My Life as an Epic Win: Providing Transitional Support to Young Adults

with High Functioning Autism Spectrum Disorders

Jeffrey Esteves

Centre for Applied Disability Studies

Submitted in partial fulfilment of the requirements for the degree of

Master of Arts in Applied Disability Studies

Faculty of Social Sciences, Brock University
St. Catharines, Ontario

© 2016

Abstract

Individuals with high-functioning Autism Spectrum Disorder (HF-ASD) face a number of challenges during the transition to adulthood. Decreased service availability, as well as persistent challenges with self-esteem, anxiety, and self-determination can lead to poor educational attainment, underemployment, dependence on parents, and poor relationship outcomes. The *My Life as an Epic Win* course was designed to address this gap in transitional support and provide young adults with HF-ASD the skills necessary to experience more positive adult outcomes. The current study looked to examine the effect of the *Epic Win* curriculum on self-esteem, transitional anxiety and problem solving, and self-determination for five participants, who had all been diagnosed with HF-ASD. The course was evaluated by administering three questionnaires and conducting interviews pre and post delivery of the *Epic Win* curriculum. It was hypothesized that there would be an increase in self-esteem, self-determination and problem solving competence, and a decrease in transitional anxiety. None of the research hypotheses were supported through analysis of the questionnaires; however, the interview provided support for increased self-esteem following completion of the course. The study's results, limitations and future direction will be discussed.

Acknowledgements

I would like to start my thanking my advisor, Dr. Rebecca Ward. Your support throughout this journey has helped me grow as a student, researcher, and person. Thank you for your help with course work, research, and for just being there to chat, when needed. It has all been so appreciated, and I hope to continue learning from you long after this thesis is submitted. I couldn't have asked for a better mentor over these past two years.

To my thesis committee members, Dr. Kendra Thomson and Dr. Fran Owen, thank you for all of your input and support throughout this process. Even when things didn't go exactly as planned, you were there with ideas and insight into how to progress. I would also like to thank Dr. Jan Frijters. While not on the committee, you provided invaluable support in the quantitative aspect of this thesis. Thank you for your time, and for all of the resources you provided me with, to ensure that I could not only progress with my quantitative analysis, but also derive meaning from whatever results were obtained.

Finally, I'd like to thank my friends and family for their continued support. Thank you for your patience and understanding over the past two years. I couldn't have done it without having you all to lean on. Here's hoping you'll stick around for the next six years!

Table of Content

List of Tables

List of Figures

CHAPTER 1: Introduction

Literature Review

      Transitioning to Adulthood. The portrait of adolescence that has been painted

throughout recent history is rather negative. G. Stanley Hall characterised this stage of life as a

period of "storm and stress" (Arnett, 2006). Hall's assertion, despite being refuted scientifically,

has stuck, and can be seen in most popular representations of this life stage. This negative

representation devalues this crucial life stage that sets the individual up for success or failure in

their coming years. What is often skimmed over in these popular representations of adolescence,

is that a major transition lies just over the horizon. Adulthood awaits, and transitioning into this

new role is no easy feat.

      Transitioning to adulthood has received relatively limited attention in the developmental

psychology literature, and has been ignored in favour of examining the effects of childhood

experience on adult mental health (Schulenberg, Sameroff, & Cicchetti, 2004). This approach

that the field has taken has largely ignored the critical transition into adulthood, which may

explain the lack of support and resources available (Arnett, 2000). This transition period involves

a major shift in both identity and social role. The emerging adult is required to forge an identity

separate from those of his/her parents, which includes an education, a career, and new

relationships, both romantic and platonic (Schulenberg et al., 2004). When these changes are

accompanied by relatively little guidance and support, this sets the stage for decreased wellbeing,

even in typically developing individuals (Zarrett & Eccles, 2006). Successful progression

through this life stage, however, can lead to increased well being, reduced depressive

symptomology and increased self-esteem (Arnett, 2007). Although the results of this transition

look positive for those who are typically developing, they look rather bleak when an Autism

Spectrum Disorder (ASD), and more specifically, a High Functioning ASD (HF-ASD) is included.

With the advent of the fifth edition of the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM-5; 2013), the diagnostic criteria for ASD have changed. The Autism Spectrum is now diagnosed in a dimension fashion, where individuals can have varying levels of symptomatology, rather than discrete categorical diagnoses (Frazier et al., 2012). What used to be known as Asperger's syndrome, is now better known as HF-ASD. Individuals who meet the criteria for this diagnosis generally have what is considered a normal to above normal IQ, and have minimal language impairments. Instead, the impairments lie in two domains: (1) the social domain, which may include the inability to understand sarcasm, an inability to read body language, and the inability to engage in joint attention, and (2) repetitive and stereotyped behaviours and interests (American Psychiatric Association, 2013). It is these impairments that make the transition to adulthood a challenge for individuals with a HF-ASD. Obtaining higher education, forming relationships, and entering the workplace can all become major challenges when little support is offered.

As one of the most educated countries in the world, about 51% of Canadian citizens hold at least an undergraduate degree (The Organization for Economic Co-Operation and Development [OECD], 2013). With such a high national educational attainment, it becomes essential to enter higher education so as to stay competitive in the workforce. Many individuals with HF-ASD are quite able on an intellectual level to meet the academic demands of tertiary education; however, limited support and accommodations make it challenging to do so (Glennon, 2001). The need for social interaction skills to engage with professors and in group work, along with the need for skills to navigate a new environment and higher level academic demands, pose challenges. Further, the unstructured nature of the academic environment can result in increased

stress, anxiety, and depression (Glennon, 2001). In a literature review examining adult outcomes for individuals with HF-ASD, Howlin (2000) reported relatively low tertiary educational attainment for this population, ranging from 5-50%, with an average of 20.5%, much lower than the national average attainment. Low educational attainment compounded with social deficits can set the stage for problems entering the workforce. Social impairments, as well as stereotyped behaviours and interests, can skew a potential employer's perception of the individual at the point of first contact. A lack of knowledge or skill regarding the interview process can further impede the individual's chances of obtaining gainful employment (Barnhill, 2007). Individuals with HF-ASD who are able to get a job tend to find themselves in a state of mal-employment, which is defined as working in a job that is considerably below both educational attainment and skill level (Barnhill, 2007). Again, Howlin's literature review paints a bleak picture. The percentage of individuals with HF-ASD who eventually found themselves in paid employment ranged from 5-55%, with an average of 31%. The same impairments that seem to limit educational and vocational opportunities also result in problems with social relationships. Individuals with HF-ASD desire close relationships, however social impairment can prevent the formation of deep, long-lasting relationships (Barnhill, 2007). Misreading social cues, invading personal space, and egocentrism often result in rejection, isolation and loneliness which greatly limits the number of individuals with HF-ASD who develop long-term relationships or become married (Howlin, 2000). The lack of support around this critical period of development could contribute to these undesirable outcomes. It is clear that efforts must be made to continue providing transitional services once the individual has aged out of the traditional childhood autism support services and networks (Taylor & Seltzer, 2011).

Anxiety. Since the conception of the term "autism spectrum disorders," anxiety has been observed as a comorbid feature. Leo Kanner (1943), in his seminal works, commented on the

elevated anxiety levels he witnessed, however he conceded that the required assessment tools to measure anxiety in this population were not available (White, Oswald, Ollendick & Scahill, 2009). Research and assessment have come a long way since those early case studies were conducted; however the findings have remained the same. In a literature review by White and colleagues (2009), prevalence rates for comorbid anxiety ranged from 11-84%. The estimates of anxiety disorders in the general population range from 10.6-16.6%, indicating a much larger range and, most likely, a higher incidence of anxiety disorders within the ASD population (Somers, Goldner, Waraich & Hsu, 2006). In a direct comparison between pre-teens and adolescents with HF-ASD and a random community sample conducted by Kim et al. (2006), the HF-ASD group displayed significantly higher scores on a variety of measures. The HF-ASD group scored significantly higher on measures of general anxiety, separation anxiety, and depression, all of which comprise an internalizing problems composite. Higher scores on these measures were associated with aggression and lower quality of relationships with friends, family, and school staff (Kim et al., 2006). Extrapolating from these results, higher incidences of anxiety may lead to elevated stress and anxiety levels during an individual's transitional period. Elevated stress and anxiety levels have the potential to interfere with transition planning, as well as with full participation in transitional support (if any) the individual is receiving.

The transition to adulthood presents a host of unique challenges within a relatively short time-span. Generally, this is the first point in time during an individual's life when he or she is required to make decisions regarding his or her adult life (Schulenberg et al., 2004). The term "quarter-life crisis" has been used to refer to this period of increased decision-making regarding an individual's adult identity and it has been associated with periods of increased anxiety (Arnett, 2007). Although most individuals who are typically developing experience increased well-being during this period, some experience an increased severity of mental health symptomatology. This

discrepancy in outcomes in the neurotypical population suggests that this transition may act as a

critical period in the development and maintenance of psychopathology (Arnett, 2007).

Refocusing our attention on those with HF-ASD or Aspergers, it seems likely that the increased

social demands and independence associated with this life stage could lead to an exacerbation of

anxiety. As anxiety is often a comorbid feature of ASDs, the transitional period should be

viewed as a period during which to maximize protective factors against the development of more

serious problems with anxiety (Somers, Goldner, Waraich & Hsu, 2006). Transitional programs,

thus, should attempt to teach skills that will reduce the anxiety associated with this phase of life.

As rapid change is characteristic of emerging adulthood, skill in problem solving and goal setting

should be considered important targets that are likely to stave off anxiety.

      Self-Esteem. The concept of self-esteem is widely used within the psychological and

psychopathology literature. The definition of self-esteem has been debated widely and is

currently defined by two components: self-competence and self-liking (Tafarodi & Milne, 2002).

Self-competence refers to the degree to which one views oneself as the causal agent of change in

his or her life. An individual who believes that he/she can actively achieve what he or she sets

out to do would be considered high in self-competence. Self-liking refers to an individual's

cognitive assessment of his or her own perceived worth. It is an evaluative process which

ultimately results in a personal schema of oneself as a "good or bad person" (Tafarodi & Milne,

2002, p. 444). These two dimensions comprise global self-esteem. The problem within the field

is the extent to which this duality is acknowledged. The Rosenberg Self-Esteem Scale (RSES),

which is the most frequently used self-esteem assessment, reflects these two dimensions and

provides a global measure of self-esteem when these two dimensions are considered together

(Sinclair et al., 2010). Both components reflect, to some degree, a social comparison process.

Self-liking can be evaluated in terms of success and accomplishment relative to peers, as can

self-competence. It could also be taken to reflect a problematic attributional style. Low self-esteem is considered to be a characteristic of Asperger's syndrome, yet there is little literature surrounding the topic (Attwood 2007; Myles & Simpson, 2002).

Williamson, Craig and Slinger (2008) examined the relationship between self-esteem and psychological adjustment among 19 adolescents with Asperger's syndrome, and 19 typically developing adolescents. To do so, four tools were administered: the Self-Perception Profile for Children (Harter, 1985), the Children's Depression Inventory (Kovacs, 1992), the Spence Children's Anxiety Scale (Spence, 1997), and the Peer and Parental Approval Questionnaire (Williamson et al., 2008). They found that the Asperger's group reported lower competencies than the typically developing group. More specifically, this group tended to report lower perception of competency in terms of likability and social competence, and athletic competence. This group also reported lower levels of approval from peers, but not from parents. There was not, however, any difference in global self-worth scores. While there was no difference in global self-worth, these results provide a clear demonstration of lower perceived competencies in individuals with Asperger's. Self-competency is one of the domains associated with self-esteem and could impact motivation to engage in the behaviours needed to perform the tasks necessary for transition into adulthood. Transitional programming should thus teach the skills necessary for individuals with Asperger's to experience an increase in feelings of self-competence.

Barnhill and Smith-Myers (2001) examined attributional style and depressive symptoms in adolescents with Asperger's syndrome. They administered the Children's Attributional Style questionnaire and the Children's Depression Inventory to 33 individuals with Asperger's. Attributional style can be classified as either externalizing, meaning that the person believes environmental events elicited a situation, or as internalizing, meaning that the person sees him or herself as responsible for the situation. Further, it can be classified as stable, meaning that the

individual's attributional style is consistent across situations, or as unstable. Finally, it can be classified as global or as specific (Barnhill & Smith-Myers). Consistently attributing negative events to internal, stable qualities, has been associated with depression and depressive symptomatology in the neurotypical population however, prior to this study, this had not been demonstrated in individuals with Asperger's syndrome. Barnhill and Smith-Myers found that 33% of the participants obtained scores on the attributional style questionnaire that were indicative of such a profile. Further, negative attribution style was significantly, moderately correlated with depressive symptoms. Individuals with Asperger's have an internal attributional bias, which appears to be related to the low self-esteem experienced by this population. Extrapolating from these results, a negative attributional style could reflect low self-liking, as indicated by thoughts of global and stable negative attributes, and low self-competence.

Self-Determination. Self-determination is defined as "acting as the primary causal agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference" (Wehmeyer & Schwartz, 1997. p. 246). The links between self-determination and the transition to adulthood are apparent. Transitioning out of the adolescent role requires separation from parents, as well as a move away from educational institutions that provide rigid structure and guidance. Throughout childhood and adolescence, parents act as the primary causal agent in the life of the individual. Relationships, educational goals, as well as independence are all heavily shaped by a parent's influence during this time. Transitioning into adulthood requires a separation from this safety net, and requires the adolescent to become self-determined. Four characteristics that determine whether an individual is self-determined include: 1) the individual must act autonomously, meaning that he or she has acted upon his or her own accord; 2) the individual must be self-regulated, meaning that he or she can determine what skill he or she needs in a given situation, and that he or she is able to

create, act on and then reflect on a course of action; 3) a self-determined individual is psychologically empowered, in that he or she has an internal locus of control; and 4) finally, he or she is self-realized, meaning that he or she holds and uses a high level of self-knowledge, and maximizes his or her strengths (Wehmeyer & Schwartz, 1997).

Self-determination has not been widely studied in the ASD population and has largely focused on individuals with intellectual, and/or learning disabilities (ID; LD). Wehmeyer and Schwartz (1997) examined the outcomes of students identified as having either an ID or LD. Self-determination was measured prior to the participants' graduation from high school, and then again post-graduation. Participants themselves or a close family member completed an adult functioning questionnaire 9 months following their / their loved one's graduation. Those who demonstrated a high level of self-determination during the first assessment seemed to fare better in their adult life than those who were rated as being low in self-determination. Participants who demonstrated a high level of self-determination were significantly more likely to: desire moving out of their parent's house, maintain a checking and savings account, be employed, and earn a higher wage (after controlling for intelligence) than the participants who demonstrated a low level of self-determination (Wehmeyer & Schwartz, 1997).

A second study conducted by Wehmeyer and Palmer (2003) confirmed the beneficial effects of being self-determined during this transitional period. Prior to graduating high school, a self-determination assessment was given to 94 students with cognitive disabilities. The research team followed up one-year post graduation, and then three years post graduation with an outcome survey. Both one and three years post graduation, individuals who were classified as highly self-determined were disproportionately more likely to have moved from the home they lived in throughout high school. At the three-year follow-up, they were significantly more likely to be living independently. The high self-determination group was also disproportionately more

likely to maintain their own finances after one year, with trends towards financial independence after three years. Related to financial well-being, participants who were high in self-determination were disproportionately likely to have a job after one year, and to have obtained benefits, such as medical, dental and drug insurance at the three year follow up (Wehmeyer & Palmer, 2003). While promising in regards to the potential positive impact of structured self-determination programming, the limitation of these studies was their correlational nature, meaning that causation cannot be attributed to variance in self-determination scores.

Wehmeyer, Palmer, Lee, Williams-Diehm and Shogren (2011) evaluated the effectiveness of a transitional program designed to promote the development of self-determination, compared to a placebo treatment, for 493 adolescents with varying disabilities including ASD. The group that received the formal self-determination intervention demonstrated a significantly higher level of self-determination, as measured by the American Institute for Research-Self-Determination Scale (AIR-SDS), when compared to the placebo treatment control group. In a related study, Wehmeyer, Palmer, Shogren, Williams-Diehm and Soukup (2013) conducted a randomized control trial involving 371 secondary school students with intellectual and/or learning disabilities. Participants assigned to the experimental group were exposed to a structured curriculum designed to improve self-determination, for a period of three years. Participants in the control group received an intervention that had not been empirically related to increased self-determination. Although all participants demonstrated increases in self-determination after the three years, participants in the experimental group demonstrated significantly higher gains in self-determination scores as measured by the AIR-SDS. Shogren, Wehmeyer, Palmer, Rifenbark and Little (2015), conducted a follow up study to these two studies, examining 779 young adults, with a variety of disabilities (including ID, ASD, LD), who had participated in a self-determination intervention during high-school. Participants were

followed two-years post-graduation, and were contacted at both the one and two-year mark to complete a variety of questionnaires. The participants' level of self-determination significantly predicted adult outcomes in a few domains including employment and community access. Youth who were more self-determined were more likely to be working, and were more likely to be accessing a wide variety of services within their community. Further, youth who had participated in the self-determination intervention in high school had higher life satisfaction and greater financial independence than did the participants who did not take part in the intervention. Participants who were involved in the high-school intervention also displayed more stability in terms of life satisfaction and independence between leaving the intervention and subsequent follow-ups. These results provide evidence for the utility and necessity of a structured self-determination intervention during these transitional years for individuals with disabilities.

In a more recent evaluation of self-determination, Chou, Wehmeyer, Palmer and Lee (2016) evaluated differences in self-determination among 222 secondary school students with ASD, LD or ID. Each group's scores were broken into the four main components of self-determination: autonomy, self-regulation, psychological empowerment, and self-realization. Participants diagnosed with ASD had the lowest scores in the autonomy domain, when compared to participants with ID and LD. Further, individuals with ASD and ID had significantly lower psychological empowerment when compared to participants with LD. Individuals with ASD had comparable levels of self-regulation and self-realization when compared to the other two groups. These results represent the first systematic evaluation of self-determination with a large sample of participants with ASD, and provide correlational evidence that self-determination is, in fact, a challenge within this population (Chou et al., 2016). The benefits of developing a sense of self-determination during the transition to adulthood are evident; however, many educational programs for individuals with a disability are academically oriented with some basic assistance

in developing life skills. Little to no emphasis is placed on the development of self-determination

(Ministry of Education, 2007, pp. 39-47).

Current Study

Currently, there is limited transitional support available through the Ministry of

Education in Ontario, with a narrow emphasis on post-secondary school preparation.

Adolescents with HF-ASD make their way through the Ontario Secondary School curriculum

with the assistance of their guidance counsellor or an educational assistant, where scholastic

achievement is the primary focus (Ministry of Education, 2007, pp. 36-39). Planning for the

transition that lies over the horizon is rarely, if at all, touched upon and when it is, it does not

usually include the adolescent but rather their parent(s). The state of special education programs

for individuals with HF-ASD in Ontario is not consistent across school boards. The transitional

services a student receives in one school may be completely different than what they would

receive if they were attending a school run by the school board in the town adjacent to them. For

example, some school boards currently have a structured self-determination program in place,

which spans from grade nine to grade twelve. Others, however, use a "transitional toolkit" which

simply involves a list of resources for the young adult's parents to use in planning for their

transition to adulthood, essentially removing the young adult from the decision making process.

To address this gap, and variance in support, the *My Life as an Epic Win* course was

developed. Initial development of the *Epic Win* course began in 2012, and was designed largely

around the self-determination literature available at the time. Developed by Rebecca Ward, Liz

Day, Chantel Grenier, and Bernie Shuttleworth (unpublished research project, 2013), the initial

goals of the course were to increase the four components of self-determination: autonomous

decision-making, self-regulation, psychological empowerment, and self-realization. Originally

conceptualized and designed as a ten-week course, the *Epic Win* curriculum, in this format, was

delivered five times across the years 2013-2015. During these iterations, the program was

informally evaluated for acceptability and feasibility through the use of an end-of-course

questionnaire, comprised of likert style questions. Overall, participants and their families found

the program to be very helpful in terms of learning to set goals, and problem solve. Parents also

indicated that they enjoyed the ability to meet other parents of youth with HF-ASD. The course

was also evaluated in a Master's thesis, which examined its effects on self-determination and

goal-setting abilities (Drake, 2016). During this study, three participants were evaluated for

changes in self-determination on the Arc's Self-Determination Scale (Wehmeyer, 1995).

Following the completion of the course, two out of the three participants demonstrated increased

in self-determination. Further, through a qualitative analysis, it was determined that the

participants' goals became clearer, more focused on one specific thing, and more age appropriate

in terms of the content of the goals (Drake, 2016). Following these results, and further

consultation with both the self-determination and behavioural literature, the course was re-

designed as a twelve week, highly engaging, innovative curriculum to teach the skills needed for

a successful transition into adulthood (see Appendix A). Behavioural principles such as self-

management, contingency contracting, and more systematic reinforcement were included to

enhance participants' engagement with the course materials, both during, and outside of group

meetings. The main curriculum remained quite similar to previous iterations, however with the

addition of two weeks, there was extra time to spend on practicing the target skills of goal setting,

action planning, problem solving and goal attainment. Further, additional weeks were dedicated

to exporing careers and education, due to prior research demonstrating the saliency of these goals

for transition aged youth (Cameto, Levine, & Wagner, 2004). Early on in the Epic Win course,

participants' limiting beliefs regarding themselves and/or their HF-ASD diagnosis are challenged,

emphasizing that thoughts and beliefs need not hold you back from designing and acting on your

ideal life goals. Throughout the course, participants are challenged to envision and develop their

Epic Life plan, taking a more self-directed approach, which has been designed to promote the

development of self-determination. The areas of relationships, work and careers, lifelong

learning and independence are the core areas of focus, with long term goals being set in each

area, along with short-term S.M.AR.T. goals (that are simple, measurable, achievable, relevant

and time bound). Participants then learn to design action plans, actively listen, problem solve,

and take the necessary steps toward each goal that they have created.

Research Hypotheses

It was hypothesized that participation in the Epic Win course would affect participants on

four different measures. We hypothesized that:

(1) Participants who participate in the curriculum would demonstrate a significant increase in

Self-Determination as measured by scores on the AIR Self-determination Scale

(described in the methods section).

(2) Participants who receive the curriculum would demonstrate a significant decrease in

transitional anxiety, and a significant increase in perceived problem solving efficacy, as

measured by the Transitional Anxiety Scale (described in the method section).

(3) Participants who receive the curriculum would demonstrate a significant increase in self-

esteem, as measured on the Rosenberg Self-Esteem Scale and the Epic Life Interview

(described in the methods section).

CHAPTER 2: METHODS

Measures

Pre-Experimental Measures. To assist in recruiting a representative sample of the HF-

ASD population, the Wechsler Abbreviated Scaled of Intelligence - Second Edition (WASI-II),

and the High-Functioning Autism Spectrum Screening Questionnaire (ASSQ) were used. The

WASI-II is an abbreviated measure of general intelligence that has been designed to provide a relatively quick and accurate composite of the individual's intellectual functioning (Axelrod, 2002). Based on the full length Wechsler Adult Scale of Intelligence (WAIS) as well as the Wechsler Intelligence scale for Children (WISC), the WASI consists of the four subtests that had the highest correlation with general intelligence (McCrimmon & Smith, 2013). The Vocabulary, Similarities, Block Design, and Matrix Reasoning subtests are administered to the participant, with the end result being an estimate of the individual's full scale IQ (FSIQ). The psychometric properties of the WASI-II are excellent (Pearson Clinical, 2011). The test demonstrates good to excellent internal, test-retest, as well as inter-rater reliability. Scores obtained on the WASI-II correlate highly with full-length intelligence tests providing evidence of concurrent validity (McCrimmon & Smith, 2013). For the purposes of this study, each potential participant completed the WASI-II. Potential participants who obtained a FSIQ score of less than 80 were excluded to ensure a certain level of homogeneity in the group, to promote group cohesion.

The ASSQ is a relatively short diagnostic screening tool for HF-ASD (refer to Appendix B). The questionnaire is designed to be completed by a teacher or parent, and is comprised of questions pertaining to the broad diagnostic features of HF-ASD as well as Asperger's syndrome (Ehlers, Gillberg & Wing, 1999). The psychometric properties of the ASSQ demonstrate concurrent validity with clinical assessment, adequate divergent validity with the diagnoses of ADHD and behavioural disorders, and excellent test-retest reliability (Ehlers, Gillberg & Wing,1999). For the purposes of this study, each participant provided proof of assessment and diagnosis; however, the ASSQ served as a diagnostic validation measure, ensuring that all participants met the cut-off score of nineteen. By doing so, systematic variation among participants was reduced.

Experimental Measures. The experimental measures of this study were administered following participant screening (after WASI-II and ASSQ administration). The measures that were administered included: the Transitional Anxiety Scale (TAS), the Rosenberg Self-Esteem Scale (RSES), the Epic Life Interview, and the AIR Self-Determination Scale (AIR-SDS). All four of these experimental measures were administered twice to each participant; once at the beginning of the Epic Win course, and once within two weeks after the course concluded.

The Transitional Anxiety Inventory. To assess anxiety in regards to transitional tasks and responsibilities, a novel instrument was developed by the author. Based upon the Transition Skills Inventory (TSI; Wehmeyer & Kelchner, 1995), the Transitional Anxiety Inventory (TAS; Appendix C) examines anxiety related to the four main components of adult living: independence, relationships, careers/employment, and education. Four questions were designed to assess anxiety related to each component. Each question features a scenario in which the participant could potentially find him or herself. Participants were then required to rate, on a 6-point Likert-type scale (0-5): (1) how anxiety provoking the situation would be to them, and (2) how confident they would be in dealing with the situation. For example, a question on the education composite presented a situation where a university/college peer has not pulled his or her weight on a group assignment. The TAS measure consists of four anxiety composite scores, one for each area of life, as well as a total transitional anxiety score. The maximum score on each domain of the TAS is 60, with higher scores (i.e. closer to 60) on the anxiety subscale indicating greater levels of anxiety, and with higher scores (i.e. closer to 60) on the problem solving subscale indicating higher feelings of competence regarding problem solving.

The psychometric properties of the tool were assessed during the summer prior to the commencement of the study, as well as following the collection of pre-post data in the current experimental group. Content validity was assessed through recruiting six previous *Epic Win*

participants. Following administration of the TAS, these participants were questioned regarding

the acceptability of the questions in regards to the relevance of the transitional tasks examined, as

well as the reading level of the assessment tool as a whole. In the post-administration interview,

all participants noted that most of the questions were relevant to their transition to adulthood, in

that they had encountered similar situations. A common criticism was that not all situations were

relatable which is to be expected due to general variation in life experiences. Further, all

participants noted that the TAS was highly readable and was easy to complete without

complication. Test-retest reliability was assessed during the experimental administration of the

tool using the participants' pre-post results. The reliability of both the problem solving and

anxiety indices was evaluated. The problem-solving index had excellent test-retest reliability,

with a correlation of $r = .90$. The anxiety index had lower, albeit acceptable test-retest reliability,

with a correlation of $r = -.75$.

   Rosenberg Self-Esteem Inventory. Two measures were used to assess self-esteem. The

RSES is a 10 question self-report questionnaire that, as mentioned earlier, produces a global self-

esteem score (see Appendix D). Early psychometric analyses of the RSES questioned the

unidimensional nature of the scale and through exploratory factor analysis, it has been broken

down into a self-liking composite and a self-competence composite with five questions in each

(Dobson, Goudy, Keith & Powers 1979; Sinclair et al, 2010; Tafarodi & Swann, 1995). In

general, higher total scores on the RSES are associated with higher global self-esteem. The

psychometric properties of the scale are good, with adequate internal consistency and test-retest

reliability (Rosenberg, 1965; Sinclair et al., 2010). The RSES shows strong convergent validity

with Harter's self-perception profile for adolescents, with both subscales (self-liking and self-

competence) correlating with the global self-worth profile. The RSES is seen as a dimensional

assessment tool with higher total scores reflecting higher self-esteem. The maximum score on the

RSES is 30, meaning that scores closer to 30 represent higher total self-esteem.

Epic Life Interview. In addition to the RSES, to introduce an additional measure of self-

esteem, interviews were conducted with each participant. The Epic Life Interview is comprised

of ten questions designed to elicit self-affirming statements (see Appendix E). A qualitative

analysis was conducted to determine how many self-affirming phrases each participant used

throughout the interview. The interview was also used to determine how each participant viewed

his or her strengths and weaknesses. Interviews were conducted both before the course began

and after the course concluded.

The AIR Self-Determination Scale. The AIR Self-Determination Scale (Wolman,

Campeau, Dubois, Mithaug, & Stolarski, 1994) is a standardized measure of self-determined

behaviours among adolescents that can be completed by a teacher, parent, or student (see

Appendix F). It is comprised of two subscales: the Capacity Scale consists of questions regarding

students' ability to engage in self-determined behaviours. The Opportunity Scale consists of

questions regarding the opportunities students have to engage in self-determined behaviours at

home and school. The student version of the AIR SDS is a 24-item self-administered

questionnaire. The psychometric properties of the scale are good, with adequate internal

consistency and test-retest reliability (Wolman et al., 1994). Further, a factor analysis provided

evidence for the conceptual underpinnings of the scale in that all items loaded onto two

independent factors: the capacity to be self-determined and the opportunity to be self-determined

(Wolman et al., 1994). The maximum score on the AIR-SDS is 120 with higher scores being

indicative of higher levels of self-determination.

Procedure

Recruitment. Five participants, aged 17-22 years ($M = 19$), who were diagnosed with

Asperger's Syndrome or HF-ASD, were recruited to participate in the study. Participants were

recruited through distribution of an on-line flier, through professional connections at Autism

Ontario, Community Living, Contact Niagara, and two local school boards (please refer to

Appendix G for the recruitment flier). Following expression of initial interest through a phone

conversation with the course developer, participants were contacted via the phone, to discuss

their time and work commitments and possible benefits and risks of the course. Once they

demonstrated interest in participating, and gave informed consent, a participant completed the

pre-experimental measures to screen for suitability for the study (please refer to Appendix H for

a copy of the consent form used). Individuals who did not meet the cut-off on the ASSQ, score

under 85 on the WASI-II, or failed to meet the inclusion criteria on both measures, would be

excluded from the study and given information about other local services for transition to

adulthood support. If the potential participant met our criteria on both measures, he or she was

invited to participate in the study. It should be noted that one participant did not meet the ASSQ

cut-off score, but was included (please refer to the participants section). Once recruitment was

finished, the group ended up being comprised of three females, and two males, and there were no

potential participants that were excluded due to their score on the WASI or ASSQ.

Participants.

Kevin. The first participant in the *Epic Win* group was a 17-year-old male who was

formally diagnosed with Asperger's syndrome. At the time of recruitment, he was enrolled in his

grade-twelve year of high school. This participant met the eligibility criteria in terms of IQ

however, he did not meet the ASSQ cut-off of 19. Although he did not meet this criterion, he had

a formal diagnosis of Asperger's syndrome, which was relatively recent. It is possible that this

participant's father (the ASSQ informant) was not sensitive to ASD symptomatology given the recent nature of this diagnosis. As mentioned, Kevin did have a formal diagnosis, and for this reason was included in the group.

Michelle. The second participant in the *Epic Win* group was a 22-year old female who was formally diagnosed with Asperger's syndrome. At the time of recruitment, she was enrolled in an undergraduate university program. She met all of the screening requirements for participation in the research study. Upon entry into the program, this participant did not have any clear vision for her future and did not have any formal plan for her life, post-graduation.

Mike. The third participant in the *Epic Win* group was a 17-year-old male who was formally diagnosed with Asperger's syndrome. At the time of recruitment, he was enrolled in grade twelve at high school. He met all of the eligibility requirements for participation in the research study. Upon entry into the program, this participant had an idea of what he would like his future to look like however, he did not believe that he had the skills necessary to achieve his goals.

Kelli. The fourth participant in the *Epic Win* group was a 19-year-old female who was formally diagnosed with Asperger's syndrome. She met all of the eligibility criteria for participation in the research study. At the time of recruitment, she had been given an academic suspension from college after failing most of her coursework, and had moved back home to live with her parents. At this time, she was unsure as to what she wanted to in the future.

Tina. The fifth participant in the *Epic Win* group was a 20-year-old female who was formally diagnosed with Asperger's syndrome. At the time of recruitment, she was enrolled in a college program. She met all of the eligibility requirements for participation in the research study. Upon entry into the program, this participant knew that she wanted to pursue a career in the

social services, however she was struggling to finish her diploma requirements and had twice

failed a required course. Please refer to Table 1 for participant demographics.

Table 1: Participant Demographic Information

Participant	Sex	Age	IQ	Formal Diagnosis	ASSQ Score
Kevin	Male	17	108	Asperger's Syndrome	14
Michelle	Female	22	129	Asperger's Syndrome	22
Mike	Male	17	112	Asperger's Syndrome	22
Kelli	Female	19	124	Asperger's Syndrome	29
Tina	Female	20	84	Asperger's Syndrome	29
Mean		19 ($SD = 2.12$)	111.4 ($SD = 17.54$)		23.2 ($SD = 6.22$)

Experimental Protocol. Following recruitment, pre-screening, and obtaining informed

consent, participants were invited to attend the *Epic Win* course in the fall of 2015. Prior to

commencing the course, every participant completed the TAS, the AIR-SDS, the RSES. The

participants also completed the Epic Win interview at this time. Following the completion of the

fall Epic Win course in March 2016, the experimental measures were administered a second time.

Experimental measures were administered within two weeks of the course completion date to

reduce the possibility of any post-experimental variation. Due to school requirements, Michelle was unable to complete the post-measures within two weeks of the course finishing; instead she completed the questionnaires four weeks after the intervention finished.

Data Analysis. Upon completion of the post-course measures, which were administered during the final session of the *Epic Win* course (Week 12), the data were analysed in a case-by-case fashion, using the Reliable Change Index (RCI). The RCI allows for a comparison of individual scores across time by comparing the change in pre-post scores to the reliability of the assessment tool used. Standard psychometric theory asserts that psychological testing introduces measurement error which can change an individual's score on a measure independent of any real, clinically significant change in the measured attribute (Kaplan & Saccuzzo, 2013, pp. 102-109). The RCI measures the change above and beyond any measurement error introduced by the assessment tool; it allows for testing as to whether there was a statistically significant change in scores once measurement error has been accounted for in the statistical model (Jacobson & Traux, 1991).

The decision to analyse the data in a case-by-case format was based on the small sample size (N=5). The sample size effectively reduced the power that the research design had to detect significant results using conventional parametric statistics. Further, with only five participants, it is unlikely that the data would have conformed to the assumptions pertinent to using parametric statistics. As mentioned earlier, the TAS was developed for use in the current study and thus does not have any published estimate of reliability. In order to use the RCI, a reliability estimate had to be available. To rectify this problem, a reliability analysis for test-retest reliability was conducted on the TAS utilizing a simple Pearson Product Moment correlation.

Analyses of the *Epic Interview* were conducted quantitatively. Two independent raters scored the audiotaped interviews for quantity of self-affirming statements, as well as the number

of strengths and limitations that participants described about themselves. For the purpose of

reliability, self-affirming statements were defined as: "Any statement about the self that is

positive in nature, and that is free of self-depreciating language. Note, that although language

may be positive, content is just as important. In order to be self-affirming, the statement must be

made about the SELF, not simply regarding a situation." Inter-rater reliability (IRR) was

calculated for both the pre-course interviews and post-course interviews. IRR was calculated on

the number of self-affirming statements described, the number of strengths, and the number of

weaknesses a participant listed. To obtain an IRR estimate, per cent agreement was calculated by

taking the smaller number of each score divided by the larger number obtained, and then

multiplying by 100. The IRR estimate for each component of the interview was added together,

and then divided by three to obtain an overall IRR estimate for the pre or post-course interview.

Pre and post course IRR estimates were then added together, and then divided by two to obtain a

final total IRR estimate for each participant's interview. To ensure that the interview analysis

possessed a high degree of IRR, a criterion of 80% was established. Further, training was

provided to the research assistant (RA), who was external to the project, prior to her analysing

the interviews. A definition of self-affirming statements was given to the RA (see above), which

included 10 quiz-like questions where the RA had to determine if the statement given was self-

affirming in nature. Further, the RA and the author co-scored Mike's pre-course interview, which

consisted of listening to, and stopping the recorded interview at 30-second intervals. When the

interview was paused, the RA and the author would compare the number of self-affirming

statements, strengths, and weaknesses that they recorded during the interval. If there were any

discrepancies, the interval would be restarted and scored again, until 100% IOA was obtained for

that interval. It should be noted that although Mike's pre-course interview was used for

establishing reliability with the RA, these IRR scores were included in the overall reliability

analysis of the epic life interview. The RA obtained 100% on this training assessment, and IRR was very high for all interviews analysed (please see results section for exact IRR estimates).

CHAPTER 3: RESULTS

Kevin

Quantitative measures. Kevin demonstrated a decrease of one point on the problem-solving index of the TAS. This did not constitute a statistically significant change. $RC = -0.24$, $p > .05$. He also demonstrated a four-point increase (i.e. a worsening of anxiety) on the anxiety index of the TAS, which did not constitute a statistically significant change, $RC = 0.61$, $p > .05$. At pre-course, Kevin displayed a total problem-solving score of 43, which was above the midpoint on the scale. At post-course, his score decreased to 42, which is still well above the midpoint of scale, indicating that his feelings of competency around problem solving remained relatively high from pre to post-course. At pre-course, Kevin had a total anxiety score on the TAS of 27, which was slightly below the midway point on the scale. At post-course, Kevin had a total anxiety score of 31, which was just slightly above the midway point on the scale, indicating a slight increase in anxiety post-course. Kevin demonstrated an increase of two points on the RSES. This did not constitute a statistically significant change: $RC = 0.46$, $p > .05$. Kevin demonstrated high self-esteem (as measured by the RSES) both pre and post course. His initial RSES score was 23, and his post course RSES score was 25. Please refer to Table 2 for a summary of the statistics used to calculate the RC values for each measure. Refer to Figures 1 and 2 for a graphical representation of the pre/post results of the TAS for all participants. Finally, refer to Figure 3 for a graphical representation of the pre/post results of the RSES for all participants. Unfortunately, the pre-course AIR-SD score was missing for this subject.

Quantitative and Qualitative Analysis of Epic Life interview. During his pre-course interview, Kevin made five self-affirming statements about himself. During his post-course

interview, he made eight self-affirming statements, resulting in an overall increase of three

statements. During the pre-course interview, he listed two strengths and three limitations

regarding himself, resulting in a ratio of 2 strengths: 3 weaknesses. At post-course, he listed four

strengths and 2 limitations, resulting in a ratio of 2 strengths: 1 weakness. Further, when

examining the interview qualitatively, there was a shift in regard to how this participant viewed

his ASD diagnosis. When interviewed prior to the course, this participant noted that his ASD

diagnosis "made him feel special," and unlike his typically developing peers. He was also

reluctant to talk about this aspect of himself. At post-course, when asked about what his

diagnosis meant to him, he noted that it "doesn't mean as much to me as it did when we first

started. It's not as bad as I used to make it out to be." Further, at pre-course, when asked what he

liked about himself, Kevin mentioned that there was "nothing really outstanding" about him. At

post-course, he listed an additional quality — his humour — that he liked about himself and,

unlike pre-test, he did not state that he felt as though there was nothing outstanding about him.

Related to this, when asked what he was particularly good at during his pre-course interview,

Kevin only discussed his ability to work with technology. At post-course, this diversified as he

discussed three things that he was good at, including: making friends, cooking, and of course,

technology. Overall, Kevin demonstrated an increase in self-affirming statements, as well as a

positive shift in the ratio of perceived strengths to weaknesses. This interview had excellent IRR.

The pre-course interview had an IRR of 100%, while the post-course interview had an IRR score

of 86%, resulting in a total IRR of 93% for this participant. Please refer to figures 5-7 for a

graphical representation of the Epic Life Interview results for all participants.

Michelle
  Quantitative measures. On the TAS, Michelle demonstrated an increase of six points

on the problem-solving index, which did not constitute a statistically significant change. $RC =$

1.44, $p > .05$. She also demonstrated a seven-point increase on the anxiety index of the TAS, which also did not constitute a statistically significant change, $RC = 1.07, p > .05$. At pre-course, Michelle displayed a total problem-solving score of 23, which was below the midpoint on the scale. At post-course, her score increased to 29, which was a move closer to the midpoint of the scale. At pre-course, Michelle had a total anxiety score on the TAS of 41, which was above the midway point on the scale. At post-course, Michelle had a total anxiety score of 48, which was again, above the midway point on the scale, indicating that she experienced a relatively high level of anxiety around transitional tasks both pre and post-course. Michelle demonstrated a decrease of two points on the RSES. This did not constitute a statistically significant change: $RC = -.46, p > .05$. With regard to the RSES, Michelle exhibited very low self-esteem both pre and post-course. Pre-course, Michelle's total RSES score was 8, and at post-course her total RSES score was 6. On the AIR-SDS, Michelle demonstrated an eight-point increase in her total self-determination score. This did not constitute a statistically significant change, $RC = 0.82, p > .05$. At pre-course, Michelle's total self-determination score was 64, which is slightly above the midpoint on the scale. At post-course, her self-determination score increased to 72, which actually represents a 5% increase in her total self-determination score. Please refer to Figure 4 for a graphical representation of the pre/post results for the AIR-SDS for all participants.

Quantitative and Qualitative Analysis of Epic Life interview. During her pre-course interview, Michelle made four self-affirming statements about herself. During her post-course interview, she made six self-affirming statements, resulting in an overall increase of two statements. During the pre-course interview, she listed five strengths and ten limitations regarding herself, resulting in a ratio of 1 strength: 2 weaknesses. At post-course, she listed six strengths and eight limitations, resulting in a ratio of 3 strengths: 4 weaknesses. Further, when examining the interview qualitatively, there was a shift in regards to how this participant viewed

her potential to obtain the adult life she envisioned. When interviewed prior to the course, this

participant noted that her challenges, in regards to ASD and anxiety, would be too much to

overcome and would be too large a barrier to achieve the life she envisioned. At post-course,

when asked about whether she would be able to achieve her envisioned life, she said the

following: "I hope I can achieve this life. If I work hard enough, I'll be able to get there, but it

seems like it's very far away." This shift in thinking for Michelle is excellent given her overall

low self-esteem (as evidenced by her low RSES scores). When asked how she felt about the *Epic

Win* course, Michelle noted that it helped her to meet other individuals with ASD, as she felt she

could relate to them. Further, she said that she felt as though she was better able to set goals and

break them down into more manageable steps. This increased sense of competency may have

contributed to the shift in Michelle's attitude regarding her ability to achieve her "epic life"

vision. Overall, Michelle demonstrated a slight increase in self-affirming statements, as well as a

positive shift in the ratio of perceived strengths to weaknesses. This interview had good IRR.

The pre-course interview had an IRR of 95%, while the post-course interview had an IRR score

of 80%, resulting in a total IRR of 88% for this participant. These results are especially important

for this participant, given her exceedingly low scores on the RSES.

Mike

        Quantitative measures. Mike demonstrated a nine-point increase on the problem-

solving index of the TAS. This change was statistically significant, *RC* = 2.15*, p* < .05. He also

demonstrated a five-point decrease on the anxiety index, which did not constitute a statistically

significant change, *RC* = -.77, *p* > .05. At pre-course, Mike displayed a total problem-solving

score of 29, which was slightly below the midpoint on the scale. At post-course, his score

increased to 38, which is substantially above the midpoint of the scale, indicating that his

feelings of competency around problem solving increased from pre to post-course. At pre-course,

Mike had a total anxiety score on the TAS of 38, which was above the midway point on the scale. At post-course, Mike had a total anxiety score of 33, which was somewhat lower, but still above the midway point on the scale. As Mike remained above the midway point on the TAS at both pre and post-course, it appears as though he experienced a relatively higher rate of transitional anxiety that was not improve through participation in the course. Mike demonstrated an increase of six points on the RSES. This did not constitute a statistically significant change, although it was in a positive direction: $RC = 1.37$, $p > .05$. Pre-course, Mike's RSES score was 13, which is under the mid-way point on the RSES. At post-course, Mike's total RSES score was 19, which is over the midway point indicating a shift from negative to more positive self-esteem. Mike did not have a pre-course AIR-SDS score due to miscommunication within the research team resulting in a failure to administer the questionnaire pre-course.

Quantitative and Qualitative Analysis of Epic Life interview. During his pre-course interview, Mike made four self-affirming statements about himself. During his post-course interview, he made nine self-affirming statements, resulting in an overall increase of five statements. During the pre-course interview, he listed three strengths and four limitations regarding himself, resulting in a ratio of 3 strengths: 4 weaknesses. At post-course, he listed ten strengths and six limitations, resulting in a ratio of 5 strengths: 3 weaknesses. At pre-course, Mike said that he was unsure if he would be able to achieve the Epic Life he envisioned because there were too many "unknown variables" that could impact his future. At post-course, Mike said that he was more confident that he would be able to achieve the epic life he envisioned, as he now had the skills to problem solve and set goals in a more manageable format (i.e. short-term and SMART goals). At pre-course, when asked what he liked about himself, Mike listed that he was a good person, that he treated others well, and that he was nice. While positive, these characteristics are all very similar, and relate to only one aspect of the self. During the post-

course interview, Mike's discussion of the things he liked about himself diversified and

increased in number. Mike discussed the fact that he was intelligent, that he had an excellent

memory, that he had a job, and that he was good at interacting with his friends. Mike

demonstrated an increase in self-affirming statements, as well as a positive shift in the ratio of

strengths to weaknesses he viewed that he possessed. This interview had excellent IRR. The pre-

course interview had an IRR of 100%, while the post-course interview had an IRR score of 96%,

resulting in a total IRR of 98% for this participant.

Kelli

   Quantitative measures. Kelli demonstrated no change on the problem-solving index of

the TAS. $RC = 0$. On the TAS, she demonstrated a seven-point decrease on the anxiety index,

which, although in a positive direction, did not constitute a statistically significant change, $RC =$

$-1.07, p > .05$. On both the pre and post-course TAS, Kelli displayed a total problem-solving

score of 35, which is slightly above the midpoint on the scale. With regard to total anxiety on

the TAS at pre-course, Kelli had a score of 49, which is well above the midway point on the

scale. At post-course, Kelli had a total anxiety score of 48, indicating that she experienced a

relatively high level of anxiety around transitional tasks that did not shift from pre to post-course.

With regard to self-esteem, Kelli demonstrated an increase of one point on the RSES. This did

not constitute a statistically significant change: $RC = 0.23, p > .05$. Kelli demonstrated a

relatively high level of self-esteem both pre and post-course. Her pre-course RSES score was 19,

while her post-course score was 20, which is five points above the midway. On the AIR-SDS,

Kelli demonstrated a three-point increase in her total self-determination score. This did not

constitute a statistically significant change, $RC = 0.31, p > .05$. At pre-course, Kelli's total self-

determination score was 83, which is well above the midpoint on the scale. At post-course, her

self-determination score increased to 86, which represents a 1% increase in total self-

determination. Please refer to figure 4 for a graphical representation of the pre/post results for the AIR-SDS for all participants.

Quantitative and Qualitative Analysis of Epic Life interview. Unfortunately, Kelli did not have recorded pre-course interview data due to loss of the audiotaped interview.

Tina

Quantitative measures. Tina demonstrated a four-point increase on the problem-solving index of the TAS. This did not constitute a statistically significant change, $RC = .49, p > .05$. She also demonstrated a ten-point decrease on the anxiety index of the TAS, which did not constitute a statistically significant change, $RC = 1.53, p > .05$. At pre-course, Tina displayed a TAS total problem-solving score of 46, which is above the midpoint on the scale. At post-course, her problem-solving score increased to 50. These scores indicate that Tina had a high level of confidence in her ability to problem-solve through transitional tasks both pre and post-course. At pre-course, Tina had a total anxiety score on the TAS of 28, which was below the midway point on the scale. At post-course, Tina had an even lower total anxiety score of 18, indicating that she experienced a relatively low levels of anxiety around transitional tasks both pre and post course. In terms of self-esteem, Tina demonstrated a decrease of two points on the RSES. This did not constitute a statistically significant change, $RC = -.46, p > .05$. Tina did, however, demonstrate high levels of self-esteem both pre and post-course, as measured by the RSES. Pre-course, she had a total RSES score of 26 which, as mentioned earlier, is only four points from the maximum score. At post-course, she had a total RSES score of 24. When looking at the AIR-SDS, Tina demonstrated a ten point increase in her total self-determination score, which did not constitute a statistically significant change, $RC = 1.03, p > .05$. At pre-course, Tina's total self-determination score was 90, which is well above the midpoint on the scale. At post-course, her self-determination score increased to 100, which actually represents a 10% increase in total self-

determination. Please refer to Figure 4 for a graphical representation of the pre/post results for the AIR-SDS for all participants.

    Quantitative and Qualitative Analysis of Epic Life interview. During her pre-course interview, Tina made three self-affirming statements about herself. During her post-course interview, she made five self-affirming statements, resulting in an overall increase of two statements. During the pre-course interview, she listed six strengths and four limitations regarding herself, resulting in a ratio of 3 strengths: 2 weaknesses. At post-course, she listed six strengths and three limitations, resulting in a ratio of 2 strengths: 1 weakness. Tina had a positive view of both her diagnosis and her ability to achieve the life she envisioned prior to and after completing the course. This positive sense of self was evident not only in her epic-interview, but also on the RSES, as her scores were high at both pre and post-course. During Tina's pre-course interview, when asked "what are some things that you like about yourself?" she said "pretty much everything." While positive, this response was very general, and did not list anything in particular that Tina liked about herself. During the post-course interview, Tina's answer became much more descriptive, and specific, as she was able to list multiple, specific things she liked about herself. She stated that she liked her persistence and determination, her ability to follow through on tasks, even when she doesn't like doing them, the fact that she's able to block out distractions when working on a project, and that she is able to pay attention to detail. Overall, Tina demonstrated a slight increase in self-affirming statements, as well as a positive shift in the ratio of strengths to weaknesses that she viewed herself as possessing. This interview had excellent IRR. The pre-course interview had an IRR of 100%, while the post-course interview had an IRR score of 86%, resulting in a total IRR of 93% for this participant.

Table 2: Reliable Change Index Statistics

Measure	Reliability	Standard Deviation	Reliable Change Criterion
RSES	.82	7.34	8.63
TAS – PBS	.90	9.55	8.2
TAS - ANX	.75	9.23	12.79
AIR-SDS	.74	13.45	19.01

Note: Reliable change criterion refers to the number of points in change required for a change in score to be considered reliable
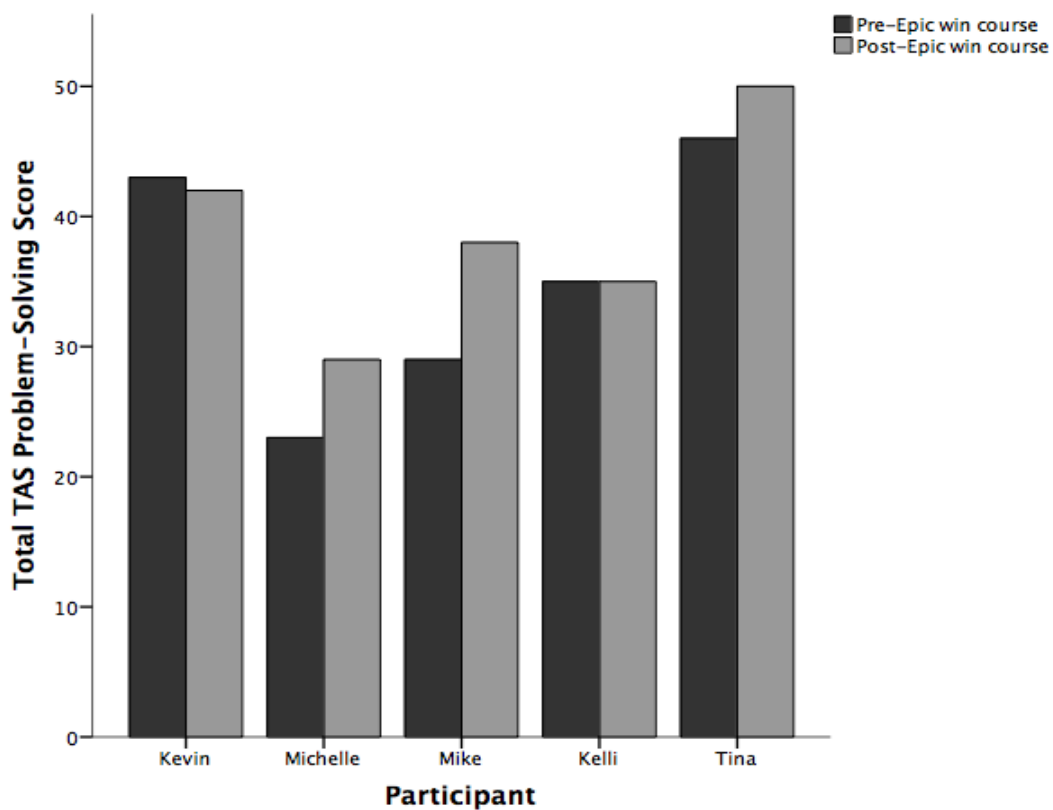
Figure 1: Problem-solving scores on the TAS, pre and post delivery of the *Epic Win* course.
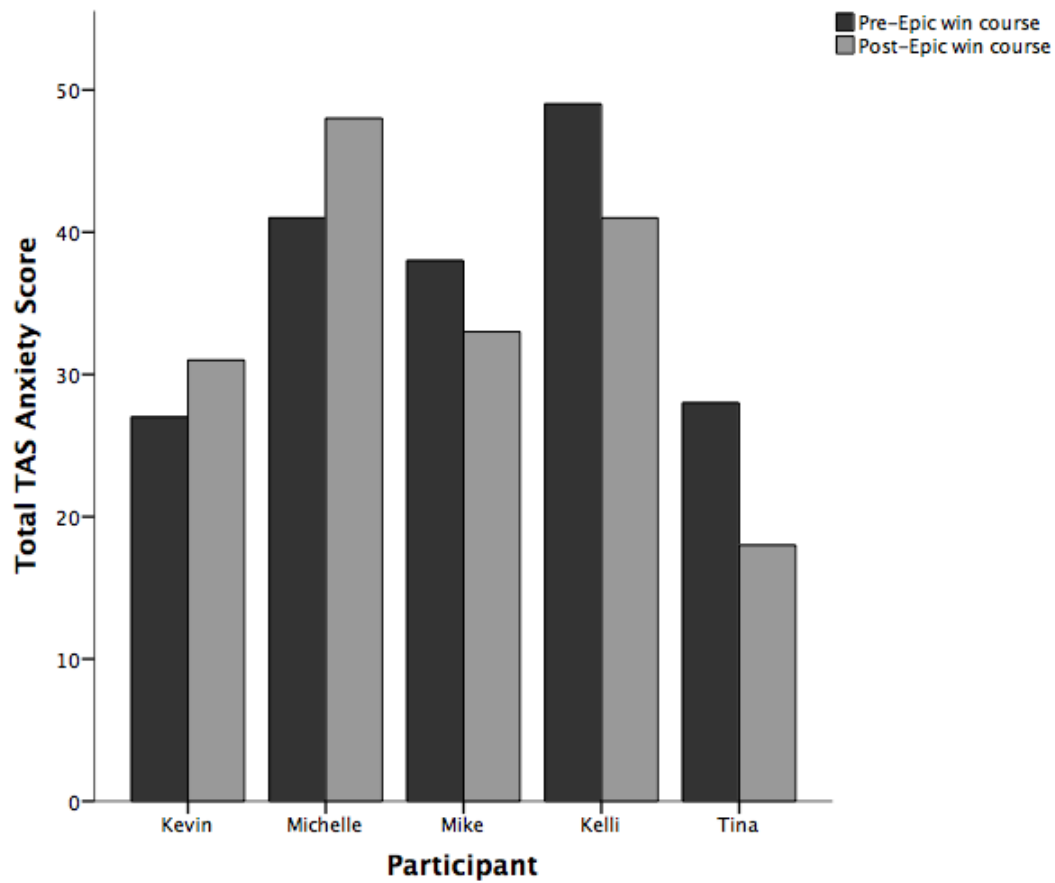
Figure 2: Anxiety scores on the TAS, pre and post delivery of the *Epic Win* course.
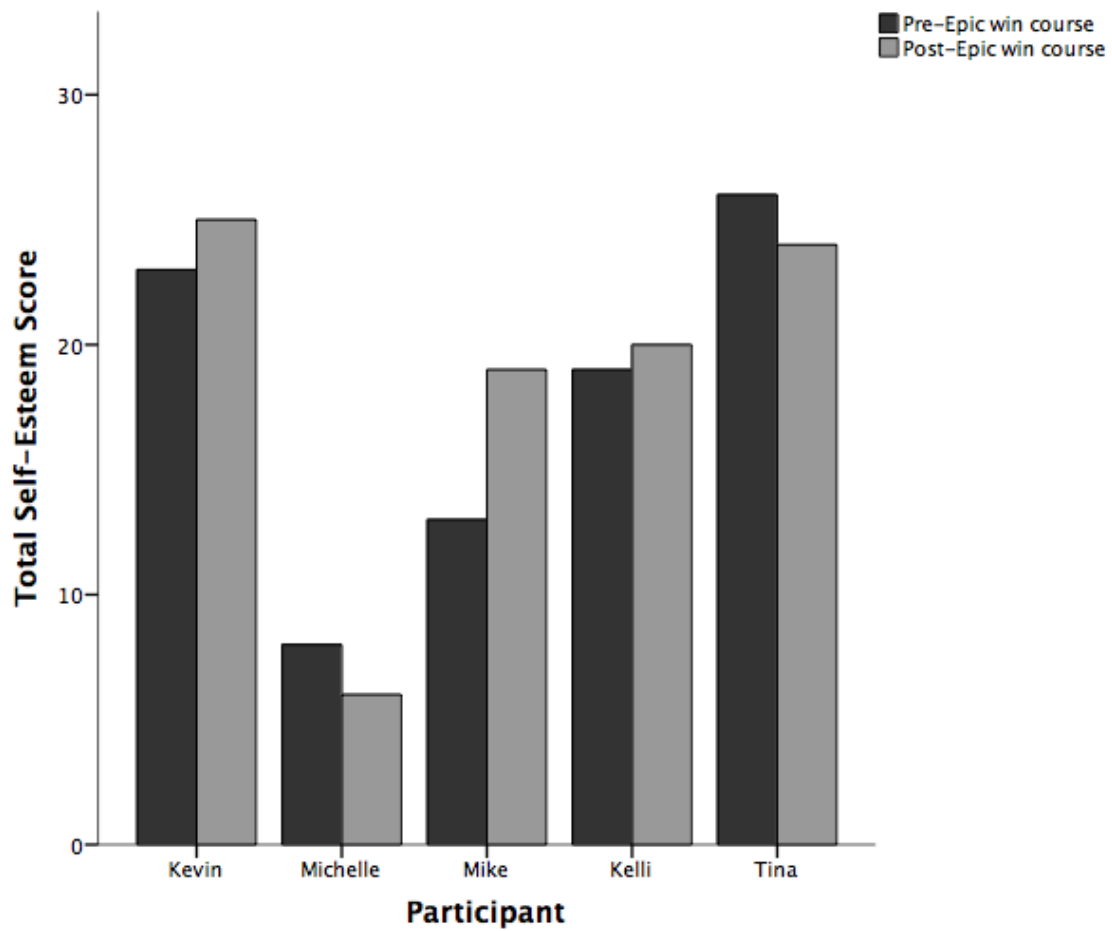
Figure 3: Total self-esteem scores on the RSES pre and post delivery of the *Epic Win* course.
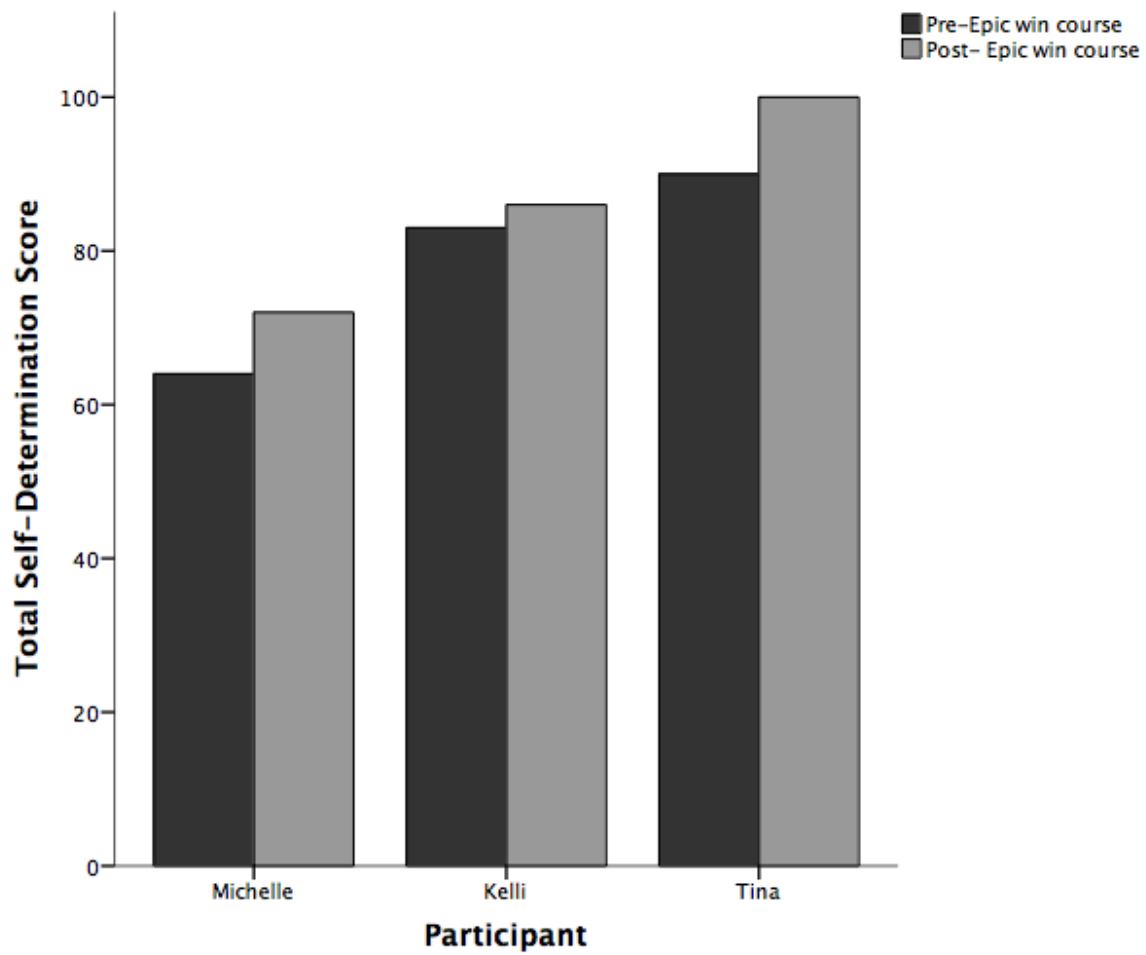
Figure 4: Total self-determination scores on the AIR-SDS pre and post delivery of the *Epic Win* course.
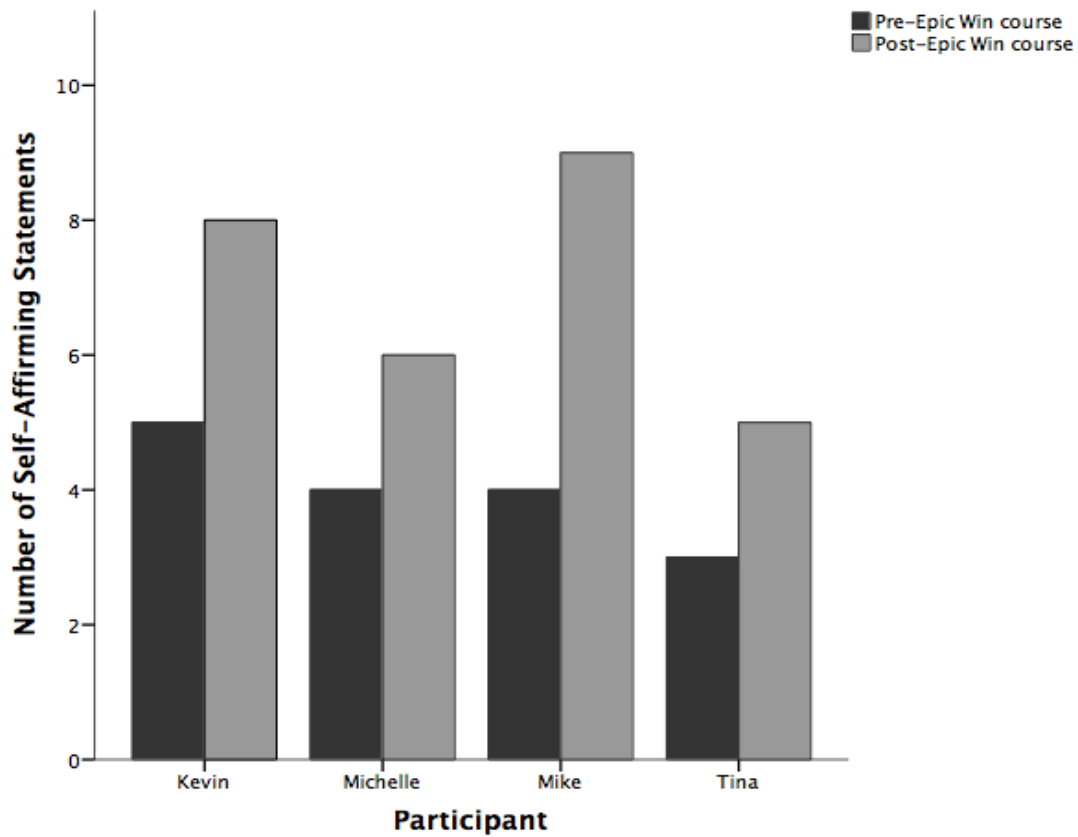
Figure 4: Number of self-affirming statements made during the Epic Life interview pre and post delivery of the *Epic Win* course.
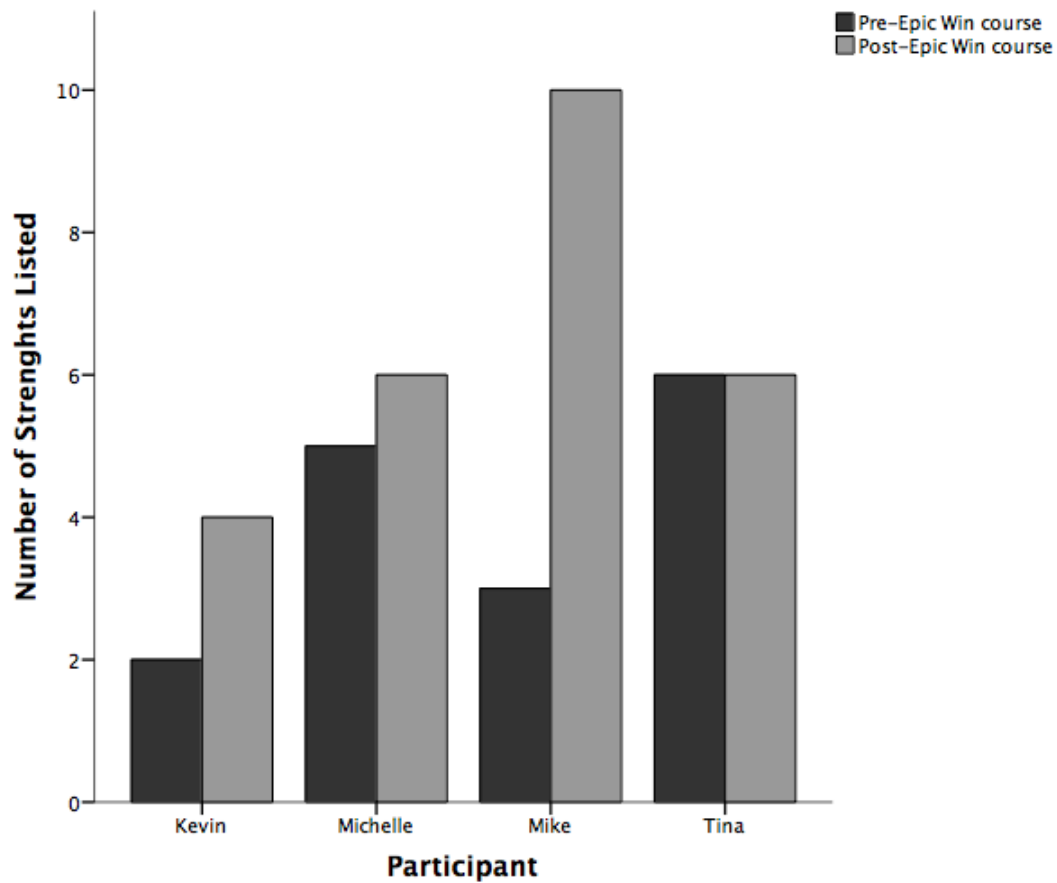
Figure 5: Number of strengths listed during the Epic Life Interview pre and post delivery of the *Epic Win* course.
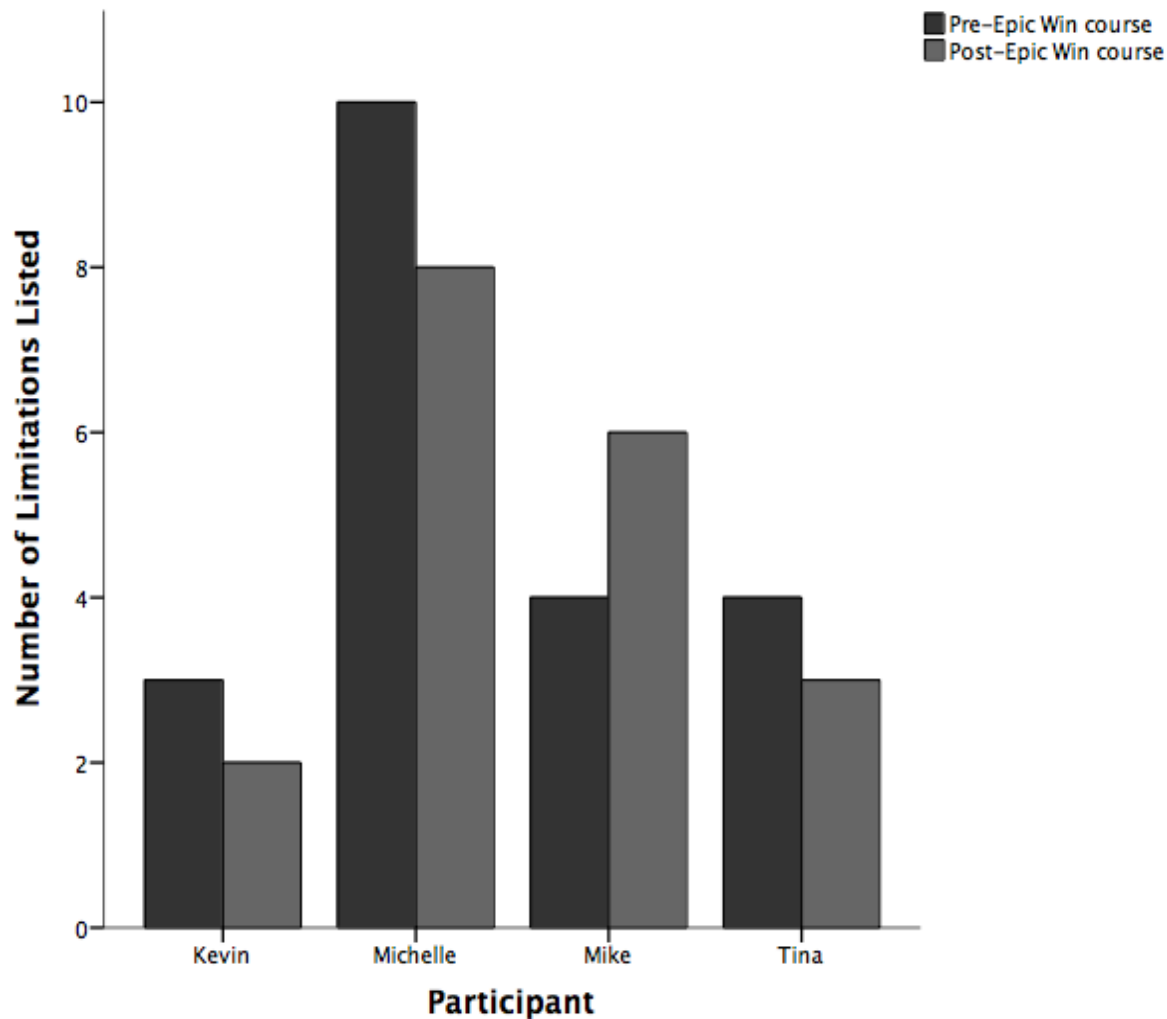
Figure 6: Number of limitations listed during the Epic Life Interview pre and post delivery of the *Epic Win* course.

CHAPTER 4: DISCUSSION

Implications of Results

Quantitative measures. Results of the study were quite heterogeneous in regard to the five participants. Three out of the five participants showed an increase in problem-solving as measured by the TAS, however only one of these increases was considered statistically significant. Three out of the five participants demonstrated a decrease in transitional anxiety, as measured by the TAS, however two participants demonstrated increases and none of these changes were considered statistically significant. Three out of the five participants demonstrated

relatively small increases in their total self-esteem score as measured by the RSES; not surprisingly, none of these changes were statistically significant. All three participants who had complete pre and post-course self-determination data demonstrated an increase in their total self-determination score as measured by the AIR-SDS, however none of these changes were statistically significant. Ultimately, none of the research hypotheses could be fully accepted, and thus the null hypotheses were accepted, from a purely statistical sense. The analysis did, however, provide some evidence to support future replication of the present study. As mentioned, there were trends in the predicted direction for the majority of participants on all three quantitative measures. Due to the small sample size, statistical power was too small to detect any significant differences. The importance of this point cannot be overstated, as there were participants who made relatively large gains (i.e. 10 points in self determination), which would have been deemed clinically significant in a larger sample size, based on previous research demonstrating significant results with fewer point differences.

Heterogeneous outcomes within the ASD population tend to be the norm, rather than the exception. For example, previous research evaluating the effectiveness of early Intensive Behaviour Intervention (IBI) provided to young children with ASD has demonstrated that roughly 50% of children demonstrate very positive outcomes, 20% demonstrate modest outcomes, while another 25% show poor/minimal outcomes (Perry et al., 2008). The results obtained in this study are quite consistent with the heterogeneous nature of this population, as 3 out of 5 participants demonstrated trends in the predicted directions while the other two showed minimal gains on the quantitative measures. It should also be noted that gains observed on the AIR-SDS were quite consistent with what Wehmeyer, the leading researcher in the field of self-determination, has observed in his work. Interestingly, many of the programs that have been evaluated have had a total duration of more than a year and, in these studies, gains of around 2-5

points on the AIR-SDS were observed (Wehmeyer et al., 2011; Wehmeyer et al., 2013), which is similar to the gains that our participants experienced after a twelve-week course. From this comparison, it seems reasonable to assume that, following several more small group replications of the Epic Win course, it may be possible to see statistically significant improvements in our quantitative measures of transitional anxiety, self-esteem and self-determination.

Qualitative Analysis of the Epic Life Interview. The results obtained from the Epic Life Interview provide support for the argument regarding insufficient statistical power, as opposed to null results, in terms of the effects of the *Epic Win* course. All four participants with pre/post interview data demonstrated an increase in the number of self-affirming statements made about themselves during the interview. Further, three of the participants demonstrated increases in the number of strengths listed. Three participants also demonstrated decreases in the number of limitations listed. All participants, however, demonstrated a shift towards a more positive strength to limitation ratio following completion of the course. These results are interesting in that they conflict with the null results obtained through analyses of the RSES. Although no conclusions can be made as to the causality of this increase (due to the absence of a control group), it appears as though all four participants with pre/post interview data viewed and talked about themselves in a quantitatively different and more positive way. Further, it seemed as though the participants discussed themselves in qualitatively different way. Three of the four participants with full interview data went into more detail regarding their strengths, and what they liked about themselves, during their post-course interview. They also seemed to diversify in regards to their perceived strengths and what they liked about themselves. During their pre-course interview, for instance, Kevin and Mike only discussed one thing that they were good at or liked about themselves (technology and kindness respectively). During their post-interview, their lists grew to include additional things that they were good at and liked about themselves

that weren't related to qualities they had discussed during their pre-course interview. Similarly,

Tina, at pre-course, was very general in her response regarding what she liked about herself.

During her post-course interview, she was able to generate new and unique qualities that she

liked about herself. These results are important in that they could potentially signal the efficacy

of the *Epic Win* course in modifying participants' beliefs about themselves. The first three weeks

of the *Epic Win* course focus extensively on participants' limiting beliefs regarding the self, as

well as on self-awareness of strengths and limitations. During the remainder of the course,

participants are taught to capitalize on their strengths and to problem-solve when they encounter

a barrier to achieving their goal. In essence, participants engage with content throughout the

entirety of the course that assists them in exploring and acknowledging their strengths. Thus, it

makes sense that the participants were able to generate a greater number and variety of strengths,

and things that they liked about themselves during their post-course interviews.

While the RSES assesses opinions and beliefs about the self, the Epic Life Interview was

designed to obtain a more behavioural measure of self-esteem. Further, due to its open-ended

nature, the Epic Life Interview provided participants with an opportunity to reflect on positive

life experiences as well as on positive aspects of the self. It was hypothesized that results

obtained by the RSES may be somewhat more transitory as time progresses, as evidenced by the

diminished test-retest reliability of the tool. In fact, in a two-week test-retest interval, the RSES

had an approximate test-retest reliability of .85, while in a 7-month interval, the reliability of the

measure dropped to .63 (Silber & Tippett, 1965; Shorkey & Whiteman, 1978). This diminished

reliability, by virtue of the progression of time, may explain the discordant results between the

RSES and the Epic Life Interview. A second hypothesis regarding these discordant results is that

the Epic Life Interview is measuring a different construct than the RSES does. Further

psychometric evaluation would need to completed on the interview to determine which of these hypotheses is correct.

Limitations

The current study is not without limitations, the first being the small sample that was utilized. Prior to commencing the study, the research team endeavoured to recruit a minimum of twelve participants, intending to run two concurrent groups of 6-8 participants. Due to difficulties in recruiting, a final sample size of five was used. Although these five cases provide insight into the individual experience and impact of the *Epic Win* course, they do not lend themselves to more traditional group-design research methods and, more specifically, to parametric statistical analyses. By analysing results at the individual level, nothing meaningful can be said about future groups or participants. Essentially, no extrapolations can be made about future iterations of the course, in terms of its effectiveness in increasing self-esteem and self-determination, and in decreasing transitional anxiety.

Consistent with the issue of small sample sizes, are the associated statistical challenges. In a small sample size, one extreme outlier can drastically impact the standard deviation of a group. When a standard deviation is large, standard error increases, meaning that there is more random error introduced into any statistical model created. Because of this, RCI estimates could be a product of large standard deviations instead of any actual treatment effects**.** Further complicating the issue of the small sample size is the fact that two participants did not have a compete data set. The AIR-SDS was not administered to Mike prior to the beginning of the course. Further, Kevin's AIR-SDS pre-course data were misplaced. These omissions further reduced the amount of data available for analysis. Although it does impact the amount of data, this oversight did not necessarily impact the results as each measure was analysed on a case-by-case basis.

The participants themselves also impact the generalizability of the current study's results. The group that the course was evaluated on was exceptional, in terms of HF-ASD, for a couple of reasons. The first reason was that the groups' mean IQ was nearly one standard deviation above the mean of the general population. It is unlikely that future groups would have such a high mean IQ; it is possible that the results obtained here may simply be a function of an increased intellectual capacity. Lending support to this hypothesis is the fact that Tina, who had a low-average IQ, had rather different results than the rest of the group members. Tina, who's IQ was 27.4 points below the group average, demonstrated consistently higher/lower scores on the quantitative measures than the rest of the participants. For example, she had the highest RSES, AIR-SDS, and TAS problem solving score in the group. She also had the lowest TAS anxiety score. Further, the sex ratio of the group (2:3 males: females) was inconsistent with typical epidemiological estimates of this population, which have been roughly 4.3:1 males: females (Newschaffer, 2007). For these reasons, it is unlikely that the results obtained here would generalize to a more typical sample of similar aged youth with HF-ASD.

There were no experimental controls in place during this study. By not implementing appropriate experimental controls, no firm statements can be made regarding the causality of the results obtained. More specifically, no statements can be made as to what actually caused the changes that were observed on the epic life interview. These results could have been a product of participation in the Epic Win course, however these changes could simply be due to the passage of time, or other external life events that were occurring for the participants at the time of the post-course interview. A final limitation of the current study is the measure that was created by the research team. The TAS, while developed in collaboration with past participants of *Epic Win* groups, was never formally evaluated for validity or reliability. Through collaboration with previous participants, the content of the TAS was determined to be relevant in terms of

transitional tasks and at a reading level acceptable to this population, however no further

analyses were conducted. Because there was no formal convergent or divergent validity

assessment conducted, there is no way to know if the tool is measuring a construct that is similar

to anxiety (as would be predicted). Therefore, any conclusions draw from the TAS should be

treated with caution.

Future Directions

As a relatively new transition to adulthood course, future research into the effectiveness

of the *Epic Win* is essential. The current research project provided relatively complete pilot data,

which can be expanded on in future replications of the course. By replicating the procedures

outlined here, future research can increase the sample size, and thus the statistical power of any

analyses conducted. Further, by replicating the course delivery over time and thus increasing the

sample size, analyses can move towards more traditional group design statistics (i.e. parametric

statistics). By doing so, it is hoped that inferences can be made about this population as a whole

regarding their transition to adulthood, and the effects the course might have on said transition.

Once a sufficient number of groups have been run to obtain a larger sample size for analysis, if

positive trends continue to be observed, the possibility of running a randomized control trial

(RCT) should be explored. Although statistically significant effects at the group level are desired,

they are not as meaningful as they would be if an RCT was conducted. An RCT is the gold

standard for program evaluation due to the fact that random assignment allows for control of any

pre-experimental differences. If the *Epic Win* course is to be used clinically within schools and

community agencies, an experimentally rigorous RCT would provide the empirical support

needed to improve consumer confidence, and to ensure that individuals with HF-ASD are

receiving services that are, indeed, effective. Manualization of the *Epic Win* course will help to

make future studies more feasible, as standardizing the protocol will allow others outside of the

original course developers to deliver and assess the program. While conducting this research

project, the course developer and facilitators collaborated on a first draft of a course manual.

Completion of this manual prior to subsequent course delivery is of paramount importance to

increase both the efficiency and effectiveness of the course.

Following manualization and RCT evaluation of the course, the effectiveness of

individual aspects of the curriculum, including the problem solving exercises, goal setting and

action planning workshops, and the behavioural components (i.e. behavioural contract,

contingency contract, self-management), should be evaluated through a component analysis.

Through this method, both effective and ineffective course material can be identified, allowing

for data based program modification which will enhance the overall delivery of the course. As

mentioned, the *Epic Win* course is delivered over the course of twelve weeks which is a

relatively short span of time. Ineffective course content, materials, or activities essentially reduce

this time further, taking away from valuable instructional opportunities. By identifying pieces of

the course that are working well, and that are effective, a more concentrated effort can be made

to enhance, and dedicate more time to these lessons and activities.

Related to this course evaluation is the need for a formal validation study on the TAS

which, as mentioned, was developed for use in this study. Separate from the delivery of the Epic

Win course, future research should examine the convergent validity of the TAS with

psychometrically valid measures of anxiety to assess whether it is measuring a construct that is

similar to anxiety. Future research should also include a longitudinal study of course participants.

By following up with participants systematically, a more complete picture can emerge regarding

the effectiveness of the *Epic Win* course in providing transitional supports that lead to long term

outcomes related to improved self-esteem and self-determination, as well as decreased

transitional anxiety. These follow-ups will also provide evidence regarding the generalization,

and maintenance of the skills taught within the Epic Win course and whether acquisition of these skills results in positive outcomes related to higher education, employment, relationships and independence.

CHAPTER 5: CONCLUSION

Adolescents with HF-ASD transitioning into adulthood tend to experience poor adult outcomes in terms of employment, relationships, post-secondary education, and independence. These outcomes are particularly poor when compared with those experienced by their typically developing peers (Barnhill, 2007; Taylor & Seltzer, 2011). Despite a growing amount of evidence citing the benefits of increased self-determination on adult outcomes for individuals with a range of disabilities, there has not been wide ranging adoption of these practices and procedures in the education system or in services that work with young adults with HF-ASD (Ontario Ministry of Education, 2007; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). Given that the *Epic Win* course systematically programs for acquisition of these skills, and given that the three participants with complete data sets demonstrated an increase in self-determination (although not a significant one), more research is warranted to explore the impact of this transition to adulthood course. The results of this study also demonstrated non-significant trends in the predicted directions in terms of self-esteem, transitional anxiety, and feelings of problem-solving competency, which should be further examined. Completion of the *Epic Win* course led to positive changes in the way the young adults talked about and viewed themselves, as evidenced by increases in self-affirming statements and a shift to a more positive strength to limitations ratio during the *Epic Life Interview*. Of all the recommendations from this study, it is most important that future research include large enough sample sizes to increase statistical power. Future research should also include a long-term follow-up of past and future participants

to see if they have, indeed, achieved some of the goals they set during their time in the *Epic Win*

course and, if the skills acquired led to the acquisition of new goals and positive adult outcomes.

References

Arnett, J. J. (2000). Emerging adulthood: A theory of development from the late teens through the twenties. *American Psychologist*, *55*(5), 469-480.

Arnett, J. J. (2006). G. Stanley Hall's Adolescence: Brilliance and nonsense. *History of psychology*, *9*(3), 186.

Arnett, J. J. (2007). Emerging adulthood: What is it, and what is it good for? *Child Development Perspectives*, *1*(2), 68-73.

Attwood, T. (2007). *The complete guide to Asperger's syndrome*. London, UK: Jessica Kingsley Publishers.

Axelrod, B. N. (2002). Validity of the Wechsler abbreviated scale of intelligence and other very short forms of estimating intellectual functioning. *Assessment, 9*(1), 17-23.

Barnhill, G. P. (2007). Outcomes in adults with Asperger syndrome. *Focus on autism and other developmental disabilities*, *22*(2), 116-126.

Barnhill, G. P., & Myles, B. S. (2001). Attributional style and depression in adolescents with Asperger syndrome. *Journal of Positive Behavior Interventions, 3*(3), 175-182.

Cameto, R., Levine, P., & Wagner, M. (2004). Transition planning for students with disabilities. A Special Topic Report from the National Longitudinal Transition Study–2 (NLTS-2). Menlo Park, CA: SRI International.

Chou, Y. C., Wehmeyer, M. L., Palmer, S. B., & Lee, J. (2016). Comparisons of self-determination among students with Autism, Intellectual Disability, and Learning Disabilities: A multivariate analysis. *Focus on Autism and Other Developmental Disabilities*, In press.

Dobson, C., Goudy, W. J., Keith, P. M., & Powers, E. (1979). Further analysis of Rosenberg's Self-esteem Scale. *Psychological Reports, 44*(2), 639-641.

Drake, A. (2016). My Life as an Epic Win: Self-Determination in Individuals with High Functioning Autism Spectrum Disorder. Unpublished Master's Thesis.

Ehlers, S., Gillberg, C., & Wing, L. (1999). A screening questionnaire for Asperger syndrome and other high-functioning autism spectrum disorders in school age children. *Journal of autism and developmental disorders*, *29*(2), 129-141.

Frazier, T. W., Youngstrom, E. A., Speer, L., Embacher, R., Law, P., Constantino, J., & Eng, C. (2012). Validation of Proposed DSM-5 Criteria for Autism Spectrum Disorder. *Journal of the American Academy of Child & Adolescent Psychiatry*, *51*(1), 28-40.

Glennon, T. J. (2001). The stress of the university experience for students with Asperger syndrome. *Work*, *17*(3), 183-190.

Harter , S . (1985) *The Self-Perception Profile for Children: Revision of the Perceived Competence Scale for Children*. Manual: University of Denver.

Jacobson, N. S., & Truax, P. (1991). Clinical significance: a statistical approach to defining meaningful change in psychotherapy research. *Journal of consulting and clinical psychology*, *59*(1), 12.

Kanner L (1943). Autistic disturbances of affective contact. *Nervous Child 2*, 217-250.

Kaplan, R., & Saccuzzo, D. (2012). *Psychological testing: Principles, applications, and issues.* Cengage Learning.

Kim, J. A., Szatmari, P., Bryson, S. E., Streiner, D. L., & Wilson, F. J. (2000). The prevalence of anxiety and mood problems among children with autism and Asperger syndrome. *Autism*, *4*(2), 117-132.

Kovacs, M. (1992) *Children's Depression Inventory: Manual*. North Tonawanda, NY:

Multihealth Systems.

McCrimmon, A. W., & Smith, A. D. (2013). Test Review: Review of the Wechsler Abbreviated

Scale of Intelligence, (WASI-II). *Journal of Psychoeducational Assessment, 31*(3),

337-341.

Myles, B. S., & Simpson, R. L. (2002). Asperger syndrome an overview of characteristics. *Focus

on Autism and other developmental disabilities, 17*(3), 132-137.

Newschaffer, C. J., Croen, L. A., Daniels, J., Giarelli, E., Grether, J. K., Levy, S. E., & Reynolds,

A. M. (2007). The epidemiology of autism spectrum disorders. *Annual. Review of Public

Health*, *28*, 235-258.

OECD Centre for Educational Research and Innovation (2013). OECD Factbook 2013:

Economic, Environmental and Social Statistics. Retrieved from: http://www.oecd-

ilibrary.org/sites/factbook-2013-en/10/01/06/index.html;jsessionid=19e28stk7ycxk.x-

oecd-live-01?contentType=&itemId=/content/chapter/factbook-2013-77-

en&_csp_=491cec5152b0cb4856cfa94aec85f33b

Ontario Ministry of Education. (2007). Effective Educational Practices for Students with Autism

Spectrum Disorders. Retrieved from

http://www.edu.gov.on.ca/eng/general/elemsec/speced/asdfirst.pdf

Pearson Clinical. (2011). *Wechsler Abbreviated Scale of Intelligence - Second Edition.* Test

Manual.

Perry, A., Cummings, A., Geier, J. D., Freeman, N. L., Hughes, S., LaRose, L., Managhan, T.,

Reitzel, J., & Williams, J. (2008). Effectiveness of intensive behavioral intervention in

a large, community-based program. *Research in Autism Spectrum Disorders*, *2*(4),

621-642.

Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton

    University Press.

Schulenberg, J. E., Sameroff, A. J., & Cicchetti, D. (2004). The transition to adulthood as a

    critical juncture in the course of psychopathology and mental health. *Development and*

    psychopathology, 16(04), 799-806.

Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Rifenbark, G. G., & Little, T. D. (2013).

    Relationships between self-determination and postschool outcomes for youth with

    disabilities. *The Journal of Special Education*, 0022466913489733.

Shorkey, C. T., & Whiteman, V. L. (1978). Correlations between standard English and

    dialectical Spanish versions of five personality scales. *Psychological Reports, 43*(3), 910

Silber, E., & Tippett, J. S. (1965). Self-esteem: Clinical assessment and measurement validation.

    Psychological reports, *16*(3 suppl), 1017-1071.

Sinclair, S. J., Blais, M. A., Gansler, D. A., Sandberg, E., Bistis, K., & LoCicero, A. (2010).

    Psychometric properties of the Rosenberg Self-Esteem Scale: overall and across

    demographic groups living within the United States. *Evaluation & the Health Professions,*

    33(1), 56-80.

Somers, J. M., Goldner, E. M., Waraich, P., & Hsu, L. (2006). Prevalence and incidence studies

    of anxiety disorders: a systematic review of the literature. *Canadian Journal of*

    Psychiatry, *51*(2), 100.

Spence, S.H. (1997)'The Spence Children's Anxiety Scale, in I. Sclare (ed.) *Child*

    Psychology Portfolio. Windsor: NFER-Nelson.

Tafarodi, R. W., & Milne, A. B. (2002). Decomposing global self-esteem. *Journal of personality,*

    70(4), 443-484.

Tafarodi, R. W., & Swann Jr, W. B. (1995). Self-linking and self-competence as dimensions of

    global self-esteem: initial validation of a measure. *Journal of personality assessment,*

    65(2), 322-342.

Taylor, J. L., & Seltzer, M. M. (2011). Employment and post-secondary educational activities for

    young adults with autism spectrum disorders during the transition to adulthood. *Journal*

    of autism and developmental disorders, *41*(5), 566-574.

Wehmeyer, M. L. (1995). The Arc's Self-Determination Scale: Procedural Guidelines.

Wehmeyer, M. L., & Palmer, S. B. (2003). Adult outcomes for students with cognitive

    disabilities three-years after high school: The impact of self-determination. *Education*

    and Training in Developmental Disabilities, *38*(2), 131-144.

Wehmeyer, M. L., Palmer, S. B., Lee, Y., Williams-Diehm, K., & Shogren, K. (2011). A

    randomized-trial evaluation of the effect of Whose Future is it Anyway? on self-

    determination. *Career Development for Exceptional Individuals*, *34*(1), 45-56.

Wehmeyer, M. L., Palmer, S. B., Shogren, K., Williams-Diehm, K., & Soukup, J. H. (2010).

    Establishing a causal relationship between intervention to promote self-determination and

    enhanced student self-determination. *The Journal of Special Education 46*(4), 195-210.

Wehmeyer, M., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A

    follow-up study of youth with mental retardation or learning disabilities. *Exceptional*

    Children, *63*, 245-256.

White, S. W., Oswald, D., Ollendick, T., & Scahill, L. (2009). Anxiety in children and

    adolescents with autism spectrum disorders. *Clinical psychology review*, *29*(3), 216-229.

Williamson, S., Craig, J., & Slinger, R. (2008). Exploring the relationship between measures of

    self-esteem and psychological adjustment among adolescents with Asperger syndrome.

    Autism, 12(4), 391-402.

Wolman, J., Campeau, P., Dubois, P., Mithaug, D., & Stolarski, V. (1994). AIR self-

determination scale and user guide. *Palo Alto, CA: American Institute for Research*, 26.

APPENDICES
Appendix A: *My Life as and Epic Win* **Curriculum Outline**

MY LIFE AS AN EPIC WIN CURRICULUM: OUTLINE

SESSION 1: MY LIFE AS AN EPIC WIN
Epic Win attitude; BEST self; Visioning your future; Vision Board; Setting goals in four areas of life: Career/Work, Further Education, Relationships, Independence

SESSION 2: LIFE CHALLENGES
Active Listening so others know you hear and understand them; Practice
Concerns for the future; Negative and limiting beliefs; Positive Re-framing
Self-management and Buddy system

SESSION 3: BUILDING A TEAM
Understanding the challenges and strengths associated with ASD
Importance of failure in building resiliency; how you are already resilient
Learning to seek support; Social skills needed to build your team
Introduction to turning Long-Term goals into SMART Goals

SESSION 4 AND 5: CAREER/WORK
GOAL SETTING around **Career/Work**: what are your strengths and possible challenges in the area of getting a job, work skills, keeping employment?
SMARTER goals and writing ACTION PLANS
PROBLEM SOLVING - role-playing solutions and discussing best solution

SESSION 6 AND 7: FURTHER EDUCATION
Goals setting around **Further Education**: what are your strengths and possible challenges in the area of going to college, university or taking development courses?
SMARTER goals and action plans
Problem Solving - role-playing solutions and discussing best solution

SESSION 8 AND 9: INDEPENDENCE
Goals setting around **Independence** what are your strengths and possible challenges in achieving the level of independence you would like?
SMARTER goals and action plans
Problem Solving - role-playing solutions and discussing best solution

SESSION 10: RELATIONSHIPS
Goals setting around **Relationships** what are your strengths and challenges in improving existing relationships, making new friends, keeping friends, romance?
SMARTER goals and action plans
Problem Solving - role-playing solutions and discussing best solution

SESSION 11: CREATING THE EPIC LIFE PLAN VIDEO
Creating Videos to represent your Epic Life Plan.

Review: Where to go next? Applying what you learned to new situations

SESSION 12: WRAP UP AND CELEBRATION
Completion of post-course questionnaires
What next?
Party to celebrate completion of Epic Life Plan and to watch Epic Life Plan videos.

Appendix B: The High-Functioning Autism Spectrum Screening Questionnaire

The High-Functioning Autism Spectrum Screening Questionnaire (ASSQ)

Name of child .... Date of birth ....

Name of rater .... Date of rating ....

This child stands out as different from other children of his/her age in the following way:

	No	Somewhat	Yes
1. is old-fashioned or precocious	[ ]	[ ]	[ ]
2. is regarded as an "eccentric professor" by the other children	[ ]	[ ]	[ ]
3. lives somewhat in a world of his/her own with restricted idiosyncratic intellectual interests	[ ]	[ ]	[ ]
4. accumulates facts on certain subjects (good rote memory) but does not really understand the meaning	[ ]	[ ]	[ ]
5. has a literal understanding of ambiguous and metaphorical language	[ ]	[ ]	[ ]
6. has a deviant style of communication with a formal, fussy, old-fashioned or "robotlike" language	[ ]	[ ]	[ ]
7. invents idiosyncratic words and expressions	[ ]	[ ]	[ ]
8. has a different voice or speech	[ ]	[ ]	[ ]
9. expresses sounds involuntarily; clears throat, grunts, smacks, cries or screams	[ ]	[ ]	[ ]
10. is surprisingly good at some things and surprisingly poor at others	[ ]	[ ]	[ ]
11. uses language freely but fails to make adjustment to fit social contexts or the needs of different listeners	[ ]	[ ]	[ ]
12. lacks empathy	[ ]	[ ]	[ ]
13. makes naive and embarrassing remarks	[ ]	[ ]	[ ]
14. has a deviant style of gaze	[ ]	[ ]	[ ]
15. wishes to be sociable but fails to make relationships with peers	[ ]	[ ]	[ ]
16. can be with other children but only on his/her terms	[ ]	[ ]	[ ]
17. lacks best friend	[ ]	[ ]	[ ]
18. lacks common sense	[ ]	[ ]	[ ]
19. is poor at games: no idea of cooperating in a team, scores "own goals"	[ ]	[ ]	[ ]
20. has clumsy, ill coordinated, ungainly, awkward movements or gestures	[ ]	[ ]	[ ]
21. has involuntary face or body movements	[ ]	[ ]	[ ]
22. has difficulties in completing simple daily activities because of compulsory repetition of certain actions or thoughts	[ ]	[ ]	[ ]
23. has special routines: insists on no change	[ ]	[ ]	[ ]
24. shows idiosyncratic attachment to objects	[ ]	[ ]	[ ]
25. is bullied by other children	[ ]	[ ]	[ ]
26. has markedly unusual facial expression	[ ]	[ ]	[ ]
27. has markedly unusual posture	[ ]	[ ]	[ ]

Specify reasons other than above:

Appendix C: The Transitional Anxiety Scale
The Transitional Anxiety Scale

Instructions: Each situation outlined below is a common obstacle or dilemma that young adults may experience. Questions will be related to one of the four areas of life: independence, relationships, careers, and higher education. For each situation, please indicate to what extent you agree with each statement regarding anxiety, and problem solving. Some of these questions may cause you to feel somewhat anxious. If you feel anxious at any time, please let us know and you can take a break. You can also skip a question if you do not want to answer it.

Independence Index

1. Your parents tell you that they will no longer be providing you with allowance/money. This means that you won't be able to buy new things (e.g., new videogames) or go places that cost anything. They say you should look for a job.

   I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

   I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

2. Your parents have decided to go away for a week. They're leaving you at home, which means that you'll need to cook for yourself. You only know how to cook macaroni-and-cheese from a box.

   I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

   I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

3. You've decided to move out on your own into an apartment. Rent is about $700 a month, however you only make $900 a month. You're worried that you won't have enough money to cover your other living expenses.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

Relationships Index

4. During your first week of college/university, you're required to go to an orientation day to learn about your program and meet the other people. You are told that this will be a great opportunity to get to know some people that may be in your classes, but you are shy about meeting new people.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

5. You have a friend who, lately, has been asking you for more and more favours and money. It's gotten to the point where you think they're taking advantage of you. You want to talk to them about it, but you don't want to lose them as a friend.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

6. Over the past few weeks, you've been getting into more arguments than usual with your family members. They are insisting that you participate in family night every Saturday evening. You know it would really make your parents happy but you have other things that you prefer to be doing.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

Career/Work Index

7. While you're at work, your supervisor comes up to you and tells you that you haven't been working as hard as they'd like you to. They provide you with some constructive feedback so that you can improve your performance, and tell you that they'll talk to you in two weeks about whether you improved, and if you can keep your job.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

8. On payday, you realize that your paycheque is much less than you were expecting. You talked to your boss about this and he has told you that it is correct. You do not agree and want to take action

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

9. After applying for a job, you get called back for an interview. You have one week to prepare. You know very little about the company, and you've had very little interview experience. You want the interview to go well, because you really want the job.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

Education Index

10. You've decided that you want to apply to university, college, or a trade program. You know what you'd like to do, but you don't know where this program is offered. All your classmates have already applied and your friend has told you that the application is due very soon.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

11. During your third week of classes, you realize that you're falling behind. You've noticed that your instructor talks much too fast, and you're having a hard time taking notes. Your first midterm is in two weeks, and you know your notes are incomplete.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

12. You've been partnered up for an assignment, and you realize that your partner hasn't been doing his/her share of the work. You're done your portion of the work, and your partner hasn't started at all. The assignment is due in three days.

I would feel anxious if I was in this situation

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

I know I would be able to problem solve and create a solution to this problem

0	1	2	3	4	5
Completely Disagree	Strongly Disagree	Somewhat Disagree	Somewhat Agree	Strongly Agree	Completely Agree

Appendix D: The Rosenberg Self-Esteem Scale

Rosenberg Self-Esteem Scale (Rosenberg, 1965)

The scale is a ten item Likert scale with items answered on a four point scale - from strongly agree to strongly disagree. The original sample for which the scale was developed consisted of 5,024 High School Juniors and Seniors from 10 randomly selected schools in New York State.

Instructions: Below is a list of statements dealing with your general feelings about yourself. If you strongly agree, circle **SA**. If you agree with the statement, circle **A**. If you disagree, circle **D**. If you strongly disagree, circle **SD**.

1.	On the whole, I am satisfied with myself.	SA	A	D	SD
2.*	At times, I think I am no good at all.	SA	A	D	SD
3.	I feel that I have a number of good qualities.	SA	A	D	SD
4.	I am able to do things as well as most other people.	SA	A	D	SD
5.*	I feel I do not have much to be proud of.	SA	A	D	SD
6.*	I certainly feel useless at times.	SA	A	D	SD
7.	I feel that I'm a person of worth, at least on an equal plane with others.	SA	A	D	SD
8.*	I wish I could have more respect for myself.	SA	A	D	SD
9.*	All in all, I am inclined to feel that I am a failure.	SA	A	D	SD
10.	I take a positive attitude toward myself.	SA	A	D	SD

Scoring: SA=3, A=2, D=1, SD=0. Items with an asterisk are reverse scored, that is, SA=0, A=1, D=2, SD=3. Sum the scores for the 10 items. The higher the score, the higher the self esteem.

The scale may be used without explicit permission. The author's family, however, would like to be kept informed of its use:

The Morris Rosenberg Foundation
c/o Department of Sociology
University of Maryland
2112 Art/Soc Building
College Park, MD 20742-1315

References

References with further characteristics of the scale:

Crandal, R. (1973). The measurement of self-esteem and related constructs, Pp. 80-82 in J.P. Robinson & P.R. Shaver (Eds), **Measures of social psychological attitudes. Revised edition**. Ann Arbor: ISR.

Rosenberg, M. (1965). **Society and the adolescent self-image**. Princeton, NJ: Princeton University Press.

Wylie, R. C. (1974). **The self-concept. Revised edition**. Lincoln, Nebraska: University of Nebraska Press.

Appendix E: The Epic Life Interview
The Epic Life Interview

1. What are some things that you like about yourself?

2. What are you particularly good at?

3. Is there anything that you struggle with?

    a. If so, how do you think you could overcome some of these challenges?

4. What are you most proud of? Why?

5. Have you received a diagnosis of Asperger's or ASD?

    a. What does this diagnosis mean to you?

        i. What are some strengths associated with your diagnosis?

        ii. What are some of the challenges associated with your diagnosis?

6. What would an epic life look like to you?

    a. Do you think that you'll be able to achieve this life? Why or why not?

Appendix F: AIR Self-Determination Scale

AIR Self-Determination Scale©

STUDENT FORM

Student's Name _____ Date_____

School Name_____ Your Grade_____

Your Date of Birth_____

                                       Month   Day   Year

HOW TO FILL OUT THIS FORM

Please answer these questions about how you go about getting what you want or need. This may occur at school, or after school, or it could be related to your friends, your family, or a job or hobby you have.

This is not a Test.	There are no right or wrong answers. The questions will help you learn about what you do well and where you may need help.
Goal	You may not be sure what some of the words in the questions mean. For example, the word **goal** is used a lot. A **goal is something you want to get or achieve**, either now or next week or in the distant future, like when you are an adult. You can have many different kinds of goals. You could have a goal that has to do with school (like getting a good grade on a test or graduating from high school). You could have a goal of saving money to buy something (a new iPod® or new sneakers), or doing better in sports (getting on the basketball team). Each person's goals are different because each person has different things that they want or need or that they are good at.
Plan	Another word that is used in some of the questions is **plan**. A **plan is the way you decide to meet your goal, or the steps you need to take in order to get what you want or need**. Like goals, you can have many different kinds of plans. An example of a plan to meet the goal of getting on the basketball team would be: to get better by shooting more baskets at home after school, to play basketball with friends on the weekend, to listen to the coach when the team practices, and to watch the pros play basketball on TV.

1   *AIR* Self-Determination Scale, Student Form

HOW TO MARK YOUR ANSWERS

EXAMPLE QUESTION:
>   I check for errors after completing a project.

EXAMPLE ANSWER:
>   Circle the number of the answer which tells what you are most like:
>   (Circle **ONLY ONE** number).

>   1 **Never…………………………**student **never** checks for errors.

>   2 **Almost Never………………**student **almost never** checks for errors.

>   3 **Sometimes…………………**.student **sometimes** checks for errors.

>   4 **Almost Always……………..**student **almost always** checks for errors.

>   5   **Always…………………………**student **always** checks for errors.

REMEMBER

There are NO right or wrong answers.

This will not affect your grade. So please think about each question carefully before you circle your answer.

THINGS I DO

1. I know what I need, what I like, and what I'm good at.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. I set goals to get what I want or need. I think about what I am good at when I do this.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

Things I Do – Total Items 1 + 2   [ ]

3. I figure out how to meet my goals. I make plans and decide what I should do.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. I begin working on my plans to meet my goals as soon as possible.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

Things I Do – Total Items 3 + 4   [ ]

5. I check how I'm doing when I'm working on my plan. If I need to, I ask others what they think of how I'm doing.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. If my plan doesn't work, I try another one to meet my goals.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

Things I Do – Total Items 5 + 6   [ ]

Please go on to the next page ⇒

HOW I FEEL

1. I feel good about what I like, what I want, and what I need to do.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. I believe that I can set goals to get what I want.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

How I Feel – Total Items 1 + 2	

3. I like to make plans to meet my goals.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. I like to begin working on my plans right away.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

How I Feel – Total Items 3 + 4	

5. I like to check on how well I'm doing in meeting my goals.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. I am willing to try another way if it helps me to meet my goals.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

How I Feel – Total Items 5 + 6	

WHAT HAPPENS AT SCHOOL

	Never	Almost Never	Sometimes	Almost Always	Always
1. People at school listen to me when I talk about what I want, what I need, or what I'm good at.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. People at school let me know that I can set my own goals to get what I want or need.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

What Happens at School – Total Items 1 + 2 [ ]

	Never	Almost Never	Sometimes	Almost Always	Always
3. At school, I have learned how to make plans to meet my goals and to feel good about them.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. People at school encourage me to start working on my plans right away.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

What Happens at School – Total Items 3 + 4 [ ]

	Never	Almost Never	Sometimes	Almost Always	Always
5. I have someone at school who can tell me if I am meeting my goals.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. People at school understand when I have to change my plan to meet my goals. They offer advice and encourage me when I'm doing this.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

What Happens at School – Total Items 5 + 6 [ ]

Please go on to the next page ⇒

5 *AIR* Self Determination Scale, Student Form

WHAT HAPPENS AT HOME

	Never	Almost Never	Sometimes	Almost Always	Always
1. People at home listen to me when I talk about what I want, what I need, or what I'm good at.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
2. People at home let me know that I can set my own goals to get what I want or need.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

What Happens at Home – Total Items 1 + 2 [ ]

	Never	Almost Never	Sometimes	Almost Always	Always
3. At home, I have learned how to make plans to meet my goals and to feel good about them.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
4. People at home encourage me to start working on my plans right away.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

What Happens at Home – Total Items 3 + 4 [ ]

	Never	Almost Never	Sometimes	Almost Always	Always
5. I have someone at home who can tell me if I am meeting my goals.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5
6. People at home understand when I have to change my plan to meet my goals. They offer advice and encourage me when I'm doing this.	Never 1	Almost Never 2	Sometimes 3	Almost Always 4	Always 5

What Happens at Home – Total Items 5 + 6 [ ]

Please go on to the next page ⇒

6 *AIR* Self Determination Scale, Student Form

PLEASE WRITE YOUR ANWERS TO THE FOLLOWING QUESTIONS…

Give an example of a goal you are working on.

_____

_____

_____

_____

_____

What are you doing to reach this goal?

_____

_____

_____

_____

_____

How well are you doing in reaching this goal?

_____

_____

_____

_____

_____

THANK YOU!

7 *AIR* Self Determination Scale, Student Form

Appendix G: Epic Win Recruitment Flier
My Life as an Epic Win
Letter of Invitation to Participate in Research

My Life As An Epic Win!!

Transitioning Into Adulthood

Do you wonder what you'll do as an adult?
Do you dream of getting a job, starting a career,
going to college or university, having more friends,
having your own apartment, being more
independent?

**If you are a teen or young adult
(17 - 23) with Aspergers or ASD,
this 12-week course
may be for you!**

In this interactive, supportive and fun 12 week course:
- ➢ Get clear on what you really want in life
- ➢ Create a roadmap to help you reach your goals
- ➢ Learn how to stay in action despite barriers
- ➢ Build a support team to fulfill on your dreams

NEXT PROGRAM STARTING SEPTEMBER __, 2015

If you would life more information, please contact:
Dr. Rebecca Ward, Centre for Applied Disability Studies
Email: bward@brocku.ca
Phone: 905-688-5550 x 5778

This research project has been reviewed, and has received clearance by the Brock University Research Ethics Board (File Number: 14-277). If you have any questions regarding this, please contact the research ethics office at: reb@brocku.ca, or 905-688-5550 x3035)

MY LIFE AS AN EPIC WIN:
TRANSITIONING INTO ADULTHOOD

Dr. Rebecca Ward, Centre for Applied Disability Studies, Brock University
Kimberly Saldanha and Jeffrey Esteves, M.A. students

The Epic Win course is for older teens and young adults with high functioning ASD designed to support them in creating an "Epic Win" in life (borrowing from gaming terminology), developing an Epic Win attitude and powerful strategies and supports to win at the game of life. This transition to adulthood empowerment program is offered to 17 to 23 year olds with diagnoses of high functioning Autism Spectrum Disorder or Aspergers disorder.

The group will consist of 8-10 youth who are in high school or graduated and are looking for support in their transition to adulthood. In this 12-week course, we will use group discussion, modeling, role-play practice with peers, in-class exercises, and homework assignments to teach and support you in learning skills for successful transition to adulthood.

Over the course, you will learn to:
1. Create a vision for your future; with long and short-term goals in areas of life that matter to you (for example, career/work, education, independence, and social relationships)
2. Create actions plans and learn to keep in action on your plan
3. Identify ineffective thinking and action patterns that may be barriers to success
4. Develop problem solving strategies to overcome barriers and challenges
5. Build a support team through active listening and improved communication skills

Concurrently, parents/guardian/parent surrogate will be coached during their own weekly group on how to effectively support their youth's transition. The parent group curriculum will mirror that of the youth, including several weeks of joint work between parents and youth.

The course culminates in creating an Epic Life video for each participant, in which you are interviewed individually about your interests, passions, strengths, accomplishments, and goals, and about the kind of supports you need for successful transition to adulthood.

This course will be evaluated as a research project through Brock University. Should you choose to participate, we will be collecting and analyzing data throughout the course to measure its effectiveness. The effectiveness of the research project will be evaluated through completion of pre-post course skill and satisfaction questionnaires. By the end of the course, it is expected that you will be more able to actively listen, work collaboratively, set goals, create action plans, problem solve, and stay in action on your goals.

Those who are interested in participating in this course as a research participant will have to complete a screening assessment to determine eligibility. This screening process will be explained to you in detail during an initial phone conversation.

For more information details about participation in this research project contact:
Dr. Rebecca Ward
Brock University, Centre for Applied Disability Studies
Phone: 905-688-5550 ext. 5778
Email: bward@brocku.ca

Appendix H: Informed Consent Form
My Life as an Epic Win
Informed Consent Form to Participate in Research on the Epic Win Course

Date: May 8, 2015
Project Title: My Life as an Epic Win Research Project

Principal Investigator (PI):
Dr. Rebecca Ward
Assistant Professor
Centre for Applied Disability Studies
Brock University
(905) 688-5550 x 5778
bward@brocku.ca

Principal Student Investigators:
Jeffrey Esteves and Kimberly Saldanha
M.A. Students
Centre for Applied Disability Studies
Brock University
(905) 807-6391 and (905) 599-3880
je13ij@brocku.ca and ks13wk@brocku.ca

INVITATION
You are invited to participate in a research study involving a transition to adulthood course called the *My Life as an Epic Win* (hereafter called, *Epic Win*). In this course, you will learn to create a vision for your future (long-term goals) and short-term goals in the areas of life that are most important to you (for example, career/work, education, independence, and social relationships). Over the 12 weeks, you will learn to set goals, create action plans, make decisions, problem solve, take actions, and build a support system to help your transition into adulthood be successful. As well, you will work on communication skills, like listening to others and expressing yourself, which are critical skills for success as an adult.

WHAT'S INVOLVED IN TAKING THE EPIC WIN COURSE:
The Epic Win course is for older teens and young adults (ages 17 to 24) with a diagnosis of Aspergers or high functioning ASD and is intended to support you in making your life an "Epic Win" (borrowing from gaming terminology.) While in this course, we will assist you in developing an Epic Win attitude, and will teach you powerful strategies and provide supports to win at the game of life.

The course will involve 7 -10 youth who are in high school or graduated and are looking for support in their transition to adulthood. In this 12-week course, we will meet weekly for three hours, use group discussion, modeling, practice with peers and parents, in-class exercises, and homework assignments to teach and support you in learning critical skills for successful transition to adulthood. That means there will be 36 hours in the course in total. The time it takes for weekly homework completion will vary depending on what actions you promise to take between sessions related to achieving goals you set.

It is our intention that, over the duration of the course, you will learn and master new skills and, by the end of the course, you will be able to achieve goals you set related to career/job, education, independence and social relationships.

CONCURRENT PARENT COURSE:
While you are in your own course, one or both of your parents (or a surrogate, such as an older sibling or grandparent) will be coached in their own weekly group on how to support your transition to adulthood. The parents will learn the same concepts and strategies as you to help improve communication and collaboration. In some weeks you will practice skills together with your parents (or surrogates) or with someone else's parents.

EPIC LIFE VIDEO:
In Session 11 of the course, you will create an Epic Life video (optional), in which you are interviewed about your interests, passions, strengths, accomplishments, and goals, and about the kind of supports you need for successful transition to adulthood. Before videoing the interview, the videographer will sign an Oath of Confidentiality, swearing to keep the content of these videos confidential and to destroy the raw footage after the videos have been edited, the Epic Life Videos saved to memory sticks, and raw footage of the interviews saved to the Principal Investigator's external hard drive, which will be securely stored in her office. This Epic Life Video is not part of the research study and will not be analysed in any way. At the end of the course, you will be given a copy of your Epic Life Video as a reminder of your life vision and as a tool to share with family members, educators and community workers who support your transition to adulthood. In the final 12th session of the course, there will be a celebration party and, if you choose, you can share your video with the other course participants.

ELIGIBILITY FOR THE RESEARCH STUDY
You and your parent will have already had a phone conversation with Dr. Rebecca Ward to get more information about the research study and to answer your questions. She will have asked you about your interest in participating in the Epic Win course as a research project. Through that phone conversation, it was determined that your participation in the research study might benefit you and you said you were interested in participating. At that point, you and your parent were asked to come to Brock University for this face-to-face meeting to complete this consent form and two screening assessments to determine if you will be included in this study. The first assessment, the Wechsler Abbreviated Scale of Intelligence -Second Edition, is an intelligence test and the second assessment, the High-Functioning Autism Spectrum Screening Questionnaire, is a tool parents complete to confirm your ASD diagnosis. Once these measures are completed, Dr. Rebecca Ward will review the measures and determine if you are eligible to participate. If you are not eligible to participate in this research study, Dr. Rebecca Ward will give your parents information about other local agencies that may provide similar transition to adulthood supports. If you choose, you may want to participate in a later *Epic Win* course that will run after this research study is complete (after June 2016).

WHAT'S INVOLVED IN RESEARCH PARTICIPATION:
Prior to the first course starting in the fall, you will be asked to come to Brock University to complete four questionnaires and participate in a brief interview. Completion of these questionnaires and the interview will take about two hours, which you can do in one or two visits. The questionnaires and interview are assessing several common aspects of transition to adulthood: goal setting, action planning, problem solving, goal attainment, self-determination, self-esteem, and anxiety. The interview that you complete will be audio and video taped so that the researchers can review and analyse what you said at a later date.

Following these pre-course assessments, you will be randomly assigned to the Epic Win course offered in the fall or to a Waitlist group that will get the Epic Win course in the winter/spring of 2016.

As we explained on the phone, the reason that we have a Waitlist group who will get the course later is so that we can compare those who get the course to those who do not get the course. We want to see if those who get the Epic Win course improve more on skills taught in the course (goal setting, action planning, problem solving, goals attainment) and on other measures of self-determination, anxiety and self-esteem than the group who did not get the Epic Win course. By doing this, we can clearly determine that the Epic Win course was responsible for any changes we might see on participant pre-post measures.

Both the Epic Win group and the Waitlist group will be assessed on the four questionnaires and interviewed again in the month following the first Epic Win course completion. The Waitlist group will be assessed a third time after their own Epic Win course has finished in the spring 2016. All interviews will be audio and video taped for analysis after the sessions are complete.

POTENTIAL BENEFITS
Possible benefits for your participation in this study include teaching, coaching, and practice in important skills needed for you to transition into adulthood. Successful participation could result in increases in self-determined behaviours such as active listening, goal setting, action planning, problem solving and learning to stay in action to attain your goals. We hope that by the end of the course you will experience increased self-esteem and decreased anxiety surrounding the transition to adulthood, which is a difficult time for many young people.

POTENTIAL RISKS
Throughout the *Epic Win* course, you will be asked to share information about yourself, your ASD diagnosis, your strengths and challenges, your goals in life, and challenges or problems you deal with in trying to achieve your goals. Throughout the course, we strive to create a safe space for sharing; however, you will never be forced to share anything you don't want to share. Due to the nature of this discussion-based course, you may at times experience discomfort, such as feelings of embarrassment or worry. For some participants, there may be some general stress associated with participating in group discussions. We will encourage everyone to participate in discussions and activities in order to experience the full effect of the *Epic Win* course; however, participation in group discussion will always be optional. In consideration of any emotional risks, you will be reminded at the beginning of each session that you are *not* required to participate during group discussion if you choose not to. If at any time during the course or in between sessions you wish to speak to the Dr. Ward about challenges you are having in the course or because of the course, you will be given contact information and can set up a time to speak outside of the sessions.

CONFIDENTIALITY
Following this consent process, you and your parent/guardian will complete two screening assessments, and then you will be asked to complete an intake form where you will provide your name, age, date of birth, and address. Any paper data forms that have your identifying information on it will be kept in a locked cabinet in Dr. Rebecca Ward's office, which is also

kept locked. Audio and video recordings will also be kept under lock and key in her office. Electronic files with identifying information will be kept on password-protected computers and no personal information about you will ever be emailed between the researchers. Paper data will be transferred in face-to-face meetings in Dr. Ward's office, and electronic files will be transferred using a USB drive to ensure participant confidentiality. The only people that will have access to your personal information will be the primary investigators, Dr. Rebecca Ward, Jeffrey Esteves, and Kimberly Saldanha. Should other graduate students at Brock join the research project as assistants, they will have to sign an "oath of confidentiality", swearing to protect the confidentiality and privacy of information about you and other participants. Once the course has finished, all of your personal information will be removed from paper copies of your data. Names will be replaced with an identification number. A master list linking participant names and identification numbers will be kept in a separate locked file and will be destroyed after 5 years when all Epic Win raw data from this study is destroyed. To ensure the confidentiality of data during the project, names of participants will not be used in any emails, and will not be used when discussing the study in areas outside of the research space.

VOLUNTARY PARTICIPATION
Participation in this study is voluntary. If you wish, you may decline to give consent to participate in this study. If you decide to participant for this research project, it is important that you are aware that you can withdraw your consent from participating at any point for any reason. You may decline to answer any question or withdraw from the study at any time (regardless of whether or not you feel comfortable). Refusing to give consent or withdrawing from this study can be done so without any concern for loss of opportunities to participate in future research or programs offered through Brock University. Should you choose to withdraw from participation in this research project, your data will be destroyed immediately. If you choose to withdraw from the research project in the middle of the course, you can still stay and participate in the Epic Win course and you will not have to complete any pre-post course research measures, although you will be expected to continue participating in the in-class discussions and exercises, and complete homework so as to get the benefits of the course. You can also withdraw from the course at any time; however, you will not be able to re-join this Epic Win course. You could, however, sign up for a new Epic Win course later in 2016.

PUBLICATION OF RESULTS
If you would like to learn the results of research study, following its completion, you will be provided with a one-page summary of the results. This one page summary will not include any identifying information, and will discuss the results of the study more generally, using group outcomes, rather than indicating any individual participant's results. You and your family will also be invited to attend a research night about 1-2 months after the study concludes in the spring 2016, where the research team will present the results of the study. In this research presentation, we will discuss the effectiveness of the Epic Win course in general terms, without specific reference to you or any participant. This night will take place after the entire project ends, which will be around June 2016.

As for publication of the results, the results will highlight the effectiveness the *Epic Win* course in increasing self-determined behaviours and increasing self-esteem among all the participants. A research paper will be written, and will be submitted for review to an academic journal for publication. A summary of the research will be submitted to various conferences in order to present the results to others who work with teens and young adults with Aspergers or high

functioning ASD. The long-term goal of this research project is to publish a manual on the *Epic Win* curriculum so that it can be used within school boards and other agencies that work with transition-aged youth.

FEEDBACK ON RESEARCH RESULTS:
Would you be interested in receiving a brief report of the results of this research study?

YES   NO

CONTACT INFORMATION AND ETHICS CLEARANCE
If you have any questions about this study or require further information, please contact Dr. Rebecca Ward using the contact information provided above.

This research project has been reviewed, and has received clearance by the Brock University Research Ethics Board (File Number: 14-277). If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Thank you for your assistance in this project.
Once signed (see following pages), we will give you a copy of this consent form for your records, along with our contact emails and phone numbers.

CONSENT TO PARTICIPATE IN EPIC WIN COURSE - SIGNATURES

I understand that by agreeing to participate in this study, I am committing to participate in the following three parts to the study (please initial on each of the lines provided):

1. I agree to complete the screening intelligence test. I understand that if I do not meet the criteria for the study, I will *not* be asked to participate in the current *Epic Win* course at this time, but will have the choice to participate in a future course. _____

2. I agree to complete the pre- and post-course interviews and the four questionnaires that will be completed before and after the *Epic Win* course. _____

3. I agree that, if I am randomly assigned to the Waitlist group, that I will complete the four questionnaires and interviews at three points: (1) before the first Epic Win course starts in the fall, (2) after the first Epic Win course ends, and (3) at the end of my own Epic Win course in the spring 2016   _____

4. I agree to attend all 12 of the *Epic Win* sessions, to participate in discussions and learning exercises, and to do the homework assignments, to the best of my ability. _____

I agree to participate in this study, as described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to ask questions and to receive any additional details I wanted about the research study and I understand that I may continue to ask further questions about the course, as my questions arise. I understand that I may withdraw this consent at any time, without any concern for loss of opportunity to participate in future research projects or courses offered through Brock University.

Participant Name: _____

Signature: _____

Date: _____

For participants under the age of 18, please have a parent or guardian sign below.

I agree for my adolescent (under the age of 18) to participate in this study described above. I have made this decision based on the information I have read in the Information-Consent Letter. I have had the opportunity to ask questions and to receive any additional details I wanted about the study. I understand that I may continue to ask questions in the future. I understand that I may withdraw this consent at any time, without any concern for loss of opportunity for my son/daughter to participate in future research projects or courses offered through Brock University.

Parent/ Guardian's Name: _____

Signature: _____

Date: _____

Participant Name: _____

Signature: _____

Date: _____

If after screening, you are not eligible to participate in this research project, would you be interested in participating in a future Epic Win course? This course would run later in 2016, and would not include any of the research measures discussed in this consent form.

☐ Yes, I would be interested in participating in a future Epic Win course

☐ No, I would not like to participate in a future epic win group

In the future, we may run a new research project based on or related to the Epic Win course. Would it be okay for us to contact you to ask if you'd be interested in participating in that research project?

☐ Yes, it would be okay for you to contact me about future research

☐ No, it would not be okay for you to contact me about future research

If you would like to participate in a future Epic Win course or in a research project, please provide us with your contact information so that we can invite you.

Name: _____

Phone Number: _____

Email: _____