FORMATIVE EVALUTION OF GROUP SELF-DETERMINATION/SELF-ADVOCACY

TRAINING FOR ADOLESCENTS WITH HIGH FUNCTIONING AUTISM OR

ASPERGER'S SYNDROME

by

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B.Sc., University of British Columbia, 2007

A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF
THE REQUIREMENTS FOR THE DEGREE OF

MASTER OF ARTS

in

THE FACULTY OF GRADUATE STUDIES

(Special Education)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

December, 2009

ABSTRACT

Over the past two decades, educators have recognized the importance of teaching students with disabilities to be self-determined, socially and emotionally competent individuals who can advocate for themselves. Unfortunately, the majority of students who require explicit instruction in these areas do not receive it. These three areas of instruction are especially important for students with high functioning autism/Asperger's syndrome (HFA/AS) because exposure to negative encounters with peers and teachers and lack of guidance during the transition from childhood to adulthood has been linked to many long-term risks. The purpose of this study was to assess the utility of a self-determination/self-advocacy (SD/SA) intervention with six adolescents with HFA/AS, using a pretest multiple-posttest design. The intervention consisted of two components – a training phase and a panel phase. During the training phase, participants were taught self-determination, self-advocacy, and social skills that would prepare them for the panel phase of the intervention. During the panel phase, the group participated in six public panel discussions in which they shared their experiences of what it is like to have HFA/AS. Six dependent variables were measured: 1) self-determination skills; 2) self-concept/self-esteem; 3) friendship development and closeness; 4) participant satisfaction; 5) parent satisfaction; and 6) audience satisfaction. The results offer preliminary evidence of an association between the SD/SA group intervention and positive outcomes in all six areas. The results are discussed with reference to contextual information and previous research. Social validity, collateral benefits, limitations, and future directions are also discussed.

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ACKNOWLEDGEMENTS

I would first and foremost like to thank the dedicated group of parents who had a vision of promoting autism awareness and acceptance within our community and had the ability, drive, and talent to make this vision a reality. Thank you Lynn Skotnitsky, Marianne Kaplan, Lesley Wells, Stella Crofts, Claire Chou, and Kirstie Glasgow – without your hard work and dedication, my project would not have existed. Thank you to my amazing participants who volunteered their time to be part of my project. Thank you to Dr. Pat Mirenda, my thesis supervisor, who dedicated her time to help me out at almost every training session, who attended almost every panel discussion, and who encouraged and guided me throughout this process. Thank you to Landa Mark, who helped me out at several training sessions and who volunteered at many of the community events. I thank my friends Danielle McGill, Adrienne Razmov, Nadine Trottier, Sarah Verheyden, Mark Boucher, Meghan O'Rourke, Peter McGrail, Eric McGill, and Naho Harada who dedicated their time to volunteer at the community events helping set up, clean up, and register over 1000 attendees. I want to give thanks to my parents, Tim and Kathleen, who have provided me with continuous support during my educational endeavours and who have pushed me to always shoot for the stars. I want to especially thank Sarah Myers, my cousin with autism, and her family (Aunt Kim, Uncle Dan, Jacqueline, Daniel, and Dalton) who inspired me to enter this field and make a difference in the lives of individuals and families who are impacted by autism. I thank Dr. Jessica de Villiers for mentoring me and influencing me to enter the research stream of my Master's degree. And finally, I want to thank my committee member Dr. Denise Buote for not only introducing me to and sparking my interest in SEL but for also providing me with guidance and support along the way.

CHAPTER 1

Introduction

This chapter begins with a description of autism spectrum disorder (ASD) and outlines the prevalence, characteristics, and gender ratios associated with two disorders that are classified under this spectrum: Autistic Disorder and Asperger's syndrome. Although individuals with ASD vary in the degree to which the associated behavioural and cognitive excesses and deficits impact their lives, they all have difficulty acquiring the self-determination skills needed to lead independent, successful lives. Thus, this chapter also includes a discussion of ASD and its relationship to social-emotional development and self-determination. Following this discussion, the various methodologies used to teach self-determination skills to individuals with developmental disabilities in general are reviewed and analyzed. Finally, the chapter concludes with a proposal for a self-determination/self-advocacy intervention aimed at providing adolescents with high-functioning autism and Asperger's syndrome the skills they need to become as independent as possible in their thoughts and actions, and to advocate for inclusion and acceptance within the communities in which they live.

Autism Spectrum Disorder

Autism spectrum disorder (ASD), also referred to as pervasive developmental disorder (PDD), is a broad continuum of cognitive and behavioural disorders marked by three core features: 1) impairments in communication; 2) difficulty with socialization; and 3) restrictive and repetitive patterns of behaviour (Filipek, et al., 1999). The American Psychiatric Association (2000) identified five neurodevelopmental disorders that are grouped under the classification of PDD in the Diagnostic and Statistical Manual of Mental Disorders

(DSM-IV-TR): Rett's Disorder, Autistic Disorder (more commonly referred to as simply "autism"), Childhood Disintegrative Disorder, Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS) and Asperger's Disorder (often called Asperger's syndrome, abbreviated AS). Although the DSM-IV-TR does not make a distinction between low functioning autism (LFA) and high functioning autism (HFA), many clinical practitioners and researchers do (Rinehart, Bradshaw, Brereton, & Tonge, 2002). This distinction will be discussed in a subsequent section.

The prevalence of ASD is estimated at 27.5/10,000 individuals (Fombonne, 2003). Of those affected, approximately 10/10,000 have a diagnosis of autism (Fombonne, 2003). Although there is little epidemiological research identifying the prevalence of LFA compared to HFA, it is estimated that less than 5/10,000 individuals with autism have HFA (Gillberg, 1998). Even fewer individuals on the autism spectrum have a diagnosis of AS, with current estimates around 2/10,000 (Fombonne & Tidmarsh, 2003). It has been reported that two to five times as many males have ASD compared to females (Fombonne, 2003). Because HFA and AS are the focus of this manuscript, definitions for both disorders are provided below.

Autistic Disorder

In the DSM-IV-TR (APA, 2000), the diagnostic criteria for Autistic Disorder are as follows:

A. The individual must have a total of six (or more) items from areas (1), (2), and (3), with at least two from (1), and one from each (2) and (3):

  (1) Qualitative impairment in social interaction, as manifested by at least two of the
      following:

    a.   marked impairment in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction

    b.   failure to develop peer relationships appropriate to developmental level

    c.   a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by a lack of showing, bringing, or pointing out objects of interest)

    d.   lack of social or emotional reciprocity

(2) Qualitative impairments in communication as manifested by at least one of the following:

    a.   delay in, or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gestures or mime)

    b.   in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others

    c.   stereotyped and repetitive use of language or idiosyncratic language

    d.   lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

(3) Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

    a.   encompassing preoccupation with one or more stereotyped patterns of interest that is abnormal either in intensity or focus

    b.   apparently inflexible adherence to specific, nonfunctional routines or rituals

       c.   stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or

            twisting, or complex whole-body movements)

       d.   persistent preoccupation with parts of objects

B. Delays or abnormal functioning in at least one of the following areas, with onset prior

to age 3 years: (1) social interaction, (2) language as used in social communication, or (3)

symbolic or imaginative play.

C. The disturbance is not better accounted for by Rett's Disorder or Childhood

Disintegrative Disorder.

      In the autism literature, the term low functioning autism (LFA) is used to describe

individuals diagnosed with autism who also display an intellectual disability (i.e., IQ below

70) (Rinehart et al., 2002). Conversely, high functioning autism (HFA) is typically associated

with average to above average cognitive functioning (Rinehart et al., 2002).

Asperger's Syndrome

      Asperger's syndrome (AS) differs from autism primarily in the lack of an associated

communication impairment. Otherwise, the DSM-IV-TR (APA, 2000) criteria for AS are

identical to those for autism in the areas of social impairment and restricted, repetitive, and

stereotyped patterns of behavior, interests, and activities. Additional criteria include: (a) a

clinically significant impairment in social, occupational, or other important areas of

functioning; (b) no clinically significant general delay in language (e.g., single words used by

age 2 years, communicative phrases used by age 3 years); and (c) no clinically significant

delay in cognitive development or in the development of age-appropriate self-help skills,

adaptive behavior (other than in social interaction), and curiosity about the environment in

childhood (APA, 2000).

Asperger's Syndrome and High Functioning Autism

Since the 1940's, when Leo Kanner (1943) first identified autism and Hans Asperger (1944) first identified the syndrome now named after him, there has been much debate about whether autism and AS are two distinct disorders with clinically different features or if AS is, in fact, simply a milder variant of autism (Dickerson Mayes, Calhoun, & Crites, 2001; Rinehart et al., 2002). Researchers who ascribe to the latter opinion (i.e., those who consider AS to be a milder variant of autism) refer to individuals on the autism spectrum who have relatively high intellectual functioning as having either HFA or AS – these two terms are often used interchangeably (Dickerson Mayes et al., 2001; Manjiviona & Prior, 1999). Over the past decade, a considerable amount of research has been done to examine what differences, if any, exist between HFA and AS. Ozonoff, South, and Miller (2000) found that individuals with AS were better at imaginative play and had more creative abilities than those with HFA. They also noted that children in their AS sample displayed more restricted interests, whereas individuals with HFA demonstrated greater insistence on sameness (e.g., always doing the same daily routine in the same way). In a review of the current literature, Rinehart and colleagues (2002) suggested that HFA and AS are distinguishable by differences in executive functioning, lateralization of impairment in the brain, and discrepancies in motor ability. According to the DSM-IV-TR, HFA is distinguishable from AS by the presence of a language delay (APA, 2000); however, most language differences between these two subgroups disappear by adolescence (Ozonoff et al., 2000). Thus, the distinction between HFA and AS becomes less clear as children grow older. At the present time, the general consensus is that the HFA and AS both refer to individuals who have

relatively mild PDD symptoms and IQs in the average to above range (Dickerson Mayes et al., 2001).

At a glance, most children with ASD are physically indistinguishable from their peers. For the most part, children and adolescents with HFA/AS fit in with their peers academically, since their cognitive functioning and language abilities typically lie within the average range. However, individuals with HFA/AS have difficulty empathizing, reading social cues, predicting others' behaviour, and acting appropriately in new situations, which often leads to peer confusion, frustration, and ultimately rejection (Heinrichs, 2003). Since many individuals with HFA/AS do well academically, teachers often fail to recognize the need to teach this group of students the social-emotional skills they are lacking (Smith Myles et al., 2007). It is becoming increasingly recognized that teaching students to be socially and emotionally competent is important, especially for students without disabilities. One of the most common frameworks for teaching these skills to typically developing students is the social-emotional learning (SEL) model developed by the Collaborative for Academic, Social, and Emotional Learning (CASEL: http://www.casel.org/).

Social Emotional Learning (SEL)

Social-emotional learning (SEL) is the process through which typically-developing individuals develop awareness and self-management of their emotions, learn to set and achieve goals, use social awareness skills to maintain positive relationships, and use effective decision-making and responsible behaviours to achieve success both in and out of school (Patrikakou & Weissberg, 2007; Zins & Elias, 2006). SEL contributes to healthy development in typically developing youth (Patrikakou & Weissberg, 2007).

Effective SEL has five key components: 1) self-awareness; 2) self-management; 3) social awareness; 4) relationship skills; and 5) responsible decision-making (Patrikakou & Weissberg, 2007). Self-awareness refers to the identification and recognition of one's own emotions, strengths, self-efficacy, and self-confidence (Zins & Elias, 2006). Self-management refers to a sense of self-control, motivation, and the ability to manage stress and set goals (Zins & Elias, 2006). An individual with social awareness is said to have good perspective-taking skills, as well as empathy and respect for others (Zins & Elias, 2006). Relationship skills (i.e., the ability to form secure attachments with others) encompass skills such as cooperation, communication, and healthy conflict resolution skills (Patrikakou & Weissberg, 2007; Zins & Elias, 2006), all of which are essential for healthy psychological development (Deci & Ryan, 1985). Finally, individuals who are responsible decision makers have the ability to make ethical choices in life (Patrikakou & Weissberg, 2007).

Recently, researchers have suggested that SEL programming promotes resiliency and also builds skills and competencies for healthy relationship development and general well-being (Poulou, 2007). Resiliency is defined as "good outcomes in spite of serious threats to adaptation or development" (Masten, 2001, p. 228). Good outcomes typically refer to mental wellness and social-emotional competence (Olsson, Bond, Burns, Vella-Brodrick, & Sawyer, 2003). Research focusing on typically developing children and adolescents has revealed a variety of factors that can counteract risk and protect against the development of maladaptive behaviours. These factors include high self-esteem, positive self-concept, the ability to self-reflect, self-reliance, the ability to think and act independently, the ability to problem solve, a positive life outlook, and the ability to interact positively with others (Place, Reynolds,

Cousins, & O'Neill, 2002). Instruction through the SEL framework can develop these skills, all of which are known to promote resiliency in at-risk youth (Poulou, 2007).

School-based programming that promotes SEL in school-aged children aims to prevent the development of high-risk behaviors and promote positive development (CASEL: http://www.casel.org/). Due to the social and emotional challenges faced by individuals with HFA/AS, this group is particularly at a high risk for experiencing poor outcomes such as social exclusion, anxiety, depression, suicide, conduct and behaviour difficulties, victimization, and bullying (Heinrichs, 2003; Portway & Johnson, 2005). Other long-term risks include underachievement and prolonged dependency on parents (Portway & Johnson, 2005). Since school-based SEL programming is often developed with typically developing individuals in mind, it is not known whether or not this approach alone is sufficient to meet the needs of individuals with HFA/AS. Thus, it would be appropriate to explore the use of strategies that are referenced against the SEL approach with this group of students, in combination with other approaches that are known to be useful for fostering healthy social-emotional development in individuals with developmental disabilities. The components of self-determination instruction in particular appear to articulate nicely with the SEL approach, as described in the next section.

Self-Determination

Self-determination can be defined as "a combination of skills, knowledge and beliefs that enable a person to engage in goal-directed, self-regulated, autonomous behaviour. An understanding of one's strengths and limitations together with a belief in oneself as capable and effective are essential to self-determination. When acting on the basis of these skills and attitudes, individuals have greater ability to take control of their lives and assume the role of

successful adults in our society" (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2).

Deci and Ryan (1985) described self-determination as a psychological need based on a

person's free choice. Due to the efforts of the independent living, normalization, and self-

advocacy movements in most developed nations, along with the Americans with Disabilities

Act (ADA) and the Individuals with Disabilities Education Act (IDEA) in the United States,

an increased concern for teaching individuals with disabilities to become self-sufficient

citizens has surfaced over the past two decades (Field & Hoffman, 1999). However, many

individuals with developmental disabilities do not yet receive the instruction required to learn

how to become more self-determined (Fiedler & Danneker, 2007).

According to Wehmeyer, Agran, and Hughes (1998) there are four essential

characteristics of self-determined behaviour: behavioural autonomy, self-regulated

behaviour, acting in a psychologically empowered manner, and self-realization. Each of these

is discussed in the sections that follow.

Autonomy

A person who is autonomous acts independently according to his or her preferences,

interests, and abilities (Wehmeyer et al., 1998). According to the self-determination theory

proposed by Deci and Ryan (1985), autonomy (i.e., the opportunity to make choices) is one

of the essential factors required for healthy development and general well being in one's life.

Instinctively, many professionals and parents who work or live with a child with a disability

want to shelter and protect these individuals from any harm. Unfortunately, overprotection

can take away one's sense of autonomy (Perske, 1972). Thus, it becomes critical to teach

individuals with disabilities how to behave autonomously. Skills such as problem solving,

choice making, and decision-making are emphasized in this regard (Wehmeyer et al., 1998).

Self-Regulation

One of the most salient characteristics of successful individuals (i.e., people who can attain what they want in life) is that they are self-regulated (Wehmeyer et al., 1998). A literature review conducted by Mithaug, Matin, Agran, and Rusch (1988) revealed four major behaviours associated with successful people – the ability to set goals, develop action plans to achieve the goals, implement the action plans, and evaluate to determine whether or not the goals are met. Many individuals with disabilities do not learn these skills incidentally and, as a result, often depend on others to take control of these aspects of their lives (Wehmeyer et al., 1998). When teaching individuals to become self-regulated, strategies such as goal setting, self-monitoring, self-evaluation, and self-reinforcement are emphasized (Wehmeyer et al., 1998).

Psychological Empowerment

Acting in a psychologically empowering manner refers to having control over one's own behavior in circumstances that are important to one's self (Wehmeyer et al., 1998). In other words, individuals who act in a psychologically empowered manner possess and apply the skills necessary to achieve what they want in life. People act in such a way when they feel competent and know that they will receive reinforcement (whether it be intrinsic or extrinsic) if they are successful because of their own efforts. According to Deci and Ryan (1985), competence is another factor that promotes healthy psychological development and general well being.

Self-Realization

Self-knowledge and self-understanding are two components that underlie self-realization (Wehmeyer et al., 1998). Individuals are self-realizing when they have

comprehensive and accurate knowledge about themselves, are able to capitalize on their strengths, and can make up for their shortcomings (Wehmeyer et al., 1998). Self-realization is formed through experiences with and interpretations of one's environment, evaluations of oneself and by others, and both intrinsic and extrinsic reinforcement (Wehmeyer et al., 1998). Self-realization is necessary for the achievement of one's maximum potential (Ward, 1988).

In summary, truly self-determined individuals show evidence of a variety of skills and attitudes that allow them to gain control over their own lives (Field et al., 1998). In other words, self-determined individuals have the skills required to lead independent lives. By the end of high school, most typically developing students are reasonably self-determined, and are also able to clearly articulate their wants and needs as well as speak up for or defend a cause or another person (Field et al., 1998). However, for students with disabilities, explicitly teaching the latter skill – referred to as self-advocacy – is often necessary. The following section will describe self-advocacy and the current literature related to its importance for individuals with disabilities.

Self-Advocacy

Self-advocacy is defined as publicly speaking out to defend a cause or person (Field et al., 1998). Individuals who are self-advocates have the ability to speak up for what they want, what they need, and what they believe in (Schreiner, 2007) and can also speak on behalf of others who do not have the ability to do so (Field et al., 1998). Individuals with developmental disabilities such as ASD rarely learn self-advocacy skills incidentally (Schreiner, 2007).

Both leadership and teamwork are important aspects of self-advocacy (Wehmeyer et al., 1998). Wehmeyer and colleagues (1998) defined leaders as those "who guide or direct others on a course of action, influence the opinion and behavior of other people, and show the way by going in advance" (p. 239). Unfortunately, a number of barriers hinder leadership development in individuals with disabilities. Wehmeyer and Berkobien (1996) recognized that people and disabilities are often viewed as incapable of leading and thus are denied opportunities or support in leadership roles. Although most educators view the importance of teaching self-advocacy and leadership skills to their students, these skills are, sadly, often neglected (Fiedler & Danneker, 2007).

Test, Fowler, Wood, Brewer and Eddy (2005) proposed a framework for teaching self-advocacy skills to students with disabilities. These skills are often taught in group settings that provide opportunities for students to practice and experience meaningful leadership roles (Wehmeyer et al., 1998). The self-advocacy framework is comprised of four components: knowledge of self, knowledge of rights, communication, and leadership. Individuals with disabilities who are self-aware recognize their interests, strengths, needs, and the attributes of their disability. Individuals who know their rights are aware and can be assertive about the legal protections to which they are entitled. People with good communication skills are able to interact effectively in one-to-one settings as well as in small or large group discussions. Communication skills that are needed in these situations include effective listening strategies, as well as the ability to negotiate, compromise, and use persuasion skills (Test, Fowler & Wood et al., 2005; Wehmeyer et al., 1998). Finally, self-advocates with leadership skills are able to advocate for others who share a common concern or belief (Test, Fowler, Wood et al., 2005). Using this framework to develop self-advocacy

interventions can be beneficial for individuals with disabilities because it incorporates the

skills they need in order to stand up and speak out for themselves and others who share their

disability.

Summary

Three interrelated frameworks have been proposed for fostering healthy development

and preparing students for success in adulthood: the SEL model, the self-determination

framework, and the self-advocacy framework. The SEL model, developed by CASEL,

emerged from the research on psychological development in typically developing children.

This model focuses on teaching children to be socially and emotionally competent by

promoting self-awareness, self-management, social awareness, relationship skills, and

responsible decision-making. The self-determination framework, proposed by Wehmeyer and

colleagues (1998), emerged from the research on individuals with developmental disabilities.

According to this framework, one must be autonomous, self-regulated, psychologically

empowered, and self-realizing in order to become self-determined. The self-advocacy

framework, proposed by Test, Fowler, Wood and colleagues (2005), also stems from

disability research. Knowledge of self, knowledge of rights, communication, and leadership

are the essential components of self-advocacy. Table 1 depicts the interrelationship between

all three models.

Table 1

Relationship between three models that promote healthy psychological development

Characteristic	Self-determination (Wehmeyer et al., 1998)	Self-advocacy (Test, Fowler, Wood, et al., 2005)	Social emotional learning (SEL) (CASEL)
Autonomy & responsible decision making	X		X
Self-regulation & self-management	X		X
Psychological empowerment & knowledge of rights	X	X	
Self-realization, knowledge of self, & self-awareness	X	X	X
Social awareness, relationship skills, & communication skills		X	X
Leadership		X	

Fostering healthy development and preparing children for adulthood is the joint responsibility of every teacher and every parent. There are a variety of components and skills that one must focus on when teaching students to take control of their lives and become successful adults within society. The following two sections will highlight the social significance and the benefits associated with teaching individuals the skills comprised in the SEL, self-advocacy, and self-determination models.

SEL, Self-Advocacy, Self-Determination, and Bullying

All three of the frameworks discussed in this chapter can be used to teach youth a wide range of skills that are needed for healthy social and emotional development. In addition, the acquisition of skills taught using these frameworks have also been recognized to promote resiliency in students who are at-risk (Poulou, 2007). For these reasons, teaching self-determination, self-advocacy, and social emotional skills is especially important for students with disabilities who may experience negative interactions with typically-developing peers in the form of teasing, taunting, or bullying. Bullying involves a "power imbalance, intent to harm, distressed target, and repeated negative actions" (Heinrichs, 2003, p. 22). Due to the very nature of their disorder, students with HFA/AS are at high risk for being bullied by their peers (Heinrichs, 2003), and have even been referred to as the "perfect victims" (Klin, Volkmar, & Sparrow, 2000, p. 6). Social impairments such as the inability to decipher body language, facial expressions, tone of voice, and jokes, combined with their behavioural anomalies and obsessions, differentiate this group of individuals from their peers (Heinrichs, 2003; Little, 2002). These factors can lead to isolation and lack of a strong peer support group for these students. Risk for bullying and shunning is increased when typically developing classmates do not fully understand what it means to have HFA/AS and when students with HFA/AS do not have the skills required to stand up for themselves (Heinrichs, 2003).

In 2002, Little conducted a survey about bullying with parents of children age 4-17 with AS and nonverbal learning disabilities. The results were alarming. Of the 411 parents surveyed, 94% reported that their child with AS had been bullied at least once in the past year. The acts of maltreatment included physical, emotional, social (i.e., shunning), and

group bullying. When compared to studies of the general population, students with AS were found to be four times more likely to be bullied (Heinrichs, 2003). Indeed, one of the major worries of parents whose children are on the autism spectrum is that their children will be bullied or teased (Heinrichs, 2003). Bullying can have severe long-term effects on a child's physical health and psychological well-being (Rigby, 2003). Thus, it is imperative that educators give students with HFA/AS the tools they need to defend themselves against bullying in the complicated social world in which they live.

Benefits of Social Emotional Learning and of Acquiring

Self-Determination, Self-Advocacy Skills

Enhancing self-determination and self-advocacy skills in individuals with developmental disabilities is associated with numerous positive outcomes, both in and outside of school. A considerable amount of research has been conducted to determine the effects of teaching self-determination skills to students with a variety of developmental disorders that range from mild to severe. The acquisition of self-determination skills has been shown to have a positive impact on school-aged individuals with disabilities by enhancing academic performance (Martin et al., 2003) and increasing participation in class (Gilberts, Agran, Hughes, & Wehmeyer, 2001). When students are taught self-determination and self-advocacy skills during their school years, they also experience more successful post-school transitions (Test, Fowler, Brewer, & Wood, 2005), improved post-school employment status (Wehmeyer & Palmer, 2003), and increased success in completing post-secondary education (Field, Sarver, & Shaw, 2003). Individuals with disabilities who are self-determined also tend to have more independence (Sowers & Powers, 1995), increased goal-oriented behaviour (Wehmeyer, Palmer, Argan, Mithaug, & Martin, 2000), enhanced quality of life (Lachapelle

et al., 2005) and enhanced confidence and self-esteem (Eisenman, Chamberlin, & McGahee-Kovac, 2005; Stevens, 2005).

The SEL framework has also been shown to contribute to healthy development in four major areas: psychological development, social relationships, physical health, and academic performance (Patrikakou & Weissberg, 2007). Research has indicated that fostering SEL skills in typically developing children can lead to increased peer acceptance, augmented sense of self-worth, and enhanced self-confidence (Greenburg et al., 2003; Zins, Weissberg, Wang, & Waldberg, 2004). A meta-analysis conducted by the Collaborative for Academic, Social, and Emotional Learning (CASEL) in 2008 indicated that SEL programming results in fewer conduct problems and less emotional distress (e.g., anxiety and depression), as well as improvements in social and emotional skills; appropriate school behaviour; achievement test scores; and attitudes about oneself, others, and school in general. In short, research indicates that, by providing structured and appropriate opportunities to practice self-determination, self-advocacy, and social and emotional competence, educators support the healthy psychological development of their students (Fiedler & Danneker, 2007). Specific approaches for teaching these skills is the focus of the next section.

Self-Determination and Self-Advocacy Curricula

 In typically developing individuals, self-determination skills develop throughout childhood and flourish across one's lifetime (Sands & Doll, 1996). SEL programming has also been used to promote healthy development in typically developing children (Patrikakou & Weissberg, 2007). This section reviews the self-determination and self-advocacy (SD/SA) curricula that have been designed to promote healthy development in terms of self-determination, self-advocacy, and social emotional intelligence. Although a review of the

SEL curricula is not included here, many of the SD/SA curricula include essential components of the SEL model, as denoted using symbols in Table 2. The majority of the curricula focus on teaching self-determination and self-advocacy skills to individuals who are in their final years of high school – that is, those who are transitioning into the "real world." However, the general consensus is that self-determination and self-advocacy instruction should be initiated much earlier than this, so that individuals can practice the component skills over time (Stang, Carter, Lane, & Pierson, 2008). Researchers in this area assert that individuals of all ages with a wide variety of disabilities can learn self-determination and self-advocacy skills (Test, Fowler, Brewer et al., 2005; Wehmeyer et al., 1998). The reason that many curricula target adolescent youth (ages 17-19) is because adolescence is the transition phase from dependent childhood to independent or interdependent adulthood; thus, during this phase, the development and expression of self-determination is especially critical (Field & Hoffman, 1997).

One of the primary goals of teaching both self-determination and self-advocacy skills to individuals with disabilities is to provide opportunities for these individuals to encounter empowering experiences (Field et al., 1998). Empowerment has been defined as "an intentional, ongoing process, centered in the local community, involving mutual respect, critical reflection, caring and group participation, through which people who are lacking in a equal share of valued resources gain greater access to and control over those resources" (Cornell Empowerment and Family Project, 1990, p. 2). In order to achieve maximum success and truly empower individuals who are learning self-determination and self-advocacy skills, one must consider many elements simultaneously. Thus, it is advantageous

to use an integrated curriculum that addresses the many skills that are required in a coordinated fashion.

Curricula Review

Numerous curricula have been developed for the purpose of promoting self-determination and self-advocacy skills in students with exceptional needs. Fourteen curricula were selected for review in this section, based on the following criteria: (1) the curriculum focuses on teaching at least one of the following components: self-awareness and understanding, goal-setting and attainment, making choices and decisions, personal self-advocacy, self-advocacy for individualized education planning (IEP), self-evaluation, problem solving, communication skills, relationship building, and self-management; and (2) the curriculum was field-tested and/or supported with published, empirical data suggesting its effectiveness with at least school-age students with developmental disabilities. Table 2 summarizes the curricula reviewed.

Table 2

Review of self-determination and self-advocacy curricula

Name of curriculum/ Author(s)	Target age group	Feature									
		Self-awareness and understanding (△○□[1])	Goal-setting and attainment (○□)	Making choices and decisions (○□)	Personal self-advocacy (△○)	Self-advocacy for IEP (△○)	Self-evaluation (○□)	Problem solving (○)	Communication skills (△)	Relationship building (□)	Self-management (○□)
Choicemaker self-determination curriculum: Take action (Huber Marshall et al., 1999)	Middle through high school		X	X			X				
Classroom competency-building program (Abery et al., 1995)	Ages 14-20	X	X	X	X		X	X	X		
Fostering self-determination (Ben et al., 1996)	Not specified	X	X	X	X	X	X	X	X		
Group action planning: An innovative manual for building a self-determined future (Longan Anderson et al. 1995)	Not specified	X	X	X		X		X			

Table 2 Continued

Name of curriculum/ Author(s)	Target age group	Self-awareness and understanding (△○□)	Goal-setting and attainment (○□)	Making choices and decisions (○□)	Personal self-advocacy (△○)	Self-advocacy for IEP (△○)	Self-evaluation (○□)	Problem solving (○)	Communication skills (△)	Relationship building (□)	Self-management (○□)
Next S.T.E.P (Zhang, 2001)	Ages 14-21		X	X		X	X				
Putting feet on my dreams: Units 1-3 (Fullerton & Coyne, 1999)	Ages 16-28	X	X						X		X
Steps to self-determination (Hoffman & Field, 1995)	Ages 15-25	X	X	X				X	X		
Summer transition program (Brinckerhoff, 1994)	College bound students	X	X	X	X			X	X		
Take charge for future (Powers et al., 2001)	Ages 14-17		X			X	X	X		X	

Table 2 Continued

		Feature									
		△○□	○□	○□	△○	△○	○□	○	△	□	○□
Name of curriculum/ Author(s)	Target age group	Self-awareness and understanding	Goal-setting and attainment	Making choices and decisions	Personal self-advocacy	Self-advocacy for IEP	Self-evaluation	Problem solving	Communication skills	Relationship building	Self-management
The road to personal freedom (Ludi & Martin, 1995)	Adolescents	X	X			X	X		X	X	
Whose future is it anyway? (Wehmeyer & Lawrence, 1995)	Ages 15-21	X	X	X		X	X	X	X		
Ezell et al., 1999	Elementary and secondary		X	X			X				
Lehmann et al., 1999	Youth transitioning out of high school	X	X	X	X	X				X	
Zirpoli et al., 1994	All ages				X						

[1]Specification of the model from which each feature is derived is indicated using the following symbols – (△) Test et al.'s (2005) self-advocacy framework; (○) Wehmeyer et al.'s (1998) self-determination model; (□) SEL model.

All but one of the 14 self-determination/self-advocacy (SD/SA) curricula (92.9%) include goal setting and attainment and as key area of focus. This is due to the fact that many students with disabilities leave school without the ability or motivation to set personal goals to guide their future (Wehmeyer et al., 1998). When individuals acquire the skills necessary to set and attain their personal goals, the quality and variety of their everyday experiences are impacted in positive ways (Wehmeyer et al., 1998). Goals that pertain to education/training, employment, and independent living are often the major focus of these curricula.

Ten of the fourteen curricula (71.4%) include how to make choices based on personal preferences and how to make responsible decisions as key areas. There is considerable overlap between these two skills. Choice making involves teaching individuals to recognize their preferences and choose from a variety of preferred alternatives. Decision making requires one to be able to make choices, but is a slightly more complex skill, in that it requires knowledge of how to assess the consequences of all possible actions and make decisions accordingly (Wehmeyer et al., 1998). Unfortunately, many parents and educators assume that individuals with disabilities do not have the capacity either to make informed choices or to make decisions. However, when students with exceptionalities, especially those with significant disabilities, acquire these skills, it positively impacts their quality of life (Wehmeyer et al., 1998).

Self-advocacy is a component of 10 of the curricula (71.4%). Of the four that do not include instruction in this area, two do emphasize the importance of teaching assertive communication, which is an important aspect of self-advocacy. The most common way self-advocacy is taught is by promoting students' active participation in their individualized education plan (IEP) meetings; seven of the curricula foster self-advocacy skills in this

manner. In addition, five curricula include personal self-advocacy skills such as knowledge of rights, speaking up for one's rights, and speaking up for oneself with regard to wants and needs. In addition to these skills, the curricula developed by Lehmann and colleagues (1999) and Zirpoli et al. (1994) focus on teaching individuals to advocate with and for other students with disabilities.

Nine of the fourteen SD/SA curricula (64.3%) focus on teaching self-awareness and self-understanding of one's strengths, abilities, limitations, disability attributes, and unique learning style. Developing self-knowledge is important because positive perceptions and beliefs about oneself contributes to a person's psychological empowerment and self-realization (Wehmeyer et al., 1998). The emergence of positive self-awareness and self-understanding can also result from autonomous behaviours such as making choices and decisions and experiencing success (Wehmeyer et al., 1998). Doll, Sands, Wehmeyer, and Palmer (1996) suggested that students must possess a sound understanding of their strengths, abilities, limitations, and unique learning abilities in order to use this knowledge in a way that enhances their quality of life. Many of the curricula use worksheets and/or visual arts to bring about self-awareness and understanding in students with disabilities.

Eight of the fourteen curricula (57.1%) also emphasize the importance of teaching self-evaluation. The ability to self-evaluate is directly linked to enhanced self-regulation (Wehmeyer et al., 1998). Self-evaluation skills are essential for tracking and assessing action plans for attaining goals, and for evaluating the outcomes of decision making and problem solving. Strategies such as self-observation and self-recording procedures are used to teach self-evaluation within these curricula.

Seven of the SD/SA curricula (50%) include problem solving as a component of self-determination. Teaching problem solving skills is important because problems needing resolution tend to arise on a daily basis for the average person (Wehmeyer et al., 1998). The majority of problem solving interventions incorporate a five-step procedure: (1) identify the problem; (2) list all possible solutions; (3) list the consequences of each solution; (4) based on each consequence, decide which solution will best meet immediate and long-term needs; and (5) implement the chosen solution.

Half of the curricula that were reviewed (50%) include communication skills as a component of the SD/SA intervention. Communication strategies such as effective listening, turn taking, appropriate body language, reading social cues (i.e., other people's body language), negotiation, persuasion, assertiveness, and compromise are typically emphasized. Role-playing is the most common strategy used to teach communication skills.

Three of the curricula (21.4%) promote relationship development with members of either a school-support team or members of the community. Youth with developmental disabilities, especially those with HFA/AS, are at high risk for social and emotional difficulties. It is a well-documented phenomenon that resiliency can be fostered in at risk youth when they have at least one secure relationship in their life (Luthar, 2003). The majority of the SD/SA curricula place an emphasis on establishing secure relationships between students with disabilities and the members of their school support teams. In addition, one of the schools that participated in the intervention developed by Lehmann and colleagues (1999) promoted relationship development among members of the community and among members of a student club that consisted of students with and without disabilities.

Only one curriculum (Fullerton and Coyne, 1999) includes self-management as a core component. In this curriculum, which was the only curriculum reviewed that was specifically designed for individuals with ASD, participants were taught to recognize their own coping strategies and learn about the coping strategies others use when faced with various obstacles and challenges. Self-management skills are one of the essential components of social and emotional competence (Patrikakou, & Weissberg, 2007).

<div align="center">**Formative and Summative Evaluations**</div>

Schonert-Reichl (2008) noted that, when developing and evaluating the effectiveness of a new curriculum, the evaluation process is not as straightforward as one might assume. Many (potentially successful) programs that aim to promote healthy psychological development in children and adolescents undergo "death by evaluation" (Datta, 2003, p. 5) when outcome studies are conducted before a program's general feasibility has been established with a particular target population in a specific context/setting. Schonert-Reichl proposed that multiple stages of evaluation should be considered and implemented, as appropriate. The Prevention Research Center at Penn State University (www.prevention.psu.edu) described three phases of evaluation that newly developed intervention programs should undergo:

1) Formative Evaluation - an evaluation designed to provide insight during the early developmental phase of an intervention. This evaluation phase asks the following three questions: a) Is it feasible to implement this intervention with this at-risk population?; b) What is the appropriateness of the content, materials, methods, and instruments for the target population?; and c) What are the immediate or short

term effects of the intervention? This evaluation phase does not require a control group.

2) Efficacy Evaluation – an evaluation designed to provide information regarding the internal validity of the intervention. This evaluation phase requires a control group in order to demonstrate that a functional relationship exists between the intervention and the results.

3) Effectiveness Evaluation – an evaluation designed to provide information regarding the external validity of an intervention. This evaluation phase also requires a control group in order to demonstrate a functional relationship between the intervention and the results across a large, representative sample of a particular population, under normal program-practice conditions.

When researchers adhere to this protocol for conducting evaluations of newly developed curricula, they can be assured that new educational programs are not dismissed prematurely and are modified appropriately to benefit those for whom they are intended.

Research Problem

Although it is clear that a variety of SD/SA curricula already exist, none of the curricula reviewed incorporate all of the essential components for self-determination, self-advocacy, and social emotional learning (see Table 2). In addition, although many studies have utilized SD/SA interventions for youth with developmental disabilities, only one (Fullerton & Coyne, 1999) was designed for students with ASD; and none have targeted individuals with HFA/AS who are in early to middle adolescence (11-16 years old). Self-determination, self-advocacy, and instruction in social and emotional competence is important for students with HFA/AS because exposure to ongoing negative encounters and

lack of guidance during the transition from childhood to adulthood has been linked to many long-term risks, including underachievement, prolonged dependency on parents, unhappiness, and vulnerability to mental health problems (Portway & Johnson, 2005). In addition, because individuals with HFA/AS are not physically distinguishable from their peers but experience numerous difficulties with social skills and social communication, they are often marginalized and isolated at school and may even experience teasing, victimization, and bullying from peers (Heinrichs, 2003). Thus, promoting relationship development and teaching these individuals how to advocate for themselves and for other students with ASD is critically important. In order to accomplish this, there is need for a novel, integrated SD/SA curriculum that incorporates all of the essential components of the three models previously discussed and is targeted at youth with HFA/AS.

The purpose of the proposed research was to conduct a formative evaluation of the STAAR (Students Teaching About Autism Reality) curriculum, a novel group SD/SA intervention for adolescents with HFA/AS. This study was designed to address the following questions:

1) How do adolescents with HFA/AS score on measures of self-determination, self-concept, and within group friendship development prior to intervention, post-training, post-practice via public panel discussions, and at 2-month follow-up?

2) How do participants with HFA/AS and their parents evaluate the SD/SA intervention? and

3) How do audience members who attend the panel discussions evaluate the performance of the participants?

CHAPTER 2

Research Methodology

The protocol and consent forms for this study were submitted to the UBC

Behavioural Research Ethics Board and approved on September 25, 2009 (see Appendix A).

Participants

Six adolescent males with HFA/AS participated in the study. They were recruited

through an ASD parent network and met the following criteria: (a) ages 11-18; (b) aware of

their HFA/AS diagnosis with an understanding of what HFA/AS means; (c) able to

communicate verbally; (d) able to sit and attend for up to one hour at a time; (e) available to

participate in a series of six group SD/SA training sessions; (f) available to attend at least 4

out of 6 evening panel discussions in the Lower Mainland/Fraser Valley of British Columbia;

(g) comfortable answering questions from an audience about their experiences as an

adolescent with HFA/AS; and (h) have a parent/caregiver willing to provide transportation to

the training sessions and the panel discussions.

During an initial interview, potential participants met with the researcher to discuss

the purpose of the study, review the eligibility criteria, and make a decision about their

participation. All six adolescents who participated in the initial interview met the study

criteria and completed the participant assent form (see Appendix B). Their parents signed the

parental consent form (see Appendix C).

To verify their children's diagnoses of HFA/AS, all participants' parents completed

the adolescent version of the Autism-Spectrum Quotient (AQ) developed by Baron-Cohen,

Hoekstra, Knickmeyer, and Wheelwright (2006). The AQ is brief survey instrument that

measures the degree to which an adolescent shows traits related to autism in the following

five areas: 1) communication; 2) social; 3) imagination; 4) attention to detail; and 5) attention switching. The AQ was standardized using three groups of participants: a) a group consisting of students with HFA/AS (mean age = 13.6); b) a group of students with autism (mean age = 12.5); and c) a group of neurotypical students (mean age = 13.6). Reliability was high in each of the five domains: 1) communication (Cronbach's α coefficient = 0.82); 2) social (α = 0.88); 3) imagination (α = .81); 4) attention to detail (α = .66); and 5) attention switching (α = .76). Test-retest reliability for the AQ was also high (r = .92). The AQ accurately differentiates between adolescents with and without a diagnosis of ASD. Adolescents with HFA/AS score above 30 on the AQ, whereas typically developing individuals will score below 30. Higher AQ scores indicate more traits related to autism.

Table 3 summaries demographic and diagnostic information for all six participants; all names are pseudonyms.

Anders. Anders is a creative and energetic 16-year-old with AS who lives at home with his mother, father, and two younger brothers. He is down-to-earth, confident, caring, and passionate about educating others about what it means to have ASD. He attends his neighbourhood secondary school where he enjoys playing in the school band, skateboarding, and hanging out with his skater friends. During his leisure time, Anders plays the guitar and videogames and collects Lego. Academically, Anders excels in math, science, and physics. However, he has difficulty with writing, time management, and articulating how he feels in an effective manner when he is upset.

Table 3

Participant demographics and diagnostic information

Name	Age at start of intervention	Grade	School	Ethnicity	Diagnosis	Diagnosed by	Age of diagnosis	Autism Quotient score
Anders	16.4 yrs	11	Secondary school	Euro-Canadian	Asperger's syndrome	Multidisciplinary diagnostic team	10 yrs	34
Brad	13.0 yrs	8	Secondary school	Taiwanese-Canadian	Asperger's syndrome	Multidisciplinary diagnostic team	10 yrs	30
Bobby	16.2 yrs	11	Virtual school	Euro-Canadian	Autism (HFA)	Multidisciplinary diagnostic team	12 yrs	32
Edgar	12.9 yrs	7	Elementary school	Mexican-Canadian	Autism (HFA)	Developmental pediatrician	3 yrs	43
Ethan	11.11 yrs	7	Middle school	Euro-Canadian	Asperger's syndrome	Child psychologist	9 yrs	30
Holden	14.6 yrs	9	Secondary/ home school	Taiwanese-Canadian	Asperger's syndrome	Psychiatrist	8 yrs	38

Brad. Brad is a smart, creative, literal 13-year-old with AS who lives with his mother, father, and younger brother. He is quiet, easy-going, and tends to follow the crowd. Brad attends his neighbourhood secondary school where he plays in the school band. He is passionate about music and playing instruments, especially the piano. He also enjoys playing videogames, reading, watching movies, and learning. Brad excels in math, science, and any task that allows his creativity to shine. Brad struggles with reading social cues and understanding when people are teasing/joking with him and when they are being serious.

Bobby. Bobby is a quiet, sincere 16-year-old with HFA. He is the second youngest of six siblings and lives at home with his parents and younger brother. Bobby is easy-going and very observant. Once he overcomes his shyness, he is very articulate. He attends a virtual school where he spends approximately 2.5 hours/day at the school receiving one-to-one tutoring and extra help from his teachers, and the rest of his day doing school work from home. Bobby is interested in horseback riding and geocaching. He is technologically gifted and excels at drafting and woodworking. Bobby has difficulty with math, spelling, and socializing in group settings.

Edgar. Edgar is an effervescent, quirky boy with HFA who lives at home with his mother, father, and older sister and was 12 years old at the start of the study. Edgar is a passionate and animated young man who attends his local elementary school. He enjoys playing trading card games, videogames, and watching movies. Edgar has good literacy skills and is technologically inclined. Edgar has some difficulty with spelling and engaging socially in a large crowd of people. When speaking quickly, Edgar also struggles with clear articulation.

Ethan. Ethan is an imaginative, optimistic boy with AS who turned 12 shortly after the start of the study and lives with his aunt and uncle. Ethan attends his local middle school, is quite talkative, and displays a positive outlook in most situations. Ethan enjoys playing video games, drawing, watching movies, and organizing parties. Academically, he is good at spelling and math. Ethan has some difficulties with writing tasks and struggles to acknowledge the challenges that come with having AS. He also resists following directions when he is asked to do something that he perceives as difficult or outside of his comfort zone.

Holden. Holden is a smart, articulate young man with AS who was 14 years old at the start of the study. At that time, he lived at home with his mother; his father visits twice annually from Taiwan. Due to problem behaviours and numerous medication changes, Holden moved into a group home approximately 5 months into the study so that he could be supported by trained staff at all times. Holden is very passionate about teaching others that individuals with HFA/AS should be treated equally and with respect, and that they can make significant contributions to society. Holden began the study in his neighbourhood secondary school and then transferred to a home school program. Holden is skilled at memorizing details and solving difficult math questions. He has a passion for high speed railways and the various forms of government throughout the world. One of Holden's biggest challenges is controlling his temper in upsetting or overwhelming situations.

Dependent Variables and Measurement

Six dependent variables were measured in this study: (1) self-determination skills; (2) self-concept/self-esteem; (3) friendship closeness; (4) participant satisfaction; (5) parent

satisfaction; and (6) audience satisfaction. Measures related to each of these variables are described in the sections that follow.

Arc's Self-Determination Scale for Adolescents. The Arc's Self-Determination Scale for Adolescents (ASDSA), developed by Wehmeyer and Kelchner (1995), is a 72-item self-report measure that was developed to promote self-efficacy and to empower adolescents with mild disabilities to share their thoughts and feelings about areas related to self-determination in their lives (e.g., choice making, goal setting) (Wehmeyer, 1995). The scale measures abilities in the four essential areas of self-determination: acting autonomously, self-regulation, responding to events in a psychologically empowered manner, and acting in a self-realizing manner. Higher scores on this measure are indicative of stronger self-determination skills. The scale was standardized based on responses of 500 individuals aged 14-22 (mean = 17.08) with mild mental retardation and/or learning disabilities. The ASDSA has high internal consistency reliability (Cronbach's α coefficient = .90). The α coefficient was also calculated for each domain, with the exception of the self-regulation subscale since this section consists of open ended questions: autonomy (α = .90); psychological empowerment (α = .73); and self-realization (α = .62). The relatively low α coefficient for the self-realization subscale is typical for measures that assess one's perceptions and beliefs (Wehmeyer, 1995). In the present study, this scale was used to determine if participants became more self-determined over the course of the intervention.

Piers-Harris Children's Self-Concept Scale-2. The Piers-Harris Children's Self-Concept Scale-2 is a 60-item self-report measure that assesses self-concept in children aged 7-18 (Piers, Harris, & Herzberg, 2002). It is used to measure self-concept by assessing the following six domains: behavioural adjustment, intellectual and school status, physical

appearance and attributes, freedom from anxiety, popularity, and happiness and satisfaction. High scores within these domains are indicative of positive self-concept. The scale has been used with children both with and without disabilities. Standardization of this measure is based on large sample of 7-18-year-old students from various ethnic backgrounds from across the United States. The Piers-Harris has high overall internal consistency, as well as in all six domains (see Table 4). Test-retest reliability data are not available for the Piers-Harris-2; however, studies that examined this property of the original Piers-Harris (which has 20 additional items) found the reliability to be high, with Kappa coefficients ranging from .65 to .96. Studies that focused on individuals with special needs had test-retest reliability coefficients ranging from .42 to .96. Reliability was found to be highest when test-retest intervals were short (i.e., less than 4 weeks). Increased self-esteem has been found in adolescents who are self-advocates (Eisenman et al, 2005); thus this scale was used to determine if participants experienced gains in self-concept over the course of the intervention.

Table 4

Internal consistency for the Piers-Harris Children's Self Concept Scale, 2nd edition (Piers &

Herzberg, 2007)

Self-Concept domain	α for total standardized sample	α coefficient by age group					
		Age 7-8	Age 9-10	Age 11-12	Age 13-14	Age 15-16	Age 17-18
Total	.91	.89	.92	.92	.91	.93	.89
Behaviour adjustment	.81	.75	.84	.81	.81	.81	.76
Intellectual and school status	.81	.76	.82	.81	.82	.82	.72
Physical appearance and attributes	.75	.72	.75	.80	.77	.73	.65
Freedom from anxiety	.81	.77	.82	.82	.82	.84	.80
Popularity	.74	.60	.72	.80	.79	.78	.62
Happiness and satisfaction	.77	.71	.82	.78	.77	.78	.71

Adolescents' Friendship Closeness measure. The measure of Adolescents'

Friendship Closeness (AFC) was developed by Beadnell et al. (2007) and adapted for use in

this study (see Appendix D). It is an 11-item measure that was designed to examine

friendships within groups of adolescents. Seven items on the measure are completed with

reference to each member of a group and an additional four questions are generic; thus, for

this group of six members, the entire assessment consisted of 46 items. Reliability and

validity of this measure were examined using a group of 454 adolescents aged 12 to 15. This measure was found to have strong internal reliability (α coefficient = .90). In this study, the AFC was used to determine how strong pre-existing friendships were within the group, to identify any friendships that developed during the course of the intervention, and to examine group closeness among members of the group.

Satisfaction surveys. Three satisfaction surveys were developed specifically for this study. Participants completed a brief 15-item survey (see Appendix E) that examined which aspects of the SD/SA intervention they liked and disliked, how they felt about being part of the study, and how their school year was in general. Twelve of these items measured personal opinions based on a five point Likert-type scale. Three of the items were open-ended questions. Participants' parents also completed a short 10-item survey (see Appendix F) that included questions regarding any changes they noticed in their child's self-esteem, self-determination skills, and friendships over the course of the study, as well as questions pertaining to their child's school year. One of these questions used a five point Likert-type scale and the remaining nine items were open-ended questions. Finally, audience members who attended one of the SD/SA panel discussions related to the intervention also completed a satisfaction survey (see Appendix G) to evaluate their perceptions of the panel. This satisfaction survey consisted of 17 items, 10 of which were based on a five-point Likert-type scale, with five additional open-ended questions and two closed-ended questions.

Research Design

This study employed a one group pretest multiple-posttest design, with posttest measures collected at three time points (Bonate, 2000). This design provides a straightforward method for assessing the utility of an intervention by comparing differences

in the dependent variables at specified time points throughout the study. The main limitation of this design is that one cannot control for confounding variables, making it difficult to interpret treatment utility (Bonate, 2000). For example, in this study, the changes in scores of self-concept/self-esteem may have been masked if a participant endured extensive bullying during the period of the study. On the other hand, self-concept and self-esteem measures may have been inflated if a participant had unusually successful academic or social experiences over the course of the study. However, because that this was a novel curriculum and the purpose of the study was to conduct a formative evaluation, the research design was appropriate and did not require a control comparison group.

The pre- and posttest measures included the ASDSA, the Piers-Harris Children's Self-Concept Scale, and the AFC. The first posttest corresponded to the end of the SD/SA training phase, in which participants received public speaking, self-determination, self-advocacy, and social skills instruction in a group setting (October 2008-February 2009). The second posttest corresponded to the completion of the SD/SA panel sessions, in which participants practiced the skills learned during the six training sessions during panel discussions that were part of six community events throughout the Lower Mainland of British Columbia (February-July 2000). At the second posttest time point, participants and their parents both completed satisfaction surveys. The third posttest occurred two months after completion of the panel phase (September 2009), to examine intervention maintenance. In addition, following each community event during the panel sessions, audience members completed a satisfaction survey related to the community event as a whole.

Procedure

The research procedures consisted of: (a) an initial interview between each participant and the researcher and collection of the pretest measures of self-determination, self-concept, and friendship closeness; (b) six group SD/SA training sessions, followed by completion of the first set of post-test measures; (c) six SD/SA panel sessions during community events (including one brush-up training session), followed by completion of the second set of posttest measures as well as participant and parent surveys; and (d) completion the third set of posttest measures, 2 months after completion of the panel sessions.

Interviews and pretest measures. The researcher traveled to the participants' homes for the initial interview and administered the pretest measures after all consent forms were signed. Although all of the participants have adequate literacy skills, they were given the choice of reading and completing the measures on their own or having the researcher read the questions aloud and/or transcribe their responses. Holden and Ethan chose to have one or more of the questionnaires read aloud; and Holden, Ethan, Bobby, and Anders chose to have the researcher transcribe their responses on one or more of the measures.

SD/SA training sessions. During this phase, participants took part in six 2-hour training sessions that were held approximately every two weeks for a 3-month period. These training sessions focused on preparing the participants for the panel phase of the intervention where they would participate in a panel discussion following the screening of a film titled "The Boy Inside" (Kaplan, 2006), about a teenager with AS who experienced bullying in his school. The film was screened at six community events aimed at promoting ASD awareness. The training sessions were held on Saturday afternoons at a centrally-located community centre and were led by the researcher, with the assistance of a colleague. During the training,

participants received public speaking, self-determination, self-advocacy, and social skills instruction via the STAAR curriculum (see Appendix H). Each SD/SA training session also focused on teaching several specific self-determination skills.

Across all training sessions, a variety of instructional techniques were utilized to support the participants in SD/SA activities. These included verbal prompting/fading; role playing; modeling; one-to-one and group verbal feedback; one-to-one and group video feedback; opportunities for self-evaluation; and positive reinforcement in the form of praise, small tangible items, and opportunities to play videogames, contingent on desired behaviors.

The goals of the first training session were for the six group members to (a) get to know one another, (b) become familiar with the film "The Boy Inside" (Kaplan, 2006) and the purpose of the study, (c) participate in a group discussion about the film and friendship in general, and (d) set personal goals for the project. Since participants would be educating others about ASD and sharing their personal experiences during the panel discussions, the second training session focused on promoting self-awareness and disability awareness. This consisted of activities that enabled students to identify their interests, strengths, weaknesses, and attributes associated with ASD. During the second training session, the researcher also began public speaking and problem solving instruction. Public speaking and problem solving skills were included in each subsequent SD/SA training session.

The focus of the third SD/SA training session was communication skills. Students were taught active listening skills and effective communication strategies (e.g., speaking slowly, clearly, and concisely) and participated in various activities to practice these skills. The fourth SD/SA training session consisted of teaching the participants to use effective listening strategies and self-management techniques. During this session, participants also

watched a videotaped panel discussion in order to become familiar with the format of this type of experience. During the fifth training session, participants had an opportunity to practice all of the skills learned in previous sessions by participating on a mock panel (with no audience) and performing self-evaluations while watching a video playback of the mock panel. Finally, the sixth session was a mock panel discussion with a real audience that consisted of UBC graduate students. During this session, participants were able to practice all of the previously learned skills in vivo. In addition to fostering SD/SA skills among these students, the adolescents were given 15 minutes at the end of each session to hang out and play video games – an opportunity for relationships to flourish.

SD/SA panel sessions. During the second phase of the intervention, the participants practiced their self-advocacy, public speaking, and social skills as they participated in public panel discussions during which they shared their experiences as adolescents with HFA/AS. The panel discussions were associated with community events that were designed to generate awareness and build more inclusive communities in the Lower Mainland for youth with HFA/AS in general. Table 5, on page 43, lists the venues, months, and audience sizes for each of the community events.

Each community event began with a screening of the award-winning documentary "The Boy Inside," (Kaplan, 2006) a 45-minute film about Adam, a teenager with AS who struggles to fit in at school and to form and maintain meaningful relationships. Following each film screening, the six adolescents participated in a panel discussion that was moderated by the researcher. During the panel discussion, which lasted approximately 30 minutes per event, the participants each introduced themselves briefly and then shared their personal experiences about HFA/AS in response to questions from the audience. Each event

concluded with an informal "meet-and-greet" session during which audience members were given the opportunity to speak personally with the participants.

Table 5

Community event venues and attendance

City	Month	Venue	Audience Size
Abbotsford	February	University of the Fraser Valley	138
North Vancouver	March	Sutherland Secondary School	144
Richmond	May	Richmond Cultural Centre	120
Vancouver	June	Langara College	90
Vancouver	June	Fifth Avenue Cinema	200
Surrey	July	Surrey Arts Theatre	400

Due to the large time gap between the North Vancouver and Richmond events (i.e., more than 2 months), an additional training session was held in early May, 2009. During this session, the adolescents participated in public speaking, communication and self-determination activities (see Appendix H, Lesson 7). During this time, the adolescents also spent 60 minutes together in a social context in which they played video games, ate pizza, and hung out.

CHAPTER 3

Results

Overview

Results of the utility of the SD/SA group intervention are presented in this chapter. The goals of the study were to: a) determine how the participants of the SD/SA group intervention scored on measures of self-determination, self-concept, and friendship development prior to intervention, post-training, post-panel, and at two-month follow-up; b) establish how the participants in the study and their parents evaluated the SD/SA intervention; and c) examine how audience members who attended the panel discussions evaluated the SD/SA group members' performance.

Test scores for the ASDSA and the Piers-Harris Children's Self-concept Scale-2 are displayed graphically. Results from the AFC measure are displayed in a table. The presence of a correlational relationship between the independent and dependent variables was assessed by examining the changes in test scores over time for each participant. Participant, parent, and audience evaluations are displayed graphically, textually, and in a table, respectively, and are analyzed qualitatively.

Self-Determination Results

In this section, the results are presented for the Arc's Self-Determination Scale for Adolescents (ASDSA). The scale measures self-determination in terms of autonomy, self-regulation, psychological empowerment, and self-realization – the four essential components of self-determined behaviour. Higher scores in each of these four domains are indicative of stronger self-determination skills.

Results for this measure are presented in graphic form for each participant. Raw data from the ASDSA was converted into "positive scores" that reflect the percentage of responses within each domain that were indicative of the participant having self-determination skills. No criteria are provided in the ASDSA manual with regard to the amount of change within each domain that constitutes "meaningful change" (Wehmeyer, 1995). Therefore, results from the self-determination measure were analyzed visually and are reported descriptively.

Anders. Figure 1 illustrates the results for Anders from the ASDSA. Anders entered the project with at least 50% positive scores in all areas and showed slight variability and improvement between baseline and follow-up, especially in the area of self-realization. Post-panel changes were noted in self-regulation, but the results did not persist into follow-up.
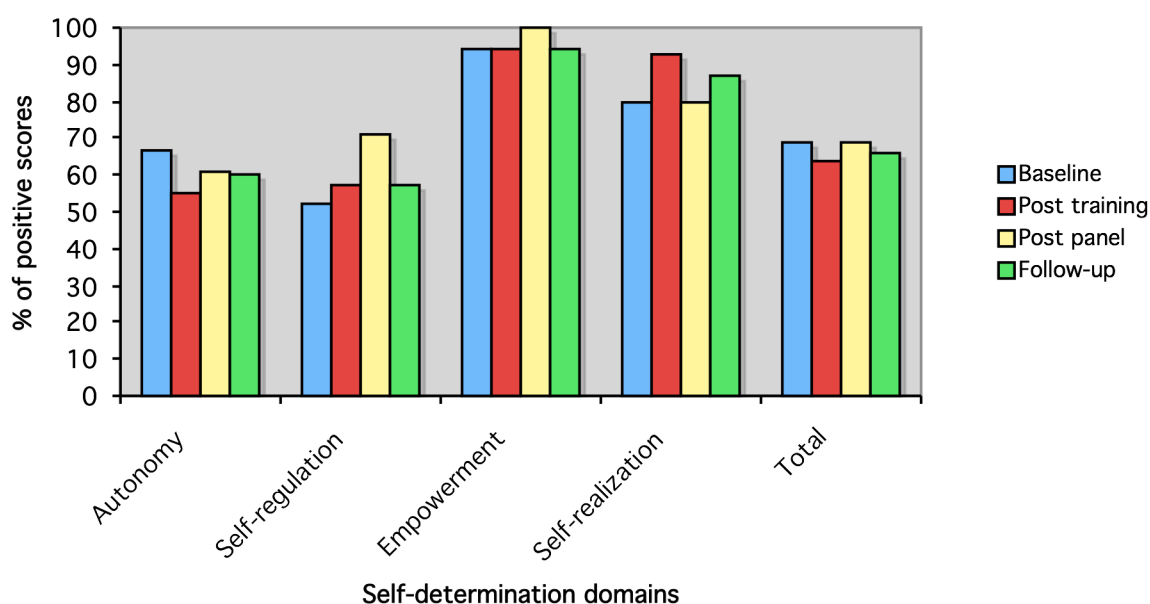

Figure 1. Arc's Self-Determination Scale results for Anders.

Brad. Figure 2 reveals the ASDSA results for Brad. Brad entered the project with at least 50% positive scores in empowerment and self-realization and, like Anders, showed slight variability and improvement between baseline and follow-up, especially in the areas of psychological empowerment and self-realization. Increases were apparent in self-regulation both post-training and post-panel, but these changes were not lasting.
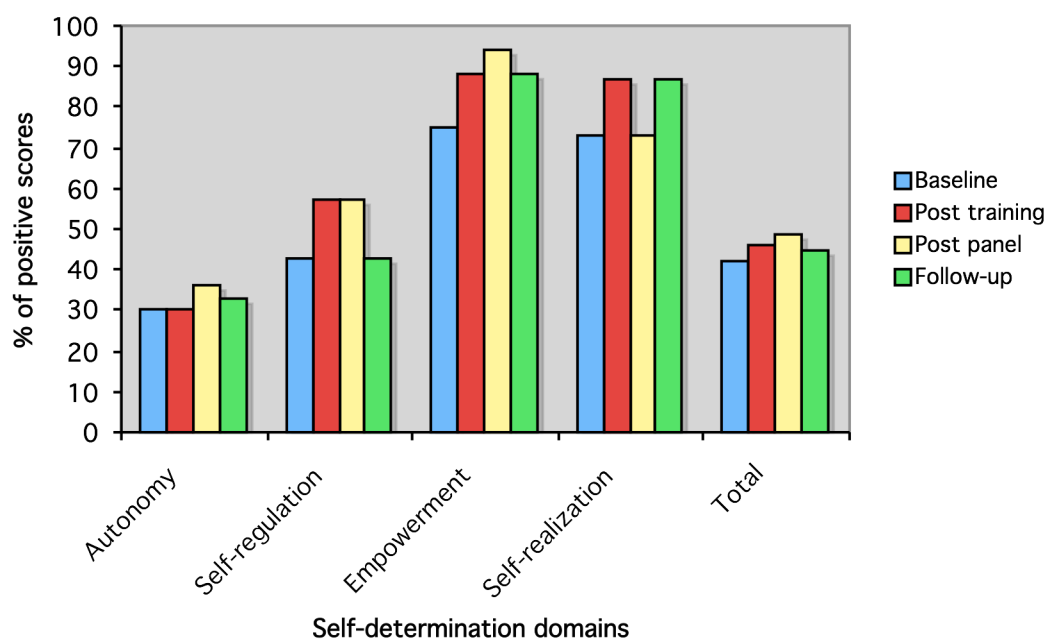
Figure 2. Arc's Self-Determination Scale results for Brad.

Bobby. Figure 3 shows the ASDSA results for Bobby. Bobby entered the project with at least 50% positive scores in all areas. Scores increased throughout the course of the study, especially in the self-regulation and psychological empowerment domains. Autonomy increased post-panel but the results were not lasting.
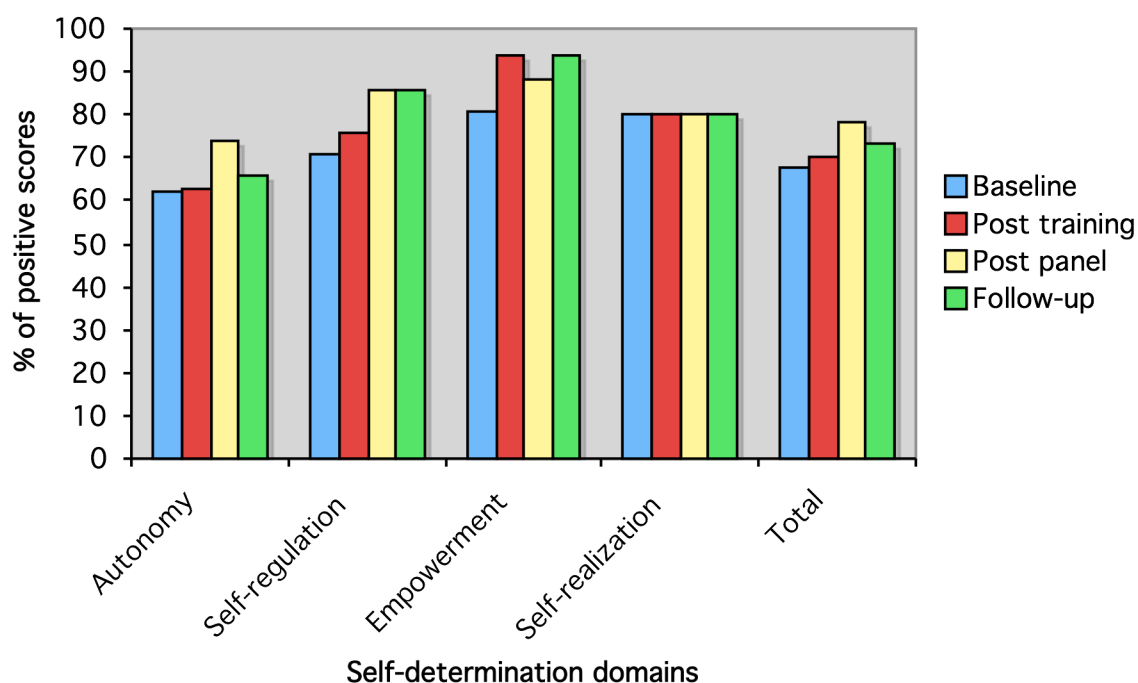

Figure 3. Arc's Self-Determination Scale results for Bobby.

Edgar. Figure 4 illustrates the ASDSA results for Edgar. Edgar entered the study with at least 50% scores in the areas of psychological empowerment and self-realization. Self-determination scores increased between baseline and follow-up in the following three domains: self-regulation, psychological empowerment, and self-realization. Autonomy scores increased post-training but the results were not lasting.
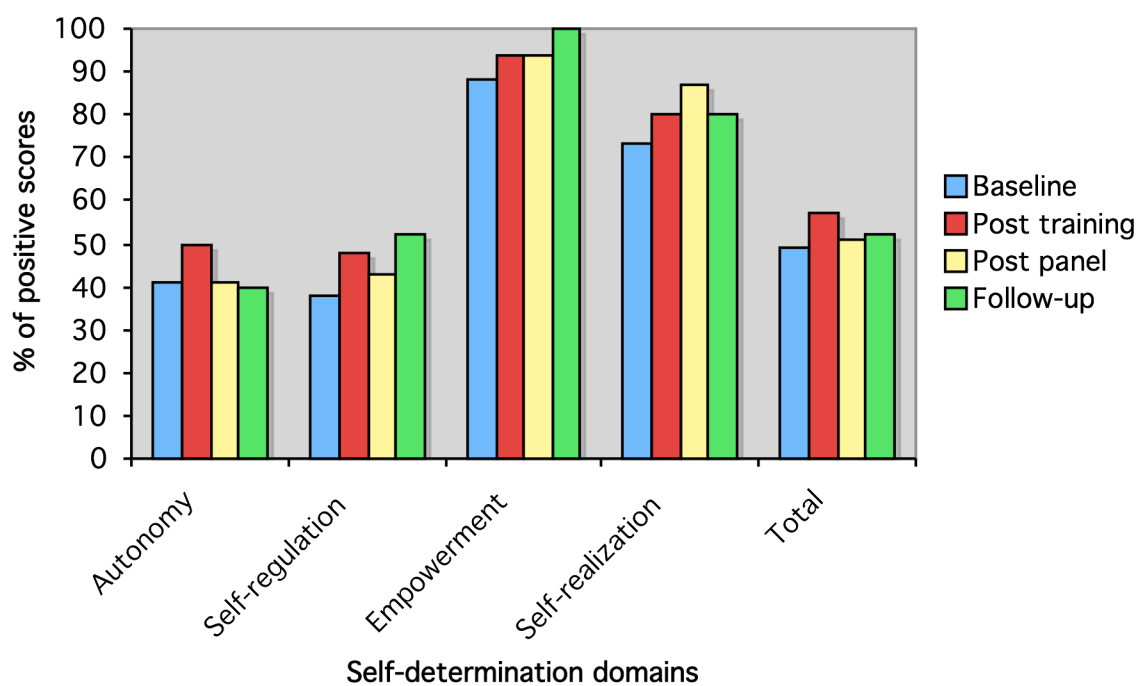

Figure 4. Arc's Self-Determination Scale results for Edgar.

Ethan. Figure 5 shows the ASDSA results for Ethan. Ethan entered the study with at least 50% positive scores in all self-determination domains. All domains showed slight variability, with improvements between baseline and follow-up in the areas of self-regulation and self-realization.
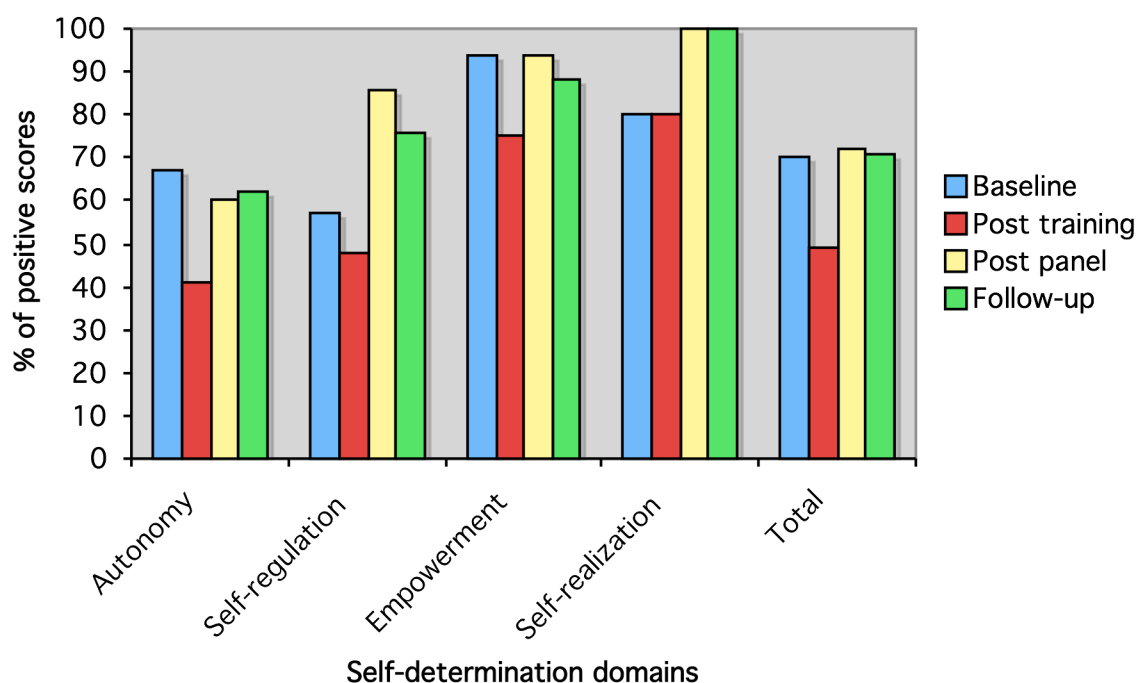

Figure 5. Arc's self-determination scale results for Ethan.

Holden. Figure 6 shows the ASDSA results for Holden. Holden entered the study with self-determination skills of at least 50% positive scores across all domains. Over the course of the study Holden's autonomy, psychological empowerment, self-realization, and total self-determination scores decreased and his self-regulation scores increased. Holden experienced a slight increase in his psychological empowerment scores post-panel, but this improvement was not lasting.
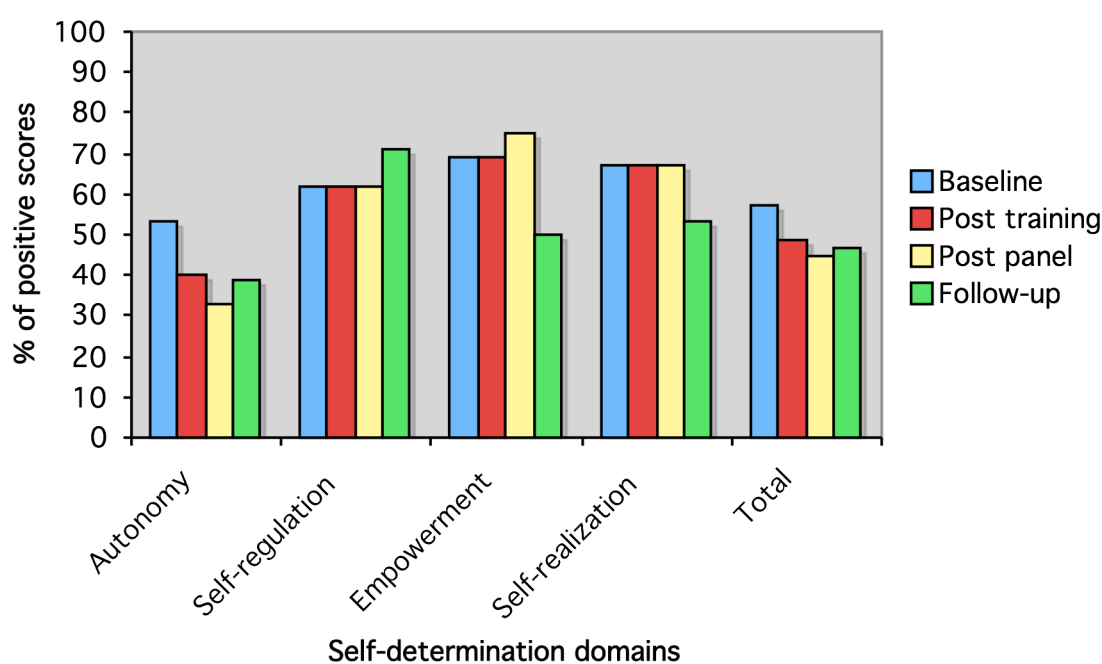

Figure 6. Arc's Self-Determination Scale results for Holden.

Table 6 summarizes the ASDSA across all participants. The self-regulation, empowerment, and self-realization domains showed increases in 50% or more of the participants. Only Holden's total scores showed evidence of a decrease.

Table 6

Summary of changes in Arc's Self-Determination Scale scores

Name	Autonomy	Self-regulation	Empowerment	Self-realization	Total
Anders	Ø	Ø	Ø	+	Ø
Brad	Ø	Ø	+	+	Ø
Bobby	Ø	+	+	Ø	Ø
Edgar	Ø	+	+	+	Ø
Ethan	Ø	+	Ø	+	Ø
Holden	-	+	-	-	-

Note. (+) indicates an increase in positive scores; (-) indicates a decrease in positive scores; (Ø) indicates no meaningful change.

Self-Concept Results

This section describes the results from the Piers-Harris Children's Self-Concept Scale-2. This measure was used to assess self-concept/self-esteem for each participant by asking questions that pertained to the following six domains: behavioural adjustment (BEH), intellectual/school status (INT), physical appearance/attributes (PHY), freedom from anxiety (FRE), popularity (POP), and happiness/satisfaction (HAP). Higher scores within these domains are indicative of a more positive self-concept.

Results of the Piers-Harris are presented as normalized T-scores. T-scores are a useful tool for interpreting and comparing data across several domain scales. To derive a t-score, a raw score is converted to follow a normal distribution with a mean of 50 and a standard deviation of 10 (Piers & Herzberg, 2007). This allows scores to be compared across domains, even when the domains themselves have different raw score maximums. T-scores can also be

used to determine how a child's Piers-Harris scores compare to the children in the standardization sample. Piers and Herzberg (2007) provided a listing of interpretive ranges for the Piers-Harris Scale-2 t-scores as follows: very low self-concept (≤29T), low (30T-39T), low average (40T-44T), average (45T-55T), and above average (≥56T).

For the purpose of this study, "meaningful change" in a self-concept domain was defined as change in one or more interpretive ranges, in either direction, between baseline and follow-up. Visual analysis of graphed t-scores for each participant was used to determine whether meaningful change occurred. Post-training and post-panel scores are also included in the graphs for the sake of completeness. Results are presented for each participant in the sections that follow.

Anders. Figure 7 shows the Piers-Harris t-score results for Anders. Overall, self-concept scores for Anders were in the low average to average range across all domains throughout the study. Meaningful change was not evident in any domain from baseline to follow-up.
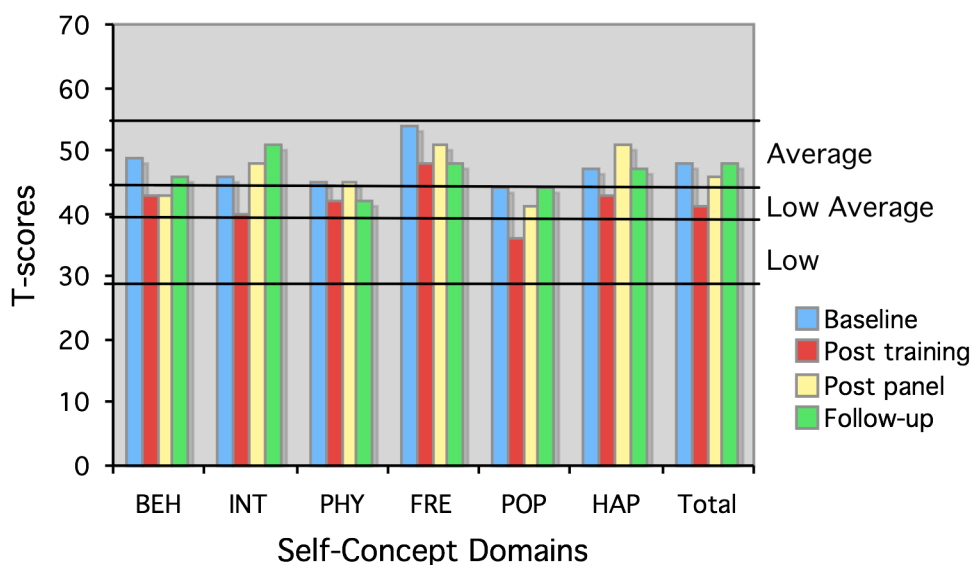

Figure 7. Piers-Harris Children's Self-Concept Scale-2 results for Anders.

Brad. Figure 8 shows the Piers-Harris results for Brad. Self-concept scores for Brad remained consistent throughout the course of the study. His scores across domains ranged from low to above average. Meaningful change was not evident in any domain from baseline to follow-up.
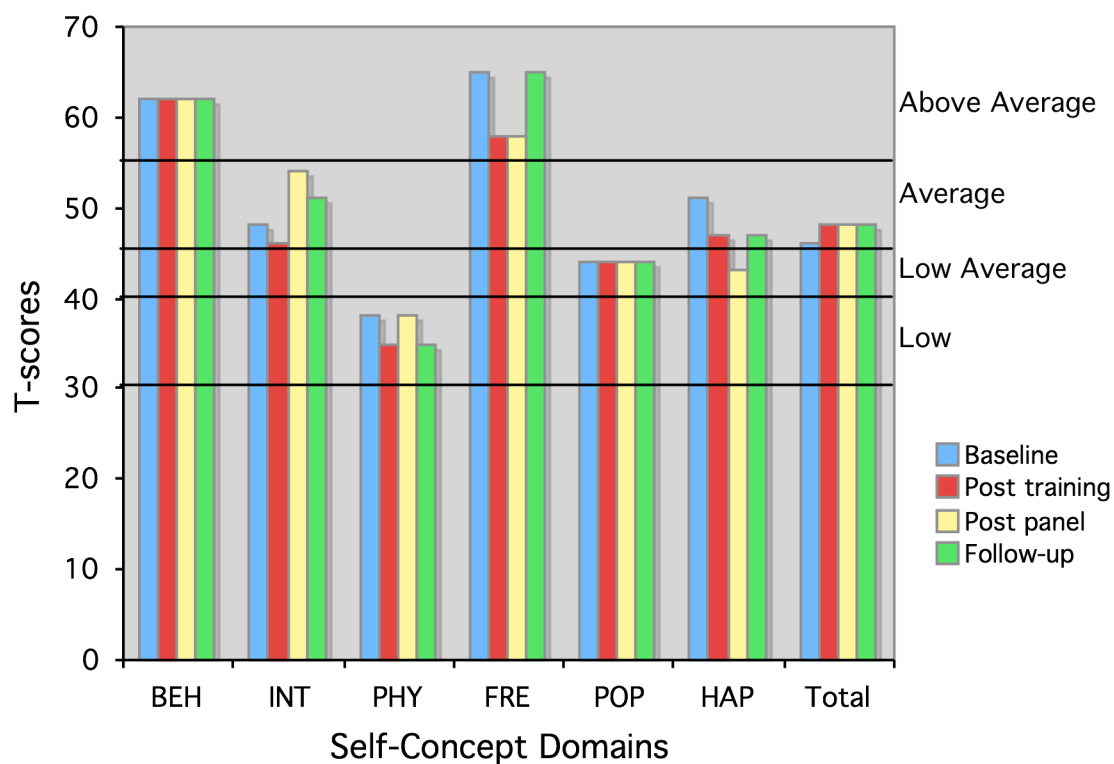

Figure 8. Piers-Harris Children's Self-concept Scale-2 results for Brad.

Bobby. Figure 9 shows the Piers-Harris results for Bobby. Bobby experienced meaningful change in four of the six domains as well as in his total score. Gains were made in both intellectual/school status and happiness/satisfaction, both of which started in the low average range and increased to above average at follow-up. The physical appearance/attributes and freedom from anxiety domains also showed evidence of meaningful change, from average at baseline to above average at follow-up. No change was evident in behavioral adjustment or popularity. Overall, Bobby's total self-concept entered the above average range during the post-panel phase and remained there at follow-up.
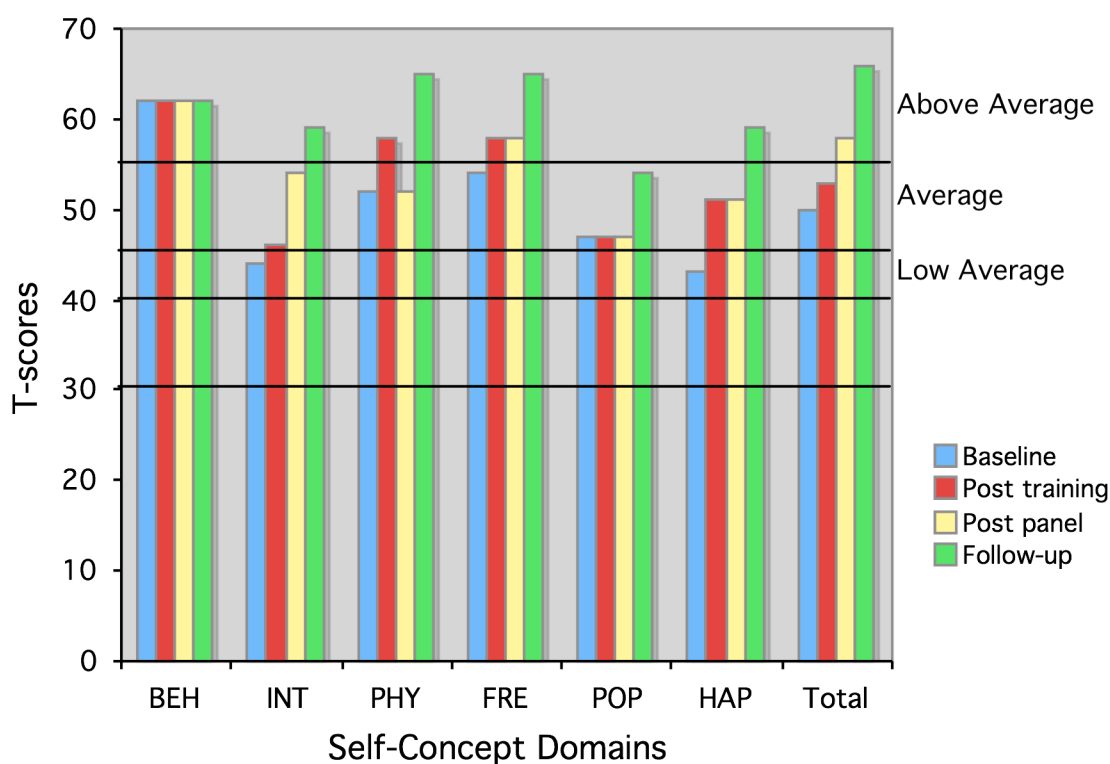

Figure 9. Piers-Harris Children's Self-concept Scale-2 results for Bobby.

Edgar. Figure 10 shows the Piers-Harris results for Edgar. Meaningful positive change occurred in two of the six Piers-Harris domains for Edgar. His behavioural adjustment scores increased from low average to average between baseline and follow-up; and his freedom from anxiety scores increased from average to above average at follow-up. Scores in intellectual/school status, physical appearance/attributes, popularity, and happiness/satisfaction fluctuated somewhat but, in general, remained stable from baseline to follow-up.
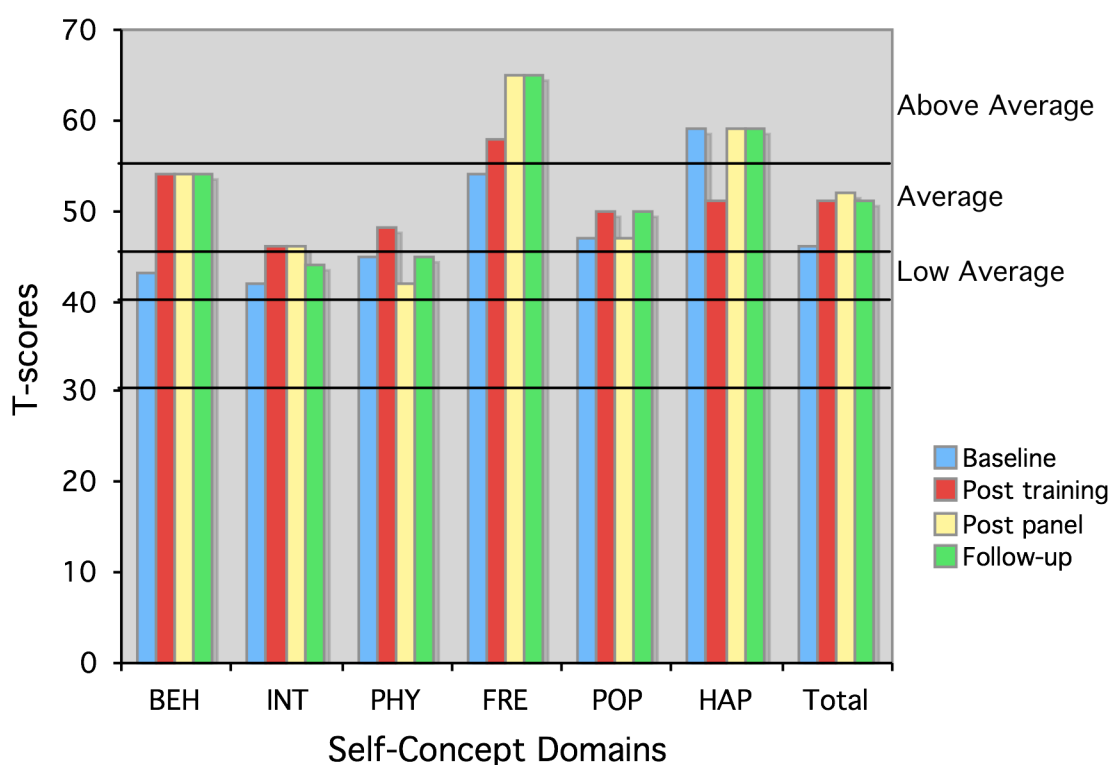

Figure 10. Piers-Harris Children's Self-concept Scale-2 results for Edgar.

Ethan. Figure 11 shows the Piers-Harris Children's Self-concept Scale-2 results for

Ethan. Overall, Ethan experienced meaningful changes in a negative direction in three of the

six self-concept domains over the course of the study. Intellectual/school status and

popularity scores, both of which were in the above average range at baseline, dropped to the

average range at follow-up. Ethan's perception of his physical appearance/attributes also

changed in a downward direction, from the average range at baseline to the low average

range at post-panel and follow-up. Because of these decreases, the total self-concept score

dropped from above average to average at the time of follow-up. Scores in behavioural

adjustment, freedom from anxiety, and happiness/satisfaction remained unchanged between
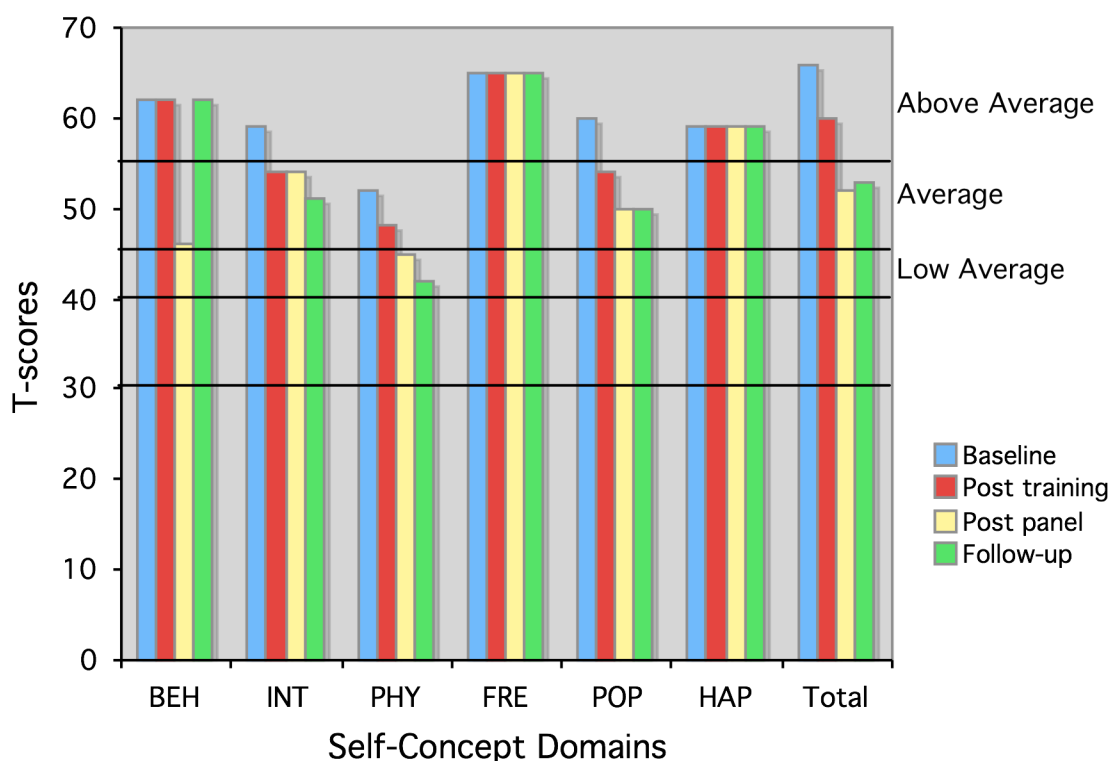
baseline and follow-up.

Figure 11. Piers-Harris Children's Self-concept Scale-2 results for Ethan.

Holden. Figure 12 shows the Piers-Harris Children's Self-concept Scale-2 results for

Holden. Meaningful negative changes in scores for four domains and meaningful positive

changes in the remaining two domains were evident for Holden. Scores for behavioural

adjustment and happiness/satisfaction were in the low range at baseline and decreased to the

very low range by follow-up. His score for intellectual/school status was average at baseline

but decreased to the low range post-training and remained there for the rest of the study.

Scores that measured freedom from anxiety were low average at baseline and dropped to the

low range for the final three time-points. Scores for physical appearance and attributes was in

the low average range at baseline and remained so at follow-up, after some positive

fluctuation. Self-reports of popularity were reported at the upper end of the low range at

baseline and improved into the bottom end of the low average range at follow-up. Overall,

the cumulative result of the negative changes in Holden's self-concept domains was a

decrease in his overall self-concept score from the low range at baseline to the very low
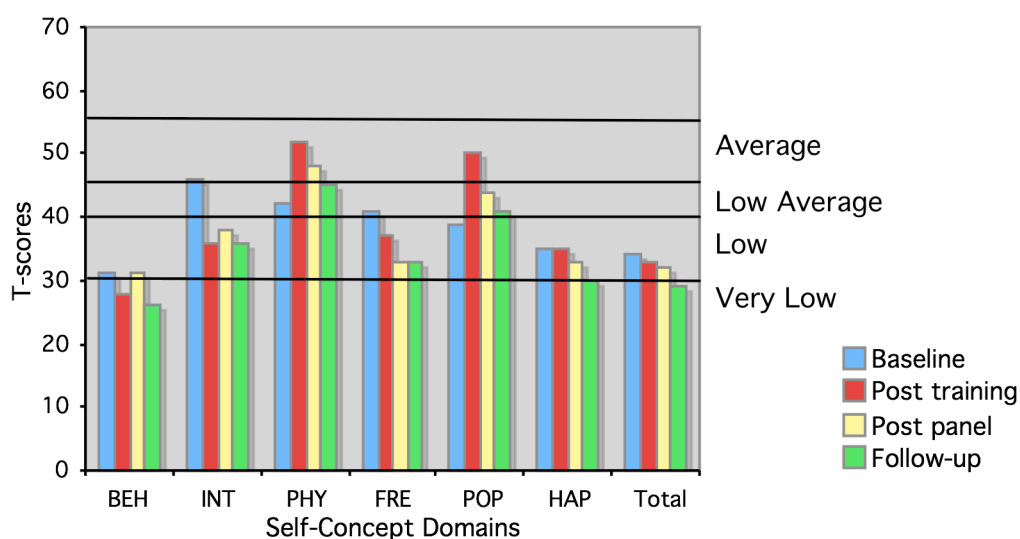
range at follow-up.

Figure 12. Piers-Harris Children's Self-concept Scale-2 results for Holden.

Summary. Self-concept as measured by the Piers-Harris Children's Self-concept Scale-2 underwent meaningful change in four of the six participants. Bobby and Edgar experienced positive changes in at least two of the six self-concept domains. Ethan reported negative changes in three self-concept domains, which resulted in a negative change in his total self-concept score. Holden experienced mixed changes in his self-concept. A summary of self-concept results can be viewed in Table 7.

Table 7

Summary of meaningful change for Piers-Harris Children's Self-concept Scale-2 results.

	BEH	INT	PHY	FRE	POP	HAP	TOT
Anders	Ø	Ø	Ø	Ø	Ø	Ø	Ø
Brad	Ø	Ø	Ø	Ø	Ø	Ø	Ø
Bobby	Ø	++	+	+	Ø	++	+
Edgar	+	Ø	Ø	+	Ø	Ø	Ø
Ethan	Ø	-	-	Ø	-	Ø	-
Holden	-	- -	+	-	+	Ø	-

Note. A (+) indicates an increase in the interpretive range (e.g., a change from low average to average), whereas a (-) indicates a decrease (e.g., a change from average to low average). Where scores increased or decreased by a change in two or more interpretive ranges, additional (+) or (-) signs were added.

Adolescents' Friendship Closeness Results

This section describes the results from the Adolescents' Friendship Closeness (AFC) measure. The AFC was used to determine if pre-existing friendships existed within the group and also to identify friendships that developed during the course of the SD/SA group intervention. The AFC allows the researcher to analyze friendship closeness and also group closeness. Results for friendship closeness among the SD/SA group are presented in a table

format for all participants. Scores for friendship closeness could range from 0 (not friends), to 1-4 (acquaintances), to 5-8 (friends), to a maximum score of 9-12 (close friends), based on questions 1 through 6 on the AFC measure (Appendix D). Each of these questions was awarded points based on a 3-point scale. A score of zero was awarded to responses that included "never," "not friends," and "not close." A score of 1 was assigned to responses that included "sometimes," "friends," and "a little close". The highest score of 2 was given to responses that included "often," "close friends," and "very close." Question 7 provides insight into how long the individual had known each group member, to expose pre-existing friendships.

  Friendship closeness. Results for friendship development and friendship closeness are presented for the SD/SA group members in Table 8. The results indicate that all group members established relationships defined as at least acquaintances with two or more members of the group throughout the course of the study. Only two group members, Brad and Holden, knew each other before the group SD/SA intervention.

Table 8

Friendship development and friendship closeness based on the Adolescents' Friendship
Closeness Measure.

Participant	# of acquaintances (score = 1-4)		# of friends (score = 5-8)		# close friends (score = 9-12)	
	Baseline	Follow-up	Baseline	Follow-up	Baseline	Follow-up
Anders	0	4	0	1	0	0
Brad	1	2	0	2	0	1
Bobby	0	2	0	0	0	0
Edgar	0	3	0	1	0	0
Ethan	0	1	0	3	0	1
Holden	1	2	0	1	0	0

Group closeness. The group closeness score was based on questions 8 through 11 in
the AFC. Scores for question 8 ranged from 0 (most negative response) to 3 (most positive
response). Questions 9 through 11 were each scored on a 5-point Likert scale, for a total of
15 points. Thus, the total score for group closeness (questions 8 + 9 + 10 + 11) could range
from 0 (not close) to 15 (very close).

The mean group closeness scores for the SD/SA group members across the post
training, post panel, and follow-up data collection phases were as follows: Anders = 11; Brad
= 13; Bobby = 8.6; Edgar = 10.3; Ethan = 12.6; and Holden = 10.3. Overall, scores for group
closeness were above 10 for most participants, indicating that they were comfortable with the
group and perceived the group members to get along well, be nice to one another, and be

friendly. Bobby's group closeness score was slightly lower than the rest of the group

indicating that he felt comfortable with the group, but perceived the group to neither like or

dislike each other, be somewhat nice to one another, and be somewhat friendly.

Participant Evaluations

Results based on the Participant Satisfaction Surveys are reported in this section. On

the Participant Satisfaction Surveys, the SD/SA group members rated their experiences as

participants in the study. Figure 13 describes the participant evaluations for questions 1

through 6 on the survey. These questions pertained to how much the participants liked or

disliked each aspect of the group training and panel sessions. Participants rated these

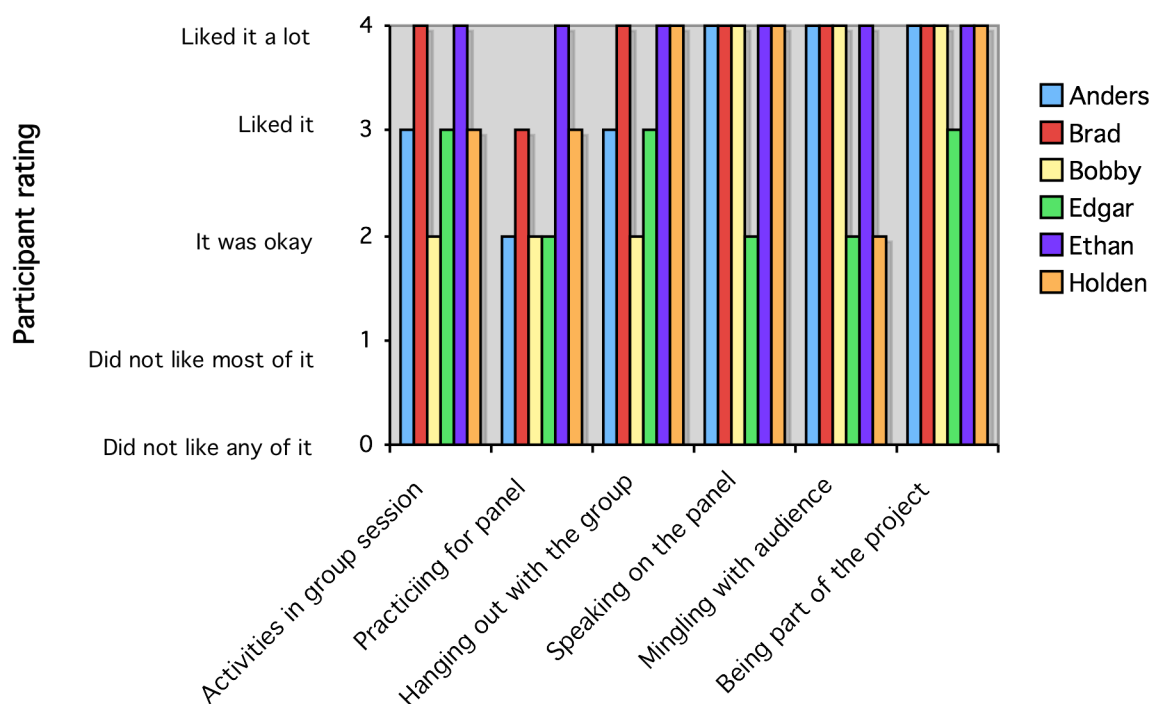questions based on a 5-point Likert scale.

Figure 13. Results from part 1 questions of the Participant Satisfaction Survey.

Overall, participants assigned positive ratings to the various components of the SD/SA intervention. On average, participants liked speaking on the panel the most and liked practicing for panel discussions the least. Five of the six participants reported that they "really liked" being part of the project and Edgar reported he simply "liked" it.

Questions from parts two and three of the Participant Satisfaction Survey pertained to group member's feelings of competence and satisfaction with regard to the SD/SA group. Figure 14 describes the participant ratings for part two of the survey. These questions were also based on a 5-point rating scale.
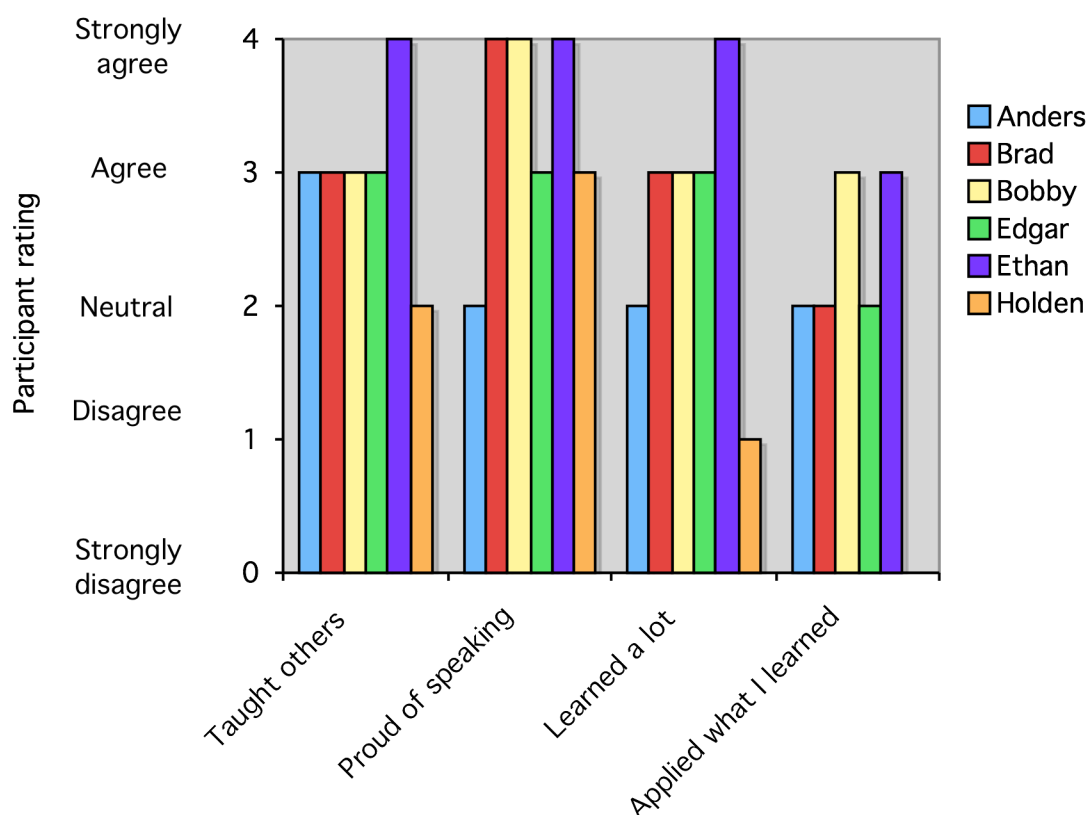

Figure 14. Results for part 2 of the Participant Satisfaction Survey

Overall, the majority of participants' responses in part two of the survey were positive. Five of the six participants reported that they either agreed or strongly agreed that they were able to teach others about ASD and were proud of themselves for speaking in a

public forum about ASD during the panel discussion. Four of the six participants agreed that they learned a lot from the project. Two of the participants indicated they applied what they have learned throughout the course of the project to their home/school life. Holden was the only participant that indicated he did not apply what he learned to other aspects of his life.

Part three of the Participant Satisfaction Survey asked participants to describe what they liked best about being part of the project and what they did not like. Anders and Ethan noted that they liked teaching others about ASD and being a positive example to others. Anders disliked how short the panel discussions were during the panel sessions. Brad noted that he enjoyed interacting with other people at the events and learning about what they thought. He especially enjoyed meeting others with ASD who attended the events. Bobby enjoyed talking to others at the events and sharing his knowledge of autism. He did not enjoy spending extended periods of time with other SD/SA group members. Edgar liked meeting new people, making new friends in the group, and earning money for his participation in the panel discussions. Holden also liked interacting with the other boys in the group.

Parent Evaluations

Results from the Parent Satisfaction Surveys are reported in this section. All parents of the participants reported that they felt the SD/SA intervention was very positive for their children. Ethan's parent reported, "[i]t has given him a lot of self-confidence and awareness both about Asperger's syndrome and himself." Anders' mom stated, "[t]o give youth a voice so they can self-advocate is by far the greatest gift given to anyone with special needs. [Anders'] realization that adults still have so much to learn about his needs and having the opportunity to hear and answer concerns and questions altered his view toward his frustration with teachers. He feels now that he has something to teach them and has/does." Bobby's

mom commented, "[i]t is hard to put into words just how great this program has been for [Bobby] in terms of self-esteem, self-confidence, self-awareness, understanding how autism affects him, how it affects others, and learning to be more tolerant. And it has given him a voice."

When asked which component of the SD/SA intervention parents felt had the most positive effect on their child, most parents mentioned the experience of speaking publicly about their disability. Holden's mom was grateful that "he learned how to tell other people about his disability in a positive, appropriate way." In response to the question, "Do you feel that your child became more independent, better at problem-solving, and/or more able to set goals and achieve them as a result of the study?" five of the six parents stated yes. In particular, Edgar's mom noted that he decided he wanted to get his babysitting license during the course of the project, which he achieved. Brad's mother noted that, over the course of the study, Brad became more independent and better at finding solutions to everyday problems. Anders' mother stated that she felt his independence, problem solving, and goal setting/attainment improved somewhat over the course of the study. When asked about improvements in their child's self-esteem over the course of the study, five of the six parents agreed that their child's self-esteem/self-concept had improved greatly. Bobby's mother commented, "He understands more about who he is as a person and what his strengths are." Anders' mom noted that he is now able to present in class without anxiety – something he was unable to do before the study. All parents reported that their children developed friendships among other members of the group throughout the course of the project. Ethan's and Edgar's parents reported that, in addition to hanging out at meetings that pertained to the

project (i.e., training sessions and community events), their children hung out together several times outside of the project.

Audience Evaluations

Almost 1,100 people attended the community events in which the SD/SA group practiced their self-advocacy skills. Of these attendees, 483 returned the Audience Satisfaction Survey, whose results are presented in this section. Four questions on the survey were of particular relevance to the SD/SA panel sessions. Audience members were asked to rate each question based on a 5-point scale that ranged from strongly disagree to strongly agree. Ratings were assigned a numerical value of 1 = strongly disagree and 5 = strongly agree and mean scores were calculated. Table 9 depicts the mean response for the four relevant audience satisfaction survey questions.

Overall ratings from audience members were quite high. In their comments, audience members described the boys as "articulate," "humorous," "self-aware," "courageous," and "confident." Comments also revealed that audience members were pleased to hear that the boys had a positive outlook about Asperger's syndrome and autism and that they gained a greater understanding of ASD from hearing the boys' stories first hand. One audience member commented, "[t]hey did a great job and gave me hope for my son's future!" Another member stated, "I learned more and was more affected today than by many other courses I have attended."

Table 9

Mean ratings from the audience satisfaction surveys.

		Questions			
Venue	Number of surveys returned	I could easily understand the panel speakers	The panel speakers gave me a better understanding of what it is like to have ASD	The event was valuable	I would recommend this event to others
Abbotsford	85	Agree	Strongly Agree	Strongly Agree	Strongly Agree
North Vancouver	70	Agree	Strongly Agree	Strongly Agree	Strongly Agree
Richmond	62	Agree	Agree	Strongly Agree	Strongly Agree
Vancouver (Langara)	81	Agree	Agree	Neutral	Agree
Vancouver (5th Ave)	62	Agree	Strongly Agree	Strongly Agree	Agree
Surrey	123	Agree	Agree	Strongly Agree	Strongly Agree
Total/Average	**483**	**Agree**	**Agree**	**Strongly Agree**	**Strongly Agree**

Contextual Information

This study was conducted over an 11-month period and the assessments were completed by each participant at four time points – baseline (pre-intervention), post training (i.e., following the six SD/SA training sessions), post-panel (i.e., following the six panel discussions, where participants practiced the skills they learned in training); and follow-up (2 months after the final panel discussion). Because the assessment instruments measured variables such as self-concept, self-perceptions of autonomy, and so forth – all of which are affected by relationships with other people and by general life events – many factors other

than the independent variables in the study might have influenced participants' responses on the assessment instruments. These include participants' emotional state on the day they completed the assessments, their experiences at school and at home during the weeks that preceded each assessment, their participation in other programs designed to teach social and/or problem-solving skills, recent medication changes, and other factors. Given the formative nature of this evaluation and lack of a control group, it is important to interpret each participant's scores on the assessment instruments in the context of the life events that they experienced over the 11 months of this project. This section provides an overview of the major life events that occurred during the study for each participant, based on information provided in the parent and participant satisfaction surveys as well as anecdotal information that was obtained over the course of the study. All information was approved for inclusion in this study by the participants and/or their parent or guardian.

Anders. On the Participant Satisfaction Survey, Anders rated his school year as "okay," although his mother reported that he had a lot of struggles getting along with his teachers and peers. Anders was disappointed and angry that none of his teachers or school staff attended the second panel discussion, which was held at his high school. Anders experienced some bullying throughout the school year but he had a strong social network of friends who (he said) provided him with good support. (Interestingly, Anders' mother did not perceive his social network as being very supportive.) During the study, Anders went into the community once a week with a support worker who indirectly worked on social skills with him. On the day of the post-training assessment, Anders was having a particularly bad day because he had had an argument with his parents and had left his home without permission for several hours.

Brad. Brad had a very good school year and got along well with his teachers. He reported that he got along "really well" with his closest group of friends and did not experience any bullying. Brad received training in a Social Thinking curriculum through a speech-language pathologist during the SD/SA intervention.

Bobby. Bobby had a good school year and did not experience any bullying. He got along "okay" with his closest group of friends. Bobby's teachers noted that, over the course of the study, he hung out in closer proximity to other students during his free time. Throughout the study, Bobby went on community outings once weekly with a support worker, who informally worked on social skill development.

Edgar. Edgar really enjoyed his school year and had good relationships with his teachers and the school staff. He did not experience any bullying at school. Edgar's mother noted that, although his classmates did not regularly invite him to participate in activities that were organized outside of school, Edgar feels that he has lots of friends at school.

Ethan. Ethan had a good school year. He reported that he got along "really well" with his closest group of friends but did experience some bullying. Ethan also received one-to-one behavioural intervention during the time of the intervention where he received specific instruction on the Social Thinking curriculum. Ethan struggles with written work and was reluctant to complete the assessments in the study. The post-training assessment was particularly difficult for Ethan because he was upset that he had already filled the forms out once before. He exhibited some problem behaviour during this time in the form of defiance and crying. When reinforcement contingencies were introduced for the following two assessments, he was more willing to cooperate and engaged in much less problem behaviour.

Holden. Holden had a difficult year with regard to many aspects of his life. One month after the beginning of the study, Holden dropped out of school and was hospitalized several times over the next few months because of problem behaviour at home. Holden also experienced a number of medication changes that negatively impacted his behaviour. Due to his unpredictable behaviour at home, Holden moved to a group home approximately 5 months into the study. Holden reported that he got along "okay" with his friends but did not get to see them often since he was not attending school. He did not experience any bullying throughout the year. Holden also received social skills training from a speech-language pathologist and began to receive behavioural support during the study as well, with particular emphasis on self-management and self-regulation during the last 6 months of the intervention. Holden decided to return to school in the fall of 2009, but on the day of the follow-up assessment, he was in a bad mood because he had just been told that he could not try out for the upcoming season of his new school's football team.

Summary of Results

A summary of all results for this study are presented in Table 10. Scores on the Arc's Self-Determination Scale for Adolescents suggested that five participants exhibited gains in at least one domain of self-determination, and one showed mixed results. With regard to the Piers-Harris Children's Self-Concept Scale, two participants displayed gains in self-concept, one exhibited a decrease, and one exhibited mixed results. Over the course of the study, all participants developed friendships within the group, as demonstrated by the Adolescent's Friendship Closeness measure. Both participant and parent satisfaction was generally positive.

Table 10

Summary of results.

	Arc's Self-Determination[1]	Piers-Harris Children's Self-Concept[1]	Adolescent's Friendship Closeness	Participant Satisfaction Survey	Parent Satisfaction Survey
Anders	+	Ø	+	+	+
Brad	++	Ø	+	+	+
Bobby	++	++++	+	+	+
Edgar	+++	++	+	+	+
Ethan	++	---	+	+	+
Holden	+/---	++/---	+	+	+

[1] Plus and minus symbols indicate the number of domains with increased (+) and decreased (-) scores.

CHAPTER 4

Discussion

This study addressed three questions regarding the utility of a novel SD/SA group

intervention for adolescents with HFA/AS: 1) From baseline to follow-up, what are the

changes in scores for self-determination skills, self-concept, and friendship development

among the participants?; 2) How do participants with HFA/AS and their parents evaluate the

SD/SA intervention?; and 3) How do audience members who attended the panel discussions

evaluate the performance of the participants? In this section I will summarize and analyze the

results, describe the collateral benefits of the study, overview the limitations of the study, and

give recommendations for future research in this area.

Summary and Analysis of Results

The results, which were comprised of multiple outcome measures, offer evidence of

an association between the SD/SA group intervention and positive outcomes in terms of self-

determination skills, self-concept, friendship development, participant satisfaction, parent

satisfaction, and audience satisfaction. The results for each dependent variable are discussed

below.

Self-determination. In order to be a self-determined individual, one must possess a

combination of skills, knowledge and beliefs that enhance engagement in goal-directed, self-

regulated, and autonomous behaviour (Field et al., 1998). Self-advocacy is a component of

self-determination whereby individuals demonstrate their ability to speak out publicly to

defend a cause or person (Field et al., 1998). In practical terms, all six participants advocated

successfully for themselves and others on the autism spectrum by speaking out during six

public panel discussions in which they revealed personal experiences linked to having

HFA/AS; answered questions from the audience; and provided advice for interacting with, teaching, and supporting individuals with ASD.

The Arc's Self-Determination Scale for Adolescents (ASDSA) is a self-report measure where individuals provide information with regard to (a) autonomy (acting independently according to one's preferences, interests, and abilities), (b) self-regulation (goal setting, goal attainment, and problem solving), (c) psychological empowerment (having control over one's own behavior in circumstances that are important to one's self), and (d) self-realization (knowledge about oneself, ability to capitalize on one's strengths, and ability to make up for one's shortcomings) (Wehmeyer et al., 1998; Wehmeyer, 1995). All six participants showed improvement in at least one domain of self-determination, and only one participant (Holden) showed evidence of a decrease in any domain. For the most part, Holden's results can be explained by the negative extraneous events that occurred in his life over the course of the study – that is, due to problem behaviour and related changes in medication, he quit attending school and moved out of his home to a group home, where he could be supported by trained staff around the clock. It is also important to note that increases in Holden's self-regulation may have also been attributed to the one-to-one training he received in this area outside of the SD/SA group intervention.

Four of the six participants experienced gains in self-regulation skills. It has been suggested that self-regulation is central to self-management (Karoly & Kanfer, 1977) and is also essential for achieving self-determination (Wehmeyer et al., 1998). The ASDSA measures self-regulation in terms of a person's ability to problem solve, set goals, and understand how to attain goals. Problem solving activities were regularly incorporated into the group training sessions. For example, during the first training session, participants were

asked to set one or two goals they wished to achieve through the project. The facilitator helped the participants realize what they needed to do in order to achieve these goals, and progress regarding goal attainment was assessed throughout the course of the study. All six boys (including Holden) achieved the goals they set out to accomplish by the end of the study. In addition, during panel sessions, the participants also had a chance to practice their problem solving skills when they were presented with questions from the audience.

At post-panel, Anders' self-regulation scores showed marked improvement; and at both post-training and post-panel, Brad's self-regulation also showed improvement. However, these improvements were not evident at the follow-up assessment. The main reason for this pertains to the goal-setting component of the ASDSA, which asks for goals related to where the person wants to live and work after graduation from high school. At post-panel, both boys noted clear goals related to employment/post-secondary education following graduation, and both listed actions they needed to take in order to attain those goals. However, at follow-up, both boys had changed their minds and were unsure of their goals involving future employment and/or post-secondary education; their uncertainty resulted in lower self-regulation scores at this time point. Research in the field of counseling psychology and education suggests that most adolescents require considerable guidance with regard to future career goals and goal attainment (Borgen & Hiebert, 2006; Hiebert, Kemeny, & Kurchak, 1998). In fact, it is quite common for adolescents to change their minds about future career goals and to experience considerable uncertainty and stress in this regard. If goal setting and attainment related to post-secondary pursuits had been emphasized more during the SD/SA group intervention, perhaps Anders, Brad, and others would have shown more lasting improvements in this area.

Four of the six participants demonstrated gains in self-realization, which consists of both self-awareness and self-knowledge (Wehmeyer et al., 1998). The ASDSA measures self-realization with 15 "agree/disagree" statements regarding self-awareness, self-acceptance, self-confidence, self-esteem, and self-actualization (Wehmeyer, 1995). Throughout the SD/SA intervention, participants focused on increasing self-awareness and self-knowledge (including disability awareness) so that they could tell others how ASD has impacted their lives. Over the course of the study, interactions with the participants consistently emphasized the ways in which they were unique and capable and de-emphasized their differences as adolescents with ASD. Bobby, who entered the study with relatively high self-realization scores, was the only group member (aside from Holden) whose scores remained unchanged; however, his high scores were maintained over the 11-month period.

Three of the six participants showed gains in empowerment. Anders and Ethan's empowerment scores, which were quite high at baseline, remained stable throughout the intervention and at follow-up, although Ethan did demonstrate decreases in his psychological empowerment score post-training. This temporary drop can largely be explained by the fact that he was not eager to complete the assessment at this time. Psychological empowerment refers to having control over one's actions in situations that are meaningful and important to one's life (Wehmeyer et al., 1998). The ASDSA assesses psychological empowerment using questions relating to locus of control, self-efficacy, and outcome expectancy (Wehmeyer, 1995). During the recruitment phase of this study, the six boys were given a choice of whether or not they wanted to participate in the group intervention and learn to speak out and educate others in their communities about ASD. All six participants chose to be part of the study because having their voices heard and promoting awareness and inclusion for

individuals with ASD was meaningful and important to them. During the panel discussions, participants were given numerous opportunities to demonstrate psychological empowerment as they each chose which questions to respond to and what information to share with the audience in order to provide insight into their experiences with ASD.

None of the participants exhibited gains in autonomy on the ASDSA. The ASDSA measures autonomy by asking participants to evaluate their independence with regards to routine personal care (e.g., dressing, grooming), family oriented functions (e.g., making meals), and choices (e.g., leisure activities, community involvement, post-school directions, and personal expressions) (Wehmeyer, 1995). Although the SD/SA group intervention did not explicitly focus on training the individuals in the study to be more autonomous in their everyday lives, it was assumed that teaching them a range of self-determination skills would generalize to more autonomous behaviour. It should be noted that, since the ASDSA relies on self-reports, it measures a snapshot of one's perception of global self-determination. However, it does not provide information about specific elements that contribute to the emergence of self-determination (Wehmeyer, 2000), nor does it include external or observable indices of autonomy (Baker, Horner, Sappington, & Ard, 2000). It is interesting to note that, in the parent satisfaction surveys, Brad, Bobby, Edgar, and Ethan's parents all noted noticeable changes in increased independence in their sons.

Self-Concept. The acquisition of self-determination skills has been associated with increases in self-confidence and self-esteem (Eisenman et al., 2005; Stevens, 2005). Therefore, it was important to examine whether or not scores changed over the course of the study with regards to the self-concept measure. Self-concept was measured using the Piers-Harris Children's Self-Concept Scale-2. This scale measures self-concept/self-esteem in six

specific domains: behaviour, intellect, physical appearance, freedom from anxiety, popularity, and happiness.

Overall, two participants showed improvements in self-concept, one showed mixed results, one demonstrated a decrease, and two participants' scores remained unchanged. It is likely that Holden's mixed results for self-concept on the Piers-Harris can be explained by the extraneous negative circumstances he experienced throughout the same time period as the intervention, as noted previously. Ethan's decreased self-concept scores are consistent with the findings of several longitudinal studies that have examined adolescent development and found a general decreasing trend in self-esteem for individuals who experience a change in school context (e.g., entry into middle school) between grades 6 and 8 (Simmons, Rosenberg, & Rosenberg, 1973; Zimmerman, Copeland, Shope, & Dielman, 1997). This school year was Ethan's first year enrolled in middle school, which may explain the decreases observed in his self-concept.

During the developmental period of adolescence, self-esteem is appreciably less consistent in males than it is in females (Block & Robins, 1993), with considerable fluctuation in boys' self-esteem during this time. A meta-analysis of research in this area revealed that significant improvements in self-esteem are unlikely unless interventions are provided that specifically focus on enhancing self-esteem/self-concept (Haney & Durlak, 1998). Given this, it is promising that the SD/SA group intervention resulted in positive changes or at least stability in the self-concept scores for four of the six participants, since this intervention did not explicitly focus on improving self-esteem/self-concept. It is encouraging to note that Anders, Bobby, Edgar, Ethan, and Holden's parents all reported a noticeable increase in their son's self-confidence and self-esteem.

Friendship development. Relationships have a tremendous impact on one's outlook on life and one's self-concept (Snell & Janney, 2000). Social relationships not only provide a sense of belonging and self-worth, they also provide a context in which adolescents can practice and develop many prosocial behaviours such as mutual caring, companionship, and empathy (Bauminger et al., 2008). Friendships also support many aspects of social, cognitive, communicative, and emotional development (Guralnick, Neville, Hammond, & Conner, 2007). Burgess, Wojslawowicz, Rubin, Rose-Krasnor, and Booth-LaForce (2006) found that a lack of social relationships early in life was associated with adjustment problems later on. Thus, friendships serve an important role in the social-emotional development of children. Individuals with ASD often struggle to develop and maintain positive social relationships because of their inability to comprehend unspoken social rules and interpret social cues (Carrington, Templeton, & Papinczak, 2003), as well as their difficulties initiating, sustaining, and terminating conversations (Boutot, 2007). Thus, it is essential to establish interventions that foster friendship development in this population.

The Adolescent's Friendship Closeness (AFC) measure was a tool that enabled the researcher to assess the closeness of any pre-existing relationships and to determine whether any relationships developed over the course of the study. Throughout this study, all of the boys became at least acquaintances with two or more of the other members of the group, and all relationships became closer as the study progressed. The AFC also measured group closeness among the participants. On average, the group rated themselves as being close – that is, they were comfortable with one another, they perceived themselves as getting along well, and they were nice and friendly to one another.

Snell and Janney (2000) proposed four essential components for fostering friendship development: 1) opportunities to be together; 2) a desire to interact; 3) the ability to socially interact/communicate; and 4) organizational, emotional, and social supports to help maintain the relationship as it develops. These four components were present throughout the SD/SA group intervention and social/communication skills were the focus of all of the training sessions, which may have contributed to the friendship development over the course of the study. Another factor important to friendship development and closeness is having common interests (Carrington, Templeton, & Papinczak, 2003) and sharing a similar orientation on contemporary teen culture (i.e., wearing similar clothes, listening to similar music, etc.) (Berndt, 1982). The group members in this study ranged from shy to quite out-going, mature to just exiting the childhood stage, and some had unique interests that were not shared by others in the group. Given this, it is not surprising that all participants did not become friends with one another, since individuals tend to develop relationships with others who are similar to themselves. However, group cohesiveness was established over the course of the project, and all group members became very supportive of one another in both public and in private forums. It is likely that sharing the common goal of educating others about ASD and working together as a team to attain this goal fostered this sense of group closeness.

Satisfaction results. Three satisfaction surveys were analyzed in this study: participant satisfaction, parent satisfaction, and audience satisfaction. All satisfaction results were very positive. The participants enjoyed the various aspects of the intervention and felt that being part of the study was valuable to them. Parents were pleased with the positive changes they observed in their children, and valued the fact that this project allowed their children to have a voice and to advocate for themselves and others with ASD. Audience

members valued the courage it took for the boys to advocate for themselves and viewed the community events as being educational and socially important. These satisfaction results contributed to the social validity of this study.

Collateral Benefits and Social Validation

Several collateral benefits arose out of this study and strengthened the social validity of the SD/SA group intervention. The participants and parents of the participants viewed the panel discussions as such a positive and empowering opportunity that they plan to continue with the group and hold additional community events. The boys' parents developed a for-profit organization through which organizations, schools, and other groups can invite the group to come and speak on a panel and share their experiences after a screening of the film "The Boy Inside." The idea to proceed with this parent-led organization was also sparked by the fact that there was such a high demand for more community events from organizations across British Columbia. Following the conclusion of the study, the group of boys were invited to speak at two public forums and are scheduled to speak at another two to date.

During the "meet and greet" sessions that followed the panel discussions, a substantial amount of interest was expressed by other teenagers with ASD who indicated a desire to be part of such panel discussion and to form social networks with the participants. The fact that other teenagers on the spectrum looked up to the boys on the panel and wanted an opportunity to be part of the project is evidence that this project had strong social validity.

Limitations

Without a control group, it is not possible to establish the degree to which the changes observed in the dependent variables can be attributed solely to the SD/SA group intervention, since maturation and history effects may have contributed to the results. Another limitation

was that all of the study participants were male, making it impossible to say whether or not changes in scores and participant/parent/audience evaluations would have been similar for a group of females, or for a mixed group of both males and females. Additional research is needed to clarify these issues.

An additional limitation was that a nonparametric statistical analysis was not conducted on the present data set. However, during this formative stage of evaluation, it was appropriate to examine the utility of the SD/SA intervention with respect to individual group members as opposed to the group as a whole. This individualized approach provided rich information about the characteristics of adolescents for whom the intervention can be appropriate, and facilitates modification of the curriculum for use in the future.

Recommendations for Future Research

This exploratory study demonstrated promising results for the SD/SA group intervention with adolescents with HFA/AS; however, future research should be considered in at least four areas. First, replication of this study with a control group is recommended, to determine if self-determination and self-concept increase as a result of the treatment alone. Second, future research should include both male and female adolescents, to examine the extent to which the curriculum can be applied successfully in these sub-populations. Third, an additional dependent variable that measures bullying and social isolation is warranted since the intervention is targeted at giving adolescents with HFA/AS a voice that enables them to stand up for themselves. Finally, measures of school belongingness (i.e., peer and teacher support), engagement in learning, and academic performance might be useful to measure collateral effects of the intervention. A recent study by Van Ryzin, Gravely, and

Roseth (2009) suggested that adolescents who perceive their school environments as supportive of their needs tend to be more engaged in learning.

Conclusion

This study provides preliminary evidence of the utility of the STAAR curriculum for adolescents with HFA/AS as a useful tool for fostering self-determination, positive self-concept, and friendship development – ultimately setting the stage for healthy psychological development in these individuals. Participants, parents, and audience members all viewed this project as being socially significant and were positively impacted by the community events (i.e., panel sessions). Although future research using a control group is required, no other study to date has offered an intervention package for individuals with HFA/AS in which they are provided with opportunities to have their voices heard in a public forum (as opposed to IEP meetings). With the training this group of adolescents received, and with the opportunities they were given to advocate for themselves, the group members themselves experienced positive changes and the people in their communities were made more aware of what it is like to live with ASD – an awareness that ultimately sets the foundation for promoting more inclusive communities for all individuals on the autism spectrum.

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Appendix A

Behavioural Research Ethics Board Approval

UBC

The University of British Columbia
Office of Research Services
Behavioural Research Ethics Board
Suite 102, 6190 Agronomy Road, Vancouver, B.C. V6T 1Z3

CERTIFICATE OF APPROVAL - FULL BOARD

PRINCIPAL INVESTIGATOR:	INSTITUTION / DEPARTMENT:	UBC BREB NUMBER:
Pat Mirenda	UBC/Education/Educational & Counselling Psychology, and Special Education	H08-01620

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:

Institution	Site
UBC	Vancouver (excludes UBC Hospital)

Other locations where the research will be conducted:
N/A

CO-INVESTIGATOR(S):

Brooke K. Myers

SPONSORING AGENCIES:
Community Living British Columbia

PROJECT TITLE:
Impact of Group Self-Advocacy Training on Adolescents with High-Functioning Autism or Asperger's Syndrome

REB MEETING DATE:	CERTIFICATE EXPIRY DATE:
September 25, 2008	September 25, 2009

DOCUMENTS INCLUDED IN THIS APPROVAL:	DATE APPROVED: September 25, 2008		
Document Name		Version	Date
Consent Forms:			
Group self-advocacy consent		1.0	September 5, 2008
Assent Forms:			
Group self-advocacy assent		1.0	September 5, 2008
Questionnaire, Questionnaire Cover Letter, Tests:			
Arc's Self-Determination Scale		N/A	January 1, 1995
Participant Satisfaction Survey		1.0	September 5, 2008
Parent Satisfaction Survey		1.0	September 5, 2008
Piers-Harris Scale		N/A	January 1, 1969
Adolescents' Friendship Closeness		1.0	September 5, 2008

The application for ethical review and the document(s) listed above have been reviewed and the procedures were found to be acceptable on ethical grounds for research involving human subjects.

Approval is issued on behalf of the Behavioural Research Ethics Board
and signed electronically by one of the following:

Dr. M. Judith Lynam, Chair
Dr. Ken Craig, Chair
Dr. Jim Rupert, Associate Chair
Dr. Laurie Ford, Associate Chair
Dr. Daniel Salhani, Associate Chair
Dr. Anita Ho, Associate Chair

Appendix B

Participant Assent Form
Impact of Group Self-Advocacy Training on Adolescents with High-Functioning
Autism or Asperger's Syndrome

Principal Investigator
Pat Mirenda, Ph.D., Professor (Faculty Advisor)
Department of Educational Psychology and Counseling Psychology, and Special Education
(ECPS), Faculty of Education, University of British Columbia
(604) 822-6296

Co-investigator
Brooke Myers, Graduate Student (Masters)
Department of Educational Psychology and Counseling Psychology, and Special Education
(ECPS), Faculty of Education, University of British Columbia
(778) 239-1483
Research for the fulfillment of degree requirements for the Masters of Arts degree. Ms.
Myers will use the data from this project for her thesis (public document)

Purpose of the Study
This study will teach me self-advocacy, public speaking, and social skills so that I can speak
on a public panel about my experiences as a teenager with high functioning autism (HFA) or
Asperger's syndrome. Self-advocacy means teaching people how to stand up for themselves
and speak out about what they believe in. Self-advocates are able to make decisions and
choices that affect their lives so that they can become more independent.

Study Procedures and Time Commitment
Before the study begins and when it is finished, I will fill out questionnaires about my self-
advocacy skills, my current friendships, and how I feel about myself. Then, I will attend six
2-hour group training sessions with 4-5 other teens who also have HFA or Asperger's
syndrome. At the first session, I will watch "The Boy Inside," a DVD about a teenager with
Asperger's syndrome and his experiences at school, and talk about the film with the other
teens. After this, I will learn and practice public speaking skills, social skills, how to answer
questions from the audience, and what to do if I feel anxious or sad when I am answering
questions about my own experiences. After the training, I will attend at least four out of six
film screenings of "The Boy Inside" and participate in panel discussions after each screening.
I will also attend 1-hour sessions after each panel, where I can talk about my experiences and
learn more skills. At the end of the intervention I will complete a short survey about what did
and did not I like about the intervention. Two months after the last screening, I will fill out
the same questionnaires I completed at the beginning and end of the intervention.

The study will begin in the Fall of 2008 and finish in the Summer of 2009. I might learn self-
advocacy, public speaking, and social skills in the study. I might also help to teach people
about how to help kids with HFA or Asperger's syndrome have better experiences at school.

Confidentiality
No one except the researchers will see the questionnaires that I fill out. No one except my family and the researchers will know that I am participating in a self-advocacy training study, but the audience members who attend the film screening will know that I have HFA or Asperger's syndrome. They will also know any information about me or my family that I tell them when I am on the panel.

Contact
If I have any questions or worries about what is happening during the study, I will ask my mom or dad or the researcher who is doing the self-advocacy training.

Consent
It's up to me to decide if I want to participate in the self-advocacy training program, which includes speaking on a public panel about my experiences as a teenager with HFA or Asperger's syndrome. If I change my mind and do not want to do this anymore, I will tell my mom or dad or the researcher. It's okay if I change my mind. If I change my mind, the researcher will try to find another teen with HFA or Asperger's syndrome to replace me.

Please check ✓ below:
☐ I have read this or someone has read this to me and I understand what it says. My mom or dad has a copy of this form.

Please check ✓ one box below:
☐ I **want to be** in this study.
☐ I **do not** want to be in this study.

I will write my name and the date on the line below.

_____   _____

Child's signature   Date

_____

Child's name (please print)

Appendix C

Informed Consent Form
Impact of Group Self-Advocacy Training on Adolescents with High-Functioning
Autism or Asperger's Syndrome

Principal Investigator
Pat Mirenda, Ph.D., Professor (Faculty Advisor)
Department of Educational Psychology and Counseling Psychology, and Special Education
(ECPS)
Faculty of Education, University of British Columbia
(604) 822-6296

Co-investigator
Brooke Myers, Graduate Student (Masters)
Department of Educational Psychology and Counseling Psychology, and Special Education
(ECPS)
Faculty of Education, University of British Columbia
(778) 239-1483
Research for the fulfillment of degree requirements for the Masters of Arts degree. Ms.
Myers will use the data from this project for her thesis (public document)

Purpose of the Study
The purpose of the study is to investigate the impact of a self-advocacy group training
intervention for adolescents with high functioning autism (HFA)/Asperger's syndrome. Your
son or daughter is eligible to participate because he or she has a diagnosis of HFA or
Asperger's syndrome; is between the age of 12 and 18; and is interested in (a) speaking on a
public panel following the screening of the film "The Boy Inside" about his or her
experiences as an adolescent with HFA/Asperger's syndrome, (b) learning self-advocacy,
public speaking, and social skills, and (c) socializing with a group of teenagers who also have
HFA/Asperger's syndrome.

Study Procedures and Time Commitment
The study will focus on improving the self-advocacy, public speaking, and social skills of
adolescents with HFA/Asperger's syndrome in order to prepare them for speaking on a
public panel. Prior to the start of the study, your child will be asked to complete three
assessment measures: the *Arc's Self-Determination Scale for Adolescents*, a measure of
Adolescents' Friendship Closeness, and the *Piers-Harris Children's Self-Concept Scale*.
Each of these will take about 20 minutes to complete and the researcher will provide
assistance to help your child read and/or understand the questions, as needed. Next, your
child will take part in six 2-hour group training sessions with 4-5 other adolescents with
HFA/Asperger's syndrome. In the first training session, he or she will watch and discuss
"The Boy Inside," a DVD about a teen with Asperger's syndrome and his experiences at
school. In the other sessions, he or she will be taught self-advocacy, public speaking, and
social skills by the researcher, using games, role playing, problem-solving stories, and other
interactive activities. The training will take place in the Fall of 2008, either at the University

of British Columbia or at another location in the Lower Mainland of BC. Following completion of the training, your child will attend public film screenings of "The Boy Inside," a DVD about a teen with Asperger's syndrome and his experiences at school, and will participate on a panel discussion following each screening. There will be a total of six film screenings in the Lower Mainland between January and August, 2009. Your child will be required to attend at least four of the six screenings and panel discussions, as well as a 1-hour debriefing session following each panel in which he or she participates. You will be responsible for arranging transportation for your child to and from the training sessions and the film screenings/panel discussions. After the final film screening and two months later, your child will complete the same three assessment measures that were administered at the beginning of the study, as well as a brief satisfaction survey. You will also be asked to complete a short questionnaire regarding the self-advocacy intervention when it is completed and two months later.

A potential risk for your child as a panel discussion participant is that he or she will talk about his or her experiences as a teen with HFA/Asperger's syndrome and will be asked questions by audience members. Your child may disclose personal information or may experience some anxiety or sadness during these discussions. To minimize the risk, your child will be taught strategies for appropriate public speaking, responding to difficult questions, and/or managing anxiety or sadness during the training sessions. In addition, your child will be informed that if he or she is embarrassed or uncomfortable answering a question, he or she can either decline from answering or can refer the question to the adult panel moderator, who will provide a general response instead. Finally, your child will have opportunities to discuss his or her experiences as a panel member and receive additional training and support during the de-briefing sessions that follow each panel.

Expected benefits to your child include having opportunities to interact and spend time with other teenagers who also have HFA/Asperger's syndrome; and improved public speaking, self-advocacy, and social skills. Your child may also benefit by knowing that he or she has helped to educate people in his or her community about HFA/Asperger's syndrome.

Confidentiality
Audience members who attend the film screenings will know that your son or daughter has HFA or Asperger's syndrome. They will also know any information shared by your child as a panel member. However, your child will not be identified by name in any reports of the completed study. All data assessment records will be kept on a password-protected computer disk or in a locked file cabinet in the Principal Investigator's lab at UBC and will be destroyed 5 years after the end of the study. Only the Principal Investigator and Co-investigator will have direct access to the data.

Contact
If you have any questions or would like more information about this project, you may contact either Brooke Myers at (778) 239-1483 or Dr. Pat Mirenda at (604) 822-6296. If you have any concerns about your child's treatment or rights as a research participant, you may contact the Director of the UBC Office of Research Services and Administration at (604) 822-8598.

Consent

I understand that my child's participation in this study is entirely voluntary. I may refuse to have him/her participate or withdraw from the study at any time without jeopardy to my future relationship with the University of British Columbia.

P**lease check** ✓ **below**:

☐ I have received a copy of the consent form.

P**lease check** ✓ **one box below**:

☐ **I consent** to my child's participation in this study.

☐ **I do not consent** to my child's participation in this study.

If you consent to having your child participate in this study, please print his or her name, print your name, and sign the appropriate section below.

_____

Adolescent's name (please print)

_____

Parent/Guardian's name (please print)

_____   _____

Parent/Guardian's signature   Date

Appendix D

Adolescents' Friendship Closeness Measure

Your Name: _____   Date:_____

Directions: Please circle the best answer.

Part 1 (to be completed before and after the intervention and 2 months later)

Think about_____, who is a member of the self-advocacy intervention group.

1. Are you and this person friends?

    Not friends   Sort of friends   Close Friends

2. How often do you share your thoughts and feelings with this person?

    Never   Sometimes   Often

3. How often do you and this person do fun things together outside of the self-advocacy group intervention?

    Never   Sometimes   Often

4. How often do you and this person talk on the phone, send text messages, or send emails to one another?

    Never   Sometimes   Often

5. How often do you tell this person things you don't tell other people?

    Never   Sometimes   Often

6. How close do you feel to this person?

    Not close   A little close   Very close

7. How long have you known this person?

    Don't know him/her   Less than 1 month   1-6 months   6 months or more

Part 2: (To be completed at the end of the intervention and 2 months later)

8. Check the statement that best describes your self-advocacy group.

_____   Some of the teens in the group didn't like each other and we did not get
        along well.
_____   Teens in the group didn't like or dislike each other, and we got along OK.
_____   Most of the teens in the group liked each other and we got along pretty well.
_____   All of the teens in the group really liked each other and we got along very well.

9. How comfortable did you feel with other members in your group?

0	1	2	3	4
Very Uncomfortable		Comfortable		Very Comfortable

10. The members of the group were:

0	1	2	3	4
Very mean	Mean	Okay	Nice	Really Nice

11. I think the members of the group were:

0	1	2	3	4
Very unfriendly	Unfriendly	Okay	Friendly	Really Friendly

Appendix E

Participant Satisfaction Survey

Group Self-Advocacy Intervention: Participant Evaluation

Name:_____   Date:_____

PART ONE: Please check the face that best describes how much you liked each aspect of the group training and panel sessions.

	I did not like it at all	I did not like most of it	It was OK	I liked it	I liked it a lot
1. Doing activities during the group sessions.	☹	😐	🙂	😊	😃
2. Practicing for the panel during the group sessions.	☹	😐	🙂	😊	😃
3. Hanging out with other teens with autism spectrum disorders	☹	😐	🙂	😊	😃
4. Speaking on the panel	☹	😐	🙂	😊	😃
5. Mingling with audience members after the panel discussion.	☹	😐	🙂	😊	😃
6. How much did you like being part of this project	☹	😐	🙂	😊	😃

PART TWO: Please circle the response that indicates how you feel.

1. I was able to teach others about what it's like to have autism/Asperger's.

strongly disagree   disagree   a little bit   agree   strongly agree

2. I feel proud of myself for speaking on a public panel about my experiences.

strongly disagree   disagree   a little bit   agree   strongly agree

3. How much did you learn from participating on this project?

strongly disagree   disagree   a little bit   agree   strongly agree

4. How often have you used something you learned in this project in your life at school or at home?

Not at all   once   a couple times   quite a few times   all the time

PART THREE

1. What did you like best about being part of this project?

_____

_____

2. Was there anything that you did not like?

_____

_____

PART FOUR

1. Overall, how would rate your school year (2008-2009)?

I did not like it at all!	I did not like most of it.	It was OK.	I liked it.	I liked it a lot!

2. Did you experience bullying at school this year? If so, how did you deal with it?

_____

_____

_____

3. Overall, how would you rate your closest group of friends this year?

I don't have any friends We fought a lot We fought sometimes We got along okay We got along really well

4. Comments:

_____

_____

Appendix F

Parent Satisfaction Survey

Group Self-Advocacy Intervention: Parent Survey

1. Do you think the self-advocacy intervention had a positive effect on your child?

1	**2**	**3**	**4**	**5**
No, not positive		**Not sure**		**Yes, very positive**

Please provide any additional comments that you feel may help us understand your rating:

_____

_____

_____

2. Which component(s) of the self-advocacy intervention did you feel had the most positive effect on your child?

_____

_____

_____

3. Do you feel that your child became more independent, better at problem-solving, and/or more able to set goals and achieve them as a result of the study?

_____

_____

_____

4. Do you feel that your child's self-esteem (i.e., how he feels about himself) improved as a result of the study?

_____

_____

_____

5. Did your child develop any friendships with other group members in the study?

_____

_____

6. Did your child receive any specific social skills training during the past 10 months, aside from that provided in this study?

_____

_____

_____

7. Did your child receive any self-advocacy instruction during the past 10 months, aside from that provided in this study?

_____

_____

_____

8. Overall, how was your child's school year (i.e., did he enjoy his classes, how were his relationships with teachers/staff/students, etc.)?

_____

_____

_____

9. During the 2008-2009 school year, was your child the victim of bullying?

_____

_____

_____

10. Please provide any additional comments that you think might be important for us to know about the intervention.

_____

_____

_____

Appendix G

Audience Satisfaction Survey

THE BOYS INSIDE: AN AUTISM & ASPERGER'S COMMUNITY PROJECT **AUDIENCE REFLECTION & DIALOGUE**

1. What interested you about coming to this event, and what are some things that you learned today?

   _____

   _____

   _____

2. What pleased or surprised you?

   _____

   _____

   _____

3. Based on what you learned at today's event, next time you encounter someone with Asperger's or autism what might you do differently?

   _____

   _____

   _____

4. What kinds of activities or programs have you noticed in your school, work place or community that honour human diversity and promote inclusion?

   _____

   _____

   _____

5. How might you make it more welcoming and accepting for people with Asperger's or autism in your school, work place, or community? How might you help someone fit in?

   _____

   _____

   _____

	N/A	Strongly Disagree	Slightly Disagree	Neutral	Agree	Strongly Agree
1. The film was informative.	☐	☐	☐	☐	☐	☐
2. The film was thought provoking.	☐	☐	☐	☐	☐	☐
3. The film was in a language I understood.	☐	☐	☐	☐	☐	☐
4. The subtitles were helpful.	☐	☐	☐	☐	☐	☐
5. I could easily understand the panel speakers.	☐	☐	☐	☐	☐	☐
6. The panel speakers gave me a better understanding of what it is like to have autism or Asperger's.	☐	☐	☐	☐	☐	☐
7. I gained a lot from the concluding group discussion.	☐	☐	☐	☐	☐	☐
8. The venue was convenient.	☐	☐	☐	☐	☐	☐
9. I felt this was a valuable event to attend.	☐	☐	☐	☐	☐	☐
10. I would recommend that others attend this event.	☐	☐	☐	☐	☐	☐

THE BOYS INSIDE: AN AUTISM & ASPERGER'S COMMUNITY PROJECT
AUDIENCE SATISFACTION SURVEY

11. How did you hear about us?
_____

12. Would you like to be part of our email list and receive information regarding our upcoming community events? NO ☐ YES ☐ email address:_____

Additional comments:
_____
_____
_____

Appendix H

S_{tudents} T_{eaching} A_{bout} A_{utism} R_{eality} Curriculum

The STAAR curriculum is a self-determination/self-advocacy intervention that aims to prepare and provide opportunities to individuals with high functioning autism and Asperger's syndrome to advocate for themselves and others with ASD on a public panel. The curriculum is comprised of two phases, a training phase and a panel phase.

Phase 1: Training

Overview of the lessons:
1. Getting to know my group and the project
2. Learning about myself and my autism spectrum disorder
3. Social skills and communication 101
4. Managing yourself in social situations
5. Public speaking
6. Practice panel and debrief
7. Review

<u>Lesson 1: Getting to know my group and the project</u>

Time required: 2 hours

Objectives:
   a. To get to know all group members
   b. To become familiar with the film "The Boy Inside" and the purpose of this project
   c. To participate in a discussion about the film and friendship
   d. To set a personal goal for this project

Materials and preparation:
   o Roll of toilet paper
   o 6 copies of "Getting to know my group" questionnaire
   o 6 pencils
   o DVD of "The Boy Inside"
   o TV
   o DVD player
   o Easel paper
   o Markers

Teaching procedures:

Activity 1 – Toilet paper get-to-know you (10 minutes)
      Pass around the roll of toilet paper. Have each group member tear off as many squares as they wish. After everyone has some toilet paper, each person must tell one thing about themselves for each piece of toilet paper they have in front of them. This

is a fun way for the group to get to know one another and also gives some practice sharing personal information to a group of unfamiliar people.

Activity 2 – "Getting to know my group" race (20 minutes)
Each person will be given a "getting to know my group" questionnaire and a pencil. The group will be given 15 minutes to go around and ask their group members the questions on the questionnaire. Rule: you may only ask one question per person at a time. The first person to complete the questionnaire will win a prize. This activity gives group members an opportunity to learn about one another and discover what they share in common. Provide verbal prompting if necessary.

Activity 3 – Describe the purpose of the project (5 minutes).

Activity 4 – Watch specific clips from "The Boy Inside" (20 minutes)
Have drinks and popcorn available.

Activity 5 – Discussion about film clips and friendship (30 minutes)
Begin with a discussion about the film. What aspects did they like? What aspects did they not like? In the film Adam has a difficult time making/keeping friends. On a piece of easel paper have the group come up with some characteristics/qualities of a good friend. On a separate piece of paper have the group come up with a list of obstacles they may have encountered trying to make friends. Once the list is complete, generate some ideas of how to overcome these obstacles. Provide guidance and ideas if group is having difficulty.

Activity 6 – Sociogram (10 minutes)
Have students complete a sociogram. This will give an idea of how many close friends they have in their life. Provide verbal prompts if necessary.

Activity 7 – Goal setting (25 minutes)
Explain to students that in this following activity they will be generating ideas about goals they would like to achieve as a result of being part of this project. On a separate piece of easel paper for each participant, the facilitator will write down their goal(s). The facilitator will provide a model for the group of their goals. As a group, brainstorm the necessary steps to achieve everyone's goals. Goals and goal progress will be reviewed routinely throughout the intervention.

Resources/references:

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Forgan, J. (2002). Using bibliotherapy to teach problem solving. *Intervention in School and Clinic, 38,* 75-82.

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Handouts/worksheets:

1) "Getting to Know My Group" Questionnaire

Instructions: Go around to people in the group and ask them a question that's on this sheet. For example, walk up to Brooke and say "do you like hockey"? If she says yes, then write her name next to the question. If she says no, then you have to go find someone else and ask them the question.

Name	Question
	Likes hockey
	Hates broccoli
	Has a dog
	Has a cat
	Was not born in Canada
	Likes the internet
	Likes watching movies
	Likes pizza
	Has a Nintendo DS
	Likes to read
	Has seen every Harry Potter movie
	Doesn't like chocolate
	Has gone skiing or snowboarding
	Plays an instrument
	Has a brother
	Has a sister
	Has been on an airplane
	Has been to Disney Land
	Has been on a train
	Likes to draw

Rule: You're only allowed to ask one question at a time to the person you're talking to. The first person to fill out all of the names will win a prize. You have three minutes to finish. Ready, set, GO!

2) Sociogram.

Directions: In each section of the circle fill out the people in your life who are important to you. In the centre write your name. In the orange ring, fill out the names of your family members who are important to you. Within the green ring, write the names of your closest friends. Within the blue ring, write the names of people who are important to you, but are only your acquaintances. Outside of the blue ring, write the names of those who are important to you, but are paid to be in your life (e.g., your doctor, teacher, tutor, etc).
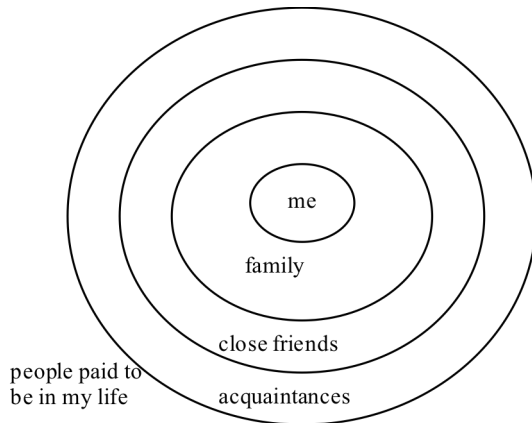
Lesson 2: Learning about myself and my autism spectrum disorder

Time required: 2 hours

Objectives:
  a. To identify interests, strengths and weaknesses
  b. To identify attributes associated with ASD
  c. To develop a sense of value and self-worth
  d. To do a short presentation in front of the group
  e. To practice problem solving strategies

Materials and preparation:
  o Easel paper
  o Markers
  o T-shirts frozen in ice
  o Handouts
  o PS2 + guitar hero

Teaching procedures:

Activity 1 – Rules (5 minutes)
  Go over prepared list of group rules. Discuss to make sure everyone understands and
  everyone feels this is fair.
  • No GameBoys/Nintendo DS/etc
  • Listen quietly while others are talking
  • Pay attention to what others are saying
  • One person speaking at a time

Activity 2 – Jeopardy Game (15 minutes)
  One of the rules is to pay attention when others are speaking. This is an activity to see
  how well the group was paying attention last week. This is a game like jeopardy
  except the questions will be about group members to see how much everyone
  remembers about each other. Facilitator asks a question, group members write down

the answer without letting anyone else see. If the member answers correctly they receive points. The person with the most points at the end wins a prize!!

Activity 3 – Identifying interests, strengths and weaknesses (20 minutes)

Explain to the group that during the panel discussions they will be answering questions about themselves. Therefore it is important for group members to have a good sense of who they are as individuals – what are their strengths, weaknesses, and interests. Getting to know oneself is a pre-requisite skill to becoming a self-determined individual. On a piece of easel paper, each group member will write down a list of their interests, their strengths, and their weaknesses. The facilitator will also complete the worksheet as a model for the group. The facilitator will help individuals brainstorm and come up with an accurate depiction of who that individual is. Have worksheets already set up on big paper. Worksheets will be taped to the wall so group members can stand and fill them out. The goal of the facilitator is to really get group members to acknowledge their strengths in order to improve self-awareness and self-appreciation.

Activity 4 – Identifying attributes associated with my ASD (15 minutes)

In pairs the group will brainstorm what it means to have ASD and think about these questions:

- What are some of the characteristics?
- What are some things you like about it?
- What do you dislike about it?

After the pairs have discussed these answers, have them go back to their easel paper (strengths/weaknesses/interests worksheet) and circle the things they feel their ASD helps them with in green and the things they feel their ASD gives them difficulty with in red. Have a group discussion about specific strengths that can be attributed to having ASD and about specific weaknesses that can be attributed to having ASD. In this discussion also talk about how individuals with ASD may be impacted differently by their disorder – each individual is unique with his own unique strengths, weaknesses, and interests. The facilitator will provide verbal prompting and guidance when necessary.

BREAK (10 mins)

Activity 5 – Presentations (20 minutes)

On the panel each member will need to introduce themselves. Have a prepared list of all the possible things that are appropriate to include in an introduction (i.e., name, age, school, grade, interests, strengths, weaknesses, what aspects of their life has having ASD impacted the most, etc.). From this list, group members will prepare a 1-minute presentation about themselves. The facilitator will give an example presentation before the group members prepare their own. Have each member of the group stand up and present in from of everyone. Provide verbal praise and corrective feedback.

Activity 6 – "T-shirt challenge". (15 minutes)
> Split up the group into 2 teams of 3. Each team gets a t-shirt that has been frozen inside a block of ice in a Ziploc bag. The first team to find a way to get rid of the ice and put the t-shirt on the facilitator will be the winner. If the groups are really stuck then provide helpful hints. The winning group gets first dibs on the PlayStation.

Activity 7 – Group decision making (10 minutes)
> As a group discuss what types of food would be best to have at the training sessions. If they choose pizza – what toppings and how much will everyone eat. As a group come up with a final decision.

Activity 8 – Hang out time. (10 minutes)
> Play PlayStation (guitar hero) and hangout.

Resources/references:

Forgan, J. (2002). Using bibliotherapy to teach problem solving. *Intervention in School and Clinic, 38,* 75-82.

Test, D., Fowler, C., Wood, W., Brewer, D., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26,* 43-54.

Wehmeyer, M. L., Agran, M., & Hughes, C. (1998). *Teaching self-determination to students with disabilities.* Baltimore: Paul H. Brookes Publishing Co.

Lesson 3: Social skills and communication 101

Time required: 2 hours

Objectives:
a. To practice problem solving skills
b. To learn active listening skills
c. To learn effective communication strategies
d. To become more confident at introductions
e. To acknowledge the primary goals of the project and recognize how these goals can be achieved.

Materials and preparation:
o Easel paper
o Tape
o Wheel of Fortune spinner
o Scrap paper
o PS2 + guitar hero
o VCR
o Video – "Intricate Minds"
o 6 pre-drawn pictures
o Microphone

Teaching procedures:

Activity 1 – Review rules (5 minutes)

Activity 2 – "Wheel of fortune" (10 minutes)
This review game will determine how much everyone was paying attention to the presentations at the previous group training session. Everyone will get a turn to spin the spinner, which lands on a certain monetary value (just like Wheel of Fortune). The facilitator will read a question aloud. Everyone in the group must write down their answers. If the student answers correctly, he wins the monetary value that was spun. The person at the end of the game with the most "money" wins first dibs on the PS2.

Activity 3 – Barrier Game (30 minutes)
The objective of this activity is to practice communicating effectively. It also demonstrates the importance of listening. Start by having the facilitators demonstrate good and bad examples of the following communication strategies:
- Speak slowly
- Speak clearly
- Speak with expression
- Think about what you're going to say so that you can say what you mean in not so many words.

In pairs, one person is designated as the foreman and the other as the designer. The foreman chooses a piece of paper out of the envelop, which has a pre-drawn robot on it and instructs the designer to draw what's on the picture using the four communication strategies discussed. The foreman must keep the pre-drawn picture behind the barrier so that the designer cannot see it. The foreman must also not peek over the barrier to see how the drawing is turning out. Once the designer has completed the drawing, compare the original picture with the one the designer made. After comparing pictures, the designer will fill out the communication evaluation for how well they felt the foreman did. The designer and foreman will reverse roles. The facilitators will model this for the group before they begin the activity. Prompting will be prompted when necessary.

BREAK – pizza (15 minutes)

Activity 4 – Discussion of the film "The Boy Inside" (40 minutes)
After watching "The Boy Inside" many of the group members felt that this was a very depressing movie that might not give people the right impression of what it is like to have ASD. Have a group discussion and ask the following questions:
- What do you remember from this video?
- Was there anything you liked about it?
- What did you not like about it?
- What do you think about showing this film to people who do not know what autism or Asperger's is and why do you feel this way?
- When we put on our events, we will start by showing the audience members this film which will then be followed by a panel discussion where you will talk about your experiences having ASD and also answer questions from the audience. How

do you think the audience members might feel if they just saw this film and went straight home without listening to the panel?
- o The reason we decided to show "The Boy Inside" is because it is important that people understand how bad it can get when people are not understanding of someone who has ASD. We want them to know this so that they can be empathetic and more understanding.
- What do you think the purpose of the panel might be?
  - o The purpose of the panel is for group members to share their real life experiences about ASD so that audience members can understand that having ASD does not necessarily mean that everyone shares the same negative experiences as Adam, from "The Boy Inside". We want to teach the audience that although our panel speakers may have ASD, they are still extremely talented at many things and are in more ways than not, just like any other teen their age. It is important that the audience learns about the experiences of the panel members so that they gain a better understanding of ASD and learn what they can do to make the experiences better of individuals with ASD better.

It is important that the group members understand that individuals with ASD all have different experiences – some of which are positive and others which are negative. Show the group the film "Intricate Minds," a film about teenagers from Toronto who talk about their experiences having ASD. This film was made by the individuals in the film as a method to teach their classmates about ASD. So instead of making a film, explain that group members in this project will form a panel in order to teach those in their community about what it is like to have ASD. Facilitate a question and answer period so the group members will have an idea about the questions they might be asked while on the panel and also so the facilitator will have an idea of what skills the group needs to work on when answering questions. Put these questions into the context that some people in the audience are going to want to know this information so they can help make changes in their environment to better the lives of individuals on the spectrum.

- Here are some questions to ask:
  - o Have you been bullied like Adam (from "The Boy Inside") and some of the kids from the "Intricate Minds" film?
  - o Do you have trouble socializing and reading social cues (with friends, with cashiers, with teachers)?
  - o Do you guys have special interests?
  - o Do you feel like you can relate to some of these kids from the "Intricate Minds"? In what way?
  - o In what way do you think you can relate to Adam?

Following these questions, ask the panel members if they feel better about showing the film "The Boy Inside" to audience members at the community events.

Activity 5 – Practice intro and answering questions using the communication strategies with microphones (15 minutes)
Hand out introduction cue cards and have everyone think of what they want to say for their 1-minute introduction. Prompt if necessary. Again, have the facilitator give a short introduction of themselves as a model for the group. Have every group member introduce

themselves using the microphone. Provide corrective feedback and praise. Following the introductions, the facilitator will ask everyone one question which they must answer (similar to questions that may be asked while they are on the panel). Provide praise and corrective feedback to the group.

- When did you find out you had Asperger's/autism and how did they tell you?
- If you could make all your teachers do one thing differently, what would that be?
- Can you give me some advice on how someone with ASD should deal with being bullied?
- Do you tell new people you meet or your friends that you have Asperger's?
- What is the hardest part about making/keeping friends?
- Do you like having ASD?
- Do you have siblings who are also on the spectrum?
- Do you have any school subjects or hobbies that you really excel at?
- What's the difference between having autism and having Asperger's?

Activity 6 – Hang out time (5 minutes)
   Play PlayStation (guitar hero).

Resources/references:

Miyata, C. (2001). Speaking rules! Classroom games, exercises, and activities for creating masterful speakers, presenters and storytellers. Markham: Pembroke Publishers Limited.

Handouts/worksheets:

1) Communication Evaluations:

Strategies	Rating			
1. Spoke slowly	NEEDS PRACTICE	OKAY	GOOD	GREAT
2. Spoke clearly	NEEDS PRACTICE	OKAY	GOOD	GREAT
3. Spoke with expression	NEEDS PRACTICE	OKAY	GOOD	GREAT
4. Said what you meant (in not so many words)	NEEDS PRACTICE	OKAY	GOOD	GREAT

2) Introduction Cue Cards:

INTRO: -name -age -school -grade -one thing you'r e good at or proud of -one thing you hav e difficulty with -how has having Asperger's affected you at school?	STRATEGIES: -speak sl owly -speak cl early -speak with exp ression -say what you mean in not so many words -eyes on th e spea ker -quiet whil e others are talking -sit in chair o r stand behind it -sit up straight
	WHEN NERVOUS OR UPSET: • take deep breaths and relax your body • it's okay to say I don't feel comfortabl e answering that question

Lesson 4: Managing yourself in social situations

Time required: 2 hours

Objectives:
  a. To learn effective listening techniques
  b. To learn self-management techniques
  c. To practice answering questions

Materials and preparation:
  o Easel paper and markers
  o Adam's Q & A DVD
  o TV + DVD player

Teaching procedures:

Activity 1 – Review Rules (5 minutes)

Activity 2 – Review Game "Who wants to be a millionaire" (10 mins)
  This game will serve as a review tool that covers material learned from the previous group training session. Each question will be worth a certain monetary value and will be asked in multiple choice format. Everyone will answer each question. The person with the most "money" at the end of the game will win first dibs on PlayStation.

Activity 3 – Effective Listening skills (10 minutes)
  In order to demonstrate the use of effective/polite and ineffective/impolite listening strategies both facilitators will act out a conversation where the listening partner engages in the following behaviours:

- Covering face with hands
- Closing eyes
- Looking at the ceiling
- Staring at the speaker without facial expression (looking bored)
- Leaning over in your chair
- Putting your head on the table
- Making goofy facial expressions
- Leaning forward looking interested
- Watching the speaker intently
- Nodding where appropriate
- Laughing during appropriate and inappropriate times
- Yawning
- Mouth shut and eyes open

While the facilitators are acting this out, the group will have two buzzers in front of them. One that says "good listening" when you hit it and is labeled as good listening, and the other which is labeled as bad listening and makes an "incorrect" sound effect. After this exercise the facilitator will go through each listening strategy and conduct a social thinking activity by asking the group members what they would be thinking and how they would feel if someone was engaging in each one of those behaviours. The goal of this activity is for the participants to become aware of how others may feel and what others may be thinking based on their behaviours while sitting and listening to questions from the audience and answers from other adolescents on the panel. Generate a list of effective listening strategies with the group. These strategies should include:

- Show the speaker with your face and body language that you're listening and you're interested in what they're saying
- Lean forward to show you are interested
- Watch the speaker
- Nod, smile, and laugh when appropriate

Activity 4 – Self Management (25 minutes)

Discuss situations that bring on nervous tension and irritation, like the dentist, timed math tests, etc. Make a list with the group. Discuss how students react physically to these situations (butterflies, feel like you have to pee, shaking limbs, pulls on sleeves, playing with hair, laughing, biting nails, feeling like you want to blow up, etc). Discuss strategies individuals can use to relax in these situations. Discuss strategies that can be used to calm down/relax specifically while public speaking on the panel. As a group, come up with the appropriate strategy to use in the following situations:

- Someone asks a dumb question.
- Someone asks a question that makes you uncomfortable.
- You're getting uncomfortable from sitting too long
- You're nervous about speaking on the panel
- What if someone on the panel answers a question and you don't agree and this makes you kind of mad

Provide praise and corrective feedback.

Activity 5 – Break (10 minutes)

Activity 6 – Watch Adam answer questions (20 minutes)
    Adam, the star of "The Boy Inside," was filmed answering questions from an audience who had just watched his film. Show this film to the group, pausing every so often so the group can evaluate how Adam answered the question and ask how might they have answered particular questions differently. Use the template for the effective communication self-evaluations when evaluating Adam's responses.

Activity 7 – Practice answering panel-like questions. (20 minutes)
    Using the microphone, have the group members line their chairs as though they are actually on a panel. During the actual panel discussions, it will be easiest to use only one microphone and pass it along so everyone has a chance to answer the questions and no one will be speaking over one another. Therefore, when one of the group members wants to answer a question, he must raise his hand in order for the panel moderator to bring him the microphone. Explain to the group members that they do not need to answer every question, and that if they have the same answer as someone who previously answered, they do not need to also answer the question. Practice this by having one of the facilitators act as the moderator and the other act as the audience. Reinforce throughout. Following this practice, have each group member fill out the self-evaluation form for how they felt they did at answering the questions. After they have completed the self-evaluation form, go over it with them individually and give them feedback.

Activity 8 – Hang out time (20 minutes)
    Play PlayStation.

Resources/references:

Brown, D. S. (2008). Goal-setting for children with disabilities: Your role is important. LD Online. Retrieved July 29, 2008, from http://www.ldonline.org/article/21026.

Miyata, C. (2001). *Speaking rules! Classroom games, exercises, and activities for creating masterful speakers, presenters and storytellers.* Markham: Pembroke Publishers Limited.

Prater, M. A., Bruhl, S., & Serna, L. A. (1998). Acquiring social skills through cooperative learning and teacher-directed instruction. *Remedial and Special Education, 19,* 160-172.

Test, D., Fowler, C., Wood, W., Brewer, D., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26,* 43-54.

Wehmeyer, M. L., Sands, D. J., Doll, B., & Palmer, S. (1997). The development of self-determination and implications for educational interventions with students with disabilities. *International Journal of Disability, Development and Education, 44,* 305-328.

Handouts/worksheets:

1) Self-Evaluations

Strategies	Rating			
1. Spoke slowly	NEEDS PRACTICE	OKAY	GOOD	GREAT
2. Spoke clearly	NEEDS PRACTICE	OKAY	GOOD	GREAT
3. Spoke with expression	NEEDS PRACTICE	OKAY	GOOD	GREAT
4. Said what you meant (in not so many words)	NEEDS PRACTICE	OKAY	GOOD	GREAT
5. Sit up straight	NEEDS PRACTICE	OKAY	GOOD	GREAT
6. Watch the speaker	NEEDS PRACTICE	OKAY	GOOD	GREAT
7. Eyes open	NEEDS PRACTICE	OKAY	GOOD	GREAT
8. Mouth shut (when listening)	NEEDS PRACTICE	OKAY	GOOD	GREAT

Lesson 5: Public speaking

Time required: 2 hours

Objectives:
- To review goals and goal progress
- To practice the skills learned throughout the intervention
- To evaluate your own performance
- To gain a better self-awareness

Materials and preparation:
- Video camera with cords that hook up to TV
- TV
- Easel paper
- Markers

Teaching procedures:

Activity 1 – Review game "Wheel of Fortune" (15 minutes)
This review game will determine how much each group member remembers from all previous training sessions. Everyone will get a turn to spin the spinner, which lands on a certain monetary value (just like Wheel of Fortune). The facilitator will read a question aloud. Everyone in the group must write down their answers. If the student answers correctly, he wins the monetary value that was spun. The person at the end of the game with the most "money" wins first dibs on the PS2.

Activity 2 – Goal Review (5 minutes)
During the first group training session, each participant set a goal for themselves that had to do with being part of this project. Review these goals and determine if all group members are still on the right track to attaining these goals. Problem solve and brainstorm new strategies to achieve goals if necessary.

Activity 3 – Brainstorm session (5 minutes)
Have the group brainstorm questions that they would like to ask each other or questions that they would like someone to ask them. This brainstorming process can be aided by asking the group if there is any particular information they would like others to know about having ASD or is there some type of information that may better the lives of many individuals on the spectrum if educators/parents/siblings knew.

Activity 4 – Video feedback (practice panel – break – feedback) (1 hour)
Set up the tables and chairs to resemble a panel. Using the microphone, do a practice panel where each panel speaker has to introduce themselves and answer both the questions that they just came up with and also any other question that might be asked at this type of event. The moderator will give the microphone to the individuals who raise their hand. This will be videotaped and will last approximately 25-minutes. Have a short break and then let the group watch their practice panel that was just recorded by

connecting the video camera to the TV. Pause this after each question and provide appropriate feedback. After the group has finished watching the practice panel, have them complete the self-evaluation forms (the same one from lesson 4). As a group go over the evaluation forms together giving each other honest, constructive feedback.

Activity 5 – Guest speaker (20 minutes)
  Adam, the star of "The Boy Inside," was invited to be a guest speaker for the group and share his experiences about having ASD, making a film about it, and answering questions at events similar to the ones we will be holding.

Activity 6 – Hang out time with Adam (15 minutes)
  Play PlayStation (guitar hero).

Resources/references:

Rapee, R. M. & Hayman, K. (1996). The effects of video feedback on the self-evaluation of performance in socially anxious subjects. *Journal of Behavior Research and Therapy, 34,* 315-322.
Rodebaugh, T. L., & Chambless, D. L. (2002). The effects of video feedback on self-perception of performance: A replication and extension. *Cognitive Therapy and Research, 26,* 629-644.

Lesson 6: Practice panel discussion and debrief

Time required: 2 hours

Objectives:
  • To practice all skills learned in a real practice panel discussion

Materials and preparation:
  • Video of the boy inside
  • DVD player
  • Easel paper
  • Markers
  • Camera

Teaching procedures:
Activity 1 – Feedback (15 minutes)
  Have the facilitator prepare a feedback sheet for each of the group members with regards to how they have progressed throughout the past three months – what skills do they excel at and what skills do they need to focus on while speaking on the panel. Sit down one-on-one with each group member to give this feedback and ask for the input of boys themselves.

Activity 2 – Complete web bios (20 minutes)
In the event that a project website is created, have the group members complete a short bio on themselves that they would like to share with the World Wide Web regarding being part of this project.

Activity 3 - What not to wear (10 minutes)
Engage in a group discussion and make a list on easel paper of things that would and would not be appropriate to wear while speaking on the panel. The group members may disagree with one another and problem solving and negotiation will have to take place.

Activity 5 – Mingling (15 minutes)
During the actual practice sessions (i.e., community events), once the panel discussion is complete audience members will have a chance to speak with the group members. During this time, group members must "mingle" with the people who attended the event. Explain to the group what mingling is. Together generate a list of the dos and don'ts of mingling.

Activity 6 - Panel discussion and mingling (45 minutes)
Invite parents, siblings, and several community members to partake in a "practice event". While the group members are engaging in activities 1 through 5, welcome the audience and let them watch the film "The Boy Inside". Following this invite the group members to sit on the panel, introduce themselves, and answer questions from the audience. The panel discussion should last approximately 30-minutes. Following the panel, provide refreshments and goodies for everyone and allow the group members to practice mingling.

Activity 7 – Debrief (15 minutes)
Bring the group members back to the meeting space. Debrief with them how the practice panel and mingling went. Everyone can provide constructive feedback to each other in order to make the real panel discussion even that much more successful. Finally, congratulate the group on what a tremendous job they did.

Resources/references:

Test, D., Fowler, C., Wood, W., Brewer, D., & Eddy, S. (2005). A conceptual framework of self-advocacy for students with disabilities. *Remedial and Special Education, 26,* 43-54.
Wehmeyer, M. L., Agran, M., & Hughes, C. (1998). *Teaching self-determination to students with disabilities.* Baltimore: Paul H. Brookes Publishing Co.

Lesson 7: Review

*Note: Since there was a two-month lag between the second and third event, a review session was held.

Time required: 2 hours

Objectives:
- To review skills learned during the training sessions
- To debrief the first two events

Materials and preparation:
- Easel paper
- Markers
- TV
- PlayStation + guitar hero
- Cranium board game

Teaching procedures:

Activity 1 – "Cranium" board game review (30 minutes)
> Make up question cards that are relevant to skills and information that the group members have been learning over the course of the project. Use a Cranium board and playing pieces. Data head questions should be true or false, or multiple choice. Star performer questions should be acting out right and wrong communication/listening strategies. Creative cat questions can be the ones that come with Cranium. Word worm questions can be practice panel questions. Each player will play individually and follow the Cranium rules. The winner get to play PlayStation first.

Activity 2 – Discussion about the panel (20 minutes)
> Have a discussion about how the group feels the past two panel discussions have gone. Have each group member tell one thing they really liked about being on the panel and also tell one thing they disliked. Problem solve with the group if necessary.

Activity 3 – Answering panel questions (20 minutes)
> During the past two events, sometimes a very boring question would be asked, or a question would be asked where all the panel speakers responded with the same question. During situations like these it may be best if the moderator only chooses a couple of the panel speakers who put their hand up to answer the question. Have a short discussion with the panel members explaining why this may be best (i.e., it give the audience members an opportunity to ask more questions and learn even that much more about the speaker's experiences). Ensure that everyone in the group feels this is fair. Practice this.

Activity 4 – Mingling discussion (20 minutes)
 Have a discussion about how the mingling has gone after the panel discussion. Have each group member tell one thing they really liked about this and also tell one thing they disliked. Problem solve with the group if necessary.

Activity 5 – Pizza party and PlayStation (30 minutes)
 Give the group members a chance to hang out with one another since many of them may not have seen each other in almost two months. Provide pizza, drinks, and cake. After everyone has eaten, the group can play PlayStation.

Resources/references:

None.