

Summary of Proposed Research Program for Doctor of Philosophy

Title

Development of an Educational and Vocational Assessment Protocol for Adolescents with High Functioning Autism/Asperger's Syndrome

Abstract

Currently there are low rates of employment of people with high functioning Autism/Asperger Syndrome (HFA/AS). These individuals often have the skills and motivation to participate in employment, but face a unique set of challenges to achieving this goal, i.e., difficulties with social situations and with being flexible in response to job demands. Despite this, there are very few HFA/AS specific tools that assist individuals to plan for their post-school pathway. For the tools that do exist, there is limited evidence supporting their psychometric properties and efficacy for this target population.

This project aims to develop a protocol to assist adults with HFA/AS and their advisors in making informed choices regarding post-school pathways. Ultimately this will result in more individuals with HFA/AS in successful long term employment.

The study will comprise five stages; 1) *Systematic Review* of current vocational tools or protocols for individuals with HFA/AS; 2) *Environmental Scan* determining the strengths and weaknesses of current vocational decision making practice for people with HFA/AS; 3) *Development and Pilot* an Educational and Vocational Assessment Protocol (EVAP); 4) *Randomised controlled trial (RCT)* testing the efficacy of the EVAP; and 5) *Q Sort* contrasting the viewpoints of the group that trialled the EVAP with the control group related to planning their transition to post-school activities.

The results from this study will inform vocational rehabilitation approaches, education practices, occupational therapy practice and employment related interventions for young adults with HFA/AS.

Objectives

The long term aim of this project is to develop a protocol to assist adolescents with HFA/AS and their advisors with post-school pathway planning. Ultimately, this will result in more individuals with HFA/AS in successful long term employment.

To address this overall aim the project will employ five studies with the following objectives:

1. Review current evidence of post-school pathway planning tools for adolescents with HFA/AS;
2. Determine strengths and weaknesses of current post-school pathway planning processes for adolescents with HFA/AS;
3. Develop an Educational Vocational Assessment Protocol (EVAP) to assist adolescents with HFA/AS in in the process of post-school pathway planning;
4. Trial and evaluate the efficacy of the EVAP with adolescents with HFA/AS in supporting them to make post-school pathway choices; and,
5. Contrast the viewpoints of the participants in the EVAP and control groups related to planning their transition to post-school activities.

Figure 1 illustrates the proposed research program that will address these objectives, and the relationship between the studies.

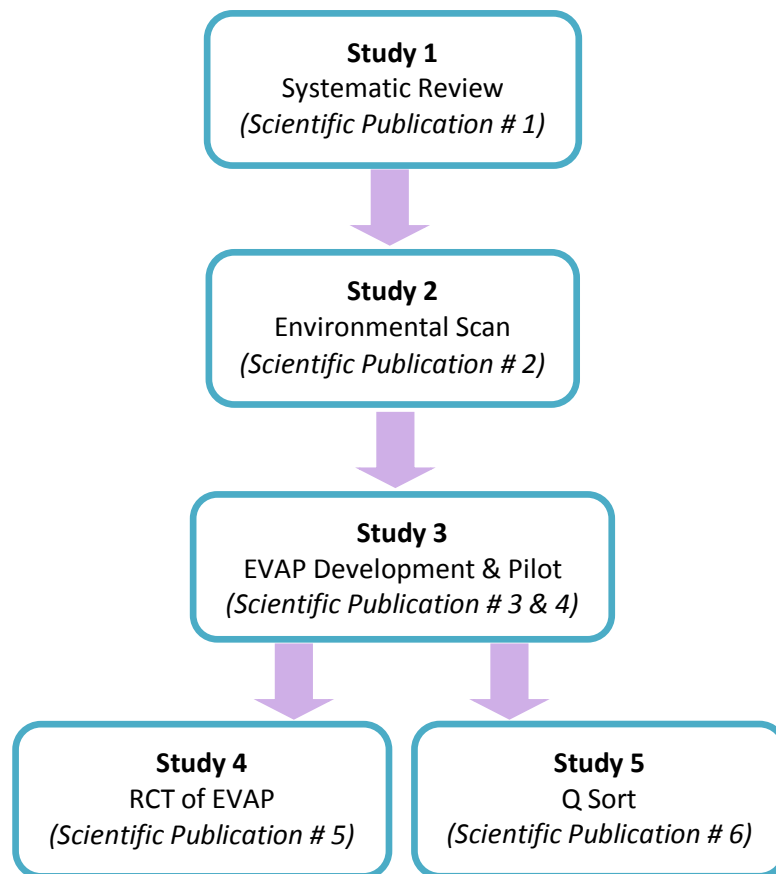


Figure 1: Proposed research program and interrelationships between the five studies

Background

Preface

This proposal will be using the terms outlined in the fourth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (1), rather than the fifth edition, the DSM-5¹ (2). This is because the target population of this project are adolescents who would have been diagnosed with Autism Spectrum Disorder (ASD) using the DSM-IV or older versions.

This project will be running in close collaboration with two other PhD projects; Melissa Scott's project which will involve the development of the Integrated Employment Success Tool (IEST) for adults with ASD and Craig Thompson's project exploring the transition to adulthood for adolescents with ASD. As a result, data and results will be shared across all three projects.

Adults with ASD finding a place in society

Individuals with autism spectrum disorders (ASD) face unique social and cognitive challenges that affect their ability to secure and maintain stable employment, establish meaningful social relationships and participate in community activities (33). These individuals have much to contribute to society, but are in urgent need of appropriate support to facilitate their engagement in employment. There are approximately 153,000 adults with ASD of working age (16-64 years) in Australia today (prevalence rates of 1 in 100), with this number expected to exceed 181,000 over the next 10 years (5). Australia is currently experiencing an unprecedented increase in number of individuals with ASD transitioning to adulthood, and it has already been recognised that adult services are under-resourced to manage this increase (37).

Adults with ASD and post-school pathways

Labour force participation rates for individuals with ASD are 34%, compared with 54% for all individuals with disabilities and 83% for individuals without disabilities in the United Kingdom (22) and in the United States of America (45). Every year, 2,500-3,000 young adults with ASD leave schools across Australia. They typically do not successfully transition into post-school activities such as higher education, vocational training or employment

¹ American Psychiatric Association has explicitly expressed that DSM-5 should be written with Arabic numbers instead of Roman numerals.

(20, 38, 43). While the transition is difficult, individuals with ASD who actually make it are often highly appreciated by their lecturers or employers for their trustworthiness, reliability and low absenteeism (18, 21). Some people with ASD also demonstrate exceptional strengths in their focus and meticulous attention to details (39). Literature has found that individuals with ASD are more drawn to the fields of science, mathematics, technology and engineering (46). The specialised skills of individuals with ASD in these fields are becoming more widely recognised, and some companies have begun seek out employees with ASD to work on tasks that are an ideal match to their characteristics. For example, the company SPECIALISTERNE in Denmark employs a majority of people with ASD due to their proficiency at performing software testing, which can be difficult and requires great accuracy, but can also be monotonous and repetitive (4). More males than females in the neurotypical population tend to work in science, technology, engineering and mathematics based professions, and this gender gap is consistent among people with ASD; wherein 39% of males with ASD compared to only 3% of females with ASD studying these fields of education (46). Therefore it is important to focus not only on the fields of science, technology, engineering and mathematics, but to consider other areas of employment and education suitable for individuals with ASD.

People with ASD are typically discussed in two groups; people with ASD who have an intellectual disability (ID) and those who do not have an ID. The latter is often referred to as high functioning Autism (HFA), which includes individuals with Asperger Syndrome (AS). Interestingly, young adults with HFA/AS are three times less likely to have day time activities compared to their peers with ASD who have an ID (43). This is because there are systems and services in place to support individuals with ID, but there is currently very limited research about specific supports for the needs of people with HFA/AS (44). The characteristics of HFA/AS are distinct from any other disability, which means generic programs would not meet their specific needs. Workplace difficulties for individuals with HFA/AS originate more often from social, communicative and cognitive challenges rather than problems with actual job performance (21). Difficulties understanding emotional and social cues in others, regulating one's own emotions, holding reciprocal conversations, considering others' perspectives and adjusting to changes in task requirements pose significant challenges for individuals with HFA/AS (28, 42). As a consequence, even when adults with HFA/AS are employed, the type of employment is often at a significantly lower level than the person's actual working potential (11). Despite some improvements using workplace education about HFA/AS and individual on-site support for employees with HFA/AS, the described difficulties continue to be significant barriers to successful employment (21).

Individuals with HFA/AS have the potential to attend higher education, due to having average or above average academic intelligence. Obtaining a higher degree is advantageous in the career market as it has been linked to improved success in obtaining employment, as well as increased earning potential and career advancement opportunities (36). The number of individuals with HFA/AS who attend higher education has recently grown. However, it is still less than the general population; a recent study found 34.7% of a large cohort of individuals with HFA/AS in the USA attended higher education in the six years after they left high school (38). Another study found that the enrolment rate of people with HFA/AS in postsecondary education in the USA was the third lowest out of 11 other disability groups (46). When people with HFA/AS do attend university, they often find it difficult and encounter many physical and social challenges that may affect their success in completing their degree (20, 29, 48). Universities are familiar with the process of supporting individuals with disabilities; however, the focus is often on support for physical or cognitive difficulties (30). Whilst these supports might be beneficial for people with HFA/AS, these programs often fail to specifically address the social, communicative and behavioural needs of these individuals (15).

Identified Gaps

The lack of effective transition planning, adult support services and policies for individuals with HFA/AS in Australia have contributed to poor post-school outcomes (3). However, with optimal post-school pathways planning and workplace adaptations, individuals with HFA/AS can pursue a range of occupations (19). To date, research exploring vocational guidance and effective methods for scaffolding the transition to productive adult outcomes for individuals with HFA/AS is scarce. The challenge is to establish: 1) what a person with HFA/AS is interested in and can do, and more importantly, how to enable them to convey these abilities and aspirations; 2) ensure the person with HFA/AS has the confidence to use their specific abilities; and 3) empower these

individuals to actively participate in and sustain post-school activities. Currently, there are no HFA/AS specific protocols to assist with post-school pathway planning that have strong evidence supporting their psychometric properties and efficacy for this target population. The term post-school pathway planning refers to assisting individuals to make informed choices regarding post-school activities such as volunteering, vocational training, higher education and work experience. The ultimate aim of engaging in these activities is acquiring suitable employment in the context of career development.

Significance

Relevance to Occupational Therapy

Wilcock (47) describes a framework providing insight into occupational perspectives on health. This framework acknowledges that occupational participation is a central contributor to well-being for humans. Wilcock talks about *doing* as the act of working towards fulfilling basic human needs like shelter and food to improve well-being. When people have internal motivation to engage in *doing* with others towards a common purpose, this gives us a sense of purpose and *belonging*. This *doing* and *belonging* ultimately enhances the individual's health and well-being. This model relates to the current project, as the EVAP will be used by occupational therapists and other allied health professionals to increase participation in employment for people with HFA/AS. Participation in the occupation of employment (*doing*) meets an individual's basic needs by providing them with financial independence and opportunities to develop social networks and supports. It also creates *belonging* in that employment provides a sense of identity, meaning and purpose to people's lives. Studies indicate that people with HFA/AS who work in supported employment experience meaningful improvements in quality of life (17, 44). It is likely that increased employment amongst the population of people with HFA/AS would reduce dependence on family members, and therefore improve quality of life for caregivers as well. Therefore, the results of this study will support people with HFA/AS to plan a pathway towards participation in a pivotal occupation that will improve quality of life for them and the people around them.

Relevance to the Wider Context

The results from this study will inform vocational rehabilitation approaches, education practices, occupational therapy practice and employment related interventions for young adults with HFA/AS. The EVAP will provide a best practice framework for working with people with HFA/AS in post-school pathway planning. The EVAP will be used by vocational rehabilitation providers around Australia, and potentially around the world to enhance success related to engagement in post-school activities.

This PhD project is a part of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC²). The Autism CRC is a national coordinated research effort looking at improving the lives of people with ASD at all stages of life. It involves a collaboration between four states; Western Australia (WA), Queensland (QLD), New South Wales (NSW) and Victoria (VIC). This project falls under *Project 3: Finding a Place in Society* which focuses on adults with ASD. Project 3 contains a series of PhD projects, as detailed in Figure 2. The projects will run concurrently and utilise the pool of participants that will be recruited in the Longitudinal Studies coordinated from VIC and NSW. In order to ensure feasibility of the project, it will be supported within the structure of the Autism CRC (see Appendix B for details), in that members of the CRC will be assisting in various stages of the EVAP project.

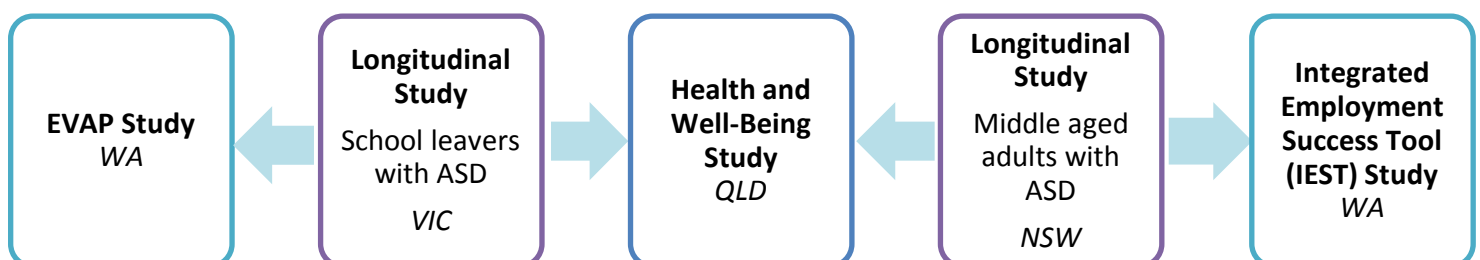


Figure 2: Autism CRC PhD Projects and interrelationships between them.

² For further information please refer to <http://www.autismcrc.com.au/>

The EVAP project will be a close collaboration with the project that will develop the Integrated Employment Success Tool (IEST). The IEST will be used by employers of people with ASD to identify areas in the workplace that can be adapted to facilitate their successful employment. These projects will run simultaneously in WA. The difference between the EVAP and the IEST is illustrated in Figure 3. The EVAP aims to match the person with the right job or vocational pathway, whereas the IEST aims to adapt the environment to facilitate success in the job. Ultimately, the EVAP and the IEST will be used together to create a successful employment outcomes for individuals with ASD.

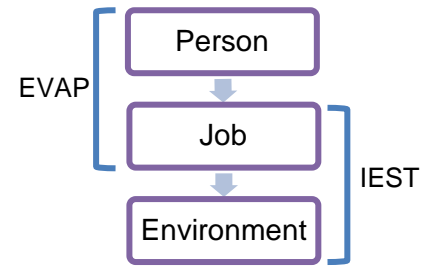


Figure 3: IEST & EVAP comparison

This project will be conducted in association with the PhD project by Craig Thompson, which aims to examine the process and experience of transition to adulthood for young people with HFA and their families. It will describe what characterises a “successful outcome” for young people with HFA as they transition to adulthood. Craig Thompson’s project will contribute important knowledge that will inform the development of the EVAP, and the statements used in the Q-sort when contrasting the viewpoints related to planning transition to post-school activities between participants in the EVAP and control groups.

The aim of Project 3 in the Autism CRC is to ensure that people with ASD: a) can effectively identify and articulate their respective skills in relation to particular employment, b) have the ability the routinely attend employment, including getting themselves to and from work, c) can effectively engage in the workplace and with the broader community, d) develop significantly higher self-esteem and a lower incidence of depression and anxiety, and e) retain long term employment options, with a career path and improved overall quality of life. These objectives are in line with a major Federal Government priority of increased workforce participation for Australians with disability, as outlined in the National Disability Strategy 2010-2020 (14). It is the first national/Australian research project of its kind to comprehensively address post-school outcomes in adults with HFA/AS. In the past, less than 1% of all research investment in ASD has been invested into post-school initiatives (23). Not only is this a series of state-of-the-art studies, but it will also have enormous benefits for affected individuals, their families, and for the broader Australian community. It will help people with ASD to feel they are contributing and productive members of society.

Research Method

The project comprises of five studies, as illustrated in Figure 1.

Study 1: Systematic Review

Aim: Review current evidence of post-school pathway planning tools for people with HFA/AS.

Design: A systematic literature review of HFA/AS specific vocational tools or protocols will be conducted.

Procedure: The review will follow a Cochrane protocol procedure and result in 20 + articles being reviewed. Relevant databases will be searched using keywords and associated MeSH terms. Keywords will be truncated and exploded as required. Inclusion and exclusion criteria will be developed, and results will be presented in a PRISMA diagram.

Data analysis: The articles will be reviewed by two independent evaluators using the KMET standard quality assessment criteria (27).

Expected results: This study is already underway and is expected to be finalised by June 2014. It will identify any existing post-school pathway planning tools for people with HFA/AS, which will inform the environmental scan in Study 2 and the development of the EVAP in Study 3. The results of this study will be published as a scientific manuscript in a peer-reviewed journal.

Study 2: Environmental Scan

Aim: Determine strengths and weaknesses of current post-school pathway planning processes for adolescents with HFA/AS.

Design: This will be a cross-sectional study. An environmental scan will be completed using a mixed-methods approach, which will collect descriptive data about post-school pathway planning processes for

adolescents with HFA/AS. This will be an inductive process that will involve gaining as much information as possible using multiple methodologies, including a survey and interviews. Professional staff utilising existing vocational guidance and transition tools, such as the TTAP (25), JobTIPS (41) and the YES Program (32), will be questioned about their strengths and limitations for use with a range of individuals with HFA/AS.

Participants: A minimum of 40 participants (10 in each of the four states participating in the Autism CRC) will take part in the environmental scan. Participants will be anyone involved in post-school pathway planning for adolescents with HFA/AS. This may include secondary school guidance officers, senior school teachers, university/VET sector staff, disability employment service providers, adolescents with HFA/AS and their parents/carers. Participants will be recruited via associates from the Autism CRC.

Procedure: A nation-wide electronic survey will be designed based on the results of the systematic review in Study 1 and in consultation with the Community Reference Group (refer to description below for details of this group). Individuals who participate in the survey will have the option of providing further information via an interview, which will be completed over the phone and/or in person.

Data analysis: Results will be analysed thematically, descriptively and with regression or structural equation modelling if a sample size of more than 100 people is obtained.

Expected results: This study will provide knowledge about current practice in post-school planning, including issues involved in this process and recommendations for improvement. The results will inform the development of an Educational and Vocational Assessment Protocol (EVAP) in Study 3. The results of this study will be published as a scientific manuscript in a peer-reviewed journal.

Study 3: EVAP Development and Pilot

Aim: Develop an Educational Vocational Assessment Protocol (EVAP) to assist adolescents with HFA/AS in post-school pathway planning, and pilot it prior to the large scale RCT.

Design: The EVAP will be developed using a bottom-up process. It will then be piloted with adolescents and their teaching/guidance staff to get initial feedback on the tool, using a Delphi approach.

Resources: Electronic version of the EVAP and survey to obtain feedback in the pilot.

Participants: Ten adolescents who are 12 months away from finishing school will pilot the EVAP with the assistance of their career guidance staff. Participants will be recruited through the Autism CRC, through contacts at the Autism Association of WA and/or the Autism Association of South Australia.

Procedure: A literature review to scope non-ASD specific protocols in tertiary education and employment models will be conducted in order to be able to take advantage of aspects of existing protocols. This review will include grey literature, web searches, etc. An analysis of the different protocols in relation to the HFA/AS specific requirements will then be conducted. These results in combination with the findings of the Study 1 and 2 will inform the development of the HFA/AS specific EVAP. The psychometric properties of the EVAP will be ascertained by the post-doctoral fellow in the Autism CRC. The EVAP will then be distributed to staff who will pilot the protocol with the adolescents with HFA/AS. The staff will be provided with a link to an electronic survey requesting feedback about the EVAP on a number of areas, including ease of use, time taken to administer, relevance and usefulness.

Data analysis: Qualitative feedback will be obtained from participants during the pilot. These data will be reviewed and individual recommendations will be considered and discussed with the Community Reference Group. Alterations will be made to the EVAP as required.

Expected results: This study will result in the EVAP, which will be refined in the pilot to ensure any issues are identified before the RCT. The pilot will also inform the design of Studies 4 and 5. The results of this study will be published in two scientific manuscripts in a peer-reviewed journal. One manuscript will describe the review of existing tools related to post-school pathway planning that meet HFA/AS specific requirements, and the other will outline the EVAP pilot.

Study 4: RCT of EVAP

Aim: Trial and evaluate the efficacy of the EVAP with school leavers with HFA/AS in supporting them to make post-school pathway choices.

Design: An efficacy trial in the form of a RCT will be undertaken. Adolescents' outcomes will be followed up 12 months post use of the EVAP regarding its effectiveness in supporting individuals to make post-school pathway choices.

Participants: There will be 80 adolescents who are 12 months away from finishing school with a confirmed diagnosis of HFA/AS participating in the study. There will be 40 participants in the EVAP group, who will be using the EVAP to assist with post-school pathway planning instead of the usual planning process. The other 40 participants will be in the control group, and they will participate in the regular post-school planning processes used at their school. This will control for any Hawthorn effect. Participants will be recruited through the Autism CRC, which will be conducting a number of longitudinal studies.

Participants will be given the opportunity to self-select classification as having HFA/AS. To confirm diagnosis, medical records will be sighted with consent. Since many will have been diagnosed several years ago, all participants will complete an ASD screening tool, such as the SRS-A (12), Autism Spectrum Quotient (AQ) (7, 9, 26) / Adult Asperger Assessment (AAA) (8) and/or the diagnostic checklist based on the ICD-10 and DSM-IV (31). Individuals with co-morbid conditions will be excluded if they are deemed to introduce distinctly different characteristics from ASD that would potentially require additional consideration in post-school pathway planning. For example, individuals with a co-morbid diagnosis of anxiety would be included as this is a common symptom of people with ASD. On the contrary, people with a co-morbid diagnosis of Attention Deficit Hyperactivity Disorder would be excluded as this would introduce a new set of characteristics to consider.

Procedure: Schools will be randomised to the use of EVAP or standard practice in the control group. Outcome measures will be completed at the commencement of the study halfway through 2015, and then repeated 12 months later. The primary outcome is the participant's progress on their post-school pathway journey. This will be measured by examining their short term plan for what activities they will engage in when they leave school at the end of the year, and their long term plan including their defined occupational goals. In addition, the participants and their parent/caregivers will rate their confidence and levels of anxiety related to making the transition out of school. Secondary outcomes will include quality of life indicators, including satisfaction in areas such as their health, personal relationships and community participation. These outcomes will be measured using the Personal Wellbeing Index-Adults (PWI-A) (24) or the LIFE-H (35). Measuring these secondary outcomes is based on recommendations for future research in current literature (44). The Autism CRC will continue to monitor these participants as part of the Longitudinal Study. This will provide the opportunity for these participants to complete the outcome measures again at the end of their first year out of school to further determine the efficacy of the EVAP. This will **not** be included as part of this current PhD project due to timeframes.

Data analysis: Group equivalence at baseline will be determined based on gender, socioeconomic status and ASD severity (using results from the ASD screening tools). The sample size allows for detection of a Cohen's d (standardized difference) of 0.6 or larger with a β -level of 0.2 and an α -level of 0.05. Primary outcomes will be analysed in two different ways. Whether participants have definite short term plans for their post-school pathway (higher education, work experience or vocational training) will yield a yes/no response, which will be analysed using a chi-square test. Confidence and anxiety related to the transition to post-school activities will be measured and the secondary outcomes looking at quality of life will be analysed using a t-test and/or Mann-Whitney U depending on which outcome measures are utilised (scale or ordinal variables).

Expected results: This study will provide evidence for the efficacy of the EVAP in providing people with HFA/AS guidance in working towards a successful post-school pathway. The results of this study will be published as a scientific manuscript in a peer-reviewed journal.

Study 5: Q Sort

Aim: Contrast the viewpoints of the participants in the EVAP and control groups related to planning their transition to post-school activities.

Design: In parallel with Study 4, the viewpoints on planning the transition to post-school outcomes will be obtained from participants, using Q-methodology (13, 16). The viewpoints of the two groups, the EVAP group and the control group, will be contrasted. Traditional approaches, such as interviews or focus groups can be difficult or uncomfortable for people with ASD due to social and communication difficulties, including concrete interpretation of questions and difficulties expressing thoughts and feelings (1). Q-methodology is therefore more

suitable for people with HFA/AS as it reduces the need for verbal communication and social interactions. Factor analysis of results allows for the most common viewpoints to be identified. As a limited number of viewpoints are identified, since the assumption is that there is a “finite diversity” and therefore a strength of this methodology is that only a limited number of participants are required (10).

Equipment: Q sort pack and sorting grid.

Participants: As in Study 4 – see above for details. This study will include both EVAP and control groups.

Procedure: A Q-sort pack will be developed. This will consist of 40-60 cards that have statements printed on them. The statements will be based on what is known as the ‘concourse’, or the current knowledge on the topic obtained from expert opinions and the current literature (as determined in the systematic review in Study 1). The Q-sort will be pilot tested and/or reviewed by the community reference group to ensure adequate coverage of the topic and that all statements are relevant. It will then be revised according to any feedback. The administration of the Q-sort will occur at sessions that will run for about 30 minutes. The participants will be required to place the cards onto the grid, rating them from strongly disagree to strongly agree. Figure 5 illustrates an individual completing a Q-sort. When the participant has completed the Q-sort they will be asked if any statement(s) were missing that they would like to add.

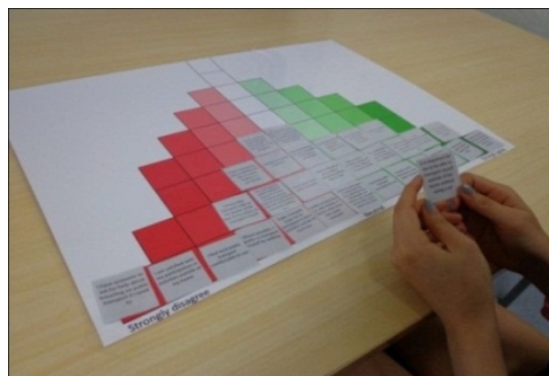


Figure 5: Completion of a Q-Sort

Data analysis: Data will be analysed using exploratory factor analysis with varimax rotation. This will identify factors that represent the most significant viewpoints amongst the participants. These factors are then interpreted and labelled according to the common theme related to the statements within each factor, producing a number of viewpoints for each group. The viewpoints from the two groups (EVAP and control) will be contrasted and commonalities and differences will be discussed.

Expected results: This study will contrast the experiences of the participants in the EVAP and control groups related to planning the transition to post-school pathways. This will assist to appraise whether the EVAP was a useful tool. It will also add to the literature about the experiences of transition to employment for people with HFA/AS. The results of this study will be published as a scientific manuscript in a peer-reviewed journal.

Ethical Issues

Ethics approval will be sought from the Curtin University Human Research Ethics Committee prior to the commencement of each study. The study design and procedures will adhere to the National Statement on Ethical Conduct in Human Research (6), specifically Section 4 referring to ethical considerations specific to participants. The study will also adhere to the Australian Code for the Responsible Conduct of Research (34). Information sheets will be provided to all potential participants, including adolescents with HFA/AS, their parents and carers and professional staff, i.e. teachers, vocational rehabilitation staff, clinicians, university/VET sector staff and career guidance officers. Information sheets will include the following (written in plain language):

- The purpose of the study and their role as a participant;
- Potential risks and benefits;
- That participation is voluntary and they will have the choice to withdraw from the study at any time without prejudice and without having to give a reason;
- Confidentiality and privacy measures that will be taken, including data storage and disposal with time frames; and
- Any potential future publications or presentations that could result from the research.

Informed consent will be obtained prior to their participation in the study. If the participant is under the age of 18 years, the participant will be asked to assent and the parent/carer will provide consent. Identification codes will be assigned to de-identify participants to ensure confidentiality and privacy is protected. Diagnostic and personal information will only be accessed by the researchers.

This research is studying a potentially vulnerable population. Therefore, an adverse events management plan will be developed in collaboration with the Community Reference Group (see below), which will include provisions such as recommending to participants that a support person be available while they are participating in the study so that in the event that they become distressed there is someone available to assist in managing this situation. In the case of an adverse event, participants will be reminded that they are free to withdraw from the study.

Facilities and Resources

The resources or facilities will be required for studies 1 and 2 will be available within the School of Occupational Therapy and Social Work (OTSW). For studies 3 and 4 the EVAP will be completed in the community. For study 5, Q-sort sessions will take place in the School of OTSW offices. Such expenses would be covered by the Autism CRC. The estimated budget can be seen in Appendix A.

Community Reference Group

Two community reference groups will be created to assist in guiding this PhD research project in a sensitive and accurate manner. The community reference groups will comprise members from the Autism Association of WA, Autism West, Edge Employment, SA Enterprises, Disability Services Commission and parents of young adults with HFA/AS, however, members will not participate in the study. One group will be composed of service providers and clinicians, while the other will be parents of young adults with HFA/AS. The community reference groups will be consulted in the process of developing each study, which will include discussion of the results to inform subsequent phases of the project. The community reference group will be consulted at least prior to the commencement and upon the completion of each phase of the research project. The reference group will be consulted on issues such as, but not limited to, the environmental scan, Q-sort, selection of appropriate standardised outcome measures and the development of adverse events management plans. The utilisation of the community reference group will ensure that the research project remains relevant to the target end users. In utilising the community reference group in this manner it is hoped that this will assist in retaining participants in the study.

Supervision Team

Professor Torbjorn Falkmer, PhD, is the primary supervisor and is a Senior Research Fellow at the School of OTSW. Professor Falkmer is the Director for *Project 3: Finding a Place in Society* in the Autism CRC. Associate Professor Marina Ciccarelli, PhD, is a co-supervisor. She has considerable research experience in the area of workplace design and clinical experience in vocational rehabilitation for people with disability. Dr Marita Falkmer, PhD, is a co-supervisor as well as the Post-Doctoral Fellow in Project 3 of the Autism CRC and has extensive experience as a special needs educator and in research related to ASD. Professor Sylvia Rodger, PhD, is a co-supervisor. She has extensive clinical and research experience on the topic of ASD, specifically around family and occupation centred practice, and is an internationally recognised authority on ASD.

Data storage

All data will be stored in locked cabinets in the supervisor's office at the School of OTSW and will be kept for a minimum of seven years after the thesis publication, as guided by the Western Australia University Sector Disposal Authority (40). After the specified time it will be destroyed if no longer needed. Electronic data will be stored under password protected files on either a secure Curtin University network drive or encrypted hard drives.

Timeline

Full-time PhD Time Schedule

2014	2015	2016
Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec	Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec	Jan Feb Mar Apr May Jun Jul Aug Sep Oct Nov Dec

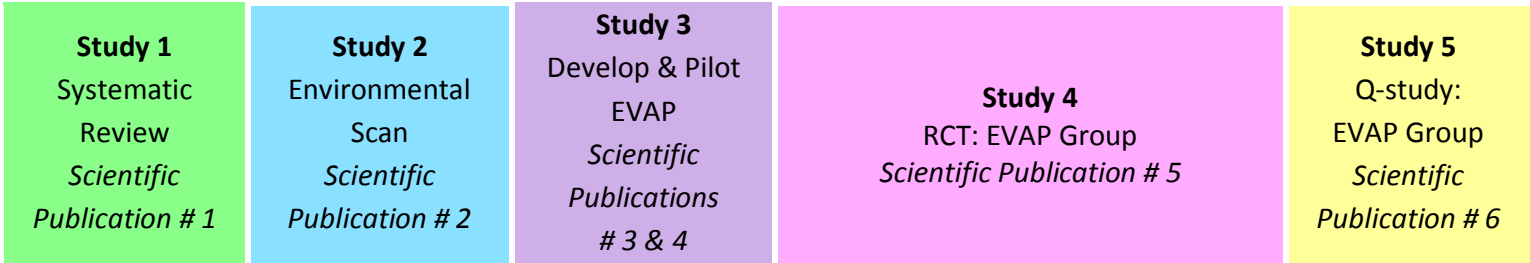


Figure 6: Schedule for the PhD Project, showing time frame for the studies.

References

1. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (4th ed, text rev.). Washington, DC: Author; 2000.
2. American Psychiatric Association. Diagnostic and statistical manual of mental disorders (5th ed, text rev.). Arlington, VA: American Psychiatric Publishing; 2014.
3. Attwood T. The complete guide to Asperger's syndrome. London: Jessica Kingsley; 2007.
4. Austin R, Wareham J, Busquets J. SPECIALISTERNE: Sense & Details. Harvard Business School [serial on the Internet]. 2008; 608-109.
5. Australian Bureau of Statistics. Survey of disability, ageing and carers; cat. no. 4430.0. Canberra, ACT: Australian Government; 2010.
6. Australian Government. National Statement on Ethical Conduct in Human Research. Canberra, ACT: Australian Government; 2007.
7. Baron-Cohen S, Hoekstra R, Knickmeyer R, Wheelwright S. The Autism-Spectrum Quotient (AQ) - Adolescent Version. *Journal of Autism & Developmental Disorders*. 2006;36(3):343-50.
8. Baron-Cohen S, Wheelwright S, Robinson J, Woodbury-Smith M. The Adult Asperger Assessment (AAA): A diagnostic method. *Journal of Autism and Developmental Disorders*. 2005;35(6):807-19.
9. Baron-Cohen S, Wheelwright S, Skinner R, Martin J, Clubley E. The Autism-Spectrum Quotient (AQ): Evidence from Asperger syndrome/high-functioning autism, males and females, scientists and mathematicians. *Journal of Autism & Developmental Disorders*. 2001;31(1):5-17.
10. Brown SR. Political Subjectivity: Application of Q Methodology in Political Science. New Haven, CT Yale University Press; 1980.
11. Cederlund M, Hagberg B, Billstedt E, Gillberg I, Gillberg C. Asperger syndrome and autism: a comparative longitudinal follow-up study more than 5 years after original diagnosis. *J Autism Dev Disord*. 2008 Jan;38(1):72-85.
12. Constantino J, Todd R. Intergenerational transmission of subthreshold autistic traits in the general population. *Biological Psychiatry*. 2005;57(6):655-60.
13. Corr S, Phillips C, Capdevila R. Using Q methodology to evaluate a day service for younger adult stroke survivors. *Operant Subjectivity*. 2003;27(1):1-23.
14. Council of Australian Governments. National Disability Strategy 2010-2020; 2010.
15. Dillon M. Creating supports for college students with Asperger Syndrome through collaboration. *College Student Journal*. 2007;41(2):499-504.
16. Fristedt S, Wretstrand A, Björklund A, Corr S, Falkmer T. Viewpoints on community mobility and participation in older age. *Journal of Human Subjectivity*. 2012;10(1):103-23.
17. Garcia-Villamisar D, Wehman P, Diaz Navarro M. Changes in the quality of autistic people's life that work in supported and sheltered employment. A 5-year follow-up study. *Journal of Vocational Rehabilitation*. 2002;17:309-12.
18. Hagner D, Cooney BF. 'I do that for everybody': Supervising employees with autism. *Focus on Autism and Other Developmental Disabilities*. 2005;20(2):91-7.
19. Hendricks D. Employment and adults with autism spectrum disorders: Challenges and strategies for success. *Journal of Vocational Rehabilitation*. 2010;32:125-34.
20. Hendricks D, Wehman P. Transition From school to adulthood for youth with Autism Spectrum Disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*. 2009 June 1, 2009;24(2):77-88.
21. Hillier A, et al. Two-year evaluation of a vocational support program for adults on the autism spectrum. *Career Development for Exceptional Individuals*. 2007;30(1):35-47.
22. Howlin P, et al. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*. 2004;45:212-29.
23. Interagency Autism Coordinating Committee (IACC). Strategic Plan for ASD Research 2011. 2011.
24. International Wellbeing Group. Personal Wellbeing Index: 5th Edition. Melbourne: Australia: Centre on Quality of Life, Deakin University 2013.
25. Keel J, Mesibov G, Woods A. TEACCH-Supported Employment Program. *Journal of Autism and Developmental Disorders*. 1997;27(1):3-9.
26. Ketelaars C, Horwitz E, Sytema S, Bos J, Wiersma D, Minderaa R, et al. Brief report: Adults with mild autism spectrum disorders (ASD): Scores on the Autism Spectrum Quotient (AQ) and comorbid psychopathology. *Journal of Autism & Developmental Disorders*. 2008;38(1):176-80.
27. Kmet L, Lee R, Cook L. Standard quality assessment criteria for evaluating primary research papers from a variety of fields. Edmonton: Alberta: Heritage Foundation for Medical Research (AHFMR). ; 2004.
28. Lawer L, Brusilovskiy E, Salzer MS, Mandell DS. Use of vocational rehabilitative services among adults with autism. *J Autism Dev Disord*. 2009 Mar;39(3):487-94.
29. Madriaga M. 'I avoid pubs and the student union like the plague': Students with Asperger Syndrome and their negotiation of university spaces. *Children's Geographies*. 2010;8(1):39-50.
30. Mason RA, Rispoli M, Ganz JB, Boles MB, Orr K. Effects of video modeling on communicative social skills of college students with Asperger syndrome. *Developmental neurorehabilitation*. 2012;15(6):425-34.

31. Matson J, Wilkins J, Boisjoli J, Smith K. The validity of the autism spectrum disorders-diagnosis for intellectually disabled adults (ASD-DA). *Research in Developmental Disabilities*. 2008;29(6):537-46.
32. Morgan RL. Job matching: Development and evaluation of a web-based instrument to assess degree of match among employment preference. *Journal of Vocational Rehabilitation*. 2008;29(1):29-38.
33. Müller E, et al. Meeting the vocational support needs of individuals with Asperger Syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*. 2003;18:163-75.
34. National Health and Medical Research Council. Australian Code for Responsible Conduct of Research. Canberra, ACT: Australian Government.; 2007.
35. Noreau L, Fougere P, Vincent C. The LIFE-H: Assessment of the quality of social participation. *Technology and Disability*. 2002;14(3):113-8.
36. Oreopoulos P, Petronijevic U. Making college worth it: A review of the returns to higher education. *The Future of Children*. 2013;23(1):41-65.
37. Schall C, Wehman P, McDonough J. Transition from school to work for students with Autism Spectrum Disorders: Understanding the process and achieving better outcomes. *Pediatric Clinics of North America*. 2012;59(1):189-202.
38. Shattuck PT, Narendorf SC, Cooper B, Sterzing PR, Wagner M, Taylor JL. Postsecondary education and employment among youth with an Autism Spectrum Disorder. *Pediatrics*. 2012 June 1, 2012;129(6):1042-9.
39. Smith M, Belcher R, Juhrs P. A guide to successful employment for individuals with autism. Baltimore: Brookes Publishing; 1995.
40. State Records Commission. Western Australian University Sector Disposal Authority. SD 2011011. Perth, Western Australia 2013.
41. Strickland DC, Coles CD, Southern LB. JobTIPS: A transition to employment program for individuals with autism spectrum disorders. *J Autism Dev Disord*. 2013 Oct;43(10):2472-83.
42. Tantam D. Psychological disorder in adolescents and adults with Asperger's syndrome. *Autism*. 2000;4(1):47-62.
43. Taylor J, Seltzer M. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism & Developmental Disorders*. 2011;41(5):566-74.
44. Taylor JL, McPheeters MK, Sathé NA, Dove D, Veenstra-VanderWeele J, Warren Z. A systematic review of vocational interventions for young adults with Autism Spectrum Disorders. *Pediatrics*. 2012;130(3):531-8.
45. Taylor JL, Seltzer MM. Employment and post-secondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disabilities*. 2010;41(5):566-74.
46. Wei X, Yu JW, Shattuck P, McCracken M, Blackorby J. Science, technology, engineering, and mathematics (STEM) participation among college students with an autism spectrum disorder. *J Autism Dev Disord*. 2013 Jul;43(7):1539-46.
47. Wilcock A. An occupational perspective of health, 2nd edition. Thorofare, NJ: SLACK Incorporated; 2006.
48. Yamamoto Y, Nihei Y. Difficulties in adjusting to college life experienced by students with pervasive developmental disorders: Comparison with schizophrenic students. *Tohoku Psychologica Folia*. 2008;67:1-5.