

Summary of Proposed Research Program for Doctor of Philosophy

Title

Understanding Successful Employment for Adults with High Functioning Autism/Asperger Syndrome: Development of the Integrated Employment Success Tool

Abstract

Background: Research has shown that only few adults with Autism Spectrum Disorder (ASD), particularly those without intellectual disability, participate in the competitive workforce. Many studies have identified the need to develop vocational support programs to enable individuals with ASD to participate in and retain employment. However, there is limited research detailing the impact of workplace environmental factors in employment and the potential successful employment outcomes that may occur from modifying the environment through the use of an ASD specific tool.

Objective: The aim of this project is to develop a tool to assist adults with ASD in gaining successful employment through targeting environmental factors.

Methods: The project will be undertaken in four stages: 1) *Systematic review* of current vocational tools and protocols and/or workplace environment modification tools or protocols for individuals with ASD; 2) Use of a *Q sort* to reveal the viewpoints of adults with ASD and employers surrounding employment, the workplace environment and subsequent success factors; 3) *Development and piloting* the Integrated Employment Success Tool (IEST), and 4) Trial and evaluation of the efficacy of the IEST in a *randomised controlled trial*.

Expected results: The project will contribute to the understanding of the role of environmental factors in mediating employment outcomes for people with ASD. It will also provide a tool that can be used by service providers, vocational rehabilitation programs, occupational therapists and other allied health professionals and prospective employers to modify the workplace environment to assist in successful employment outcomes for adults with ASD.

Objectives

As part of the CRC Living with Autism Spectrum Disorders, the overall aim of this project is to support community participation for individuals with HFA/AS, by developing the IEST. The IEST is a tool that will be used by adults with HFA/AS when seeking employment and will comprise of a needs assessment tool matching personal characteristics (skills, interests, abilities), to the job tasks/characteristics in the workplace, i.e., adapting the workplace environment for successful employment. It is hoped that the end product the IEST, will be used to ensure that people with HFA/AS can effectively engage in a specifically modified workplace, retain long term employment, with subsequent opportunities for career development and improved quality of life. This project will also ensure that prospective employers have the capacity to meet the needs of individuals with HFA/AS. To reach the overall aim, the research project will employ three studies with the following objectives:

1. Conduct a needs assessment to assist in the development of the IEST through a review of current evidence successful of environmental modifications in the workplace and adults with ASD
2. Identify key environmental workplace factors required for adults with HFA/AS to successfully engage in open employment
3. Develop the IEST for adults with HFA/AS, based on the environmental workplace factors identified in objective two
4. Pilot the IEST with adults with HFA/AS seeking employment and their prospective employers and service providers.
5. Trial the effectiveness of the IEST with adults with HFA/AS seeking employment and their prospective employers and workplace

Background

The Integrated Employment Success Tool (IEST) aims to adapt the environment to facilitate a successful workplace for adults with High Functioning Autism (HFA)/ Asperger Syndrome (AS). This project will be undertaken in close collaboration with two other PhD projects; the development of the Educational and Vocational Assessment Protocol (EVAP) for adolescents with HFA/AS, by Megan Hatfield and exploration of transition to adulthood for adolescents with HFA/AS, by Craig Thompson. All three PhD projects are part of the Cooperative Research Centre for Living with Autism Spectrum Disorders (Autism CRC¹). The Autism CRC is a national coordinated research effort looking at

¹ For further information please refer to <http://www.autismcrc.com.au/>

improving the lives of people with Autism Spectrum Disorder (ASD) at all stages of life. As a result of such close collaboration in the PhD projects, recruitment information and data will be shared across all three projects; however, each project will occur independently.

While the EVAP and IEST are closely aligned, there are clear points of difference. The IEST aims to adapt the *environment* to facilitate a successful workplace for the individual, whereas the EVAP aims to match the *person* to the best-suited job or vocational pathway. Together, the IEST and the EVAP will be used to achieve successful employment outcomes for adults with HFA/AS.

To ensure that the research project remains relevant and sensitive to the target end users a community reference group comprised of members from vocational rehabilitation providers and disability service providers, clinicians and parents of adults with HFA/AS will be utilised. It is hoped that the community reference group's life and professional experiences and continuous input will assist in retaining participants in the study.

This proposal uses terms for ASD outlined in the fourth version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) (1), rather than the fifth edition, the DSM-5² (2). This is because the target population of this project is adults who would have been diagnosed with ASD using the DSM-IV or older versions. The terms HFA/AS will be used throughout to represent adults with ASD who do not have an intellectual disability (ID). However, HFA/AS is not a recognised diagnosis in the DSM-IV.

Autism spectrum disorders (ASD) represent a distinct category of developmental disabilities, characterised by difficulties in social reciprocity, communication and unusual or repetitive behaviour (22). Individuals with ASD experience lifelong challenges in their social and cognitive functioning, which impacts on their ability to apply for and maintain stable employment (37). There are approximately 153,000 adults with ASD in Australia (prevalence of 1 in 100), in the working age 16-64 years. These numbers are expected to increase to 181,000 over the next 10 years (5). This increase in the number of individuals diagnosed with ASD may be partly true to a change in the diagnostic criteria, resulting in a more accurate and earlier diagnosis (27). As many adolescents with ASD are now exiting the school system and entering into adulthood, adult services in Australia are aware that they are under resourced to manage this period of transition (48).

The labour force participation rate for adults with ASD is 34%, compared with 54% for all people with disabilities, and 83% for people without disabilities (21, 47). People with ASD have limited postsecondary employment opportunities (19); this is especially so for those with ASD without an ID, i.e., those with HFA/AS. Research has shown that individuals with HFA/AS are three times less likely to participate in daytime activities than those with ASD and ID (20, 47). Unfortunately, despite individuals with HFA/AS having high levels of skills and the desire to work (19), they continue to remain unemployed or underemployed (12). The consequences of unemployment remains an important issue, as participation in work not only provides the opportunity to earn a livelihood, but is important in developing one's identity (25). Work offers a sense of accomplishment and competence, provides structure, offers an outlet for socialisation and involves individuals in society (13, 25). Unfortunately, individuals with HFA/AS experience difficulties in social emotional areas (26, 44), which result in ongoing problems finding and maintaining employment (36), rather than their actual job performance influencing their successful participation in the workplace (20). As a result, the benefits of work participation and previously learnt skills are lost (13, 25).

Research has identified the need for vocational supports and strategies for persons with HFA/AS for successful employment based on training strategies to overcome difficulties in social reciprocity and communication in the workplace (20). However, there is very little research examining the role of environmental factors in the workplaces of adults with HFA/AS facilitating their successful employment. Environmental factors are an essential component in understanding the complex interactions and possible success factors for individual with HFA/AS participating in the workplace (32). The International Classification of Functioning, Disability and Health (ICF) (52) highlight the role that environmental factors play as either a barrier or facilitator to participation in areas such as work (35, 42). The ICF is a framework that describes health and health-related states and encompasses two components, namely, 'Body functions and structures' and 'Activity and Participation' (40), as well as contextual factors, which include both environmental and personal factors (42). Environmental factors include, 'the physical, social and attitudinal environment in which people live and conduct their lives' (40, 42). Therefore, from the perspective of the ICF, environmental factors and their impact on employment for persons with HFA/AS are i.e., products and technology, natural and human made changes to the environment, support and relationships, attitudes, and services, systems and policies (42). A better understanding of these environmental factors will assist in developing targeted interventions for people with disability (29, 42). Therefore, it is essential to consider the impact of contextual factors, both personal and environmental, when addressing the need for successful employment for individuals with HFA/AS.

² American Psychiatric Association has explicitly expressed that DSM-5 should be written with Arabic numbers instead of Roman numerals.

Identified gaps

The lack of effective transition planning, adult support services and policies for individuals with HFA/AS in Australia has contributed to poor post-school outcomes (4). However, with optimal post-school pathways planning, specialised vocational support programs and workplace adaptations, individuals with HFA/AS can pursue a range of occupations (19). It is particularly important to ensure appropriate employment ‘fit’ for adults with HFA/AS to guarantee retention in work (41). To date, research indicates that there are no valid and reliable job-matching tools available to assist with vocational decision making and matching the strengths of adults with HFA/AS, with jobs and individualised environmental supports (34). 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) job-matching these individuals based on their abilities and skills to an appropriate work environment; 3) establish potential workplace environment factors and a modification plan specific to the individual, and 4) implement the environmental adaptations and continuously adjust the plan as the individual requires depending on career development, changes to work tasks and change in management in the place of employment. Currently, there are no HFA/AS specific tools to assist with specialised and integrated vocational planning that have strong evidence supporting their psychometric properties clinical utility and efficacy for this target population. Hence, there is a need to develop such a tool to ensure workplace modification for successful employment outcomes.

Significance

To Occupational Therapy

The results from this study will inform occupational therapy practice and other allied health, vocational rehabilitation approaches and employment related interventions for adults with HFA/AS. Wilcock (50) describes a framework, which provides an insight into occupational perspectives of health. This framework acknowledges that occupational participation is a central contributor to well-being for humans. Wilcock describes *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 provides a sense of purpose and *belonging*. *Doing* and *belonging* ultimately enhances an individual’s health and well-being. This PhD project adopts the occupational perspective of health and draws on the concept of occupational participation. It focuses on employment (*doing*) (7), which meets an individual’s basic needs for financial independence, development of one’s identity, opportunities to develop social networks and ultimately provides a sense of *belonging*, meaning and purpose to people’s lives. Research evidence indicates that people with HFA/AS who work in supported employment experience meaningful improvements in quality of life (17, 45). It is likely that increased employment amongst the population of people with HFA/AS will reduce dependence on family members, and therefore improve family quality of life. Therefore, the results of this study will support people with HFA/AS to maintain participation in a pivotal occupation.

To the wider context/community

The IEST will provide a protocol for working with people with HFA/AS once employed. The IEST will assist employers to recognise areas of difficulty in the workplace and adapt the work environment suited to adults with HFA/AS. The IEST will be used by vocational rehabilitation providers across Australia, with the potential to be used globally by support services to increase participation in employment.

To the research community

The IEST project will be closely aligned with the EVAP. The EVAP will be used by *adolescents* with HFA/AS in year 10 and 11 of high school, as well as their respective advisors, including parents, teachers and career and guidance counsellors. The EVAP will assist these individuals in planning and making informed choices regarding their post-school pathways. The EVAP project will run concurrently with the IEST project. The difference between the IEST and the EVAP is illustrated in Figure 1. Figure 1 illustrates that the EVAP and the IEST come from two different perspectives. The IEST aims to adapt the environment to facilitate a successful workplace for *adults* once employed, whereas the EVAP aims to match the person to the best suited job or vocational pathway. Eventually, the EVAP and the IEST will be used together to assist individuals with HFA/AS to achieve successful employment outcomes as they transition into adulthood.

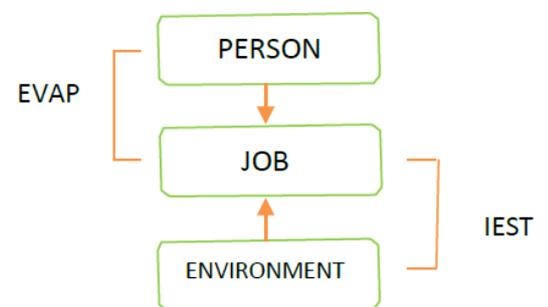


Figure 1: IEST and EVAP comparison

This PhD project is part of the Autism CRC, which is a collaboration across four states: Western Australia (WA),

Queensland (QLD), New South Wales (NSW) and Victoria (VIC) (39). The current study falls under *Program 3: Finding a Place in Society*, which focuses on adults with ASD. The aim of Program 3 is to promote people with ASD to: a) effectively identify and articulate their respective skills in relation to particular employment, b) have the ability to routinely attend employment, including getting themselves to and from work, c) 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 aims are in line with a major Federal Government priority to increase workforce participation for Australians with disability, as outlined in the National Disability Strategy 2010-2020 (16). It is the first national/Australian research project of its kind to comprehensively address post-school outcomes in adults with ASD. In the past, less than 1% of all research into ASD has been invested in 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. Indeed, it will help people with ASD to feel they are contributing and productive members of society.

Program 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 C for details), in that members of the CRC will be assisting in various stages of the IEST project.

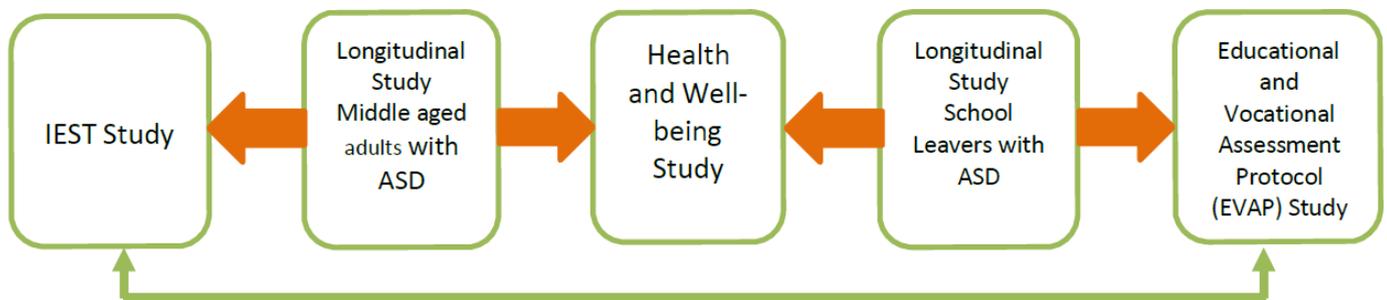


Figure 2: Autism CRC Projects and the interrelationships between them

Research Method

Needs Assessment

The design of effective intervention programs is an ongoing challenge for health care service providers, often due to a lack of consideration of the needs of all parties associated (30). As a result, conducting a needs assessment has emerged as an imperative element in the design of health interventions (18). A Needs Assessment is used to link theory with practice in the context of client-determined health perspectives such that the development of interventions are relevant to the needs of the target group, as well as supporting their use and success (30). Therefore, in developing the IEST, an environmental workplace intervention for adults with HFA/AS, it is essential to ensure that the users themselves are actively consulted with regards to their perceptions of employment success factors and assessment of their needs (30). Accordingly, a community reference group will be utilised to assist in guiding the research of this project in a sensitive manner. The community reference group will comprise of members from vocational rehabilitation providers and disability service providers, clinicians and parents of adults with HFA/AS, to ensure holistic viewpoints are obtained. The community reference groups will be consulted prior to the commencement and upon the completion of each phase of the research project. Therefore, to ensure the needs assessment is effectively executed, the use of the PRECEDE planning model is required.

PRECEDE is a stepwise planning model which supports participatory planning and systematic diagnosis of the needs of the target group (18). PRECEDE is an acronym for “Predisposing, Reinforcing and Enabling Constructs in Educational/Ecological Diagnosis and Evaluation. PRECEDE is characterised by phases of assessment, with each phases building logically onto the next. From its origin, PRECEDE has encouraged ‘best practice knowledge’ from research abroad to be translated locally on the problem, population and circumstances at hand (18). PRECEDE supports a systematic review of those factors that influence the health of a particular group and identify resources, which can enhance quality of life (30). PRECEDE ensures that the final intervention is well established in theory, scientific evidence and is of relevance to the target group.

When undertaking a needs assessment, PRECEDE promotes the use of a wide range of information sources to provide a more in-depth understanding (18). The needs assessment for this study will involve three steps as illustrated in Figure 3.

Step one involves a systematic review of the literature and consultation with experts in the field of ASD and disability to construct a ‘protocol’ for environmental modifications in the workplace. This review will focus on the adults with HFA/AS in the workplace and actions required by employers to modify the workplace environment for a successful participation outcome. *Step two*, a Q sort will be developed to reveal the viewpoints of adults of HFA/AS and employers surrounding factors for successful employment. Lastly, *step three* involves the development and pilot of the IEST. The results from the Q sort, systematic review and consultation with experts in the field of the disability service systems will inform the development of the IEST. Ultimately, the findings of the needs assessment will provide the context and conceptual basis that will be used to develop the intervention to be implemented in a randomised controlled trial (RCT)

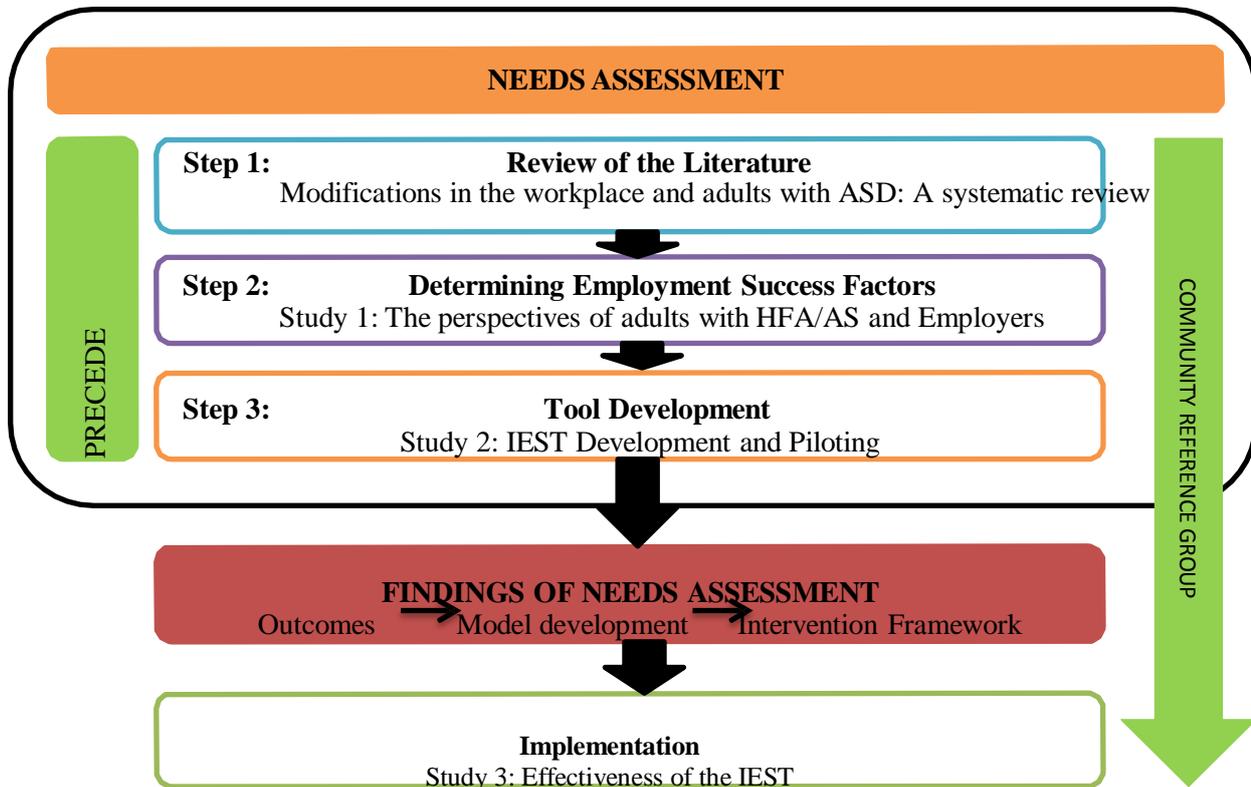


Figure 3: Needs Assessment Outline

Study One: The perspectives of adults with HFA/AS and employers

Aim: To determine the perspectives of adults with HFA/AS and employers on employment success factors. *Design:* Q methodology (10, 33) will be utilised in this study to reveal the viewpoints from adults with HFA/AS and employers regarding factors for successful employment. Q methodology has been selected, as attaining the viewpoints of individuals with ASD can be a difficult process. Due to difficulties with communication, social reciprocity and the ability to express thoughts and feelings, the traditional methods, such as interviews and focus groups can often leave individuals feeling uncomfortable and despondent (3). Therefore, Q methodology is an effective tool for exploring and generating a greater understanding of the viewpoints of adults with ASD, as it reduces the need for verbal communication and social interaction (24).

Equipment: Q-Sort pack and a sorting grid.

Participants: Two groups of participants will be recruited, group one will include adults with HFA/AS and group two will include employers.

Group 1: Adults with HFA/AS: Inclusion criteria: self-selection of adults aged between 18-35 years (n=40) with a confirmed diagnosis of HFA/AS will occur in 3 stages: 1) verbal confirmation of diagnosis, 2) medical record confirmation of diagnosis and 3) validation of medical record through one of the following ASD screening tools: the Autism Spectrum Quotient (AQ) (7, 9) or Adult Asperger Assessment (AAA) (8), or Social Responsiveness Scale for Adults (SRS-A) (14) or the diagnostic checklist based on the ICD-10 and the DSM-IV TR (31). Exclusion criteria: 1) participants who are unable to follow the Q-sort instructions or

comprehend the set statements and 2) co-morbid conditions with distinctly different characteristics from ASD that would potentially require additional consideration in successfully attaining employment; this includes ADHD, epilepsy, major depression and psychotic disorders.

Group 2: Employers: Inclusion criteria: 1) Employers of open employment (n=40) presently employing adults with ASD and/or have employed adults with ASD therefore, are accustomed to the employment procedure and management of the workplace environment.

Recruitment:

Group 1 adults with HFA/AS: state autism service providers and disability employment networks.

Group 2 employers: employers' association with state autism service providers and disability employment networks.

Procedure: The first stage of Q methodology is defining the concourse (15). The concourse will be defined through a systematic review of the literature regarding employment. From the concourse, approximately 40-50 statements will be developed, piloted and amended as necessary, before commencing data collection with participants. Participants will be presented with a Q sort (40-50 statements drawn from the concourses and typed on cards to make up the Q sort) and will need to sort the statements on a sorting grid, which ranges from strongly agree to strongly disagree, as shown in Figure 4 (15). The Q-sorts will occur at a location that is convenient to the participant within a single 30-minute session or may be completed online. As this research is assessing a vulnerable population an adverse events management plan will be developed. This will include informing participants that a support person is available on site or over the telephone while they are participating in the study so that in the event that participants become distressed there is someone available to assist in managing this situation. Should participants continue to feel distressed they will be reminded that they will be able to withdraw from the study, without consequence.

Data analysis: This will occur through factor analysis, using varimax rotation to identify the factors from the participants' viewpoints (51). These factors will represent the most significant viewpoints amongst the participants (11). Once the factors have been identified, they will be described and interpreted to gain a better understanding of the participants' subjectivity (51).

Expected result: This study will reveal the participants' viewpoints regarding what factors influence successful employment, from both the perspectives of adults with HFA/AS and prospective employers. These results will assist in the development of the IEST. The results of this study will be published in as scientific manuscript in a peer-reviewed journal.

Study Two: IEST Development and Piloting

Aim: To develop the IEST to assist adults with HFA/AS in finding a suitable workplace environment, and pilot it prior to the effectiveness study (study 3).

Design: The IEST will be developed using an inductive approach. It will then be piloted with adults with HFA/AS seeking employment and their prospective employer and service provider.

Equipment: Electronic version of the IEST, which will be developed by Dr Soon³ as part of her project developing software for autism friendly tools. A survey will be used to obtain feedback regarding the pilot.

Participants: Inclusion criteria: adults aged between 18-64 years (n=5) with a diagnosis of HFA/AS seeking open employment. Diagnosis confirmation will occur through the same process as discussed in study 1. Exclusion criteria: participants with co-morbid conditions as mentioned above in study 1.

Recruitment: Through the Autism CRC and Autism Associations in WA and NSW.

Procedure: A literature review will be conducted in order to search for non-ASD specific protocols in employment models, 'Return-to-Work' vocational programs and workplace modification guidelines, to take advantage of aspects of these existing protocols. This review will include a search of the grey literature. Investigation of the different protocols in relation to the HFA/AS specific

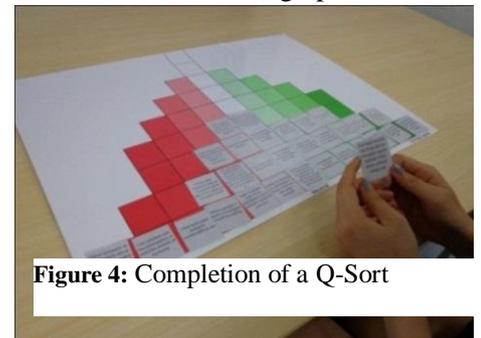


Figure 4: Completion of a Q-Sort

³ Dr Soon is software engineer and will be assisting the Autism CRC in the development of software for autism tools. adults with HFA/AS and subsequently identifies possible areas of environmental workplace difficulties that may occur. It highlights what possible actions and/or modification are required to resolve these difficulties and recommends services, products or educational training courses that can be accessed to assist in creating a suitable workplace environment for the adult with HFA/AS, employers and co-workers. Due to the IEST being an intervention and not an outcome measure, psychometric properties are not required to be established. The IEST will be distributed to service providers, who will pilot the tool with adults with HFA/AS seeking employment. The service providers will be provided with a link to an electronic survey requesting feedback about the IEST on a number of areas, including; time taken to administer, relevance and usefulness, ease of use and any possible constructive feedback.

requirements will then be conducted. Together with the literature review, consultation with experts in the fields of ASD, disability employment services and the policies and procedures regarding employment for people with disability will take place. The literature review, expert panel advice and the results of study 1, 'employment success factors' will advise the development of the IEST and contribute to its feasibility, usefulness and face validity. It is important to note that the IEST is not an outcome measure. The IEST is a 'protocol'/ 'checklist' to be used by employers of adults with HFA/AS to create an awareness of the characteristics of

Data Analysis: Qualitative feedback will be obtained from participants during the pilot. This information will be reviewed and discussed in conjunction with the Community Reference Group. As a result, the necessary modifications will be made to the IEST.

Expected Results: This study will develop the IEST, which will be revised and modified of any issues or concerns before its use in the RCT. The results of this study will be published in two scientific manuscripts in a peer-reviewed journal. One manuscript will explain the review of the literature of existing employment models and the process for developing the IEST. The second manuscript will describe the pilot study of the IEST.

Study Three: Effectiveness of the IEST

Aim: To trial and evaluate the effectiveness of the IEST in modifying the workplace environment for successful employment outcomes for adults with HFA/AS

Design: A trial in the form of a cluster RCT will be undertaken with adults with HFA/AS and their prospective workplace. Outcome measures for the workplace environment, employers and adults with HFA/AS will be measured at baseline and followed up at 1, 3⁴, 6 and 18⁵ months post the use of the IEST.

Participants: Inclusion criteria: 1) adults aged between 18-64 years (N=120) with a diagnosis of HFA/AS seeking open employment. Diagnosis confirmation will occur through the same process as discussed in study 1. Exclusion criteria: participants with co-morbid conditions as mentioned above in study 1.

Equipment: Electronic version of the IEST.

Recruitment: There will be three groups of participants recruited, *IEST Intervention group*, *Treatment as Usual group* and *the Gold Standard group*. Eighty job seekers will be recruited through Centrelink and/or vocational rehabilitation providers. Once recruited, 40 participants will be allocated to the 'IEST intervention' group and 40 participants will be allocated 'Treatment as Usual'⁶ group. The remaining 40 participants will be recruited through AIM Employment Services at Autism Association of Western Australia⁷ (AAWA). This will be the 'Gold Standard' group. This group is considered the 'Gold Standard' group due to AIM Employment Services providing effective, continuous support to adults with ASD in employment. AIM Employment Services currently has a five star DEEWR⁸ rating. The 'Gold Standard' group will control for any possible Hawthorn effect.

Procedure: This is a cluster randomised controlled trial, therefore once participants seeking employment through Centrelink and/or Disability Employment Services are employed, clustering and randomising of the workplaces will occur. Participants will then be allocated either to the 'IEST Intervention' group or the 'Treatment as Usual' group. Participants seeking employment through AIM Employment services will be assigned to the 'Gold Standard' group once employed. Due to the unpredictable nature of gaining employment and the varying economic statuses between states, the trial will begin in April 2015 and will run till May 2016.

~~This timeline allows for at least a 6- month period of employment for all participants, particularly if the last participants are recruited in November 2015.~~ Upon initial assessment for participants seeking employment through Centrelink and/or Disability Employment Services and AIM Employment, baseline measurements will occur and then repeated at 1, 3, 6 and 18 months into employment. The primary outcomes will focus on 1) the implementation of the IEST in the workplace, 2) job retention of participants and 3) employer satisfaction. *Implementation of the IEST:* an Evaluation checklist will be used to measure if the IEST has been used in the workplace and if the necessary modifications have been made. As outlined in the background the IEST will be based on environmental factors listed in the ICF (46). This Evaluation checklist will assess every component of the IEST. Job retention will be measured according to the number of months a participant remains in employment and through the use of the Work Limitations

⁴ Three months was chosen based on the standard probation period policy for new employees in the workplace, for further information on please refer to <http://www.fairworkcentral.com.au/newsblog/General?What-is-a-Probationary-Period/>

⁵ Due to the time constraints of a PhD outcome measures at 18 months will be completed by the Autism CRC.

⁶ 'Treatment as Usual' is the process an adults with HFA/AS follows when seeking employment through Centrelink. Centrelink assesses their capacity to work by using a Job Capacity Assessment and refers adults to CRS Australia who is contracted by the Australian Government to provide Disability Employment Services (DES).

⁷ AIM Employment is a Disability Employment Service provider set up through the AAWA to assist people with ASD to gain and maintain employment. For further information please refer to <http://www.autism.org.au>

⁸ Department of Education, Employment and Workplace Relations

Questionnaire (WLQ) (28) and employer satisfaction through a survey. A secondary outcome will include job satisfaction of the adults with HFA/AS using the Minnesota Satisfaction Questionnaire Short Version (MSQ) (49).

The Autism CRC will continue to monitor these participants as part of the Longitudinal Study for Middle-aged Adults. This will provide the opportunity for these participants to complete the outcome measures again at 18 months to further determine the efficacy of the IEST. This will not be included as part of this current PhD project due to timeframes. Please refer to Appendix A for RCT flow chart.

Data Analysis: Group equivalence at baseline will be determined on type of employment and/or workplace. The sample size of 120 will allow for the effect size of 0.6 or larger with a β -level of 0.2 and an α -level of 0.05. This sample size allows for expected attrition rate that may occur throughout the period of the study trial. ANOVA will be used to analyse the difference; within individuals, within groups and between the groups.

Expected results: This study will provide evidence for the efficacy of the IEST in modifying the workplace environment for people with HFA/AS, in working toward successful employment. The results of this study will be published as a scientific manuscript in a peer-reviewed journal.

Ethical Issues

Since this project aims to study potentially vulnerable adults with HFA/AS within the community it is of utmost importance that this study adhere to the Australian Code for the Responsible Conduct of Research (38). 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 conform to the National Statement on Ethical Conduct in Human Research (6), specifically Section 4 referring to ethical considerations specific to participants. Information sheets will be distributed to all potential participants and informed consent will be obtained prior to participation in the study, after the process of each study has been explained. The information sheet will provide details of the purpose of the study and the role of the participant. They will include explanations that participation is voluntary, and that they have the right to withdraw from the study at any time, without prejudice and consequence and without giving a reason. Potential risks and benefits will be clearly stated. Confidentiality and privacy issues will be stated, detailing how data will be stored and disposed of after the required time frame. Participants' confidentiality and privacy will be maintained through the use of identification codes to de-identify them, as well as, all diagnostic and personal information will only be accessed by the researchers.

Facilities and Resources

The materials required for study one are available with the School of Occupational Therapy and Social Work (OTSW). Study two, the interviews and/or participate observation will be conducted at the participant's workplace, home, university, TAFE or at the School of OTSW. For studies three and four, the IEST will be conducted in the community. Such expenses will be covered by the Autism CRC. Please see Appendix B for the estimated budget.

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 (43). 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.

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 development of the concourse for the Q-sort, discussion guides for interviews, 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 Torbjörn Falkmer, PhD, is the primary supervisor and is a Senior Research Fellow at the School of OTSW. Professor Falkmer has extensive experience in ASD research and is the director for *Program 3: Finding a Place in Society* in the Autism CRC. Dr Sonya Girdler, PhD, is a co-supervisor and is a Senior lecturer at the School of OTSW. Dr Girdler has extensive experience in disability research and most recently the transition to adulthood for people with Down syndrome. Dr Marita Falkmer, PhD, is a co-supervisor, as well as the Post-Doctoral Fellow in *Program 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 an associate supervisor. She has extensive clinical and research experience on the topic of ASD, specifically around family and occupation centered practice, and is an internationally recognised authority on ASD.

Data Storage

The data storage provisions are outlined in the attached Research Data Management Plan and meet the Curtin University Research Data and Primary Materials Policy.

Timeline

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
Step 1				Study 1				Study 2				Study 3								Write-up and editing															
Needs Assessment				Q Sort				Development and Pilot				RCT of IEST																							
Systematic Review				Scientific publication #2				Scientific publication #3 & #4				Scientific publication #5																							
Scientific publication #1																																			

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. Association. AP. Diagnostic and statistical manual of mental disorders. (4th, text rev.) ed. Washington, DC: Author; 2000.
4. Attwood T. The complete guide to Asperger's syndrome. London: Jessica Kingsley; 2007.
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 RA, Knickmeyer R, Wheelwright S. The Autism-Spectrum Quotient (AQ)-- Adolescent Version. *Journal of autism and developmental disorders*. [Empirical Study; Quantitative Study]. 2006 Apr;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*. [Empirical Study; Quantitative Study]. 2005 Dec;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 and developmental disorders*. [Empirical Study]. 2001 Feb;31(1):5-17.
10. Brown S. *Political Subjectivity: Application of Q Methodology in Political Science*. New Have, CT: Yale University Press; 1980.
11. Brown S. Q Methodology and Qualitative Research. *Qualitative health research*. 1996;6(4):561-7.
12. Burke RV, Andersen, M. N., Bowen, S. L., Howard, M. R., & Allen, K. D. Evaluation of two instruction methods to increase employment options for young adults with autism spectrum disorders. *Res Dev Disabil*. [Clinical Trial Comparative Study Research Support, Non-U.S. Gov't]. 2010 Nov-Dec;31(6):1223-33.
13. Capo LC. Autism, employment, and the role of occupational therapy. *Work*. 2000;16:201-7.
14. Constantino JN, Todd RD. Intergenerational transmission of subthreshold autistic traits in the general population. *Biological Psychiatry*. 2005 3/15/;57(6):655-60.
15. Corr S. An Introduction to Q Methodology, a Research Technique. *British journal of occupational therapy*. 2001;64(6):293-7.
16. Council of Australian Governments. *National Disability Strategy 2010-2020*;2010.
17. Garcia-Villamizar D, Wehman P, Diaz Navarroa 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. Green LW, & Kreuter, M. W. *Health Promotion Planning: An Educational and Ecological Approach*. 3 ed. California: Mayfield Publishing Company; 1999.
19. Hendricks D. *Employment and adults with autism spectrum disorders: Challenges and strategies for success*. 2010.
20. Hillier A, Campbell, H., Mastriani, K., Izzo, M. V., Kool-Tucker, A.K., Cherry, L et al. Two-Year Evaluation of a Vocational Support Program for Adults on the Autism Spectrum. *Career Development for Exceptional Individuals*. 2007;30(1):125-34.
21. Howlin P, Goode S, Hutton J, Rutter M. Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*. 2004;45(2):212-29.
22. Hume K, Loftin R, Lantz J. Increasing independence in autism spectrum disorders: a review of three focused interventions. *Journal of autism and developmental disorders*. 2009 Sep;39(9):1329-38.
23. Interagency Autism Coordinating Committee (IACC). *Strategic Plan for ASD Research 2011*. 2011.
24. Kielhofner G. *Research in Occupational Therapy: Methods of Inquiry for Enhancing Practice*. Philadelphia, PA: F. A. Davis Company; 2006.
25. Krieger B, Kinebanian A, Prodinge B, Heigl F. Becoming a member of the work force: perceptions of adults with Asperger Syndrome. *Work*. 2012;43(2):141-57.

26. Lawer L, Brusilovskiy E, Salzer MS, Mandell DS. Use of vocational rehabilitative services among adults with autism. *Journal of autism and developmental disorders*. 2009 Mar;39(3):487-94.
27. Leonard H, Dixon G, Whitehouse AJO, Bourke J, Aiberti K, Nassar N, et al. Unpacking the complex nature of the autism epidemic. *Research in Autism Spectrum Disorders*. 2010 10//;4(4):548-54.
28. Lerner. D, Amick, B.C. III., Rogers, W.H, et al. The Work Limitations Questionnaire. *Medical Care*. 2001;39:72- 85.
29. Lin T, Luiselli JK, Gilligan K, Dacosta S. Preventing injury from child aggression: a single-case evaluation of the effects of staff-worn protective equipment. *Developmental neurorehabilitation*. 2012;15(4):298-303.
30. Lorig K. *Patient Education: A Practical Approach*. 3 ed. California: SAGE Publications; 2001.
31. Matson JL, Wilkins J, Boisjoli JA, Smith KR. The validity of the autism spectrum disorders-diagnosis for intellectually disabled adults (ASD-DA). *Res Dev Disabil*. 2008 11//;29(6):537-46.
32. McDougall J, Wright V, Rosenbaum P. The ICF model of functioning and disability: incorporating quality of life and human development. *Developmental neurorehabilitation*. 2010;13(3):204-11.
33. McKeown B, & Thomas, D. B. *Q Methodology*. Fox J, editor. London: SAGE Publications; 2013.
34. Morgan RL. Job matching: Development and evaluation of web-based instrument to assess degree of match among employment preferences. *Journal of Vocational Rehabilitation*. 2008;29:29-38.
35. Morgan RL. Job matching assessment: inter-rater reliability of an instrument assessing employment characteristics of young adults with intellectual disabilities. *Journal of Vocational Rehabilitation*. 2011;34(1):25-33.
36. 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.
37. Muller E, Schuler A, Burton BA, Yates GB. Meeting the vocational support needs of individuals with Asperger syndrome and other autism spectrum disabilities. *Journal of Vocational Rehabilitation*. 2003;18:163-75.
38. National Health and Medical Research Council. *Australian Code for Responsible Conduct of Research*. Canberra, ACT: Australian Government.; 2007.
39. 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.
40. Organization WH. *ICF: International Classification of Functioning, Disability and Health*. Geneva: World Health Organization; 2007.
41. Schaller J, Yang NK. Competitive employment for people with autism: correlates of successful closure in competitive and supported employment. *Rehabilitation Counseling Bulletin*. 2005;49(1):4-16.
42. Schneidert M, Hurst, R., Miller, J., & Ustun, Berdirhan. The role of Environment in the International Classification of Functioning, Disability and Health (ICF). *Disability and Rehabilitation*. 2003;25(11-12):588-95.
43. State Records Commission. Western Australian University Sector Disposal Authority. SD 2011011. Perth, Western Australia 2013.
44. Tantam D. Psychological disorder in adolescents and adults with Asperger syndrome. *Autism*. 2000 Mar;4(1):47-62.
45. Taylor JL, McPheeters MK, Sathe 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.
46. Taylor JL, McPheeters ML, Sathe NA, Dove D, Veenstra-Vanderweele J, Warren Z. A systematic review of vocational interventions for young adults with autism spectrum disorders. *Pediatrics*. 2012 Sep;130(3):531-8.
47. 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 disorders*. 2011 May;41(5):566-74.
48. Taylor JL, Seltzer MM. Developing a vocational index for adults with autism spectrum disorders. *Journal of autism and developmental disorders*. 2012 Dec;42(12):2669-79.
49. Weiss J, Dawis, R., ENGLAND, V, & George, W. *Manual for the Minnesota Satisfaction Questionnaire*. Minnesota Studies in Vocational Rehabilitation. 1967;22:120.
50. Wilcock A. *An occupational perspective of health*, 2nd edition. Thorofare, NJ: SLACK Incorporated; 2006.
51. Wolf A. Subjectivity in Q Methodology. *Journal of Human Subjectivity*. 2010;12:55-72.
52. World Health Organization. *International Classification of Functioning, Disability and Health*. Geneva: Author; 2001.

APPENDICES WERE PROVIDED BUT ARE NOT INCLUDED