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

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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-ATM). 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-ATM 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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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
Table of Contents

Chapter 1  INTRODUCTION .................................................................................................................................................................................. 1
  1.1  Post-school outcomes for people on the autism spectrum ........ 1
  1.2  Transition planning .......................................................................................................................................................................... 4
    1.2.1  Core concepts for transition planning .................................................. 5
      1.2.1.1  Active involvement of adolescents ........................................... 5
      1.2.1.2  External support ........................................................................... 6
      1.2.1.3  Structured transition program ....................................................... 7
      1.2.1.4  Life skills ......................................................................................... 8
      1.2.1.5  Community activities ................................................................. 9
      1.2.1.6  Strengths-based career exploration ............................................ 10
      1.2.1.7  Begin in early adolescence ............................................................ 10
  1.3  Existing transition planning interventions ........................................ 11
  1.4  Summary of introduction ........................................................................ 13
  1.5  Overall aim ........................................................................................................... 14
  1.6  Thesis structure ........................................................................................................... 14
    1.6.1  Phase 1: Needs Assessment ................................................................. 16
    1.6.2  Phase 2: Program Development ............................................................ 16
    1.6.3  Phase 3: Program Evaluation ................................................................. 16
List of Figures

Figure 1-1. Overall structure of thesis .............................................................. 15
Figure 5-1. Transition planning objectives for adolescents on the autism spectrum .......................................................... 38
Figure 5-2. Schedule of enrolment, intervention, and assessments ................... 38
Figure 6-1. Flowchart of the BOOST-A effectiveness study .............................. 65
Figure 7-1. Overview of the four modules of the BOOST-A™ online program ............................................................. Error! Bookmark not defined.
Figure 7-2. Summary of participant ratings of the BOOST-A™, percentages (parents n=39, adolescents n=33). Error! Bookmark not defined.
Figure 8-1. Overall conceptualisation of thesis findings in the Self-Determined Learning Model .......................................................... 85
List of Tables

Table 5-1. BOOST-A™ overview ................................................................. 38
Table 6-1. Overview of the BOOST-A™ transition planning program .......... 60
Table 6-2. Participant demographics by group............................................. 66
Table 6-3. Outcomes at baseline (T1) and at 12 months post-intervention
    (T2). ............................................................................................................. 68
Table 7-1. Characteristics of questionnaire respondents (n=39)*.................. Error! Bookmark not defined.
Table 7-2. Interview participants (n=13).................................................. Error! Bookmark not defined.
Table 7-3. Proposed changes to the BOOST-A™ based on process evaluation
    findings................................................................. Error! Bookmark not defined.
List of publications, conference presentations, and awards

This doctoral thesis consists of the following publications:


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


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- The Patricia Howlin CRC PhD Scholar Prize, 2014
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Key abbreviations

ASD: Autism Spectrum Disorder

BOOST-ATM™: 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. 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. 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.

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.\(^3\) 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.\(^3\)^4 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.


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.
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-ATM). 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-ATM 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-ATM 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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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: Survey

Study 1 was written as a publication, which is unable to be reproduced here due to copyright restrictions.

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 publication can instead be accessed via:
http://dx.doi.org/10.1111/1471-3802.12388

Study 2: Interviews

Study 2 was written as a publication, which is unable to be reproduced here due to copyright restrictions.


The publication can instead be accessed via:
http://dx.doi.org/10.1111/1471-3802.12377
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).
3.4 References

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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™.
This chapter (Study 3) was written as a publication, which is unable to be reproduced here due to copyright restrictions.


The publication can instead be accessed via:
http://dx.doi.org/10.1111/1440-1630.12410
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,¹ 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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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
Evaluation of the effectiveness of an online transition planning program for adolescents on the autism spectrum: trial protocol

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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...
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 higher rates of 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 goal 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 path they will take without feeling they have to rely heavily on others [24]. Self-determined people are goal-oriented, 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 their talent, rather than on how the individual can change to meet society’s expectations. The strengths-based approach is 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 conducted 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.
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.
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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 research 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 Quadrics 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 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 (α = .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 [52] 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 α = .84; career exploration α = .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 (α = .82) and construct validity (comparative fit index = .96) [64]. Sensitivity to change
was demonstrated in a study that used the PWLSC 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 (α = .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 normally 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 v22) 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 the study design, 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 written consent for their participation. Principals of the schools attended by participants in the intervention group will provide written informed consent 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 (#ACTRN12615001195994). 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 programs 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
BOSS: A Better Outcomes & Successful Transitions for Autism (BOOST-R); ID: intellectual disability.

Authors’ contributions
MH, MG, TP, MF contributed to the design of the trial. MH drafted the manuscript. MG, TC, MF reviewed the manuscript. All authors read and approved the final manuscript.

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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 the trial has been obtained from Curtin University Human Research Ethics Committee (Approval number H1110/2014), 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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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.

This manuscript was accepted for publication on 27 September 2017, and is in press. The post-print version has been included in the thesis as a typescript.

Please note, the copyright remains with the journal.

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

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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 need 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-ATM™) program was developed to address this need. The BOOST-ATM™ 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-ATM™ 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-ATM™ 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.

<table>
<thead>
<tr>
<th>Module</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. About Me</td>
<td>Adolescents completed six activities to identify their interests, strengths, work preferences, life skills, training goals, and learning style.</td>
</tr>
<tr>
<td>2. My Team</td>
<td>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.</td>
</tr>
<tr>
<td>3. First Meeting</td>
<td>The team met to review career options and formulate goals, based on best-practice recommendations that are built into the program.</td>
</tr>
<tr>
<td>4. My Progress</td>
<td>The team met once per school term following the first meeting to review goal progression and positive learning experiences.</td>
</tr>
</tbody>
</table>

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.
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.

<table>
<thead>
<tr>
<th>Pre-intervention</th>
<th>Group (N=94)</th>
<th>P Value</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Intervention n=49</td>
<td>Control n=45</td>
</tr>
<tr>
<td><strong>Adolescent Age in years</strong></td>
<td>14.8 (12-17, 1.2)</td>
<td>15.1 (13-18, 1.2)</td>
</tr>
<tr>
<td><strong>Adolescent Gender (#, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>10 (20.4)</td>
<td>12 (26.7)</td>
</tr>
<tr>
<td>Male</td>
<td>39 (79.6)</td>
<td>33 (73.3)</td>
</tr>
<tr>
<td><strong>Socioeconomic Status</strong></td>
<td>7.4 (4-10, 2.0)</td>
<td>5.8 (1-10, 2.5)</td>
</tr>
<tr>
<td><strong>Autism Severity (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Within normal</td>
<td>0 (0)</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Mild</td>
<td>5 (10.2)</td>
<td>5 (11.1)</td>
</tr>
<tr>
<td>Moderate</td>
<td>13 (26.5)</td>
<td>16 (35.6)</td>
</tr>
<tr>
<td>Severe</td>
<td>31 (63.3)</td>
<td>24 (53.3)</td>
</tr>
<tr>
<td><strong>Comorbid diagnoses (n, %)</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Attention deficit hyperactivity disorder</td>
<td>7 (14.3)</td>
<td>10 (22.2)</td>
</tr>
<tr>
<td>Anxiety</td>
<td>5 (10.2)</td>
<td>5 (11.1)</td>
</tr>
<tr>
<td>Dyslexia</td>
<td>1 (2.0)</td>
<td>2 (4.4)</td>
</tr>
<tr>
<td>Depression</td>
<td>2 (4.1)</td>
<td>2 (4.4)</td>
</tr>
<tr>
<td>Other</td>
<td>7 (14.3)</td>
<td>8 (17.8)</td>
</tr>
</tbody>
</table>

*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 12 months post-intervention (T2).

<table>
<thead>
<tr>
<th></th>
<th>Intervention group n=88§</th>
<th>Control group n=83§</th>
<th>Group by time</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>T1 Mean (SD)</td>
<td>Difference T2–T1 (SD)</td>
<td>T1 Mean (SD)</td>
</tr>
<tr>
<td><strong>Parent reported outcomes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-determination (AIR)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>56.6 (9.2)</td>
<td>2.3 (8.3)</td>
<td>58.6 (8.10)</td>
</tr>
<tr>
<td>Do</td>
<td>14.7 (4.3)</td>
<td>1.1 (3.5)</td>
<td>14.8 (4.0)</td>
</tr>
<tr>
<td>School</td>
<td>20.1 (4.6)</td>
<td>0.37 (3.8)</td>
<td>20.4 (4.5)</td>
</tr>
<tr>
<td>Home</td>
<td>22.8 (3.3)</td>
<td>0.9 (2.2)</td>
<td>23.6 (2.9)</td>
</tr>
<tr>
<td>Transition-specific self-determination</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Career planning (CDI-A)</td>
<td>21.5 (8.4)</td>
<td>4.1 (8.8)</td>
<td>21.3 (8.0)</td>
</tr>
<tr>
<td>Career exploration (CDI-A)</td>
<td>23.0 (6.2)</td>
<td>3.4 (5.6)</td>
<td>24.7 (6.2)</td>
</tr>
<tr>
<td>Learning climate (LCQ)</td>
<td>4.1 (1.2)</td>
<td>0.4 (0.9)</td>
<td>4.1 (1.0)</td>
</tr>
<tr>
<td>Personal Wellbeing Index (PWI-SC)</td>
<td>63.4 (14.8)</td>
<td>-0.9 (13.5)</td>
<td>63.3 (12.8)</td>
</tr>
<tr>
<td>Happiness – life as a whole (PWI-SC)</td>
<td>60.6 (26.3)</td>
<td>3.1 (23.3)</td>
<td>62.0 (22.7)</td>
</tr>
<tr>
<td><strong>Adolescent reported outcomes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-determination (AIR)</td>
<td>73.7 (21.2)</td>
<td>6.2 (18.2)</td>
<td>76.5 (18.3)</td>
</tr>
<tr>
<td>Total</td>
<td>18.0 (4.8)</td>
<td>1.1 (4.0)</td>
<td>18.0 (5.2)</td>
</tr>
<tr>
<td>Do</td>
<td>18.5 (5.4)</td>
<td>0.8 (4.6)</td>
<td>19.2 (5.1)</td>
</tr>
<tr>
<td>Feel</td>
<td>18.9 (6.2)</td>
<td>1.2 (6.8)</td>
<td>17.9 (5.3)</td>
</tr>
<tr>
<td>School</td>
<td>21.3 (6.0)</td>
<td>1.2 (5.1)</td>
<td>22.7 (4.9)</td>
</tr>
<tr>
<td>Home</td>
<td>86.0 (23.0)</td>
<td>11.4 (22.7)</td>
<td>90.4 (23.7)</td>
</tr>
<tr>
<td>Transition-specific self-determination</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Career planning (CDI-A)</td>
<td>27.9 (10.0)</td>
<td>1.5 (9.6)</td>
<td>30.0 (8.1)</td>
</tr>
<tr>
<td>Career exploration (CDI-A)</td>
<td>26.5 (7.1)</td>
<td>2.3 (6.4)</td>
<td>28.7 (5.4)</td>
</tr>
<tr>
<td>Learning climate (LCQ)</td>
<td>4.6 (1.3)</td>
<td>0.2 (1.1)</td>
<td>4.8 (0.9)</td>
</tr>
<tr>
<td>Personal Wellbeing Index (PWI-SC)</td>
<td>70.8 (20.1)</td>
<td>-0.7 (18.2)</td>
<td>71.5 (13.8)</td>
</tr>
<tr>
<td>Happiness – life as a whole (PWI-SC)</td>
<td>67.9 (27.4)</td>
<td>1.0 (25.7)</td>
<td>66.5 (16.4)</td>
</tr>
</tbody>
</table>


*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 forth 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 is 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-ATM™ and was also the first author of the manuscript which describes the effectiveness of the BOOST-ATM™. The design of the trial has taken this into account in order to minimise such bias.

Funding

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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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6.8 References

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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.

This manuscript was accepted for publication on 14 September 2017 and is in press. The post-print version has been included in the thesis as a typescript.

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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-ATM) 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-ATM 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-ATM was evaluated in Phase Three, in which a quasi-randomised controlled trial found that the BOOST-ATM 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-ATM. The structure and strengths-focus of the BOOST-ATM 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-ATM 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-ATM 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-ATM acknowledges that change is not just dependent on the adolescent, but also on the significant adults in their lives who support them. The BOOST-ATM 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.

![Diagram showing self-determined learning model]

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

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™.
8.6 References


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Megan Hatfield

[Signature]

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:

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
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)

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<td>☐ Year 12</td>
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<tr>
<td>☐ Not currently doing</td>
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<td>transition planning</td>
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<td>or unsure</td>
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</table>
2. People who participate in transition planning
(tick as many that apply)

<table>
<thead>
<tr>
<th>Currently</th>
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<tbody>
<tr>
<td>☐ Adolescents</td>
<td>☐ Adolescents</td>
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<tr>
<td>☐ Parents</td>
<td>☐ Parents</td>
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<tr>
<td>☐ Extended family</td>
<td>☐ Extended family</td>
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<tr>
<td>☐ Teacher/s</td>
<td>☐ Teacher/s</td>
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<tr>
<td>☐ School coordinator for special needs students</td>
<td>☐ School coordinator for special needs students</td>
</tr>
<tr>
<td>☐ Career guidance officer</td>
<td>☐ Career guidance officer</td>
</tr>
<tr>
<td>☐ Government Disability Coordinator</td>
<td>☐ Government Disability Coordinator</td>
</tr>
<tr>
<td>☐ Therapist/s</td>
<td>☐ Therapist/s</td>
</tr>
<tr>
<td>☐ Disability employment service provider/s</td>
<td>☐ Disability employment service provider/s</td>
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<tr>
<td>☐ Other: ___________________________</td>
<td>☐ Other: ___________________________</td>
</tr>
<tr>
<td>☐ Not currently doing transition planning or unsure</td>
<td>☐ Not currently doing transition planning or unsure</td>
</tr>
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</table>

3. Person who manages/coordinates the plan
(tick one box in each column)

<table>
<thead>
<tr>
<th>Currently</th>
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<tbody>
<tr>
<td>☐ Adolescents</td>
<td>☐ Adolescents</td>
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<td>☐ Parents</td>
<td>☐ Parents</td>
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<td>☐ Extended family</td>
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<td>☐ School coordinator for special needs students</td>
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<td>☐ Career guidance officer</td>
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<td>☐ Government Disability Coordinator</td>
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<td>☐ Therapist/s</td>
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<td>☐ Disability employment service provider/s</td>
<td>☐ Disability employment service provider/s</td>
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<td>☐ Other: ___________________________</td>
<td>☐ Other: ___________________________</td>
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<tr>
<td>☐ Not currently doing transition planning or unsure</td>
<td>☐ Not currently doing transition planning or unsure</td>
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</tbody>
</table>
4. Frequency the team meets to review the transition plan
(tick one box in each column)

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<th>Currently</th>
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<tr>
<td>[ ] Once a month</td>
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<tr>
<td>[ ] Once every 3 months</td>
<td>[ ] Once every 3 months</td>
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<tr>
<td>[ ] Once every 6 months</td>
<td>[ ] Once every 6 months</td>
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<td>[ ] Once a year</td>
<td>[ ] Once a year</td>
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<tr>
<td>[ ] Not currently doing transition planning or unsure</td>
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</table>

5. Documentation of the transition plan
(tick one box in each column)

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<thead>
<tr>
<th>Currently</th>
<th>Ideally</th>
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<tbody>
<tr>
<td>[ ] Not formally documented</td>
<td>[ ] Not formally documented</td>
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<tr>
<td>[ ] Included in education plan</td>
<td>[ ] Included in education plan</td>
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<tr>
<td>[ ] Included in one big plan (including goals for other things like therapy)</td>
<td>[ ] Included in one big plan (including goals for other things like therapy)</td>
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<tr>
<td>[ ] Specific and separate document for transition plan</td>
<td>[ ] Specific and separate document for transition plan</td>
</tr>
<tr>
<td>[ ] Not currently doing transition planning or unsure</td>
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</table>
6. Areas considered/assessed during transition planning
(tick as many that apply)

<table>
<thead>
<tr>
<th>Currently</th>
<th>Ideally</th>
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</table>
| **Career planning**<br>☐ Interests<br>☐ Strengths<br>☐ Career goals<br>**Academic skills**<br>☐ Academic strengths<br>☐ Academic weaknesses<br>☐ Cognitive skills (memory, attention)<br>**Autism specific factors**<br>☐ Communication skills<br>☐ Sensory preferences<br>☐ Need for structure or routine<br>☐ Social skills<br>☐ Special interests<br>☐ Learning style (visual, verbal, etc.)<br>☐ Anxiety<br>☐ Triggers for meltdowns/behavioural difficulties<br>**Job readiness skills**<br>☐ Independence in daily activities<br>☐ Organisational skills<br>☐ Transportation skills (driving or catching public transport)<br>☐ Experience in the community<br>☐ Technology skills<br>☐ Motivation to work<br>☐ Awareness of behaviour required in a workplace<br>☐ Other: _________________________<br>☐ Not currently doing transition planning (please still tick a box in ideally column)<br>**Career planning**<br>☐ Interests<br>☐ Strengths<br>☐ Career goals<br>**Academic skills**<br>☐ Academic strengths<br>☐ Academic weaknesses<br>☐ Cognitive skills (memory, attention)<br>**Autism specific factors**<br>☐ Communication skills<br>☐ Sensory preferences<br>☐ Need for structure or routine<br>☐ Social skills<br>☐ Special interests<br>☐ Learning style (visual, verbal, etc.)<br>☐ Anxiety<br>☐ Triggers for meltdowns/behavioural difficulties<br>**Job readiness skills**<br>☐ Independence in daily activities<br>☐ Organisational skills<br>☐ Transportation skills (driving or catching public transport)<br>☐ Experience in the community<br>☐ Technology skills<br>☐ Motivation to work<br>☐ Awareness of behaviour required in a workplace<br>☐ Other: _________________________
7. Experiences to prepare your child for post-school activities
(tick as many that apply)

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<tr>
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<tr>
<td>□ Volunteering</td>
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<tr>
<td>□ Work experience</td>
<td>□ Work experience</td>
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<tr>
<td>□ Social skills training</td>
<td>□ Social skills training</td>
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<tr>
<td>□ Life skills training, e.g., transport,</td>
<td>□ Life skills training, e.g., transport,</td>
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<tr>
<td>independent food preparation</td>
<td>independent food preparation</td>
</tr>
<tr>
<td>□ Job skills training, e.g., interviews,</td>
<td>□ Job skills training, e.g., interviews,</td>
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<tr>
<td>resumes, etc.</td>
<td>resumes, etc.</td>
</tr>
<tr>
<td>□ Mentoring programs</td>
<td>□ Mentoring programs</td>
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<td>□ Other: __________________________</td>
<td>□ Other: __________________________</td>
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<tr>
<td>□ Not currently doing transition</td>
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<td>planning (please still tick a box in</td>
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<td>ideally column)</td>
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</table>

8. Please describe the most helpful aspects in transition planning
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

9. Please describe the most challenging aspects in transition planning
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________

Please provide any additional comments:
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
________________________________________________________________________________________
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 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 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

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

Alternatively, you can via post to the following address:
Megan Hatfield
School of Occupational Therapy and Social Work
Kent Street
Bentley WA 6102

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

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

To  Professor Torbjorn Falkmer, School of Occupational Therapy and Social Work

From  Professor Peter O’Leary, Chair Human Research Ethics Committee

Subject  Protocol Approval HR 110/2014

Date  16 June 2014

Copy  Associate Professor Marina Ciccarelli, School of Occupational Therapy and Social Work
Miss Megan Hafield, School of Occupational Therapy and Social Work

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 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

<table>
<thead>
<tr>
<th>State</th>
<th>Catholic Education</th>
<th>Department of Education</th>
</tr>
</thead>
</table>
| Western Australia| 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 |
| Queensland       | 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 |
| Victoria         | 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 |
| New South Wales  | Catholic Education Office Sydney  
Approved: 06/05/15  
Reference number: 939 | New South Wales Department of Education and Communities  
Approved: 15/5/15  
SERAP number: 2015192 |
| South Australia  | Catholic Education Office South Australia  
Approved: 11/05/15  
Approved: 13/10/15  
Reference number: CS/15/00004-1.8 |
| Tasmania         | 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 or (08) 6380 5118.

I wish you all the best with your research.

Yours sincerely

[Signature]

Dr Tim McDonald
Appendix J  Department of Education
New South Wales ethical approval

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

Dear Miss Hattfield,

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:

<table>
<thead>
<tr>
<th>Researcher name</th>
<th>WWCC</th>
<th>WWCC expires</th>
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<tbody>
<tr>
<td>Megan Hattfield</td>
<td>999013 WA</td>
<td>18-Feb-2018</td>
</tr>
<tr>
<td>Torbjorn Falkmer</td>
<td>2141120 WA</td>
<td>31-May-2017</td>
</tr>
</tbody>
</table>

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
You may also be asked to present on the findings of your research.

I wish you every success with your research.

Yours sincerely,

[Signature]

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