at Curtin and in the Autism CRC, and especially to Melissa Scott. I think the fact that people always gets us mixed up speaks volumes about how much we have stuck together and supported each other during this journey. To my broader friendship circle of occupational therapy friends, you never fail to provide me with stimulating discussions or just comic relief when I need it most.

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Finally, my most heartfelt gratitude to Michael. I really could not have done this without you. You make the impossible seem possible and your unwavering optimism has gotten me through all of the tough times. Your support and willingness to listen to me talk about my work was so appreciated. I feel like I can achieve anything with you by my side, and I can't wait to marry you.

# Dedication

I dedicate this thesis to Emeritus Professor Sylvia Rodger.

A role model in many ways; a female researcher demonstrating integrity and passion, an occupational therapist prompting a paradigm shift in paediatric practice, and a genuine and compassionate friend and mentor. You will be missed.

*My mission in life is not merely to survive, but to thrive; and to do so with some passion, some compassion, some humour, and some style.*

— Maya Angelou

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# List of publications, conference presentations, and awards



This doctoral thesis consists of the following publications:

1. Hatfield M, Ciccarelli M, Falkmer T, Falkmer M. Factors related to successful transition planning for adolescents on the autism spectrum. *JORSEN*. 2017; Early online view. doi:10.1111/1471-3802.12388
2. Hatfield M, Falkmer M, Falkmer T, Ciccarelli M. "Leaps of faith": Parent and professional viewpoints on preparing adolescents on the autism spectrum for leaving school. *JORSEN*. 2017; 17(3):187-197. doi:10.1111/1471-3802.12377
3. Hatfield M, Murray N, Ciccarelli M, Falkmer T, Falkmer M. Pilot of the BOOST-A: An online transition planning program for adolescents with autism. *Aust Occup Ther J*. 2017; Early online view. doi:10.1111/1440-1630.12410
4. Hatfield M, Falkmer M, Falkmer T, Ciccarelli M. Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: Trial protocol. *Child Adolesc Psychiatry Ment Health*. 2016; 10(48). doi:10.1186/s13034-016-0137-0
5. Hatfield M, Falkmer M, Falkmer T, Ciccarelli M. Effectiveness of the BOOST-A online transition planning program for adolescents on the autism spectrum: A quasi-randomised controlled trial. *Child Adolesc Psychiatry Ment Health*. 2017; In press.
6. Hatfield M, Falkmer M, Falkmer T, Ciccarelli M. Process evaluation of the BOOST-A transition planning program for adolescents on the autism spectrum: A strengths-based approach. *J Autism Dev Disord*. 2017; In press.

**Appendix A:** Murray N, Hatfield M, Falkmer M, Falkmer T. Evaluation of career planning tools for use with individuals with autism spectrum disorder: A systematic review. *Res Autism Spectr Disord.* 2016; 23:188-202. doi:10.1016/j.rasd.2015.12.007

The following conference presentations were completed during the duration of the thesis:

- Hatfield M, Murray N, Falkmer M, Ciccarelli M, & Falkmer T. Pathway to Employment: Development of a protocol to assist adolescents with Autism Spectrum Disorders (ASD) with their transition from school to employment. Poster session presented at the biannual Australasian Society for Autism Research (ASfAR) Conference. 2014. Melbourne, VIC, Australia.
- Hatfield M, Falkmer T, Ciccarelli M, & Falkmer M. "Leaps of faith": The current and ideal transition planning processes for adolescents with high functioning autism/Asperger's Syndrome. Oral presentation at the biannual Asia Pacific Autism Conference (APAC). 2015. Brisbane, QLD, Australia.
- Hatfield M, Falkmer T, Ciccarelli M, & Falkmer M. Seeing the big picture: Transition planning processes for adolescents with high functioning autism/Asperger's Syndrome in Australia. Poster presented at Asia-Pacific Regional IMFAR. 2015. Shanghai, China.
- Hatfield M, Murray N, Falkmer M, Ciccarelli M, & Falkmer T. Preparing adolescents with autism for leaving school: Pilot of the BOOST-A online protocol. Poster session presented at the biannual XI Autism Europe Conference. 2016. Edinburgh, Scotland.
- Hatfield M, Ciccarelli M, Falkmer M, & Falkmer T. Development of the BOOST-A: An online program preparing adolescents with autism for leaving school. Poster presentation at the Mark Liveris Student Research Seminar. 2016. Perth, WA, Australia.
- Hatfield M, Falkmer M, Falkmer T, & Ciccarelli M. Preparing adolescents with autism for leaving school: Efficacy of the BOOST-A online protocol. Oral

presentation at the biannual Australasian Society for Autism Research (ASfAR) Conference. 2016. Perth, WA, Australia.

The following awards were presented to the author for work related to the thesis:

- The Patricia Howlin CRC PhD Scholar Prize, 2014
- Runner-up Best Poster Presentation Award, Mark Liveris Student Research Seminar, 2016

# Key abbreviations

ASD: Autism Spectrum Disorder

BOOST-A™: Better Outcomes & Successful Transitions for Autism

DSM: Diagnostic and Statistical Manual of Mental Health Disorders

ID: Intellectual Disability

NLTS: National Longitudinal Transition Study of Special Education Students

PPM: PRECEDE-PROCEED Planning Model

SEIFA: Socio-Economic Indexes for Areas

USA: United States of America

# Explanation of terms and delineation of thesis

It is acknowledged that members of the autistic community have diverse views on terminology.<sup>1</sup> In this thesis, the terms 'on the autism spectrum' and 'with autism' were used as consistently as possible to describe people with a diagnosis of Autism Spectrum Disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, fourth (DSM-IV) or fifth edition (DSM-5). This included people with Asperger's Syndrome and Pervasive Developmental Disorder – Not Otherwise Specified, as formerly delineated in the DSM-IV. These terms were chosen to be consistent with the Autism CRC style guide.<sup>2</sup> The exception to this is in earlier conference presentations and publications (i.e., the systematic review in Appendix A). The reason for this inconsistency is due to increasing recognition of strengths-based language to describe people on the autism spectrum in recent years.

Australian spelling and Vancouver referencing style was used consistently throughout the thesis. The exceptions to this are the two published manuscripts (Chapter 2 – Interviews, Chapter 5 - Trial Protocol) that are included as a PDF as the published versions that follow the referencing style and spelling outlined in the journal guidelines. Furthermore, manuscripts vary in structure (i.e., headings, abstract format) to adhere to individual journal guidelines.

Three frameworks were chosen to guide the development of the transition planning program. The term 'theoretical frameworks' was used in one published manuscript (Chapter 5 – Trial Protocol). However, since the paper's publication, the decision was made to use the term 'frameworks' because not all of the frameworks were based on theories.

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<sup>1</sup>Kenny L, Hattersley C, Molins B, Buckley C, Povey C, Pellicano E. Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*. 2015; 40(4):442-62. doi: 10.1177/1362361315588200

<sup>2</sup> Autism CRC. Cooperative Research Centre for Living with Autism (Autism CRC) Style Guide. Long Pocket, Brisbane: Australia. 2016.

This thesis aimed to develop and evaluate a transition planning program to support adolescents on the autism spectrum to feel better prepared for leaving school. The focus of the thesis was supporting adolescents to gain employment. Whilst there are many other important areas of focus during this transition, such as friendships, romantic relationships, leisure and independent living, there was not scope in the thesis to address all aspects of the transition out of school. Employment was chosen as the focus, as employment was rated as the greatest priority by parents of adolescents on the autism spectrum in Australia, as they viewed employment as a gateway to other meaningful roles for their adolescents.<sup>3</sup> The program was not developed as a transition planning assessment, and therefore there was no need to determine the reliability and validity of the program. The program was developed to provide guidance on all of the steps involved in transition planning to gain employment, not specific elements of this process. Therefore, whilst the program promotes skill development, it does not provide specific intervention for skill development in areas such as self-regulation, social skills, interview skills, or on-the-job strategies to enhance workplace success.

This thesis focused on adolescents on the autism spectrum without intellectual disability (ID) because this group often have difficulty accessing transition services and subsequently have poorer post-school outcomes than adolescents with a diagnosis of autism and ID.<sup>3,4</sup> In addition, it was important to focus the research on a specific group to ensure the program would meet the needs of its target audience. Thus, this thesis did not aim to address comorbid diagnoses that are associated with autism. For example, whilst the high prevalence of anxiety and depression amongst this population is recognised as a key factor that impacts on transition planning during high school, the transition planning program in this thesis did not aim to address these conditions specifically.

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<sup>3</sup> Neary P, Gilmore L, Ashburner J. Post-school needs of young people with high-functioning Autism Spectrum Disorder. *Res Autism Spectr Disord*. 2015; 18:1-11. doi:10.1016/j.rasd.2015.06.010

<sup>4</sup> Taylor JL, Seltzer M. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *J Autism Dev Disord*. 2011; 41:566-74. doi:10.1007/s10803-010-1070-3

# Preface

Before starting my PhD, I worked as an Occupational Therapist in the community. One of my clients was a young man named Mark who was on the autism spectrum. Mark had just started secondary school. I loved working with him; he was a kind-hearted soul who had a passion for music and loved animals. His mother was very proactive and an amazing advocate for her son. One day, Mark's mother mentioned that she was very worried about what he would do after he left school. She was concerned he would never get a job or develop independence. She mentioned Mark was also starting to express anxiety around this transition. So, we set a goal around supporting Mark to feel ready for leaving school.

First, we approached the employment services. They all said they thought it was great to start planning now, but that they could not help Mark because they were not funded to assist adolescents before they left school. Next, we approached the school. We had a meeting with the teachers, with Mark and his mother present. The teachers said they would love to help but did not really have the time because they had to focus on Mark's academic work. I will never forget how everyone talked about Mark like he was not there, and how uncomfortable he looked in that meeting. I asked my therapist colleagues for advice; they all shrugged their shoulders and said they did not know what to do. There were resources for transition from primary school to secondary school, but nothing for the transition out of school.

I felt I had failed as a therapist. Here was this amazing young man with many talents and strengths, and a proactive mother who wanted to do something to ensure her son became an autonomous and contributing member of society. However, there seemed to be no guidance on what to do to prepare Mark for leaving school. In one of the biggest transitions of this adolescent's life, everyone around him seemed stumped as to what to do. My experience working with Mark was what I thought of as I began my PhD journey in developing a transition planning program for adolescents on the autism spectrum.

# Chapter 1 INTRODUCTION

The purpose of this thesis was to develop and evaluate an autism-specific transition planning program to support adolescents to prepare for leaving school. Chapter 1 describes post-school outcomes for adolescents on the autism spectrum, provides an overview of current transition planning literature and outlines the need for an autism-specific transition planning program.

## 1.1 Post-school outcomes for people on the autism spectrum

In 2012 it was estimated that one in every 200 people had autism in Australia (0.5%), and that the prevalence of autism had increased by 79% between 2009 and 2012 (1). Autism is characterised by difficulties in socialisation, communication, and repetitive or restricted behaviours or interests, as outlined in the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5; 2). Autism represents a heterogeneous group of characteristics, including varied abilities and difficulties in the areas of cognitive functioning, sensory processing, attention, and executive functioning; i.e., problem solving or cognitive flexibility (3). People with autism have many strengths that are unique to each individual. For example, people with autism can have special knowledge and skills related to topics of interest, excellent memory recall, superior skills in pattern recognition, high levels of creativity, and a love of learning (4-6).

Unfortunately despite their strengths, adolescents on the autism spectrum often have difficulties transitioning to post-school activities, such as university and employment (7). Autism is one of the most common disabilities in Australia (1), yet people on the autism spectrum appear to be the group left behind when it comes to post-school outcomes. This may be because there is very little research focused on adolescents and adults on the autism spectrum, despite autism being a lifelong condition (8). The transition from school to adulthood has been described as a pivotal period of development in which adolescents form their identity and explore new adult roles; developing a sense of autonomy and finding a place in society (9).

Role transitions occur in three main areas: productivity, leisure, and socialisation (10). Difficulty with transitioning into these new roles can result in a lack of self-esteem and poor self-concept (11). Adolescents on the autism spectrum need support during the transition from school to negotiate their shift in roles; from student to employee, from child to adult (11). Regrettably, there is a gap in research related to effective interventions for this critical stage of development for people on the autism spectrum, resulting in less than ideal outcomes in many areas including employment, post-secondary education, socialisation, and independent living (12-14).

People on the autism spectrum often have characteristics that make them excellent employees, such as trustworthiness, reliability, low absenteeism (15, 16), exceptional focus on tasks and meticulous attention to detail (17), as well as an aptitude with technological devices (18). Adults on the autism spectrum have been recognised to excel in certain fields, such as software testing and research (5). However, they still face many challenges in gaining employment (19). As a result, the Australian labour force participation rate of people on the autism spectrum is low (42%) in comparison to young adults with other disabilities (53%) and people without disabilities (83%) (1). Even when adults on the autism spectrum do find work, they are often underpaid and underemployed for their education level, and report that they have less positive experiences at work than people without autism (13, 20). Many adults on the autism spectrum work in sheltered employment or as volunteers (12, 21). For adults on the autism spectrum without a diagnosis of intellectual disability (ID), employment outcomes obtained are generally lower than one would expect based on their intellectual functioning (22). Only 16% of young adults on the autism spectrum without ID in Australia were employed full-time after leaving school (23). In addition, this group are three times less likely to have any vocational activities compared to their peers on the autism spectrum who have an ID (24).

An additional barrier to employment for people on the autism spectrum is difficulties obtaining post-secondary education qualifications (22). This can limit career development, as obtaining a post-secondary qualification can increase success in gaining employment, improve earning potential, and provide career

advancement opportunities (25, 26). Only 19% of people on the autism spectrum in Australia report having completed a post-secondary degree, which is less than those with other disabilities and those without disability (1). In addition, the enrolment rate of people on the autism spectrum in post-secondary education in the United States of America (USA) is the third lowest when compared to 11 other disability groups (27). When young adults on the autism spectrum do attend post-secondary education, they can encounter challenges that have an adverse effect on their ability to complete their degree (22, 28, 29). Social anxiety can be exacerbated by loud and crowded common areas (28, 30), and difficulties may arise when managing multiple classes and competing demands (31). The disability services in post-secondary education institutions are generally more tailored towards people who have physical difficulties (32), and often do not support the specific cognitive, social, and communication needs of young adults on the autism spectrum (33).

Community participation is another area of difficulty for this group. Many young adults on the autism spectrum continue to require support after they leave school in the areas of self-care, communication, transport, and in cognitive and emotional activities (1, 21). Young adults on the autism spectrum experience a decline in social relationships after they leave school and often report isolation from support networks (34). They tend to engage in solitary leisure activities, such as computer use or watching television, in preference to social or community-based activities (34). Lack of friendships and community participation are likely to impact on the mental health of this group, as loneliness is associated with increased anxiety and depression, and decreased wellbeing amongst adults on the autism spectrum (35).

Overall, research indicates that young adults on the autism spectrum experience difficulties when transitioning to adult roles including employment, post-secondary education, independent living, and social relationships (36). One key area that may be contributing towards these poor post-school outcomes for this group is a lack of targeted and comprehensive transition planning (37).

## 1.2 Transition planning

Transition planning is a process that involves a coordinated set of activities to prepare adolescents for leaving secondary school and progressing to post-school activities, including vocational training, post-secondary education, and employment (38, 39). Transition planning involves engaging the adolescent in career exploration, goal setting, and activities that will increase their preparedness for leaving school. Transition planning can lead to improved self-determination, greater happiness, enhanced success in employment and post-secondary settings, and improved community participation (11, 40). The aim of transition planning is to support adolescents to successfully navigate the shift to adult roles that align with their strengths, needs, and goals (11). Milestones on the pathway towards a successful transition are developing a strong sense of self-knowledge, acquiring skills in areas of interest, and fostering an environment in which the adolescent perceives they have support from community resources (11, 38).

Transition planning for people with a disability has a long history (41); however, a turning point in transition planning came during the 1990s with the publication of findings from the National Longitudinal Transition Study of Special Education Students (NLTS) in the USA (42). The NLTS revealed that post-school outcomes for adolescents with disability were inferior to their peers without disabilities in multiple areas, including employment, post-secondary education, and independent living (42). Another seminal piece of work published in this decade was Kohler's taxonomy for transition planning (43). Kohler's taxonomy aimed to bridge the gap between research and practice by proposing five key areas for services to target in order to support the transition from school for adolescents with disability. Kohler's taxonomy, along with the findings of the NLTS, prompted reauthorisation of the Individuals with Disabilities Education Act (IDEA) in 2004 (44). The IDEA mandated that transition planning had to commence for all adolescents with disability in the USA by the age of 14 years, with subsequent goals developed and included in their Individualized Education Program (IEP; 44). The emergence of Kohler's taxonomy

and the legislative changes in the USA prompted an increased focus on transition planning research.

## **1.2.1 Core concepts for transition planning**

To summarise existing information related to transition planning, current literature was reviewed. Recurrent concepts related to transition planning for adolescents with disability were identified. Seven concepts emerged: 1) active involvement of adolescents; 2) external support; 3) structured transition program; 4) life skills; 5) community activities; 6) strengths-based career exploration; and 7) begin in early adolescence. Each concept was explored in relation to existing literature regarding adolescents on the autism spectrum.

### **1.2.1.1 Active involvement of adolescents**

Active participation of adolescents with disabilities in transition planning is considered best practice (43, 45-47). It has been linked to the development of self-awareness (11, 22), as well as improved post-school outcomes, increased self-determination, and higher expectations by parents and professionals (48). Many transition planning initiatives have been unsuccessful because the focus was on improving the system rather than empowering adolescents and their families to take action (49). Adolescent participation in transition planning can be enhanced through engagement in self-advocacy and self-determination training (50, 51).

Unfortunately, adolescents on the autism spectrum are less likely to be active participants in transition planning when compared to peers with other disabilities (52, 53). Only 77% of adolescents on the autism spectrum attended their transition planning meetings, and of those who attended meetings, almost half (45%) reported minimal participation (52, 53). In comparison, adolescents with other types of disabilities attended 80-95% of meetings and 69% were moderately involved in meetings (53). Barriers to active participation for adolescents on the autism spectrum are reported to be a lack of interest and limited opportunities for preparation before meetings (54). There is thus a need for research to identify methods of promoting active participation of adolescents on the autism spectrum.

### 1.2.1.2 External support

An important element of effective transition planning is having external support from family, peers, formal support services, and community members, such as neighbours and employers (37, 45). Adolescents report that one of the most important factors to support their success after school is having people around them who are willing to make accommodations for their specific needs (55). However, over-dependence on services should be avoided by providing integrated supports and through genuine relationships (49). Trusted relationships are a key to inspiring confidence in adolescents to try new things and engage in the process of change (49). A family-centred approach is recommended, wherein the family is viewed as the experts in all matters related to their children and they are empowered through a clear process and being provided choices throughout their transition journey (11). Family-centred practice has been demonstrated to lead to a greater level of satisfaction with overall outcomes (56) and improved post-school outcomes in employment, post-secondary education and independent living (50). Family involvement may be facilitated through methods such as flexibility with meeting times and access to conference calls if physical attendance is difficult (57).

Interagency collaboration involves cooperation between different services, such as schools, therapists and employment service providers, to support the adolescent with transition. Interagency collaboration has been correlated with post-secondary education attendance (51). Adolescents should be linked with post-school supports and therapy services as needed, such as speech pathology, psychology and occupational therapy (22, 58). Development of strong collaborations between families and services during the school years may create more durable partnerships that persist post-school. These partnerships can aid to address the decline of support that often occurs in the period after the adolescent leaves school (45). Unfortunately, there is a lack of evidence-based interventions to encourage collaborations between services, making interagency-support the least substantiated practice in transition planning (47, 50).

The characteristics of adolescents on the autism spectrum are diverse (3), meaning their post-school aspirations are widely varied and transition planning needs to be highly individualised (52). This can present a challenge to the educators and professionals who work with this group (37). For adolescents on the autism spectrum without ID, the education system tends to focus on academic performance rather than transition planning (45). As a result, these adolescents are often less prepared for the transition from school to work due to a limited opportunity to engage in work experience and job readiness interventions (45). In addition, adolescents on the autism spectrum without ID may not have support from employment service providers as they do not qualify for employment support services (37, 59). Even if they are fortunate to receive these services, unfortunately many service providers are not knowledgeable in the specific needs of people on the autism spectrum (19). Given adolescents on the autism spectrum receive less support, it is not surprising that their parents have reported feeling more worried about transition planning than parents of children with other disabilities (60). Consequently, there is a need for programs to ensure adolescents with autism have access to external supports (i.e., educators and employment services) to guide them through the transition planning program.

### **1.2.1.3 Structured transition program**

Having a structured transition program is recommended to provide families and adolescents with a process to follow (57). Engaging in a structured transition planning process is a predictor of success in employment post-school (medium effect size, .46) (51). It is also a predictor of increased engagement in post-secondary education (small to large effect size, .26 to .61) (51). Transition planning should include goal setting, which increases engagement in transition planning and has been linked to greater post-school success (46) and increased self-determined behaviour (48). Providing opportunities for adolescents to set and actively work on achieving goals is linked to greater engagement in transition planning meetings (46). Recommended goal-areas include: social skills, leisure, home skills, and employment-readiness skills related to transition (22).

A structured transition program is likely to assist adolescents on the autism spectrum in managing changes in routine, which can cause anxiety for this group (37, 61). In contrast, a lack of structure in transition planning is likely to exacerbate anxiety as there are various shifts in roles and routines that occur during the transition out of school (37). In addition, young adults on the autism spectrum report that although they have goals for the future, they are often unsure of what steps they need to take to achieve them (62). Therefore, a structured program may reduce anxiety and support goal setting for adolescents on the autism spectrum, allowing successful navigation of the transition planning process. Furthermore, it is likely that adolescents on the autism spectrum need a structured transition program that is specialised to their needs. Results from the second National Longitudinal Transition Study (NLTS-2) indicated that even though transition planning recommendations are met for the majority of adolescents with disabilities, people on the autism spectrum are still achieving poorer outcomes (53, 63). Transition planning outcomes for adolescents on the autism spectrum appear to be worse than for other groups (52). An autism-specific transition planning process may better support the unique needs of this group.

#### **1.2.1.4 Life skills**

Life skills are an important prerequisite to finding and keeping a job (45, 51). Skill areas relevant to the transition planning process include activities of daily living (e.g., dress and hygiene), community access/transport and self-advocacy (57). Teaching life skills to adolescents with disability has a moderate to strong level of evidence supporting its efficacy (47). There is a need for a 'citizen focused curriculum' in which attention shifts from teaching academic skills to life skills that are integral in becoming a functioning member of society, such as planning for living out of home and getting a job (49). Adolescents with a disability should also be supported to develop employment-related skills, such as problem-solving, time-management, interviews and job-searching (45).

People on the autism spectrum face unique challenges in socialisation and communication (45). They may encounter difficulties in post-school activities that

originate from navigating the social and emotional demands of the tasks, such as group work or lunch room discussions, rather than problems with actual task performance (15). This can lead to difficulties obtaining employment through poor interview performance, or potential job dismissal for social communication issues; i.e., not understanding instructions, asking too many questions or difficulty with understanding tone of voice and non-verbal cues (19). Consequently, transition planning for adolescents on the autism spectrum should include the teaching of social skills and emotional regulation strategies to promote success in post-school settings.

### 1.2.1.5 Community activities

Community-based experiences are important for supporting adolescents with disabilities to learn employment related skills in their natural environment (47, 57). Community activities can include volunteering, part-time jobs, or apprenticeships (45, 58). Community experiences are linked to improved levels of employment (medium effect size, .39) (51). Paid or unpaid work experience has been described as the most substantiated practice in transition planning that assists adolescents to get employment (50). Adolescents may benefit from on-the-job support whilst engaging in work-experience or part-time work to support the development of job related skills (57). A mentor can provide adolescents with a positive adult role model to assist them to problem solve difficult situations (55). Community activities support adolescents to develop life skills, resilience, and social skills (11). These activities also support the development of self-determination, providing the opportunity for risk-taking and problem solving (64). Indeed, engaging in community experiences has been found to be more effective than school-based skills training because it assists in the generalisation of skills (11).

Many adolescents on the autism spectrum are not participating in community activities that can teach them life and employment skills (37). In the USA, only 14% of adolescents on the autism spectrum at school had paid part-time work and only 1% had an apprenticeship or internship (65). The lack of participation in community

activities amongst adolescents on the autism spectrum needs to be explored further, given the importance of these activities in preparing adolescents for leaving school.

#### **1.2.1.6 Strengths-based career exploration**

Strengths-based career exploration assists adolescents to identify their assets and interests that they can then leverage into potential careers (45). Interest inventories and informal strengths assessments are recommended to assist adolescents to identify their strengths and develop career awareness (54, 57). In addition, experiences such as job fairs or open days for post-secondary education are important in exploring a diverse range of career options and making community connections (45). Career exploration strategies assist adolescents to decide on a career path (39). Increased career awareness has been linked to improved outcomes in post-secondary education and employment (small effect sizes, .27 and .23) (51). Alongside career exploration, adolescents should be supported to develop an in-depth understanding of their strengths and capabilities. A strong sense of self-knowledge is linked to an improved ability to self-advocate (39, 58). Focussing on strengths improves self-determination and supports high expectations (51).

Leveraging strengths is particularly important for individuals on the autism spectrum, who have many strengths that could be considered unique assets to potential employers (45). Focusing on strengths rather than weaknesses is particularly important for this group, due to their vulnerability to developing anxiety and depression in adolescence (66). Whilst the reasons for this are complex, focusing on strengths may support the development of resilience and boost self-esteem (67).

#### **1.2.1.7 Begin in early adolescence**

As mentioned, the IDEA (2004) in the USA mandated that formal transition planning in schools for adolescents with disabilities should commence at 14 years of age (44). However, only a few studies addressed the issue of an exact time to start transition planning, with two studies providing support that transition planning should start when adolescents with disabilities are 14 years old (46, 54). One study suggested that informal planning should start between the ages of 10 and 13 years, with more

formal transition planning starting in middle teenage years (22). Prior studies have described how transition planning generally begins too late for adolescents with disabilities, with one study providing a colourful description of the current situation; “actual decisions were made in a mad scramble in the summer when school was already at an end” (p308, 49). The age that transition planning begins for adolescents on the autism spectrum has not been explored in the literature as of yet.

### 1.3 Existing transition planning interventions

There are numerous school-based transition planning interventions for adolescents with a disability, and a number of systematic and literature reviews have been published on this topic (38, 68-70). In this section, existing career and transition planning programs for adolescents with disability were critically reviewed to determine their relevance to adolescents on the autism spectrum.

The majority of existing transition planning interventions have been developed for adolescents with a disability in general, and are not autism-specific. A systematic review that aimed to identify autism-specific transition planning interventions that improved employment outcomes did not find any studies that met their inclusion criteria (68). Another systematic review looking at transition planning for adolescents with disabilities in general identified 31 studies (38). Fourteen were qualitative, describing experiences related to transition planning. Seventeen were quantitative studies that described transition planning interventions, none of which are autism-specific. Most studies utilised a pre-test/post-test design without randomisation and did not have a control group. Overall, this systematic review concluded that higher level studies are needed to determine the efficacy of interventions, and more emphasis needs to be placed on interagency collaboration and program structure (38).

A meta-analysis of interventions that taught self-determination skills to adolescents with disabilities identified 22 studies in this area (70). The review concluded that adolescents with disabilities can learn self-determination skills, which can subsequently impact on post-school outcomes. The authors found that most

existing research focused on adolescents with intellectual and learning disabilities, and stated the need for interventions for adolescents on the autism spectrum. Recommendations included that future interventions should focus on creating opportunities for self-determined behaviour in the home and school environments (70).

A literature review of interventions that aim to enhance student participation in IEP meetings found 16 qualitative and quantitative studies (69). All interventions were targeted at adolescents with a disability in general. The review identified a number of programs that have found positive outcomes related to student participation in IEP meetings; for example, the *Whose Future Is It Anyway?* program, which was found to enhance self-determination in a randomised controlled trial (N=493) (71). However, it concluded that there is a need for programs that include parents in the transition planning process. In addition, future transition planning programs should look at the impact of the intervention on the adolescents' everyday lives.

A number of transition planning interventions were identified that were not included in the aforementioned reviews. The *Life Centered Career Education* curriculum consists of teacher-led lessons aimed at teaching adolescents life skills and providing occupational guidance (72). The curriculum was found to improve vocational identity for the adolescents with disabilities, however the sample size was small (N=38), and the study had a control group that consisted of adolescents who did not have disabilities, introducing potential confounding factors. The *Choices-in-Transition Intervention*, aims to develop goal-setting and help-recruiting skills in adolescents with disabilities via teacher-led modules (73). The intervention resulted in significant differences in students' help-recruiting skills, however the study did not have a control group and had a small sample size (N=41). The *Student-Directed Transition Planning* (74) and *MY VOICE* (75) programs both utilised teacher-led modules to teach students with disabilities skills related to leadership in IEP meetings. Both were found to have positive outcomes, however, the outcome measures used to assess the *Student-Directed Transition Planning* program were developed by the researchers and had not been validated (74). In addition, the *MY*

VOICE program was evaluated by asking participants to recall pre-test outcomes three years after the project commenced, which introduced recall bias (75).

Two existing programs have been developed specifically for adolescents on the autism spectrum. The *Putting Feet on My Dreams* program consists of teacher-led modules to improve self-determination (76). The program was evaluated using interviews in a pre-post design (N=23), in which some participants reported benefits related to self-knowledge, communication and planning. The second program aims to prepare adolescents for leaving school through structured meetings with planners (14). A randomised controlled trial (N=47) identified that the intervention group had superior expectations for the future and self-determination, but these differences were not maintained at the one year follow-up. While both these studies provide preliminary evidence, they had methodological limitations, such as small samples (14, 76) and evaluating the program with a qualitative approach (76). In addition, both studies targeted adolescents aged 16 years and older, which is an older cohort than recommended by current literature.

## 1.4 Summary of introduction

The discrepancy in post-school outcomes for adolescents on the autism spectrum suggest that the transition planning process needs to be autism-specific. Whilst there is a significant body of research describing elements of high-quality transition planning for adolescents with disability in general, there is very limited evidence exploring the specific needs of adolescents on the autism spectrum (37). It should be noted that there is some emerging literature providing valuable recommendations to support the transition for adolescents on the autism spectrum (22, 37, 39, 45). However, due to the limited availability of autism-specific studies, recommendations are often based on literature that focuses on people with disability in general. In addition, there are a number of existing transition planning programs for adolescents with disability that demonstrate encouraging outcomes (14, 38, 69, 71, 74-76). However, the majority of these interventions are not autism-specific and focus on specific skills (e.g. self-determination or job readiness) rather than the entire transition planning process. Many of the studies evaluating these

interventions have methodological limitations. The lack of a control group reduced internal validity (73, 75, 76), or a small sample size increased the risk of Type 2 error (14, 76). Some studies utilised outcome measures that were not validated (74, 77). Furthermore, all existing transition planning programs have been developed and trialled in the USA. To the author's knowledge, there are no existing transition planning interventions related to adolescents on the autism spectrum conducted in the Australian context. Thus, there is a need for research that is specific to an Australian context because of the legislative differences between countries. In Australia, transition planning is encouraged, but not legislated. Education and disability services in Australia are governed by each individual state and territory, making it difficult to implement best practice transition planning procedures across the country. Therefore, there is a need for an autism-specific transition planning program for use within the Australian context.

## 1.5 Overall aim

The overarching aim of the thesis was to develop and evaluate an autism-specific transition planning program for the Australian context.

## 1.6 Thesis structure

This thesis consists of three traditional chapters; *Chapter 1 Introduction*, *Chapter 3 Frameworks*, and *Chapter 8 Discussion and Conclusion*. The *Introduction* and *Discussion and Conclusion* chapters bookend the six individual studies that make up the content of the thesis. The *Frameworks* chapter provides an overview of the three frameworks that were chosen to underpin the development of the BOOST-A™. The studies are presented in the form of peer-reviewed journal manuscripts. References are included at the end of each chapter.

As developing a program to promote behavioural change can be a complex and multistage process, the PRECEDE-PROCEED Planning Model (PPM; 78) was used to guide the development of the transition planning program. The PPM provides a guide for the development and evaluation of programs that promote behavioural

change. It ensures programs are evidence-based and meet the needs of the target group (79). The PPM has been used previously to develop successful interventions (80, 81). The PPM breaks the program development process into two main parts; planning and evaluation (82). The first part of the PPM is PRECEDE, which guides the planning of the intervention. This stage involves identifying the needs of the target group and factors that will support effective implementation of the intervention (78). The second part of the PPM model is PROCEED, which guides the implementation and evaluation of the intervention (83).

The development of the program took part in three discrete phases. Figure 1-1 provides an overview of the thesis in these three phases, and how this related to the PPM framework.

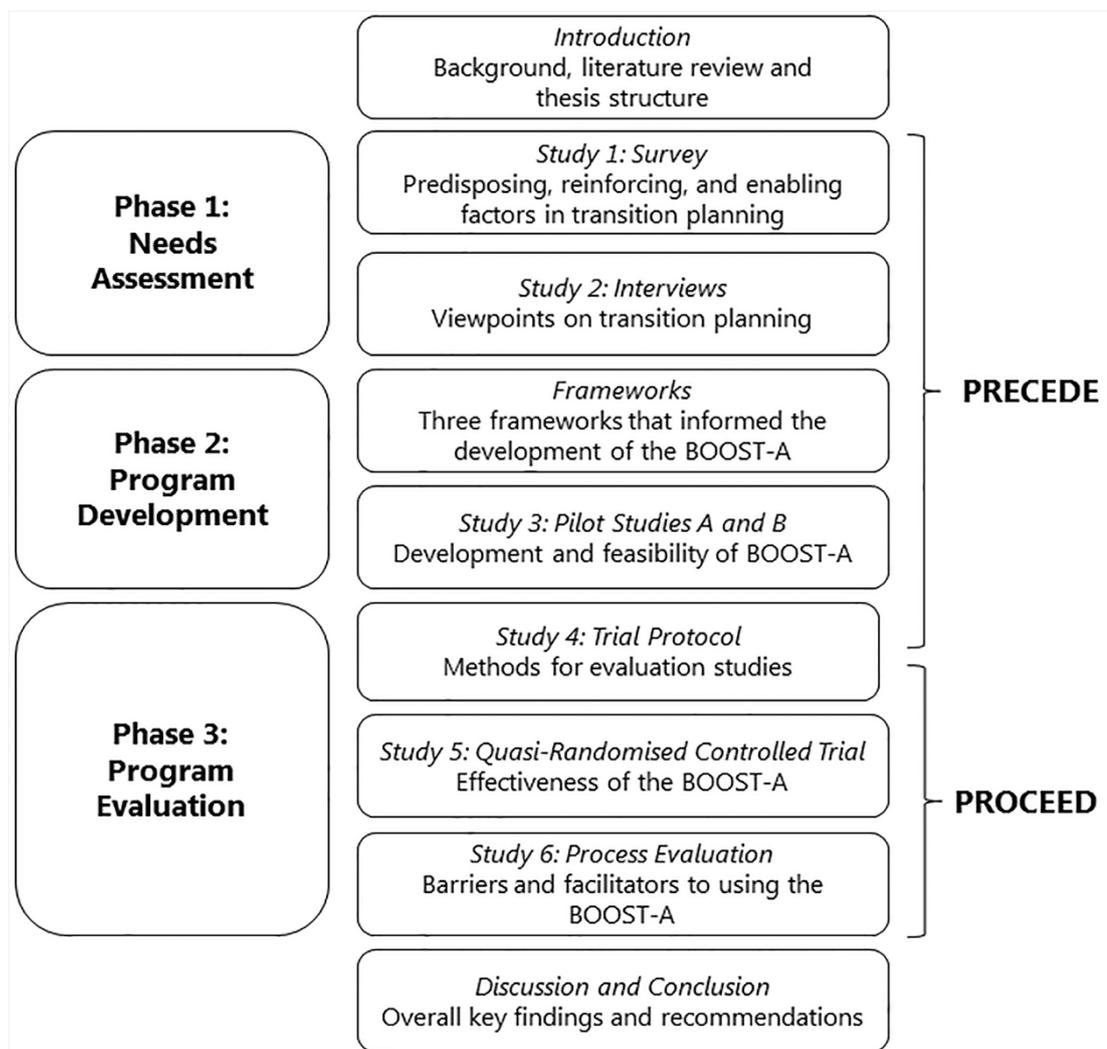


Figure 1-1. Overall structure of thesis

### **1.6.1 Phase 1: Needs Assessment**

Phase 1 identified autism-specific objectives related to transition planning. This phase was part of the PRECEDE stage of the PPM, in which a needs assessment was conducted to determine the issues that have a major impact on the population of concern (84). The needs assessment consisted of a survey and interviews that identified factors related to successful transition planning for adolescents on the autism spectrum (78).

The results from Phase 1 are described in Chapter 2, addressing the following research objectives:

1. Determine the predisposing, reinforcing, and enabling factors that impact on successful transition for adolescents on the autism spectrum.
2. Identify viewpoints related to autism-specific needs in transition planning from the perspective of parents and professionals.

### **1.6.2 Phase 2: Program Development**

Phase 2 was the development of the transition planning program, the Better Outcomes & Successful Transition for Autism (BOOST-A™). Phase 2 contributed to the PRECEDE stage of the PPM. This phase consisted of two pilot studies to determine the feasibility of the program, and to provide formative and process feedback to enhance the usability of the program.

The results from Phase 2 are described in Chapters 3 and 4. The research objective associated with this phase was to:

3. Develop the BOOST-A™ and determine its feasibility and viability for use with adolescents on the autism spectrum to prepare them for leaving school.

### **1.6.3 Phase 3: Program Evaluation**

The final phase of the thesis aimed to determine the efficacy of the program, based on the PROCEED component of the PPM. A quasi-randomised controlled trial aimed to determine the effectiveness of the BOOST-A™ in enhancing self-determination. In

addition, a process evaluation was conducted that utilised interviews to explore participants perceptions of the barriers and facilitators to using the BOOST-A™.

The results from Phase 3 are described in Chapters 5, 6 and 7, addressing the following research objectives:

4. Determine the effectiveness of the BOOST-A™ in improving self-determination; quality of life; access to environmental supports; career planning and exploration; and domain-specific self-determination among adolescents on the autism spectrum.
5. Describe the perceptions of adolescents on the autism spectrum and their parents regarding the effectiveness and usability of the BOOST-A™, and the barriers and facilitators to using the program.

An Honours project was conducted alongside this thesis, led by Miss Nina Murray. A systematic review was conducted as part of the Honours project that identified existing career planning tools for use by adolescents on the autism spectrum. It is located in Appendix A, and was published in *Research in Autism Spectrum Disorders* in 2016. The Honours student was supervised by Megan Hatfield, Torbjörn Falkmer, Marita Falkmer, and Marina Ciccarelli.

## 1.7 References

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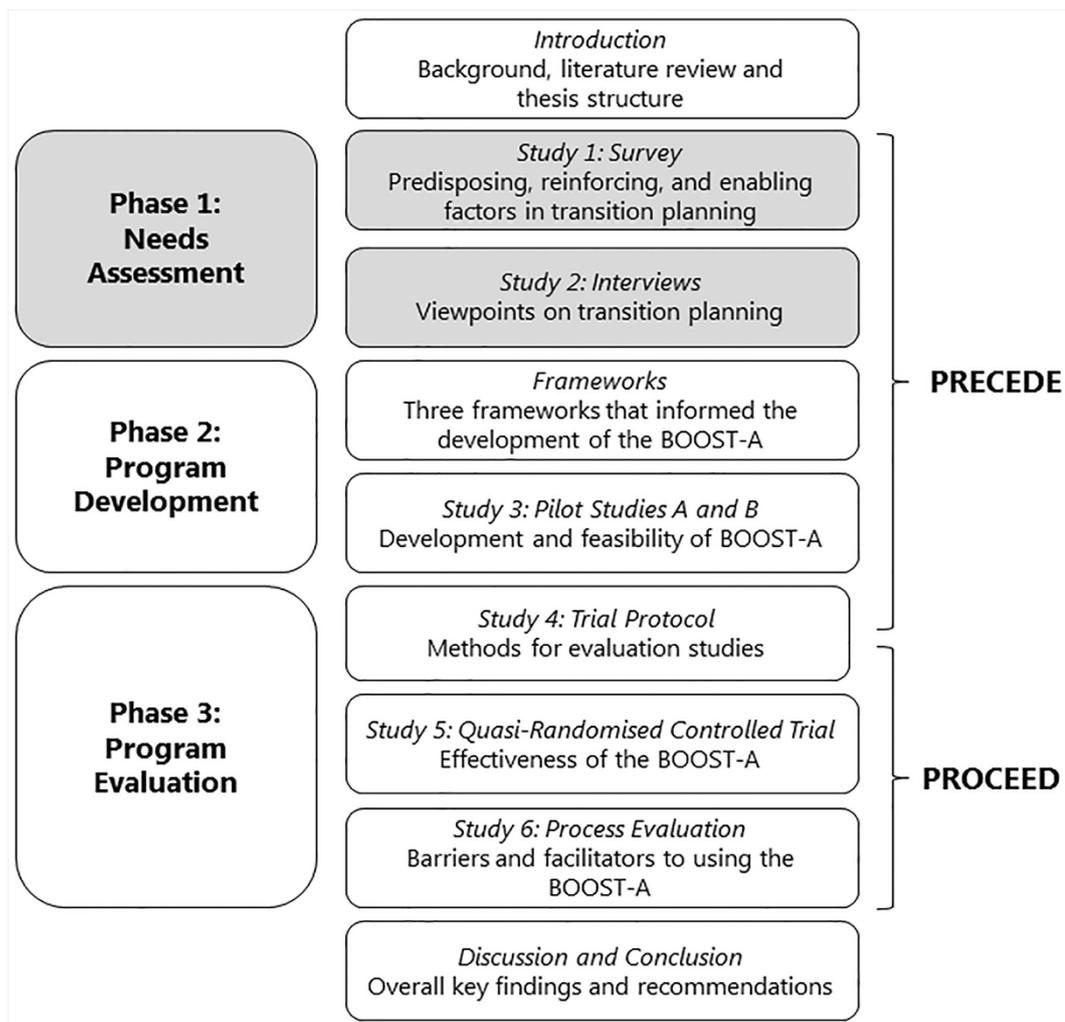
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# Chapter 2 NEEDS ASSESSMENT

Chapter 2 outlines the findings from Phase 1 of the thesis, the needs assessment. Two studies were conducted as part of the needs assessment. Study 1 was a survey of adolescents on the autism spectrum, parents, and professionals that described factors associated with successful transition planning. Study 2 presents the results of interviews with parents and professionals to obtain their views on preparing adolescents on the autism spectrum for the transition from school. Together, these studies identified autism-specific needs in relation to transition planning. Results of the needs assessment informed the development of transition planning objectives for adolescents on the autism spectrum. These objectives were used to develop the transition planning program in Phase 2 of the thesis.



Study 1, the survey, was accepted for publication on 15 February 2017, and has been published as:

**Hatfield M, Ciccarelli M, Falkmer T, Falkmer M. Factors related to successful transition planning for adolescents on the autism spectrum. JORSEN. 2017; Early online view. doi:10.1111/1471-3802.12388**

The **post-print** of the article has been included in the thesis as a typescript.

The final publication is available via <http://dx.doi.org/10.1111/1471-3802.12388>

Study 2, the interviews, was accepted for publication on 27 October 2016, and has been published as:

**Hatfield M, Falkmer M, Falkmer T, Ciccarelli M. "Leaps of faith": Parent and professional viewpoints on preparing adolescents on the autism spectrum for leaving school. JORSEN. 2017; 17(3):187-197. doi:10.1111/1471-3802.12377**

The **post-print** of the article has been included in the thesis as a typescript.

The final publication is available via <http://dx.doi.org/10.1111/1471-3802.12377>

# Study 1: Survey

## **Author Contribution Statement**

As co-authors of the paper entitled, '*Factors related to successful transition planning for adolescents on the autism spectrum*', we confirm that Megan Hatfield 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; and
- 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 collection, analysis, and interpretation; and
- Review and editing of the manuscript.

*Signed:* Torbjörn Falkmer Date: 25/05/17

*Signed:* Marina Ciccarelli Date: 25/05/17

*Signed:* Marita Falkmer Date: 25/05/17

# Factors related to successful transition planning for adolescents on the autism spectrum

Megan Hatfield<sup>1,2,\*</sup>, Marina Ciccarelli<sup>1,2</sup>, Torbjörn Falkmer<sup>1,2,3</sup> and Marita Falkmer<sup>1,2,4</sup>

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Perth, Western Australia, Australia

<sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia

<sup>3</sup> Department of Medicine and Health Sciences (IHM), Linköping University and Pain Rehabilitation Centre, Sweden

<sup>4</sup> School of Education and Communication, Institution of Disability Research Jönköping University, Sweden

\* Corresponding author

## 2.1 Abstract

**Introduction:** Adolescents on the autism spectrum often have difficulties with the transition from high school to post-school activities. Despite this, little is known about the transition planning processes for this group. This study explored predisposing, reinforcing, and enabling factors related to the transition planning processes for adolescents on the autism spectrum in Australia.

**Methods:** The PRECEDE model guided a needs assessment, in which descriptive data about transition planning processes were collected via an online questionnaire from adolescents on the autism spectrum, their parents, and professionals (N=162).

**Results:** Predisposing factors included: an individualised and strengths-focused approach, and adolescent motivation, anxiety and insight. Reinforcing factors included: support and guidance, skill development and real-life experiences. Enabling factors were: having a clear plan with a coordinated approach, scheduled meetings and clear formal documentation.

**Discussion:** Whilst some factors aligned with transition planning recommendations for adolescents with disabilities in general, there were some autism-specific factors. For example, anxiety, motivation, and insight were important predisposing factors, and providing choice and flexibility were enabling factors.

**Key words:** Asperger syndrome, Child development disorder, Pervasive developmental disorder, Employment, Vocational education, College, University, Career planning and development.

## 2.2 Introduction

A key priority of the Australian National Disability Strategy 2010-2020 is increased workforce participation for people with disabilities (1). Unfortunately, people on the autism spectrum are a group left behind; they have lower employment rates (42%) than people with other types of disabilities (53%), and people without a diagnosed disability (83%) (2). Adolescents on the autism spectrum are also significantly less likely to attend post-secondary education and training than other disability groups (44%,  $p < 0.021$ ) (3). Most adults on the autism spectrum continue to live at home after leaving school, and those that do move out of home often require continued support by their parents (4). In addition, people with autism often experience a decline in their social relationships after leaving school and mostly engage in solitary leisure activities (4). Interestingly, people on the autism spectrum without an intellectual disability (ID) are three times less likely to engage in post-school activities when compared to people with autism who have an ID (5). The poorer outcomes for this group are likely due to a number of reasons. They may not qualify for employment or study support programs (6) and face unique difficulties with transitions, social skills and emotional regulation (7).

A common barrier to improving post-school outcomes for adolescents on the autism spectrum is a lack of quality transition planning (8). Transition planning involves a set of coordinated activities that support adolescents in secondary school to successfully negotiate the move from school into adult life (9, 10). It includes preparation for the transition to employment, post-secondary education and vocational training (10). Transition planning has been found to improve self-determination, employment rates, post-secondary education completion, happiness, and participation in the community (11). Currently, the focus of schools is on the academic performance of adolescents on the autism spectrum, rather than engaging in comprehensive and autism-specific transition planning (12). Even when transition planning requirements are met for adolescents with autism, their outcomes are still inferior to their peers with other disabilities (3). This indicates that transition planning practices for adolescents on the autism spectrum need to be further

explored (8, 13). Studies have found that up to 23% of adolescents with autism are not involved in transition planning at all, and even when afforded the opportunity to be involved in transition planning, they were less likely to be described as active participants than students in other disability groups (14). This suggests that adolescents with autism may have specific transition planning needs that are not being met.

Whilst there is a large amount of research describing elements of high-quality transition planning for adolescents with disabilities in general (9, 11, 15-17), evidence that is specific to adolescents on the autism spectrum is less prolific (12, 18, 19). Furthermore, autism-specific recommendations are often inferred from general studies about adolescents with disabilities, introducing the risk that important elements are missed. More research is required to determine the transition planning needs specific to adolescents on the autism spectrum (12).

### 2.2.1 The PRECEDE model

Identifying intervention needs for a specific population is a complex process, hence it is beneficial to have a framework to guide this process (20). The PRECEDE model provides such a framework; it describes a number of phases that allow for the systematic application of theory and in the development of interventions (21). The PRECEDE model has been used in previous studies to identify the intervention needs of specific groups (22, 23).

One of the key phases in the PRECEDE model is conducting a comprehensive needs assessment to identify factors relevant to the target group (24). The model describes three groups of factors that influence the outcome of interest: predisposing, reinforcing, and enabling factors (21). *Predisposing factors* are cognitive mindsets or ways of thinking that bring about behaviour, including knowledge, attitudes, and self-efficacy (25). *Reinforcing factors* promote and reward continued engagement in behaviour; for example, social support, external incentives, or peer influences (25). Finally, *enabling factors* are external and environmental conditions that impact on people's ability to adopt behaviours, such as accessibility of services, availability of resources, and policies (21).

## 2.2.2 Aim

The primary aim of the current study was to conduct a needs assessment to determine the predisposing, reinforcing, and enabling factors that impact on successful transition for adolescents on the autism spectrum. A secondary aim was to link these factors to perceptions of current and ideal transition planning processes.

## 2.3 Methods

### 2.3.1 Participants

Purposive sampling was utilised to obtain multiple perspectives from three independent groups:

- adolescents or young adults on the autism spectrum without ID, who were in years 9-12 in high school or who had finished high school in the past five years;
- parents/carers of adolescents who fit the above criteria; and
- professionals who worked with adolescents on the autism spectrum in transition planning.

The groups were key stakeholders in the transition team, and collaboration between these groups is recommended in transition planning (9, 26, 27).

### 2.3.2 Recruitment procedure

Participants were recruited via e-mails distributed to families with a child on the autism spectrum through a variety of sources across Australia, including schools (mainstream, education support, public and private schools); support networks for people with autism and their families; and autism-specific associations or organisations. Professional participants were recruited via e-mails sent out to organisations that provide services for people with disabilities and disability support services at universities throughout Australia.

### 2.3.3 Data collection instrument

An online questionnaire was developed with Qualtrics software (Version 2013; 28) and used to collect data. The questionnaire utilised both closed- and open-ended questions to gain insights and “give voice” into the perspectives of the adolescents, their parents, and professionals critical to improving transition planning (29).

Questionnaire content was based on the results of a systematic review (30), and further developed through consultation with a community reference group comprised of three stakeholder groups: young adults on the autism spectrum, parents/carers, and professionals (31). Language and content of the questionnaire was tailored for each of the groups. The questionnaire was pilot tested with 10 people (including young adults with autism, parents and professionals) prior to administration to ensure feasibility for each group.

The questionnaire comprised of three sections:

1. **Demographic information.** Participants were asked to provide demographic details, such as gender, residential postcode, and diagnosis. Questions were developed based on a previous questionnaire conducted at Curtin University in Western Australia (32), and Australian Bureau of Statistics questionnaires measuring the demographics of children and families (2).
2. **Current and ideal transition planning.** Participants answered questions about their experiences with transition planning (i.e., the current situation) and what they would prefer to happen (i.e., the ideal situation). Participants were asked about the following aspects of transition planning: the school year that transition planning starts; composition of the transition planning team; team coordinator; transition planning assessment; frequency of transition planning meetings; documentation of the transition plan; and transition planning activities.
3. **Barriers and enablers in transition planning.** Participants were invited to describe the ‘most helpful’ and ‘most challenging’ aspects to transition planning using open-ended responses.

See Supplemental materials (Appendix B) for the full parent version of the questionnaire.

### 2.3.4 Data analyses

Data related to current and ideal transition planning were analysed using the Statistical Package for the Social Sciences (SPSS v.20; 33). Given that the stakeholder groups were independent (not related), data were analysed at the group level. The questionnaire data were de-identified, and descriptive statistics were used to summarise participants' responses regarding current transition planning processes and what they would ideally like. A new dichotomous variable for each item was created to denote whether there was a match between current and ideal transition planning processes or a gap from the perspectives of each stakeholder group. Generalised estimating equations (GEE) modelling was performed to determine whether participants' responses about their ideal for transition planning matched their current experiences. The results of the GEE modelling are reported using odds ratios (OR), 95% confidence intervals (95% CI), and p values. Kruskal Wallis tests were performed to determine if there was a difference between stakeholder groups with regard to matches or gaps between current experiences in transition planning and their perceptions of the ideal. The level of significance for all statistical tests was  $p < 0.05$ .

Qualitative responses from each stakeholder group were independently coded by two researchers to enhance credibility of results (34). Responses were read, coded, and then re-coded as needed, using principles of constant comparison within and between the responses (35, 36). This resulted in a number of different emergent themes for each group related to the predisposing, reinforcing, and enabling factors described in the PRECEDE model (25). The themes were then compared and contrasted between each stakeholder group.

### 2.3.5 Ethical considerations

Approval to conduct the study was granted by the Curtin University Human Research Ethics Committee (approval number HR110/2014) in Western Australia (WA), the Catholic Education Office of WA, and the Department of Education WA. Participants received an email that included a participant information sheet and the electronic link to the online questionnaire. Participants provided informed written

informed consent by replying in the affirmative to the first question of the questionnaire. Skip-logic was utilised to ensure that only those participants who provided informed consent could access and complete the remainder of the questionnaire. There is increasing recognition of the importance of including adolescents and young adults on the autism spectrum in research, with a growing body of work in this area (37). In this study, it was crucial to ensure the perspectives of adolescents were considered in how to improve the transition planning process. Ethical concerns for this group were taken into consideration, as informed participation for adolescents on the autism spectrum may be compromised due to difficulties with communication and social understanding that accompany the diagnosis (38). To ensure ethical standards were upheld, participants under 18 years of age provided informed assent and their parents provided informed consent for their participation. In the information forms, the direct relevance of the research to adolescents on the autism spectrum was outlined for participants, as recommended for this group (39). In addition, the language used in the information and consent forms was tailored to support adolescents understanding of the project as recommended for this population (38), and this was approved by the aforementioned ethical committees.

## 2.4 Results

### 2.4.1 Demographics

One hundred and sixty-two participants completed the questionnaire including 83 parents, 26 adolescents on the autism spectrum, and 53 professionals. As shown in Table 2-1, 73% of adolescents on the autism spectrum were male; 50% had left school and the other 50% were still attending school. Parent participants were mainly female (83%) and most had children who were still attending school (70%). Socio-Economic Indexes for Areas (SEIFA) deciles were used to determine relative socio-economic advantage and disadvantage of participants (40). SEIFA deciles range from 1 to 10, where 1 indicates that a participant resides in an area within the lowest 10% of socio-economic advantage, and so on up to 10 which indicates the participant resides in an area within the highest 10% of socio-economic advantage.

The majority of adolescents and parents were in the top two SEIFA deciles - 35% and 40%, respectively. The adolescents and parents were mainly from Western Australia - 88% and 83%, respectively. Some adolescents and parents had not commenced transition planning yet, and thus only answered the questions about their perceptions of the ideal transition planning process. Therefore, there were fewer responses to questions about the current transition planning experiences than to questions about the ideal process.

**Table 2-1. Demographics of participating parents (n = 83) and adolescents on the autism spectrum (n = 26)**

Characteristic		Parents n (%)	Adolescents on the autism spectrum n (%)
Gender	Male	14 (16.9)	19 (73.1)
	Female	69 (83.1)	7 (26.9)
Child's Year at School	Year 7	1 (1.2)	0 (0)
	Year 8	2 (2.4)	0 (0)
	Year 9	16 (19.3)	3 (23.1)
	Year 10	17 (20.5)	5 (19.2)
	Year 11	9 (10.8)	2 (7.7)
	Year 12	8 (9.6)	3 (11.5)
	Left school	30 (36.1)	13 (50)
Socio- economic Status (SEIFA)	1-6	35 (42.2)	8 (30.7)
	7-8	12 (14.4)	7 (26.9)
	9-10	33 (39.8)	9 (34.6)
	Did not provide postcode	3 (3.6)	2 (7.7)
State	New South Wales	1 (1.2)	2 (7.7)
	Australian Capital Territory	0 (0)	0 (0)
	Victoria	3 (3.6)	0 (0)
	Queensland	4 (4.8)	0 (0)
	South Australia	1 (1.2)	0 (0)
	Western Australia	69 (83.1)	23 (88.4)
	Tasmania	1 (1.2)	0 (0)
	Northern Territory	1 (1.2)	0 (0)
	Did not provide State	3 (3.6)	1 (3.8)

The majority of professionals were female (87%); held the roles of Disability Employment Coordinators/Officers (36%), therapists (26%), and teachers/lecturers

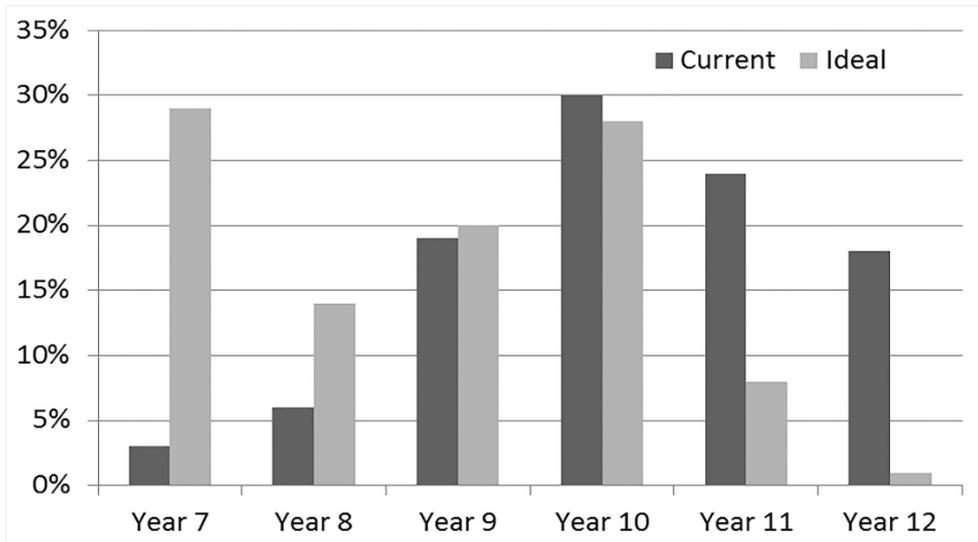
(19%); and had more than five years of experience working with people on the autism spectrum (51%), as shown in Table 2-2.

**Table 2-2. Demographics of participating professionals (n = 53)**

Characteristic		Professionals n (%)
Gender	Male	7 (13.2)
	Female	46 (86.8)
Profession	Disability Employment Coordinator/Officer	19 (35.9)
	Local Government Disability Coordinator	4 (7.5)
	Therapist	14 (26.4)
	Teacher/Lecturer	10 (18.9)
	Other	6 (11.3)
	Experience in Current Profession	0-5 years
	6-10 years	14 (26.4)
	11-15 years	4 (7.5)
	16-20 years	3 (5.7)
	20+	6 (11.3)
Organisation	School	9 (17)
	Disability Service	22 (41.5)
	Employment Service	14 (26.4)
	Private Organisation	4 (7.5)
	Other	4 (7.5)

## 2.4.2 Year that transition planning starts

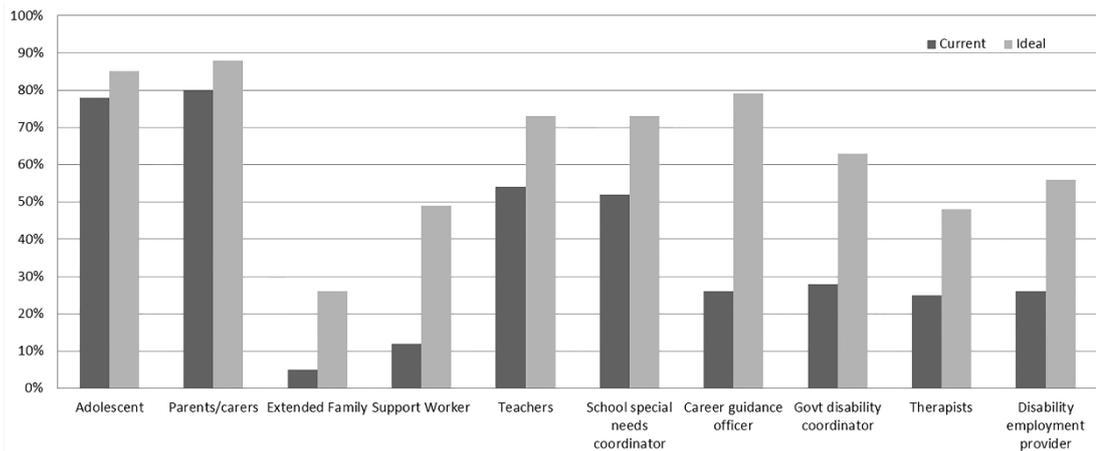
Participants identified the school year in which transition planning currently started and when they thought it should ideally start (Figure 2-1). Most adolescents on the autism spectrum reported they started transition planning in Year 10 or later (72%). There was no consensus on the ideal school year in which to start transition planning; however, Years 7 and 10 were the most popular across all groups (29% and 28%, respectively). There was a mismatch or gap between the current and the ideal school year to start transition planning reported across all groups; with 65% of participants reporting they would have liked transition planning to start earlier. No between-group differences were found ( $p > .05$ ).



**Figure 2-1. Year to start transition planning (all groups, current n = 95, ideal n = 121)**

### 2.4.3 Transition planning team

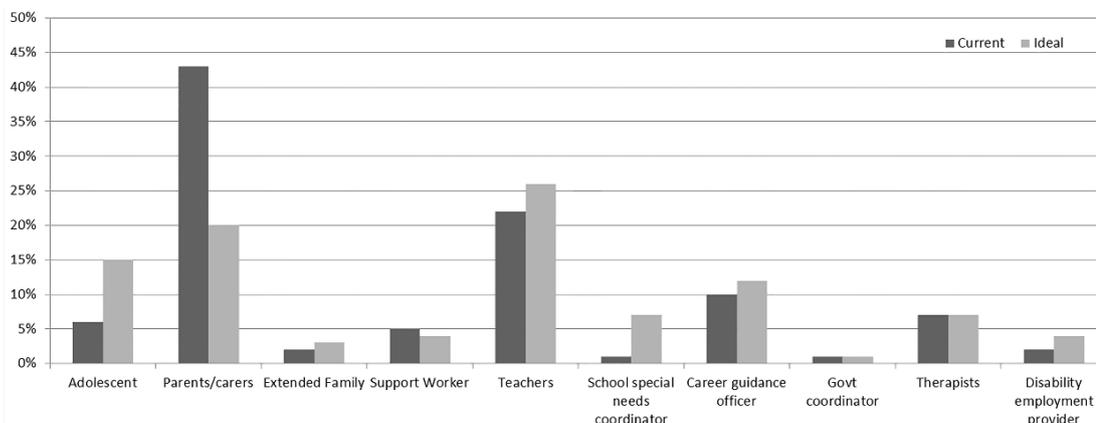
Participants identified the people who were currently in the transition planning team, and who they thought should ideally be in the team (Figure 2-2). Seventy-eight per cent of participants reported the adolescent was currently in the team, and 84% believed the adolescent should ideally be on the team. Similarly, 80% reported that parents were currently in the team and 87% believed the parent should ideally be on the team. There was no consensus among all stakeholders with regard to the ideal composition of the transition planning team. The proportion of professionals who believed there was a gap between the current and ideal team composition (80%) was significantly higher than the adolescents (52%; OR=2.7, 95% CI=1.3-5.5, p=.006).



**Figure 2-2. Transition planning team members (all groups, current n = 95, ideal n = 121)**

### 2.4.4 Team coordinator

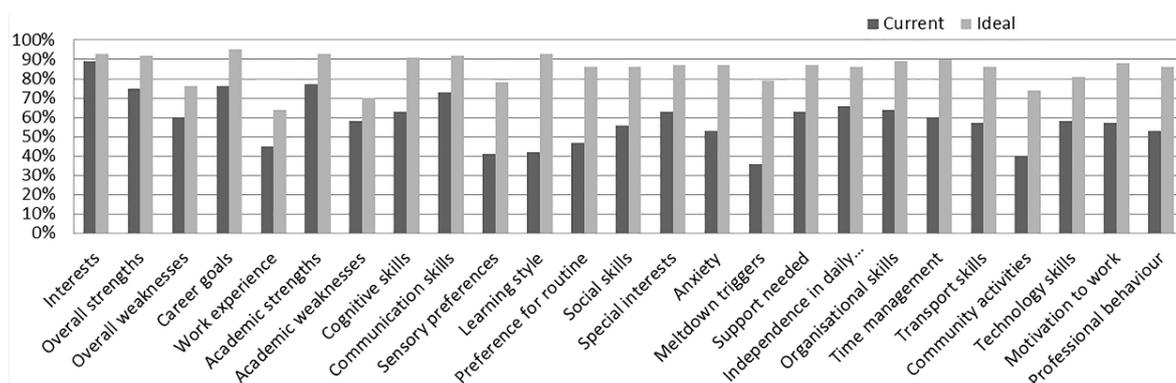
Participants identified who the current coordinator of the transition planning team was and who should ideally coordinate the team (Figure 2-3). Parents were most frequently reported to be the coordinator (43%); followed by teachers (22%). Only 5% of participants reported that the adolescent coordinated the transition planning team. There was no consensus among all stakeholders with regard to who should ideally be coordinator of the transition planning team. The majority of adolescents (71%) reported that the person who currently coordinated their transition planning was also the ideal person for the role. In contrast, 61% of parents and 79% of professionals reported that the person who currently coordinated the transition planning was not their ideal choice for team coordinator ( $\chi^2_{(2)}=10.21$ ;  $p=.006$ ).



**Figure 2-3. Transition planning team coordinator (all groups, current n=83, ideal n=121)**

## 2.4.5 Transition planning assessment

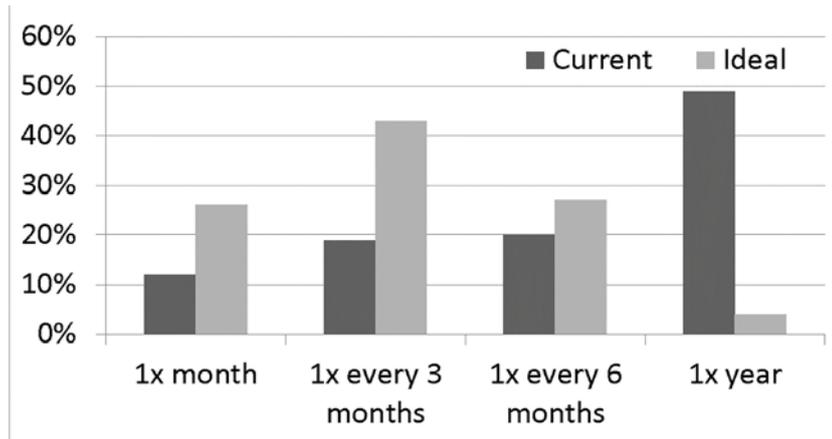
Participants identified the aspects of the adolescent that were currently assessed during transition planning and what they thought should ideally be assessed (Figure 2-4). Interests (89%), career goals (76%) and strengths (75%) were the most frequently reported aspects currently assessed. The least frequently reported aspects were triggers for meltdowns (36%); participation in community activities (40%); sensory preferences (41%); and learning style (42%). Overall, participants reported that ideally all the aspects pertaining to the adolescent listed in the questionnaire should be assessed during transition planning. However, this was not currently happening, resulting in a gap between the current and ideal assessment processes. There were no between-group differences identified ( $p > .05$ ).



**Figure 2-4. Transition planning assessment areas (all groups, current n=81, ideal n=118)**

## 2.4.6 Frequency of transition planning meetings

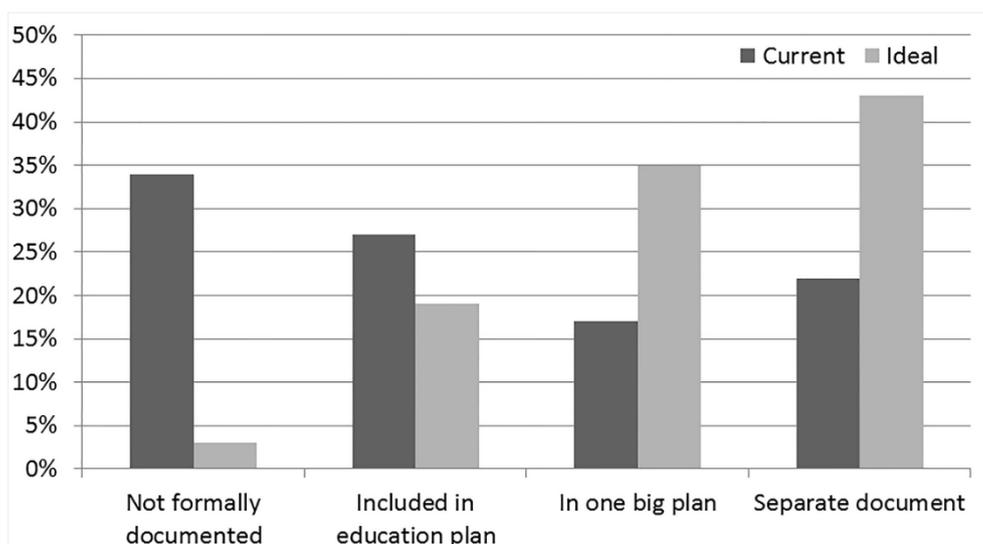
Participants identified how often the transition planning team currently met and how often they believed the team should ideally meet (Figure 2-5). Nearly half of participants reported that meetings were currently conducted once a year (49%). The most frequently reported ideal meeting schedule was once every three months (43%). Parents (68%) and professionals (83%) wanted to meet more frequently to review the transition plan; however, 64% of the adolescents reported the current meeting schedule was ideal ( $\chi^2_{(2)} = 13.03, p = .001$ ).



**Figure 2-5. Frequency of transition planning meetings (all groups, current n=69, ideal n=119)**

### 2.4.7 Documentation of the transition plan

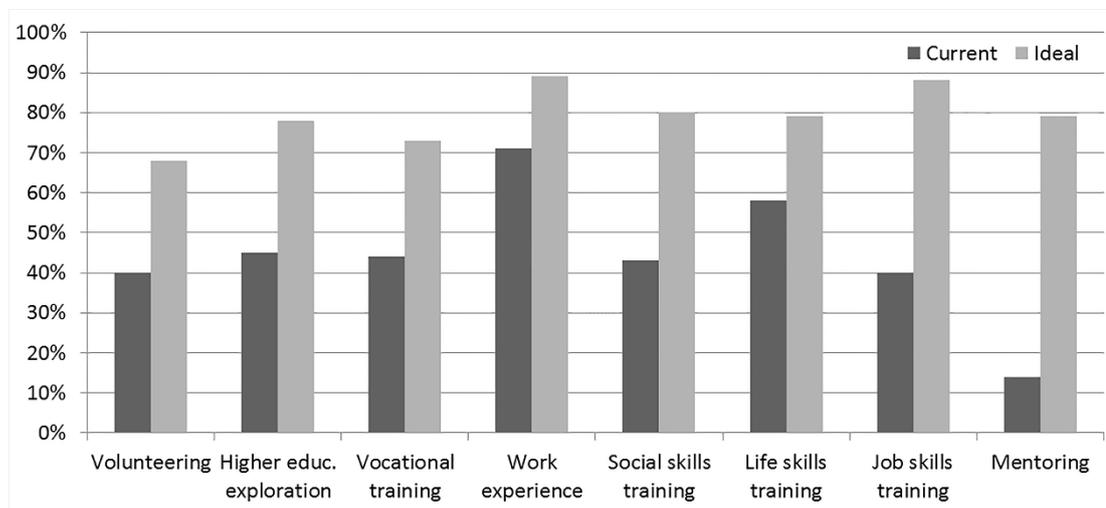
Participants identified the current format used to document the transition plan, and what they believed should be the ideal format (Figure 2-6). One third (34%) of participants reported there was no current formal documentation of the transition plan. Participants ideally would like the transition plan to either be written in a separate document, or in one cohesive plan. The majority of parents (82%) and professionals (74%), and half of the adolescents (50%) believed the transition plan should be documented in a format different to that which was currently used. There were no between-group differences identified ( $p > .05$ ).



**Figure 2-6. Documentation of the transition plan (all groups, current n=77, ideal n=119)**

## 2.4.8 Transition planning activities

Participants identified the current activities used to prepare for leaving school and those they believe should ideally be included (Figure 2-7). Work experience was the most commonly reported activity currently engaged in (71%), and mentoring the least (14%). The other activities were only completed by about half the respondents currently; despite many reporting that ideally all the activities should be used to prepare for the transition from school. Parents and professionals believed that more activities should ideally be done in transition planning compared to adolescents (OR=2.4, 95% CI=1.1-5.1, p=.023).



**Figure 2-7. Transition planning activities (all groups, current n=84, ideal n=120)**

## 2.4.9 Predisposing factors

### 2.4.9.1 Individualised and strengths-focused approach

A predisposing factor in transition planning identified by all groups was the use of an individualised and strengths-focus approach. All groups reported that the focus needed to be on assisting the adolescent to identify their strengths, and supporting the development of a sense of purpose. Parents and professionals identified that special interests that can be leveraged as strengths to enhance confidence and reduced anxiety: "enabled a person to visualise their version of personal success." Adolescents endorsed an individualised process to meet their needs, and being able to "tell the teacher what I really like and I'm good at" which led to enhanced confidence. Professionals indicated that the heterogeneity of the autism population

enhanced the need for a person-centred approach. One area in which there was not group consensus was that parents and professionals identified the need to work on the adolescent's weaknesses; however, adolescents did not identify weaknesses to be an important area of focus.

#### **2.4.9.2 Adolescent motivation, anxiety, and insight**

Adolescent motivation, anxiety, and insight, and how this impacted on the adolescent's willingness to get involved in the transition planning process was described by both parents and professionals as a predisposing factor. One parent commented that there is a need for a "balance between being aware of possible anxiety points, communicating these, without then overloading the person." Parents reported adolescents sometimes had reduced insight into why transition planning was important, this impacted on their motivation to engage in the process.

Adolescents did not identify motivation or insight as an issue, but described how thinking about the future caused anxiety and that they felt pressurised by timeframes and deadlines. This linked to a theme that was raised by parents and professionals, who reported that it was helpful to start thinking about transition planning early, to ensure that there was enough time to develop a solid pathway.

### **2.4.10 Reinforcing factors**

#### **2.4.10.1 Support and guidance**

The importance of support and guidance during the transition process was identified by parents, professionals and adolescents. However, they had different beliefs about from whom the support should come from. Professionals felt support was needed from parents and families; while parents wanted support from professionals as part of a whole-family approach, and for teachers to link them in with resources.

Adolescents wanted "parents and others to help." Parents and professionals agreed on the importance of including the adolescent in the transition planning process, and adolescents reported they wanted "to be listened to". In addition, professionals reported that expectations impacted on transition planning outcomes; when parents supported their children's dreams and provided opportunities for them to challenge

themselves, the adolescent tended to thrive. Parents also acknowledged this and added that professional expectations were also important to “give them [the adolescent] a chance to prove themselves, and that they can actually work independently.” Conversely, parents also spoke about being realistic about the adolescent’s future in order to prevent disappointment for their child.

#### **2.4.10.2 Skill development and real-life experiences**

The development of skills as a reinforcing factor in the transition planning process was identified by all groups. Adolescents identified developing social skills and gaining life skills to be important to assist with things like job applications. Parents also described the importance of social skills, communication, transport, anxiety management and organisational skills. Professionals mentioned skill development the least out of the three groups, and referred to it more in terms of the end goal of independence. All groups discussed the importance of work experience or real life skills. Adolescents reported real life experiences helped them to know the difference between school and work; “to know what it’s like in the real world.” Parents discussed having a mentor as an important support to help adolescents succeed in real-life experiences.

### **2.4.11 Enabling factors**

#### **2.4.11.1 Having a plan**

The main enabling factor in transition planning identified by all three groups was the importance of having a plan with clear goals and a defined structure. Many parents and adolescents reported that currently they did not have a formal transition planning process in place, but that this would have been very helpful. Parents reported having a clear process to follow provided the opportunity to “put together a road map to get to the goal.” Adolescents reported that they would like a clearer understanding of the planning process, and there was a strong sense that they wanted flexibility and options with “the ability to discuss and compromise on which pathways are available.” Many adolescents reported they felt they wanted the ability to change their minds if they needed; one participant described a “fear of the finality

of your decision.” Professionals emphasised the need for concrete goals, avoiding abstract objectives that can be confusing for adolescents with autism.

#### **2.4.11.2 Coordinated approach**

All participants reported that the coordination of a transition plan is one of the biggest challenges to transition planning. The success or failure of the plan hinged on the ability to coordinate times to meet and methods of communication. Parents reported that everyone needs to be on the same page for coordinated services, and adolescents felt it was important to “to get everyone together to discuss the planning process.” However, all groups identified that getting everyone together to discuss the plan was a challenge, especially when multiple agencies were involved. In particular, professionals identified the lack of time they had to fit in transition planning. Parents also acknowledged school resource pressures and emphasised the importance of coordinated communication.

## **2.5 Discussion**

The predisposing, reinforcing, and enabling factors described in this study provide insight into how transition planning could be targeted specifically to adolescents on the autism spectrum. Some factors align with current recommendations for transition planning for adolescents with disabilities in general, including having a coordinated plan, a strengths-focused approach, support from a team, and skill development (19, 26, 41). Some novel findings of this study include the importance of adolescent motivation, insight, and anxiety in predisposing transition planning, considering autism-specific characteristics and providing a clear but flexible plan. In addition, this study appears to be the first to describe the predisposing, reinforcing and enabling factors in transition planning using the PRECEDE model. This insight into the process may support parents and professionals to gain understanding of potential intervention areas.

An interesting finding of the study was the difference in how adolescents on the autism spectrum perceived the ideal transition planning process, compared to parents and professionals. Adolescents tended to report that the current situation

was ideal. Parents and professionals tended to report that there was a mismatch between the current and ideal. Therefore, the perceptions of the transition planning process may be different for adolescents when compared to parents and professionals. These findings could be indicative of a divergence in thinking between parents and their children that often occurs in adolescence. Neurotypical adolescents have different goals for their future than their parents have for them (42). In addition, they viewed the future in a broader, more individualistic manner, whereas parents looked more at the normative transition to adulthood. During high school, adolescents often develop their own 'horizontal' identity that contrasts the 'vertical' identity that is passed on from one's family (43). This further supports a strengths-based and individualised transition planning process that incorporates the adolescent as a key part of the transition team. Individualised planning allows for the adolescents voice to be heard and their identity as an individual is cultivated.

The first predisposing factor was the importance of an individualised and strengths-focused approach. It is encouraging then that participants reported that strengths and interests were the most commonly assessed areas in transition planning. The importance of this has been confirmed by literature; a strengths-based approach has been linked to improved self-determination in adolescents with disabilities (26). A focus on preferred interests may reduce anxiety for adolescents, and many adults with autism engage in post-secondary education and employment options in their area of interest (44). Autism-specific characteristics, such as triggers for meltdowns, sensory preferences, and learning styles were reported to be the least frequently assessed areas in transition planning. Existing literature focuses on the importance of assessing social and communication skills in adolescents with autism (12, 18). However, little is mentioned about other important autism-specific factors. Sensory preferences could impact on the type of job environment the adolescent may select, and consideration of the adolescent's learning styles could increase success in achieving transition planning goals. This highlights the need for a more tailored assessment approach.

The adolescent's motivation, anxiety, and insight are predisposing factors in transition planning. Decreased motivation and increased anxiety have been

described as specific challenges for youth with autism (45-47). In this study parents and professionals identified adolescents on the autism spectrum sometimes had reduced motivation to engage in transition planning. In addition, adolescents reported that anxiety is amplified by tight timeframes and the uncertainty of not knowing what will happen after leaving school. This links to the parents' and professionals' suggestions of starting transition planning early. Prior research also recommends transition planning for people with disabilities commence at 14 years of age, or around Year 9 (48-50). Unfortunately, 72% of adolescents in the current study started transition planning in Year 10 or later. More emphasis must be placed on starting earlier and on exploring strategies to motivate the student to get involved in transition planning.

A key reinforcing factor was having guidance from a team; however there was no consensus on who should be included in the transition team. The team composition is likely to be different for each adolescent, consistent with person-centred practice principles (51). The adolescent was included in transition planning 85% of the time, however they only lead the team in 5% of cases. This may indicate that adolescents on the autism spectrum are not currently actively taking part in the team, which is consistent with current literature (14). This is an important differentiation, as it is active participation, and where possible leadership, of the transition team that has been linked to improved post-school outcomes and increased self-determination (18, 49). Therefore, adolescents on the autism spectrum need increased support to be active participants in the planning process, and to cope with the social and communication demands that come with team participation (52).

Another important reinforcing factor is supporting the adolescent to develop skills and engage in real-life experiences. It was positive that the majority of adolescents had engaged in work experience, as it is a key element of successful transition planning (11, 12, 15, 18, 53). However, many adolescents had not engaged in activities such as career preparation, life skills training, volunteering and part-time work. These activities are important for all adolescents with disabilities; however, they are particularly important for adolescents on the autism spectrum for two reasons. Firstly, they develop "help recruiting skills", or the social skills needed to

seek help from others to overcome barriers (54). Secondly, these activities allow adolescents with autism to see the big picture; or to gain insight into the importance of getting a job and what life might be like after leaving school. This may be particularly difficult for adolescents on the autism spectrum, as they are not able to intuitively understand abstract concepts (55). This was reflected in comments from the adolescents, who reported that it was difficult “trying to make decisions about things that haven't happened yet”, and that they needed experiences to help them to understand what life is like in the real world.

One of the enabling factors was having a clear transition plan. Literature recommends a structured plan that provides adolescents and parents with a clear process to guide their transition out of school (56). In fact, having a clear transition process increases the chance of gaining employment after leaving school (medium effect size, 0.46) and getting into post-secondary education (small to large effect size, 0.26 to 0.61) (26). However, many parents and adolescents reported a lack of a clear and formal plan, and that the transition plan was not documented.

Furthermore, the adolescents identified the need for options, and a pathway that was clear but flexible. This is an interesting finding, as it appears to contradict the diagnostic criteria for people with autism of insistence on sameness and rigid patterns of thinking (57). Rather than insisting on having one option for their futures, adolescents reported that they preferred being given multiple choices and the opportunity to change their transition pathway. This desire for choice and flexibility in transition planning should be considered in future transition planning for adolescents on the autism spectrum.

Another key enabling factor was having a coordinated approach, including making the time to meet and ensuring open communication. Strong team communication and a coordinated approach have been linked to improved transition outcomes (58). Parents and professionals in the current study expressed the need for more regular meetings; however, the adolescents did not. Adolescents on the autism spectrum may find meetings uncomfortable, possibly because of difficulties with social communication. This further supports the need for autism-specific strategies to support engagement in transition planning meetings (59).

## 2.5.1 Limitations

The current study included responses from 162 participants across Australia, which is comparatively a small sample. The questionnaire was disseminated to potential participants across Australia; however, most responses came from one state - Western Australia. There may be differences in school transition planning processes between states because education in Australia is managed at a state government level. In addition, most of the adolescents and parents came from higher socio-economic areas, limiting the generalisability of the findings. There were fewer adolescents on the autism spectrum who participated in the study, and adolescents answered fewer questions about the current transition planning process than other parts of the questionnaire. This was possibly because they had either not started transition planning or did not know about their current plan. While this was a limitation to the study, it further supports the need for active involvement of adolescents in transition planning.

Many professionals who participated in the study had less than five years of experience working with people on the autism spectrum. This lack of experience needs to be considered when interpreting the professionals' responses. Furthermore, 83% of the parents were mothers and the views of fathers may differ. The questionnaire used was developed specifically for this study, and was not previously tested for validity and reliability. However, the aim of the questionnaire was to capture participants' perceptions of the transition planning process and there were no existing valid and reliable tools relevant to this aim.

## 2.6 Conclusion

This study revealed some unique transition planning factors for adolescents on the autism spectrum. For example, the predisposing factor of considering the adolescents anxiety, motivation and insight, and the enabling factor of having a structured but flexible transition plan. This indicates a need for an autism-specific transition planning process that is tailored to support the distinct needs of this group.

## 2.7 Declarations

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### **Authors' contributions**

MH, MC, MF, TF contributed to the design of the study. MH collected data, completed analyses and wrote the manuscript. MC, MF, TF reviewed the manuscript. The manuscript has been read and approved by all authors.

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# Study 2: Interviews

## Author Contribution Statement

As co-authors of the paper entitled, *“Leaps of faith”: Parent and professional viewpoints on preparing adolescents on the autism spectrum for leaving school*, we confirm that Megan Hatfield has been the principal researcher and has made the following contributions:

- Conceptualisation and design of the research;
- Data collection, analysis, and interpretation; and
- Writing the manuscript and critical appraisal of the findings.

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 collection, analysis, and interpretation; and
- Review and editing of the manuscript.

*Signed:* Torbjörn Falkmer Date: 25/05/17

*Signed:* Marina Ciccarelli Date: 25/05/17

*Signed:* Marita Falkmer Date: 25/05/17

# “Leaps of faith”: Parents’ and professionals’ viewpoints on preparing adolescents on the autism spectrum for leaving school

Megan Hatfield<sup>1,2</sup>, Marita Falkmer<sup>1,2,3</sup>, Torbjörn Falkmer<sup>1,2,4,5</sup> and Marina Ciccarelli<sup>1,2,\*</sup>

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Perth, Australia

<sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Brisbane, Queensland, Australia

<sup>3</sup> School of Education and Communication, Institution of Disability Research Jönköping University, Sweden

<sup>4</sup> School of Occupational Therapy, La Trobe University, Melbourne, Australia

<sup>5</sup> Department of Medicine and Health Sciences (IHM), Linköping University and Pain Rehabilitation Centre, Sweden

\* Corresponding author

## 2.9 Abstract

**Background:** Adolescents on the autism spectrum experience difficulty transitioning from secondary school to post-school activities, often due to transition planning processes that do not meet their unique needs. This study identified parents and professionals viewpoints on transition planning for adolescents on the autism spectrum.

**Methods:** Interviews were completed with nine parents of adolescents on the autism spectrum and four professionals who worked with adolescents on the autism spectrum. A constant comparison approach was used to analyse the transcripts.

**Results:** Four themes were identified, reflecting parents and professionals viewpoints on how to meet the transition planning needs of adolescents on the autism spectrum. Supporting adolescents *to grasp the big picture* can enhance motivation to participate in transition planning. Autism can be an 'invisible disability'; therefore encouraging adolescents to be active participants and *to be seen* in transition planning ensures their individual needs are met. Encouraging adolescents *to have high aspirations* in transition planning develops their self-determination. Finally, *to be prepared* for the transition from school may reduce the adolescent's anxiety.

**Conclusions:** Adolescents on the autism spectrum face unique challenges in transition planning. The themes identified in this study provide insight into how parents and professionals might support adolescents with these challenges.

**Key words:** Asperger's Syndrome, Autism Spectrum Disorder, disability, employment, interviews, transition planning.

## 2.10 Introduction

Transition planning in high school involves preparing adolescents for leaving school and moving into activities such as vocational training, tertiary education and employment (1). It involves setting goals and engaging the adolescent in activities that will teach them skills so that they feel confident about leaving school. When transition planning is undertaken in high school, it can assist adolescents to successfully negotiate the move from school into adult life (2). Transition planning can lead to improved self-determination, increased rates of employment, enhanced success in post-secondary settings, greater happiness, and improved participation in the community (3, 4).

A lack of transition planning is a common barrier to successful employment for adolescents on the autism spectrum (5). Autism is characterised by difficulties in socialisation and communication as well as restricted interests and repetitive behaviours (6). People with autism have difficulties coping with change due to a preference for routines; even minor changes in the environment and daily activities can cause anxiety (7). Therefore, periods of transition can be difficult, and during these times there is a need for strong preparation and communication to ensure anxiety is reduced (8). Transition can be made even more difficult for adolescents on the autism spectrum who have average or above intellectual abilities, as schools tend to focus on academic performance rather than on engaging in transition planning (9). As a result, these adolescents often do not successfully transition to employment; only 16% of adolescents on the autism spectrum without an intellectual disability (ID) in Australia are employed full-time after leaving school, with 33% being employed part-time (10). Those who do have a job are often under-employed and in roles that do not reflect their level of education (11, 12). In addition, young adults on the autism spectrum with average or above intellectual abilities are three times less likely to have post-school vocational activities when compared to their peers on the autism spectrum who have an ID (13). This contradicts the common assumption that adolescents on the autism spectrum without ID have better outcomes because of their intellectual abilities. Parents of

adolescents on the autism spectrum have reported that the most serious problems arose when their adolescents were transitioning from high school, and that they felt unsupported in transition planning (14). Furthermore, people with autism often do not qualify for adult services, and few adult services have the specialised knowledge to meet the needs of people on the autism spectrum (15, 16). In addition, little is known about the effectiveness of adults employment support programs, with current evidence limited by small sample sizes, lack of randomisation and control groups, and poor conceptualisation of outcomes (17). Overall, transition is a difficult period for adolescents on the autism spectrum (18).

One reason for the difficulty transitioning out of school could be that individuals on the autism spectrum without an ID have unique transition planning needs that are currently not being met. While neurotypical adolescents reported feeling stressed about academic achievement; adolescents on the autism spectrum reported stress concerning getting a job, interpersonal relationships and transport, and also reported feeling that they were likely to fail in the future (14). This suggests that adolescents on the autism spectrum may have poor self-determination, a key predictor of successful transition into an independent adult life (19). In addition, one study in the United States of America (USA) found that even when general transition planning requirements were met, adolescents on the autism spectrum still experienced inferior outcomes in comparison to other disability groups (20, 21). Parents of adolescents on the autism spectrum have reported feeling more worried about the transition from school than parents of children with other disabilities (22). They are less likely to perceive the transition planning process as being useful (23), and more likely to report that they would have liked to be more involved in the process (20, 22). These results indicate that adolescents on the autism spectrum have unique transition planning needs, and further research needs to be conducted to determine what these unique needs are.

Two groups that often are involved in the transition planning process for adolescents on the autism spectrum are their parents and the professionals who work with them. However, there is very little research exploring their viewpoints on the transition planning process. One study examined barriers and facilitators of

transition planning for adolescents on the autism spectrum (24). However it focused specifically on youth in foster care. Further to this, most current research exploring the transition planning needs of adolescents on the autism spectrum is from the USA (25) (20, 26-28). Given the legislative differences between countries, there is a need to explore this topic in an Australian context. Overall, there is a gap in the literature exploring parents and professionals viewpoints on preparing adolescents on the autism spectrum for leaving school.

### **2.10.1 Aim**

To investigate views about the transition process for adolescents on the autism spectrum from the perspectives of their parents and professional staff who assist in this process.

## **2.11 Methods**

This study sought parents' and professionals' views of transition planning for adolescents on the autism spectrum, and how they make sense of this phenomenon (29). Consistent with this approach, the literature was reviewed after data collection to minimise assumption or conjecture in interpreting results and to maintain an openness to the phenomenon of interest (30).

This study included parents/carers of adolescents and young adults on the autism spectrum without a diagnosis of ID, and professional staff that were involved in the transition planning process for this group. Study participants were recruited from across Australia via dissemination of study information on the websites of autism service providers; local autism advocacy groups; at conferences and community events; and via government and non-government secondary schools in Western Australia.

Participants who consented to be interviewed were a subset of respondents to an online survey about transition planning for adolescents on the autism spectrum. At the end of the online survey, respondents had the opportunity to nominate their interest in participating in the interviews. Thirty parents indicated in the survey that

they would like to participate in an interview. These parents were contacted in a random order generated in Microsoft Excel. Nine parents were interviewed before saturation was reached, or when the collection of additional data did not reveal any new issues (31), so no further parents were interviewed. Six professionals who completed the survey indicated that they would like to participate in an interview. The first author contacted all six professionals; two declined and four agreed to be interviewed.

Adolescents and young adults on the autism spectrum were invited to complete the online survey to provide their information about their experiences in transition planning, the results of which are reported elsewhere (32).

Nine guiding questions were used in the semi-structured interviews (see Figure 1), along with interview techniques such as probing and cross-checks (33). The interview guide was applied in a flexible way depending on the participants' role and experience in the transition planning process. Interviews were completed either by telephone or conducted in person. The duration of the interviews ranged between 30 and 60 minutes.

**Figure 2-8. Guiding questions for semi-structured interviews**

1. Please describe your experience with transition planning to date.
2. Please describe your perception of the ideal transition planning process for adolescents on the autism spectrum.
3. How do you support the adolescent on the autism spectrum to be involved in the planning process?
4. What information is helpful in transition planning?
5. Can you describe how you determine progress in the transition plan?
6. Please describe any activities you have supported the adolescent on the autism spectrum to participate in during transition planning.
7. Can you describe how transition planning with adolescents on the autism spectrum may be different to planning for other groups?
8. (For professionals only) Please describe the most successful transition planning process for an adolescent on the autism spectrum that you have been involved in.

Interviews were audio-recorded, transcribed verbatim and analysed using NVivo 10 to identify key themes that emerged from the data. Transcripts were read several times by the first author and initial codes were developed and labelled by category; these were further condensed or sorted into sub-categories as needed (31). Using principles of constant comparison within and between the transcripts (34), emergent themes were named and revised by the first author and peer-reviewed by the co-authors.

A number of steps were taken to improve the trustworthiness of the data. An in-depth description of the study participants is provided in Table 1 and data collection methods are described in detail above, to provide sufficient detail to allow readers to determine the extent to which the current research is applicable to other settings (35, 36). Use of a purposive sample (i.e., parents and professionals with first-hand experience in the transition planning process) further improved the transferability of the study findings. Dependability and credibility of the findings were improved through peer examination of the data to ensure 'fresh perspectives' on emergent themes, and through the use of an audit trail during data coding (36). In addition, a journal was kept by the primary researcher to practice reflexivity and to improve confirmability of the findings.

Ethics approval was obtained from Curtin University Human Research Ethics Committee in Western Australia (approval number HR110/2014), the Catholic Education Office of Western Australia, and the Western Australian Department of Education. Informed written consent was provided by all participants. This consent procedure was approved by all aforementioned ethics committees. An Adverse Events Management Plan was utilised, which included steps to follow if a participant became distressed during interviews and general information about how interviewees could seek support following the interview, if required.

## 2.12 Results

### 2.12.1 Participants

Thirteen participants were interviewed for this study. A detailed description of the nine parents (mothers= 8; fathers= 1) and four professionals is provided in Table 1. Parents were mainly from Western Australia (WA), with two from Queensland (QLD). Their adolescent children were majority male and still in high school, two parents had adolescents who had recently left school. Professionals were all from WA, and had a range of job titles and experience working with adolescents with autism, ranged from three years to 13 years.

**Table 2-3. Participant information (Parents N=9, Professionals N=4)**

<b>Parent Participant ID</b>	<b>State or Territory</b>	<b>Relationship to adolescent</b>	<b>Adolescent's gender, age (years) and grade at school</b>
1	Western Australia (WA)	Mother	Male, age 15, Year 9
2	WA	Mother	Male, age 14 , Year 9
3	Queensland (QLD)	Mother	Male, age 17, First year university
4	WA	Mother	Male, age 14, Year 9
5	WA	Mother	Male, age 19, Left school Female, age 21, Left school
6	WA	Mother	Male, age 17, Year 12
7	WA	Mother	Male, age 15, Year 9
8	WA	Father	Female, age 15, Year 10
9	QLD	Mother	Female, age 15, Year 11
<b>Professional Participant ID</b>	<b>State or Territory</b>	<b>Job title</b>	<b>Years working with people with autism</b>
1	WA	Job support coordinator	3 years
2	WA	Teacher at an education support school	13 years
3	WA	Occupational therapist	5 years
4	WA	Speech pathologist	4 years

## 2.12.2 Themes

Four core themes were derived from the interviews; to grasp the “big picture”; to be seen; to dream big; and to be prepared. Each represents the participants’ experiences and viewpoints on transition planning with adolescents on the autism spectrum. Data analyses revealed considerable agreement between parents and professionals, and therefore the data were considered together and the themes are representative of both groups.

### 2.12.2.1 To grasp the big picture

Grasping the big picture was described by parents and professionals as the ability to anticipate how current actions may influence future prospects, and hypothesising what life might be like after school. For example, understanding what might be involved in a job or what skills might be needed to live out of home: “He needs to understand what’s going to happen after school and what will be expected of him as an adult” (Parent 7). Participants described how their experience was that adolescents on the autism spectrum may not understand these concepts intuitively, and that this may impact on their motivation to engage in the process of planning for their future. One parent described how her son appeared content to imagine a future where he continued living at home and did not have a job, because this was the current situation; *“He’s not very receptive to the idea of one day having to provide for himself ‘cause he’s quite comfortable where he is; he doesn’t have the big picture”* (Parent 2). This parent described how part-time work provided her son with the motivation to engage in transition planning. Part-time work helped her son to understand the intrinsic reward related to being productive in the workplace and earning one’s own money. Participants described how supporting adolescents to understand the big picture motivated the exploration of new opportunities in the community and active involvement in transition planning.

Real-life experiences emerged as the best way of assisting adolescents to see the big picture. Volunteering, work experience, part-time work, and after-school community activities were all powerful tools for providing adolescents with insight into life after school. These activities also assisted adolescents to develop life and employability

skills, and promoted autonomy, self-esteem and resilience. Volunteer work and community activities provide an opportunity to learn skills without too much pressure and were perceived as a stepping stone into paid employment. Part-time work after school or on weekends was sometimes seen as “unrealistic” for adolescents on the autism spectrum, but was described as an important part of teenage development:

“Neurotypical teenagers are expected to get a job of some form around fourteen or fifteen, you know they’re working for two or three years of their high school life, and they’re much better set up when they leave school” (Professional 4).

Overall, the importance of real-life experiences in transition planning could not be overstated, “It’s more difficult to have less experience no matter if you have a diagnosis or not” (Professional 3).

Career exploration was also described as helpful to assist adolescents to see the big picture, including activities such as exploring higher education options, meeting people working in the area of interest and having a mentor. Life and employability skills training in areas such as personal care, social skills and organisational skills was also reported to assist the adolescents’ understanding of what life would be like after school.

#### 2.12.2.2 To be seen

To be seen was an important theme that emerged from the study, as autism was described as an invisible disability by both parents and professionals, that is not immediately apparent to an everyday observer, “The biggest thing is they look so normal and they can sound for the most part very normal, until you know them well enough ... it’s the invisible disability” (Parent 4). Therefore, adolescents on the autism spectrum without an ID often ‘fly under the radar’ because they appear to be coping well and do not receive support to prepare for leaving school, leading to a feeling of helplessness and abandonment; “It’s a black hole. The Abyss... And that’s the time the parents are least equipped for” (Parent 3). Participants described how each adolescent on the autism spectrum is unique and multi-faceted, emphasising the

importance of individualising the transition planning process to the person, rather than using a generic approach, "He doesn't fit a box" (Parent 3).

To ensure the adolescent is seen and supported as the unique individual they are, it is important to include the adolescent on the autism spectrum in the transition process. Involving the adolescent gave them a sense of control and therefore increased their motivation to participate, "The more input that he has, the more likely he is to want to do it ... he needs to feel that he has control" (Parent 7). Participants suggested strategies to assist the adolescent to successfully participate in transition planning, which included; discussing the agenda with the adolescent prior to the meeting, and providing the adolescent with choices about where meetings are held, who attends, and how they want to communicate in the meeting. In addition, the team should also alter their communication style to meet the adolescent's needs, taking into account learning styles, ensuring questions are concrete and providing choices in discussions.

### 2.12.2.3 To dream big

Participants described the value of encouraging the adolescent to dream big and supporting them to aim high, "We look at whatever the student's dream is and help them so that they can achieve that ... we never say anything's impossible" (Professional 2). Adolescents were more engaged and motivated when the focus was on their dreams, and this increased the chance of success post-school. An optimistic approach was helpful, in which "failures" were viewed as learning experiences:

"That their mindset is in a positive mode, where rather than looking at it as 'Oh, God, this is just another thing that I've got to, that I can't do'; looking at it as 'This is something that I haven't learnt how to do yet' " (Parent 5)

Having high expectations was important for developing the adolescent's self-determination and resilience, "We always encouraged him to take those leaps of faith and we're always there to help him if he fails, but never took the experience of failing away from him ... High expectations but flexible" (Parent 3). Another

important part of dreaming big was supporting the adolescent to feel they could change their mind, and that there was more than one way to achieve their dream:

“We’ve talked about the different pathways to get to one point, but we said all of those pathways can give you lots of different options, so it’s not an issue if you change your mind about what you want to be part way through. Yeah, he’s feeling like ‘oh you know it’s only gonna be good’ ” (Parent 7).

#### 2.12.2.4 To be prepared

Participants reflected on the importance of being prepared for leaving school. This included starting transition planning early, because adolescents on the autism spectrum, “Suffer from much higher anxiety than the average child, so to be forewarned is to be prepared, so that would help lower their anxiety” (Parent 1). Parents and professionals felt reported that formal transition planning should start in Years 9 or 10 and should involve planning the pathway for the last few years of high school; choosing subjects, planning further study and developing a career plan. Informal transition planning should start in primary school; working on life skills, resilience and self-advocacy.

Having a clear process for the transition period was also important, “A flowchart of activities they go through, a suggested timeline of how long things take” (Professional 3). According to participants, the transition planning process should include setting goals, which keeps everyone task-orientated and on track. Goals were perceived as particularly important for adolescents on the autism spectrum, as they assist them to understand the “big picture”. However, goals must be broken down, as participants reported that adolescents on the autism spectrum preferred this so that they could understand the smaller concrete steps required and see that they are making progress towards their goal.

Having a team of people around the adolescent was an integral part of preparing for leaving school. A strong transition team was described as cohesive and collaborative, with each team member providing a different, but equally useful, perspective. Parents were regarded as pivotal team members because in their view they need to

drive the process and advocate for their child. The team should also include community members and other people in the adolescent's natural networks, "They've got their networks and realising who's in their community who can support them" (Professional 2).

## 2.13 Discussion

The findings of this study provide insight into the unique challenges that adolescents on the autism spectrum face in transition planning from the perspective of parents and professionals. These included; difficulty seeing the big picture, the 'invisibility' of their diagnosis leading to a lack of support, and anxiety which can be heightened by the prospect of leaving school. The four key viewpoints represent how parents and professionals felt they may be able to assist adolescents to overcome these difficulties, which include supporting adolescents to grasp the big picture, be seen, dream big and be prepared. This is one of the first studies to identify the unique factors that assist transition planning for adolescents on the autism spectrum; previous studies have mostly explored transition planning experiences of adolescents with other disabilities, such as intellectual disability or developmental delay (25, 28, 37). There are some commonalities between the findings in these studies and the current study, including the importance of setting goals, participating in community-based experiences and encouraging adolescent participation in transition planning. Some studies have explored transition planning for adolescents on the autism spectrum in the USA (26, 38). These studies also describe how transition planning can increase anxiety for adolescents on the autism spectrum, and that motivation for this group can be challenging. However, the findings of the current study highlight some unique transition planning viewpoints that may be specific to parents of and professionals who work with adolescents on the autism spectrum in an Australian context.

To grasp the big picture was a new finding from this study, which has not previously been discussed in the literature. This might be because this is an issue that is specific to adolescents on the autism spectrum, who may not intuitively understand the big picture due to their difficulties with gestalt processing, or the tendency to focus on

the details rather than the whole, meaning they can miss the overall meaning or significance in a task (39). This may result in a difficulty understanding why an activity like part-time work may assist them with gaining a job after school, hence reducing motivation to participate in transition planning. In addition, adolescents on the autism spectrum struggle with abstract thinking (40), and consequently may not be able to conceptualise what life may be like after school. Difficulties with abstract thinking and gestalt processing are distinct characteristics related to autism, and therefore a focus on the big picture could potentially be lacking in current transition planning processes, which are generic and not tailored specifically for adolescents on the autism spectrum. To develop understanding of life after school, participants recommended that adolescents should engage in real-life experiences, such as volunteering, work experience, part-time work, after-school community activities and having a mentor. Participants described how these real-life activities provided adolescents with concrete, hands-on experience of what life might be like after school, hence increasing their understanding of the need for transition planning and developing their self-determination. This in turn enhanced adolescents' motivation to participate in transition planning.

Another key viewpoint for adolescents on the autism spectrum is to be seen, and to be actively involved in the transition planning process. Student involvement in transition planning is linked to greater success post-school (41), as well the development of self-determination (7). When adolescents are actively involved in transition planning they are more likely to take ownership of their post-school plans, leading to increased autonomy, relatedness and competence, all of which promote intrinsic motivation (42). Furthermore, goals that are determined by the adolescent themselves are linked to increased motivation and persistence in reaching that goal (43). This is especially relevant to adolescents on the autism spectrum, as motivation to participate in transition planning has been identified as a significant barrier (26). In addition, autism is often an invisible disability, making it difficult for adolescents to get the support they need during the transition planning process. The concept of autism as an invisible disability has not been explored in-depth in the transition planning literature to date; however it is acknowledged that

adolescents on the autism spectrum without an ID frequently lack access to formal post-school services (9). Participants described strategies to support adolescents on the autism spectrum to be actively involved in transition planning. Strategies included preparing the adolescent for what to expect and providing choices in relation to meeting location, attendees and their communication method in the meeting. These strategies augment another recent study, which affirms the use of preparation, flexible meeting agendas and alternative means of communication as key to increase participation for adolescents on the autism spectrum (44). Further research on this topic should explore the perspective of adolescents on the spectrum in regards to active participation in transition planning meetings, and further strategies that they feel would support in this process.

To dream big was another crucial theme that emerged from this study. There is a strong relationship between high expectations and improved employment outcomes amongst people on the autism spectrum, as well as in the general population (2, 9, 45). In addition, having a strengths-focus has been found to increase success in post-school avenues (3, 14, 44). However, there is evidence that parents of adolescents on the autism spectrum have lower expectations for their children (46), and interestingly participants in this study focused more on what issues arose related to autism and transition planning, rather than the unique strengths of the adolescents. Parents who have low expectations may not provide their children with opportunities to develop life skills and the sense of self-determination required for successful transition (2). For example, some parents of children on the autism spectrum may remove their children from social, academic or employment situations because these may cause stress for their children; inadvertently reducing exposure to important social- and resilience-building opportunities (47). Therefore, it is particularly important to support adolescents on the autism spectrum to dream big and have high expectations during transition planning.

To be prepared is particularly important for adolescents on the autism spectrum, as they frequently experience high levels of anxiety associated with transition, change and unpredictability (48). This anxiety is likely to be amplified by the uncertainty of not knowing what will happen after leaving school. Therefore, early preparation and

having a plan is expected to assist in reducing uncertainty and anxiety. The important elements of being prepared were to have clear and concrete goals and a strong team, all of which have been linked to improved transition outcomes (27, 44, 49). Having a team is important for increasing feelings of relatedness, and achieving goals increases competence, all important elements for developing a strong sense of self-determination (42).

Goals are also important, because the range of choices available after school may be overwhelming for people on the autism spectrum who have difficulty with uncertainty and prefer a pre-determined path. Setting goals is associated with increased odds of attending college after high school for adolescents on the autism spectrum (4). Having a clear plan with defined goals breaks the task of transition planning into manageable portions, and provides the adolescent with a sense of progress, appealing to the adolescents' preference for concrete and tangible steps (40). Goal setting may also lead to increased motivation to participate in transition planning due to greater ownership of the plan, and increased self-determination (50).

The findings of this study reflect the viewpoints of parents and professionals, and therefore it is important to consider how their views may differ from those of adolescents on the autism spectrum. Waltz (51) describes how professionals may describe experiences from a position of power, and parents may present their viewpoints in alignment with a deficit-based and normalcy paradigm, rather than one of acceptance. Parents and professionals may also have different views, with an example being what term should be used to describe autism; whilst people with autism and parents preferred the term 'autistic', professionals endorsed the term 'people with autism' (52).

A recent shift in autism literature advocates movement away from deficit-based discourse to supporting people on the autism spectrum to embrace their unique culture and diversity (53). Whilst parents and professionals in this study advocated for the individualisation of transition planning and high expectations, they also placed importance on adolescents developing skills for life, employment, and social

situations. These are skills that are valued in Western society, and therefore the underlying presumption is that adolescents on the autism spectrum need to change their behaviours to better fit norms and social expectations. An alternate perspective is that the focus should shift from the individual to society, and how workplaces and post-secondary institutions can modify environments to be more 'autism-compatible' (53). Prior studies support the view that the environment plays a significant factor in supporting people with autism to successfully transition from school (25, 54). These studies also suggest that adolescents have some similar views to parents and professionals, such as the importance of being prepared, having a strong team, and being actively involved in the process (25, 38, 54). Adolescents in these studies had similar aspirations to those in the current study, including wanting to go to college and get a job, and they perceived their personal characteristics as presenting both barriers (social skills, sensory preferences) and facilitators (cognitive abilities, kindness) to achieving these goals. Therefore, there are likely to be similarities and differences between the views of parents and professionals, and adolescents, which require further exploration.

Most of the parents who participated in this study were mothers, who perceived that the responsibility for transition planning was often left to them. They felt it was their role to advocate for their child, to organise team meetings, and to follow-up on goals. The pressure felt by mothers is also apparent in how they often feel scrutinised by services to ensure they are meeting their child's 'needs' (55). Traditional gender roles are still apparent in the differences between how mothers and fathers respond to having a child with autism. Mothers take the role of the active carer in daily matters and this directly impacts on their emotional well-being (56). In contrast, fathers describe feeling concerned about their child's future, but that this has less of an impact on their emotional well-being. It appears that traditional gender roles may be present in transition planning, with the mother often taking the leadership role in supporting their adolescent on the autism spectrum to prepare for leaving school.

It is important to acknowledge the complexity of transition, and the many factors that contribute to the outcome of transition from high school to post-school

activities. Contextual determinants of expectations for young people have evolved in the past few decades, including enhanced educational opportunities, shifting cultural norms for women, and increased inclusion and participation opportunities for people with disabilities (57). This has led to life stages becoming increasingly blurred, with significant shifts in the times of expected milestones for young people that no longer follow cultural or social expectations (16). The themes presented in this paper represent the participants' experience of transition planning related to leaving high school, and cannot represent the entirety of the influences that may impact on the outcomes in transition to adult life.

### **2.13.1 Limitations**

The study information was disseminated to potential participants across Australia; however, most interview participants came from one state; Western Australia. As education is managed at a state government level, there may be differences in school transition planning processes between states. This could limit the generalisability of our findings.

Only six of 53 professionals who participated in the survey indicated an interest in being interviewed, and only four actually participated in the interviews. Therefore, fewer professionals were interviewed than parents, when ideally it would have been preferable to have a more even range of participants.

### **2.13.2 Recommendations for Future Research**

Including young people on the autism spectrum in interview-based research is crucial to ensure their voice is heard (58), and therefore it is recommended that future research related to transition planning focuses on using more in-depth methodologies to obtain insights from adolescents on the autism spectrum. Techniques to support this group to participate in interviews include preparation during pre-interview home visits; and questions that embed visual supports, provide concrete examples and allow for extra time to respond (58). Other methods that have been successfully utilised are 'walking interviews' that include walking around a location relevant to the topic whilst taking photographs of important landmarks;

'activity based' interviews that involve discussions using activities such as drawing (59) and card sorting activities (60) or Q-sorts (61).

## 2.14 Conclusion

This study identified viewpoints related to the unique transition planning difficulties faced by adolescents on the autism spectrum from the perspective of parents and professionals. These include supporting adolescents to grasp the "big picture"; be seen; dream big; and be prepared. It is suggested that future studies explore the viewpoints of adolescents on the autism spectrum in relation to transition planning, and how these compare to the views of parents and professionals.

## 2.15 Declarations

### **Authors' contribution**

MH, MC, TF, MF contributed to the design of the study. MH collected the data and drafted the manuscript. MH, MC, TF, MF reviewed the manuscript. The manuscript has been read and approved by all authors.

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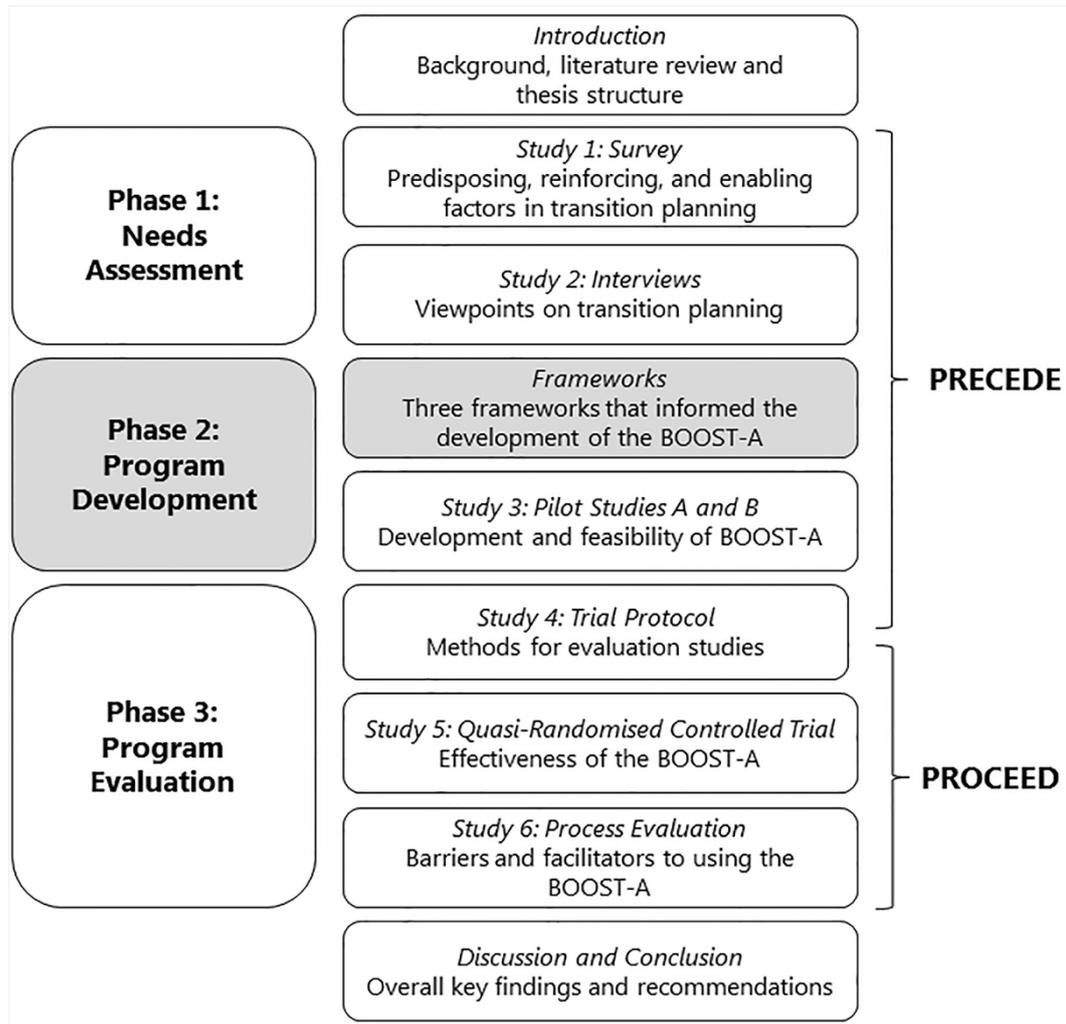
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# Chapter 3 FRAMEWORKS

Based on the results of the needs assessment in Phase 1, three main frameworks were chosen to guide the development of the BOOST-A™: self-determination theory, a strengths-based approach, and a technology-based approach. Chapter 3 provides an overview of each framework.



## 3.1 Self-determination theory

Self-determination theory presents a framework for understanding human motivation, with the central premise being that goal achievement is directly related to the ability to satisfy basic psychosocial needs (1). There are many different frameworks used to understand self-determination. There are three that are drawn upon in this thesis, the first being the broader and most widely used Self-determination theory (SDT) by Deci and Ryan, which proposes that humans have a natural tendency towards growth and development, seeking opportunities for mastery, and integrating experiences into their sense of self (2). There are three main psychological needs that people strive to fulfil whilst engaged in growth and goal-directed behaviour: autonomy, competence, and relatedness (3). Autonomy is the feeling of control over one's own personal circumstances and is a necessary precursor to the development of a sense of personal volition (2). Competence is the feeling associated with the experience of mastery, which enhances self-esteem and resilience. Finally, relatedness is the connection with others, having a shared sense of purpose, and being shown reciprocal affection. Social contexts can nurture or impede these three needs and have a significant impact on intrinsic motivation and personal growth (1). When all three psychological needs are met, self-determination is optimised and intrinsic motivation increases. Alternatively, when these needs are not met motivation and self-esteem decrease.

There are two self-determination theories that are specific to students with disabilities. Wehmeyer's Functional Theory of Self-determination (4) focuses on the individual and the cumulative personal characteristics that lead to self-determined behaviour (5). Wehmeyer's theory takes a developmental approach, in which self-determined behaviour must meet the following pre-determined criteria: it must be autonomous, behaviour must be self-regulated, the person must act in an empowered manner and the actions lead to self-realisation (4). This is in contrast to Mithaug's Self-Determined Learning Theory (6), which attempts to understand the process through which students become self-determined learners, and has two main constructs: capacity and opportunity (6). The main distinguishing point with

Mithaug's theory is that it views self-determination as an interactional process, in which students engage with just-right opportunities in the home and school environment that develop their capacity to act in a self-determined manner (5). Opportunities provided by parents and teachers were also identified as an important reinforcing factor in the needs assessment in Phase 1 of the thesis, and therefore Mithaug's theory was chosen as the primary framework for the study. Mithaug's theory was used as the basis for the development of the American Institutes for Research Self-Determination Scale (AIR; 7), which was used as the primary outcome measure in Study 5, the quasi-randomised controlled trial.

Self-determination is an important concept in transition planning, because transition is a period of growth and development that requires high levels of intrinsic motivation for success (8). Adolescents must develop a sense of autonomy to ensure they have the ability to direct their own life and to feel confident about the choices they make without relying heavily on others (9). A strong sense of competence is important to articulate strengths, which are leveraged to set goals and problem-solve any barriers to achieving their dreams (10). Lastly, a sense of relatedness is important in feeling connected with members of a transition team who understand their aspirations (11).

For adolescents with a disability, a high level of self-determination is a predictor of improved post-school employment (12). An adolescent with a strong sense of self-determination is able to advocate for himself or herself and overcome any difficulties he or she may face during the transition journey (13). Unfortunately, the development of self-determination among people with a disability can be hindered by a high level of dependence on caregivers and service providers, reducing feelings of autonomy and competence (8). A focus on self-determination is important for adolescents on the autism spectrum, because studies have described that this group feel they have poor coping strategies and believe they are likely to fail in the future (14). A strong sense of self-determination can be developed through active involvement in transition planning (15, 16) and participation in community activities (17). In addition, adolescents need to consistently receive positive messages that reinforce their confidence and sense of control (18). Self-determination in

adolescents on the autism spectrum can be increased when parents and teachers hold high expectations for them, which is also linked to greater post-school success (16).

## 3.2 Strengths-based approach

The strengths-based approach aims to empower individuals, build collaboration, and inspire feelings of confidence in future outcomes (19). The strengths-based approach arose in the 1980s to contest the medical model of disability that focused on identifying deficits and areas for improvement (20). In the medical paradigm, individuals with disabilities are fundamentally flawed, implying that individuals are responsible for their difficulties and they need to change to meet society's expectations (21). The strengths-based approach challenged this assumption by advocating that individuals with disabilities are an asset to society and that the responsibility lies with the community to support people with disability to leverage their talents. This approach emphasises the individual's expertise and motivation, and how these are used to enhance relationships and promote change (19). Strengths can be used to support and enhance areas of difficulty. For example, focusing on the special interest areas of adolescents with autism has been found to enhance social behaviour, communication skills and joint attention, and to reduce anxiety (22). The strengths-based approach is increasingly being used by health professionals (23) and career development professionals (24).

The strengths-based approach may be particularly applicable to adolescents on the autism spectrum because their special interests can correlate with high performance in certain areas (25). When preferred interests are treated as strengths rather than deficits they can be leveraged to create opportunities for post-secondary education and employment (22). In addition, families of children on the autism spectrum and who are strengths-focused describe their child as more resilient and report improved overall family connectedness (26). Interventions with a strengths-focused approach have yielded positive outcomes for children on the autism spectrum. The iSTAR program, which supports children on the autism spectrum to leverage a special interest in graphic design to promote social skills and career exploration,

improved peer relationships and improved parent and sibling perceptions of the child on the autism spectrum (27, 28). In another study, Lego Therapy was used to improve social learning opportunities with parents, with findings indicating improved family relationships and improved communication skills in the child on the autism spectrum (29). Despite these studies having methodological limitations (i.e., small sample sizes, lack of control group), initial findings are promising in promoting the strengths-based approach for children on the autism spectrum. The strengths-based approach also clearly aligns with self-determination theory because awareness of personal strengths is an essential prerequisite to self-determination (30, 31).

### 3.3 Technology-based approach

Technology-based programs can be appealing to people on the autism spectrum for a number of reasons including their predictability, freedom from social-demands, and use of visual cues (32, 33). Therefore, interventions that utilise a technology-based approach may be especially beneficial for adolescents on the autism spectrum. A meta-analysis of technology-based interventions for people on the autism spectrum found that they can be effective in improving outcomes in a number of areas including social skills, communication, and emotional recognition (32). It also found that technology-based interventions appear to be growing in popularity for this group, with an increase in the number of studies published on the topic in the last decade. To the author's knowledge, there are no existing autism-specific transition planning programs that use a technology-based approach. However, there is emerging evidence supporting the use of technology to improve the transition planning process for adolescents with a disability in general. An evaluation of a technology-based transition planning intervention for adolescents with developmental disabilities found that participants not only reported increased satisfaction with the outcomes of the planning process, they also experienced increased self-determination (34). An internet-based program targeting interview skills of adolescents on the autism spectrum enhanced verbal interview skills (35). In addition, accessible software designed to support decision making was found to

increase self-determination and engagement of adolescents with disabilities (36). Finally, a technology-based approach is appropriate for an Australian context because it has the potential to enhance accessibility. This is especially important for adolescents on the autism spectrum and their families who may be living in regional or remote areas of Australia (37).

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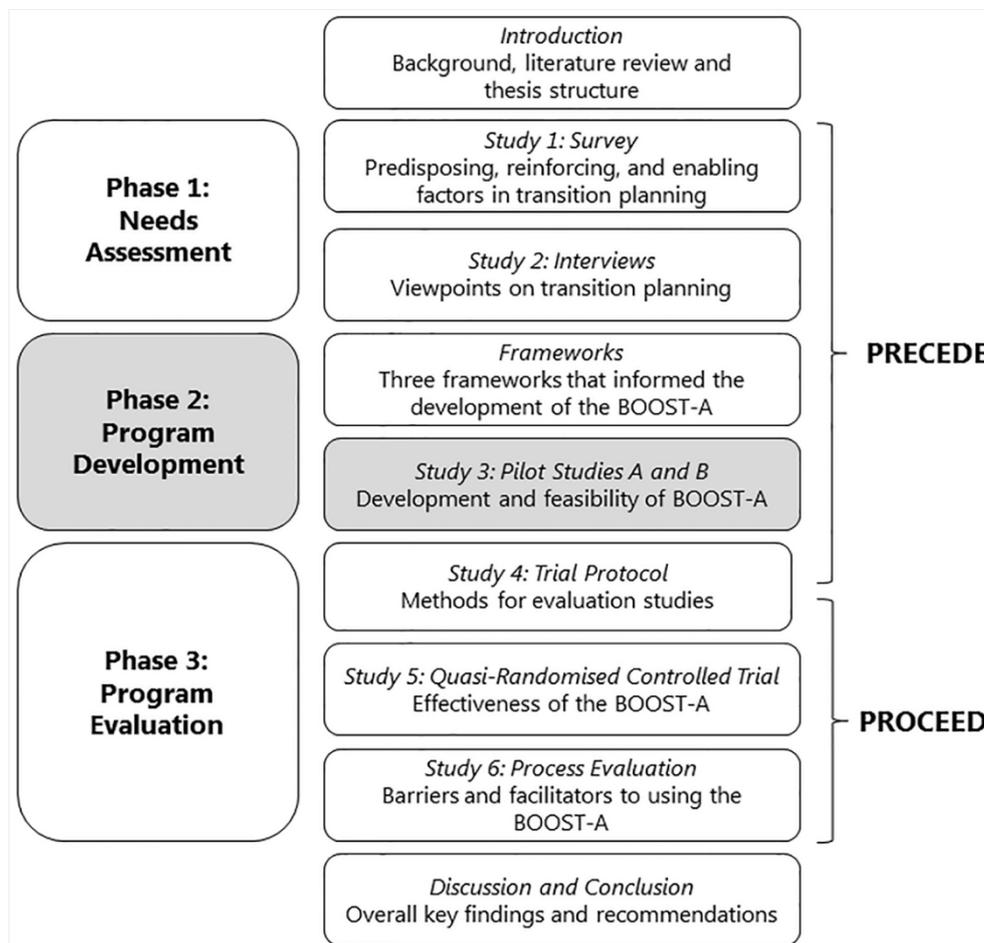
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# Chapter 4 PILOT STUDIES A AND B

Chapter 4 describes Phase 2, the development and pilot of the Better Outcomes & Successful Transition for Autism (BOOST-A™) program. Phase 1 of the thesis confirmed the need for a transition planning program that was specific to adolescents on the autism spectrum and suitable for the Australian context. To meet this need, BOOST-A™ was developed. Two pilot studies were conducted to determine the feasibility of the BOOST-A™.



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# Pilot of the BOOST-A™: An online transition planning program for adolescents with autism

Megan Hatfield<sup>1, 2, \*</sup>, Nina Murray<sup>1</sup>, Marina Ciccarelli<sup>1, 2</sup>, Torbjörn Falkmer<sup>1, 2, 3</sup> and Marita Falkmer<sup>1, 2, 4</sup>

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Australia

<sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Long Pocket, Brisbane, Queensland, Australia

<sup>3</sup> Department of Medicine and Health Sciences (IHM), Linköping University and Pain and Rehabilitation Centre, Sweden

<sup>4</sup> School of Education and Communication, Institution of Disability Research, Jönköping University, Sweden

\* Corresponding author

## 4.1 Abstract

**Introduction:** Many adolescents with autism face difficulties with the transition from high school into post-school activities. The Better Outcomes & Successful Transitions for Autism (BOOST-A™) is an online transition planning program which supports adolescents on the autism spectrum to prepare for leaving school. This study describes the development of the BOOST-A™ and aimed to determine the feasibility and viability of the program.

**Methods:** Two pilot studies were conducted. In Pilot A, the BOOST-A™ was trialled by six adolescents on the autism spectrum, their parents, and the professionals who worked with them, to determine its feasibility. In Pilot B, 88 allied health professionals (occupational therapists, psychologists, and speech pathologists) reviewed the BOOST-A™ to determine its viability.

**Results:** Participants rated the BOOST-A™ as a feasible tool for transition planning. The majority of allied health professionals agreed that it was a viable program. Based on participant feedback, the BOOST-A™ was modified to improve usability and feasibility.

**Conclusion:** The BOOST-A™ is a viable and feasible program that has the potential to assist adolescents with autism in preparing for transitioning out of high school. Future research will determine the effectiveness of the BOOST-A™ with adolescents across Australia.

**Key words:** Adolescence, autism spectrum disorder, disability, schools, work.

## 4.2 Introduction

Transition from high school is a pivotal period of development for adolescents, in which they develop a sense of identity through exploring adult roles and building autonomy (1). Adolescents experience role transitions in many occupational areas including socialisation, productivity, and leisure (2). Challenges that occur with successful role transitions at this stage can impact on the development of self-esteem and self-concept (3). For adolescents on the autism spectrum, the transition out of high school is often difficult; the employment rate of people with autism is 42%, which is less than people with other disabilities (53%), and people without disabilities (83%) (4). In addition, this group are less likely to attend post-secondary education (5). After leaving school, adolescents with autism can often be isolated and have reduced social participation (6). Therefore, there is a need for increased focus on the transition period for adolescents with autism to ensure successful participation in adult roles.

Transition planning is an important strategy to improve post-school outcomes for adolescents on the autism spectrum (7). Transition planning in high school involves engaging adolescents in activities that prepare them for leaving school (8).

Transition planning has been shown to improve self-determination, which is linked to improved post-school outcomes and greater community participation (9). Health professionals (i.e., occupational therapists, speech pathologists, psychologists) have a key role in transition planning by providing support in anxiety management, behavioural support, environmental modifications and enhancing social, communication, and independence skills (10). Best practice in transition planning recommends that parents, teachers and health professionals work together to provide holistic support (11, 12).

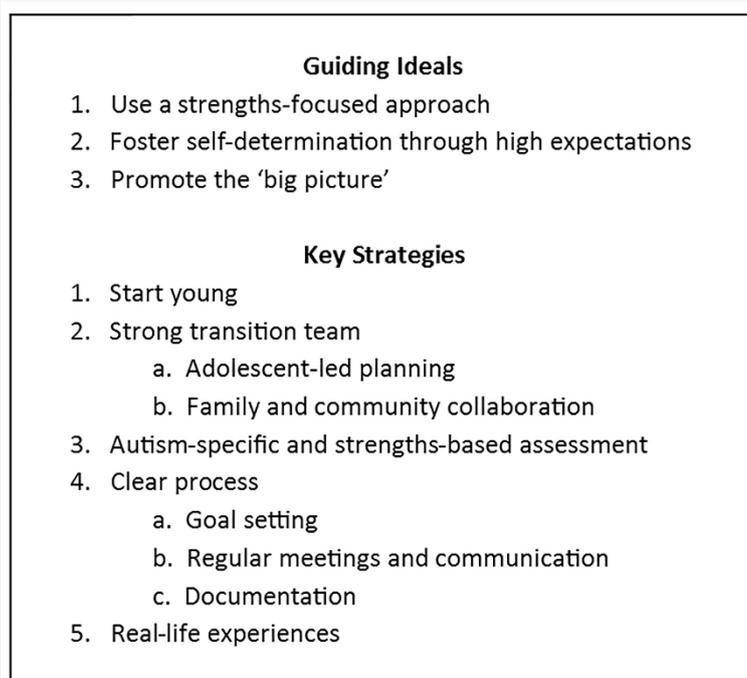
To the authors' knowledge, currently there are no validated transition planning programs specifically for adolescents on the autism spectrum to prepare for leaving school developed for the Australian context. A systematic review of 85 existing transition planning programs for adolescents on the autism spectrum found that none could definitively predict successful transition to employment (13). Therefore,

there is a need for autism-specific transition planning programs that have been rigorously developed. To meet this need, the Better Outcomes and Successful Transitions for Autism (BOOST-A™) program was developed.

#### **4.2.1 Frameworks guiding the development of the BOOST-A™**

The BOOST-A™ is an autism-specific, online transition planning program that is based on three main frameworks: self-determination theory, a strengths-based approach, and a technology-based approach. Self-determination theory explores the intrinsic motivation that one has to work towards their goals (14). Self-determination is an important concept for adolescents with disabilities, as it is a predictor of engagement in employment post-school (15). The strengths-based approach emphasises an individual's assets over their difficulties, and has been increasingly endorsed in its applicability to career development and transition planning (16). A technology-based approach has been found to enhance the engagement of adolescents with autism (17) and improve accessibility for families who lived in remote and regional areas (18).

The BOOST-A™ was developed to meet transition planning objectives (Figure 4-1), which were formulated based on a needs assessment (19, 20). Within the objectives are three guiding ideals and five key strategies.



**Figure 4-1. Transition planning objectives for adolescents on the autism spectrum**

The three guiding ideals informed the overall development of the BOOST-A™. Having a strengths-focused approach was a predisposing factor to successful transition planning (20) because high parental expectations have been associated with post-school success for adolescents (12). Participants in the needs assessment reported that promoting the 'big picture' assisted adolescents with autism in gaining an understanding of what life might be like after school, which enhanced motivation to participate in transition planning (19).

The five key strategies were based on specific recommendations; i.e., start when the adolescent is 14 years old (21, 22) and create a strong transition team with support from family and formal services (11, 12). Adolescent-led planning has been linked to improved self-determination and better post-school outcomes (11, 22). Using a strengths- and autism-based assessment assists adolescents with autism to identify interests that they can leverage into potential careers (11). Providing a clear process with regular meetings and communication is a predictor of post-school success (23, 24). Goal setting is associated with increased self-determined behaviour (22, 25). Finally, real-life experiences have been linked to post-school success because they promote skill development in a community context (15, 23).

## 4.2.2 Description of the BOOST-A™

The BOOST-A™ consists of four online modules and is delivered via a web-based platform. It begins with an **Introduction** that provides adolescents with an understanding of the purpose of transition planning and the justification for starting transition planning early.

The first module **About Me** is comprised of six activities that guide the adolescent to explore their strengths and autism-related characteristics to enhance career awareness.

- i. 'Interests': The Career Interest Test (CIT; 26) is a 63 item forced-choice questionnaire. Permission for use was granted by the author of the CIT, James Athanasou, along with the current rights holder for the CIT, Education Services Australia.
- ii. 'Strengths': Adolescents rate their strengths in areas such as technology, science, arts and physical activities on a five-point Likert scale.
- iii. 'Work Preferences': Adolescents rate their preferences related to socialising, sensory input (e.g. noise and movement) and routine.
- iv. 'Training after School': Adolescents nominate their preferred training pathway (i.e., tertiary study, training centre or hands-on training).
- v. 'My skills': Adolescents rate their current participation in community activities and daily activities.
- vi. 'Learning Styles': Adolescents identify how they learn best; via visual, auditory, or kinaesthetic input, or by reading or writing.

Informal assessments are utilised in this module, as supported by the literature (21, 23). All questions in this module were developed based on recommendations from the literature and the needs assessment (8, 19, 20, 27).

The second module, **My Team**, guides the adolescent and their parents to bring together appropriate people to support the transition planning process. In this module, adolescents are supported to become an active member of the team to promote increased self-determination. The adolescent is provided with strategies to support their involvement in meetings, determined by the literature review and needs assessment (19, 20).

The team all meet to complete the third module, **First Meeting**. They review recommendations for job ideas that leverage the adolescent's strengths, and develop goals including action steps and timeframes. Goals are suggested by the program that encourage the adolescent to gain real-life experiences; i.e., acquiring a part-time job, work experience, a mentor, career-exploration, and developing life skills.

The team complete the final module, **My Progress**, at all subsequent team meetings to review the transition plan. The adolescent is encouraged to gradually increase their involvement with each subsequent meeting, with the long term aim of the adolescent leading the meetings. The team reviews the job ideas and goals, and progress is shown as a percentage of the number of the steps completed. The module encourages positive reflection, and development of resilience, as the adolescent is supported to view any experiences that may not have gone to plan as opportunities for development, rather than failures.

### 4.2.3 Aim

Two pilot studies were conducted with the following objectives:

- i. Pilot A: Determine the feasibility of the BOOST-A™ for adolescents on the autism spectrum, their parents, and professionals who work with them.
- ii. Pilot B: Explore allied health professionals' perspectives on the viability of the BOOST-A™.

## 4.3 Materials and methods

### 4.3.1 Participants

Participants for **Pilot A** were recruited using convenience sampling from an expression of interest list. Potential participants were emailed an information sheet about the study and a link to an online consent form. Inclusion criteria for participating in this study were:

1. Adolescents on the autism spectrum and their parents living in Perth, Western Australia;
2. Enrolled in Years 8 to 11 at school (including mainstream, special education or home-schooled programs);
3. Ability to read and write in English; and
4. Adequate computer skills to enable use of the BOOST-A™.

Adolescents on the autism spectrum who were already enrolled in a different transition planning program were excluded from participating in the study.

In **Pilot B**, health professionals were recruited via snowball sampling. Recruitment materials (information sheet and a link to the online survey) were disseminated via the newsletters of state and national professional associations, special interest groups, and social media for health professionals. Health professionals who were known to the researchers agreed to distribute the survey among colleagues. Organisations, including disability services, private practices, and hospitals, distributed the survey among allied health employees. Inclusion criteria were:

1. Australian accredited occupational therapists, speech pathologists, or psychologists; and
2. Current or previous experience working with an adolescent with autism.

### 4.3.2 Data collection

An online survey to obtain participants' perspectives about the BOOST-A™ was designed using Qualtrics software (Version 2013; 28). The first section was

comprised of demographic questions. The second section asked participants to rate each module of the BOOST-A™. Participants ranked the following five statements on a four-point Likert scale, anchored by strongly disagree and strongly agree:

1. This module is **helpful** for transition planning for adolescents with autism.
2. This module is **realistic** to complete in transition planning for adolescents with autism.
3. This module is **meaningful** to transition planning for adolescents with autism.
4. This module is **relevant** to transition planning for adolescents with autism.
5. It is **easy to understand** how to use/fill in this module.

Participants had the opportunity to provide additional free text feedback about each module of the BOOST-A™. The survey was piloted with two experienced health professionals, one parent, and one adolescent on the autism spectrum. Feedback was integrated to improve the survey before distribution to participants.

Allied health professionals provided an additional overall evaluation of the BOOST-A™. The following three statements were rated from strongly disagree to strongly agree on a four-point Likert scale:

1. The BOOST-A™ would take an appropriate **length of time**.
2. I **would use** the BOOST-A™ for transition planning with adolescents with autism.
3. An adolescent with autism would be **able to complete** the BOOST-A™.

### 4.3.3 Procedure

In Pilot A, adolescents and parents completed the first two modules of the BOOST-A™; About Me and My Team, in their own homes. Subsequently, participants met with their team and then completed the third module, First Meeting. The fourth module, My Progress, was not completed, as it would typically be completed three months after the first meeting, which did not fall within the time constraints of the pilot. Therefore, participants were provided with a simulated demonstration of the 'My Progress' module. Participants completed the online survey to provide feedback on each module in the BOOST-A™ directly after completing each module.

In Pilot B, allied health professionals provided feedback by viewing screen shots of the four modules of the BOOST-A™, that were embedded into the online survey. After each screen shot, participants rated the module on the above five statements.

#### **4.3.4 Data analysis**

Survey data were collated electronically via Qualtrics (Version 2013; 28) and transferred to the Statistical Package for the Social Sciences (SPSS v.20; 29) for analysis. Descriptive statistics were used to determine the percentage of responses for each category on the four-point Likert scale, indicating agreement and disagreement for each survey item. For Pilot B, between-group differences were calculated using Kruskal-Wallis for discipline, and Mann-Whitney U for length of practice. Length of practice was categorised as one of two variables: i) experienced (15+ years); or ii) less experienced (0-15 years). A critical  $\alpha$ -level of 0.05 was used in all analyses. Content analysis was used for free text feedback to identify common issues. In Pilot B, the frequency that these issues were raised was also calculated.

#### **4.3.5 Ethical considerations**

Ethics approval was granted by Curtin University Human Research Ethics Committee (approval number HR110/2014 and RDHS-01-15). Catholic Education Office and the Department of Education of Western Australia provided ethics approval for Pilot A. The study followed the National Statement on Ethical Conduct in Human Research (30) and the Australian Code for the Responsible Conduct of Research (31). Written informed consent was obtained by participants over the age of 18 years. Participants under 18 years of age provided written informed assent and their parent provided written informed consent for their participation. Written approval was provided by principals of schools that participated in Pilot A.

### **4.4 Results: Pilot A**

#### **4.4.1 Demographics**

Six adolescents on the autism spectrum and their parents/carers participated in the study (Table 4-1). The adolescents were in years 10 and 11, with the majority being

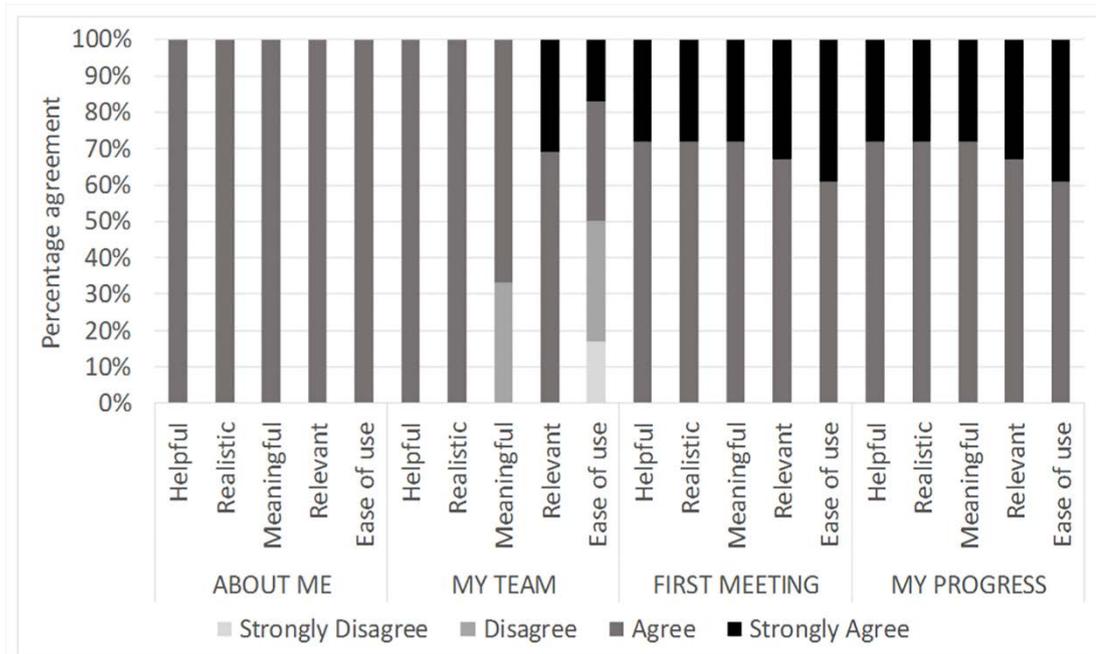
male. Overall, twelve professionals participated in the team meetings, including teachers, Local Government Coordinators, Occupational Therapists, a Speech Pathologist and a Support Worker. One participant withdrew after completing the first two modules, and therefore did not provide feedback on the third and fourth module. The participant withdrew due to experiencing difficulties with anxiety impacting on school participation.

**Table 4-1. Participant demographics Pilot A (N=6) and Pilot B (N=88)**

<b>Pilot A – Adolescents</b>	<b>n (%)</b>
Gender	
Male	4 (66.7)
Female	2 (33.3)
State	
Western Australia	6 (100)
School year	
Year 10	3 (50)
Year 11	3 (50)
<b>Pilot B – Allied health professionals</b>	<b>n (%)</b>
Gender	
Male	4 (4.5)
Female	84 (95.5)
State	
Western Australia	16 (18.2)
Northern Territory	2 (2.3)
South Australia	3 (3.4)
Queensland	12 (13.6)
New South Wales	31 (35.2)
Victoria	14 (15.9)
Australian Capital Territory	5 (5.7)
Tasmania	5 (5.7)
Qualification	
Occupational Therapist	29 (33.0)
Psychologist	29 (33.0)
Speech Pathologist	26 (29.5)
Other	4 (4.5)
Experience (years)	
0-5	20 (22.7)
6-10	12 (13.6)
11-15	13 (14.8)
16-20	12 (13.6)
21+	31 (35.2)

## 4.4.2 Feasibility ratings

The ratings for all of the modules in the BOOST-A™ program can be seen in Figure 4-2.



**Figure 4-2. Pilot A module ratings**

The **About Me** module was rated as being helpful, realistic, meaningful, relevant, and easy to understand (100%). However, participants reported that the Interests activity had too many questions and was too long. Some adolescents reported difficulty understanding some of the options in the CIT, e.g., ‘engineering’ and ‘agriculture’. Some professionals recommended that parents should review their adolescent’s answers in this module, because sometimes their responses were “unrealistic”.

The **My Team** module was rated as helpful, realistic, and relevant by all participants (100%), and most agreed that it was meaningful (66.7%). However, participants were divided on whether it was easy to understand (50% agreed; 50% disagreed). Adolescents reported that they did not understand the purpose of having a team.

All participants agreed that the **First Meeting** module was helpful, realistic, relevant, meaningful, and easy to understand (100%). Many participants reported it was helpful to create a transition planning team; one parent stated “Getting everyone

together in one place was worth its weight in gold." Parents reported that adolescents may benefit from an overview of what the meeting would involve to assist them to prepare for the meeting.

Participants rated the **My Progress** module as helpful, realistic, relevant, meaningful, and easy to understand (100%). Participants supported the positive focus when reviewing goals: "I love the section about how there are no failures, only learning opportunities". Participants suggested that the team should be emailed a report summarising the meeting content.

### 4.4.3 Free text responses

Participants reported that having an overall transition planning process was helpful. For example, one parent stated "this program will help guide us through the process of transitioning my child from high school to adult life a lot easier than if I had to do this alone." The main barrier identified was accessibility. The BOOST-A™ was initially developed using Java software, and many participants reported encountering difficulty downloading and using the BOOST-A™ on this platform. Parents also reported that written explanations were difficult for the adolescents to understand. However, they endorsed the importance of supporting the adolescent to understand the big picture, and recommended using visuals to support in the understanding of this concept.

## 4.5 Results: Pilot B

### 4.5.1 Demographics

Eighty-eight allied health professionals provided feedback on the BOOST-A™ (Table 4-1). Participants were from all six states and two territories in Australia and the majority were female. Participants' gender and location per jurisdiction were representative of national health professional demographics (32). The majority of participants had practiced for 21 years or longer. There was no difference between professionals in different disciplines or based on the two different levels of experience ( $p > 0.05$ ) in how they rated the BOOST-A™ overall or for each module.

## 4.5.2 Viability ratings

Allied health professionals' ratings for both the overall and each individual module of the BOOST-A™ are shown in Figure 4-3. Overall, the majority of health professionals agreed or strongly agreed the BOOST-A™ was appropriate and feasible (75% and 69%, respectively) to support the transition planning process for adolescents with autism. In addition, 84% reported they would use the BOOST-A™ in the future (see usability in Figure 4-3). The majority of participants reported they either agreed or strongly agreed the modules were viable (average percentage of agreement for each module: About Me 90%, My Team 86%; First Meeting 86%; My Progress 88%).

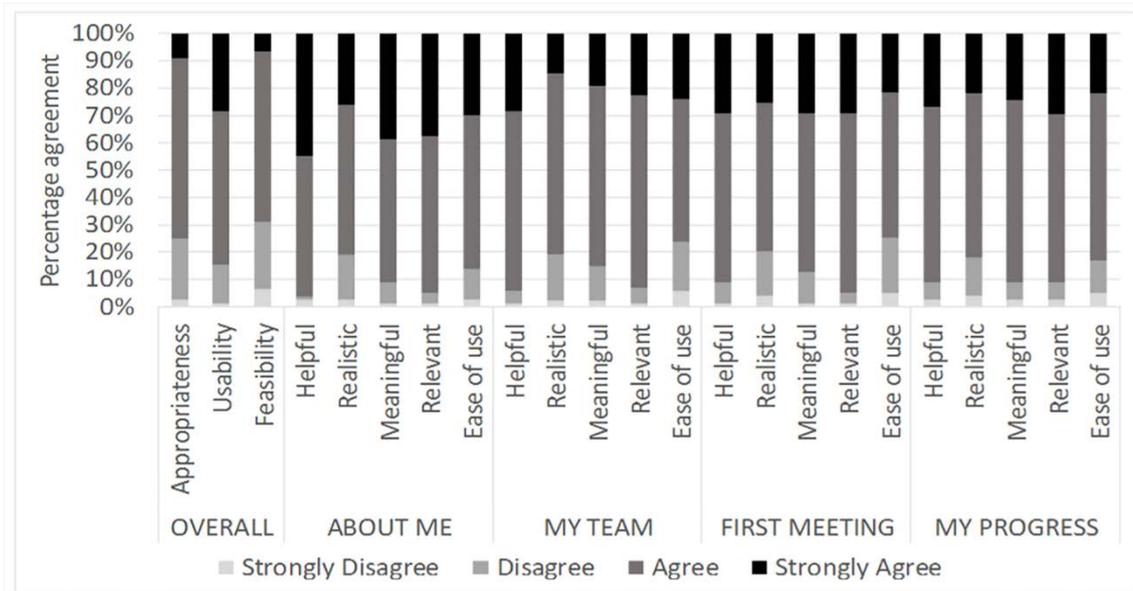


Figure 4-3. Pilot B overall and module ratings

## 4.5.3 Free text responses

Seventy-one participants provided free text feedback. Overall, participants reported the BOOST-A™ filled a gap in transition planning, and would be valuable: “badly needed both for students and those assisting them...”, and “provides a nice structure for transition planning for this population”. Analysis of free text feedback identified three common issues to be considered for the development of the BOOST-A™. The main issue participants reported was that the language used was verbose (44% of comments). Some participants suggested increasing visual and graphic explanations

(18% of comments) to remedy this. Another issue was the BOOST-A™ required relatively high levels of insight and meta-cognition by the adolescent on the autism spectrum (39% of comments). Furthermore, 17% of comments referred to a need for more overall guidance in how to use the BOOST-A™; i.e., instructions for use, recommended level of assistance, and suggested timeframes.

## 4.6 Modifications to the BOOST-A™

Recommendations from the pilot participants were discussed with a community reference group before modifications were made to the BOOST-A™. The main revision was the conversion to a web-based platform to enhance accessibility and functionality. Improvements to the navigation and flow of the program were incorporated to improve intuitiveness and ease of use. A flowchart was included in the introduction page that outlined each module. Text explanations were replaced with short animated videos. Information sheets were developed for parents and professionals using an infographic-style emphasising the three key ideals of the program, including the suggestion that an adult support the adolescent to complete the **About Me** module.

To reduce the number of questions in the **About Me** module, the CIT short form was used reducing the number of questions from 63 to 21. The CIT short form has been found to have good construct validity and it retained the original factor structure of the original version (33). In addition, images and an explanation of each option were added to appear when the mouse hovers over the image. An animated video at the start of the **My Team** module was added to explain the purpose of a team. Suggestions were added to support the adolescent to actively participate in meetings; i.e., using a sensory strategy to support their engagement in the meeting. The **First Meeting** module was modified to include an overview of what the meeting would involve, to better prepare the adolescent. A prompt was added to encourage the team to intermittently check-in with the adolescent, to ask if they need a break and if the pace is suitable for them. Goal setting was modified so that it was more structured, including a number of recommended steps towards achieving each goal and encouraging team members to take ownership of tasks to encourage

accountability. The **First Meeting** and **My Progress** sections were both updated, so an automatic email was sent to team members after each meeting with a summary of what was discussed.

## 4.7 Discussion

The majority of participants in pilot studies A and B reported that the BOOST-A™ was helpful, realistic, and relevant. This indicates that participants perceived the BOOST-A™ as a feasible and viable protocol with the potential to assist adolescents on the autism spectrum in the transition planning process. One potential reason for this positive feedback may be that the BOOST-A™ was developed based on transition planning objectives for adolescents on the autism spectrum. The BOOST-A™ encourages team collaboration, active engagement of the adolescent, goal-setting, and engagement in real-life experiences; all of which are considered best-practice in transition planning (24). Modifications based on the feedback from participants were made to improve overall usability to the program. For example, the conversion to a web-based program, increased use of visual graphics and an overall reduction in the length of the program.

Participants in Pilot A reported that forming a team was one of the most helpful elements of the BOOST-A™ process, which aligns with literature that promotes multi-disciplinary participation in transition planning (10). Given the importance of inter-agency support, it is crucial for all professionals to be in agreement about the transition planning process. In Pilot B, there were no differences between groups based on professional discipline or level of experience, indicating that participants considered the protocol to be viable regardless of profession or experience level. This suggests that the BOOST-A™ could be used to enhance collaboration among multi-disciplinary teams.

In both pilots, participants identified concerns about whether the adolescents on the autism spectrum had the cognitive skills to complete the BOOST-A™. Literature is inconsistent about whether adolescents on the autism spectrum are able to accurately assess their own abilities. A lack of self-understanding has been described

as a characteristic of autism (34). Other studies have found that some people on the autism spectrum feel that those closest to them, such as parents, have greater insight into their personalities and internal states than themselves (35, 36). In contrast, adolescents on the autism spectrum have been identified as having the same level of insight as their neurotypical peers (37). Due to the inconsistency in the literature on this topic, instructions in the BOOST-A™ now include the recommendation that adolescents should be supported by parents or other team members when using the program.

### **4.7.1 Future research opportunities**

The two pilot studies determined the feasibility of the BOOST-A™. In a planned future study, the BOOST-A™ will be trialled with a sample of 80 adolescents on the autism spectrum to determine its efficacy in increasing self-determination. Self-determination is associated with improved post-school outcomes for adolescents with disabilities (9).

### **4.7.2 Limitations**

A limitation to Pilot B was that participants provided feedback on screenshots of the BOOST-A™. Unfortunately trialling a live version of the program was not possible due to technical difficulties with the Java version of the program. This provided further justification for developing the BOOST-A™ into a web-based program. The relatively small number of participants per profession may have introduced Type II error when determining between-group differences. In Pilot A, it would have been preferable to trial the BOOST-A™ with a larger number of participants.

A potential limitation for both pilot studies included possible sampling bias, as participation relied on participants to self-nominate. Hence, participants may have been specifically interested in transition planning, possibly resulting in a positive bias. However, participants with an interest in transition planning are likely more appropriate to provide feedback on the BOOST-A™ than those without any interest in the process.

## 4.8 Conclusion

The BOOST-A™ was considered by all stakeholders to be a feasible and viable intervention to assist adolescents on the autism spectrum to feel more prepared for leaving school and transitioning to adult life.

### 4.8.1 Key points for occupational therapy

- Occupational therapists play a key role in transition planning for adolescents with autism.
- Occupation-centred and strengths-based approaches align well with best-practice in transition planning; i.e., high-expectations and real-life experiences.
- Further research is needed to advance occupational therapists' role in transition planning for adolescents with autism.

## 4.9 Declarations

### **Funding**

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### **Authors' contribution**

MH, NM, MC, TF, MF contributed to the design of the study. MH and NM collected the data and drafted the manuscript. MH, NM, MC, TF, MF reviewed the manuscript. The manuscript has been read and approved by all authors.

### **Conflict of interest**

We have read and understood the Australian Occupational Therapy Journal's policy on declaration of interests and declare the following interests: MH developed the BOOST-A™ and was also the first author of the manuscript which describes the pilot of the BOOST-A™.

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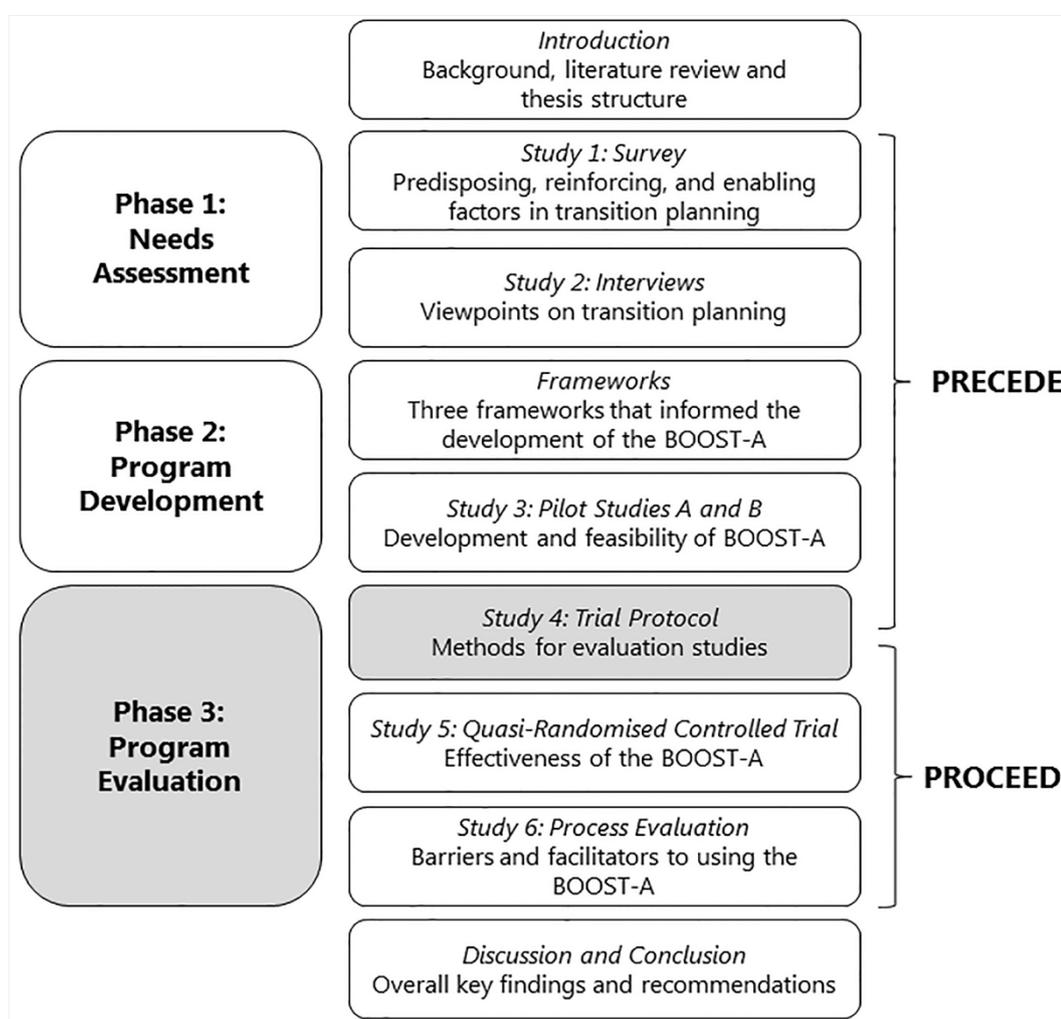
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# Chapter 5 TRIAL PROTOCOL

Chapter 5 outlines the trial protocol for the evaluation of the effectiveness of the BOOST-A™. The trial protocol followed principles of the SPIRIT guidelines,<sup>1</sup> which aim to reduce publication bias and improve replicability of studies. This chapter provides an overview of the preceding phases, including the needs assessment and development of the BOOST-A™. It describes the methodology for determining the efficacy of the BOOST-A™ in Phase 3, including the quasi-randomised controlled trial and process evaluation.



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The manuscript is presented in PDF format and formatted as per the guidelines for the Child and Adolescent Psychiatry and Mental Health.

## Author Contribution Statement

As co-authors of the paper entitled, '*Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: Trial protocol*', we confirm that Megan Hatfield 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; and
- 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 collection, analysis, and interpretation; and
- Review and editing of the manuscript.

*Signed:* Torbjörn Falkmer Date: 25/05/17

*Signed:* Marina Ciccarelli Date: 25/05/17

*Signed:* Marita Falkmer Date: 25/05/17

RESEARCH ARTICLE

Open Access



# Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: trial protocol

Megan Hatfield<sup>1,2\*</sup>, Marita Falkmer<sup>1,2,5</sup>, Torbjorn Falkmer<sup>1,2,3,4</sup> and Marina Ciccarelli<sup>1,2</sup>

## Abstract

**Background:** The transition from high school to post-secondary education and work is difficult for adolescents on the autism spectrum. Transition planning can be an effective way of supporting adolescents on the autism spectrum to prepare for leaving school and to succeed in obtaining employment; however, there is a need for an autism-specific transition planning program with proven effectiveness. This paper describes a trial protocol for evaluating the Better Outcomes & Successful Transitions for Autism (BOOST-A™); an online interactive program that empowers adolescents on the autism spectrum to plan their transition from school to further study, training, or employment.

**Methods:** The trial will involve adolescents on the autism spectrum in high school and their parents, who will be alternately assigned to a control group (regular practice) or an intervention group (using the BOOST-A™). The BOOST-A™ was developed using the PRECEDE-PROCEED model, and is based on the self-determination model, and the strengths- and technology-based approaches. It involves participants completing a series of online modules. The primary outcome will be self-determination, because high self-determination has been linked to successful transition to employment among adolescents on the autism spectrum. Secondary outcomes will include domain-specific self-determination, career planning and exploration, quality of life, and environmental support. Data will be obtained from questionnaires completed by the adolescent on the autism spectrum and their parent/s. Data collection will take place at baseline (Time point 1) and 12 months later (Time point 2).

**Discussion and conclusions:** This trial will provide evidence of the effectiveness of the BOOST-A™ to assist adolescents on the autism spectrum to successfully transition from school.

*Trial registration #ACTRN12615000119594*

**Keywords:** Asperger's syndrome, Autism spectrum disorder, Employment, High school, Post-secondary education, Self-determination theory

## Background

People on the autism spectrum experience difficulties with socialization and communication, as well as restricted interests and repetitive behaviours [1]. The term 'people on the autism spectrum' is the one of the

preferred terms by members of the autism community [2] and describes people with a diagnosis of autism spectrum disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM-5) [1]. This includes individuals with Asperger's syndrome and pervasive developmental disorder—not otherwise specified, as previously delineated in the DSM-4 [3]. The transition from school to post-school activities is difficult for adolescents on the autism spectrum [4, 5], who are significantly less likely to attend post-secondary education

\*Correspondence: Megan.Hatfield@curtin.edu.au

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Perth, Australia

Full list of author information is available at the end of the article



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and training than young people with other disabilities [6]. People on the spectrum who have an intellectual ability within or above the average range have difficulty securing employment; only 16% in Australia have full-time employment after leaving school and 33% work part-time [7]. In addition, adolescents on the autism spectrum are three times less likely to participate in vocational activities compared to their peers on the autism spectrum who also have an intellectual disability (ID) [8].

A lack of transition planning can contribute to poor post-school outcomes for adolescents on the autism spectrum [6]. Transition planning involves the setting of personal goals to prepare the adolescent for leaving high school. Transition planning has been linked to improved self-determination, increased rates of employment, improved success in post-secondary education, and higher community participation among adolescents with disability [9]. Unfortunately, current transition planning practices have resulted in inferior outcomes for adolescents on the autism spectrum when compared to adolescents with other disabilities [10]. Only 23% of adolescents with autism are involved in transition planning [11]; and even when they are involved, they are less likely to be active participants in the process. Fewer parents of adolescents with autism perceive the transition planning process as useful [11], and have reported that they want to be more involved in the process [10, 12]. Currently, schools tend to focus on the academic performance of adolescents on the autism spectrum who do not have an ID, rather than engaging them in comprehensive transition planning [13]. In addition, autism-specific challenges are often not taken into consideration. These include difficulties conceptualizing hypothetical future events, managing anxiety, and communicating their preferences to others [13]. Therefore, there is a need for a more tailored transition planning program for students with autism.

Further to this, there is a need for a transition planning program that has proven effectiveness [14]. Current generic transition planning programs have little empirical evidence to prove their efficacy [15] and many focus on limited aspects of transition planning [16–18]; failing to provide an overall guide for adolescents and their parents on how to navigate the entire transition planning process. There is a need for an accessible and tailored transition planning program for adolescents on the autism spectrum that is proven to be effective in improving their self-determination.

This paper describes a trial protocol for the development and evaluation of a transition planning program called the Better Outcomes & Successful Transitions for Autism (BOOST-A™). The BOOST-A™ aims to target the specific needs of adolescents on the autism spectrum, to empower them to plan their transition from

school to further study, training or paid/unpaid work. This trial follows principles of the SPIRIT guidelines for protocols that support high-quality conduct and reporting of clinical trials [19].

#### Objectives of the trial

The hypothesis for the trial is that the BOOST-A™ will improve self-determination in adolescents on the autism spectrum transitioning to post-school life. The objectives of the trial are to:

- (1) determine the effectiveness of the BOOST-A™ in improving self-determination in adolescents on the autism spectrum; and
- (2) determine the effectiveness of the BOOST-A™ in improving quality of life; access to environmental supports; career planning and exploration; and vocational exploration among adolescents on the autism spectrum.

#### Methods

##### PRECEDE-PROCEED model

The PRECEDE-PROCEED model [20] was used to guide the development and evaluation of the BOOST-A™. The model provides a stepwise guide to developing evidence-based interventions that meet the needs of the target group [21]. The model has been used to develop previous health interventions [22, 23]. The PRECEDE component guides the development of an intervention through the application of available research and an appropriate theoretical framework [20], and was used in the development of the BOOST-A™. The PROCEED component provides guidance on trialing and evaluating an intervention, and was used to structure the trial of the BOOST-A™.

##### Theoretical frameworks

The BOOST-A™ was based on three main theoretical frameworks: the self-determination model, a strengths-based approach, and a technology-based approach.

##### Self-determination model

Self-determination is an individual's ability to direct their own life; that is, to make choices about the pathway they will take without feeling they have to rely heavily on others [24]. Self-determined people are goal-orientated, have strong problem-solving abilities, and know their strengths and weaknesses. The environment plays a pivotal role in the development of a young person's self-determination, with the greatest environmental influences being their family, school, and the wider community [25]. Self-determination is influenced by an individual's sense of autonomy, competence and relatedness; all of which impact on intrinsic motivation [26].

Self-determination can be fostered by incorporating four key facets: promotion of self-knowledge; consistent support between family, school and professionals; opportunities to take risks; and supporting reflective practice [27].

Self-determination has particular importance for people with a disability, because it is a predictor of successful transition into an autonomous adult life, and is crucial to living an empowered life [25, 27–29]. People with developmental disabilities who feel a greater sense of control in their lives are more likely to be employed in the regular workforce [30]. Therefore, the model of self-determination was used to underpin the development of the BOOST-A™.

#### **Strengths-based approach**

A strengths-based approach advocates focusing on the individual's strengths, as opposed to the focus on deficits that is often associated with the medical model [31]. The strengths-based approach was developed in the 1980s to challenge the paradigm that disability is a weakness and a fundamental flaw in the individual, and that individuals were to blame for their difficulties [32]. In contrast, a strengths-based approach views the individual as an asset to society and focuses on how the community can support them to leverage their talents, rather than on how the individual can change to meet society's expectations. The strengths-based approach is being increasingly utilized by many health professionals [33], as well as in the career development arena [34]. In addition, families with children on the autism spectrum who focused on their child's strengths had a more positive view of disability and described their child as being more resilient [35]. Thus, the strengths-based approach was used in developing the BOOST-A™.

#### **Technology-based approach**

Technology-based interventions for individuals on the autism spectrum are growing in popularity [36]. A meta-analysis of technology-based training for people with autism supported the effectiveness of these interventions and advocated their use with this population [37]. Furthermore, parents and students with developmental disabilities who used technology in transition planning were significantly more satisfied with the outcomes of the planning process and experienced increased self-determination [16]. The use of technology-based interventions could be particularly relevant for people on the autism spectrum, as they often have an interest in, and aptitude for, technology [38]. An online program also has the potential to increase accessibility to the transition planning process, especially for adolescents and their families living in regional or remote areas. Therefore, a

technology-based approach was used for the development of the BOOST-A™.

#### **Needs assessment**

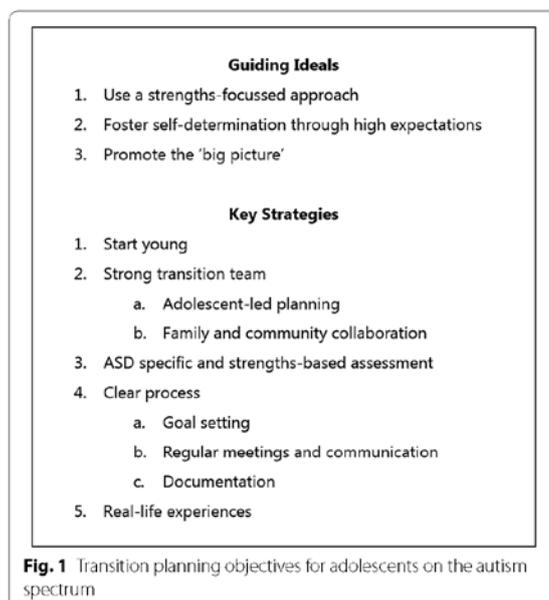
As recommended by the PRECEDE model, a needs assessment was completed to determine the priority areas in transition planning for adolescents on the autism spectrum [20]. The needs assessment encompassed a range of information sources and included both quantitative and qualitative data, as recommended in the literature [39]. The needs assessment involved two phases: (i) a survey of the adolescents on the autism spectrum, their parents and the professionals who work with them; and (ii) interviews with the parents and professionals. In addition, a systematic review was completed to appraise career planning tools for use with individuals on the autism spectrum [40], and a comprehensive literature review was conducted to identify current best-practice in transition planning.

The findings of the literature review and the needs assessment shaped the transition planning objectives for adolescents on the autism spectrum (Fig. 1). The objectives consisted of three guiding ideals and five strategies to direct the overall development of the BOOST-A™. The ideal of 'Promote the big picture' is particularly important for adolescents on the autism spectrum, as it advocates the importance of assisting adolescents to understand what life will be like after school. Adolescents with autism may not implicitly understand the 'big picture' due to difficulties with abstract thought [41], which may cause them to be less motivated to take part in transition planning. Therefore, assisting adolescents on the autism spectrum to understand the 'big picture' may enhance their motivation and participation in transition planning. The full findings of the needs assessment are reported elsewhere [42].

#### **The intervention: BOOST-A™**

Using the transition planning objectives for adolescents on the autism spectrum (Fig. 1), the primary researcher (MH) developed the BOOST-A™. The BOOST-A™ was written in plain language at a year five reading level. This reading level has been recommended as being appropriate to disseminate health communication materials to the community, including low-literacy readers [43]. Feedback was obtained by a community reference group comprised of young people on the autism spectrum, parents and professionals throughout the development of the BOOST-A™ to ensure it met the needs of adolescents on the autism spectrum.

The BOOST-A™ is delivered in four online modules with an introduction via a website that requires a login. Table 1 shows the objectives addressed in each module.



Each of the BOOST-A™ modules contains interactive cartoon videos that explain to the adolescent the overall purpose of transition planning, as well as the aim of each module. This links back to the guiding ideal identified in the needs assessment of 'promote the big picture.'

The first module is 'About Me', in which the adolescent completes a number of activities to identify their interests and strengths. The focus is on leveraging the adolescent's strengths, rather than focusing on their weaknesses

[32]. The second module is 'My Team', which assists the adolescent and their parents to identify people who may support them in their transition planning journey. Being actively involved in transition planning and having people who provide tangible assistance and encouragement is pivotal to promoting self-determination [44, 45]. Therefore, this module encourages and supports the adolescent to become an integral and active member of the team. The third module, 'First Meeting', guides the team to develop goals; providing recommendations for goals that are based on the adolescent's strengths and best-practice recommendations from the research literature, such as the importance of engaging in real life experiences [9]. The fourth module, 'My Progress', is completed by the team at all subsequent team meetings to review how the adolescent's goals are progressing. This module encourages the team to reflect on progress in a positive manner and to view all experiences as learning opportunities, rather than failures.

**Pilot studies**

Two pilot studies were conducted to determine the feasibility of the BOOST-A™, and to provide formative and process feedback. The pilot studies were:

- (1) Pilot A: with adolescents on the autism spectrum, their parents, teachers and other professionals; and
- (2) Pilot B: with allied health professionals.

*Pilot A* consisted of adolescents on the autism spectrum (n = 6), their parents (n = 6) and the professionals who worked with them (n = 12); who were recruited using convenience sampling from a database of people

**Table 1** BOOST-A™ overview

Module	Description	Who and where	Objectives addressed
Introduction	Information about the process and what to expect in the program, and why it is important to engage in transition planning from an early age	Adolescent and their parent/s at home	1, 2, 4
1. About Me	Six activities to identify the adolescent's interests, strengths, work preferences, training goals, life skills and learning style	Adolescent and their parent/s at home	2, 3, 4, 5
2. My Team	Guides how to identify a team of people to support the adolescent in their transition planning, and how to book the first team meeting. Adolescents choose how they want to get involved in the team meetings, with graded prompts provided	Adolescent and their parent/s at home	2, 4, 5
3. First Meeting	Guides the first meeting; when the team are provided with recommendations for job areas and goals based on the adolescent's strengths and evidence from the literature	Adolescent, their parent/s and their team at the first meeting	2, 3, 4, 5
4. My Progress	Guides the progress meetings; when the team review how the adolescent's goals are progressing; and discuss positive learning experiences	Adolescent, their parent/s and their team at subsequent team meetings	2, 3, 4, 5

who had registered their interest in the research project. Participants were asked to use the BOOST-A™ along with their team and to provide feedback on the process. All participants rated the BOOST-A™ as helpful, realistic and relevant (100%). Participants rated the 'My Team' section as low for usability (50%), and provided recommendations for improvement.

*Pilot B* included 88 allied health professionals, including speech pathologists (n = 26), psychologists (n = 29) and occupational therapists (n = 29) registered to practice in Australia, and recruited through allied health forums and professional networks. Participants completed an online survey comprised of questions about whether the BOOST-A™ was helpful, realistic, meaningful, relevant, and clear. Approximately three out of four (76%) of the allied health professionals rated the BOOST-A™ as appropriate, usable, and feasible; and 84% reported they would use BOOST-A™ in the future. Participants identified three main areas for improvement: (i) verbose language, (ii) need for support from parents in the 'About Me' section, and (iii) need for guidance overall in the program; and provided suggestions for improvement.

Based on feedback from both pilots, the BOOST-A™ was modified to enhance usability of the program, with the conversion from a Java platform to a web-based program that allowed for improved navigation and increased use of graphics and animations, and an overall reduction to the length of the program. The full results from these pilot studies are reported elsewhere [46].

#### **Trial design and procedures**

A controlled clinical trial [47] will be used to determine the effectiveness of the BOOST-A™ in improving the self-determination of adolescents on the autism spectrum; and in improving their outcomes of quality of life, access to environmental supports, and career planning skills. The trial will be a cluster group, two-arm, superiority trial with 1:1 allocation ratio. The trial will aim to detect any difference in these outcomes between participants in the intervention group (BOOST-A™) and a control group. Figure 2 shows the schedule of enrolment, intervention, and assessment for the trial. Participants in the intervention group will complete the BOOST-A™ at home and/or at school. Participants will complete the BOOST-A™ over a period of 12 months. This timeframe was chosen to ensure the participants have adequate time to complete all four modules, including the initial team meeting and at least one review meeting. Adherence will be monitored via website analytics, including number of modules completed and number of logins to the BOOST-A™ website. Participants allocated to the control group will participate in the existing post-school planning process used at their school (regular practice).

#### **Participants**

*Identification and recruitment* Potential participants will be recruited via social media and community organization websites, flyers, and posters located in services for people on the autism spectrum. Community organizations, health professionals, and schools will be asked to email any potential participants directly. Recruitment material will consist of a flyer outlining the inclusion criteria and requirements of the trial. The flyer will request prospective participants to contact the primary researcher (MH) directly via email or telephone to register their interest in the trial. At the initial contact, each potential participant will be screened by MH for eligibility, and they will be sent the electronic participant information form and a link to an online consent form.

*Inclusion and exclusion criteria* Inclusion criteria for participating in this trial are as follows:

- Adolescents diagnosed with Autism spectrum disorder, as defined by the diagnostic and statistical manual of mental disorders, fifth edition (DSM-5) [1] or the fourth edition (DSM-4) [3];
- Living in Australia;
- Able to read and write in English at a year five reading level;
- Enrolled in years 8–11 at school (including mainstream, special education or home-schooling programs); and
- Possess basic computer skills to enable use of the online BOOST-A™.

Adolescents will have a formal diagnosis of autism prior to participating in this trial. Diagnosis will be verified by the Social Responsiveness Scale-Second Edition (SRS-2) [48]. The SRS-2 is a diagnostic screening tool, and has been used in previous trials to verify diagnosis [49, 50]. Whilst it would be preferable to have used the autism diagnostic observation schedule (ADOS) [51] for diagnosis, it is not possible for the researchers to administer this 60 min assessment in person given the wide geographic distribution of participants across Australia. Further verification of diagnosis will be provided by parent report, as previous studies have verified the validity of diagnostic information reported by parents [52]. Exclusion criteria will be if the adolescent on the autism spectrum has an ID, as this will limit their ability to use the program, or if the student is enrolled in another transition planning program. Whilst it would have been ideal to complete an assessment of cognitive functioning for each participant, this is not feasible as the sample will be recruited from across Australia and the trial will be completed only online.

	STUDY PERIOD				
	Enrolment	Allocation	Post-allocation		Close-out
TIMEPOINT	-t <sub>1</sub>	t <sub>1</sub>	0 months	12 months	t <sub>2</sub>
<b>ENROLMENT:</b>					
Eligibility screen	X				
Informed consent	X				
Allocation		X			
<b>INTERVENTIONS:</b>			↔		
Intervention Group: BOOST-A™			X	X	
Control Group: Regular Practice			X	X	
<b>ASSESSMENTS:</b>					
Autism Diagnosis		X			
Self-determination		X			X
Domain Specific Self-determination		X			X
Career Planning and Exploration		X			X
Quality of Life		X			X
Environment Support		X			X

**Fig. 2** Schedule of enrolment, intervention and assessments

**Treatment allocation** Following initial screening, potential participants will be allocated to either the intervention or control group according to the order in which they register interest. The first participant will be allocated to a group based on a coin toss completed by a researcher who will not be directly involved in liaising with participants. The exception to this allocation scheme is that if a newly enrolled participant is attending a school that a previously or currently enrolled trial participant attends, then the newly enrolled participant will be allocated to the same treatment group as the previous student. The reason for this is to reduce the risk of contamination, since school staff will be involved in administering the intervention. Participants will be blinded to their treatment; however, non-blinded allocation and lack of randomization could introduce potential bias. Once allocated to a group, participants will be sent the participant information and consent form. Forms for the intervention group will differ slightly from those for the control group, as they will contain information about the BOOST-A™, to ensure

blinding to treatment is maintained. Participants who provide written consent will then be assigned a unique participant identification number. A strength of the trial is that the BOOST-A™ will be administered by parents and professionals who are not a part of the research team, thereby minimizing researcher bias. In addition, the primary researcher will have minimal information about the participants at time of randomization.

**Sample size** Altman’s nomogram equation was used to determine the sample size. A total sample of n = 80 (n = 40 in each group) would be the minimum required to identify a standardized difference of 0.6 (i.e., Cohen’s *d*) [53], with a power of 80% and a critical alpha value of .05.

**Data collection**

Outcome data will be collected via an online survey using Qualtrics software (Version 2016). The survey containing the outcome measures for the trial will be emailed to participants at two data collection points: at baseline

(Time point 1), and 12 months later (Time point 2). Participants will complete the online survey in their own environments, which could be home, work, or school. Demographic information will be collected from parents at Time point 1. This information will include the adolescent's age, gender, year level at school, and their residential postcode (to determine socioeconomic status). It is anticipated that completing the online outcome measures will take 30–45 min each time. Participants will be given a leeway of two months after each scheduled data collection point to complete the outcome measures. Participants will be reminded, as needed, by the primary researcher via telephone and email to complete the outcome measures. The trial commenced on 26 November 2015 (Time Point 1), and data collection for the post-measures began on the 26 November 2016 (Time Point 2).

The Social Responsiveness Scale-Second Edition (SRS-2) [48] will be used to classify autism severity. Parents will complete the School Age Rating Form, which is designed for children aged 4–18 years. The SRS-2 consists of 65 items and can be administered in 15–20 min. The scale results in a total score and a *t-score*, which can be used as an index of severity of social deficits on the autism spectrum. Scores can be interpreted as falling into one of the following four categories: within normal limits, mild deficit, moderate deficit, and severe deficit. The scale has been standardized using a nationally representative sample, and has strong psychometric properties including high internal consistency ( $\alpha = .95$ ); construct validity (two strong factors); test–retest reliability ( $r = .88-.98$ ); and interrater reliability ( $r = .91$  between mothers and fathers) [48]. Studies have shown that the SRS-2 can detect clinically meaningful and statistically significant differences between typically developing children and those diagnosed with autism [54]. Additional independent variables for this trial will be comorbidities (including mental health), gender, age, and socioeconomic status.

#### Outcome measures

Outcome measures were determined based on a literature review of all suitable measures and their psychometric properties. Outcome measures were chosen based on the transition planning objectives for adolescents with autism, as identified in the needs assessment (Fig. 1). For example, fostering self-determination through high expectations is linked to the outcome of self-determination, and having a strong transition team is linked to measuring learning climate. As the BOOST-A™ was developed based on these objectives, the aim was to determine if it was effective in bringing about change in these areas. Particular emphasis was placed on each measure's sensitivity to detect change. The outcome

measures are all self-report, eliminating the risk of assessor bias. All of the outcome measures were trialed in Pilot A with six adolescents on the autism spectrum and their parents to ensure they were appropriate for use with these groups. Modifications were required for two of the questionnaires, as described below.

**Primary outcome measure** The adolescent's self-determination will be measured by the AIR Self-Determination Scale (AIR) [55], including their ability, knowledge and perceptions about their self-determination, and what opportunities exist for them to use their knowledge and abilities at home and school. Self-determination has been chosen as the primary outcome measures, as high self-determination is correlated with successful transition to employment in adolescents on the spectrum [25, 27–30]. The AIR consists of 24 items, as well as some free-form, short-answer questions. The AIR has good test–retest reliability ( $r = .74$  based on two administrations three months apart), internal consistency (split half test  $r = .95$ ), and construct validity (four factors explained 47% of the variance) [55]. Sensitivity to change was demonstrated in previous studies that used the AIR as an outcome measure for students with disabilities [56, 57]. The AIR has been established as a reliable instrument to use with adolescents on the autism spectrum [58].

**Secondary outcome measures** Career planning and exploration will be measured by the Career Development Inventory—Australia (CDI-A) [60]. Career planning and exploration is defined as the ability to explore one's skills and interests in relation to work, and to seek information related to one's career to assist in making an informed decision [59]. The first two sections of the CDI-A [60] will be used for this trial as they specifically target career planning and exploration. These two sections contain 18 items and are valid and reliable, independent from the entire CDI-A [60]. The CDI-Australia has been found to have adequate internal consistency (career planning  $\alpha = .84$ ; career exploration  $\alpha = .63$ ), concurrent validity ( $r = .6-.8$ ), and construct validity (four factors explaining 44.7% of the variance) [61].

Quality of life will be measured by the Personal Wellbeing Index-School Children (PWI-SC) [62], which is based on the Subjective Wellbeing Homeostasis Theory [63], which asserts that an individual operates to maintain their wellbeing around an average point. The PWI-SC contains seven items; one for each of the seven domains: standard of living, personal health, achievement in life, personal relationships, personal safety, community-connectedness, and future security [62]. The PWI-SC has high internal consistency ( $\alpha = .82$ ) and construct validity (comparative fit index = .96) [64]. Sensitivity to change

was demonstrated in a study that used the PWI-SC as an outcome measure for a youth support program [65].

Environment support will be measured using the Learning Climate Questionnaire (LCQ) [66], which measures an individual's perception of support from their team, or the environmental aspects that contribute to the development of self-determination. The LCQ consists of 15 items, and has been found to have good construct validity (one factor explaining 63% of the variance) and high internal consistency ( $\alpha = .96$ ) [66]. The LCQ has been used to evaluate how instructor's support impacts on students' learning in college, demonstrating its sensitivity to change [67]. Based on feedback from Pilot A, the LCQ was adapted to meet the needs of adolescents on the autism spectrum and to ensure it was transition planning specific by removing three questions and slightly modifying the language.

Domain specific self-determination was measured by the Transition Planning Objectives Scale (TPOS). The TPOS was designed specifically for this trial, because the authors could not identify an existing standardized tool that comprehensively evaluated the transition planning objectives identified in the needs assessment (Fig. 1). The primary researcher (MH) developed the scale based on the transition planning objectives and the measure of processes of care (MPOC) [68]. The MPOC was designed to assess parents' perceptions of the care provided to their children by health professions in rehabilitation centers. Its underlying concepts align with those of the transition planning objectives, including enabling partnerships and family-centered care. The TPOS consists of 16 items, each of which addresses an objective in Fig. 1. Each item is rated on a 10-point Likert scale, anchored by strongly disagree to strongly agree. The measure was reviewed by the research team and then piloted with six adolescents on the autism spectrum and their parents, after which minor modifications were made. Since the validity and reliability of the transition planning objectives scale is not yet known, the data obtained from this measure will be interpreted and reported with caution. In addition, it is recommended that future studies aim to validate this outcome measure.

**Statistical analysis** Simple descriptive statistics (frequencies and percentages for categorical variables; means, standard deviations, ranges for continuous variables) will be used to summarize the demographic and baseline profiles of participants. These baseline variables will include the assessment of autism severity (using the SRS-2), and the outcome measures described above. The Chi square or *t* test (as appropriate) will be used to compare the profiles of participants between the intervention and control groups. If any continuous data are found to be not nor-

mally distributed (from the Kolmogorov–Smirnov test), these data may either be transformed to improve their normality or analyzed using an appropriate non-parametric test.

Effectiveness of the intervention for the AIR, the primary outcome, will be determined by calculating the change from Time point 1 to Time point 2, and comparing the changes within and between intervention and control groups using dependent and independent *t* tests (or non-parametric Wilcoxon signed rank tests and Mann–Whitney U test if the data are not normally distributed). If the analysis reveals differences in baseline characteristics between the intervention and control groups, the analyses will be adjusted for these differences using a general linear model (GLM). Analysis of secondary outcomes will be performed using a multivariate ANOVA (MANOVA). Analyses will be performed using an intention-to-treat strategy, where participants will be classified as belonging to the group (intervention or control) to which they were initially allocated, regardless of the treatment they actually received. Participants who do not provide outcome data at Time point 2 will still be included in the trial, and their Time point 1 data will be used for Time point 2 to allow for intention-to-treat analysis of the data. The Statistical Package for the Social Sciences (SPSS v.22) will be used to analyze the data, and a *p* value of .05 will be used as the level of statistical significance in all inferential analyses.

#### **Process evaluation**

The process evaluation will explore the usability and feasibility of the BOOST-A™ to determine whether the results of the trial were influenced by external factors, such as the implementation process or contextual issues. The objectives of the process evaluation are to describe the participants' experiences when using the BOOST-A™; participants' perceptions of the usability of the BOOST-A™; and to identify facilitators and barriers impacting participants' use of the BOOST-A™.

The process evaluation will use quantitative and qualitative feedback from participants in the intervention group [69]. Quantitative data will be obtained from website analytics, including the number of modules completed and the number of logins to the BOOST-A™ website. In addition, participants will complete a survey at the conclusion of the trial to provide feedback on the strengths of the program, suggestions for improvement, and the number of team meetings held during the trial period. Qualitative data will be collected using semi-structured interviews, to obtain in-depth information about participants' experiences when using the BOOST-A™. Interviews will be conducted over the telephone with parents and adolescents together, within one month after

completion of the trial. Interviews will be conducted by an independent researcher who has not been involved in previous stages of the project, to minimize any potential bias. Data collection will conclude when saturation is reached, or when interviews cease to provide any further insight into the topic of exploration [70]. Interviews will be audio-recorded, transcribed verbatim, and data de-identified. Transcripts will be analyzed using thematic analysis with constant comparison of the data within and across participants. In addition, the primary researcher (MH) will keep field notes for the duration of the trial, to document any incidental feedback obtained from participants, as well as any preconceptions she might have regarding the participants and/or their outcomes.

#### **Ethics, consent and permissions**

Ethics approval to conduct this trial has been obtained from Curtin University Human Research Ethics Committee (approval number HR110/2014), and the Catholic Education Offices and Departments of Education in Western Australia, Victoria, Queensland, New South Wales, Tasmania and South Australia. Written informed consent will be obtained from all adult participants. Participants under 18 years of age will provide informed written assent, and their parents will provide informed written consent for their participation. Principals of the schools attended by participants in the intervention group will provide informed written approval for their staff to use the BOOST-A™; consent is not required by this group because the teachers are not taking part in data collection. Participants in the control group will be offered the opportunity to use the BOOST-A™ once the trial is complete, if it is proven to be effective in achieving the trial objectives.

The trial design and procedures will adhere to the National Statement on Ethical Conduct in Human Research [71] and the Australian Code for the Responsible Conduct of Research [72]. The trial is registered with the Australia and New Zealand Clinical Trial Registry (#ACTRN12615000119594). The trial was developed according to the Consolidated Standards of Reporting Trials (CONSORT) 2010 guidelines [73].

#### **Discussion**

The BOOST-A™ is one of the first transition planning program that specifically targets and addresses the needs of adolescents on the autism spectrum. The needs assessment conducted prior to this trial revealed a number of unique areas of need that are specific to adolescents on the autism spectrum. For example, due to difficulties in gestalt processing [74] and abstract thinking, adolescents on the autism spectrum benefit from support to

understand the ‘big picture’, and why they need to get a job after school. These areas have not been addressed in existing transition planning programs.

The BOOST-A™ will be one of the first transition planning programs to be empirically tested to provide evidence of its efficacy. The BOOST-A™ has been developed using a rigorous approach and by applying the PRECEDE-PROCEED model. The development phase involved a literature review and needs assessment, and the identification of transition planning objectives. Two pilot studies were completed to ensure the viability and feasibility of the program. The planned trial will determine the efficacy and usability of the BOOST-A™. To our knowledge, this level of rigor has not been applied to any existing transition planning interventions. In addition, the BOOST-A™, to the authors’ knowledge, is one of the first transition planning programs that is online. Having an online program may be beneficial for several reasons: increasing engagement of adolescents; allowing increased accessibility of the program from rural and remote areas; and allowing participants to use the intervention in their own homes, and at their own pace.

This trial will, to the authors’ knowledge, be the first national Australian research project of its kind to comprehensively address transition planning for adolescents on the autism spectrum. The objectives of the BOOST-A™ are in line with the major Australian Federal Government priority of increased workforce participation for Australians with disability, as outlined in the National Disability Strategy 2010–2020 [75]. Positive findings from this trial will have significant benefits for adolescents on the autism spectrum because the BOOST-A™ can be used to support them to find suitable employment as they move into adulthood. Participation in work is important for a number of reasons, including providing financial independence, and opportunities to develop social networks and supports [76]. It also provides a sense of identity, meaning, and purpose to people’s lives. Studies indicate that employed people on the autism spectrum experience meaningful improvements in quality of life [8]. Therefore, the BOOST-A™ may be able to support people on the autism spectrum to plan their pathway towards employment; an outcome that may ultimately enhance their quality of life and assist in reducing the unemployment of people with autism in Australia.

#### **Conclusions**

The BOOST-A™ is the first online autism-specific transition planning program of its kind. This trial aims to provide evidence of the effectiveness of the BOOST-A™ to assist adolescents on the autism spectrum to successfully plan their transition from school into further study, training, or work.

**Abbreviations**

BOOST-A: Better Outcomes & Successful Transitions for Autism (BOOST-A); ID: intellectual disability.

**Authors' contributions**

MH, MC, TF, MF contributed to the design of the trial. MH drafted the manuscript. MH, MC, TF, MF reviewed the manuscript. All authors read and approved the final manuscript.

**Author details**

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Perth, Australia. <sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Long Pocket, Brisbane, QLD, Australia. <sup>3</sup> School of Occupational Therapy, La Trobe University, Melbourne, Australia. <sup>4</sup> Department of Medicine and Health Sciences (IHM), Linköping University and Pain and Rehabilitation Centre, Linköping, Sweden. <sup>5</sup> School of Education and Communication, Institution of Disability Research, Jönköping University, Jönköping, Sweden.

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**Competing interests**

The authors declare that they have no competing interests.

**Availability of data and materials**

Once the data for this trial have been collected and finalized, it will be placed on an appropriate public repository.

**Ethics approval and consent to participate**

Ethics approval to conduct this trial has been obtained from Curtin University Human Research Ethics Committee (approval number HR110/2014), and the Catholic Education Offices and Departments of Education in Western Australia, Victoria, Queensland, New South Wales, Tasmania and South Australia. Written informed consent will be obtained from all adult participants. Participants under 18 years of age will provide written informed assent, and their parents will provide written informed consent for their participation.

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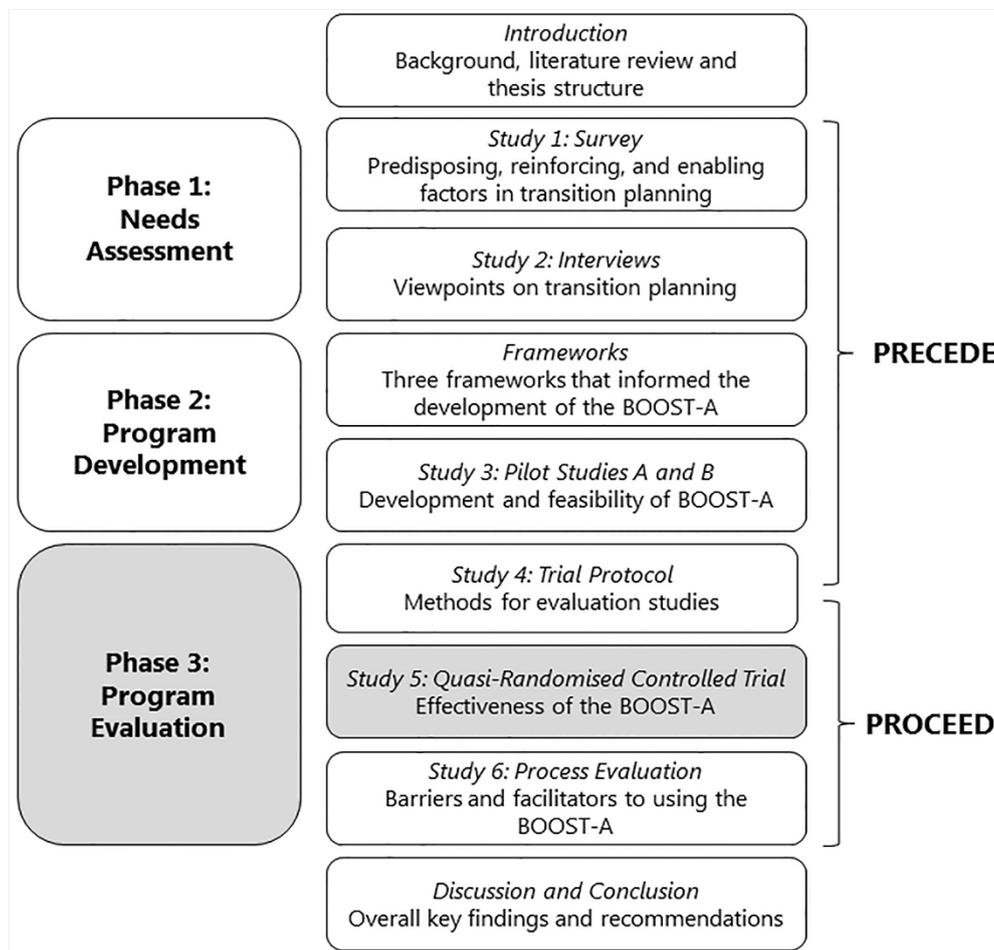
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# Chapter 6 QUASI-RANDOMISED CONTROLLED TRIAL

Chapter 6 describes the results from the quasi-randomised controlled trial conducted in Phase 3. The trial aimed to determine the efficacy of the BOOST-A™ in increasing self-determination; quality of life; access to environmental supports; career planning and exploration; and domain-specific self-determination for adolescents on the autism spectrum.



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## Author Contribution Statement

As co-authors of the paper entitled, '*Effectiveness of the BOOST-A online transition planning program for adolescents on the autism spectrum: a quasi-randomised controlled trial*', we confirm that Megan Hatfield 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; and
- 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 collection, analysis, and interpretation; and
- Review and editing of the manuscript.

*Signed:* Torbjörn Falkmer Date: 25/05/17

*Signed:* Marina Ciccarelli Date: 25/05/17

*Signed:* Marita Falkmer Date: 25/05/17

# Effectiveness of the BOOST-A™ online transition planning program for adolescents on the autism spectrum: a quasi-randomised controlled trial

Megan Hatfield<sup>1, 2\*</sup>, Marita Falkmer<sup>1, 2, 3</sup>, Torbjörn Falkmer<sup>1, 2, 4</sup> and Marina Ciccarelli<sup>1, 2</sup>

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Perth, Australia.

<sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Long Pocket, Brisbane, Queensland, Australia

<sup>3</sup> School of Education and Communication, Institution of Disability Research  
Jönköping University, Jönköping, Sweden

<sup>4</sup> Department of Medicine and Health Sciences (IHM), Linköping University and Pain and Rehabilitation Centre, Linköping, Sweden

\*Corresponding author

## 6.1 Abstract

**Background:** The majority of existing transition planning programs are focused on people with a disability in general and may not meet the specific need of adolescents on the autism spectrum. In addition, these interventions focus on specific skills (e.g. job readiness or self-determination) rather than the overall transition planning process and there are methodological limitations to many of the studies determining their effectiveness. The Better Outcomes & Successful Transitions for Autism (BOOST-A™) is an online program that supports adolescents on the autism spectrum to prepare for leaving school. This study aimed to determine the effectiveness of the BOOST-A™ in enhancing self-determination.

**Methods:** A quasi-randomized controlled trial was conducted with adolescents on the autism spectrum enrolled in Years 8 to 11 in Australian schools (N=94). Participants had to have basic computer skills and the ability to write at a Year 5 reading level. Participants were allocated to a control (n=45) or intervention (n=49) group and participants were blinded to the trial hypothesis. The intervention group used the BOOST-A™ for 12 months, while the control group participated in regular practice. Outcomes included self-determination, career planning and exploration, quality of life, environment support and domain specific self-determination. Data were collected from parents and adolescents.

**Results:** There were no significant differences in overall self-determination between groups. Results indicated significant differences in favor of the intervention group in three areas: opportunity for self-determination at home as reported by parents; career exploration as reported by parents and adolescents; and transition-specific Self-determination as reported by parents.

**Conclusions:** Results provide preliminary evidence that the BOOST-A™ can enhance some career-readiness outcomes. Lack of significant outcomes related to self-determination at school and career planning may be due to the lack of face-to-face training and parents being the primary contacts in the study. Further research is

needed to determine effectiveness of the BOOST-A™ related to post-secondary education and employment.

**Trial registration:** #ACTRN12615000119594

**Key words:** Asperger's Syndrome, Autism Spectrum Disorder, disability, employment, high school, post-secondary education, self-determination theory, strengths-based, career development.

## 6.2 Background

### 6.2.1 Post-school transition for adolescents with autism

As adolescents transition out of secondary school to adult life, they engage in a number of new roles including employment, post-secondary education, expanded community involvement, and home maintenance (1). This transition out of high school can be particularly difficult for adolescents on the autism spectrum for a number of reasons. A key feature of autism is difficulty coping with uncertainty, which is linked to increased levels of anxiety (2). The period of transition out of secondary school can be particularly anxiety provoking for adolescents on the autism spectrum as they face the insecurity that accompanies changing life roles (3). Adolescents on the spectrum face unique social and communication challenges during the transition out of school (4), and difficulties often arise with managing increasing social demands, rather than challenges with actual task performance (5, 6). Adolescents on the autism spectrum experience poorer quality of life than people without a diagnosis of autism (7) and have poorer post-school outcomes in the areas of employment and post-secondary education than adolescents with other types of disabilities as well as people without disability (8). This suggests that existing transition planning processes may not be meeting the needs of adolescents on the autism spectrum.

### 6.2.2 Transition planning interventions

Transition planning can support adolescents with autism to navigate the shift in roles and to prepare for leaving school (9). Transition planning involves exploring potential careers, setting goals, and engaging in new experiences (10). Most existing transition planning interventions target adolescents with a disability in general. A meta-analysis of interventions that taught self-determination skills to adolescents with disabilities identified 22 studies that were targeted at adolescents with intellectual disability (ID) and learning disabilities, and highlighted the need for autism-specific interventions (11). A literature review identified 12 quantitative

studies of interventions that aim to enhance student participation in individualized education program (IEP) meetings (12). All interventions targeted adolescents with a disability in general. The review identified that all 12 studies reported increases in either student participation in IEP meetings or increased self-determination; for example, the *Whose Future Is It Anyway?* program enhanced self-determination in a randomized controlled trial (N=493) (13). However, the authors of the review concluded that there is a need for transition planning programs that include parents in the transition planning process and that impact the adolescents' everyday lives. Another systematic review of transition planning interventions for adolescents with disabilities in general identified that research in this area is predominantly qualitative (9). In the existing quantitative studies, a lack of methodological rigour was identified, including use of pre-test/post-test design and no control group. For example, an evaluation of the MY VOICE program found participants were satisfied with the program but the study had no control group and used retrospective pre-testing (14). The results of a randomized controlled trial of the *Whose Future Is It Anyway?* teacher-led program favored the intervention group (13), with significant between-group differences in self-determination. However, the sample included people with disabilities in general and the study did not address autism-specific needs for transition planning.

A few autism-specific transition planning studies have been published recently. One study aimed to describe important elements of effective transition planning for adolescents on the autism spectrum (15), but much of the reviewed literature was not autism-specific and findings were based on studies of people with disabilities in general. A systematic review of interventions to support transition planning for adolescents on the autism spectrum found no studies that met the inclusion criteria of quantitative research that focused on employment as an outcome, and therefore the review described qualitative research that explored transition planning for this group (16). The authors of the review concluded that further research utilizing rigorous designs was needed to determine the effectiveness of transition planning programs for adolescents with autism.

An evaluation of an autism-specific transition planning program, Putting Feet on My Dreams, reported increased goal-directed behavior (17), but findings should be interpreted with caution due to small sample size, no control group, and use of interviews to determine the effectiveness. The results of a randomized controlled trial evaluating and autism-specific transition program found a significant between-group difference in favor of the intervention for vocational decision making ability, expectations for the future, and self-determination at year 1 (18). However, this difference was not maintained by year 2, and the small sample size (n=47) introduced a threat to external validity.

In summary, most existing transition planning programs were not autism-specific, and the studies that determined their efficacy had methodological limitations. Most programs were developed in the United States of America and are not validated in an Australian context. This is important because of differences between countries in legislation, funding models, and service provision methods. Therefore, there is a need for a rigorously developed and evaluated autism-specific transition planning program for Australian adolescents. The Better Outcomes & Successful Transitions for Autism (BOOST-A™) program was developed to address this need. The BOOST-A™ is an online autism-specific program developed for an Australian context that aims to prepare adolescents on the autism spectrum for leaving school. The BOOST-A™ was developed for adolescents on the autism spectrum without an ID because studies have shown that this group often have poorer outcomes than adolescents with ID because of lack of access to transition support and services (19, 20).

### **6.2.3 Aims**

The primary aim of the trial was to determine the effectiveness of the BOOST-A™ in improving self-determination among adolescents on the autism spectrum. The secondary aim was to determine the program's impact on quality of life; access to environmental supports; career planning and exploration; and domain-specific self-determination among adolescents on the autism spectrum.

## 6.3 Methods

The effectiveness of the BOOST-A™ was determined in a quasi-randomized controlled trial, in which outcomes for the intervention group (BOOST-A™) were compared to the control group (regular transition planning practice). The trial was a cluster group, two-arm, superiority trial with 1:1 allocation ratio. The full details of the study protocol have been published elsewhere (21).

### 6.3.1 Participants

Participants were recruited between June and November 2015 via community organisations for people on the autism spectrum. A recruitment flyer was distributed on websites, social media, in person, and through email. Inclusion criteria for participants included:

- Formal diagnosis of Autism Spectrum Disorder, as defined by the Diagnostic and Statistical Manual of Mental Disorders, DSM-IV (22) or DSM-5 (23);
- Living in Australia;
- Enrolled in Years 8 to 11 at school; and
- Ability to write at a Year 5 reading level and basic computer skills.

Adolescents were excluded from the study if they had a diagnosis of ID or if they were currently enrolled in another transition planning program. Statistical power calculations indicated a minimum total sample of  $N=80$  ( $n=40$  in each group) was required to detect a standardized difference of 0.6 (Cohen's  $d$ ) (24), with a critical alpha of 0.05 and power of 80%.

### 6.3.2 Intervention

The BOOST-A™ is an online program that aims to support adolescents on the autism spectrum with their transition from high school. The development of the BOOST-A™ was guided by the PRECEDE-PROCEED model (25). A needs assessment was completed, which resulted in the development of transition planning objectives for adolescents on the autism spectrum (26, 27). The objectives were comprised of three guiding ideals and five strategies that directed the development of the

BOOST-A™. Furthermore, based on the needs assessment, three main frameworks were chosen to underpin the BOOST-A™: the self-determination model (28, 29), a strengths-based approach (30, 31), and a technology-based approach (32). The BOOST-A™ was piloted in two studies by adolescents on the autism spectrum, their parents, educators, and allied health professionals (33), who confirmed the program was appropriate, useable, and feasible. Feedback from the pilot studies was used to modify the BOOST-A™ to enhance usability.

The BOOST-A™ consists of four modules (shown in Table 1) delivered via a website that is accessed by an individual login. The BOOST-A™ has a number of features that make it unique and autism-specific. These include provision of a clear process that supports the adolescent’s preference for structure and routine, consideration of sensory preferences and learning styles, and the inclusion of a number of animated videos that help the adolescent to understand the purpose of each module.

Adherence to the intervention was monitored using website analytics; i.e., number of logins, number of modules completed, and feedback from participants about the number of times they met with the team.

**Table 6-1. Overview of the BOOST-A™ transition planning program.**

Module	Description
1. About Me	Adolescents completed six activities to identify their interests, strengths, work preferences, life skills, training goals, and learning style.
2. My Team	Adolescents and parents identified a team of people to support their transition planning, and then booked the first meeting. Adolescents selected their level of involvement in team meetings.
3. First Meeting	The team met to review career options and formulate goals, based on best-practice recommendations that are built into the program.
4. My Progress	The team met once per school term following the first meeting to review goal progression and positive learning experiences.

The control group partook in the regular practice at their respective schools. This may have included any generic transition planning processes utilized at the school, but did not include any structured or disability-specific transition planning

programs. Participants in the control group were given access to the BOOST-A™ at the conclusion of the study.

### 6.3.3 Procedures

Participants who expressed an interest to be in the study were screened for eligibility and sent a participant information sheet and consent forms. Because the adolescents were under 18 years of age, they provided written informed assent, and their parents provided written informed consent for the adolescent's participation and their own. For the intervention group, school principals provided informed written approval for school staff to use the BOOST-A™ with the adolescents. Consent was not required from individual teachers because no data were collected from them during the study. Participants were allocated to the intervention or control group upon enrolment to the study using an alternate allocation method. The first participant was allocated to a group based on a coin toss that was completed by a researcher who was not in contact with the participants, and the second enrolled participant was allocated to the other group, and so on. The exception to this was when a new participant was attending the same school that a currently enrolled participant attended. In this case, the newly enrolled participant was allocated to the same treatment group as the currently enrolled participant. The aim of this allocation scheme was to reduce the risk of contamination, as school staff were involved in the administration of the BOOST-A™. The trial commenced on 26 November 2015 (Time point 1, T1), and post-measures were completed within two months of 26 November 2016 (Time point 2, T2). The 12 month timeframe was chosen to allow participants adequate time to complete the multiple modules of the BOOST-A™ program. Given the outcome measures were online, there was a two month period in which participants completed the outcome measures at the T2 measurement point. This could have resulted in some participants having slightly longer than 12 months to complete the BOOST-A™. Therefore, dosage was measured by the number of modules completed and the number of logins to the program.

### 6.3.4 Outcomes

Demographic information was collected at baseline for all participants. Socio-economic status of participants was determined by Socio-Economic Indexes for Areas (SEIFA) deciles, utilising the Commonwealth Department of Education, Employment, and Workplace Relations' measure of relative socio-economic advantage and disadvantage (34). Data from self-reported outcome measures were collected twice: at baseline (T1) and 12 months later (T2). The Social Responsiveness Scale – Second Edition (SRS-2; 35) was used to classify autism severity based on a raw cut-off score of 57 (36). Detailed information about the outcome measures and their psychometric properties was previously published in a study protocol paper (21).

The primary outcome of this trial was self-determination, as measured by the AIR Self-Determination Scale (AIR; 37). The AIR has good test-retest reliability, internal consistency, and construct validity (37), as well as demonstrated sensitivity to change (38, 39). There were four secondary outcomes. Career planning and exploration was measured by the Career Development Inventory – Australia – Short Form (CDI-A; 40). The CDI-A has been found to have adequate internal consistency, concurrent validity, and construct validity (41). Quality of life was measured by the Personal Wellbeing Index-School Children (PWI-SC; 42). The PWI-SC has high internal consistency and construct validity (43) and demonstrated sensitivity to change (44). Environment support was measured by the Learning Climate Questionnaire (LCQ; 45), which has been found to have good construct validity and high internal consistency. The final outcome was domain specific self-determination, measured by the Transition Planning Objectives Scale, which was designed for this trial to evaluate the transition planning objectives identified in the needs assessment.

### 6.3.5 Statistical analysis

The Kolmogorov-Smirnov test was used to determine normality of the data. To determine the effectiveness of the BOOST-A™ 12 months after the intervention (T2), the change in each outcome from T1 and T2 for each participant was calculated. Then the changes between intervention and control groups were compared using

the independent samples t-test and/or Mann-Whitney U test. There were departures from normality in several of the outcomes, so both parametric and non-parametric tests were used to compare the outcomes of participants in the intervention and control groups at baseline (T1). Results were reported using parametric statistics because analyses revealed that both the parametric and non-parametric tests produced consistent results. An intention-to-treat approach was used so that participants' data were analyzed according to the original group they were allocated regardless of actual treatment received. For participants who did not provide outcome data at T2, the last observation carried forward method was used, in which it was assumed that no change occurred in these outcomes from T1 to T2. In order to reduce the chance of a Type I error through the conducting of t-tests on the different outcomes, a multivariate analysis of variance was also conducted (implemented as a random effects regression model). In this analysis the respondent was classified as a random effect, the question number and group (intervention or control) were the independent variables, and the change in score on each question was the dependent variable. Questions included for analysis in this model were those that appeared to be significant through univariate analyses. The Statistical Package for the Social Sciences (SPSS v.22; 46) was used to analyze the data, and a  $p$  value  $< 0.05$  was taken to indicate a statistically significant difference in all tests. Any differences in baseline characteristics between the intervention and control groups were taken into account using a general linear model.

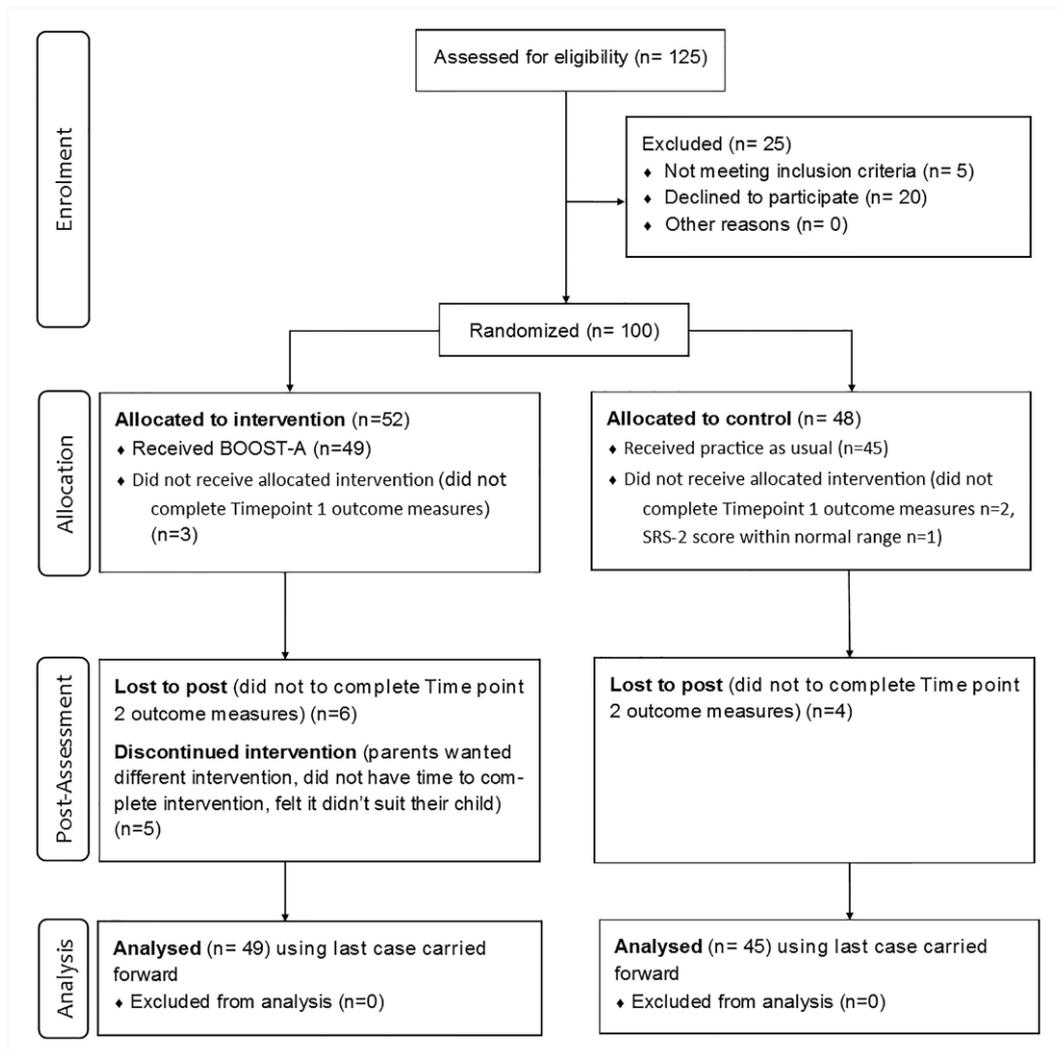
### **6.3.6 Ethics**

The trial received ethics approval from Curtin University Human Research Ethics Committee (approval number HR110/2014), and the Departments of Education and Catholic Education Offices in New South Wales, Western Australia, Victoria, Queensland, South Australia, and Tasmania. The trial adhered to the Australian Code for the Responsible Conduct of Research (47) and the National Statement on Ethical Conduct in Human Research (48). The trial was also registered with the Australia and New Zealand Clinical Trial Registry (#ACTRN12615000119594) and was developed in accordance with the Consolidated Standards of Reporting Trials (CONSORT) 2010 guidelines (49).

## 6.4 Results

### 6.4.1 Participants

Of the 125 participants who expressed an interest in participating in the study, 100 met the inclusion criteria and enrolled in the study. A number of participants did not complete the baseline (T1) outcome measures (n=3 in the intervention group, n=2 in the control group) and the data from one participant in the control group were withdrawn because the SRS-2 score was within the normal range. This resulted in 49 participants in the intervention group and 45 in the control group (N=94). The sampling procedure and the participant dropout rate can be seen in the CONSORT diagram in Figure 1.



**Figure 6-1. Flowchart of the BOOST-A effectiveness study.**

Baseline data reported in Table 2 shows that participants were mostly male (intervention 79.6%; control 71.7%), and the average ages of the adolescents in the intervention and control groups were 14.8 years and 15.1 years, respectively. SEIFA deciles range from 1 to 10; where 1 indicates the participant’s residential area is within the lowest 10% socio-economic advantage and 10 indicates the participant resides in an area within the highest 10%. The average SEIFA was 7.4 for the intervention group and 5.8 for the control group. Autism severity ranged from mild to severe in both groups. A number of participants had comorbid diagnoses, the two most common being attention deficit hyperactivity disorder (intervention 10.2%; control 20.0%) and anxiety (intervention 10.2%; control 11.1%).

**Table 6-2. Participant demographics by group.**

Pre-intervention	Group (N=94)		P Value
	Intervention n=49	Control n=45	
Adolescent Age in years (mean, range, SD)	14.8 (12-17, 1.2)	15.1 (13-18, 1.2)	0.215
Adolescent Gender (#, %)			
Female	10 (20.4)	12 (26.7)	0.479
Male	39 (79.6)	33 (73.3)	
Socioeconomic Status (SEIFA mean, range, SD)	7.4 (4-10, 2.0)	5.8 (1-10, 2.5)	0.001*
Autism Severity (n, %)			
Within normal	0 (0)	0 (0)	0.662
Mild	5 (10.2)	5 (11.1)	
Moderate	13 (26.5)	16 (35.6)	
Severe	31 (63.3)	24 (53.3)	
Comorbid diagnoses (n, %)			
Attention deficit hyperactivity disorder	7 (14.3)	10 (22.2)	0.318
Anxiety	5 (10.2)	5 (11.1)	0.887
Dyslexia	1 (2.0)	2 (4.4)	0.508
Depression	2 (4.1)	2 (4.4)	0.931
Other	7 (14.3)	8 (17.8)	0.644

\*Significant difference between Intervention and Control Group;  $p < 0.05$

## 6.4.2 Baseline comparisons

There were no significant differences for age (t-test) or for gender and autism severity (Chi-square test) between the intervention and control groups at baseline (T1) as shown in Table 2. However, there were baseline differences between groups for SEIFA classification (Chi-square test;  $p = 0.001$ ). There were no between group differences for the parent or adolescent self-reported outcome measures at baseline (T1).

## 6.4.3 Dosage and fidelity

Dosage of the BOOST-A™ intervention was measured by the number of logins to the program and the number of modules completed, obtained through program

analytics. Participants in the intervention group logged into the BOOST-A™ an average of five times (range = 0 to 14, *SD* = 3.4). On average, participants completed three of the four modules by T2 (range = 0 to 4; *SD* = 1.1). Participants reported an average of two team meetings at T2 (range = 0 to 5; *SD* = 1.0).

#### 6.4.4 Intervention effects

AIR There were no significant differences between the intervention and control groups for the primary outcome of overall self-determination as determined by the AIR. The mean (*SD*) difference in the AIR change score before and after the intervention (i.e. T2-T1) among parents in the intervention group was 2.3 (8.3) compared to parents in the control group (-0.2 (7.8);  $p=0.13$ ). Similarly, there was no difference in the mean (*SD*) AIR change score before and after the intervention among the adolescents in the intervention group (6.2 (18.2)) compared to the control group (0.5 (18.9);  $p=0.19$ ).

Most outcomes improved over time, with greater improvements for the intervention group, as seen in Table 3. Overall quality of life for the adolescents decreased over the 12 months for both groups, as indicated by the personal well-being index. There were significant between-group differences in three summary score areas favoring the intervention group: career exploration for parents ( $p=0.03$ ) and adolescents ( $p=0.01$ ); the self-determination sub-scale of Home for parents ( $p=0.01$ ); and transition-specific self-determination for parents ( $p=0.01$ ). The summary scores for the remaining outcome measures showed no significant differences between groups. Because there was a between-group difference in socio-economic advantage at baseline, a general linear model was used to test whether the differences persisted after adjustment for the SEIFA. Results indicated that the significant differences found in career exploration, the self-determination sub-scale of home, and transition-specific self-determination remained after adjustment for SEIFA. Findings from fitting the random effects regression model agreed with the findings drawn from Table 3, and are therefore not shown in detail here.

**Table 6-3. Outcomes at baseline (T1) and at 12months post-intervention (T2).**

	Intervention group n=88 <sup>§</sup>		Control group n=83 <sup>§</sup>		Group by time	
	T1 Mean (SD)	Difference T2 – T1 (SD)	T1 Mean (SD)	Difference T2 – T1 (SD)	<i>t</i>	<i>p</i>
<i>Parent reported outcomes</i>						
Self-determination (AIR)						
Total	56.6 (9.2)	2.3 (8.3)	58.6 (8.10)	-0.2 (7.8)	1.52	0.13
Do	14.7 (4.3)	1.1 (3.5)	14.8 (4.0)	0.7 (2.4)	0.61	0.55
School	20.1 (4.6)	0.37 (3.8)	20.4 (4.5)	-0.3 (3.7)	0.78	0.44
Home	22.8 (3.3)	0.9 (2.2)	23.6 (2.9)	-0.4 (2.6)	2.59	0.01*
Transition-specific self-determination						
Career planning (CDI-A)	21.5 (8.4)	4.1 (8.8)	21.3 (8.0)	2.6 (7.9)	0.87	0.39
Career exploration (CDI-A)	23.0 (6.2)	3.4 (5.6)	24.7 (6.2)	0.8 (5.6)	2.27	0.03*
Learning climate (LCQ)	4.1 (1.2)	0.4 (0.9)	4.1 (1.0)	0.1 (0.9)	1.79	0.08
Personal Wellbeing Index (PWI-SC)	63.4 (14.8)	-0.9 (13.5)	63.3 (12.8)	-1.1 (11.3)	0.08	0.94
Happiness – life as a whole (PWI-SC)	60.6 (26.3)	3.1 (23.3)	62.0 (22.7)	63.9 (26.0)	0.50	0.62
<i>Adolescent reported outcomes</i>						
Self-determination (AIR)						
Total	73.7 (21.2)	6.2 (18.2)	76.5 (18.3)	0.5 (18.9)	1.34	0.19
Do	18.0 (4.8)	1.1 (4.0)	18.0 (5.2)	0.4 (5.3)	0.58	0.57
Feel	18.5 (5.4)	0.8 (4.6)	19.2 (5.1)	0.1 (5.6)	0.54	0.59
School	18.9 (6.2)	1.2 (6.8)	17.9 (5.3)	1.4 (4.9)	-0.13	0.89
Home	21.3 (6.0)	1.2 (5.1)	22.7 (4.9)	-0.1 (5.9)	1.01	0.32
Transition-specific self-determination						
Career planning (CDI-A)	86.0 (23.0)	11.4 (22.7)	90.4 (23.7)	5.2 (21.0)	1.25	0.22
Career exploration (CDI-A)	27.9 (10.0)	1.5 (9.6)	30.0 (8.1)	1.8 (8.5)	-0.11	0.91
Learning climate (LCQ)	26.5 (7.1)	2.3 (6.4)	28.7 (5.4)	-1.7 (6.0)	2.78	0.01*
Personal Wellbeing Index (PWI-SC)	4.6 (1.3)	0.2 (1.1)	4.8 (0.9)	0.0 (1.0)	0.64	0.53
Happiness – life as a whole (PWI-SC)	70.8 (20.1)	-0.7 (18.2)	71.5 (13.8)	-1.5 (12.9)	0.22	0.83
Happiness – life as a whole (PWI-SC)	67.9 (27.4)	1.0 (25.7)	66.5 (16.4)	4.1 (19.1)	-0.58	0.56

§: Intervention group: parent n=49, adolescent n=39. Control group: parent n=45, adolescent n=38.

\*Significant difference between Intervention and Control Group; p<0.05

## 6.5 Discussion

### 6.5.1 Primary outcome: Self-determination

Self-determination was the primary outcome of the study because of the previously established correlation between high levels of self-determination and post-school employment and education (50-52). There was no change in the total self-determination score found in this study. A potential reason for this may have been the varied levels of adherence to the BOOST-A™, as the average number of modules completed was three indicating many participants did not complete the My Progress module. Another explanation may be the lack of face-to-face training in how to use the BOOST-A™, which was delivered remotely via an online platform. A meta-analysis of the effectiveness of technology-based programs for adolescents on the autism spectrum found that programs that were entirely self-directed by participants had a smaller effect than programs administered by a specialist (32). Whilst there is a need for programs that are not only effective but also easily accessible, affordable, and user-friendly (32), technology should not be used as a substitute for face-to-face support(53). Therefore, ensuring direct access to a trained professional to facilitate use of the BOOST-A™ may be an important consideration for future iterations of the program.

A significant difference was found in self-determination between the intervention and control groups was in the Home subscale. This may suggest that the BOOST-A™ supported parents to provide increased opportunities for the adolescent to practice decision-making, goal setting, and problem solving in the home environment. This finding is of interest, given that current literature tends to focus on school as the context to improve adolescents' self-determination skills, with less focus on the home environment (54). In addition, the majority of existing transition planning programs focus on supporting school staff to enhance the self-determination of students with disabilities in the school environment (13, 17, 55, 56). However, parents are possibly the most consistent and enduring influence in their adolescent's life, especially during the transition from school into post-secondary education or employment (54, 57). Parents model self-determined behavior in the home

environment and provide opportunities for adolescents with autism to make choices; take appropriate risks; and develop skills in problem solving, self-regulation, and assertive communication (58). A strength of the BOOST-A™ is that it can be used either at school or at home and can be championed by parents and/or teachers.

The increase in opportunities provided at home reflects a potential shift in parents' expectations for their children, as supported by the results from the process evaluation (59). Parents who hold high expectations for their adolescents with autism can increase the adolescent's self-determined behavior and improve their post-school outcomes (15). Furthermore, increased frequency of discussions about post-school plans in the home environment has been correlated with increased participation of adolescents on the autism spectrum in transition planning meetings at school (60). Therefore, changes in the behavior of the parents may result in increased opportunity to engage in transition planning for adolescents on the autism spectrum.

A possible explanation for the observed increase in the Home subscale of self-determination, but not the School subscale is that parents were the primary contacts in this trial and the key point of liaison with the research team. . Further research in this area might assist in understanding the relationship between the home and school settings, and the opportunities for self-determined behavior provided to adolescents on the autism spectrum in these settings.

### **6.5.2 Secondary outcomes:**

The BOOST-A™ led to a significant increase in career awareness among the adolescent participants. Career awareness is defined as the level of engagement with external sources of career information, such as parents, teachers, and written information, as well as the adolescents attitude towards these sources of information (40). Career awareness is predictive of being productively engaged in education and employment in the first year out of school (61, 62). The finding that the BOOST-A™ increased career awareness supports the hypothesis that adolescents on the autism spectrum who use the program may have an increased likelihood of transitioning to post-secondary study and employment after school. No significant differences were

found in career planning, which is the amount of planning that has been completed (40). The lack of significant increases in career planning may have been because not all participants completed the fourth module which supported them to revise goals and progress through planning.

There was also a significant increase in transition-specific self-determination favoring the intervention group. The Transition-specific Self-determination scale looked at the adolescents' opportunity for active engagement in transition-specific team meetings; exploration of interests and strengths; goal setting; and real-life experiences, such as work experience, mentoring, and part-time work. However, the psychometric properties of the Transition-specific Self-determination scale are currently unknown and so these results should be interpreted with caution. Future research to validate this scale is recommended.

For both groups, adolescent quality of life decreased, whilst happiness with life as a whole increased. The overall reduction in quality of life during adolescence is consistent with a decrease in quality of life that is seen in mid to late adolescence for the general population (63). This decrease in quality of life is likely because adolescence is a period in which young adults experience a shift in roles and seek greater independence, which is often at odds with their continued dependence on caregivers (63). In addition, adolescents are presented with many new challenges as they transition out of high school that are likely to impact on quality of life. Overall quality of life for both groups was below the normative range for Australia, which is between 73.4 – 76.4 points out of 100 (42). Evidence suggests that quality of life among people on the autism spectrum is lower than that of people without autism across the lifespan (7). Therefore, further research is warranted that looks at quality of life during the transition period for adolescents on the autism spectrum, and how this compares to adolescents without autism.

There appeared to be a discrepancy in that overall quality of life decreasing whilst happiness with life as a whole increased. One possible explanation is provided by the concept of 'just right challenge' in self-determined learning theory, which describes how opportunities should provide an optimal level of challenge to enhance

adolescents capacity to regulate their feelings and actions (64). Whilst encountering challenges in transition planning period, adolescents may describe a reduction in overall their quality of life, but an increase in happiness as they learn new skills and overcome challenges. Parents in this study rated their adolescent's quality of life lower than the adolescents' self-ratings. This finding is consistent with previous research that proposed adolescents on the autism spectrum may perceive the difficulties they face to be less of a problem than their parents (7). In addition, parents may have made assumptions on the meaning of a good life without asking their children what would make them happy, which is an important prerequisite for emotional wellbeing (65). Discrepancies between parent and adolescent perspectives of quality of life is an issue requiring further exploration in future research.

Overall, only one area showed a significant difference as reported by the adolescents, in comparison to three areas as reported by parents. The lack of significant differences as reported by adolescents is noteworthy, because the aim was to improve adolescents' perceived autonomy and control, as this has been linked to improved post-school outcomes (66), and increased subjective quality of life (63). This indicates more work may need to be done to improve adolescent outcomes in the transition planning process using the BOOST-A™.

The lack of between-group differences for many of the outcomes suggests that the BOOST-A™ was more helpful for some adolescents on the autism spectrum than it was for others. This finding may be due to the range of characteristics that people on the autism spectrum possess and is consistent with evidence that there is a wide variability in outcomes for children on the autism spectrum (67, 68). Another potential reason for the varied results for participants could be that some had comorbid diagnoses such as attention deficit hyperactivity disorder and anxiety, which could have introduced additional considerations related to transition planning. A process evaluation was performed immediately following the quasi-randomized controlled trial to determine individual characteristics and contextual factors that support positive outcomes from using the BOOST-A™. The process evaluation found that whilst the BOOST-A™ supported some adolescents to engage in the transition planning process and develop new insights that led to clearer plans

for the future, barriers included not having access to a professional to guide the way and difficulty motivating the adolescent to engage in the process (59). Full results of the evaluation are reported separately (59).

### 6.5.3 Limitations

A limitation of this study was that the participating adolescents' autism diagnosis was based on parent-report and confirmed by the SRS-2 (35). Ideally, the Autism Diagnostic Observation Scale (ADOS; 69) would have been used to verify autism diagnosis, since it has good sensitivity and specificity (70). However, this was not possible because the ADOS is administered face-to-face and study participants came from a wide spread of geographic locations across Australia. The study had a low attrition rate for parents (9% control; 12% intervention), but higher for the adolescents (10% control; 31% intervention). Consequently, the final analysis was based on a sample containing less than 40 adolescents in each group, which may have resulted in the study being underpowered to detect between-group differences for the outcomes measured.

Use of a quasi-randomized and non-blinded treatment allocation presented potential sources of bias. However, baseline comparisons revealed no significant differences between the control and intervention group in outcomes and demographic variables other than socio-economic status. A general linear model confirmed that the significant between-group differences for the intervention effects remained after adjustment for socio-economic status. Given the difference in socioeconomic status, it would have been optimal to have collected information about parent's academic qualifications and professions to determine if there between-group differences in these areas. Although participants were excluded if they were participating in any other formalized transition planning program, it would have been optimal to gather data from the control group about any informal transition planning that may have been initiated by parents or schools during the study period. Different types of regular practice undertaken by the control group may have influenced their outcomes, so this study may have underestimated the

true impact of BOOST-A™ over a standardized control group with only basic transition planning.

The timeframes for this study did not allow for follow-up to determine whether the effects of the intervention were maintained or to gather information about participants' employment outcomes after graduation from school. This is a limitation because career readiness outcomes, such as self-determination, that were used in the study are only correlated with employment. Their observed improvement in this study may not necessarily lead to an increase in employment (71). The use of employment as an outcome would have reduced the risk of bias introduced by the use of self-report measures, such as social desirability. It is recommended that future studies are of sufficient duration to explore the maintenance of the changes in career exploration and self-determination over time, as well as post-school employment outcomes after using the BOOST-A™.

Strengths of the current study included the use of multiple raters (parents and adolescents), blinding of participants to trial hypothesis, as well as self-report measures that eliminated the need for blinding of evaluators. The inclusion of a control group in the study ensured maturation bias did not influence results, especially given the 12-month duration of the study.

## 6.6 Conclusion

This study found that there were no significant differences between groups for the primary outcome of overall self-determination. There is preliminary evidence that the BOOST-ATM is effective in increasing career exploration and opportunities for self-determination in the home environment for adolescents on the autism spectrum.

## 6.7 Declarations

### **Availability of data and material**

Data will be available on the CRC data repository.

### **Conflict of interest**

The authors declare that they have read Biomed Central's guidance on competing interests and wish to declare the following interests: MH developed the BOOST-A™ and was also the first author of the manuscript which describes the effectiveness of the BOOST-A™. The design of the trial has taken this into account in order to minimise such bias.

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### **Authors' contributions**

MH, MC, TF, MF contributed to the design of the trial. MH collected and analysed the data, and drafted the manuscript. MH, MC, TF, MF reviewed the manuscript. The manuscript has been read and approved by all authors.

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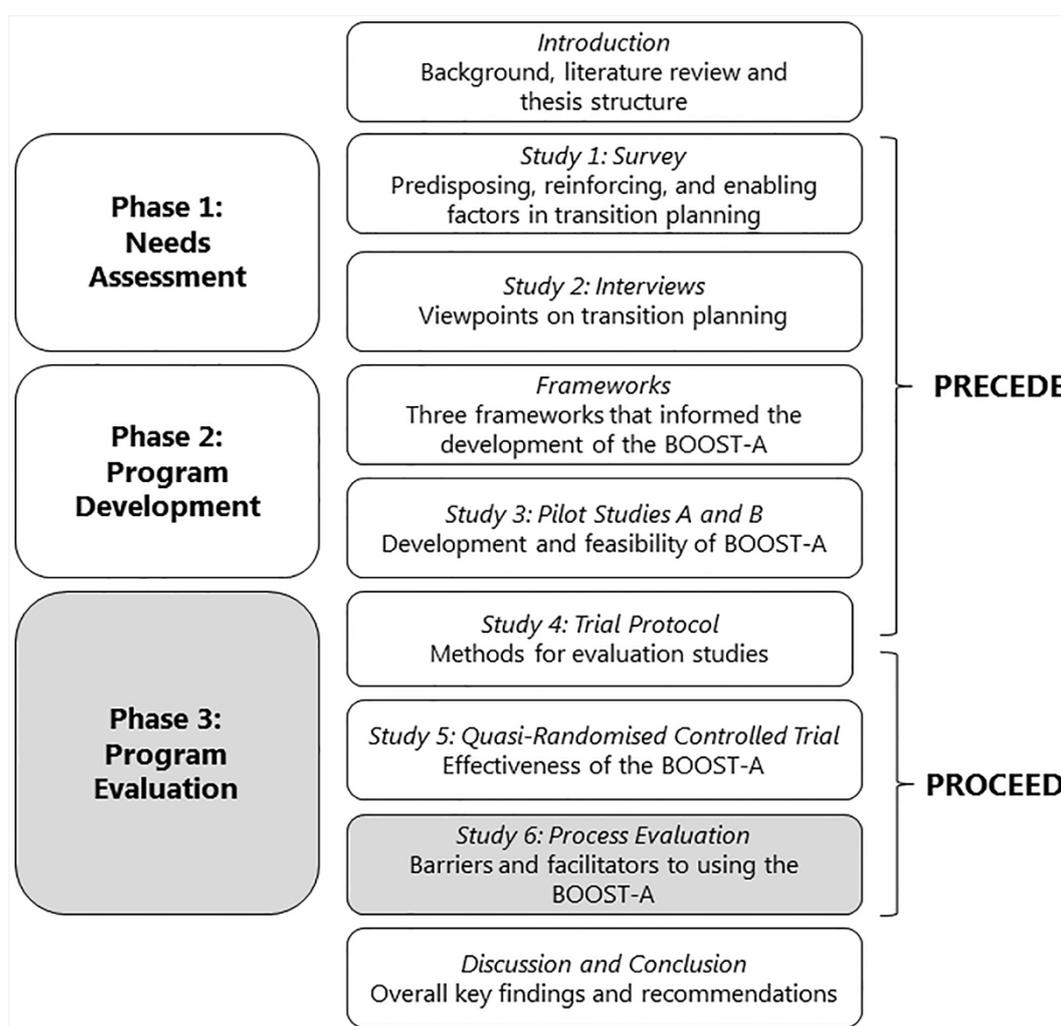
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# Chapter 7 PROCESS EVALUATION

Chapter 7 outlines the findings of the process evaluation of the BOOST-A™. The process evaluation was conducted in Phase 3 to determine the effectiveness, usability, and the barriers and facilitators to using the BOOST-A™. It was conducted at the conclusion of the quasi-randomised controlled trial, and consisted of a survey and interviews with participants from the intervention group.



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## Author Contribution Statement

As co-authors of the paper entitled, '*Process evaluation of the BOOST-A™ transition planning program for adolescents on the autism spectrum: A strengths-based approach*', we confirm that Megan Hatfield 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; and
- 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 collection, analysis, and interpretation; and
- Review and editing of the manuscript.

*Signed:* Torbjörn Falkmer Date: 25/05/17

*Signed:* Marina Ciccarelli Date: 25/05/17

*Signed:* Marita Falkmer Date: 25/05/17

# Process evaluation of the BOOST-A™ transition planning program for adolescents on the autism spectrum: A strengths-based approach

Megan Hatfield<sup>1, 2\*</sup>, Marita Falkmer<sup>1, 2, 3</sup>, Torbjörn Falkmer<sup>1, 2, 4</sup> and Marina Ciccarelli<sup>1, 2</sup>

<sup>1</sup> School of Occupational Therapy and Social Work, Curtin University, Perth, Western Australia, Australia.

<sup>2</sup> Cooperative Research Centre for Living with Autism (Autism CRC), Long Pocket, Brisbane, Queensland, Australia

<sup>3</sup> School of Education and Communication, Institution of Disability Research Jönköping University, Jönköping, Sweden

<sup>4</sup> Department of Medicine and Health Sciences (IHM), Linköping University and Pain and Rehabilitation Centre, Linköping, Sweden

\*Corresponding author

## 7.1 Abstract

A process evaluation was conducted to determine the effectiveness, usability, and barriers and facilitators related to the Better Outcomes & Successful Transitions for Autism (BOOST- A™), an online transition planning program. Adolescents on the autism spectrum (n=33) and their parents (n=39) provided feedback via an online questionnaire. Of these, 13 participants were interviewed to gain in-depth information about their experiences. Data were analysed using descriptive statistics and thematic analysis. Four themes were identified: i) taking action to overcome inertia, ii) new insights that led to clear plans for the future, iii) adolescent empowerment through strengths-focus, and iv) having a champion to guide the way. The process evaluation revealed why BOOST-A™ was beneficial to some participants more than others.

**Trial registration:** #ACTRN12615000119594

**Key words:** Asperger's Syndrome; employment; high school; pervasive developmental disorder; self-determination theory; vocational education.

## 7.2 Introduction

Research about adults on the autism spectrum tends to focus on the difficulties they face and how they experience poorer quality of life compared to adults without autism (1). Adults on the autism spectrum have lower satisfaction in work, living arrangements, social relationships, and future perspectives on life, even when compared to people with other childhood diagnoses such as attention deficit hyperactivity disorder (2). However, recent attention on the wellbeing and happiness of adults with autism (3), coincides with a shift in focus from the deficits to the strengths associated with autism (4, 5). Engagement in vocational activities may improve quality of life and performance in activities of daily living and reduce autism symptoms for people on the autism spectrum (Taylor, Smith, & Mailick, 6).

Unfortunately, many adolescents on the autism spectrum have difficulty transitioning into employment and post-secondary education (7), and they are less likely to have employment than their peers with disabilities or without a diagnosis (7). When they do gain employment many work part time and are under-employed in positions that are not commensurate with their education level (8, 9). This is despite the many strengths they bring to the workplace, such as reliability, and low absenteeism, and above average memory recall for topics related to their special interests (4, 10, 11). Low employment rates may be due to the unique challenges faced by people on the autism spectrum in the transition into post-school roles, including difficulties coping with uncertainty (12) and understanding the big picture of what life after school entails (13).

Employment outcomes for adolescents on the autism spectrum may be enhanced through transition planning during early secondary school. . Transition planning involves a set of coordinated activities that prepare the adolescent for leaving school (14) and improves post-school outcomes in the areas of employment and/or post-secondary education (15, 16). Most existing transition planning programs are generic and designed for adolescents with a disability (17-21), and these may not meet the unique needs of adolescents on the autism spectrum. Autism-specific programs that exist (22, 23) were developed in the United States of America and

may not be applicable to the Australian context. It is important to develop autism-specific interventions that support Australian adolescents to transition from secondary school into post-secondary education and employment.

The Better Outcomes & Successful Transition for Autism (BOOST-A™) is an online program that was developed to support adolescents on the autism spectrum in Australia to prepare for leaving school. A process evaluation was conducted to explore any contextual factors that may have affected the effectiveness of the BOOST-A™ and any variation in between-groups effects (24, 25). A process evaluation is a recommended key component of intervention development for a number of reasons (24). Firstly, it assists in determining the *effectiveness* of the intervention based on feedback from the target group. It also provides insights into possible improvements to make the intervention more effective and easier to use; i.e., *usability*. Finally, a process evaluation identifies possible reasons for 'implementation failure' of the intervention; i.e., it distinguishes between any inherent issues in the intervention and issues in the implementation of the intervention. These issues are referred to as *barriers* or *facilitators*. The effectiveness of the BOOST-A™ in enhancing self-determination among adolescents on the autism spectrum was established in a quasi-randomised controlled trial, the results of which have been published elsewhere (26).

## 7.2.1 Objectives

The objectives of the process evaluation were to:

1. describe participants' experiences of using the BOOST-A™ as part of transition planning (*effectiveness*);
2. describe participants' perceptions of the usability of the BOOST-A™ (*usability*);
3. identify perceived factors that assisted use of the BOOST-A™ (*facilitators*); and
4. identify perceived factors that limited use of the BOOST-A™ (*barriers*).

## 7.3 Methods

The process evaluation obtained feedback from participants using an online questionnaire and semi-structured interviews. Full details of the study protocol, including the quasi-randomised controlled trial, are reported elsewhere (27).

### 7.3.1 Participants

Participants who completed the questionnaire were adolescents on the autism spectrum and their parents who received the intervention in the quasi-randomised controlled trial. Inclusion criteria were: i) living in Australia; ii) a diagnosis of Autism Spectrum Disorder, meeting the criteria of the Diagnostic and Statistical Manual of Mental Disorders, fourth (28) or fifth edition (29); iii) enrolled in Years 8 to 11 at secondary school; and iv) able to read at a Year 5 reading level and possess basic computer skills to enable use of the BOOST-A™. Exclusion criteria were a diagnosis of intellectual disability (ID) or current participation in a formal transition planning program. The study focused on adolescents on the autism spectrum who did not have ID because this group have greater problems in accessing support for transition planning and subsequent poor outcomes (30, 31). Since the process evaluation aimed to evaluate the BOOST-A™, only the participants from the intervention group in the controlled trial were included.

Thirty-nine parents and 33 adolescents on the autism spectrum responded to the questionnaire to provide feedback on the BOOST-A™ (see Table 7-1). Six adolescents on the autism spectrum declined to participate along with their parents. The adolescents were on average aged 14.8 years and mostly male (80%). Autism severity ranged from mild to severe, as determined by the Social Responsiveness Scale – Second Edition (SRS-2) (32). The Socio-Economic Indexes for Areas (SEIFA) deciles were used to determine the socio-economic status of participants. The SEIFA uses the Australian Commonwealth Department of Education, Employment, and Workplace Relations' measure of relative socio-economic advantage and disadvantage (33). The SEIFA deciles range from 1 to 10; where 1 signifies the participant resides within an area that falls in the lowest 10% of socio-economic

advantage, and 10 signifies the residential area where the participant lives is within the highest 10% of advantage. The average SEIFA was 7.7 for the participants in the process evaluation questionnaire.

**Table 7-1. Characteristics of questionnaire respondents (n=39)\***

Characteristics	
Age of adolescent	
Mean years (SD; range,)	14.8 (0.4; 12-17)
Adolescent gender (n, %)	
Female	8 (20.5)
Male	31 (79.5)
Socio-economic Status	
SEIFA Mean decile (SD; range,)	7.7 (1.9; 4-10)
Autism Severity (n, %)	
Within normal	0 (0)
Mild	4 (10.3)
Moderate	10 (25.6)
Severe	25 (64.1)

\*Characteristics of the adolescent children of the 39 parents who responded to the questionnaire.

A subset of the parents and adolescents who took part in the questionnaire were invited to take part in an interview to provide more in-depth information about their experiences using the BOOST-A™. Purposive sampling for the interviews was used to ensure a diverse sample that represented a range of adolescents' ages and levels of success with the BOOST-A™. This helped ensure that diversity of opinions and a range of perspectives were obtained (34).

Thirteen interviews were conducted before saturation of data was achieved. Sixteen participants were invited to interview, and three parents were unable to take part in the interviews. Characteristics of interview participants are described in Table 7-2. Only 10 interviews were dyads of a parent and adolescent because three adolescents declined to participate in the interviews. One interview included the teacher instead of the parent because the teacher had been the primary liaison during the trial, with informed consent of the adolescent's parents. Participants were from four of the five participating states in Australia and were attending school in Years 9 to Year 12;

however, a majority of interviewees were in Year 10 (n=6) and from Western Australia (n=9).

**Table 7-2. Interview participants (n=13)**

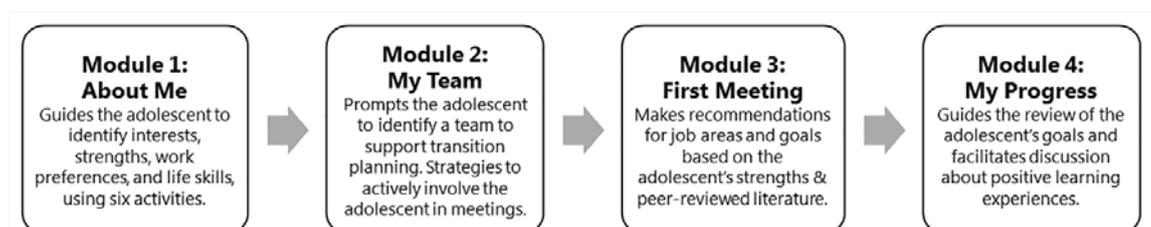
ID	Participants	State	Year at school
1	Mother and son	Victoria	Year 12
2	Mother	Western Australia	Year 10
3	Mother	New South Wales	Year 9
4	Mother and daughter	Western Australia	Year 11
5	Father and son	Western Australia	Year 12
6	Mother and son	Queensland	Year 10
7	Teacher and female student	Western Australia	Year 10
8	Mother and son	Western Australia	Year 11
9	Mother	Western Australia	Year 10
10	Mother and son	Western Australia	Year 9
11	Mother and son	Western Australia	Year 10
12	Mother and son	Queensland	Year 10
13	Mother and son	Western Australia	Year 11

### 7.3.2 Intervention: The BOOST-A™

The BOOST-A™ was developed using a rigorous process based on the PRECEDE-PROCEED model (35) for intervention development. Three frameworks informed the development of the BOOST-A™, including self-determination theory (36), the strengths-based approach (37) and technology-based approach (38). A comprehensive needs assessment determined priority areas related to transition planning for adolescents on the autism spectrum (13, 39). The BOOST-A™ was piloted in two studies, in which adolescents on the autism spectrum, parents, and professionals provided comprehensive feedback (40). The BOOST-A™ is a web-based program that consists of four modules, as shown in Figure 7-1. Participants accessed the online program with an individualised login, under which all their data were stored.

Given the importance of the adolescent being an active participant in transition planning (41-44), the adolescents were involved in every step of the process in the BOOST-A™ with support from their parents. The program utilized cartoon animations and visuals to engage the adolescent and provide structured guidance in

all modules. The first module, About Me, was completed at home with the parent and the adolescent. It consists of six activities that support the adolescent to identify their job preferences. For example, the adolescent completed the Career Interest Test (CIT) short form (45) to determine their interests, and they identified their sensory preferences in relation to the work environment (e.g. noise, wearing personal protective equipment). The adolescent and their parent completed the second module, My Team, at home to identify people who would support them in transition planning. This module guided parents to book the first meeting, and helped the adolescent to identify how they wanted to be involved in the team meeting (e.g. sitting and listening, providing written information, active speaking). The first and second modules take approximately 1-1.5 hours to complete, and can be done over multiple sittings as needed. The third module, First Meeting, is completed with the team members. At this meeting the team review the adolescent's strengths and interests, the adolescent is presented with some potential job pathways to consider and discuss, and they begin setting goals that are recommended by the BOOST-A™. The first meeting generally takes about one hour. The final module, My Progress, is completed at subsequent meetings with the team, where the adolescent is encouraged to take an increasingly active role in the meetings, goals are reviewed, and any challenges are discussed and framed as learning experiences that build resilience. These meetings may be between 1-1.5 hours duration.



**Figure 7-1. Overview of the four modules of the BOOST-A™ online program.**

### 7.3.3 Data collection

#### 7.3.3.1 Quantitative data

Participants completed an online questionnaire at the conclusion of the quasi-randomised trial. Participants were asked to rate their agreement against the

following statements using a Likert scale that ranged from 1 (strongly disagree) to 5 (strongly agree):

1. The BOOST-A™ helped me/my child feel more ready for leaving school (objective 1)
2. The BOOST-A™ program was easy to use (objective 2)
3. I would recommend the BOOST-A™ to someone else (objective 1)

### 7.3.3.2 Qualitative data

The questionnaire also asked participants to describe the barriers and facilitators to using the BOOST-A™ using open-ended responses (objectives 3 and 4). In addition, semi-structured interviews were conducted in person or via telephone within two months after completing the trial. Interviews were completed by a third-party research assistant who had not been involved in the quasi-randomised controlled trial. This limited any preconceptions that the interviewer had about the BOOST-A™ program, and also allowed participants to feel comfortable to share constructive feedback during the interview. Data collection concluded when interviews ceased to provide further understanding of the topic of exploration (46). Each question corresponded to the objectives of the process evaluation, as described in the literature (24, 25). The questions were broad and non-directive, so that each participant could provide information on their own experiences. See Appendix C for the interview guide.

### 7.3.4 Analysis

For quantitative data, descriptive statistics were used to determine percentage agreement for each statement related to the usability and effectiveness of the BOOST-A™. For qualitative data, including data from both the questionnaire and interviews, a descriptive approach was the theoretical framework chosen for the analysis, since the interviews were part of a process evaluation of the BOOST-A™. Interviews were audio-recorded, transcribed verbatim, and de-identified. Interviews and responses from the open-ended questions were imported into NVivo (Version 11; 47), and coded into individual nodes.

Transcripts and responses to open-ended questions were analysed using thematic analysis, with constant comparison of the data within and across participants. Themes identified by the primary researcher were peer reviewed and verified by two other researchers. Disagreements surrounding themes were resolved through discussion and by returning to the original transcripts, until consensus was reached. Themes were refined and combined to create a rich description of the experiences of the participants. Triangulation of data from multiple sources (i.e., adolescents and parents) and using multiple data collection methods (i.e., rating scales, written open-ended questions and verbal interviews) improved the credibility of the findings. Dependability was improved through reflexivity of the primary researcher in keeping field notes for the duration of the controlled trial; documenting incidental feedback provided by participants and any preconceptions the researcher held regarding the participants and/or their outcomes (46). An audit trail of the development of the themes was recorded using NVivo (46, 48).

### **7.3.5 Compliance with ethical standards**

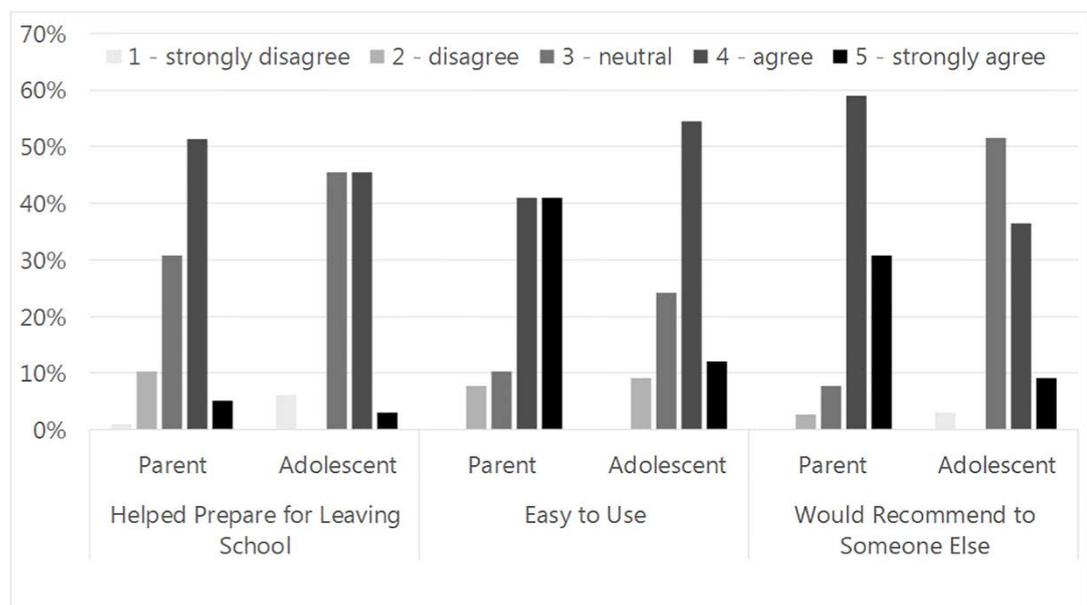
All procedures performed in this study were granted formal approval from the Curtin University Human Research Ethics Committee (approval number HR110/2014), and by the Catholic Education Offices and the Departments of Education in Queensland, Western Australia, Victoria, New South Wales, South Australia, and Tasmania. Informed consent was obtained from all adult participants in the study. For participants under 18 years of age, their parents provided written informed consent and the adolescent provided written informed assent. Names of participants reported in this paper have been replaced with a pseudonym.

The BOOST-A™ trial was registered with the Australia and New Zealand Clinical Trial Registry (#ACTRN12615000119594). The trial conformed to the National Statement on Ethical Conduct in Human Research (49) and the Australian Code for the Responsible Conduct of Research (50).

## 7.4 Results

### 7.4.1 Quantitative data

Participants' ratings of the BOOST-A™ regarding usability and effectiveness are represented in Figure 7-2. Eighty-two per cent of parents and 67% of adolescents agreed that the BOOST-A™ was easy to use. With regard to effectiveness, 57% of parents agreed that the BOOST-A™ helped their child to prepare for leaving school and 90% agreed that they would recommend the program to another person. By contrast, 49% of adolescents agreed that the BOOST-A™ helped them to prepare for leaving school and 46% agreed that they would recommend the program to another person. Many adolescents chose the neutral option for these two questions (26% and 56%, respectively).



**Figure 7-2. Summary of participant ratings of the BOOST-A™; percentages (parents n=39, adolescents n=33).**

### 7.4.2 Qualitative data

Thematic analysis of the interview data resulted in four core themes: i) taking action to overcome inertia, ii) new insights that led to clear plans for the future, iii) adolescent empowerment through strengths-focus, and iv) having a champion to guide the way. The themes represent the experiences of the participants when using

the BOOST-A™, including the barriers and facilitators. There was overall agreement between parents and adolescents for the core themes, with minor differences of opinion as reported in the description of each theme.

#### 7.4.2.1 Taking action to overcome inertia.

Many participants reported that the BOOST-A™ assisted in initiating the process of preparing for the future, as it provided a clear and structured process to follow. A number of parents and adolescents reported that they had previously put off transition planning because of the anticipated enormity of the process.

For us, doing those steps, you get onto thinking of a whole lot of things that we would've delayed thinking about because we thought of them as being 'too hard'. And they're not as hard as we thought they were. (Parent 4)

A number of parents and adolescents reported that the BOOST-A™ gave them "courage" (Parent 13) and allowed them to overcome a fear that they had about what would happen in the future: "now my future seems to be a little bit clearer... I felt pretty scared about it, but now I am less scared than I was before" (Adolescent 7).

Some parents reported that they felt that starting planning early had given them an advantage and many reported that they would have liked access to the program earlier: "It could even apply to primary schools ... just to give them an idea of a future beyond school" (Parent 1). Some participants who used the BOOST-A™ later in their schooling found the program less helpful because they had already started thinking about leaving school. Parent 4 reported that "there wasn't too much of a take away" and that the program did not add anything new because their child was in Year 12 at school and they had already started thinking about the transition out of school before using the program.

The majority of participants reported that the BOOST-A™ provided clarity around what steps to take and supported them to take action to prepare for leaving school. Many adolescents engaged in a number of new activities after using the BOOST-A™ including: part-time jobs, work experience, receiving mentoring, attending training

courses, career open days, and training in life skills, social skills, and emotional regulation. Adolescent 7 and her teacher shared details of the adolescent's recent work experience at a clothing shop after she identified her strengths and work interests using the BOOST-A™. The teacher described the work experience: "It's been hugely beneficial.", and the adolescent then commented "It has. I really think the BOOST-A was a big part of this whole thing." Several participants attributed their engagement in these opportunities to the BOOST-A™: "It's one of the things that really inspired me to take the job interview was the fact that I thought BOOST-A was assisting me in my career path" (Adolescent 12), and "it looks like he might have a job and that wouldn't have happened without this" (Parent 11). Participants described how they would have liked the final module, My Progress, to be developed further. Participants also recommended the inclusion of content that built employment readiness skills: "that would have been a great stepping stone actually, for them to start talking about, at a workplace, what's expected of you" (Teacher 7).

#### 7.4.2.2 New insights that led to clear future plans.

The majority of participants reported that the BOOST-A™ helped them develop a plan for what they wanted to do in the future: "I got a clear view of what kind of jobs I could choose, like for me to have in the future" (Adolescent 10). Adolescents felt they had an increased choice of jobs that they could do when they left school that utilised their strengths and interests.

"I think it's useful for helping me map out where my interests are and where to improve so that I can – if I find a workplace I can work in a better and more suitable environment and I know where to improve on in my working strategies. Particularly the social ones. Also overall, I think I'll find this program useful in the long term." (Adolescent 5).

They also reported that the BOOST-A™ supported them to understand what life might be like in the future in a more tangible way: "it gave me ideas of other things that I could actually do, making it less abstract as well" (Adolescent 12). Ultimately, it gave them a pathway to follow: "Um, yeah! I have a better idea of where I'm heading

right now" (Adolescent 8) and "Now that I'm growing up I still don't know what I want to do, but now my future's becoming a little bit clearer" (Adolescent 7).

Some parents and professionals described how they gained new insights into the adolescents' strengths and interests, and believed that their child had greater options for their future. One parent commented that the autism-specific nature of the BOOST-A™ allowed her to gain an insight into her son's world "because it's more geared towards kids on the spectrum... some of the stuff that came up in the answers Andrew gave was really interesting to me. Because he doesn't express that sort of stuff naturally" (Parent 11). Parents also described how they learned things about the adolescent that they may not have without the BOOST-A™.

I thought I knew Ryan like the back of my hand and some of the things that came up I was surprised by, pleasantly surprised and grateful for. It broadened my outlook on what his future was going to be rather than having a rather tunnel vision – well, he likes this, he doesn't like this, he'll end up doing A, B, or C. And now there's more scope and that gives me peace of mind. We really liked it. (Parent 1)

For some participants, the BOOST-A™ helped them to make the link between the autism-specific characteristics and what kind of job might be suitable for the adolescent: "we know that he has acute hearing and he doesn't like lots and lots of noise and crowds but then when you see that, going by the results, that he would work best in an office for example... it's like the penny dropped" (Parent 1). Some parents reported feeling excited that their child had achieved things that they had not believed to be possible before using the BOOST-A™.

Jason recently went to his first job interview. If you'd asked me before the BOOST-A, I would have said that's not going to happen anytime soon. But he did, and he did really well, and it's like wow! (Parent 12)

#### **7.4.2.3 Adolescent empowerment through strengths-focus**

The BOOST-A™ empowered some adolescents to engage with the process of transition planning. Adolescents described how they found the program engaging: "I loved the program, the cute videos, and like the planning" (Adolescent 7).

Engagement allowed them to develop a clear direction for the future: "I think it was the program that really made us start thinking about after school, and I wasn't that bored with it" (Adolescent 8). Many adolescents commented on how the program supported them to identify their strengths and understand how these strengths could be leveraged into job opportunities: "It showed what sort of jobs would be applicable for my skills and where I could put my strengths into a job" (Adolescent 12). Some participants commented that the program helped them feel excited for the future: "I don't think I'm afraid now, I mean I'm doing a course next year so I'm totally ready for that, I'm pumped!" (Adolescent 7).

Some parents found that the program facilitated adolescent engagement through its ease of use and focus on the adolescent's strengths: "it was non-threatening, no right or wrong and it was always about empowering the adolescent and looking at strengths" (Parent 1). Parents contrasted using the BOOST-A™ with past experiences of transition planning, where their adolescents disengaged with programs because they were perceived as intimidating or uninteresting. Participants also commented that the autism-specific elements of the BOOST-A™ facilitated its use: "the interface, it was very ASD-friendly, which I don't believe that other career programs are" (Teacher 7).

Conversely, some parents reported they were unable to engage their adolescent in the transition planning process using the BOOST-A™. A few parents reported that their adolescent disengaged because they felt the program was not age-appropriate, as one parent commented: "because he's so high functioning it was almost a little bit too simple, a little bit babyish" (Parent 9). In contrast, other parents reported that program was too difficult for their children. Participants described how disengagement was a big barrier to moving forward with the transition planning process. In addition, a few participants reported that the program was difficult to use on a smartphone or tablet because the website was not compatible with the platform, which resulted in wasted time during team meetings.

#### 7.4.2.4 Having a champion to guide the way

One of the key issues affecting the success of the BOOST-A™ was whether participants had a “champion” to support their planning. Champions were people who had enthusiasm to support the transition planning process: “We’ve just been really lucky, we’ve got a teacher who is really passionate about what she’s doing” (Parent 6). Having a champion helped provide new information and opportunities: “I liked the school being on board ... already it's opened a few doors” (Parent 10). Who the champion was differed depending on the situation; “that champion’s either going to be the parents... or the career counsellor could be a champion in some schools, or the special needs teacher” (Parent 12). Allied health professionals were rarely identified as champions since most adolescents no longer accessed therapy services because parents felt they were not needed at this age.

Not having a champion was a major barrier to using the BOOST-A™: “Trying to track down somebody who might be willing to help – to kind of work as a part of that ‘team’ – we found that really difficult” (Parent 4). Participants reported fewer benefits from the program when they did not have someone to champion the transition planning process. Parents felt that education and health professionals might not be proactive or engaged in the process because “everybody thinks it’s someone else’s job” (Parent 4). One parent suggested that this could be improved by developing “guidelines for team members – the objectives of the meeting and some sort of framework of the discussion session” (Parent 5). Participants described the importance of having someone other than parents involved because professionals’ perspectives were taken more seriously: “If somebody else comes on board, that just gives mum a bit more weight I think” (Parent 9). Selecting the team carefully was crucial to ensure the planning process ran smoothly. As one parent stated: “If you’ve got the right people involved, it would be very beneficial ... you had sort of a filter that you can go, righto, well, this person is proactive” (Parent 3).

## 7.5 Discussion

The process evaluation revealed that the main benefit of the BOOST-A™ was the clarity it provided around the transition planning process for participants. The majority of parents rated the program as easy to use and stated that they would recommend it to other people. The BOOST-A™ assisted participants to overcome inertia, develop a clear plan for their future careers, and ease anxiety. This was facilitated by the usability and the structure of the BOOST-A™, which breaks the transition planning process into clear and measurable steps. However, only 57% of parents and 49% of adolescents reported that they felt the program helped them to prepare for leaving school. This may have been due to the barriers of not having a champion to guide the process and the adolescent disengaging because they perceived the program to be too simplistic.

Participants described how they had previously avoided or procrastinated engaging in transition planning because of a fear associated with this task. This is consistent with literature that links procrastination to a fear of failure (51). Procrastination is also influenced by task averseness; tasks that are perceived as boring or unpleasant are put off. If a task is perceived as too hard or it induces anxiety, there will be inaction even if motivation is high (51). When tasks are perceived as being simpler, specific, interesting, and achievable then people are less likely to procrastinate. Participants described how the BOOST-A™ simplified transition planning and made it easier for adolescents to engage in this process. Enhancing the usability and appeal of the program may have helped adolescents overcome their fear of failure and shift them into action one step at a time. In addition, the BOOST-A™ supported adolescents to set goals and to take steps to achieve them. Participants described achieving goals related to getting work experience, part-time jobs, and learning new skills. Goal achievement provides a sense of progress and increases feelings of competency, which enhances self-determination (52).

The BOOST-A™ supported the adolescents to be actively engaged in transition planning, helping them to develop a clear picture for their future. Adolescents on the autism spectrum benefit from an understanding of the big picture and being

actively engaged in the transition planning process (13, 39). People on the autism spectrum have a proclivity for detail and have difficulties using context to understand the broader meaning of situations (53). The BOOST-A™ supported engagement in real-life experiences, which may have enabled the adolescents to understand the bigger picture of how transition planning assists in getting a job. Autonomy is an important precursor to self-determination and occurs when adolescents are provided with choices, and their feelings and decisions are acknowledged (52). Many participants stated that the BOOST-A™ made them aware that they had multiple job pathways available for the future. Furthermore, a sense of autonomy was enhanced by the strengths-focus of the BOOST-A™. Many adolescents in this study reported they had a better understanding of how to leverage their special interests towards certain jobs. This aligns with the strengths-based view of autism (4, 54), where diagnostic features such as special interests that are often viewed as a deficit are viewed positively and can be leveraged into employment opportunities (55). Parents described gaining new insights into their adolescent's strengths and that the process heightened their expectations for their child. Professionals who participated in the pilot trial of the BOOST-A™ recommended that adolescents on the autism spectrum should have support to complete the interests section because sometimes their responses were "unrealistic" (40). This perception appears to be challenged by the findings of the process evaluation, in which the reverse appeared to occur; that is, parents raised their expectations of what their adolescent could achieve with their interaction with the BOOST-A™; rather than the adolescents lowering their expectations. This outcome aligns with the intention of the BOOST-A™; that is, to shift the focus from autism being seen as a deficit towards a strengths-orientated view (56).

The most frequently reported barrier to the implementation of the BOOST-A™ was difficulty engaging team members or finding a champion. Having a champion who is highly regarded in a school or organisation is an important element of effective program implementation (57). Self-determination theory describes how relatedness can increase intrinsic motivation and how the presence of a responsive and supportive individual can facilitate increased engagement in a task (52). In self-

determined learning theory (58), adolescents must be provided with opportunities to set goals and take subsequent actions at home and in school. Participants in the BOOST-A™ trial who did not have a champion did not have the opportunity to set goals and get real life experiences, and therefore it is likely that the BOOST-A™ did not improve their self-determination. Involvement of professionals has been described as a key facilitator in the transition to university of people on the autism spectrum (59). Furthermore, involvement of a human trainer was recommended by a meta-analysis about using technology-based interventions for people on the autism spectrum (38). Technology should be used to augment, not replace, face-to-face contact (60). Therefore, it is recommended that the BOOST-A™ is used in combination with face-to-face training and ongoing support of adolescents, parents, and teachers in the transition planning process. In addition, it is recommended that further research focus on the development of strategies to empower parents to be the champions in transition planning and to enhance parent confidence and effectiveness in communicating with professionals (61). This may result in improved parent and adolescent outcomes from using the BOOST-A™.

Although most participants reported that they felt the BOOST-A™ facilitated adolescent engagement because it was easy to use, some reported that it was too simplistic, while others found it too complex. In addition, only 36% of adolescents on the autism spectrum reported that they would recommend the BOOST-A™ to someone else, and 52% were neutral about recommending it. A possible explanation for this is the variability in the characteristics of each individual on the autism spectrum. Indeed, literature highlights this as the challenge in determining the effectiveness of interventions for adolescents on the autism spectrum; there may be individual characteristics that predict responsiveness to certain interventions (62). Another explanation for some participants not finding the program helpful may be that they were in the precontemplation stage of change related to thinking about life after school, and therefore less likely to engage in the transition planning process (63). In this stage, people have no intention to engage in a process of change, because they are unaware of the difficulties that might arise from inaction. Adolescents on the autism spectrum might be in the precontemplation stage

because of difficulties understanding the big picture of what life might be like after school, and hence why there might be a need to plan for this (13, 39). Further research should explore motivation to participate in transition planning from the perspective of the adolescent on the autism spectrum.

### 7.5.1 Proposed changes to the BOOST-A™

There are a number of proposed amendments to the BOOST-A™ based on the findings of the process evaluation (see Table 7-3). The theme *having a champion to guide the way* described the importance of having someone to guide the transition planning process. Therefore, the first recommendation is to ensure there is a suitable experienced and qualified professional to train and support parents and staff in the use of the BOOST-A™ in transition planning. To improve the usability of the BOOST-A™, it is recommended that the program be developed into an application for use on mobile telephones and tablets to enhance ease of access in multiple contexts. Parent feedback provided recommendations for improving the clarity and content of sections of the program. For example, the inclusion of additional information in the final module, My Progress, about work-related skills and additional goals. Finally, using gamification to increase intrinsic reward for adolescents as they participate in the program modules might improve adolescent engagement in each stage of the transition planning process (64).

**Table 7-3. Proposed changes to the BOOST-A™ based on process evaluation findings**

Improvement	Justification	Action Required
'Champion' to guide the BOOST-A™ process.	Getting a team together was greatly assisted by having an external person to guide the process.	Professional to train and endorse guiding principles of BOOST-A™. Develop guidelines for team meetings.
Enhance adolescent engagement in the BOOST-A™.	Some adolescents were difficult to engage in the BOOST-A™.	Add virtual rewards for completion of online modules, or 'gamify' the BOOST-A™.
Improve accessibility to the BOOST-A™.	Some participants found the BOOST-A™ difficult to use on phones and tablets.	Develop the BOOST-A™ into an application for use on phones and tablets.

Improved clarity and content in some areas of the BOOST-A™.	Participants reported that they did not like the forced response questions, and that the final module seemed incomplete. One participant reported timeframes were too vague.	Provide a third option in the interests questionnaire – ‘Neither’. More information in the final module. Clearer timeframes at the beginning.
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## 7.5.2 Limitations

Adolescents and parents were given the opportunity to provide written and verbal feedback on the BOOST-A™. However, using a variety of data collection methods may have allowed more in-depth understanding of the adolescents’ experiences using the BOOST-A™. Interview data may have been enhanced by including visual supports in questions (65), such as ‘activity-based’ interviews including drawing during discussions (66), or Photovoice, where participants talk about photographs they had taken of their experiences (67). Interviewing parents and adolescents as dyads may have affected how candid adolescents were in their responses. Therefore, it may have been preferable to interview adolescents and parents independently to encourage honest responses from participants.

Purposive sampling for the process evaluation was used in an attempt to get a range of participants from different parts of Australia. However, the majority of the participants who nominated to take part in the interviews were from Western Australia. Education is managed at a state level in Australia and the lack of equal representation of participants from each state in Australia could have resulted in an imbalanced perspective of the facilitators and barriers to using the BOOST-A™; particularly within school settings. The survey respondents were predominantly males with autism classified in the severe range as determined by the SRS-2. This might also explain the mixed reports of effectiveness of the BOOST-A™ in the questionnaire.

In addition, it would have been beneficial to interview professionals supporting adolescents who used the BOOST-A™ in the trial, to get their perspectives on the

usability and effectiveness of the BOOST-A™. Therefore, it is recommended that future research explores the insights of professionals, such as teachers, career counsellors, and learning support staff, regarding using the BOOST-A™ during the transition planning process.

## 7.6 Conclusion

The process evaluation revealed that participants found the BOOST-A™ easy to use, and that parents would recommend the program to others. The facilitators and barriers to using the BOOST-A™ were represented in four themes. The BOOST-A™ supported participants to take action to overcome inertia that accompanied a fear of change in leaving school, and develop new insights that led to clearer plans for the future. The strengths-focus of the BOOST-A™ empowered adolescents in the transition planning process. One of the biggest barriers to gaining benefit from the program was not having a champion to guide the way in setting goals and taking action.

## 7.7 Declarations

### **Availability of data and material**

Study data will be made available on the Cooperative Research Centre data repository.

### **Conflict of interest**

MH developed the BOOST-A and was also the first author of the manuscript that describes the effectiveness of the BOOST-A. The design of the process evaluation has taken this into account in order to minimise bias.

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### **Authors' contribution**

MH, MC, TF, MF contributed to the design of the trial. MH collected and analysed the data, and drafted the manuscript. MC and MF completed a peer review and verified themes. MH, MC, TF, MF reviewed the manuscript. All authors read and approved the manuscript.

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# Chapter 8 DISCUSSION AND CONCLUSION

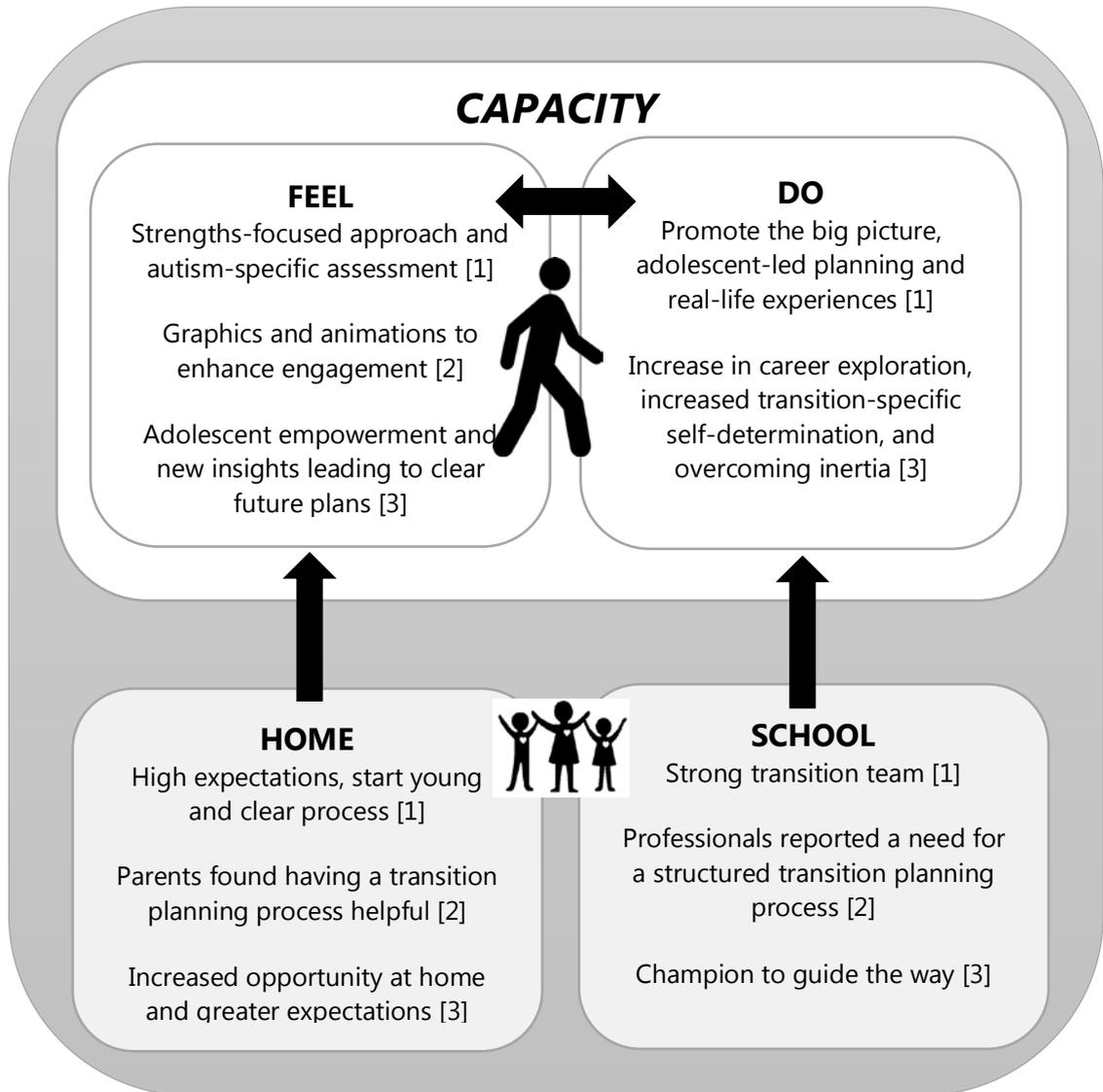
## 8.1 Summary of studies and findings

The thesis aimed to develop an autism-specific program that would support adolescents on the autism spectrum to prepare for leaving school. The Better Outcomes & Successful Transitions for Autism (BOOST-A™) was developed using a rigorous process based on the PRECEDE-PROCEED Planning Model (1). In Phase One, the needs assessment identified autism-specific factors that related to successful transition planning, including supporting adolescents to see big picture and focusing on special interests. In Phase Two, the BOOST-A™ was developed based on three frameworks that arose from a scoping review, and then piloted with two groups that provided feedback on the program. The BOOST-A™ was evaluated in Phase Three, in which a quasi-randomised controlled trial found that the BOOST-A™ enhanced self-determination at home, transition-specific self-determination and career awareness. A process evaluation provided insight into the facilitators and barriers to using the BOOST-A™. The structure and strengths-focus of the BOOST-A™ supported participants to overcome inertia and take action, however barriers included difficulty finding a champion and challenges motivating the adolescent to participate in the process.

## 8.2 General discussion

The focus of the BOOST-A™ was determined by the needs assessment, which highlighted the importance of having a strong team that held high expectations for the adolescent. Therefore, the BOOST-A™ was developed to target not only the adolescent on the autism spectrum, but also their parents and the team of professionals who work with them. The design of the BOOST-A™ acknowledges that change is not just dependent on the adolescent, but also on the significant adults in their lives who support them. The BOOST-A™ aligns with self-determined learning theory (2), which places equal emphasis on the individual's actions and the

environmental aspects of self-determination. The theory is predicated on the process of increasing self-determination, rather than just the characteristics of being self-determined (3). The theory has two main constructs: capacity and opportunity. The self-determined learning theory was used to frame the general discussion for this thesis, as seen in Figure 8-1.



**Figure 8-1. Overall conceptualisation of thesis findings in the Self-Determined Learning Model**

\*[1] = Phase 1 Needs Assessment, [2] = Phase 2 Program Development, [3] = Phase 3 Program Evaluation

## 8.2.1 Adolescent capacity for self-determination

Capacity refers to the knowledge, ability, and perceptions that allow the adolescent to become an autonomous and self-governing adult (4). Capacity has two components: *feel* and *do* (5).

Adolescents have to *feel* they have the autonomy and control over their life, in order for them to act or engage in challenging activities, such as planning for getting a job or going to university (6). The needs assessment identified having a strengths-focused approach as a guiding ideal for transition planning. The BOOST-A™ was developed to address this guiding ideal by placing emphasis on an adolescent's strengths and interests, and how these could be leveraged into future employment. After using the BOOST-A™, participants in the process evaluation reported they had new insights into the adolescents' strengths and had a more optimistic view of the adolescents' future. This indicates that the strengths-based approach of the BOOST-A™ was successful in enhancing positive feelings for some participants. By focusing on positive feelings and happiness in people on the autism spectrum, there is the potential to improve their ability to cope with stress and enhance their flexibility of thinking (7). Focusing on enhancing positive feelings is especially pertinent given the high rate of depression and anxiety amongst adolescents with autism (8).

The needs assessment also identified that transition planning should be autism-specific. This was particularly important because many participants described how the adolescents' lack of motivation was a frequent barrier in transition planning. Motivation is the link between the feeling and doing components of the self-determined learning model; the adolescent must feel intrinsically engaged in the transition planning process to take action in this process. A positive attitude towards career exploration is a prerequisite of career maturity and impacts on the degree to which an adolescent is proactive in exploring work options and career preferences (9). The pilot trial of the BOOST-A™ provided valuable insights on how to motivate adolescents; for example, participants recommended the use of graphics and animations to enhance adolescents' engagement with the online materials. The process evaluation revealed that using these strategies did support many

adolescents to engage with the BOOST-A™. Adolescents reported they were motivated and empowered by the user-friendly, autism-specific, and positive nature of the program; however, some parents reported that motivating the adolescent to get involved was still a challenge.

To become self-determined, the adolescent must *do*, or engage in experiences that provide a sense of autonomy and competence (6, 10). The needs assessment revealed that adolescents on the autism spectrum had difficulties understanding the 'big picture', or what life might be like after school. Participants in the needs assessment interviews described how a lack of understanding of the big picture impacted on participation in the transition planning process. Difficulty understanding the big picture could be due to challenges with abstract thought and gestalt processing (11). Understanding the big picture is also likely to be impacted by context blindness; that is, difficulty using contextual information to make sense of the world (12). Context blindness affects executive functions such as cognitive flexibility and problem solving (12), which are important in the transition planning process. Context blindness also affects comprehension of non-literal language. For example, the term 'work' means something different depending on the context; it could mean working on a farm, teaching students in a classroom, or completing research on autism (12). Another possible explanation for difficulties understanding the 'big picture' may be that adolescents with autism encounter difficulties with episodic future thinking, or imagining future experiences, as described in recent literature (13). This relies on being able to integrate information from multiple areas of the brain and mentally project oneself through time (14). Adolescents with autism may have difficulties when asked to think about a specific event in the future, especially if they are asked to verbalise this under social and time pressures rather than writing it down (15). The needs assessment identified engagement in real life experiences, such as work experience or part-time employment, as an important strategy for supporting the adolescent to understand the big picture. This strategy is likely to be effective because it contextualises the meaning of work for the adolescent, and provides real life experiences to support adolescents to imagine future experiences in employment.

The BOOST-A™ enhanced adolescents' career exploration, and while it did not result in significant improvements in overall capacity for self-determination, there was a significant improvement in transition-specific self-determination in goal-attainment and involvement in real-life experiences. The process evaluation confirmed that the BOOST-A™ facilitated participants to overcome inertia and take action, with a number of participants reporting that it assisted them to reach their goals of doing work experience and getting part-time work. Engaging in real-life experiences provides contextual cues and information. There is emerging evidence that context-specific interventions might improve outcomes for people with autism. For example, children on the autism spectrum have shown improvements in emotional recognition and expression of appropriate emotions when the intervention incorporated sufficient contextual information (16, 17).

## 8.2.2 Opportunities for self-determined behaviour

Opportunity refers to the chance to apply knowledge and utilise abilities to engage in new and challenging tasks (3). Opportunities for self-determined behaviour can occur at home or school (5). Opportunities need to be presented as a *just-right challenge*, so that the task is difficult enough for the adolescent to develop new skills and gain a sense of accomplishment, but not so difficult that it exceeds their capacity and they give up; resulting in a sense of failure (2). Opportunities that provide an optimal level of challenge are pursued and capacity is enhanced as adolescents learn to adjust and regulate their feelings and actions (3). Therefore, opportunity and capacity have a cyclical relationship - opportunity promotes capacity building, and with greater capacity comes additional opportunities.

The BOOST-A™ attempted to enhance opportunity in the home and school environments. However, the results of the quasi-randomised controlled trial indicated that the BOOST-A™ resulted only in a significant increase in opportunity at *home*. Findings from the process evaluation also reflected an increased opportunity at home, with parents reporting that the BOOST-A™ provided them with better insight into their adolescent's strengths. The BOOST-A™ supported parents to raise their expectations of what their child could achieve. This positive outcome reflects a

guiding ideal identified in the needs assessment, that is, to foster self-determination through high expectations. The importance of starting planning young and providing a clear process were also key strategies identified in the needs assessment. The BOOST-A™ provided parents with a clear transition planning process to follow and enhanced their understanding of their child's strengths. Consequently, it is likely that parents were better able to provide appropriate and *just-right* opportunities at home. In addition, having a clear process helped parents to overcome inertia and start the transition planning process earlier. The increased opportunities for self-determined behaviours in the home by using the BOOST-A™ is noteworthy, since other interventions mostly focus on enhancing self-determination in the school setting, with encouragement for family input (18-21). Focusing on the school environment is a practical approach, since the frequency and duration of time adolescents spend at school make it an ideal environment in which to conduct interventions. However, providing opportunity for self-determination in the home environment is equally, if not more, important because of the consistency of the parents' presence in their child's life (4). Greater frequency of discussions about post-school plans at home is correlated with increased participation in transition planning meetings at school in adolescents on the autism spectrum (22). Whilst there are general recommendations for parents to enhance the self-determination opportunities for their child (23), there are few structured programs that support parents with this endeavour.

The results of this thesis have also highlighted the importance of the team - the adolescent, family, and professionals - working together in transition planning. The need to involve external stakeholders, such as teachers, in transition planning may be because adolescence is a period of individuation, in which the child develops their own identity, separate to that of their parents (4). Parents in Pilot A reported that one of the most helpful aspects of the BOOST-A™ was getting a team together. Unfortunately, the BOOST-A™ did not result in a significant increase in opportunity at *school*. The results of the process evaluation identified a potential reason for the lack of significant differences in opportunity at school. Some participants found that one of the biggest difficulties in using the BOOST-A™ was getting a team on board,

or finding someone to 'champion' the transition planning process. Therefore, in the cases where participants had difficulty finding a team, it was unlikely that opportunity at school would increase. Difficulty getting a team together may be because of the lack of clarity around whose role it is to lead the transition planning process - a problem that was identified by participants in the needs assessment and process evaluation, and is also described in existing literature (24). Consequently, there is a need for more evidence-based interventions to support collaboration between parents and professionals in providing opportunities for adolescents in transition planning (25, 26).

## **8.3 Recommendations**

### **8.3.1 Recommendations for transition planning services**

Given that a major barrier in transition planning was identified as the lack of a champion to drive the process, future work should focus on enhancing collaboration in transition planning. Teachers have acknowledged the importance of collaboration in transition planning (24); however, many report that they do not have enough knowledge about transition planning to implement it in schools (27). This indicates a need for improved professional development training for teaching professionals to enhance their knowledge in how to support adolescents on the autism spectrum and their families in transition planning (28). Teachers' attitudes towards collaboration can affect parent involvement in transition planning. Teachers are more likely to involve the parent in a cooperative manner if they value parental contributions (24). Training about the importance of collaboration could be embedded into teachers' college education. Interactive coursework assignments that promote partnerships with parents and multi-disciplinary team members are effective in promoting positive attitudes towards collaboration among a variety of professionals (29).

Parent involvement could be promoted using interventions that empower parents and provide them with the skills to be the champion in the transition planning

process. Parent-led transition planning would address issues associated with high turnover of teachers or other professionals, and allow sustainability of the process after the adolescent leaves school. However, it is important that parents are supported to empower their child to advocate for themselves, as greater parent involvement at school is linked to reduced active participation in transition planning by adolescents on the autism spectrum (22). One example of an intervention to empower parents is the coaching or parent-professional partnership model, which is an emerging model most frequently used in early intervention services (30). This model utilises techniques, such as expertise-sharing, mutually agreed upon goals, and collaborative problem solving to improve confidence and reduce stress among parents who have children on the autism spectrum (31). It is important to ensure the coaching model is used to empower parents and develop their advocacy skills, rather than placing all of the responsibility for transition planning on their shoulders (32). Most of the available evidence on coaching is related to young children on the autism spectrum, so further work is needed to develop the coaching model to be appropriate to use with parents of adolescents on the autism spectrum in transition planning.

Whilst parents are described as the most significant and valued source of support for adolescents on the autism spectrum, the involvement of health professionals should also be promoted in the transition planning process (33). The process evaluation indicated health professionals were not always perceived as an important part of the transition planning team. This may be because the emphasis in the literature is early intervention for children on the autism spectrum (34), and health professionals focus their efforts on children rather than working with adolescents. Health professionals could be 'champions' for transition planning for adolescents on the autism spectrum, potentially reducing current pressures on teachers and parents. The role of health professionals in the transition planning process is currently not well defined (35, 36). However, there is emerging evidence that health professionals provide valuable input in transition planning (37-39). For example, the Cognitive Orientation to daily Occupational Performance (CO-OP) approach (40) is an intervention used by occupational therapists that could be used to support goal

achievement in transition planning (41). The CO-OP approach utilises structured cognitive strategies to support the adolescent to develop problem solving skills that enhance occupational performance. The CO-OP has been used with adolescents on the autism spectrum to support the development of social, organisational, and life skills (41, 42). The CO-OP is applicable to goal setting and evaluation in the BOOST-A™; promoting positive self-evaluation and problem solving skills. Social Thinking is a teaching model that supports adolescents on the autism spectrum to understand the 'why' of the social world (43). Social thinking could be an effective tool to support adolescents on the autism spectrum to understand the big picture of transition planning, and the social expectations of work environments (44). It is recommended that future research focuses on exploring the role of health professionals in transition planning for adolescents on the autism spectrum.

### **8.3.2 Recommendations for future research and further development of the BOOST-A™**

Parents in the process evaluation reported a need for informal transition planning to begin before secondary school. Self-determination is an important skill for success in post-school endeavours (45), and children on the autism spectrum could begin engagement in programs that enhance self-determination in primary school. Developing self-determination skills early in life may enhance the success of the formal transition planning process that begins in early secondary school. Existing programs, such as The Self-determined Learning Model of Instruction (46) and the 'Putting Feet on My Dreams' program (47) support the development of self-determination in adolescents with disabilities. Strategies are needed to develop self-determination in children before they enter secondary school, where expectations for the child increase significantly. In addition, further research should explore whether features of these self-determination programs might meet the needs of adolescents on the autism spectrum, including the importance of understanding the big picture. Enhanced self-determination is linked to active participation in transition planning, which is essential to ensure the adolescent feels prepared for leaving school (26, 28, 48, 49). In addition to promoting self-determination, programs should support self-advocacy skills in children and adolescents on the autism spectrum.

Advocacy skills may be of particular importance, as disclosure of autism diagnosis is a predictor of employment (50).

Furthermore, future research should explore different techniques to assist adolescents on the autism spectrum to facilitate participation in real-life experiences so that they understand the importance of transition planning. For example, video-modelling interventions that demonstrate how to use skills in context (51). Video-modelling has been used to support adolescents in their on-the-job performance to provide an opportunity to review work performance in a controlled and non-threatening manner, with more time to pick up contextual indicators (52). Peer-mediated interventions (PMIs) are another potential option to help adolescents develop job-related skills. In PMI, a typically-developing peer is included in the intervention along with the adolescent on the autism spectrum to enhance the availability of natural social supports and provide increased opportunities to practice new skills in the relevant setting (53). There is emerging evidence for PMI, which has been used to support children on the autism spectrum to learn social skills (53) and adolescents on the autism spectrum to improve their conversational abilities (54). PMI could be used in transition planning to support adolescents on the spectrum to generalise work-related skills from structured settings into everyday contexts. In addition, mentoring was reportedly a useful strategy in transition planning in retrospective exploratory studies (55); however, more research is required on this topic. The aforementioned approaches may be helpful in supporting adolescents on the autism spectrum to develop skills relevant to employment, and therefore enhance understanding of the importance of transition planning.

The BOOST-A™ currently targets adolescents on the autism spectrum who do not have a diagnosis of ID. A number of participants in the process evaluation commented that with modification, the program may be applicable to adolescents with ID and other diagnoses. Therefore, further iterations of the BOOST-A™ may be needed to suit different target groups. The Cooperative Research Centre for Living with Autism (Autism CRC) intends to make the BOOST-A™ accessible to the public via an online platform that will house a number of resources for people on the autism spectrum and their families. However, it may be helpful to also provide an

offline, paper-based version of the BOOST-A™ for those who would prefer this format, or who do not have consistent access to the Internet. It is also important to consider process evaluation findings that suggest the BOOST-A™ would be best utilised when there is someone to champion the process. It is recommended that the BOOST-A™ is distributed alongside training for parents and professionals to ensure users have a good understanding of the principles underlying the program.

Another potential focus for future research might be to incorporate game theory into the BOOST-A™ to increase motivation of adolescent engagement. Video game use is higher among adolescents on the autism spectrum (41%) (56) than the general population (18%) (57). People on the autism spectrum have described how they enjoy video games because they are fun, entertaining and provide a sense of autonomy and achievement (58). Video games are likely to meet the *just-right challenge* that is needed to facilitate self-determination (2). The transition planning process would be a good fit with the serious game framework, which aims to support the development of specific skills that are perceived as difficult and not intrinsically motivating to participants (59, 60). It would be important to observe the core design elements of serious games, which include immersive storylines that contextualise learning, goals that support skill development, rewards that shape learning, and choices with increasing levels of challenge to enhance feelings of autonomy (59). As adolescents on the autism spectrum tend to have difficulties with context blindness and generalising learning, this can be addressed by using a hybrid model that incorporates real-life activities outside of the game (59). Utilising a serious game framework in transition planning may increase its intrinsic appeal to adolescents, and enhance their motivation to engage in this process and sense of autonomy. This is important, because increasing adolescents' perceived autonomy and control has been linked to improved post-school outcomes (61), and increased subjective quality of life (62).

It is promising that in recent years there has been a clear shift towards a strengths-based approach for individuals on the autism spectrum that emphasises outcomes related to happiness and quality of life (7, 63, 64). The findings of the present thesis add to a growing body of evidence about the efficacy of a strengths-based

approach (63-66), and provide support for using this approach in future interventions for people on the autism spectrum. Supporting parents and professionals to increase their expectations for their child could improve how adolescents on the autism spectrum perceive their worth, and perhaps promote a shift in how the community views autism (67, 68). This may, in turn, promote a shift in the subjective norm where the focus is the strengths of people on the autism spectrum rather than deficits.

There has been increasing momentum towards participatory action research and including individuals on the autism spectrum in the research process (69). Public involvement in research is reported to increase recruitment, improve trial design, ensure relevant outcome measures, and benefit not only participants but also the people involved in the research consultancy process (70). Throughout the development of the BOOST-A™, adolescents on the autism spectrum were consulted through a community reference group. In addition, adults who had a diagnosis of autism worked in the project as research assistants completing data transcription. However, involvement of individuals on the autism spectrum could have been improved in a number of ways. People on the autism spectrum could have been included in the project design, assisting to shape the aim of the research (70). In addition, adolescents should have been included in the interviews that were completed for the needs assessment, and visual or experiential techniques could have been used in the process evaluation interviews to augment adolescent participation (69, 71, 72). Additional participation avenues include peer-interviewing or involvement in data analysis and interpretation, enhancing credibility and preventing misinterpretation of findings (70). Adolescents and adults with autism could be hired to further develop and enhance to the BOOST-A™ program, given that software and game development is an area of interest for some individuals on the autism spectrum (73). Future research into transition planning should include individuals on the autism spectrum not just as participants, but as key players in the development of future interventions and the implementation of research related to this topic (74).

## 8.4 Strengths and limitations of the research conducted in this thesis

### Strengths

- The BOOST-A™ was developed using the PRECEDE-PROCEED Model, which is a rigorous and well-established framework for program development. End-user consultation was conducted at all stages of the program development process.
- The needs assessment identified autism-specific factors that support the transition planning process, including some that are not considered in existing transition planning interventions.
- Two pilot studies were done with multiple stakeholders and their feedback was utilised to improve the BOOST-A™.
- The sample size (N=94) for the quasi-randomised controlled trial was larger than was required to detect significant differences in outcomes between intervention and control group as determined by the power calculation. Contamination was avoided by allocating participants who attended the same schools to the same intervention group.
- Trustworthiness of the findings of the process evaluation was improved through triangulation of data from multiple stakeholders, and peer-review of the themes that emerged from the qualitative data.

### Limitations

- The questionnaire used in the needs assessment was developed for use in the study, but it was not validated, or tested for reliability. It would have been preferable to use pre-existing outcome measures with established validity and reliability; however, to the author's knowledge there were no existing tools that addressed the topic of interest.
- Pilot A had a small sample size (N=6) and Pilot B relied on feedback from health professionals based on a simulated version of the BOOST-A™. It would have been ideal to run a pilot randomised controlled trial using the online BOOST-A™ prior to the larger trial. This would likely have assisted in identifying issues

related to randomisation, and assisted in validating the Transition-specific Self-determination scale.

- The BOOST-A™ is an indirect, online intervention. This enhanced accessibility of the program for study participants from different geographic regions in Australia, but also introduced difficulties related to adherence and fidelity to the intervention for some participants. For example, not having face-to-face support from a professional to support use of the BOOST-A™ may have contributed to participants not completing all four modules in the program.
- Use of quasi-randomisation and lack of blinding for allocation of participants to treatment groups could have introduced potential systematic bias in the trial. Lack of long-term follow-up means that it is not known if the changes in self-determination and career awareness will be maintained after the completion of the trial. The Transition-specific Self-determination scale that was used in the controlled trial is yet to be validated and tested for reliability.
- Participants were asked to self-nominate their interest to participate in the interviews for the process evaluation. This could have resulted in a sample that had more success using the BOOST-A™, and resulted in a positively biased view of the program.

## 8.5 Summary and conclusions

The BOOST-A™ was developed to address the need for an autism-specific transition planning process in an Australian context. The program was based on guiding principles obtained in Phase 1 of the study; the needs assessment. The final iteration was evaluated in a quasi-randomised controlled trial with 94 adolescents on the autism spectrum and their caregivers. Findings indicated that the BOOST-A™ is a user-friendly, feasible, and acceptable intervention to support transition planning for adolescents on the autism spectrum. The BOOST-A™ increased career exploration, opportunities for self-determination at home, and self-determined behaviour specific to transition planning.

Further research is needed to determine if the BOOST-A™ has a long-term impact on post-school outcomes, including employment and post-secondary education.

Incorporating coaching models and a serious game framework into the transition planning process may enhance engagement and motivation to use the BOOST-A™.

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Megan Hatfield

# Appendix A Published systematic review

This research identified a need to review literature on existing career planning tools rather than programs that could aid in the transition planning process for adolescents on the autism spectrum. Therefore, a systematic review was conducted as part of an Honours project that linked to the thesis project.

The systematic review manuscript was accepted for publication on 18 December 2015, and has been published as:

**Murray N, Hatfield M, Falkmer M, Falkmer T. Evaluation of career planning tools for use with individuals with autism spectrum disorder: A systematic review. Res Autism Spectr Disord. 2016; 23:188-202.  
doi:10.1016/j.rasd.2015.12.007**

This publication was written by Nina Murray, an Honours student supervised by Megan Hatfield, Marita Falkmer, Marina Ciccarelli and Torbjörn Falkmer. The systematic review provides background to the work that was done in the development of the BOOST-A™. This manuscript was submitted for the award of an Honours degree for Nina Murray. Therefore, the reference to this publication has been included in this thesis for contextual information only and not for examination.

The PDF version of the publication has been removed for copyright reasons.

The publication is available via <http://dx.doi.org/10.1016/j.rasd.2015.12.007>

# Appendix B Study 1 – Survey for parents

## Survey for Parents Transition Planning for Adolescents on the Autism Spectrum

Thank you for taking the time to complete this survey.  
The following questions relate to assisting adolescents on the autism spectrum to plan what they will do when they leave secondary school. We call this '**transition planning**'. Transition planning involves preparing for activities such as vocational training, higher education, work experience and volunteering. The ultimate aim of this planning is to assist adolescents to get a job.

The following questions are about different aspects of the Transition planning process. Please tell us how they currently are, and how you think they should ideally be.

1. Year of schooling that **formal** transition planning starts  
(tick one box in each column)

Currently	Ideally
<input type="checkbox"/> Year 7	<input type="checkbox"/> Year 7
<input type="checkbox"/> Year 8	<input type="checkbox"/> Year 8
<input type="checkbox"/> Year 9	<input type="checkbox"/> Year 9
<input type="checkbox"/> Year 10	<input type="checkbox"/> Year 10
<input type="checkbox"/> Year 11	<input type="checkbox"/> Year 11
<input type="checkbox"/> Year 12	<input type="checkbox"/> Year 12
<input type="checkbox"/> Not currently doing transition planning or unsure	

2. People who participate in transition planning

(tick as many that apply)

Currently	Ideally
<input type="checkbox"/> Adolescents <input type="checkbox"/> Parents <input type="checkbox"/> Extended family <input type="checkbox"/> Teacher/s <input type="checkbox"/> School coordinator for special needs students <input type="checkbox"/> Career guidance officer <input type="checkbox"/> Government Disability Coordinator <input type="checkbox"/> Therapist/s <input type="checkbox"/> Disability employment service provider/s <input type="checkbox"/> Other: _____ <input type="checkbox"/> Not currently doing transition planning or unsure	<input type="checkbox"/> Adolescents <input type="checkbox"/> Parents <input type="checkbox"/> Extended family <input type="checkbox"/> Teacher/s <input type="checkbox"/> School coordinator for special needs students <input type="checkbox"/> Career guidance officer <input type="checkbox"/> Government Disability Coordinator <input type="checkbox"/> Therapist/s <input type="checkbox"/> Disability employment service provider/s <input type="checkbox"/> Other: _____

3. Person who manages/coordinates the plan

(tick one box in each column)

Currently	Ideally
<input type="checkbox"/> Adolescents <input type="checkbox"/> Parents <input type="checkbox"/> Extended family <input type="checkbox"/> Teacher/s <input type="checkbox"/> School coordinator for special needs students <input type="checkbox"/> Career guidance officer <input type="checkbox"/> Government Disability Coordinator <input type="checkbox"/> Therapist/s <input type="checkbox"/> Disability employment service provider/s <input type="checkbox"/> Other: _____ <input type="checkbox"/> Not currently doing transition planning or unsure	<input type="checkbox"/> Adolescents <input type="checkbox"/> Parents <input type="checkbox"/> Extended family <input type="checkbox"/> Teacher/s <input type="checkbox"/> School coordinator for special needs students <input type="checkbox"/> Career guidance officer <input type="checkbox"/> Government Disability Coordinator <input type="checkbox"/> Therapist/s <input type="checkbox"/> Disability employment service provider/s <input type="checkbox"/> Other: _____

4. Frequency the team meets to review the transition plan

(tick one box in each column)

Currently	Ideally
<input type="checkbox"/> Once a month <input type="checkbox"/> Once every 3 months <input type="checkbox"/> Once every 6 months <input type="checkbox"/> Once a year <input type="checkbox"/> Not currently doing transition planning or unsure	<input type="checkbox"/> Once a month <input type="checkbox"/> Once every 3 months <input type="checkbox"/> Once every 6 months <input type="checkbox"/> Once a year

5. Documentation of the transition plan

(tick one box in each column)

Currently	Ideally
<input type="checkbox"/> <b>Not</b> formally documented <input type="checkbox"/> Included in education plan <input type="checkbox"/> Included in one big plan (including goals for other things like therapy) <input type="checkbox"/> Specific and separate document for transition plan <input type="checkbox"/> Not currently doing transition planning or unsure	<input type="checkbox"/> <b>Not</b> formally documented <input type="checkbox"/> Included in education plan <input type="checkbox"/> Included in one big plan (including goals for other things like therapy) <input type="checkbox"/> Specific and separate document for transition plan

6. Areas considered/assessed during transition planning  
(tick as many that apply)

Currently	Ideally
<p><b>Career planning</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Interests</li> <li><input type="checkbox"/> Strengths</li> <li><input type="checkbox"/> Career goals</li> </ul> <p><b>Academic skills</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Academic strengths</li> <li><input type="checkbox"/> Academic weaknesses</li> <li><input type="checkbox"/> Cognitive skills (memory, attention)</li> </ul> <p><b>Autism specific factors</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Communication skills</li> <li><input type="checkbox"/> Sensory preferences</li> <li><input type="checkbox"/> Need for structure or routine</li> <li><input type="checkbox"/> Social skills</li> <li><input type="checkbox"/> Special interests</li> <li><input type="checkbox"/> Learning style (visual, verbal, etc.)</li> <li><input type="checkbox"/> Anxiety</li> <li><input type="checkbox"/> Triggers for meltdowns/behavioural difficulties</li> </ul> <p><b>Job readiness skills</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Independence in daily activities</li> <li><input type="checkbox"/> Organisational skills</li> <li><input type="checkbox"/> Transportation skills (driving or catching public transport)</li> <li><input type="checkbox"/> Experience in the community</li> <li><input type="checkbox"/> Technology skills</li> <li><input type="checkbox"/> Motivation to work</li> <li><input type="checkbox"/> Awareness of behaviour required in a workplace</li> </ul> <p><input type="checkbox"/> <b>Other:</b> _____</p> <p>_____</p> <p><input type="checkbox"/> Not currently doing transition planning (please still tick a box in ideally column)</p>	<p><b>Career planning</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Interests</li> <li><input type="checkbox"/> Strengths</li> <li><input type="checkbox"/> Career goals</li> </ul> <p><b>Academic skills</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Academic strengths</li> <li><input type="checkbox"/> Academic weaknesses</li> <li><input type="checkbox"/> Cognitive skills (memory, attention)</li> </ul> <p><b>Autism specific factors</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Communication skills</li> <li><input type="checkbox"/> Sensory preferences</li> <li><input type="checkbox"/> Need for structure or routine</li> <li><input type="checkbox"/> Social skills</li> <li><input type="checkbox"/> Special interests</li> <li><input type="checkbox"/> Learning style (visual, verbal, etc.)</li> <li><input type="checkbox"/> Anxiety</li> <li><input type="checkbox"/> Triggers for meltdowns/behavioural difficulties</li> </ul> <p><b>Job readiness skills</b></p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Independence in daily activities</li> <li><input type="checkbox"/> Organisational skills</li> <li><input type="checkbox"/> Transportation skills (driving or catching public transport)</li> <li><input type="checkbox"/> Experience in the community</li> <li><input type="checkbox"/> Technology skills</li> <li><input type="checkbox"/> Motivation to work</li> <li><input type="checkbox"/> Awareness of behaviour required in a workplace</li> </ul> <p><input type="checkbox"/> <b>Other:</b> _____</p> <p>_____</p>

7. Experiences to prepare your child for post-school activities  
(tick as many that apply)

Currently	Ideally
<input type="checkbox"/> Volunteering <input type="checkbox"/> Higher education exploration <input type="checkbox"/> Vocational training <input type="checkbox"/> Work experience <input type="checkbox"/> Social skills training <input type="checkbox"/> Life skills training, e.g., transport, independent food preparation <input type="checkbox"/> Job skills training, e.g., interviews, resumes, etc. <input type="checkbox"/> Mentoring programs <input type="checkbox"/> Other: _____ _____ <input type="checkbox"/> Not currently doing transition planning (please still tick a box in ideally column)	<input type="checkbox"/> Volunteering <input type="checkbox"/> Higher education exploration <input type="checkbox"/> Vocational training <input type="checkbox"/> Work experience <input type="checkbox"/> Social skills training <input type="checkbox"/> Life skills training, e.g., transport, independent food preparation <input type="checkbox"/> Job skills training, e.g., interviews, resumes, etc. <input type="checkbox"/> Mentoring programs <input type="checkbox"/> Other: _____ _____

8. Please describe the most helpful aspects in transition planning

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9. Please describe the most challenging aspects in transition planning

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Please provide any additional comments:

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## Appendix C Study 6 - Interview guide for process evaluation

1. Please describe your experience of using the BOOST-A in preparing you/your child for leaving school.

*Prompts: What goals have you achieved? Describe any ways you may have benefited, connections you have made and was the adolescent involved in the process. What did you and your child get out of the BOOST-A?*

2. Can you describe how easy it was to use the BOOST-A?

*Prompts: Instructions, access, technical issues, how often did you use it.*

3. Please describe anything that facilitated successful use of the BOOST-A?

*Prompts: Any helpful elements of the BOOST-A, any particular people or settings.*

4. Please describe anything that caused barriers or limited use of the BOOST-A?

*Prompts: Any challenges, recommended changes to the BOOST-A to address barriers.*

5. Do you have any other comments about the BOOST-A?

# Appendix D Study 5 – Participant information form

**Note:** This participant information form has been included as an example.

## **Parent and Adolescent Information Form** **Transition Planning for Adolescents on the Autism Spectrum**

### **What is this study about?**

My name is Megan Hatfield, from Curtin University. I am part of a team that has developed a protocol that will assist adolescents with high functioning autism or Asperger's Syndrome to plan what they will do when they leave school.

### **We invite you to participate**

You have been invited to participate in this study because you are in Year 8, 9, 10 or 11, and you have high functioning autism or Asperger's Syndrome (including PDD-NOS).

### **What will you be asked to do?**

If you choose to take part in the study, you will be asked to use the protocol (which is a software program) to plan what you will do when you leave school. You will use the protocol with your parents and anyone else who would normally help with this process. Your school may choose not to participate, and if this happens you can choose to use the protocol outside of school. We will also ask you to complete a questionnaire (30-45 minutes) two times; halfway through 2015, and then halfway through 2016. You can complete the questionnaire online, or fill out a paper copy and mail it back to us. You will be able to do this at home.

To assist with the study, we will ask parents to complete a short questionnaire about your child's current experience of having Autism Spectrum Disorder (ASD) or Asperger's Syndrome. This is important because without this, we are unable to publish results.

### **What might be the benefits?**

You will assist us to make it easier for you and other adolescents with high functioning autism or Asperger's Syndrome to plan what you are going to do after school. In the longer term, we hope this will lead to more people with high functioning autism and Asperger's Syndrome employed in jobs that suit them and they enjoy.

### **Are there any risks to me?**

There are no known risks involved with participating in this study. Your involvement is completely voluntary. You may decide to withdraw at any time without having to provide a reason, at which point you will be given the option of removing the information you have supplied from the study.

If participating in this study makes you feel upset at all, we encourage you to use the skills and strategies which you know work best when feeling upset and distressed. If the distress continues, assistance is available through contacting your GP, local counselling services like Relationships Australia (1300 364 277) or Lifeline (13 11 14), or if you are under 25 years of age, you can call KidsHelpLine (1800 55 1800). If you would like information regarding services for people with Autism Spectrum Disorder you can contact your local autism association.

### **Confidentiality**

All data will be stored and used confidentially. Results will be presented so your name and personal details cannot be linked to your information. The data gathered will be published as scientific articles, as theses and presented at relevant conferences.

### **Further information**

If you have any questions or would like some more information about the study, please contact me on 9266 3600 or [megan.hatfield@curtin.edu.au](mailto:megan.hatfield@curtin.edu.au) for more information. Or, you can contact my supervisors, Professor Torbjörn Falkmer, Dr Marita Falkmer or Associate Professor Marina Ciccarelli by telephone on 9266 3600.

If you would like to be involved in the study, please fill out the online consent form via the link provided to you in the email. As a token of our appreciation for participating in this study, you can choose to receive a \$20 voucher every time you fill out our online survey or the card sort.

This project is supported by the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC). Visit [www.autismcrc.com.au](http://www.autismcrc.com.au) for more information.

Thank you for your time and consideration.

Kind regards,



Megan Hatfield  
PhD Candidate  
School of Occupational Therapy &  
Social Work, Curtin University  
Phone: 9266 3600  
Email: [megan.hatfield@curtin.edu.au](mailto:megan.hatfield@curtin.edu.au)



Dr Marita Falkmer  
Post-Doctoral Fellow  
School of Occupational Therapy and  
Social Work, Curtin University  
Phone: 9266 3600  
Email: [marita.falkmer@curtin.edu.au](mailto:marita.falkmer@curtin.edu.au)



Dr Torbjörn Falkmer  
Professor/Senior Research Fellow  
School of Occupational Therapy &  
Social Work, Curtin University  
Phone: 9266 3600  
Email: [t.falkmer@curtin.edu.au](mailto:t.falkmer@curtin.edu.au)



Dr Marina Ciccarelli  
Associate Professor  
School of Occupational Therapy &  
Social Work, Curtin University  
Phone: 9266 3600  
Email: [marina.ciccarelli@curtin.edu.au](mailto:marina.ciccarelli@curtin.edu.au)

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This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR110/2014). 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 WA 6845 or by telephoning 9266 9223 or by emailing [hrec@curtin.edu.au](mailto:hrec@curtin.edu.au).

# Appendix E Study 5 - Participant consent form

**Note:** This participant consent form has been included as an example.

## **PARENT**

### **Transition Planning Study - Consent to Participate** **Transition Planning for Adolescents on the Autism Spectrum**

- I consent to ***both my child and I*** participating in this Transition Planning Study as outlined to me
- I have been informed of, and understand, the purpose of the study
- I am aware I can ask questions about this research, and I have been given the researchers' contact details
- 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 reason and 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 to the researchers contacting my school to enquire about whether it's possible for them to participate in this study. I understand that the school may choose not to participate, and if this happens I can choose to use the protocol outside of school.

Parent Name: \_\_\_\_\_

Parent Email Address: \_\_\_\_\_

Parent Phone Number: \_\_\_\_\_

Adolescent Name: \_\_\_\_\_

School name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

*(This contact information will be used for communication about this project.)*

Would you like to be informed about future studies?  Yes  No

Do you consent for the information provided to be used in other studies?  Yes  No  
(These would be similar kinds of studies. Your information would remain confidential)

Please provide the details of the professionals you would like to be involved in trialling the protocol, and we get in touch with them about the project.

**School Teacher/s**

Name of teacher/s most likely to do transition planning: \_\_\_\_\_

School: \_\_\_\_\_

**Therapist/s and/or Disability Employment Service Provider**

Name: \_\_\_\_\_

Organisation: \_\_\_\_\_

Email address: \_\_\_\_\_

Phone number: \_\_\_\_\_

**Local Area Coordinator/My Way Coordinator**

Name: \_\_\_\_\_

Email address: \_\_\_\_\_

Phone number: \_\_\_\_\_

**Other**

Name: \_\_\_\_\_

Organisation: \_\_\_\_\_

Email address: \_\_\_\_\_

Phone number: \_\_\_\_\_

**ADOLESCENT**  
**Transition Planning Study - Assent to Participate**  
**Transition Planning for Adolescents on the Autism Spectrum**

- I agree to participate in this Transition Planning Study
- I understand the reason for the study
- I am aware I can ask questions about this research
- I understand that there are no known risks involved in the study
- I understand that participation is my choice and that I can pull out of the study at any time I like and without giving a reason
- I understand that all my personal information will be kept private

Name: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

*You can return this consent form via email by scanning this form and sending it to:*  
[megan.hatfield@curtin.edu.au](mailto:megan.hatfield@curtin.edu.au)

*Alternatively, you can via post to the following address:*

Megan Hatfield  
School of Occupational Therapy and Social Work  
Kent Street  
Bentley WA 6102

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This study has been approved by the Curtin University Human Research Ethics Committee (Approval Number HR110/2014). 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 WA 6845 or by telephoning 9266 9223 or by emailing hrec@curtin.edu.au.

# Appendix F Adverse Events Management Plan

## Adverse Events Management Plan Transition Planning for Adolescents on the autism spectrum

### Preventative Measures:

- Participants will be provided with information about what to do if distressed at any stage of the project, e.g., when completing the outcome measures.

*Please Note: If completing this survey has made you feel upset at all, we encourage you to do what you would normally do if you are feeling upset or distressed. This might be talking to your family or friends.*

*If the distress continues, assistance is available through contacting your GP, local counselling services like Relationships Australia (1300 364 277) or Lifeline (13 11 14). If you would like information regarding services for people with Autism Spectrum Disorder you can contact your local autism association.*

- Participants will be supported by the people and services that regularly assist them.
- Most of the research occurs in the participants' own environment and does not involve direct contact with the researcher.

### Steps taken if a researcher observes participant distress during the study:

*This may be observed via written or verbal communication with the participant over email, phone or teleconference.*

1. **Identify** – Early identification of distress will be ensured observing any visual, written or verbal signs of distress (i.e., significant changes in behaviour, changes in voice or way of writing, etc.).
2. **Stop** - If the participant is becoming upset or distressed, state:  
*'I can hear that you are feeling upset, we can stop our discussion for now'*
3. **Empathy/Comfort** –  
*'I can see that must be very difficult for you.'*  
*'It sounds like this is a hard time for you.'*
4. **Ensure Stable** – once the client has calmed down the researcher will ensure that they are stable by asking *'Are you feeling ok?'*
5. The researcher will ask about the person's **normal coping strategies** for when they are distressed or upset:  
*'What do you normally do when you are upset? Is there someone you would like to talk to?'*
  - a. If they identify something they normally would do, the researcher will suggest they partake in these activities after they leave/finish talking.

- b. If the person wants to speak to someone, be it a friend, family member or health service, the researcher will ask if they can assist the participant to get in touch with them:  
*'Would you like me to contact this person for you?'*  
If they say yes, the researcher would take the details and contact the person for the participant.
    - c. If the participant declines the researcher's assistance to contact someone:  
*'I would encourage you talk to a friend or family member after you leave/we finish talking today.'*
6. Ask the participant if they would like to continue or postpone the study or withdraw from the study.
  - a. If they wish to **continue**, the researcher will ensure the participant is ok and continue with the discussion.
  - b. If they wish to **postpone**: *'When would be a good time to call you to discuss another time to complete the study?'*  
Once the researcher has established a date and time: *'I would like to thank you for your time today and will call you (insert time and day here). Would it be alright if I contact you tomorrow to check you are ok?'*  
If yes, the researcher will contact them the following day.
  - c. If they wish to **withdraw**: *'I would like to thank you for your time today. As discussed, I would encourage you to do what you would normally do if you are feeling upset or distressed.'*  
*'Would it be alright if I contact you tomorrow to check you are ok?'*  
If yes, the researcher will contact them the following day.
7. **Refer** - At the end of the discussion, or if at any time the participant appeared to be significantly distressed:  
*If this feeling of distress continues, you can access support from any of the following:*
  - *Your local GP;*
  - *Lifeline (13 11 14);*
  - *Local counselling services like Relationships Australia (1300 364 277); or*
  - *The autism association in your state.*

**Steps taken if an adolescent rates themselves as below 2 on 5 or more questions on the Personal Wellbeing Index (PWI):**

1. **Personal phone call to the adolescent's parent** – Discuss that PWI ratings indicated that it may be helpful to talk to the adolescent about how they are feeling currently and potentially get some support with this.
2. **Empathy/Comfort** – If the parent appears to get significantly distressed, follow the steps described above for this situation.
3. **Support** – If the parent expresses interest in getting support, the following options could be discussed:
  - *Local GP, who can refer for a Better Access to Mental Health Plan;*
  - *Lifeline (13 11 14);*
  - *Local counselling services like Relationships Australia (1300 364 277);*

- *The adolescent's school; or*
- *The autism association in your state can provide you with information on services in your area.*

*Note:* The researcher has received training in counselling and mental health as a part of her Bachelor of Science in Occupational Therapy. She also has over four years of experience as an Occupational Therapist, which has involved providing support to distressed persons on multiple occasions.

# Appendix G Curtin University Human Research Ethics Committee approval



## Memorandum

<b>To</b>	Professor Torbjorn Falkmer, School of Occupational Therapy and Social Work
<b>From</b>	Professor Peter O'Leary, Chair Human Research Ethics Committee
<b>Subject</b>	Protocol Approval <b>HR 110/2014</b>
<b>Date</b>	16 June 2014
<b>Copy</b>	Associate Professor Marina Ciccarelli, School of Occupational Therapy and Social Work Miss Megan Hatfield, School of 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](mailto:hrec@curtin.edu.au)

Thank you for providing the additional information for the project titled "*Development of an Educational and Vocational Assessment Protocol (EVAP) for adolescents with high functioning autism/Asperger's Syndrome*". 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 110/2014**. *Please quote this number in any future correspondence.*
- Approval of this project is for a period of four years **17-06-2014 to 17-06-2018**.
- 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](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

## Appendix H List of ethical approvals for schools

<b>State</b>	<b>Catholic Education</b>	<b>Department of Education</b>
<b>Western Australia</b>	Catholic Education Office Western Australia Study 1: 18/06/14 Study 2&3: 04/12/14 Reference: Development of the Successful Transition to Employment Protocol – Autism Spectrum Disorders (STEP-A)	Government of Western Australia Department of Education Study 1: 10/09/14 Reference number: D14/0427650 Study 2&3: 04/03/15 Reference number: D15/0067919
<b>Queensland</b>	Brisbane Catholic Education Approved: 01/4/15 Reference number: 164	Queensland Government Department of Education and Training Approved: 16/07/15 Reference number: 550/27/1580
<b>Victoria</b>	Catholic Education Office Melbourne Approved: 27/3/15 Reference number: #2075 Hatfield	Department of Education and Training Victoria Approved: 09/07/15 Reference number: 2015_002650
<b>New South Wales</b>	Catholic Education Office Sydney Approved: 06/05/15 Reference number: 939	New South Wales Education & Communities Approved: 15/5/15 SERAP number: 2015192
<b>South Australia</b>	Catholic Education Office South Australia Approved: 11/05/15 Reference: Development of the Successful Transition to Employment Protocol – Autism Spectrum Disorders (STEP-A)	Government of South Australia Department for Education and Child Development Approved: 13/10/15 Reference number: CS/15/00004-1.8
<b>Tasmania</b>	Tasmanian Catholic Education Approved: 26/05/15 Reference: Development of the Successful Transition to Employment Protocol – Autism Spectrum Disorders (STEP-A)	Department of Education Tasmania Approved: 23/6/15 Reference number: 2015-22

# Appendix I Catholic Education Western Australian ethical approval

**Note:** This approval letter has been included as an example.

4 December 2014

Professor Marina Ciccarelli  
School of Occupational Therapy and Social Work  
Curtin University  
GPO Box U1987  
BENTLEY WA 6845



Dear Professor Ciccarelli

**RE: DEVELOPMENT OF AN EDUCATIONAL AND VOCATIONAL ASSESSMENT  
PROTOCOL (STEP-A) FOR ADOLESCENTS WITH HIGH FUNCTIONING  
AUTISM/ASPERGERS SYNDROME**

Thank you for your completed application received 27 November 2014, whereby this project aims to develop a protocol to assist adolescents with HFA/AS in planning what they will do when they leave school. The results from this study will inform vocational rehabilitation approaches, education practices, and employment-related interventions for adolescents with HFA/AS.

I give in principle support for the selected Catholic schools in Western Australia to participate in this valuable study. However, consistent with the Catholic Education Office of Western Australia (CEOWA) policy, participation in your research project will be the decision of the individual principal and staff members. A copy of this letter must be provided to principals when requesting their participation in the research.

The condition of CEOWA approval is that as your research project is being conducted for longer than one year, a completion of annual reports as well as a final report are to be forwarded to the CEOWA.

Responsibility for quality control of ethics and methodology of the proposed research resides with the institution supervising the research. The CEOWA notes that the Curtin University Human Research Ethics Committee has granted permission for this research project until 17 June 2018 (Approval Number: HR 110/2014).

Any changes to the proposed methodology will need to be submitted for CEOWA approval prior to implementation. The focus and outcomes of your research project are of interest to the CEOWA. It is therefore a condition of approval that the research findings of this study are forwarded to the CEOWA.

Further enquiries may be directed to Jane Gostelow at [gostelow.jane@ceo.wa.edu.au](mailto:gostelow.jane@ceo.wa.edu.au) or (08) 6380 5118.

I wish you all the best with your research.

Yours sincerely



Dr Tim McDonald



EXECUTIVE DIRECTOR OF CATHOLIC EDUCATION  
50 Ruislip Street, Leederville WA 6007 | PO Box 198, Leederville WA 6903  
T (08) 6380 5210  
E [mcdonald.tim@ceo.wa.edu.au](mailto:mcdonald.tim@ceo.wa.edu.au) W [ceo.wa.edu.au](http://ceo.wa.edu.au)

# Appendix J Department of Education New South Wales ethical approval

**Note:** This approval letter has been included as an example.



Miss Megan Hatfield  
GPO Box U1987  
PERTH WA 6845

CORP15/7235  
DOC15/286154  
**SERAP 2015192**

Dear Miss Hatfield

I refer to your application to conduct a research project in NSW government schools entitled *Development of the Successful Transition to Employment Protocol - Autism Spectrum Disorders (STEP-A)*. I am pleased to inform you that your application has been approved.

You may contact principals of the nominated schools to seek their participation. **You should include a copy of this letter with the documents you send to principals.**

This approval will remain valid until 15-May-2016.

The following researchers or research assistants have fulfilled the Working with Children screening requirements to interact with or observe children for the purposes of this research for the period indicated:

Researcher name	WWCC	WWCC expires
Megan Hatfield	999013 WA	18-Feb-2018
Torbjorn Falkmer	2141120 WA	31-May-2017

I draw your attention to the following requirements for all researchers in NSW government schools:

- The privacy of participants is to be protected as per the NSW Privacy and Personal Information Protection Act 1998.
- School principals have the right to withdraw the school from the study at any time. The approval of the principal for the specific method of gathering information must also be sought.
- The privacy of the school and the students is to be protected.
- The participation of teachers and students must be voluntary and must be at the school's convenience.
- Any proposal to publish the outcomes of the study should be discussed with the research approvals officer before publication proceeds.
- All conditions attached to the approval must be complied with.

When your study is completed please email your report to: [serap@det.nsw.edu.au](mailto:serap@det.nsw.edu.au)  
You may also be asked to present on the findings of your research.

I wish you every success with your research.

Yours sincerely

A handwritten signature in black ink, appearing to read 'R. Stevens'.

Dr Robert Stevens  
**Manager, Quality Assurance/Research**  
15 May 2015



Policy, Planning and Reporting Directorate  
NSW Department of Education and Communities  
Level 1, 1 Oxford Street, Darlinghurst NSW 2010 – Locked Bag 53, Darlinghurst NSW 1300  
Telephone: 02 9244 5060 – Email: [serap@det.nsw.edu.au](mailto:serap@det.nsw.edu.au)