

Perspectives of young adults with autism spectrum disorder: Integrating values in
exploring self-determination

Keeley White

School/Applied Child Psychology

A Dissertation

Submitted to McGill University in partial fulfillment of the requirements of the degree of
Doctor of Philosophy

McGill University, Montreal

December 2016

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Abstract

There has been a significant change in the way we view individuals with disabilities over the last few decades. Life possibilities for individuals with disabilities are now reflected in terms of quality of life, self-determination, strengths and capabilities, normalization, and the provision of individualized supports (Wehmeyer & Schalock, 2001). Self-determination (SD), which is implicated in choice and decision making, is an important educational goal that can help individuals with Autism Spectrum Disorders (ASD) as they attempt to negotiate or transition their way into college, work, community involvement, and independent living (Carter, Lane, Pierson, & Stang, 2008; Deci & Ryan 1994; Thoma & Gretzel, 2005). The aim of this dissertation is to gain a better understanding of SD for young Canadian adults with ASD without an intellectual disability (ID). In this mixed-methods study, SD, the participants' value and importance ratings of SD components, and the factors influencing the development of SD were explored using an online survey. Participants were 125 young adults between the ages of 18 and 30 with ASD without an ID across Canada. The results indicated that the sample's mean levels of SD were lower than those reported in the literature for people with ID or other disabilities. Young adults with ASD above 23 years of age who were more educated reported higher levels of SD. However, level of SD did not significantly differ in relation to gender, living situation, or employment status. A hierarchical multiple regression analysis indicated that a person's age, SD capacity, and importance ratings predicted higher levels of SD. Furthermore, mean SD satisfaction scores were lower than mean SD importance scores, which has implications for intervention. A thematic analysis revealed SD-related themes associated to success in adulthood, including capacity, control, knowledge of strengths and weaknesses, attaining adult outcomes, and support. Factors that facilitated or hindered participants' SD included SD skills, mental

health, societal perceptions about disability, support networks, opportunities, and early educational and life experiences. The knowledge gained from this research will allow researchers and practitioners a better window into the needs and values of persons with ASD regarding their SD, and will provide invaluable information concerning effective and individualized support services.

Keywords: self-determination, autism spectrum disorder, young adults, importance and values, predictors, barriers and facilitators, mixed-methods design, thematic analysis

Résumé

Le regard que nous portons sur les personnes présentant des incapacités a considérablement changé au cours des dernières décennies. Les possibilités de ces personnes ont désormais trait à la qualité de vie, l'autodétermination, aux forces et aux capacités, à la normalisation et au soutien individualisé offert (Wehmeyer et Schalock, 2001). L'autodétermination (AD), qui implique faire des choix et prendre des décisions, est un objectif éducatif important qui peut aider les personnes atteintes de troubles du spectre autistique (TSA) lorsqu'elles tentent de réussir leur transition vers le collège, le travail, la participation communautaire et la vie autonome (Carter, Lane, Pierson, et Stang, 2008; Deci et Ryan, 1994; Thoma et Gretzel, 2005). L'objectif de cette thèse est de mieux comprendre l'AD chez les jeunes adultes canadiens atteints de TSA sans déficience intellectuelle (DI). Dans le cadre de cette étude utilisant une méthode mixte, l'AD, la valeur ou l'importance perçue par les participants, et les facteurs qui influent sur le développement de l'AD sont explorés par un sondage en ligne. Les participants sont 125 jeunes adultes canadiens avec un TSA sans DI, âgés de 18 à 30 ans. Les résultats démontrent que le niveau moyen d'AD est plus bas chez les jeunes adultes canadiens atteints de TSA que chez les individus présentant une DI d'autres incapacités. Les jeunes adultes atteints de TSA étant âgés de plus de 23 ans et ayant atteints de plus hauts niveaux de scolarité, démontraient plus d'AD. Par contre, le niveau d'AD n'était pas significativement influencé par le sexe, la condition de vie, et le statu d'emploi des participants. Une analyse de régression multiple hiérarchique a indiqué que l'âge d'un individu ainsi que leur capacité à s'autodéterminer et leur cote d'importance d'AD prédit un niveau plus élevé d'AD. En outre, les cotes moyennes de satisfaction en AD étaient plus élevées que les cotes d'évaluation de l'importance de l'AD. Ceci pourrait avoir des implications pour l'intervention. Une analyse thématique révèle plusieurs thèmes liés à l'AD qui

sont associés au succès à l'âge adulte, par exemple: la capacité, le contrôle, une connaissance de ses forces et faiblesses, l'atteinte d'objectifs à l'âge adultes, et le soutien. Les facteurs qui à facilitent ou entravent l'AD des participants incluent: les habiletés d'AD, la santé mentale, les perceptions sociales des incapacités, le réseau de soutien, la présence d'opportunités, ainsi que les premières expériences de vie et d'éducation. Les connaissances obtenues grâce à cette recherche permettront aux chercheurs et aux praticiens de mieux connaître les besoins et les valeurs des personnes atteintes de TSA en ce qui a trait à leur AD et fourniront des renseignements précieux concernant les services de soutien efficaces et individualisés.

Mots clés : autodétermination, trouble du spectre autistique, jeunes adultes, importance et valeurs, prédicteurs, obstacles et facilitateurs, modèle multi-méthodes, analyse thématique

Acknowledgements

I have received a great deal of support and guidance from many individuals during my journey toward becoming a scientist-practitioner in the field of disability. I wholeheartedly appreciate and am grateful to each one of these individuals. Many thanks are due to my doctoral supervisor, Dr. Tara Flanagan. I deeply appreciate her mentorship and support over the past five years and her trust in my abilities as a scientist-practitioner to coordinate the McGill Transition Support Program for young adults with ASD. I would also like to thank the other individuals who provided support throughout my doctoral studies and in the process of preparing this dissertation. This includes my dissertation committee members, Drs. Armando Bertone and Ingrid Sladeczek, as well as Drs. Rosemary Condillac and Aparna Nadig, who provided me with invaluable mentorship throughout my academic career. Furthermore, without the support of the participating young adults with ASD across Canada, this research would not have been possible. So, thank you for your contributions! The understanding and support provided by my friends and family, especially Catherine Loiselle, who has always provided me with constructive feedback enabling me to become a more critical researcher. To my mother, whose unconditional love and support has served as a secure anchor during the ups and downs, ♥ mostest. Lastly, to my father, who while unable to witness the completion of this journey, never doubted that I could accomplish anything. All of you have given me the strength and motivation to pursue my goals and complete my doctoral degree.

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CHAPTER 1: INTRODUCTION

Introduction

The utilization of the self-determination (SD) construct dates back to the late 1600s and is related to the philosophical doctrine of determinism (Wehmeyer, 2005). The doctrine of determinism suggests that all actions, including human behaviour, are consequences of previous events (Wehmeyer, 2005). As such, SD or self-determinism relates to the idea that one causes oneself to act, as opposed to other individuals, settings, or occasions causing one to act (Mithaug, 1998; Wehmeyer, 2005). Since its conceptualization, the construct of SD has carried multiple meanings that may cause confusion and misunderstanding in research and in practice (Wehmeyer, 2004, 2005). Nevertheless, most definitions focus on the internal attributes of an individual. The earliest works of Field and Hoffman (1994), Ward (1998), and Wehmeyer (1996a) have played a significant role in the conceptualization and application of SD for individuals with disabilities. While Field and Hoffman (1994) and Ward (1996) both stressed the value of goal setting and attainment in defining SD, Wehmeyer noted the importance of volitional actions and causal agency. Wehmeyer defined SD as the “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). Thus, self-determined behaviour refers to behaviour that is caused or determined by the person as opposed to being caused by someone or something else. To better understand the notion of SD, Wehmeyer (2005) put forth a caveat about what SD is not. SD is not a process or outcome; is not a set of skills; is not independent performance of

behaviours, self-reliance, or self-sufficiency; is not successful behaviour; is not student involvement or something you do; and is not just choice.

Given that the aim of this dissertation is to gain a better understanding of SD for young Canadian adults with Autism Spectrum Disorder (ASD) without an intellectual disability (ID), this chapter will introduce the concept of SD in the context of the disability field by outlining a brief historical view of individuals with disabilities, SD within the field of psychology and disability, and more specifically for individuals with ASD. The purpose of the study, definition of terms, organization of the dissertation, and significance of the study will also be delineated.

Self-Determination in the Context of the History of Disability

Self-determination is rooted in the political right for people with disabilities to have autonomy and independence (Wehmeyer, 2004). Since the early 1990s, enhancing the SD of individuals with disabilities has received significant attention in advocacy, research, and practice in the field of disability (Shogren, 2002). Historical and current perspectives often consider individuals with disabilities as being incapable of being meaningful participants in their lives and in society (Ward, 1996; Wehmeyer, 2013). In fact, most individuals with disabilities were denied access to education and exposed to services and treatments that reduced opportunities for personal development (Szymanski & Trueba, 1994). To better understand the concept of disability various models of disability were put forth, namely the medical or deficit model and the social model.

The medical or deficit model of disability was the most commonly used approach to understanding disability (Hutchison, 1995; Johnson, 1996; Llewellyn & Hogan, 2000) and emerged from the social institutions that existed to “treat” or “cure” individuals with disabilities (Szymanski & Trueba, 1994). The medical model viewed disability as core difficulties situated

within the individual that required the attention of educated professionals (Johnson, 1996; Llewellyn & Hogan, 2000), such as psychiatrists. This suggested that a person's core difficulties are the essence of any disadvantages experienced. Consequently, this view of individuals with disabilities from a deficit model perspective provided the reasoning for the treatments that were delivered and the systems that were upheld (Johnson, 1996; Llewellyn & Hogan, 2000). That is, these disadvantages could only be rectified by treatment or a cure.

Important changes began to prevail in the field of disability services and supports during the latter part of the 20th century (Shogren, 2002). At this time, the medical model was less prevalent, as the social model of disability began to shape the provision of services. It was the social model of disability that was essential to dismantling the traditional conception of a disability as a personal tragedy and the oppression it created (Llewellyn & Hogan, 2000). This resulted from an increasing emphasis on the importance of social factors in conceptualizing disability. The social model of disability viewed a person's experience of disability as shaped by their environment (Terzi, 2004). These environmental factors may either pose as barriers or facilitators to participation and inclusion. Taken together, the social model of disability began to shift attention from core difficulties within the person to core difficulties within society as a primary cause of the adverse outcomes often experienced by individuals with disabilities (Llewellyn & Hogan, 2000; Terzi, 2004).

This shift in ideology led to modifications in conceptualizations, such as constructs like mental retardation, and in recommendations for best practices (Luckasson et al., 1992; Luckasson et al., 2002; Schalock et al., 2010). For example, services began to focus on building individual's skills and strengths rather than on their core difficulties, with accompanying interests in person-centered supports (Luckasson et al., 2002; Schalock et al., 2010). Another

reason for these changes in conceptualization and intervention for individuals with disabilities, aside from the shift to the social model of disability, was the normalization movement (Nirje, 1969, 1999; Wolfensberger, 1972). Wolfensberger's principle of "normalization" focused on contextual factors, such as large segregated institutions, that might lead to feelings of hopelessness, helplessness, and powerlessness (Wolfensberger, 1972). Normalization is the "utilization of means which are as culturally normative as possible in order to establish and/or maintain personal behaviours and characteristics which are culturally normative as possible" (Wolfensberger, 1972, p. 28). More specifically, the normalization movement encouraged the importance of supporting individuals with disabilities to experience and live "normal" lives, emphasizing independence, inclusion, and SD (Wolfensberger, 1972).

Nirje (1972) was one of the first to discuss the value of SD in the lives of individuals with disabilities. In his work, he expressed the right of individuals with disabilities to develop SD and be provided with opportunities to express SD. Nirje stated:

...the choices, wishes, desires, and aspirations of a [individual with a disability] have to be taken into consideration as much as possible in actions affecting him. To assert oneself with one's family, friends, neighbors, co-workers, other individuals, or vis-à-vis as agency is difficult for many persons. It is especially difficult for someone who has a disability or is otherwise perceived as devalued. But in the end, even the [person with a disability] has to manage as a distinct individual, and thus has his identify defined to himself and to others through the circumstances and conditions of his existence. Thus, the road to self-determination is indeed both difficult and all-important for a [individual with a disability] (p.177).

Despite Nirje's efforts to increase attention for SD for individuals with disabilities, it went unnoticed for years. Approximately a decade later, professionals working with individuals with disabilities were becoming progressively cognizant of and alarmed about the poor adult outcomes that were experienced. Particular attention was given to the lack of opportunities individuals with disabilities had to act as causal agents in their own lives (Whemeyer, Bersani, & Gagne, 2000). It was also the time that self-advocacy for individuals with disabilities rights to exert control over their lives, as well as independent living movements began to flourish (Wehmeyer, 2013).

Analogous to the principle of normalization, parent advocacy groups, human rights movements, shifts in political philosophies, and legal actions also played essential roles in the conceptualization of a disability and the use of positive- and strength-based approaches to service delivery in the field of disability (Buntinx & Schalock, 2010; Edwards, 1982; Schalock, 2011; Schalock et al., 2007; Wehmeyer et al., 2008). For instance, the powerful slogan of the individuals with disabilities movement, "Nothing About Us Without Us" (Aspis, 2000) has challenged researchers and historians to address the disputed issue of enabling individuals with disabilities to have a voice in the services they receive (Atkinson & Walmsley, 2010). The United Nations Convention on the Rights of Persons with Disabilities, an international law, was a significant step towards realizing the rights and voice of individuals with disabilities (United Nations, 2006). The convention addresses discrimination, to change perceptions, and to combat stereotypes and prejudices. However, it also placed an obligation on governments to ensure that they assist individuals with disabilities to achieve equality, or "normalization" relative to individuals without disabilities. This adoption (United Nations, 2006) provided momentum to

acknowledge and support individuals with disabilities as they continue to face rights violations and barriers to equal participation in society.

Overall, the implications of such catalysts have been significant, such that the creation and provision of services has begun to focus on a person's needs, strengths, and capabilities within the context of "typical" community-based settings with appropriate and adequate supports (Schalock et al., 1994; Shogren, Wehmeyer, Buchanan, & Lopez, 2006). Consequently, SD helped capture this changing vision together with quality of life, through which Schalock (2000) believes that justice, empowerment, and increased life satisfaction could be attained. Therefore, it is imperative that we gain a better understanding of SD regarding persons with disabilities and in particular young adults with ASD provided its value in promoting a life of quality.

The Construct of Self-Determination

Although the issues related to SD are relatively novel to the field of disability, SD has been considered in disputes about free will and determinism for many years within the discipline of philosophy (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). Specifically, John Locke utilized the term to describe his "soft" determinist position, which noted that human action was both caused and volitional, that is, human action was both self- and other-determined (Hergenhahn, 2008; Wehmeyer et al., 2003). Locke's perspective is one of the central foundations for our contemporary notions of SD. From Locke's work and more, we recognize the multiple determinants (or causes) of human behaviour, including individuals, structural, environmental, and organismic factors that interact and impact an individual's ability to be self-determined (Wehmeyer et al., 2003). The discipline of psychology has also identified the value of SD within the field.

The SD construct stayed hidden within philosophical debates until the last half of the nineteenth century (Wehmeyer et al., 2003). With the evolution of the social sciences, issues of self- and other-determinism were commonly considered (Shogren, 2002). For instance, social workers have identified SD as a core value of practice (Reamer, 1998), while researchers and practitioners have recognized its implications as a goal of education in transition planning and a core dimension of quality of life (Field, Martin, Miller, Ward, & Wehmeyer, 1998; Field, Sarver, & Shaw, 2003; Schalock, 1996). Within the discipline of psychology, two sub-areas namely personality and motivational psychology developed outside the realm of behavioural psychology concerning SD flourished (Wehmeyer et al., 2003).

Angyal (1941) theorized that the interaction between self- and other-determinants is crucial to understanding individual differences in personality (as cited by Wehmeyer et al., 2003). Angyal believed that as personality developed, individuals became more autonomous or self-governing. Furthermore, interaction with environmental or other-determinants often influenced the development and expression of individual autonomy, or SD. More specifically, Angyal believed that to express SD, individuals must assert themselves against the other-determinants that govern behaviour. Thus, understanding the process by which individuals engage in self-regulation, choice-making, and self-advocacy over their environment was fundamental to understanding personality development (Wehmeyer et al., 2003).

Deci and Ryan (1980, 1985, 2002b) built upon Angyal's (1941) concept of SD and integrated it within the field of motivational psychology (Wehmeyer et al., 2003). Theories of motivation attempted to explain SD by focusing on the reasons (i.e., why) people act as they do. Deci and Ryan theorized SD as an innate need that motivates an individual to engage in behaviours "with a full sense of wanting, choosing, and personal endorsement when self-

determined individuals are acting in accord with, or expressing themselves” (Deci, 1992, p.44).

Therefore, Self-Determination Theory (SDT) suggests that individuals engage in behaviours that they find innately interesting and not for reasons involving reinforcement, motivations, or other-determinants, that is, the locus of control is internal to his or her self. Deci and Ryan believe that there is an innate tendency toward commitment and growth:

“All individuals have natural, innate, and constructive tendencies to develop an ever more elaborated and unified sense of self. That is, we assume individuals have a primary propensity to forge interconnections among aspects of their own psyches as well as with other individuals and groups in their social world” (Deci & Ryan, 2002a, p. 5).

Aside from an innate tendency towards integration involving both autonomy and integration, SDT also recognizes that there are “clear and specifiable social-contextual factors that support this innate tendency, and that there are other specifiable factors that thwart or hinder this fundamental process of human nature” (Deci & Ryan, 2002a, p.5). SDT identifies three basic psychological needs: competence, relatedness, and autonomy (Deci & Ryan, 2000). Competence refers to the ability to successfully control and master the environment and outcome.

Relatedness refers to having emotional relationships with others and a sense of belonging to one’s community. Autonomy refers to acting upon one’s interests and integrated values and perceiving oneself as a causal agent. Particularly, the degree to which individuals engage in self-determined behaviour will vary depending on level of environmental support for competence, relatedness, and autonomy. When these psychological needs are satisfied, individuals exhibit optimal motivation and wellbeing (Ryan & Deci, 2000). Building upon the importance of environmental support for these basic psychological needs and the characteristic differences in

communication and social interaction of individuals with ASD, further research is warranted to better understand the unique needs and values required to promote SD in this population.

Self-Determination in Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) refers to a group of neurodevelopmental disorders including pervasive difficulties with social communication and social interaction across multiple contexts, with restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). The Centers for Disease Control [CDC] (2014) report the 2010 rate of ASD to be 1 in 68 births in the United States. This is compared with 1 in 88 in 2008 (CDC, 2012), 1 in 110 using combined data from 2006 and 2004 (CDC, 2009), and 1 in 150 in 2002 (CDC, 2007). Similar rates have been reported in Canada. Since 2003, the National Epidemiologic Database for the Study of Autism in Canada (NEDSAC) has been monitoring the prevalence of ASD in Newfoundland and Labrador, Prince Edward Island, and the Southeastern region of Ontario. Based on data collected from 2008 and 2010, the NEDSAC's best estimate of the prevalence of ASD in Canada is 1 in 94 (Ouellette-Kuntz et al., 2009, 2014; Ouellette-Kuntz, Coe, Yu, & Lewis, 2012). Given the increased prevalence of ASDs over the past 10 to 15 years, we are facing a significant population of individuals with ASD entering adulthood.

As individuals with and without ASD enter adulthood, they are typically faced with transitions such as completing high school, gaining employment, postsecondary education, independent living, participating in the community, and experiencing personal and social relationships (Wehman et al., 2014). These transitions are difficult for everyone. Although, research has shown that the core area of difficulties associated with ASD have shown to improve with increasing age (Matson & Horovitz, 2010), a higher IQ and more complex language in adulthood are not sufficient for independence (Farley et al., 2009; Howlin & Moss, 2012). That

is, the additional core difficulties associated with having a diagnosis of ASD make transitioning to adulthood challenging even with transition planning. In fact, the vast majority of adults with ASD with or without an ID are faced with significant obstacles in multiple areas as they attempt to negotiate, or transition, their way into college, work, community involvement, and independent living (Billstedt, Gillberg, & Gillberg, 2005; Gerhardt & Lainer, 2011; Hendricks & Wehman, 2009; Howlin & Moss, 2012; Sterling, Dawson, Estes, & Greenson, 2008). For example, an average of 50-60% of adults with ASD leave school without educational or vocational credentials, 76% are unable to find work, and 90-95% are unable to establish romantic relationships or meaningful friendships (Levy & Perry, 2011).

Few studies describe outcomes for adults with ASD without an ID (and with average or above average intellectual abilities), a population that is associated with greater variability in individual outcomes (Engstrom, Ekstrom, & Emilsson, 2003; Howlin, 2003; Howlin, Goode, Hutton, & Rutter, 2004). In fact, Howlin (2000) and Tsatsanis (2003) reviewed the literature on outcomes for adults with ASD without an ID and found that a minority had received university education, lived semi-independently, had close friendships, were married or had a paid job. Given such poor outcomes for adults with ASD without an ID, SD-based interventions should be considered a means to obtaining more positive outcomes provided their positive implications for individuals with ID.

In studies of individuals with ID, SD has been found to be associated with the attainment of positive academic (Fowler, Konrad, Walker, Test, & Wood, 2007; Konrad, Fowler, Walker, Test, & Wood, 2007; Lee, Wehmeyer, Soukup, & Palmer, 2010) and transition outcomes, including employment and independent living (Martorell, Gutierrez- Rechacha, Perda, & Ayuso-Mateos, 2008; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). SD is also linked

with more positive recreation and leisure outcomes (McGuire & McDonnell, 2008), community involvement and increased individual success (Hendricks & Wehman, 2009), as well as better quality of life and life satisfaction (Wehmeyer & Schwartz, 1998; Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006). For example, researchers have found that students with ID who had higher levels of SD prior to graduating from high school were more likely to be employed with better earnings and to be living independently one and three years after high school relative to students with lower levels of SD (Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). These studies demonstrate the positive outcomes of having better-developed SD skills relative to those who are less self-determined, revealing the potent influence of SD on post-secondary outcomes.

Given that these studies have led to an increased emphasis of SD for persons with ID, it is believed that similar outcomes will be found for individuals with ASD without an ID. Specifically, the reported gains obtained from promoting SD in individuals with ID are believed to exist for those with ASD without ID when provided with appropriate supports to meet their unique SD needs. Although there are mixed results regarding the impact of cognitive abilities on SD (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Garner, 2003), it is believed that promoting SD in adults with ASD, regardless of the presence or absence of an ID, will demonstrate positive outcomes. Given the lack of research focused specifically on individuals with ASD, as well as the associated positive benefits of exhibiting self-determined behaviours, a better understanding of the development of SD, as well as the factors that influence its development is needed to better support individuals with ASD live a life of quality as they transition into adulthood.

Purpose of the Study

In light of the limited information about the SD in individuals with ASD and the positive outcomes that could be achieved if enhanced, the purpose of this dissertation is to gain a better understanding of SD for young Canadian adults with ASD without an ID. The goal of this dissertation research is to explore SD as well as investigate the possible demographic variables that explain the levels of SD. Furthermore, predictors and factors influencing the development of SD will be explored. Unique to this dissertation research, the self-perceived importance of SD based on Arc's Self-Determination Scale (*SDS*; Wehemyer, 1996b; Wehmeyer & Kelchner, 1995) in attaining adult outcomes will be investigated. Particularly, knowledge of the importance and satisfaction of SD will help to elucidate the current SD needs of young adults with ASD. This knowledge will better inform future efforts to create environmental conditions that are supportive of the development of SD, to inform efforts to promote SD based on the needs and values of persons with ASD, and further our understanding of the construct of SD.

Definition of Terms

The following definitions are provided to ensure uniformity and understanding of these terms throughout the study (Wehmeyer & Kelchner, 1995; Wolman, Campeau, Dubois, Mithaugh, & Stolarski, 1994).

Autonomy: Acting independently and acting on the basis of preferences, beliefs, values and abilities.

Capacity: Knowledge, abilities, and perceptions that enable individuals to be self-determined and feel good about it.

Opportunity: Individuals' chances to use their knowledge and abilities.

Psychological Empowerment: Related constructs of locus of control, self-efficacy and outcomes expectancy, which provide an overall indicator of perceived control (i.e., beliefs in ability, perceptions of control, and expectation of success).

Self-Determination: A dispositional characteristic defined as “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117).

Self-Realization: Includes self-awareness, self-acceptance, self-confidence, self-esteem and self-actualization.

Self-Regulation: Includes interpersonal cognitive problem-solving, goal-setting and task performance.

Organization of the Dissertation

Chapter 1 will present the introduction, purpose of the study, research questions, significance of the study, definition of terms, and limitations. Chapter 2 will contain the review of literature and research related to the problems being investigated. The method and procedures used to gather data for the study will be presented in Chapter 3. The results of analyses and findings to emerge from the study will be contained in Chapter 4. Chapter 5 will contain a summary of the study and findings, conclusions drawn from the findings, a discussion, and recommendations for further study.

Significance and Implications

This large-scale survey will provide valuable information and help to fill the literature gap with regards to SD for young adults with ASD across Canada. In order to more effectively meet the needs of adults with ASD without an ID, significant changes to policy and transition planning are necessary. Understanding the perspectives of adults with ASD without an ID regarding how

to best encourage their expression of SD is imperative not only to developing meaningful supports (e.g., employment, independent living) that are important to them, but also to target potential environmental influences (e.g., opportunities, supports) not previously explored by researchers that may result in improved outcomes for adults with ASD. Despite considerable efforts directed towards understanding and increasing the SD of individuals with intellectual disabilities (ID), little is known about SD for young adults with ASD without an ID. Descriptive information addressing the skills, knowledge, opportunities and perceptions of young adults with ASD in the area of SD would assist researchers and practitioners to identify specific areas of strength and need, to develop instructional objectives and curricular materials, and to design effective interventions. This information will have clear and direct relevance to individuals, families, organizations, service providers, and to policy makers in social services and education sectors throughout Canada.

CHAPTER 2: LITERATURE REVIEW

Introduction

The SD process requires time and an awareness of personal strengths and challenges together with the knowledge and skills required for adulthood (Fullerton & Coyne, 1999). These skills are difficult for individuals with ASD; and without the instructional methods to meet their learning needs, adults with ASD might go through life without fully understanding and applying SD behaviours in their lives. SD is a developmental phenomenon that changes over a person's lifespan and involves parallel fields of continuous development in emotional, social, communication, and behavioural skills (Malian & Nevin, 2002). Arguably, SD is the hallmark of adulthood and an essential attribute needed for achieving a good quality of life (Lachapelle et al., 2005; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998). This chapter contains the

theoretical framework of the study, relevant theories and models to SD, an overview of SD within the field of disabilities (including ASD) and relevant research findings related to the research questions of this study.

Theoretical Frameworks or Models of Self-Determination

In the most common conceptual model of SD in the field of disability, Wehmeyer (1992) defined SD as “the attitudes and abilities required to act as the primary causal agent in one’s life and to make choices regarding one’s actions free from undue external influence or interference” (p. 305). However, he later noticed that what was missing from the original definition was the notion that self-determined actions contribute to one’s quality of life. Wehmeyer (1996a) has thus adapted his definition to include “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (p. 22). In 1999, Wehmeyer delineated four essential characteristics or latent constructs that comprise SD: behavioural autonomy, self-regulation, psychological empowerment, and self-realization. These essential characteristics led to Wehmeyer’s current and revised definition, which now includes the volitional nature of self-determined behaviour. SD is the “volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). That is, individuals who are self-determined cause things that are aligned with their preferences and interests to happen in their lives (Wehmeyer et al., 2010).

In this dissertation, the functional theory of SD developed by Wehmeyer and colleagues (Wehmeyer, 1996a, 1997, 1999, 2001; Wehmeyer et al., 2003), as well as Mithaug, Mithaug Agran, Martin, and Wehmeyer’s (2003) self-determined learning theory will serve as the organizing frameworks. The functional theory of SD was based on an exhaustive review of the

literature on SD in philosophy and psychology, including Angyal (1941), Deci and Ryan's (1980, 1985, 2002b) work, as well as research on how attitudes and abilities foster and encourage an individual's SD (Wehmeyer, 1999). Wehmeyer (2005) characterized SD as a dispositional characteristic defined as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (p.117). According to the functional theory of SD, self-determined behaviour is a set of actions that are identified by the function or purpose they serve for the individual and by the four "essential characteristics" noted above: behavioural autonomy, self-regulation, psychological empowerment, and self-realization (Wehmeyer, Abery, Mithaug, & Stancliffe, 2003). That is, an individual engaged in self-determined behaviour if they acted autonomously, the behaviour(s) were self-regulated; the individual initiated and responded to event(s) in a psychologically empowered manner, and acted in a self-realizing manner (Wehmeyer, Kelchner, & Richards, 1996; Wehmeyer, 1999). That is, Wehmeyer and colleagues denote self-determined behaviour as a function of the role it serves in individuals' lives as well as those who consistently employ these essential behaviours be regarded as self-determined. Personal characteristics (e.g., age, capacity) and environmental conditions (e.g., opportunities, context) can impact the extent to which these essential characteristics are present, as a result the relative SD expressed by an individual will vary over time and across environments (Wehmeyer, 1999; Wehmeyer & Schalock, 2001). Taken together, SD is considered to be a dispositional characteristic of an individual who is a causal agent (i.e., to act with authority to make things happen) in their lives. Particularly, their behaviour was purposeful, volitional (i.e., conscious choice), and without undue influence towards achieving a goal.

Wehmeyer's functional theory posits that SD emerges across the lifespan and is acquired through specific learning experiences as individuals learn skills and develop attitudes that enable them to be causal agents in their lives and to act volitionally (Wehmeyer, Sands, Doll, & Palmer, 1997; Wehmeyer, 1999). These skills and attitudes are known as "component elements" of self-determined behaviour and are developed and acquired over time (Wehmeyer, et al., 1997). These include: choice-making, decision making, problem-solving, goal setting and attainment, self-monitoring, self-advocacy, an internal locus of control, perceptions of self-efficacy and outcome expectancy, self-awareness and self-knowledge (Wehmeyer, 1999). Each of these component elements has a unique developmental course and is acquired through specific learning experiences (Doll, Sands, Wehmeyer, & Palmer, 1997; Wehmeyer, 1999). These component elements are important to the development of self-determined behaviour, and should therefore be considered in childhood and into adulthood (Wehmeyer, 1999). Consequently, a major emphasis of Wehmeyer and colleagues' work has been developing curricula and programs to promote these skills (Agran, Blanchard, & Wehmeyer, 2000; Wehmeyer, Palmer, Agran, Mithaug, & Martin, 2000).

In Mithaug, Mithaug, Agran, Martin, and Wehmeyer's (2003) theoretical framework, self-determined learning theory reflects the process by which individuals become self-determined learners. More specifically, this theory tries to explain how individuals "interact with opportunities to improve their prospects of getting what they want and need in life" (Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994, p. 4), and theorizes that SD depends on the individual's interaction between capacities and opportunities. Capacity refers to the knowledge, abilities, and perceptions that enable individuals to become self-determined whereas opportunity refers to the chances provided to individuals to apply their knowledge and abilities related to SD

(Wolman et al., 1994). Thus, when individuals pursue opportunities, they learn to adjust and regulate their thoughts, feelings, and actions. This perspective is beneficial as it considers the importance of opportunities in understanding the construct of SD, which will provide invaluable information for researchers and practitioners as they implement and evaluate interventions to promote SD. In comparing these two theories, the functional theory focuses on the personal characteristics that lead individuals to act in a self-determined manner, while the self-determined learning theory focuses on the process through which individuals become self-determined (Shogren et al., 2008). Both theories contribute uniquely to the conceptualization and measurement of SD for individuals with disabilities.

Measurement of Self-Determination

An important aspect in advancing the field's application of this construct involves the availability of theoretically based measures of SD (Shogren et al., 2008). However, it has been noted that SD cannot physically be measured because it is a heuristic that assists in explaining and predicting human behaviour characterized by freedom and self-governance (Wehmeyer, 2005). Nevertheless, several assessments of SD have been developed. For instance, within the field of special education, many assessments focus on assessing the degree to which students have mastered skills related to SD curricula (Hoffman, Field, & Sawilowsky, 1996; Martin & Marshall, 1995) whereas others evaluate the environmental characteristics involved in opportunities to practice SD (Abery, Stancliffe, Smith, McGrew, & Eggebeen, 1995a; 1995b). Two primary measures of SD have been developed: the *Arc's SD Scale (SDS)*; (Wehmeyer & Kelchner, 1995) and the *American Institutes for Research SD Scale (AIR)*; (Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994). Both of these measures were developed with the purpose of measuring global SD based on empirically validated theoretical frameworks (Wehmeyer,

1996b; Wehmeyer & Mithaug, 2006; Wolman et al., 1994). The *SDS* and *AIR* were developed based on different theoretical perspectives yet share much in common. They both measure global SD but focus on different aspects of the SD construct (Shogren et al., 2008).

The *SDS* is based on a functional theory of SD developed and validated by Wehmeyer (1995, 1997, 1999, 2001) and Wehmeyer, Abery, Mithaug, and Stancliffe (2003). As mentioned above, Wehmeyer's functional theory describes SD as a dispositional characteristic of individuals, and refers to causal and volitional actions that are identified by the four essential characteristics (e.g., behavioural autonomy, self-regulation, psychological empowerment, and self-realization). The *AIR*, however, was developed based on self-determined learning theory proposed by Mithaug (1993, 1996), Mithaug, Mithaug, Agran, Martin, and Wehmeyer (2003), Wehmeyer et al. (2003), and Wolman et al. (1994). The self-determined learning theory emphasizes the process by which individuals become self-determined learners, which is dependent on individuals' capacity and opportunities for SD. Both the *SDS* and the *AIR* employ more objective questions by utilizing rating scales to measure a person's capacity and/or opportunity to make goals, decisions, choices and other SD behaviours alike. The *SDS* and *AIR* have been implemented in research examining the relationship between SD and other important outcomes, such as quality of life (Lachapelle et al., 2005; Wehmeyer & Schwartz, 1998) and postsecondary outcomes (Wehmeyer & Palmer, 2003); differences between the levels of SD of individuals with and without an intellectual disability (Mithaug, Campeau, & Wolman, 2003; Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006); and the effect of interventions to enhance SD (Algozzine et al., 2001; Karvonen et al., 2004; Test & Neale, 2004). These two theoretical perspectives share much in common, but there are distinct differences. This suggests

that researchers and practitioners consider their aim for using the *SDS* and *AIR* in relation to the theoretical frameworks that underlie both measures (Shogren et al., 2008).

Self-Determination and Individuals with Disabilities

SD has more recently become a central concept in service delivery for persons with disabilities across their lifespan (Field, Sarver, & Shaw, 2003), in part due to the result of the increased visibility of persons with disabilities due to the independent living, normalization and self-advocacy movements of recent decades (Ward, 1996). However, SD's increased recognition can also be attributed to its relation to quality of life. Quality of life (QoL) reflects "a person's desired conditions of living related to the eight core dimensions of one's life" (Schalock, 2000, p. 121), one of which includes SD (Schalock, 1996). As previously mentioned, self-determined behaviour refers "to volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117), thus signifying that SD is best understood within the context of a person's overall QoL (Lachapelle et al., 2005). The concept of QoL has emerged as a unifying theme in the disability field that is "rooted in individual perceptions and values and capable of contributing to the identification of necessary supports and services" (Schalock et al., 2002, p. 458). There are eight core dimensions of QoL: (1) emotional well-being, (2) interpersonal relations, (3) material well-being, (4) personal development, (5) physical well-being, (6) SD, (7) social inclusion, and (8) individual rights (Schalock, 1996; Schalock et al., 2002). These dimensions interact and influence each other to shape an individual's perceived QoL, which highlights the variability of the relative contributions of each dimension over time (e.g., in part due to personal preferences and cultural beliefs) and consequently his or her QoL.

Despite the variability, research has shown that there is an association between the level of SD and QoL for individuals with disabilities. In fact, two cross-sectional studies have examined their association. Wehmeyer and Schwartz (1998) investigated the relationship between SD and QoL for 50 adults with an ID. After controlling for level of intelligence and environmental factors that were thought to contribute to more SD, they found that SD predicted membership in a high QoL group ($r = 0.25$). Similarly, an international study conducted by Lachapelle et al. (2005) examined the SD and QoL relationship in 182 adults with a mild ID living in community settings in Canada, United States, Belgium and France. They found that the essential characteristics of SD (i.e., autonomy, self-regulation, self-realization, and psychological empowerment) predicted membership in the high QoL group and that overall SD and QoL were significantly correlated ($r = 0.49$). Taken together, these findings indicate a positive moderate relationship (Cohen's 1988) between QoL and SD, as theorized by Schalock (1996) and Wehmeyer (1996a). That is, individuals who are highly self-determined experience higher QoL, whereas individuals who lacked SD tend to experience poor QoL. Given the positive contribution SD has for enhanced QoL in adulthood, it is not surprising that it has been an outcome of interest in the field of disability.

Research has shown that adults with disabilities are less self-determined than their typically developing peers. Specifically, researchers have shown that individuals with ID (Wehmeyer & Metzler, 1995), learning disabilities (Field, 1996; Field, Sarver, & Shaw, 2003; Pierson, Carter, Lane, & Glaeser, 2008), emotional and behavioural disorders (Carter, Lane, Pierson, & Glaeser, 2006; Pierson et al., 2008) and ASD (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2015) are less self-determined than their typically developing peers. However, it is imperative to note that this finding does not reflect the capacity of individuals with disabilities to

become self-determined. Researchers have evidently shown that individuals with disabilities have many fewer opportunities to make choices and communicate preferences in their daily lives than their typically developing peers (Chambers et al., 2007). There is currently an interesting literature base concerning the application of SD construct to the field of disability, including theory development and validation, measure and assessment, intervention, follow-up, policy, as well as curricular and instructional models (Algozzine, Browder, Karvonen, Test, & Wood, 2001; Karvonen, Test, Wood, Browder, & Algozzine, 2004; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003).

This literature is sufficient enough to support meta-analyses, comprehensive reviews, and syntheses of SD (Algozzine et al., 2001; Chambers et al., 2007; Cobb, Lehmann, Newman-Gonchar, & Alwell, 2009; Test & Neale, 2004). For example, Algozzine et al. (2001) reviewed single-subject and group design meta-analyses of studies focused on promoting component elements of self-determined behaviour (e.g., goal setting, problem solving). Algozzine and colleagues recognized the efficacy of numerous intervention strategies to enhance the component elements of self-determined behaviour. Similarly, Test and Neale (2004)'s review of the literature on the efficacy of interventions to promote student involvement in educational planning also examined the influence of these practices. These studies focused on the component elements (i.e., goal setting and self-regulation) and not the global construct of SD, as measured by total scores on measures like the *SDS* and *AIR*. Chamber et al. (2007), however, reviewed interventions and outcomes measuring global SD and concluded that SD contributes to more positive outcomes. It was also noted that there is a need for teacher training and support, implementation of strategies in educational settings, instruction and involvement of families in supporting SD, and for the promotion of SD in younger students (Chambers et al., 2007).

SD interventions within the educational settings can have valuable implications for students' later outcomes as they transition into adulthood. Researchers have demonstrated the importance of student involvement in individual education program (IEP) meetings with students who were more highly involved in their meetings were more self-determined relative to students who had less involvement (Williams-Diehm, Wehmeyer, Palmer, Soukup, & Garner, 2008). A more recent intervention study examined the effect of various SD interventions for students between 11 and 21 years (Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, (2012). In this randomized control trial, high school students with ID were randomly assigned to treatment and control groups. The 235 students in the treatment group received SD instruction using a variety of instructional methods and increased student involvement in educational planning meeting over three years. The 132 students in the control group received no intervention (i.e., teachers received a placebo intervention to promote family involvement). Using the *SDS* and the *AIR*, students' SD was measures at baseline, and two and three years after the intervention. Findings revealed that students with ID who participated in the intervention group over the course of three years demonstrated significantly more SD than students in the control group. These studies demonstrate the desire to promote SD in educational settings. In fact, since the 1990's a considerable amount of attention has been given to the importance of SD in the education for students with disabilities (Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012).

After a decade of developmental and empirical research on SD, it was considered an essential element of high-quality transition services (Field, 2003; Wehmeyer, Bersani, & Gagne, 2000) and of disability advocacy supports and services (Chambers et al., 2007) in the United States. Less emphasis has been placed on SD in a Canadian context. Given what we know about

SD, including the empirical link between promoting SD and the attainment of essential academic, social, and behavioural outcomes (Lachapelle et al., 2005; Wehmeyer & Palmer, 2003), SD should be considered an essential component of transition services in Canada. For example, SD has been found to be positively related to employment, access to health and other benefits, financial independence, and to independent living for young adults with intellectual and developmental disabilities at 1 and 3 years post-high school graduation (Wehmeyer & Palmer, 2003; Whemeyer & Schwartz, 1997). This is not surprising, as Wehmeyer and Schalock (2001) explain that individuals who are more self-determined cause things to happen to accomplish a goal, such as obtaining employment; and these changes are by definition designed to enhance a person's QoL. The promotion of SD skills in practice with individuals with disabilities is thus important as individuals with disabilities are often given little choice when it comes to the important decisions that impact their lives.

Factors that Influence Self-Determination in Individuals with Disabilities

Research has documented the influence of diverse intra-individual factors and environmental factors that serve as mediating or moderating variables in efforts to promote SD (Nota et al., 2007; Shogren et al., 2007; Stancliffe, Avery, & Smith, 2000; Wehmeyer & Bolding, 2001; Wehmeyer & Garner, 2003). In theory, the interaction between personal characteristics and environmental conditions positively or negatively impacts an individual's expression of SD (Field & Hoffman, 1994; Wehmeyer & Garner, 2003). For instance, Wehmeyer and Garner (2003) described the functional theory of SD by proposing that capacity (which is influenced by learning history and development), opportunity (which is influenced by environment and experience), and supports or accommodations (that enable individuals to practice self-direction) all influence the expression of SD. Multiple studies have shown that

individual and environmental factors affect a person's relative SD (Nota et al., 2007; Shogren et al., 2006; Wehmeyer, & Bolding, 1999, 2001; Wehmeyer & Garner, 2003). Initially, researchers focused on living situation as the primary factor influencing SD given the history of institutionalization and the normalization movements. That is, individuals with disabilities who live and work in more integrated settings tend to be more self-determined than those who live and work in segregated settings (Stancliffe, Abery, & Smith, 2000; Wehmeyer & Bolding, 1999, 2001). For instance, Wehmeyer and Bolding (1999) found that individuals with developmental disabilities who were living or working in community-based settings (e.g., independent living or competitive employment) were more self-determined and autonomous, had more opportunities to make choices, and were more satisfied (QoL) than were their cognitive- and age-matched peers living and working in non-community based congregates (e.g., sheltered employment or group homes). There were reported differences in level of SD among individuals with ID even when cognitive abilities, age, and gender were controlled for suggesting that their living and work environments played a significant role in the differences reported. Comparably, Wehmeyer and Bolding (2001) found significant positive changes in SD among individuals with ID before and after they had moved from a more restrictive to less restrictive working or living environments. The impact of the environment has also been established within an educational context. In a sample of 44 students with ID, Zhang (2001) found that the mean frequencies of the expression of self-determined behaviours by students with ID were significantly higher in resource classrooms than in regular classrooms. Again, highlighting the influence of the environment on the promotion of SD for individuals with disabilities.

Later, researchers began to focus on more personal characteristics such as disability, intellectual level, age, and gender. Disability label is the most researched variables related to SD

(Carter et al., 2006; Shogren, Palmer, Wehmeyer, Williams-Diehm, & Little, 2012; Shogren et al., 2007; Wehmeyer et al., 2012). For example, Shogren, Kennedy, Dowsett, and Little (2014) examined the levels of three of the four essential characteristics of SD (i.e., autonomy, psychological empowerment, and self-realization) using data from the National Longitudinal Transition Study-2 in students across twelve disability categories (ASD, deaf-blindness, ID, hearing impairment, multiple disabilities etc.). The findings indicated significant variability within and across disability groups, which suggested that disability alone does not explain differences in SD. In regards to intellectual level, researchers have found a positive relationship between SD and cognitive functioning (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Stancliffe, Abery, & Smith, 2000; Wehmeyer, 1996b; Wehmeyer & Garner, 2003). However, Wehmeyer and Garner (2003) revealed that cognitive functioning (i.e., IQ scores) was not a significant predictor of SD status using a discriminant function analysis, but that choice availability was the primary predictor. However, Nota, Ferrari, Soresi, and Wehmeyer (2007) examined the impact of cognitive abilities, age, gender, and social abilities on SD of 141 adults with ID. They found no differences in SD across the range of ages, however, they did find that social and cognitive abilities were significantly correlated with SD indicating that individuals with higher levels of SD also had higher levels of adaptive behaviour. That is, individuals with the most severe ID showed the lowest levels of SD, QoL, and social abilities. Research investigating differences in SD by gender has been somewhat limited and mixed. Wehmeyer and Garner (2003) found no significant differences on overall SD by gender for individuals with disabilities. Conversely, researchers have found that gender significantly affected SD, with males having higher SD in an Italian sample (Nota et al., 2007) and females having higher SD in an American sample (Lee et al., 2012; Shogren et al., 2007).

However, Lee et al. (2012) revealed that instructional (group assignment to SD intervention versus control group), knowledge (knowledge of transition planning), and dispositional (self-efficacy and outcome expectancy) factors were stronger predictors of students' SD than personal predictor variables, such as cognitive abilities, age, and gender. In particular, self-efficacy and outcome expectancy scores, student-directed transition planning instruction, and students' pre-intervention transition planning knowledge were predictive of higher SD scores among students, whereas level of intelligence, age and gender was not a significant predictor of high and low levels of SD. Similarly, Shogren et al. (2007) investigated the predictive relationship between students' level of SD and various individual and environmental factors. The findings revealed that capacity, opportunity, and transition empowerment predicted level of SD. Nevertheless, more research is required to help identify and categorize the contextual factors that may influence the theoretical notions of SD. This could be a first step in the development of a framework that promotes consistent consideration of contextual factors when designing, implementing, and evaluating supports to enhance QoL and SD for individuals with ASD.

In addition to individual and environmental predictors of SD, a better understanding of the barriers and facilitators of becoming self-determined is imperative, as it will elucidate the specific factors (e.g., attitudes at the individual and systemic level, opportunities to practice SD skills) that promote or hinder the expression of SD. For instance, Shogren et al. (2007) explored ecological factors related to SD, and found that teachers' perceptions of students' capacity for SD varies based on students' level of ID, but not according to their opportunities for SD. Shogren and her colleagues highlighted the impact of stereotypes about students' capacity for SD and how these can potentially influence the number and the quality of opportunities, supports,

and accommodations. In another study that examined the factors that facilitated and hindered the SD of adults with physical disabilities, Stoner et al. (2006) found that both individual (e.g., personal fortitude, self-doubt) as well as environmental (e.g., support networks, physical accessibility) variables impacted their ability to be self-determined. Nonnemacher and Bambara (2011) explored the perceptions of 10 self-advocates with ID. These adults were asked to discuss their understanding of SD, as well as the ways in which the support staff have supported or hindered their SD. Findings revealed ten themes that characterized the actions of the support staff (Nonnemacher & Bambara, 2011). The actions that were reported to hinder SD included: (1) assuming decision-making and control, (2) controlling personal spending, (3) being unapproachable or inaccessible, (4) failing to follow through, and (5) obstructing and coercing. The actions that were said to facilitate SD included: (6) expanding options and experiences to encourage choice, (7) supporting access to people of authority, (8) being approachable and accessible, (9) listening without judgment, and (10) providing support for follow through. Taken together, this research highlights the nuances inherent in SD research and points to a need to examine the environmental and social influences using a model that can account for this complexity.

Accordingly, Shogren (2013) discussed a social-ecological lens to examine SD research while attempting to understand the contextual factors that impact the development and expression of self-determined behaviour. This model highlights the complex interplay between a person and their environment, explaining the importance of the person-environment fit (Schalock et al., 2010), as well as the value of a systematic consideration of contextual factors when designing, implementing, and promoting SD (Shogren, 2013). Based on Bronfenbrenner's (1977; 1979) ecological theory, the framework considers contextual factors that impact SD

across the microsystem (individual factors), the mesosystem (school factors), the macrosystem (community factors, culture, public policy) and the chronosystem (change over time in research, policy and practice). Given the lack of knowledge regarding predetermined barriers and facilitators of SD, Shogren's social-ecological framework will help to identify the factors that may or may not impact SD for young adults with ASD. This knowledge can help to better understand the complexity of promoting SD across the lifespan by highlighting attitudes, policies, and practices that facilitate or hinder its development.

The SD literature has generally focused on youth and young adults with ID. However, researchers have asserted the importance of SD for individuals with ASD. Particularly, Wehmeyer, Shogren, Zager, Smith, and Simpson (2010) described the paucity of research in SD for individuals with ASD, indicating that promoting SD is an increasingly valuable component in their education. They also suggested that this lack of research might be attributable to the lack of SD measures studied and their appropriateness with this population. Without appropriate measurement, it is difficult to describe the SD of individuals with ASD. Recent research used item analysis and a confirmatory factor analysis on the *SDS* and *AIR* with 95 high school students with ASD between 13 and 21 years (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2015). Findings revealed that both measures show reliability and validity in the measurement of global SD in students with ASD. Furthermore, parameter estimates and the model fit results supported the factor structure of the *AIR* and *SDS*, indicating that the measures could be considered for individuals with ASD. Knowledge of SD among individuals with ASD would be an important first step to narrowing the gap in the literature to learn more about the importance of SD for young adults with ASD. This is especially important since educational practices are evaluated

based on their relationship with empirically supported theories and evidence to support their efficacy and effectiveness (Whemeyer et al., 2010).

Autism Spectrum Disorder and Adult Outcomes

An ASD was once thought to be a rare neurological brain disorder affecting a person's ability to communicate, respond to their environment, and form relationships. Currently, ASD refers to a group of neurodevelopmental disorders including pervasive difficulties with social communication and social interaction across multiple contexts, and with restricted, repetitive patterns of behaviour, interests, or activities (APA, 2013). The CDC (2014) currently reports the rate of ASD to be 1 in 68 births in the United States. Similar, yet lower, rates have been estimated in Canada with the NEDSAC reporting that 1 in 94 children have a diagnosis of ASD (Ouellette-Kuntz et al., 2009, 2014; Ouellette-Kuntz, Coe, Yu, & Lewis, 2012). Diagnoses of ASD and concomitant ID account for about 50-70% of all cases, resulting in a significant proportion of individuals with ASD without an ID (CDC, 2012; Matson & Shoemaker, 2009). In fact, one study revealed that across 9 states of the US, 43.9% of children with an ASD were classified in the average or above average range of intellectual ability (Christensen et al., 2016). Given the increased prevalence of ASD over the past 10 to 15 years (CDC, 2012), there is a significant population of individuals with ASD without ID entering adulthood. The prevalence of ASD in adults is similar to that found in children (Brugha et al., 2011; Piven, Rabins, & Autism-in-Older Adults Working Group, 2011), supporting the notion that ASD is a lifelong diagnosis that can have an impact on outcomes throughout the lifespan.

Despite the strength in cognitive abilities, individuals with ASD without ID continue to demonstrate difficulties with social pragmatic language, use of social norms and subtleties, nonverbal cues, and a tendency to interpret information literally (APA, 2013). Associated with

these core difficulties, adults with ASD with or without an ID reportedly experience poor adult outcomes (Billstedt, Gillberg, & Gillberg, 2005; Gerhardt & Lainer, 2011; Hendricks & Wehman, 2009; Howlin & Moss, 2012; Levy & Perry, 2011; Sterling, Dawson, Estes, & Greenon, 2008). For neurotypical young adults it is assumed that after graduating from secondary school they will assume some level of independence as they leave the immediate family. However, for many adults with ASD, the situation is vastly different. Once they leave the school system, they may become even more invisible to society, and they may become even more dependent on their caregiver (Graetz, 2010; Gray, 2002). Graetz (2010) examined 143 caregivers in the United States supporting a family member with ASD. Caregivers reported a need for more information regarding financial planning, life-long planning, and finding ways to advocate for their family member. They noted that there is a lack of opportunities for their family member in employment and residential living environments and for social inclusion. In fact, Taylor and Seltzer (2010) found that more than 25% of young adults with ASD without ID had no occupational, educational, or day activities available to them compared with 8% of those with ID. Alongside the existing waiting lists for adult services, such limited opportunities to achieve independence in adulthood (Howlin, Alcock, & Bukin, 2005) significantly impact the quality of life for adults with ASD without ID.

Few studies address ASD in adulthood and even fewer describe the outcomes or quality of life for adults with ASD without ID, a population associated with greater variability in individual outcome (Barnhill, 2007; Engstrom, Ekstrom, & Emilsson, 2003; Farley et al., 2009; Howlin, 2003; Howlin, Goode, Hutton, & Rutter, 2004). For instance, Howlin (2000) and Tsatsanis (2003) reviewed the literature on outcomes for adults with ASD without an ID and found that a minority had received university education, lived semi-independently, had close friendships,

were married or had a paid job. More recently, Howlin and Moss (2012) reviewed 23 follow-up studies on adults with ASD with and without ID. Findings revealed that regardless of the positive outcomes attained by some, young adults with ASD, including those with average IQ, are significantly disadvantaged regarding employment, community involvement, social relationships, physical and mental health, and QoL relative to their typically developing peers.

In a longitudinal study, Howlin, Goode, Hutton, and Rutter (2004) followed up in adulthood with a group of children who were grouped according to IQ levels (all above an IQ of 50). They reported that a fifth of their sample of 68 people with ASD obtained some academic qualifications (e.g., complete or partial college, undergraduate, or graduate degree), a third were employed, and only about a quarter of the group reported having friends with shared interests or activities. Furthermore, six individuals were in paid employment and also showed a higher level of independence, while the rest of the participants remained highly dependent on their families and support services. Only 22% were rated as having a “very good” or “good” outcome. Of particular importance, individuals without ID in childhood (IQ of at least 70) had better outcomes than those with an IQ below 70. However, individual outcomes remained very variable among those with an average IQ, and neither verbal nor performance IQ scores were consistent prognostic indicators. Specifically, Howlin et al. (2004) noted that there was little difference in adulthood between those with a childhood IQ of 100 or more relative to those with an IQ between 70 and 99, with those with higher IQs reporting many problems in adulthood at work and in the community. Consequently, it becomes apparent that functioning successfully in adulthood may depend as much on the supports received in adulthood as on cognitive abilities (Howlin et al., 2004).

Taken together, the literature demonstrates that the core difficulties associated with ASD persist into adulthood and that the outcomes are extremely variable (Billsted, Gillberg, & Gillberg, 2007; Howlin, 2004). Particularly, some individuals with ASD reside in residential programs, while others live in social isolation and remain dependent on their families (Matson & Rivet, 2007). Nonetheless, some individuals pursue professional careers, are employed, marry, and raise children (Howlin, 2004). Research also demonstrates that symptom severity decreases over time for some (Orsmond, Krauss, & Selzter, 2004), whereas others may experience increased behavioural challenges (Matson & Rivet, 2007). Although social skills might increase with age, many individuals with ASD transition into adulthood with poor social skills (Orsmond et al., 2004).

Although much of the current state of the ASD literature focuses on children and adolescents, ASD continues into adulthood. That is, ASD is a lifespan diagnosis that is associated with social-communication difficulties and behaviours that remain into adulthood and impact opportunities at home, work, and in the community (Herhardt & Lainer, 2011; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004). However, ASD in adulthood is a relatively novel area of interest in research. For example, Edwards, Watkins, Lotfizadeh, and Poling (2012) examined the age of the participants included in autism intervention research. Findings showed that out of 295 participants in 87 articles, only 1.7% were older than 20 years (Edwards et al., 2012). Given that promoting SD has been identified as a best practice in special education and transition services (Test et al., 2009), and considering its link with positive adult outcomes (Wehmeyer & Palmer, 2003), including quality of life (Lachapelle et al., 2005), and SD-based interventions should be considered a means to obtaining more positive outcomes for adults with ASD.

Self-Determination and Autism Spectrum Disorders

It is apparent from the abovementioned SD literature that a higher level of SD is associated with positive outcomes for individuals with disabilities, especially as they transition into adulthood. Given the shifts in prevalence, the increasing population of young adults with ASD without ID is faced with financial concerns, unemployment, social inclusion and community involvement difficulties, and a lack of services designed to meet their specific needs. This population would greatly benefit from SD-based interventions prior to exiting post-secondary school and into adulthood. Unfortunately, the lack of empirical support documenting the construct of SD as well as the efficacy of SD instruction and intervention for this population remains limited. This was well established as early as 2001, when Algozzine, Browder, Karvonen, Test, and Wood (2001) noted that most research on SD focused on individuals with learning disabilities or ID. A decade later, Wehmeyer and colleagues (2010) described a lack of research in SD for individuals with ASD. Individuals with ASD have not been excluded from the literature per se, as students with ASD were sometimes included as participants in the previously mentioned intervention studies of individuals with ID. However, the total number of individuals with ASD was limited. For instance, out of the 493 middle or high school students with disabilities who participated in an SD intervention study, only 27 reported having ASD (Wehmeyer, Palmer, Lee, Williams-Diehm, & Shogren, 2011).

Given the increased awareness of the lack of understanding of how SD emerges in individuals with ASD, researchers have begun to embark upon exploratory studies. For instance, the National Longitudinal Transition Study-2 (NLTS-2) examined outcomes for 922 individuals aged 13 to 26 with ASD (Wagner, Newman, Cameto, Levine, & Marder, 2007). Wagner and colleagues found that youth with ASD reported lower rates of SD and satisfaction compared to

youth with other disabilities. These differences across disabilities also existed for psychological empowerment autonomy, as youth with ASD did report lower levels of psychological empowerment and autonomy than their peers with other disabilities (Wagner et al., 2007). This is consistent with earlier research that found that adults with an ASD have been shown to be less self-determined than their typically developing peers (Ward & Meyer, 1999). Therefore, our understanding of SD can only be contextualized as it relates to individuals with ID and other disabilities, as such further research among individuals with ASD is warranted.

The core difficulties associated with a diagnosis of ASD as well as the executive functions that impact initiation and generalization may contribute to poor SD for adults with ASD (Hume, Boyd, Hamm, & Kycharczyk, 2014; Ozonoff & Schetter, 2007). However, none of these core difficulties exclude individuals with ASD from developing SD-related skills and attitudes (Wehmeyer et al., 2010). In fact, research has demonstrated that individuals with ASD can, with supports and accommodations and more importantly with opportunities, acquire the skills that contribute to SD, such as choice-making, self-regulation (Wehmeyer & Shogren, 2008). For instance, research has shown that focusing on making abstract concepts more concrete with accompanying visual supports are key ingredients to curriculum adaptation (Krasny, Williams, Provencal, & Ozonoff, 2003). Fullerton and Coyne (1999) recommended that SD curriculum for individuals with ASD should incorporate topics including self-knowledge related to ASD, communication, life planning, and self-directed goal setting and attainment. Further, it is imperative that opportunities are provided to enable individuals with ASD to practice their SD skills in real world situations, as there is an increased risk for many of these skills to be learned in a rote manner without fully understanding the application of the skills in their lives (Fullerton & Coyne, 1999).

Nevertheless, individuals with ASD have diverse and multifaceted needs with a range of strengths and abilities. Knowledge of SD and how it manifests across the lifespan for these individuals is necessary prior to designing and evaluating best practices. Understanding the perspectives of young adults with ASD regarding how to best encourage their expression of SD is imperative not only to develop meaningful supports that are important to them, but also to target potential environmental influences not previously explored by researchers that may result in improved outcomes. To better incorporate the voices of young adults with ASD in our attempt to further explore the concept of SD, the history and use of the concept of QoL in the field of disability will help to establish next steps. Further, rethinking SD based on the QoL literature will help to incorporate the importance and satisfaction of SD among young adults with ASD.

Rethinking Self-Determination based on the Quality of Life Literature

Individuals with disabilities, including those with ASD, do not have opportunities to make personal choices or express their personal preferences about the outcome of their lives (e.g., work, living situation). For instance, they are often told what and with whom they can do, and where, when, and how they can do it (Carr et al., 2002). This perspective is associated with the institutionalization movement and the predominant role of the deficit or medical model in the provision of services. However, the shift in focus toward values, perceptions, and environmental conditions, normalization, and advocacy have led to an increase interest in quality of life (QoL). In fact, QoL was adopted to challenge the existing theory and applied research regarding social policy and service provisions (Schalock et al., 2002).

Within the field of disability, the most prevalent definition refers to QoL as “a concept that reflects a person’s desired conditions of living related to eight core dimensions of one’s life:

emotional well-being, interpersonal relationships, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights” (Schalock, 2000, p. 121). With this definition in mind, “quality” is associated with values (e.g., happiness, success, wealth, and satisfaction); whereas, “life” suggests that the concept refers to vital aspects of the human existence (Brown et al., 2000; Schalock et al., 2002). Consequently, QoL is used in an effort to explain and comprehend the conditions that enhance and engender a life of satisfaction (e.g., food, shelter, safety) and life enrichers (e.g., values, beliefs, needs, interests) (Brown et al., 2000), emphasizing the importance of the views and experiences of the individual. Focusing on QoL therefore suggests that we value quality and want to improve or maintain the activities that will add quality to the lives of individuals with disabilities (Schalock, 2000). Further, the construct of QoL is often used as a sensitizing notion (i.e., focus on the individual’s perspective), a social construct (i.e., enhance well-being), and as a unifying theme (i.e., common language or framework) (Schalock et al., 2002).

The development of a conceptual model of QoL in the disability literature has been underway since 2002 (Cummins, 2005; Schalock et al., 2002). However, the field has not yet adopted a unified construct for its measurement. In fact, there are many debates about which indicators constitute a satisfactory QoL, or whether some indicators are more important or predictive of QoL for different populations (Burgess & Gustein, 2007). Normally, researchers measure QoL indicators that can be observed and appear to be universally held, for example, material success, social relations, and life opportunities (Brown et al., 2000; Schalock et al., 2002). However, measuring QoL from the individual’s perspective has also been debated and involves identifying values and matching them to perceptions of personal satisfaction and

happiness (Schalock et al., 2002). Whether QoL is a subjective or an objective notion has been the focus of theoretical discussion since the emergence of the QoL concept.

Assessment strategies use subjective and/or objective measures reflecting the abovementioned core dimensions of QoL (Brown, 1996; Cummins, 1996; Felce & Perry, 1996; Schalock, 1996). The subjective approach reflects the quality revolution (e.g., empirically-based supports, person-centered) that followed the institutionalization movement (Schalock, 2000). Generally, the subjective nature of QoL is measured by asking the person about their satisfaction of the various aspects of their life (Schalock, 2000). For instance, in Schalock and Keith's (1993) *Quality of Life Questionnaire (QoL-Q)*, respondents are asked "*How satisfied are you with your current home or living situation*" using a 3- to 5-point Likert scale indicating their level of self-perceived satisfaction. The objective approach, however, reflects a more functional measure of QoL by utilizing rating scales, observations, and questionnaires (Schalock, 2000). For instance, using ordinal rating scales, researchers can ask "*How many civic or community clubs do you belong to?*" (Schalock, 2000). This approach includes more objective and performance-based measures, allowing for the comparison of groups and for the possibility of feedback for service providers.

Advocates of both the subjective (Edgerton, 1996) and objective (Casas, 1997) approaches provide strong rationales, especially as some of the eight core dimensions of one's life are more amenable to either approach (Schalock, 2000). However, the significant transition in the 1990's toward outcome-based evaluation and person-referenced outcomes reflect the subjective nature of QoL (Schalock, 2000). As such, a person's measured level of satisfaction became the most commonly used dependent measure in assessing one's perceived QoL, allowing practitioners to measure the relative importance and value of the respective dimensions (Cummins 1996; Felce

& Perry, 1996; 1997). The subjective nature of QoL suggests that it can be defined and valued differently by individuals and can vary across one's lifespan (Schalock, 2000), which is more aligned with the positive psychology and self-advocacy movements in which the person with disability is viewed as an expert in their own life.

Consequently, there has been a shift in the QoL literature towards methodological pluralism that incorporates more subjective measures alongside traditional objective measures (Schalock, 2004a; Schalock et al., 2002). For instance, persons with disabilities are now typically asked how satisfied they are with the various facets of life (Wehmeyer & Schalock, 2001). This is important to consider, as science tells us how we can change things, but values tell us what is worth changing (Carr, 1996). It has been noted that individuals may view their own QoL as effective and satisfactory when objective criteria might tell a different story (Brown & Brown, 2005). This might reflect a deviation from social norms and expectancy, as what is quality for one may not be for the other. Nevertheless, this discrepancy can be somewhat dangerous when developing policy for application, which often relies on more objective outcomes.

As in the measurement of QoL, the measurement of SD should address each objective and subjective component of SD that is important to individuals with ASD. Analogous to the initial QoL literature's use of objective measures, SD currently relies on more objective measures. However, to equate SD with specific outcomes (e.g., goals, employment) is contradictory to SD because it takes away from the person's freedom of choice (Browder, Wood, Test, Karvonen, & Algozzine, 2001). We need to remember that promoting SD means respecting the person with disability's choices, and not achieving outcomes that are valued by someone else. This is best exemplified in Schalock et al. (2005) study in which they asked 778 individuals with disabilities

receiving services, 491 family members of a person with disability, and 773 professionals in the field of disability from Canada, China, Latin America, Spain, and the United States to rank the importance of core indicators of QoL. Individuals with disabilities ranked the importance of SD significantly higher than did professionals and family members. Interestingly, of all the QoL core dimensions, professionals and family members rated SD as the lowest in importance to them. These findings suggest that researchers or practitioners may not always be aware of what is important to individuals with disabilities and that subjective measures should be included in the design of research and services. In fact, the availability of opportunities and decision making for choices, which are found in subjective and self-report measures, is an essential component of QoL for individuals with disabilities (Brown & Brown, 2009). For these reasons, information on the importance of SD for individuals with ASD will provide significant insight into the many aspects of SD that are important for the individuals themselves, and may more accurately reflect the volitional nature of SD.

On a similar note, QoL also represents how well needs are met, or, the extent to which individuals perceive satisfaction or dissatisfaction in various life domains (Costanza et al., 2007). It is interesting that satisfaction is used as the primary metric of QoL, as satisfaction can vary according to the opportunities available for interactions with others within the individual's context (Wehmeyer, 1999). Knowledge of whether SD needs are being met, or individual's satisfaction with their level of SD have implications to help guide policy and make decisions about services. While both objective and subjective approaches to measurement have offered insight into SD, there are a number of limitations to using each of these approaches separately; the most notable limitation is that individuals' values are not being captured. Consequently, utilizing both approaches to measure SD may provide a more realistic picture of a person's SD.

As such, we need to further explore what young adults with ASD perceive to be important and whether they are satisfied with their current level of SD.

Self-Determination Importance Rating

Throughout history, human rights advocates have actively encouraged individuals with disabilities to advocate for themselves and to voice their opinions about how they would like to be supported. Although some researchers have supported this self-advocacy movement (Bradley et al., 2001), the findings have mostly focused on changes at the system level rather than gaining a better understanding of the influences of SD from an individual perspective (Nonnemacher & Bambara, 2011). Given the lack of voice of individuals with disabilities in research on SD, researchers have generally been interested in caregivers', educators' and paraprofessionals' value in promoting SD (Cooney, 2002; Carter et al., 2013; Stang, Carter, Lane, & Pierson, 2009; Carter, Sisco, & Lane, 2011). For instance, Carter et al. (2013) investigated parents' assessment of SD in students with ASD, such that parents rated the importance of fostering their child's SD. Parents highly valued all of the SD skills (e.g., self-advocacy, problem solving, decision making), despite having reported fairly low performance skills for their children. Educators and paraprofessionals rated the value of SD skills similarly (Stang et al., 2009; Carter et al., 2011). Stang, Carter, Lane and Pierson (2009) reported that elementary and high school teachers' report that it is important to teach SD; special education teachers consistently assigned a higher importance to teaching SD skills than did general education teachers. Cho, Wehmeyer, and Kingston (2010) surveyed 407 elementary school teachers and found that special educators were more familiar with SD than general educators. However, either group of teachers did not differ in the value they place on teaching SD, which is a finding shared by other researchers (Stang et al., 2009). Caregivers and educators play a pivotal role in fostering SD, however, individuals

with disabilities should have a voice in the decisions that affect their lives (Agran, Storey, & Krupp, 2010). A recent study employed a survey to examine how 55 adults with ASD rated different aspects of their lives (Parsons, 2014). The findings revealed that the participants were the least satisfied with their employment status, but were the most satisfied with their interpersonal relationships. However, there was substantial individual variation which points to the need to value, respect, and meaningfully include the voices of adults with ASD in research (Parson, 2014).

Furthermore, when we consider the SDT, which is a theory of motivation, it asserts that everyone, despite their difficulties, possesses inherent growth tendencies and innate psychological needs that provide a motivation for autonomy (Ryan & Deci, 2000; Deci & Ryan, 2002a). This theory also acknowledges that individuals may reject opportunities for growth, lack self-motivation, and act irresponsibly. In fact, it is this researcher's belief that the *SDS* and *AIR* may not accurately capture Wehmeyer's most recent definition of SD (2005). Wehmeyer noted, "*volitional* actions enable one to act as the primary causal agent" [italics added]. In psychology, volition is the cognitive process by which an individual decides on and commits to a particular course of action (i.e., which involves choice- and decision-making). It should be noted that volitional control does not necessarily implicate rational control. However, the concept of volitional control is generally based on the assumption that humans have rational control; these concepts are related in that a reduction in rational control can be viewed as a lack of volitional actions, or SD. For instance, individuals can demonstrate great determination in achieving a goal that may not otherwise be adaptive (e.g., deciding not to work). The individual may then be considered to display a lack of SD, when in fact they possess excellent SD, but "irrational" choices. The above-highlighted measures (i.e., *SDS* and *AIR*) require the participant to respond

to questions about pre-determined (rational) tasks or choices that combine to make up an overall level of SD. However, humans are not always rational and will often serve various other motivations aside from reason. Thus, in order to gain more information into some of the possible reasons behind the responses regarding SD, the *SDS* will be modified to include Likert-scales asking participants to indicate how important the skills or abilities that make up SD are to them. The modification will allow for a closer examination of the importance of the items that make up the *SDS* without impacting the validity and interpretability of the original measure. This knowledge may more accurately describe the volitional nature of this otherwise objective measure of SD.

In summary, as described in Wehmeyer's functional model of SD, which emphasizes the function of a person's behaviour, it is imperative to explore individuals' unique beliefs, needs, and preferences (or values). Although researchers have begun to identify the critical importance of values (Shogren & Turnbull, 2006; Wehmeyer et al., 2003), much research is still needed to ascertain the values of young adults with ASD. The lack of diversity of responses in the literature with regard to outcomes among adults with ASD highlights the perils in establishing normative and categorical assumptions about outcomes (Parsons, 2014). Specifically, the lack of focus on SD among individuals with ASD in research may further "disable" or minimize them by omitting their perspectives and values. This has also been deemed a caveat in the QoL literature (Plimley, 2007). This understanding in relation to the importance young adults with ASD place on SD and its component elements will benefit the development of measures that both give them a voice and might more accurately measure the volitional nature of their SD.

Original Contribution

Arguably, SD is the hallmark of adulthood and an essential attribute needed for achieving a good QoL (Wehmeyer & Palmer, 2003). This study will provide invaluable information on promoting SD in young adults with ASD who are or will be approaching the transition to adulthood within a Canadian context. The descriptive information obtained addressing the skills, knowledge, and perceptions of young adults with ASD in the area of SD will assist researchers and practitioners in identifying specific areas of strength and need, developing instructional objectives and curricular materials, designing effective interventions; and impacting policy development. Aside from the limited information on SD in young adults with ASD without ID, there is also little research on SD in the field of disability within a Canadian context. The Canadian provision of services and policies are uniquely different from the United States where the vast majority of the research is being conducted by Michael Wehmeyer and his colleagues. Understanding SD in young Canadian adults with ASD would have invaluable implications for policy development and reforms in Canada as many individuals with ASD without ID do not have the desired services necessary to support them during and throughout the transition to adulthood. Overall, my dissertation is an original contribution that captures the aims of the 21st century by embracing and promoting positive psychology, while ascertaining that a better understanding of SD for individuals with ASD can inform us about the supports required to teach SD skills or create opportunities for SD in educational contexts, while supporting them to get the things they want and need out of life.

Research Questions

The current study is exploratory. As such, exploratory questions were posed rather than directional hypotheses in order to avoid examining only one end of the distribution of

possibilities. Furthermore, the vast majority of behavioural research utilizes two-tailed tests, as it is difficult to justify predictions about outcome that occur in only one direction (Punch, 2013).

To contribute to the limited literature regarding the SD of young adults with ASD, the following exploratory questions were developed:

1. What are the SD levels of young adults with ASD across Canada as measured by *The Arc's SD Scale (SDS; Wehmeyer & Kelchner, 1995)* and the *AIR SD Scale – Student (AIR; Wolman, Campeau, Dubois, Mithaugh & Stolarski, 1994)*?
2. Do demographic variables (level of education, gender, living situation, age) explain levels of SD, based on the *SDS* total score (Wehmeyer, 1995)?
3. Do participants' reported level of SD importance predict SD (as measured by the *SDS*) above and beyond individual (i.e., age, gender, education, capacity of SD) and environmental (i.e., opportunity) factors?
4. What are the self-perceived value or reported importance and satisfaction ratings of SD among young adults with ASD's? Is there a discrepancy between their satisfaction and their values?
5. Has SD helped participants to succeed in adulthood? Do themes emerge from the free response item (i.e., *Do you think that being self-determined would help or have helped you succeed in adulthood? For example, gain employment, success in post-education opportunities and develop and maintain relationships? Explain.*) that is associated with the theorized components of SD?
6. What are the self-perceived barriers and facilitators that impact the development of SD?

CHAPTER 3: METHOD

Introduction

This exploratory study examined the perceived levels of SD of young adults with ASD across Canada. The possible predictors of SD (i.e., age, gender, education, capacity of SD, opportunity for SD, and importance rating of SD), the importance and satisfaction ratings of SD, as well as the barriers and facilitators to SD among young adults who self-identified as having ASD were also explored. This information will provide insight into not only the factors influencing SD from a quantitative perspective, but will also provide qualitative contributions of the values (i.e., importance and satisfaction ratings) young adults with ASD express in relation to SD. Asking participants directly about the factors that hinder and facilitate their SD will shed light on individual and environmental conditions that could be considered when developing curricula or discussing policy reforms. In addition, themes were explored to identify reasons why SD is valuable to participants in attaining successful outcomes in adulthood. To accomplish this task, a mixed-methods design was employed. This chapter will provide a rationale for using quantitative and qualitative methods, and elaborate on the specific methodological tenets of the study including a description of the participation, recruitment, measures implemented, procedures, and data analysis plan.

Study Design

The current non-experimental study is descriptive in nature, however it will also incorporate more explanatory research (i.e., predictors of SD). The study utilized was a mixed-method approach. Within psychology, the mixed-method approach allows for enriched findings, which enables better generalizability of results as well as attains a greater understanding of the studied phenomena (Hanson, Creswell, Clark, Petska, & Creswell, 2005). That is, qualitative

research can be effective in exploring SD from the perspective of young adults with ASD as they transition into adulthood. There are, however, limitations to employing a mixed-method design. For instance, it is very time intensive requiring a significant portion of time to analyze the data. Nevertheless, a mixed-methods design has developed as a viable alternative to a strictly quantitative or qualitative research (Hanson et al., 2005; Leech & Onwuegbuzie, 2009). It also not only answers research questions, but also helps guide and inform future research from the perspective of the participant (Johnson, Onwuegbuzie, & Turner, 2007). In the current study, the use of mixed-methods was warranted, as it was likely to generate superior and richer information on SD due to the nature of the research questions. Particularly, the researcher employed a partially mixed concurrent dominant status approach, as both the quantitative and qualitative elements were conducted concurrently in their entirety before being mixed at the data interpretation stage (Leech & Onwuegbuzie, 2009). A partially mixed methods approach pertains to the quantitative and qualitative phases being distinct (i.e., not mixed) across stages of the research process. The dominant status approach was employed as the quantitative phases of the study have a significantly higher priority than the qualitative phases.

Participants

The participants in the study were 125 young adults across Canada (which included British Columbia, Alberta, Manitoba, Ontario, Quebec, Nova Scotia, Prince Edward Island, New Brunswick, and Newfoundland), were between the ages of 18 and 30, and identified as having ASD without an ID. In order to participate in the study, participants had to meet the following requirements: (a) a chronological age between 18 and 30 years; (b) have a diagnosis of ASD which was confirmed by using a cut-off of 26 on the Autism-Spectrum Quotient (Baron-Cohen

et al., 2006); (c) live in Canada; (d) a self-reported confirmation of not having an ID (as it was not possible to administer cognitive assessments online).

Power

The power analysis computer software GPower-3 (Faul, Erdfelder, Lang, & Buchner, 2007) was used to conduct an *a priori* power analysis for each proposed statistical analysis to determine sample size. Particularly, GPower provides the relationships between a desired effect size, level of significance, desired power level, and the sample size required to increase the validity of the statistical tests performed. A power of .95, alpha of .05, and a medium effect size ($d = .3$; Cohen's, 1988) were utilized in each power analysis. The minimum sample size calculated for the hierarchical regression analyses was 77. This sample size represents a balance between feasibility and statistical power. For the regression analysis specifically, this sample size should yield an adequate power for detecting a moderate sized effect when employing the traditional 0.05 criterion of statistical significance.

Procedure

Following approval from the Research Ethics Board II at McGill University, participants were recruited widely across Canada via a variety of sources. These included national associations and organizations that service individuals with ASD via their websites, social media, newsletters, and direct mailings. Specifically, associations and organizations across Canada, including all provinces and Northwest Territories, were contacted to participate. The researcher also contacted Cégep and University Offices for Students with Disabilities across Canada via the Canadian Association of College and University Student Services resource list. Participants were contacted directly via flyers and letters of invitations (see Appendix A), which included a short introduction to the study, a request to participate, and the hyperlink to access the web

survey. Upon receiving the email, administrators were asked to inform potential participants with ASD about the online survey and forward the URL link. With one click on this link, participants were directed to the informed consent form (See Appendix B). Informed consent was obtained from each participant, for example, participants were ensured of the opportunity for subsequent withdrawal at any stage of the study and that all provided information would remain autonomous and confidential. Once the participant had clicked “I agree to participate”, the survey appeared on the screen. The survey took approximately 30 to 45 minutes to complete, depending upon the participants’ prior experience with web-based surveys. After completing the survey, a “Thank You” page appeared prompting participants to indicate their interest in receiving a summary of the research results and information about participating in future studies. Furthermore, participants who wanted to be compensated for their time received an email with a link to redeem a \$15.00 gift certificate from a store of their choice (e.g., iTunes, Amazon, Chapters, Cineplex etc.).

There are numerous advantages to using an online survey to address our specific research questions (Wright, 2005). In the current study, advantages included access to a wide variety of participants in an efficient manner. We assumed this was most likely reaching individuals with ASD rather than individuals with other diagnoses because the respondents were a part of the networks we recruited from. Anonymity of an online survey might have been particularly helpful in making young adults with ASD feel comfortable to report honestly, especially in regards to disclosing more sensitive information like mental health issues. Another advantage is that an online survey is time-efficient and cost-effective. Contacting a multitude of individuals with ASD in a short amount of time despite being separate by geographical distances, while also eliminating the financial costs by moving to an electronic medium from a paper format.

An area of concern related to using an online survey was ensuring an accurate response rate. Previous research has investigated a large number of factors that increase response rates and improve data quality. In terms of online surveys, the most important factors to consider are follow-ups, incentives, and length and presentation of questionnaires (Dillman, 2000). Considering “Dillman’s Tailored Design Method” (Dillman, 2000), an advance notice email was sent to all administrators or participants informing them about the upcoming survey. Approximately one week later, an “invitation to participate” email was sent to all individuals at the national associations, organizations, or universities asking representatives to forward the invitation to potential participants. A third email was later sent as a reminder to forward the study information on to potential participants, which has been identified as essential for maximizing the response rate (Dillman, 2000). A “thank you” email was then sent to those who had completed the survey and then a final reminder was sent to the contact list (See Appendix C).

Dillman’s “Tailored Design Method”, which is based on social exchange theory, states, “actions of individuals are motivated by the return these actions are expected to bring” (Dillman, 2000, p.14). That is, individuals will do things that are rewarding. Consequently, the use of monetary incentives was used as they have been declared as being effective in increasing the response rate in online surveys (Dillman, 2000). Dillman also noted that the relationship between the length and response rate is important. As such, the survey took approximate 30 to 45 minutes to complete. Finally, Dillman reported that “respondent-friendly” design of surveys might help improve the response rate, as it may make it a more enjoyable experience for the respondent and therefore put in more effort and answer more seriously. Survey Monkey is an adequate server for creating surveys as it provides basic graphics that may make the proposed

survey “respondent-friendly” without too many advanced features (e.g., pictures, videos) that would make the survey more difficult to access and complete and lead to longer download times, which would consequently reduce the response rate (Dillman, 2000).

Measures

A comprehensive survey (see Appendix D) was developed that included brief indicators of SD. It was made available via an online option (using Survey Monkey) and a paper-and-pencil option for participants without Internet access. Also, participants were made aware of the accessibility features (e.g., read out loud questions) offered when using the survey (on Survey Monkey). An online survey was a preferred method, as it allowed for access to a large percentage of participants and ease of participant response. The survey included the following measures:

Autism-Spectrum Quotient – Adult Version. The Autism-Spectrum Quotient – Adult Version (AQ; Baron-Cohen et al., 2006) is a self-report scale that assesses the severity of ASD characteristics among adults. It is comprised of 50 items and five subscales: social skills, attention switching, attention to detail, imagination, and communication. Each subscale includes 10 behavioural statements that participants are asked to rate using a 4-point Likert scale ranging from definitely agree (0) to definitely disagree (3). Items are subsequently coded dichotomously into 0 and 1 to reflect the absence or presence of each symptom. A Total *AQ* score can be obtained, with the lowest score (i.e., 0) suggesting no traits of ASD and the highest score (i.e., 50) indicating higher levels of severity traits of ASD. For the purpose of this study, only participants with an *AQ* score at or above 26 were included in the analyses. Previous research has found that 90% of adolescents with ASD scored at least 30, while none of the controls scored in that range (Baron-Cohen, Hoekstra, Knickmeyer, & Wheelwright, 2006). However, a cut-off

value of 26 has been suggested for a clinical population and a cut-off value of 32 for the general population (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001; Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005). Therefore, a cut-off of 26 was deemed appropriate for the purpose of the current study. The *AQ* has strong test–retest reliability ($r = .92$, $p = .001$) and strong internal consistency for the overall measure (alpha coefficient = .79; Baron-Cohen et al. 2006). Internal consistency for the overall scale (alpha coefficient) will be reported for the purpose of this study.

ARC's Self-Determination Scale. The *Arc's Self-Determination Scale (SDS)* (Wehmeyer & Kelchner, 1995) is a 72-item self-report measure based on the functional theory of SD. The *SDS* has four subscales representing the four essential characteristics of self-determined behavior: Autonomy, Self-Regulation, Psychological Empowerment, and Self-Realization (Wehmeyer, 1996a; Wehmeyer, Kelchner, & Richards, 1996). The first section measures *Autonomy*, which is a person's level of independence and capacity to act based on their personal beliefs, values, and interests. Participants rate the 32 items in this section on a scale from 0 (I do not even if I have the chance) to 3 (I do every time I have the chance). The second section consists of 9 items that reflect *Self-Regulation*, and includes problem solving and goal-setting and task performance. For the problem-solving section, scores are assigned on a scale of 0 to 2 points depending on the effectiveness of the participants' solution to resolve the social problem. For the goal setting and task performance section, scores are accumulated based on the presence of a goal and the steps identified to attain the goal (0 = no plan; 1 = goal without steps; 2 = goal with 1-2 steps; 3 = goal with 3-4 steps). In the third section, participants respond to 16 questions measuring *Psychological Empowerment*, that is, a person's perceptions of control, efficacy, and outcome expectations. Scores are assigned with either 0 (answer not reflecting a psychologically

empowered belief) or a 1 (answer reflecting a psychologically empowered belief) point. The final section of 15 items measures *Self-Realization*, which includes self-awareness and self-knowledge. Scores of either 0 or 1 are given based on whether the answer reflects positive self-awareness and self-knowledge. Subscale scores as well as a total SD score can be calculated. A total of 148 points are available on the scale, with higher scores indicate higher levels of SD. Wehmeyer (1996b) reported adequate reliability and validity for the SDS in the measurement of SD in a sample of 500 adolescents with and without disabilities (e.g., ID, learning, emotional, physical) between the ages 14 and 22 years. The Cronbach's α for this study will be reported.

Further, the *SDS* was modified to include Likert-scales asking participants to indicate how important the skills or abilities that make up SD are to them (i.e., "*Please rate how important this skill or ability is for you?*"). The modification allowed for a closer examination of the importance of the items that make up the *SDS* without impacting the validity and interpretability of the original measure.

AIR Self-Determination Scale. The *AIR Self-Determination Scale* (*AIR*; Wolman et al., 1994) is a measure of SD based on self-determined learning theory. The *AIR* is available in a student, educator, and parent version. For the purposes of this study, the student (*AIR-S*) version was utilized. The *AIR-S* consists of 24 questions, which were rated on a scale from 1 (*never*) to 5 (*always*) and provide information on participants' capacity and opportunity for SD. Capacity and Opportunity subscale scores can be calculated as well as a total SD score, which is the sum of the Capacity and Opportunity subscales. The *AIR-S* Capacity subscale consists of two domains: Things I Do, related to SD, and How I Feel, about performing these behaviors. The *AIR-S* Opportunity subscale includes questions about the opportunities students have to engage in SD behaviors at home and school. The *AIR-S* was developed and normed with 450 students

with and without disabilities in California and New York (Wolman et al., 1994), and demonstrates adequate reliability and validity in the measurement of SD for students with and without disabilities between the ages of 6 and 25 years. The Cronbach's α will be reported for the purpose of this study.

SD in ASD Survey. The overall survey also included some additional items and scales measuring constructs for which suitable measures do not exist. First, questions about participant demographic information were included (e.g., age, education, mental health). In order to explore participant's value or importance of SD, the *SDS* was slightly modified by including a 5-point Likert scale for each item and/or subscale asking participants to "*Please rate how important this skill or ability is for you*". The survey also included two questions on participant satisfaction (i.e., "*How satisfied are you with your current level of self-determined behaviour?*") and importance (i.e., "*How important is it for you to be a self-determined individual?*") to explore whether there might be a discrepancy between their satisfaction and their values. Participants were also asked an open-ended question about why SD was important in adulthood (i.e., "*Do you think that being self-determined would help or have helped you succeed in adulthood? For example, gain employment, success in post-education opportunities, and develop and maintain relationships? Explain.*"). Finally, participants were asked to identify possible barriers and facilitators that impact the development of SD (e.g., support network, opportunities and choices provided, mental health problems).

Data Collection

Data were collected via an Internet survey using survey software, Survey Monkey. Survey Monkey was chosen as it provides basic graphics that may make the proposed survey "respondent-friendly" without too many advanced features (e.g., pictures, videos) that would

make the survey more difficult to access and complete (Dillman, 2000). The survey excluded direct identifiers, with the exception of an email address (in case participants wanted to request a honourium). All of the collected data were kept confidential. Participants were able to access the website at their leisure during the specified 8-month period of data collection. There was no direct interaction between participants and researchers unless requested by the participant. Once collected, the researcher imported the participants' data directly from Survey Monkey into the Statistical Package for the Social Sciences (SPSS) for analysis, which was stored on a password protected electronic file on a secure computer.

Response rate

A total of 271 young adults with ASD across Canada completed the online survey. After screening for zoomers (i.e., participants who completed the survey in under 15 minutes) and non-Canadian residents, 145 participants remained (53.5%). These participants were then carefully examined to ensure that they met inclusion criteria (i.e., between 18 and 30 years old age, no self-reported ID, and met the cut-off of 26 on the *AQ*). As such, this resulted in the current sample size of 125 young adults with ASD (without an accompanying self-declared intellectual disability), specifically retaining 86.2% of the completed surveys.

Missing Data Analysis

Missing data can be classified as either ignorable or non-ignorable (Enders, 2010). Mechanisms that correspond to ignorable missing data are missing completely at random (MCAR), where the missing data has no relationship with other variables present and missing at random (MAR), where a relationship exists between the missing value and other variables, excluding the variable with missingness. Data that are missing via MCAR or MAR mechanisms can be successfully estimated using maximum likelihood procedures such as multiple imputation

that allow for unbiased estimation of the missing data (Enders, 2010). In the current study, a small amount of data was missing for several variables. The mean percentage of missing data across all of the variables in the data set was 0.52% (109 values missing). Little's MCAR test was employed to examine whether the data was missing at random before imputing missing data variables for analyses (Little, 1988). In particular, the Little's test examines the hypothesis that the data are missing completely at random, which is an assumption that must be satisfied prior to replacing missing values with various imputation techniques. The data in the current study were missing completely at random as indicated by a non-significant Little's MCAR test, $\chi^2 = 904.376, p > .05$.

In order to have a complete data set to run the regression analyses, a Missing Value Analysis, specifically an Expectation-Maximization (EM) imputation algorithm using the SPSS program was used to impute the missing data using the totality of information within the data set. If cases with missing values are systematically different from the cases without missing values, the result may be misleading. Additionally, missing data may reduce the precision of the calculated statistics because there is less information than initially planned (Tabachnik & Fidell, 2013). The EM procedure randomly draws numbers to match the distribution of the variable, which allows for better generalization to the population. In so doing, the important characteristics of the data set were preserved, and the potential deleterious effects of not including all available data in the data analysis process were avoided, and the ability to calculate unbiased and efficient parameter estimates was improved (Tabachnik & Fidell, 2013). This procedure is superior to the mean imputation because replacing missing values with the mean harms generalizability and hurts power (Tabachnik & Fidell, 2013).

Analytic Procedure

Quantitative Analysis. All scores were initially examined for outliers and unusual distributional properties (e.g., skewness and kurtosis) and any corrective steps taken or variables dropped. A quantitative analysis of data used descriptive statistics, independent samples t-tests, analysis of variances (ANOVA), and a hierarchical multiple regression analysis were conducted across various variables of interest and their relation to SD.

Qualitative Analysis. The researcher utilized thematic analysis as an analytic strategy to examine a free response item related to the importance of SD in adulthood. Thematic analysis has been used previously in an online-survey study examining emotional experiences of individuals with ASD (Jones, Zahl, & Huws, 2001). The thematic analysis guidelines outlined by Braun and Clarke (2006) were employed as the framework for analyzing the qualitative information.

Thematic analysis allowed the researcher to recognize, investigate, and report any themes that emerged as related to the importance of SD in young adults with ASD. A thematic analysis was preferred to other existing qualitative analytic methods for its flexibility, as well as its utility and accessibility for researchers who are less familiar with qualitative analysis (Braun & Clarke, 2006). Specifically, Braun and Clarke (2013) have emphasized that thematic analysis is a method of analysis, as opposed to more complex qualitative methods, which could be identified as methodology. In fact, they asserted that because thematic analysis is independent of existing theoretical frameworks, it could be learned and utilized without the knowledge required for other qualitative approaches (Braun & Clarke, 2013). In the current study and in alignment with Braun and Clarke's (2006) recommended guidelines, the free response survey item was carefully read and based upon the content, coding structures were identified.

Analysis of participants' responses was done using both an inductive and deductive approach. The process of an inductive analysis involved allowing the themes to emerge from the data, without trying to fit it into a pre-established coding frame or the researcher's assumptions (Braun & Clarke, 2006). The strength of this approach is that it can be applied to understudied topics such as SD in the context of young adults with ASD. This approach allowed the researcher to uncover reasons why young adults with ASD find SD to be imperative in adulthood that may not be captured by existing theories of SD. Conversely, a deductive approach is guided by a theoretical interest and thus tends to yield less rich description of the data (Braun & Clarke, 2006). Deductive themes captured data related to the functional theory of SD such as autonomy, self-regulation, psychological empowerment, and self-realization; the causal agency theory (i.e., volitional action, agentic action, action-control beliefs); the component elements of SD (e.g., choice-making, decision-making, internal locus of control); self-determined learning theory (i.e., capacity and opportunity); as well as the basic psychological needs. The inclusion of both approaches allowed for a more rich and detailed thematic analysis that was able to capture unique elements of the data.

Braun and Clarke's (2006) six phases of thematic analysis were employed (see Table 1). First, the researcher became familiar with the data by thoroughly reading the provided responses. While reading, the researcher noted possible commonalities across responses. Second, after reading through the data, initial codes were generated by the researcher and then refined. The responses were analyzed based on a semantic approach. More specifically, the researcher examined the responses based on their explicit meanings, then summarized and interpreted the information looking for implications and overall meanings (Braun & Clarke, 2006). Third, this information was then sorted into broader themes by the researcher; that is, the researcher

combined these codes based upon how they came together to comprise overarching themes. Fourth, after generating themes, the researcher reviewed and refined the themes in order to determine if there was enough support for a given theme, or if multiple themes could be collapsed into one. Fifth, the researcher reviewed all the themes and generated clear definitions and names for each theme. Finally, compelling extract examples were selected to help produce a report of the analysis. A third party reviewed all the codes and examples to ensure that they accurately reflected the findings/themes.

Excel spreadsheets were used to display the coding matrices to determine frequencies of deductive and inductive themes. More thorough analysis across themes was done using pivot tables to determine, for example, the number of participants indicating capacity as a valuable component to SD. Pivot tables were also used to understand other inductive themes of interest, which were informed by previous research.

CHAPTER 4: RESULTS

The purpose of this study was to examine SD among young adults with ASD without an ID. The survey consisted of three parts. Part one included demographic information that was utilized as IVs for grouping and comparing responses on survey items. Part two of the survey included the *SDS* and *AIR* measures, and part three asked quantitative and qualitative questions about participants' importance rating of SD and their perceived barriers and facilitators to becoming self-determined. This chapter presents the results, specifically the demographic information of the participants, the data analysis and results in relation to each research question, and a summary of the findings.

Internal Consistency

Internal consistency was examined for each scale and subscale by calculating Cronbach's alpha (Cronbach, 1951). Cronbach's alpha is most appropriately utilized when items measure different substantive areas within a single construct. Specifically, it determines how much the items on a scale are measuring the same underlying dimension (Dunn, Baguley, & Brunsden, 2014; Zinbarg, Yovel, Revelle, & McDonald, 2005). What constitutes a good level of internal consistency differs depending on what source you refer to. Generally, an alpha value of .70 describes an acceptable lower bound for scale reliability ($>.80$ = good, $>.90$ = excellent; DeVellis, 2003; Kline, 2005).

In the current study, Cronbach's alpha for the *SDS* as a whole was .897 (63 items rather than 72 items, with the self-regulation scale taken out), indicating good internal consistency for the scale. The subscale alphas were adequate or near acceptable: .88 (Autonomy), .73 (Self-Regulation), .79 (Psychological Empowerment), and .73 (Self-Realization). These alpha values were similar to or higher than those calculated with the norming sample of 500 students with disabilities (.90, .73, and .62 for the Autonomy, Psychological Empowerment, and Self-Realization subscales, respectively; .90 for the three as a whole; Wehmeyer, 1995). These alpha values were also similar to or higher than those calculated with a sample of 95 students with ASD between the ages of 13 and 21 years old from the United States (Chou et al., 2015). Particularly, .90 (Autonomy), .77 (Self-regulation), .70 (Psychological Empowerment), and .69 (Self-realization), as well as .90 for the four as a whole; together, these indicate excellent internal consistency for the scale.

The reliability of the *AIR* was also supported, with the Cronbach's alpha of .93 for the Capacity and Opportunity subscales, respectively. Alpha for the *AIR* as a whole was .94 (which

denotes excellent reliability according to Lance, Butts, and Michels (2006). This was comparable with the reliability estimate (i.e., split-half coefficient of .95) derived from the initial sample of students with and without disabilities used to develop the scale (Wolman et al., 1994) as well as with a study of 95 students with ASD between the ages of 13 and 21 years old from the United States (.91 and .87 for Capacity and Opportunity, and .93 for the whole; Chou et al., 2015).

The reliability of the *AQ* was somewhat supported, with the Cronbach's alpha of .729 for the overall score. The internal consistency of items in each of the five domains was also calculated, and Cronbach's alpha coefficients were all low to moderate (Social = .443; Communication = .48; Imagination = .59; Local Details = .48; Attention Switching = .62). These were slightly lower than those calculated with 58 adults with ASD (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). Particularly, .65 (Communication), .77 (Social), .65 (Imagination), .63 (Local Details), and .67 (Attention Switching), as well as .63 for the scale as a whole indicating moderate to high internal consistency across domains (Baron-Cohen et al., 2001).

Demographic Information

Study participants were 125 young adults with ASD without a self-reported intellectual disability. Women constituted 46.4% of the sample, men also constituted 46.4% of the sample, and 7.2% identified as transgender. Female ($M = 23.81$, $SD = 3.85$), male ($M = 22.62$, $SD = 3.39$), and transgender ($M = 22.33$, $SD = 2.57$) participants all ranged in age from 18 to 30 years ($M = 23.15$, $SD = 3.65$). The vast majority of the participants were Caucasian (79.2%), although participants from other racial or ethnic groups were also represented in the sample. Descriptive statistics of the demographic variables appear in Table 2.

Participants were recruited from rural, urban, and suburban areas across Canada as a part of an online survey examining SD in young adults with ASD. All participants (100%) reported currently living in Canada, however 15 (12%) participants indicated that they were born outside of Canada. Nevertheless, the majority of these participants indicated living in Canada for more than a decade. The vast majority of participants reported living in Ontario (43.2%) and Quebec (15.2%), with some representation from the west (28.8%) and east (12.8%) coasts provinces examined individually. Unfortunately, no representation from Saskatchewan and the Northwest territories was indicated. Most participants reported English as their first language (88.8%).

In terms of education, 32.8% of the participants noted having a college/university or graduate degree. However, 35.2% reported attending partial college (at least one year). Approximately a quarter of the sample (23.2%) completed high school, with 8.8% of participants reporting having not completed high school. That is, the vast majority of the sample attended post-secondary education, with approximately 35% discontinuing college and 5.6% with a graduate degree. Of the 125 participants, 46 (36.8%) reported that they were currently employed. That is, 79 participants (63.2%) reported not being employed. Of those who reported being employed, most had part-time employment (63.0%), with 36.9% reporting having full time employment. See types of occupations reported in Table 2.

Of particular interest were the services that participants reported to have used previously or were currently utilizing. The vast majority of participants indicated having previously received mental health services (64.8%), post-secondary educational programs (60%), and recreational or leisure programs (60%). Other services previously received included: employment services (43.2%), social skills programs (40%), employment or day programs (40%), life skills training (33.6%), and transition support programs (23.2%). Visual inspection was used to examine the

percentages of participants reporting their current services. Of the small number of participants who reported using services, the majority (39.2%) indicated that they were receiving psychological services. See Table 3 for a summary of the results.

Of the 125 participants who completed the full survey, 118 (94.4%) reported having an official diagnosis of an ASD (i.e., Autism, Asperger Syndrome, Pervasive Developmental Disorder (PDD), PDD-Not Otherwise Specified, or ASD). Participants were reminded that an official diagnosis is provided by a regulated health professional. Particularly, 61% identified as having Asperger Syndrome, 22% as having ASD or PDD, 12.7% Autism/Autistic Disorder, 4.2% PDD-NOS, and 5.6% preferring not to self-disclose their specific diagnosis. For the 7 (5.6%) participants who did not report an official diagnosis, they reported identifying as being part of the ASD community and made the cut-off score on the *AQ*. In fact, all participants were retained in the sample if their *AQ* total score was at or above 26 ($M = 33.46$, $SD = 5.82$, $range = 26 - 46$). Furthermore, all participants did not identify as having an intellectual disability (i.e., intelligence quotient or IQ lower than 70). Due to the nature of the study, the researcher was not able to confirm that all participants had average IQ scores. Although they were reminded that an IQ of less than 70 represented an ID, participants were not reminded that an official diagnosis of ID is provided by a regulated health professional (as done with the ASD diagnosis). However, participants were asked to describe their level of support typically required on a daily basis (See Table 4 for support level definitions). Specifically, 41.6% noted infrequent or no support required and 45.6% intermittent support. The remaining participants 12.8% reported requiring limited (8.8%) or frequent (4%) support.

The researcher was concerned about the 12.8% of participants reporting higher supports (i.e., limited or frequent). As such, cross-tabulations were completed to investigate any

extraneous factors that could be contributing to the support level for these individuals other than an existing ID (i.e., low adaptive skills). For instance, significant mental health issues would “explain” why they require extra support, while education levels would “corroborate” their probable daily living skills. Out of the 16 (12.8%) participants who reported having higher support needs, half of them (6.4%) started or completed college or university, while the other half either completed (4.8%) or did not complete (1.6%) high school. In terms of reported number of mental health concerns, 4 participants (3.2%) reported 1 or 2 official mental health issues, while 10 participants (8%) reported more significant co-morbidities (3 or more official diagnoses). See Table 5 for a list of official and unofficial mental health diagnoses reported in the current sample. Furthermore, all of the participants with higher support needs also reported living with parents (11.2%) or other family members (1.6%).

Descriptive Statistics for the Variables of Interest and Autism Spectrum Disorder

Table 6 presents the descriptive statistics of participant responses for the overall total and subscale scores for the *AQ*, *SDS*, and *AIR*. Pearson product correlations were also calculated (see Tables 7, 8, and 9). Total *AQ* negatively correlated with *SDS*' self-realization, $r = -.24, p < .01$. In fact, the self-realization domain was negatively correlated with all of *AQ* subscales, with the exception of attention to detail, which was positive associated ($r = .27, p < .01$). Total *SDS* was negatively associated with social skills ($r = -.22, p < .05$) and attention to detail ($r = -.32, p < .01$). A closer examination of the subdomains revealed that *SDS*' autonomy was positively correlated with attention to detail, $r = .27, p < .01$, whereas self-regulation was positively associated with attention switching ($r = .18, p < .05$) and communication ($r = .21, p < .05$). Psychological empowerment was negatively associated with social skills ($r = -.34, p < .01$) and imagination ($r = -.21, p < .05$) and positively associated with attention to detail ($r = .23, p < .01$).

Furthermore, Total *AQ* was negatively correlated with *AIR* total score ($r = -.31, p < .01$), particularly social skills ($r = -.31, p < .01$) and imagination ($r = -.30, p < .01$). Social skills and imagination were negatively correlated across both domains (i.e., capacity and opportunities) and subdomains of the *AIR* (i.e., things I do, how I feel, school, and home).

SDS and *AIR* total scores were positively correlated, $r = .52, p < .01$. All domains of the *SDS* and *AIR* were significantly positively correlated (see Table 10). Interestingly, autonomy and self-regulation were not correlated with the *AIR*'s opportunity domain and subdomains (i.e., home and school). Furthermore, *SDS* total was positively correlated with age ($r = .36, p < .01$) and education ($r = .29, p < .01$), and negatively correlated with support level ($r = -.22, p < .05$).

Descriptive Analysis of Self-Determination

The research questions outlined previously will be addressed in turn.

Research Question (RQ) 1: *What are the SD levels of young adults with ASD across Canada as measured by The Arc's SD Scale (SDS; Wehmeyer & Kelchner, 1995) and the AIR SD Scale – Student (AIR; Wolman, Campeau, Dubois, Mithaugh & Stolarski, 1994)?*

The mean *SDS* Total for the sample was 83.19 ($SD = 19.40$, range = 29-125). The mean for the *SDS* *Autonomy* subdomain was 52.49 ($SD = 14.04$, range = 12-91), of the *Self-Regulation* subdomain was 10.94 ($SD = 4.81$, range = 0-19), of the *Psychological Empowerment* subdomain was 10.96 ($SD = 3.49$, range = 1-16), and the *Self-Realization* subdomain was 8.81 ($SD = 3.17$, range = 1-15). With the exception of the *Self-Regulation* mean, these were all slightly below the mean for the *SDS* norms and those in Wehmeyer et al. (2007). However, the mean *SDS* total and domain scores in the current study were closer in comparison to the 74 middle and high school students with ASD in Chou's (2013) study.

The mean *AIR* Total for the sample was 80.37 ($SD = 17.86$, range = 24-120). The mean for the *AIR* *Capacity* subdomain was 41.00 ($SD = 9.65$, range = 12-60), while the *Opportunity*

domain mean was 39.38 ($SD = 10.90$, range = 12-60). Although there are no normative means presented in the manual, the current participants scored lower in capacity, but higher in opportunity compared to a sample of 74 middle and high school students with ASD (Chou, 2013).

RQ2: *Do demographic variables (level of education, gender, living situation, age) explain levels of SD, based on the SDS total score (Wehmeyer, 1995)?*

A one-way ANOVA was conducted to determine whether there was a significant difference between participants' level of education in relation to their reported SD using the *SDS*. There were no outliers and the data were normally distributed for each group (i.e., junior high/middle school, partial high school, high school graduate, partial college, college/university graduate, graduate degree), as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. Levene's Test of equality of variances indicated similar variances across education with regard to SD, $F(5, 119) = .91$, $p > .05$. This indicates that variances between groups are equal with regard to these variables (i.e., satisfying the assumption of homogeneity of variances). However, the samples sizes were unequal requiring the use of the Welch ANOVA, a modified version of the ANOVA (Field, 2009). Using the Robust Tests of Quality of Means, the level of SD was significantly different for levels of education, *Welch's* $F(5, 27.530) = 10.10$, $p < .001$. *SDS* total score increased from junior high ($M = 71.00$, $SD = 1.41$) to partial college ($M = 81.95$, $SD = 19.93$), and college/university ($M = 90.15$, $SD = 18.08$). Games-Howell post hoc analysis revealed that the mean increase from junior high to partial college (10.95, 95% CI [1.41, 20.50]) was statistically significant ($p = .017$), as well as the increase from junior high to college/university (19.15, 95% CI [9.23, 29.06], $p = .00$).

An independent sample *t* test was performed to determine whether there is a difference between employed and unemployed participants in relation to the *SDS* total score. There were

no outliers and the data were normally distributed for each group, as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. The results of the Levene's Test suggest that equal variances are assumed, $F(1, 123) = .310, p > .05$. Therefore, the values of the t tests with equal variances assumed are reported. The results of the independent samples t -test suggests that there is no significant difference between *SDS* total scores across employment conditions, $t(123) = 1.89, p = .06$. However, there is a trend and the examination of the descriptive statistics suggests that individuals who are employed ($M = 87.53, SD = 18.85$) reported higher levels of SD ($M = 80.75, SD = 19.40$).

A one-way ANOVA was conducted to determine whether there was a significant difference between participants' current living situation in relation to their reported self-determination using the *SDS*. Specifically, groups were defined as living: with parent/caregiver, with another family member, independently with some financial assistance, independently with roommates (you pay your share), and independently (you pay for all of your own bills). There were no outliers and the data were normally distributed for each group, as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. Levene's Test of equality of variances indicated that variances across living conditions in regards to SD, $F(5, 119) = .911, p > .05$. This indicates that variances between groups are equal with regard to these variables. However, the sample sizes were unequal requiring the use of the Welch ANOVA. Using the Robust Tests of Quality of Means, the level of SD was not statistically significantly different for different living conditions, *Welch's F* ($4, 17.863$) = 2.434, $p > .05$. As such, a Games-Howell post hoc analysis was not examined.

A one-way ANOVA was conducted to determine whether there is a significant difference between participants' gender in relation to their reported self-determination using the *SDS*.

There were no outliers and the data was normally distributed for each group (i.e., female, male, and transgender), as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. Levene's Test of equality of variances indicated that variances across living conditions in regards to SD, $F(2, 122) = .357, p > .05$. This indicates that variances between groups are equal in regards to these variables. However, the samples sizes were unequal requiring the use of the Welch ANOVA, a modified version of the ANOVA. Using the Robust Tests of Quality of Means, the level of SD was not statistically significantly different for different genders, *Welch's F* (2, 22.78) = 1.44, $p > .05$. As such, a Games-Howell post hoc analysis was not examined.

An independent sample t test was performed to determine whether there is a difference between younger and older participants in relation to the *SDS* total score. Older and younger age categories were created based on a median split (median age = 23). There were no outliers and the data were normally distributed for each group, as assessed by boxplot and Shapiro-Wilk test ($p > .05$), respectively. The results of the Levene's Test suggest that equal variances are assumed, $F(1, 123) = .31, p > .05$. Therefore, the values of the t tests with equal variances assumed are reported. The results of the independent samples t -test suggests that there is a significant difference between *SDS* total scores across younger and older adults with ASD, $t(123) = -2.73, p = .007$. Particularly, older ($M = 87.63, SD = 18.80$) young adults reported higher levels of SD, based on the *SDS*, than younger ($M = 78.38, SD = 19.04$) adults.

RQ3: *Do participants' reported level of SD importance predict SD (as measured by the SDS) above and beyond individual (i.e., age, gender, education, capacity of SD) and environmental (i.e., opportunity) factors?*

Distribution and Normality Analysis

See Table 11 for descriptives on each variable. The distribution for each variable was normal, with the exception of SD rating of importance. Importance was extremely negatively

skewed, with a skewness of -1.23 (SE = 0.22). However, no transformations were performed. When importance was reflected and inversed, the skew was corrected (skewness = -.49, SE = 0.22) but the kurtosis increased (skewness = -1.59, SE = 0.43). Consequently, the researcher decided to leave it untransformed (Field, 2009), as transformed variables are more difficult to interpret (Tabachnick & Fidell, 2013). In fact, Tabachnick and Fidell (2013) recommend that skewness and kurtosis is appropriate if below 2 (and perfectly fine if below 1). Furthermore, the distribution of responses across the five categories of importance (i.e., Likert-scale 1-5) appears to be normally distributed (upon visual inspection). Standard z-scores did not exceed ± 3.29 ($p < .001$, two tails), which suggested the unlikelihood for univariate outliers (Tabachnick & Fidell, 2013). Thus, outliers were not excluded from the analyses.

Examination of the Hierarchical Multiple Regression Assumptions

To determine if the multivariate assumptions (i.e., normality, linearity, and homoscedasticity) had been violated, the dependent variable (DV) was run against the independent variables (IVs). As shown in Figure 1, the P-P plot of regression standardized residuals indicated that the assumption of linearity was met (Tabachnick & Fidell, 2013). Additionally, the residuals were normally distributed, such that the assumption of normality was met (see Figure 2). A Durbin-Watson value of 2.373 indicates that the residuals did not have serial correlation with one another (Norusis, 2008; Field, 2009; Tabachnick & Fidell, 2013).

The Pearson-product moment correlation revealed small correlations between several of the IVs. However, the correlations were all below 0.7 (see Table 12; Field, 2009). Furthermore, collinearity statistics indicated a tolerance that was < 1 , suggesting that multicollinearity was not evident. More specifically, all the Tolerance values were greater than 0.1 (the lowest is 0.600), as such, there is no problem with collinearity.

Outliers, leverage, and influence were also examined. The casewise diagnostic output in SPSS was not produced, indicating that all of the cases have standardized residuals less than ± 3 . Furthermore, Mahalanobis distance was utilized to search for multivariate outliers and can be evaluated using the χ^2 distribution. Tabachnick and Fidell (2013) suggests that a conservative probability estimate for identifying outliers is $p < .001$ for the χ^2 value (22.46). Thus, using Mahalanobis distance, no multivariate outliers were present. In terms of leverage, there were no leverage values above the “safe” value of 0.2 (Laerd Statistics, 2015). In addition, there were no Cook’s Distance values above 1 (Cook and Weisberg, 1982), suggesting there are no cases that are influential.

Hierarchical Multiple Regression

A hierarchical multiple regression was used to determine if the addition of importance improved the prediction of SD over and above individual and environmental factors. Specifically, the first block included age, gender, education, and capacity. Opportunity was entered in the second block. Importance, that is, participants’ ratings (on a 5-point scale) on the questions, “*How important is it for you to be a self-determined individual?*” was entered in the third block to examine the influence it has on SD over and above that which was explained by the individual and environmental predictors. See Table 13 for full details on each regression model.

The full model to predict *SDS* total (Model 3) was statistically significant, $R^2 = .50$, $F(6, 118) = 19.74$, $p < .05$; adjusted $R^2 = .48$. Model 1 was statistically significant, $F(4, 120) = 28.16$, $p < .05$. The addition of opportunity to the prediction of *SDS* total (Model 2) did not lead to a significant increase in R^2 , $R^2 = .00$, although the model was significant, $F(5, 119) = 22.35$, $p < .05$. The addition of SD importance to the prediction of *SDS* total (Model 3) did lead to a

statistically significant increase in R^2 of .02, $F(6, 118) = 19.74, p < .05$. Particularly, the hierarchical multiple regression indicated that age and capacity significant predicted level of SD, $\beta = .20, t(118) = 2.63, p = .01$ and $\beta = .51, t(118) = .61, p < .01$, explaining 48.4% of the variance. Interestingly, importance was a significant predictor of *SDS* total, $\beta = .15, t(118) = 1.98, p = .05$. Together, age, capacity, and importance explained 50.1% of the variance. Additionally, upon inspection of the part and partial correlations for both regressions, there was no suggestion of any moderator effects; hence, further investigation was not required.

RQ4: *What are the self-perceived value or reported importance and satisfaction ratings of SD among young adults with ASD's? Is there a discrepancy between their satisfaction and their values?*

Self-Determination Importance

Upon inspecting the descriptive values of the importance and satisfaction ratings, it is apparent that the vast majority of participants reported higher ratings of importance and satisfaction, ranging from *somewhat important* to *very important*. See Table 14 for a summary of the results.

Cross tabulations were employed to examine the relation between satisfaction and importance scores (see Table 15). Cohen's k was run to determine if there was agreement between young adults reported levels of satisfaction and importance of self-determination. There was poor agreement ($< .20$) between satisfaction and importance, $k = .19, p < .00$ (Altman, 1999; Landis & Koch, 1977). These findings suggest that young adults with ASD reported levels of satisfaction were not in line with their respective levels of importance. Specifically, 40% ($n = 50$) of the current sample indicated that they were not satisfied with their current level of SD, which they regarded as important. Forty-four percent ($n = 55$) of the sample noted similar levels

of satisfaction and importance. However, 13.6% reported not being satisfied and not valuing SD; and, 2.4% indicated that they were satisfied, but did not value SD.

Table 16 outlines the level of importance at the item level of the *SDS*, and how their ratings of importance combine and relate to their scores on the *SDS*. In terms of autonomy, just over a third of participants either were not autonomous and did not report autonomy to be important (36.17%) or reported the complete opposite (37.5%). The vast majority of participants noted that they felt psychologically empowered and that this was important to them (53.8%).

Approximately 37% of participants reported that they were self-realized, which was important to them. However, approximately 42% reported that self-realization was not important to them with half of these young adults scoring as self-realized while the other half did not.

RQ5: *Has SD helped participants to succeed in adulthood? Do themes emerge from the free response item (i.e., explain why SD would help or have helped them succeed in adulthood) that is associated with the theorized components of SD?*

One hundred and fifteen participants (92%) reported that they believe that SD would help or have helped them succeed in adulthood (e.g., gain employment, succeed in post-education opportunities, and development and maintain relationships). When asked to identify why they believe SD would help or have helped them succeed in adulthood, 87 young adults (75.65%) provided responses. It is interesting to note that participants' responses varied tremendously demonstrating their personal and subjective needs and values in regards to SD. The responses to this question were analyzed by thematic analysis. Significant inductive and deductive themes that emerged from the thematic analysis has been organized into a visual representation, see Table 17. The results of the thematic analysis yielded 5 number of major themes: (a) capacity, (b) control, (c) knowledge of strengths and weaknesses, (d) adult outcomes, and (e) support. There were also a number of subthemes including: perspective, motivation, progress, barriers,

and opportunity. Each theme and subtheme is reflected by both positive and negative aspects or by the ways in which respondents described each theme as either having helped or as a current need to be met in relation to SD. In the following sections, participants' quotes are used to illustrate the themes.

Theme 1: Capacity

The theme of capacity refers to the knowledge, abilities, and perception that enable individuals to become self-determined. Twenty-two participants (25%) indicated that they viewed that their SD abilities were related to their success in adulthood. Approximately half of these participants noted that their SD capacity has helped them in adulthood, while the other half indicated that having more skills would be beneficial. The most frequently reported skill was goal setting and attainment (29%), with approximately half of these individuals indicating this skill as having helped attain adult outcomes while the remaining half reported that they require more support (i.e., need) with setting goals and following through. In addition, participants noted a higher need to learn more interpersonal and cognitive problem solving skills (7%). Interestingly, there was less indication of choice making (3%), decision-making (8%), problem solving (6%), self-advocacy (6%) and self-monitoring (7%).

“I want autonomy and I want to be able to set goals and move towards them, even slowly. I feel as though I am stagnant and absolutely need someone to guide and supervise me, which makes me feel guilty. I would like to rely on myself more to be a functional individual and to develop skills/pursue my interests.” – Transgender, 24

“In order to progress properly in my own life, I need to be able to learn how to make choices and decisions on my own since individuals aren't always going to be there to guide me around. I need to be able to solve problems in order to come up with a good outcome for my life too. Setting a goal can be beneficial in order to track my progress and see what I need to do in order to improve. I also need to learn to advocate for myself because I should have the right to be respected. I should also try to be aware of myself and my knowledge in order to figure out my progress through life to see how I can attain my goals and what I should do in order to reach these goals.” – Woman, 19

“Without effective self-determination, I would not be able to articulate my goals or build appropriate networks” – Man, 23

“Problem solving skills are very important to do” – Woman, 30

“Having the ability to problem solve effectively for myself is something that I'm really working hard on. For example, sometimes my brain gets 'stuck' on something even though I'm acutely aware at the time that it is not helpful and I'd like to be able to get on with other things that are useful. I've been trying to work very hard with a psychologist on ways to deal with this, but so far it has not been effective (and not having that ability makes me feel less independent and less in-control of my day goes). This relates to 'self-determination' because I feel that not having that skill is limiting my current ability to be self-determined (and, as I stated, this is only one example).” – Woman, 28

“I struggle with self advocacy. I'm in therapy working with mindfulness and self-valuation (I can't remember if that is the proper term - basically recognizing myself for my value and saying I'm worth my space and advocating). Previously, I spent five years working for a company where I was emotionally abused (at times even physically - my boss would kick my chair a lot - even after I said i had been in a car accident and was recovering from whiplash). I might have been better able to handle those situations today, as I'm learning and more able to 'keep space' and advocate for myself. I still am nowhere near able to advocate for myself in a healthy manner but previously i could not do it at all. I'm also learning when I need to advocate for myself by learning to deescalate issues by just 'letting things go'.” - Woman, 29

Themed 2: Perceived Control

The theme of control refers to the extent to which the participants believed they could control events affecting their life. Thirty-three participants (38%) reported that locus of control beliefs impacted their success in adulthood in relation to SD. Fortunately, the vast majority of these individuals (85%) expressed beliefs about having control (i.e., that they were responsible for their own success), while the remaining 15% reported that their success (or lack thereof) was caused by uncontrollable factors, such as other individuals. Similarly, participants also mentioned self-efficacy (15%), outcome expectancy (16%), control expectance/when (3%), and positive attributions of efficacy (17%).

“I feel that we are the makers of our own destiny, and strive to always be self-determined and knowledgeable of my actions and learn from the mistakes I make on the journey of life” – Man, 24

“I feel that if someone else decided how I should live my life, I would not enjoy it as much. Just because they like it, it does not mean that I will like it” – Man, 23

“Having control over one's life seems to be a requirement to succeed in life.” – Man, 21

“Ultimately you're the only one who can choose how your life is and direct how you'd like it to be. Things in life such as jobs aren't just handed to you. If you want something you have to work for it usually, such as by setting goals and slowly working towards the end result. Others in your life can help you along the way but no one can live your life for you. My dad has always said to me no one can determine your happiness in life but yourself.” – Woman, 29

“Some individuals think they should get what they want without working for it (they're smart so they will get a good grade without studying) or that they won't get what they want because they aren't good enough. I think you get where you want by working hard and nothing else. I don't know about relationships though cause I'm not very good with emotions and individuals who try to share them.” – Transgender, 23

“I have been told that as an Aspie, I may have trouble with executive functioning. That is, I can see patterns, connections and make progress in areas that other individuals often can't, yet I often lack the ability to follow-through on my plans. For example, when working on a big reading essay, I often wait until the last week to start working on it, even when I have been given three months and intended to start two months before the deadline. Since this failure happens often, I often think it's a curse that I cannot get back up on my feet. But if I keep working at it, I know I will achieve this goal. I know I can finish my assignments early and make goal-setting work again. (I feel like it often hasn't for the last twelve years - but there are probably loads of counter-examples). I needn't be afraid of failure, but learn from my past failures so I know exactly what to change. The company I will be working for during the summer is famous for doing a Failure Report every quarter, which summarizes operational failures and identifies strategies to mitigate and change the situation. I yearn to apply what I identify to myself.” – Woman, 20

“Yes. It is up to me to be the person to set about what I want. While I'm not always be able to do everything I know that I can use it to try and do what I want and that is all that really matters” – Man, 27

“When things get to be stressful and the power to control big aspects (eg. living situation, employment status, etc.) are out of my hand, being able to focus on something I can control helps me realize the outlook of the situation is all on me to changes. I can be sad, depressed and let it affect relationship (shutting myself off from others), or I can find the bright side and means to escape the negativity” – Woman, 21

“Self-determination would have helped me in many areas of adulthood as I still feel like a alienated child in this adult body of mine. I also see that my self-determination also comes across as too strong or aggressive to others when I focus on a certain goal and

will see it through. I always say there is another way and never give up but most individuals in the social world do not take that openly as it may affect cost-benefit-factors. For me, self-determination and the path towards self-betterment and understand to application is an experience (job) on its own. Sometimes I feel like a wizard and sometimes I feel like a lost child.” – Man, 28

“Society will not do work for you, if you stall or fall behind, you will be left behind. In general, individuals are self-serving and do not care about helping you, if you want to get something done, you must do it yourself or enable others with authority to do it for you.” – Man, 22

“Decision making and self-monitoring and positive outcome expectancy can be difficult for me, but I need to work on these skills because they will greatly impact the outcomes in my life. I want to be the determining factor in my own happiness and satisfaction, so it is important that I proactively try to improve in these areas.” – Woman, 30

“While I will ask for input on career development and relationship situations, I also have to develop my own instincts on these matters. Not so much from my peer groups, but some advice from older family members is very much steeped in fear and uncertainty, and I decided around the time I was diagnosed in 2010 that a) I don't need to allow additional self-doubt and anxiety into my life, b) doing things that seem scary are usually fairly mundane in practice, and c) I don't have expectations on myself for a traditional lifestyle, and am thus free to pursue exciting opportunities if I can get over my own anxieties enough to do so.” – Woman, 30

“Self-determination helps you set your limits so that you can control what is going on in your life. As long as you plan properly, that means you can attain your goals and get what you want and/or need.” – Woman, 20

“Well first of all, I would feel very good about myself, knowing that I am the reason for my accomplishments as opposed to someone else being the reason. I already do feel good about myself as I become more independent. My mom still does some things for me because I don't know how to do them (for example, taxes), but it's not too irregular if you compare me to other individuals my age. However, eventually I'll know how to do it all by myself. Until I reach that point, I just take things step-by-step, learning one thing at a time. I also think that in fostering my independence, it helps me gain skills as well as confidence in my abilities and self-worth. Becoming successfully independent harbours so much joy and happiness in me.” – Woman, 20

“While I believe that being successful is largely a matter of luck when it comes to opportunities presented to you, I also think that if you don't prepare for it you'll end up missing out on opportunities if and when they come. As such while there is a chance that anything I do will be useless, doing nothing would be even worse.” – Man, 21

“When I am determined that things might work out sometimes they do.”- Woman, 20

“It's because I have gained so many skills that I never knew I had. With every passing opportunity to learn new abilities, I take advantage of them and use them to better not only myself, but also to get farther in life.”- Man, 28

Theme 3: Knowledge of Strengths and Weaknesses

Participants also frequently noted their strengths and weaknesses, demonstrating insight into their abilities. Self-awareness or participants' accurate understanding of their strengths and needs was prevalent in approximately 28% of participants. Fifteen percent of participants reported that they utilized this self-knowledge to maximize their success. Other components of self-realization were reported, including self-confidence (13%), self-esteem (3%), and self-acceptance (2%). None of the participants expressed self-actualization, which corresponds to the prevalence of the population who are self-actualized according to Maslow's hierarch of needs.

“Of course it would. Self-determination is basic freedom. Self-determination is self-affirmation. Without self-determination, how can you even define success?” – Man, 20

“The things that I want to do and are good at are very specific. I am aware of my limitations in a way that others aren't. I usually do not succeed tasks when I am not enjoying them. I will however perform tasks that I do not want to do if I can see the benefit in them or can see how they will help me achieve a greater goal, in which case I can do tasks so long as I have made the decision to do them myself. If I do not make my own decisions about what to do or what not to do I do not succeed.” – Woman, 23

“Being self-determined has helped me to continue my yoga practise and has helped me understand that I want to help others understand the benefits of yoga. It has also helped me get the promotion at work also when my boss at first felt that I could not because I failed the test the first time. I had made really good progress within my first two months as a cashier to where our assistant manager was very proud of my achievements with regards to total sales. My boss was very grateful for me proving him wrong. Even though I had failed the test and they rarely give it a second time I was worth giving it to a second time. He was able to understand that what he thought about and that what the person thought may not be the same and to give someone a chance to prove they can do what they know they can.” - Woman, 29

“It would allow the person to meet goals that they want as opposed to what someone else wants, which will, in long run, lead them to be happier individuals because they will like what they are doing because it is what they want to be doing. This would lead them to be more successful in their lives as they will put more effort towards succeeding because they are enjoying themselves.” – Woman, 20

“It is important to figure out my life that I'm living irrespective of the rules and what others are doing. My life has to be good for me, so I need to be able to make it that way.”
– Woman, 30

“If I could make the hard decisions I have to make to keep myself healthy (sobriety, diet, etc.) then I would be far more in control of my life.” – Man, 26

“Difficulty with decision making, goal setting and attainment, and self-monitoring have definitely been problems for me.” – Transgender, 24

“Being self-determined gives you an advantage because you have an encouragement to get what you want simply by expressing yourself.” – Woman, 26

“If I do nothing by choice then I have achieved nothing” – Man, 19

“When you are self-determined, you can develop yourself based on your own self-knowledge, which would be better than anyone else's knowledge of you. This would enable you would design the best goals and plans for yourself based on this self-knowledge. I feel that studying what I was interested in (and motivated) has allowed me to achieve very highly in my academic career. As a result of my motivation and passion, I was able to extend the topic of my studies to professional development activities that also helped me understand my academic materials as well as build skills and confidence for my future pursuits. Also, self-knowledge helped me understand what interest I should focus on for my career of choice.” – Woman, 24

“Yes it would make me more confident and confidence would give me to motivation to do things because I would believe I could do them instead of thinking I am not capable and therefore setting no plans for myself.” – Woman, 23

“Ultimately, you know yourself better than anyone else” – Man, 26

Theme 4: Adult Outcomes

Various adult outcomes were frequently noted by almost half (42%) of the participants as having been associated with their SD. Approximately 33% of participants reported how SD has helped them attain these outcomes successfully, whereas the remaining 9% of participants indicated that if they had better SD abilities they would have better adult outcomes. Participants specifically mentioned SD as having positively impacted their employment outcomes (24%),

social relationships (16%), education (14%), and mental health (10%). Other outcomes reported included adaptive skills, social communication, and independent living.

“These skills are important in fostering academic success, acquiring social and communicative skills, establishing relationships with others, managing personal and emotional behaviours, as well as better job performance” - Woman, 25

“Yes, since I have always written my own letters of intent, applied to the educational institutions of my choice and engaged in activities that correspond to my interests and long-term goals. Being self-determined enabled me to pursue both my career goals and personal goals.” – Man, 20

“Choosing and finding better relationships (friends and dating). Furthering academic career by communicating my interests to other colleagues.” – Man, 27

“I have a very good work ethic. I have learned this work ethic from the barn where I horse ride. this has helped me get good marks since I am determined to get good marks. this has helped me get into university and pass my classes this year (first year university)” – Woman, 19

“Succeed in university and achieve employment” – Woman, 27

“It helps me make friends and keep them and employment possibilities are higher.” – Woman, 18

“I have been living independently for almost two years and have a much higher level of self-confidence; less depression and anxiety, hold my own job and pay for all my own bills and take care of myself. I make plans to and attempt to develop and maintain social relationships as well but so far have failed to figure out how to succeed socially and do not yet have any friends.” – Woman, 26

“I got into university and I'm doing well.” – Man, 20

“I want to stand on my toes, so job and maintain social relationships very important” – Man, 26

“Helps me see where I can get a job and keep it” – Man, 18

“I think it helps me do well in school my setting my own plans and goals.” – Woman, 25

Theme 5: Support

The final theme of support refers to participants' level of need for support in adulthood. Approximately 30% of participants reported that being self-determined enabled them to be

independent, about half of whom noted that they are overly dependent on others to succeed.

Autonomy was frequently (15%) referred to as a skill that participants possess or need to achieve a greater level of SD. Many participants also mentioned that a support system or connectedness to others served to facilitate their self-determination and to attain better adult outcomes.

Particularly, relatedness (24%) and interpersonal relations (15%) were reported.

“A lack of self-determination is frowned upon in this culture. I get criticized a lot for relying on others. If I need help to do things, employees are less likely to hold on to me. Post-secondary institutions require a high degree of independence to get to school on time, to complete homework, etc. Basic living skills alone require a high degree of self-determination to make sure you do what you need to do when you need to do it.” – Man, 27

“You need to have the right influence of individuals. Being around negative individuals will make you less determined to meet your goals, and vice versa with positive” – Woman, 20

“I cannot be always relying on others to tell what to do or how to do it. Those that I normally rely on don't know how to get to the places that I want to go.” – Man, 20

“It is important to be able to be self determined however this means that others need to accept what I am trying to tell them and then seek to help me in the way(s) that I ask to be helped, rather than at face value dismissed as being unrealistic with my expectations around the situations that I am asking for the accommodations I have asked for.” – Man, 30

“My parents believed that I was less capable than I was. Upon moving out my situation improved dramatically.” – Man, 27

“Taking charge of my own life and doing what I think is best has already gotten me much further than feeling helpless and letting the opinions of others determine my decisions.”- Woman, 21

“I don't feel like I have much control over myself. I spend most of my time feeling overwhelmed and over-stimulated by the world, and am usually unable to interact with others to achieve goals. My parents, or sometimes friends, have to act on my behalf. It's humiliating, and I can see that other individuals who don't have the problems I do don't need others to do things for them. I had to drop out of college and move back in with my parents because I was unable to manage myself or live independently. My non-autistic friends didn't have to do that. I feel that I could definitely be self-determined with my autism, but I don't know how.”- Woman, 23

“I want to be independent always my aunts cant help” – Woman, 25

“Well first of all, I would feel very good about myself, knowing that I am the reason for my accomplishments as opposed to someone else being the reason. I already do feel good about myself as I become more independent. My mom still does some things for me because I don't know how to do them (for example, taxes), but it's not too irregular if you compare me to other individuals my age. However, eventually I'll know how to do it all by myself. Until I reach that point, I just take things step-by-step, learning one thing at a time. I also think that in fostering my independence, it helps me gain skills as well as confidence in my abilities and self-worth. Becoming successfully independent harbours so much joy and happiness in me.” – Woman, 20

Subthemes

There are also five subthemes that emerged using inductive or data driven coding, including: (a) pattern of thinking, (b) motivation, (c) progress, (d) barriers, and (e) opportunities. There was a clear indication of the participant's perspectives on their life and adult outcomes in their responses. Specifically, approximately 84% of participants expressed a more future-oriented or forward thinking perspective. However, about 31% of participants' responses reflected a more pessimistic or negative thinking style.

“I find that with my low self-determination, I've been wasting lots of time in my adulthood. I should have a job and be making money. I should be a working member of society.” – Woman, 19

“There are lots of things that I want, but will never take the steps to reach. Goals have always been a difficult concept. I can daydream and create all sorts of magnificent plans; but I never actually take that first step. I procrastinate and come up with every excuse possible, but at the end of the day I don't actually know what holds me back. Maybe my life could be more if I tried to make something of it. The lost potential bothers me.” – Woman, 21

I am not as proactive as I could be when seeking employment, and I very rarely ask anyone out even if I'm interested in them. – Transgender, 20

“I have been living independently for almost two years and have a much higher level of self-confidence; less depression and anxiety, hold my own job and pay for all my own bills and take care of myself. I make plans to and attempt to develop and maintain social relationships as well but so far have failed to figure out how to succeed socially and do not yet have any friends.” – Woman, 26

“I don't feel like I have much control over myself. I spend most of my time feeling overwhelmed and over-stimulated by the world, and am usually unable to interact with others to achieve goals. My parents, or sometimes friends, have to act on my behalf. It's humiliating, and I can see that other individuals who don't have the problems I do don't need others to do things for them. I had to drop out of college and move back in with my parents because I was unable to manage myself or live independently. My non-autistic friends didn't have to do that. I feel that I could definitely be self-determined with my autism, but I don't know how.” – Woman, 23

Not sure how to explain it as I'm not really good at explaining stuff – Man, 27

“I need to assert myself more to get what I want and need”- Transgender, 19

Similarly, participants' responses also reflected either progress or moving forward into adulthood (17%) whereas a handful of individuals expressed that their current situation is static (8%).

“I feel as though I am stagnant and absolutely need someone to guide and supervise me, which makes me feel guilty. I would like to rely on myself more to be a functional individual and to develop skills/pursue my interests.” – Transgender, 24

“I believe that self-determination has helped me grow, especially in these past two years where I have lived on my own and have had to work on my Major Research Essay.” – Woman, 23

“Without self determination I can't move forward in my life, there won't be my parents with me always” – Man, 24

“It will help me stay on track and be able to move forward.” – Woman, 25

Although motivational theory is the foundation of the literature on SD, a minority of participants demonstrated learned helplessness (9%) and hopefulness (8%).

“The ability to internally motivate one's self is vitally important, because being entirely reactive vastly limits the ability to live a fulfilling life.” – Man, 18

“Without the drive and motivation to accomplish something, one cannot expect to meet any of their goals. Drive is a very powerful tool, and this alone can be used to accomplish almost anything.” – Man, 18

“The things that I want (or might want) require effort, like a good job and relationships.” – Woman, 24

“When you are self-determined, you can develop yourself based on your own self-knowledge, which would be better than anyone else's knowledge of you. This would enable you would design the best goals and plans for yourself based on this self-knowledge. I feel that studying what I was interested in (and motivated) has allowed me to achieve very highly in my academic career. As a result of my motivation and passion, I was able to extend the topic of my studies to professional development activities that also helped me understand my academic materials as well as build skills and confidence for my future pursuits. Also, self-knowledge helped me understand what interest I should focus on for my career of choice.”- Woman, 24

“Yes it would make me more confident and confidence would give me to motivation to do things because I would believe I could do them instead of thinking I am not capable and therefore setting no plans for myself.” – Woman, 23

“I think self-determination would help for me to be successful. When I am determined to do something, and have the focus to do it I can often be able to work on something for hours at a time. However, I often am not very self-determined, or I forget about something to do, and therefore it never gets done.”- Woman, 26

“I think self-determination has played a pretty big role in the successes I've had so far in adulthood. I've faced a lot of adversity, but I've always been determined to reach my goals no matter how hard it's been. I'm pretty stubborn and I don't give up easily. Despite the challenges, I feel I've been able to accomplish a lot and feel I've come a long way.” – Woman, 29

“Taking charge of my own life and doing what I think is best has already gotten me much further than feeling helpless and letting the opinions of others determine my decisions.” – Woman, 21

“If I was more self determined I'm pretty sure it would make me more motivated to be more successful and I wouldn't be so down all the time” – Man, 19

There was also some mention of factors that hinder their success in adulthood in relation to SD. Mental health was a frequent barrier (10%), which is not surprising given the prevalence of mental health in this population. Of particular interest were the systemic influences (5%), such as societal expectations at work, and other individuals' attitudes (10%). Finally, a small proportion of participants (5%) reported that having been provided with opportunities have or would have helped them in adulthood.

Barriers and Facilitators

RQ6: *What are the self-perceived barriers and facilitators that impact the development of SD?*

The factors that hinder and facilitate the development of SD are presented in Figures 3 and 4, respectively. The vast majority of participants reported the following barriers to developing SD: do not have the skills (68%), mental health issues (65.6%), no support network (59.2%), stereotypes about disability (58.4%), no opportunities or choices available (56.8%), and societal perceptions about disability (56.8%). Other barriers noted included: lack of flexibility in allowing other to help/support (49.6%), and early educational and life experiences have not prepared (29.6%). Only one person reported that the lack of financial assistance and transition support programs serve as a hindrance.

With regard to the most prevalent facilitators noted, participants reported the following: possess the skills required (80.8%), having a support network available (79.2%), being provided with opportunities and choices at a system level (77.6%), other individuals providing me with opportunities to make my own decisions (62.4%), no stereotypes about my abilities (57.6%), have adequate early educational and life experiences that have prepared me (55.2%), and being flexible to allow others to provide help and support (50.4%). Other facilitators included: not having a mental health issue (45.6%) and societal perceptions about disability (40.8%). A couple of individuals reported that having financial assistance, access to transition services, and not having to self-disclose their diagnosis would help with developing their SD.

Taken together, it is apparent from the participants' perceptions that skill and capacity development is an important factor to developing SD. Another valuable factor was having a support network. A common barrier was mental health challenges in adulthood. At a societal or

systems level, participants noted that stereotypes about their ability or disability impact their development of SD.

CHAPTER 5: DISCUSSION, IMPLICATIONS, AND CONCLUSIONS

The aim of this study was to add to the literature base regarding SD among individuals with ASD, while also suggesting topics for consideration when providing support to this population. This chapter will provide a brief recap of the entire study, with particular emphasis on the findings as they related to the purpose of the study and to the existing literature. Following the discussion, the limitations, implications, and recommendations for future research and practice will be presented.

Summary of Findings by Research Question

The purpose of this study was to examine SD in young adults with ASD, with a particular emphasis on giving a voice to participants by reporting on the importance of SD in adulthood. This study makes several contributions to the literature addressing SD among young adults with ASD. The findings indicated that young adults with ASD reported lower mean levels of SD relative to their peers with ID and other disabilities indicated in the literature. However, young adults above 23 years of age with ASD in our study who were more educated reported higher levels of SD. This suggests that age and education play a significant role in the promotion of SD, whereas the findings revealed that gender, living situation, and employment status was not significant. A hierarchical multiple regression analysis indicated that a person's age, SD capacity, and importance rating predicted higher levels of SD. Furthermore, mean SD satisfaction scores were lower than their mean SD importance scores, which have implications for intervention. A thematic analysis demonstrated major SD-related themes associated to success in adulthood, including capacity, perceived control, knowledge of strengths and

weaknesses, attaining adult outcomes, and support. Factors that facilitated or hindered participants' SD included SD skills, mental health, societal perceptions about disability, support network, opportunities, and early educational and life experiences.

Level of Self-Determination. One of the most prominent factors to receive attention in the SD literature is disability category and/or the characteristics associated with specific disability categories, such as IQ, adaptive behaviour, and support needs (Shogren, Kennedy, Dowsett, Villarreal, & Little, 2014). Although the current study did not sample comparison groups to investigate difference across disability category or typically developing adults, the mean levels of SD in the current sample were compared to those in the literature. Particularly, young adults with ASD reported lower overall levels of SD relative to normative and comparable samples on the *SDS* (Chou, 2013; Wehmeyer, 1995; Wehmeyer et al., 2007) and the *AIR* (Chou, 2013). That is, young adults with ASD in the current study appear to have lower mean levels of SD compared to those with other disabilities (e.g., ID, learning disability) represented in the literature. This was especially true for the *Autonomy* domain (on the *SDS*), with our participants scoring much lower than the comparison samples in the literature. However, our sample reported higher mean levels of *Self-Regulation* (on the *SDS*) and *Opportunity* (on the *AIR*) indicating that although our participants possess limited SD, they noted having more opportunities to develop skills and knowledge related to SD than samples of individuals with disabilities in the literature.

The current findings corroborate recent research revealing lower levels of autonomy in individuals with ASD (Chou, 2013; Chou Wehmeyer, Palmer, & Lee, 2016). In a study of 95 middle and high school students, aged 13 through 22 years, Chou (2013) found that students with ASD had lower levels of autonomy when compared to students with learning disabilities (LD).

An extension of this study sampled 222 students with ASD, ID, and LD between 13 and 22 year in the United States (Chou, Wehmeyer, Palmer, & Lee, 2016). Using a multivariate analysis of covariance, the findings revealed that students with ASD had significantly lower levels of autonomy compared to students with either an ID or LD. Contrary to our findings of higher levels of self-regulation, research has shown that students with ASD had significantly lower levels of self-regulation and self-realization than students with LD (Chou, Whemeyer, Palmer, & Lee, 2016). Interestingly, self-regulation skills have been empirically shown to have a positive association with classroom involvement (Agran et al., 2005), academic performance (Uberti, Mastopieri, & Scruggs, 2004), and problem solving skills (Palmer, Wehmeyer, Gibson, & Agran, 2004), which may relate to the reportedly higher levels of education in the current sample.

Taken together, these findings suggest that individuals with ASD may have a different profile of SD relative to individuals with other disabilities. That is, a person's support needs may influence his or her capacity for SD (Wehmeyer & Garner, 2003). The lower mean levels of SD reported by young adults with ASD in the current study demonstrate the need for support in the area of SD. We know that all students can develop SD when they have access to appropriate supports and accommodations (Wehmeyer & Garner, 2003). Though, to provide appropriate supports and accommodations, caregivers and educators must understand the individual and environmental factors that affect relative levels of SD.

Demographic variables and SD. Considering the individual and environmental factors that impact SD can inform future efforts to design, validate, and implement interventions and provide guidance in creating environmental conditions and supports that promote SD (Algozzine, Browder, Karvonen, Test, & Wood, 2001). In the current study, the findings indicated that there are significant mean differences between participants' level of education and age and their

perceived levels of SD, with older and more educated individuals reporting higher levels of SD. Although there was no significant mean difference between participants' employment status and their level of SD, there was a trend indicating that young adults who were employed generally reported higher levels of SD. Finally, these differences in SD did not exist based on the participants' gender or living situation.

Post-secondary education. The findings revealed that young adults with ASD who were more educated reported higher levels of SD. Further, the vast majority of the sample attended post-secondary education; however, over a third of participants reported having discontinued college. Evidence has indicated that the rate of completing post-secondary education in young adults with ASD is low (Van Bergeijk, Klin, & Volkmar, 2008; Wei, Yu, Shattuck, McCracken, & Blackorby, 2013). For instance, Wei et al. (2013) noted that students with ASD in the US experience low rates of college enrolment than all disability groups with the exception of those with an ID. These findings have been corroborated in other studies, with over 50% of young adults not being in education during the initial years following secondary school (Shattuck et al., 2012). Similar rates are noted in the UK (Howlin et al., 2004). Many students with ASD are intellectually capable of completing their studies but end up dropping out because of excessive stress (i.e., self-regulation), poor daily living skills, high dependence on families, and social skill difficulties (Glennon, 2001; Howlin et al., 2004; Jobe and White, 2007; Van Bergeijk & Volkmar, 2008).

Although social skills are a commonly investigated variable in research of educating students with ASD (Beaumont & Sofronoff, 2008; Bellini, Peters, Benner, & Hopf, 2007; McConnell, 2002; Sansosti & Powell-Smith, 2008), they are only moderately correlated with overall levels of SD (Faherty, 2000; Fullerton & Coyne, 1999; Nota, Ferrari, Soresi, &

Wehmeyer, 2007; Pierson, Carter, Lane, & Glaeser, 2008). In the current sample, the social skills domain of the *AQ* was negatively correlated (ranging from weak to moderate) with the *SDS* and *AIR* (-.219 and -.312, respectively), suggesting that more social difficulty was related to lower levels of SD. It seems plausible that the social skills required to successfully navigate school responsibilities and environment may impact SD significantly, such that there may be limitations in autonomous functioning resulting from the social interaction difficulties.

Employment status. Although employment status was not a significant factor in the current study, it is possible that the relationship is reversed such that it is SD that predicts better employment outcomes. In fact, research has shown that SD at the end of high school significantly predicts more positive employment and career goals in individuals with ID (Shogren, Wehmeyer, Palmer, Rifenbark, & Little, 2015). Given the rates of unemployment and underemployment in individuals with ASD (Ballaban-Gil et al., 1996; Eaves & Ho, 2008; Howlin et al., 2004; Shattuck et al., 2012), including the similar rates found in the current sample, it was surprising that employment status was not significant. However, this may be due to the limited range, as the vast majority of participants' reported no or low employment. Researchers have also defined employment not simply by having a job, but rather by the number of hours worked, wages, and benefits (Shogren et al., 2015). Therefore, our current findings may also be explained by how employment was conceptualized and measured relative to other studies in the literature.

Age. Similar to Wehmeyer's (1996) study, the current study found that age was a significant predictor of SD, where SD scores increased as a function of age. However, other researchers have found contradictory evidence (Nota, Ferrari, Soresi, & Wehmeyer, 2007; Wehmeyer & Garner, 2003). For instance, Wehmeyer and Garner (2003) found that age did not

predict the membership in a high or low SD group for adults with ID. Age did predict membership in a high or low autonomy group, with older individuals more likely to be in the high autonomy group. Despite the current findings, we don't know what aspect of getting older helps to promote SD, when most individuals with ASD across the lifespan are still facing the same life circumstances (i.e., employment, education, living situation). Additionally, the absence of an ID in our sample could have impacted the findings; however, other researchers have found that cognitive functioning is not a significant predictor of SD (Wehmeyer & Garner, 2003).

Gender. Our findings revealed no significant difference in SD across gender, although the trend in the data suggests that women reported the highest levels of SD followed by men and transgender. Nevertheless, the existing data pertaining to differences in SD by gender is limited and mixed. Similar to our findings, Wehmeyer (1996b) found no significant differences between men and women on overall SD scores, although women scored higher than men with ID and LD. Other researchers have found gender difference in relation to SD, such that women with ID had higher SD scores than men (Nota, Ferrari, Soresi, & Wehmeyer, 2007). In an Italian sample, however, men tended to show higher levels of SD than women (Soresi, Nota, & Ferrari, 2004). However, Wehmeyer and Garner (2003) also found no differences on SD scores by gender for 300 individuals with ID. Relevant to the results of the current study, it is important to recognize that there is an increasing population of individuals with ASD who are experiencing gender dysphoria and gender variance, or the feeling of incongruence between their assigned sex at birth and their gender identity (De Vries, Noens, Cohen-Kettenis, van Berchelaer Onnes, & Doreleijers, 2010; Janssen, Huang, & Duncan, 2016). For instance, De Vries et al. (2010) examined the rates of ASD in a sample of 204 children and adolescents referred to a gender

identity clinic and reported a 7.8% incidence of ASD. These trans individuals with ASD might experience SD in varying ways, and should further be considered.

Living situation. Living situation did not indicate significant differences in SD scores in our sample. This was surprising given that we know that living environments have an impact on SD (Stancliffe et al., 2000; Wehmeyer et al., 1995). Wehmeyer and Bolding (2001) measured SD in individuals with ID before and after they moved from more restrictive environments. There were significant changes on measures of SD, goal setting, and choice-making after the move. Given the high dependence on families that was reported in the current sample (i.e., living with parents), it was expected that young adults with ASD who reported living independently would demonstrate higher levels of SD on the *SDS* compared to those living with their parents. However, this was not the case. Given that the vast majority of participants reported living with their parents or caregivers, perhaps families are better equipped to support SD of their sons and daughters (Wehmeyer, 2014). This might have impacted the varying level of SD reported across living environments. Further research into the role of the family in promoting SD is required, especially as little is known about the context of caregiving by parents of adults with ASD (Krauss, Seltzer, & Jacobson, 2005).

Individual and environmental predictors of SD. There has been a greater emphasis on investigating the impact of individual and environmental factors on SD in recent years (Walker et al., 2011; Wehmeyer, et al., 2011). Individual and environmental factors are important to identify as they likely play a role in the development of SD and may interact with interventions to promote SD. This suggests the value of these factors in designing effective interventions that address the unique support needs of young adults with ASD. The current study's hierarchical multiple regression sought to investigate whether level of SD importance predicts SD above and

beyond individual (i.e., age, gender, education, capacity of SD) and environmental (i.e., opportunity) factors. The results revealed that age, capacity, and importance explained 50.1% of the variance within SD, with age and capacity explaining the most variance.

Capacity building has always been a central focus in the provision of services to individuals with disabilities, including those with ASD. Using the *SDS*, Shogren et al. (2007) revealed that capacity was a strong, positive predictor of SD. The literature, combined with the findings from the current study points to the critical importance of capacity development as proposed by the functional theory of SD. Similarly, a central theme of the self-determined learning theory is that individuals who are more self-determined have greater capacity to frequently learn about, deal with, adjust to, and shape different circumstances and experience favorable opportunities for producing SD. Individuals who are more self-determined seek out, create, or are provided with frequent opportunities to engage in self-determined behaviours (e.g., goal setting, choice making, decision making, problem solving, self-advocacy), while these opportunities, in turn, provide the context within which students can further refine their SD behaviours (Mithaug, Mithaug, Agran, Martin, & Wehmeyer, 2003). That is, capacities and opportunities for SD affect prospects for SD. However, in accordance with the current findings, opportunities did not significantly predict SD, which may be due to the higher reported mean level of opportunities. Research is critically needed to better develop our understanding of these aspects of SD. Nevertheless, building capacity in young adults with ASD is imperative; as such, more services are required that target these skills.

Finally, participants' SD ratings of importance significantly predicted SD. However, importance only uniquely explained 1.7% of the variance in the model. Although importance was significant, the low variance might be related to the fact that though young adults with ASD

are indicating the significance of SD in their lives, they might not have reported higher levels of SD. Consequently, the quantitative methods of analysis may not be capturing the significance of values nor their importance in predicting SD. A qualitative analysis is warranted to further explore this relation. Nevertheless, considering the importance placed on SD is significant, as it might better capture individuals' expression of SD. Exploring individuals' values or importance for SD is critical to better understanding SD among individuals with disabilities, including ASD (Shogren & Turnbull, 2006; Wehmeyer & Garner, 2003).

Importance and satisfaction ratings and SD. The vast majority of participants in the current study reported high levels of importance and satisfaction in relation to their SD. However, participants' mean satisfaction scores were lower than their importance scores. The majority of participants indicated that they regarded SD as important, with half of these individuals indicating that they were satisfied, while the other half were not satisfied. Fortunately, only a small portion of individuals noted that they were not satisfied with their current level of SD, which they viewed as unimportant.

These findings demonstrate a need for services for young adults with ASD in the areas of SD, while also requiring more research on the measures of SD as many items on the *SDS* were found to be unimportant to participants. This is important given the lack of voice of individuals with disabilities in research on SD as researchers have generally been interested in caregivers', educators' and paraprofessionals' value in promoting SD (Cooney, 2002; Carter et al., 2013; Stang, Carter, Lane, & Pierson, 2009; Carter, Sisco, & Lane, 2011). This is not only the case in Canada or the US, but occurs across the world. For example, UK researchers reported a significant disconnect between the researcher priorities of funding agencies and the needs of individuals with ASD and their families (Pellicano, Dinsmore, & Charman, 2013). Specifically,

individuals with ASD and their families reported that they were not involved in research and frustrated that research efforts were not focused on things that were important to them, such as intervention for life skills and services to more effectively support a range of needs across the lifespan (Pellicano, Dinsmore, & Charman, 2013). Further research is warranted to better bridge the gap between research and practice, while emphasizing the voice of all stakeholders involved in the lives of individuals with ASD.

The benefits of SD and success in adulthood. The results of the qualitative analysis yielded a number of major themes, including capacity, control, knowledge of strengths and weaknesses, adult outcomes, and support. There were also a number of subthemes including: perspective, motivation, progress, barriers, and opportunity. These themes are particularly germane to the daily lives of individuals who have ASD. In reviewing the themes and subthemes that emerged from participants' responses, it is evident that the current study reveals qualitative support for the existing SD theories in the literature, including Wehmeyer's functional theory of SD, Wehmeyer, 1992; 1995), the self-determined learning theory (Mithaug et al., 2003; Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994), and the SDT (Ryan & Deci, 1980; 1985; 2002b).

Capacity. Similar to the abovementioned quantitative results, capacity was reported to be helpful to participants' success or lack of success in adulthood. Goal setting and attainment, a component of most SD theories, was the most frequently reported area valuable to participants in order to obtain positive outcomes in adulthood. This is consistent with the literature on SD-based interventions (Abery et al., 1995; Cho, Wehmeyer, & Kingston, 2010; Halpern et al., 1997; Martin & Marshall, 1995; Mithaug, Wehmeyer, Agran, Martin, & Palmer, 1998). For instance, in a study of 407 elementary school teachers, goal setting was perceived as an

important skill to teach students (Cho, Whemeyer, & Kingston, 2010). Goal setting and attainment require individuals to identify and define goals that are clear and measurable, develop a series of objectives to achieve the goal, and specify and conduct the actions necessary to achieve their goal. Dealing with new situations and processing complex information are areas of difficulty for individuals with ASD (Minsheu, Meyer, & Goldstein, 2002), which also happen to be common occurrences when functioning independently in everyday life. In fact, research has suggested that individuals with ASD are more sequential in their goal-directed behaviours and have trouble engaging in multiple goal-directed activities, often shifting from activity to activity in the goal attainment process (Ruble & Scott, 2002).

Although capacity building is imperative, it is not to say that individuals with ASD require prerequisite skills in order to be self-determined (Browder, Wood, Test, Karvonen, & Algozzine, 2001). Despite the fact that self-determination requires many academic, cognitive, social, and language skills (that may be core difficulties for individuals with ASD), conquering these skills is not a prerequisite to becoming self-determined (Browder et al., 2001). That is, all individuals have the right to be self-determined and proper efficacious interventions can be successful in promoting SD. For instance, complex goals could be broken down into smaller, sub-goals for the individual to complete in less time and fewer steps (Whemeyer et al., 2010). Wehmeyer and Schalock (2001) stated that professionals should include individuals with disabilities in their educational planning and decision-making while focusing on identifying and describing specific goals, implementing plans and taking actions to achieve the goals, and self-monitoring progress towards goals.

Locus of control. Locus of control has been defined by a person's expectation of a specific reinforcement in a situation is dependent more on their attitude toward the situation

rather than the situation itself (Rotter, 1996). Particularly, individuals who perceive having control over the outcomes in their life tend to have greater action capacity than individuals who perceive external forces as having control over the outcomes they experience (Shogren et al., 2006). The lack of control over many aspects of our daily life and the inability to affect future goals and planning has directly been associated with increased risk for psychiatric disorders and other mental health problems, including depression and learned helplessness (Clark, Olympia, Jensen, Heathfield, & Jenson, 2004). This included not only that lack of control over important aspect of one's life regardless of one's ability level, but also the perception of loss. Additionally, perception of loss of control has negative implications on self-esteem and self-concept (Clark et al., 2004). In fact, co-morbid mental health issues, such as depression, are associated with reduced independence among individuals with ASD (Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010; Gillberg & Billstedt, 2000).

Participants in the current study reported that having control is equated to SD and success in adulthood. A significant portion of young adults with ASD described having less adaptive perceptions of control or efficacy (others having control over their lives), which may be associated with the reported mental health concerns in this sample. Approximately half of the sample reported official diagnoses of depression (44.8%) and anxiety (59.2%), as well as other mental health issues (e.g., OCD, ADHD, LD, Bipolar). However, with increases in personal choice and control, psychological health can be enhanced and maladaptive behaviours decreased (Taylor, Kemeny, Reed, & Bower, 2000). Nevertheless, some participants also alluded to being hopeful, referring to Zimmerman (1990) who noted "learned hopefulness" to focus on positive psychological aspects of perceived control and empowerment, which is part of the SD construct (Wehmeyer, 1996).

Self-awareness and knowledge. Self-awareness or knowledge of participants' own abilities was also frequently reported in the current study. Understanding one's strengths, abilities, learning style, support needs, and limitations, as well as using this knowledge to increase success and growth is imperative (Whemeyer et al., 2004; Whemeyer et al., 2010). Expressing personal preferences, making autonomous decisions based on those preferences, and assuming personal responsibility for the course of one's life choices are expressions of freedoms most of us enjoy. For individuals with ASD, however, this experience can be very limited at best (Clark et al., 2004). Despite the current service provisions that have advanced, there remains the inherent, but often unstated, beliefs that individuals with ASD (and disabilities in general) cannot make appropriate choices in important areas of lives. This belief often skews individuals with ASD' perceptions about themselves and influences how they interact with their environment (Wehmeyer et al., 2010).

Self-knowledge is an important aspect of growing older and developing SD. For example, Fullerton and Coyne (1999) conducted pre-post intervention assessment with 23 youth and young adults with ASD and revealed that self-knowledge regarding ASD and coping skills for sensory, cognitive, and social challenges play an important role in the development of SD. This self-awareness and knowledge of abilities and limitations was also highlighted in Faherty's (2000) approach that emphasized guiding students to understand the impact of their disability as well as to support their transition planning and goal setting and attainment. The value of self-knowledge has been echoed in the education literature with a focus on strengths (Lehr, Johnson, Bremer, Cosio, & Thompson, 2004) and strength-based transition planning and instruction (Trainor, 2007). Wehmeyer et al. (2004) explained that individuals with disabilities' "understanding of one's strengths and limitations together with a belief in oneself as capable and

effective are essential in self-determination” (p.414). Accordingly, Wehmeyer et al. believe that when people act on the basis of these skills and attitudes, they possess a greater ability to take control of their lives and assume the role of successful adults in society (p. 414).

Positive adult outcomes. In the current study, the vast majority of participants noted how SD could help them attain positive adult outcomes, such as employment, education, and interpersonal relationships. This perception corroborates the existing literature demonstrating the positive benefits of being a self-determined individual in academia (Konrad, Fowler, Walker, Test, & Wood, 2007; Fowler, Konrad, Walker, Test, & Wood, 2007; Lee, Wehmeyer, Soukup, & Palmer, 2010) and transition outcomes, including more positive employment and independent living (Martorell, Gutierrez- Rechacha, Pereda, & Ayuso-Mateos, 2008; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1997). Benefits have also been found in regards to recreation and leisure outcomes (McGuire & McDonnell, 2008), community involvement and increased individual success (Hendricks & Wehman, 2009), and more positive quality of life and life satisfaction (Wehmeyer & Schwartz, 1998; Lachapelle et al., 2005; Nota, Ferrari, Soresi, & Wehmeyer, 2007; Shogren, Lopez, Wehmeyer, Little, & Pressgrove, 2006). Consequently, promoting SD might be best recognized as a means to enhancing the lives of individuals with ASD, especially as they transition into adulthood.

Support level. The young adults with ASD in the current study also frequently mentioned the significance of receiving supports from the people in their lives and their role in the development of their SD. It is not expected or required that individuals with or without ASD accomplish these daily skills alone. Neurotypical or not, it is important to have support systems. In fact, you can still act in a self-determined fashion while requiring help or support to problem solve, make decisions, or attain a goal. Therefore, it seems like the *quality* of support is what

makes a difference. For example, adults with ID identified the quality of interpersonal relationships formed with support staff impacted SD (Nonnemacher & Bambara, 2011). Specifically, if the adults with ID viewed their relationship with the support staff as positive, it allowed for a context that made it easier for supportive actions (e.g., initiating help, sharing information, being receptive to guidance) to shadow (Nonnemacher & Bambara, 2011). There should be a balance in support and independence, as limited independent performance and an overreliance on prompts and feedback are also hindrances to developing SD (Hume, Loftin, & Lantz, 2009).

Subthemes. There are also a number of subthemes that emerged from the data, including motivation, systemic barriers, and a lack of opportunities. However, the most prominent subtheme was individuals' overarching perspective or view in their responses. In line with locus of control, participants' responses were coded as either positive (i.e., optimistic thinking) or negative (pessimistic thinking). Research suggests that individuals' outcome expectancies are critical to the performance of goal directed behaviours, which is consistent with existing SD theories (Wehmeyer, 1992; 1995). Individuals with high hope, or optimists tend to be more successful in attaining their goals and experience more positive emotions, whereas individuals with low hope, or pessimists tend to have more difficulty attaining goals and therefore experience more negative emotions (Carver & Scheier, 2002, 2003; Lopez, Snyder, & Teramoto-Pedrotti, 2003; Shogren et al., 2006; Snyder et al., 2002). It has been suggested that individuals' perspectives on intrinsic motivators prompted their growth into self-determined adults (Hogansen et al., 2008). That is, individuals with disabilities have noted that it's important to believe in self as a necessary precursor to SD.

Self-perceived barriers and facilitators of SD. A number of factors were reported as facilitating or hindering participants' SD: SD skills, mental health, societal perceptions about disability, support networks, opportunities, and early educational and life experiences. The most prevalent factors that facilitated their SD were the exact opposite of what individuals noted as barriers, implying probable value as factors in the promotion of SD in young adults with ASD. It is apparent from the participants' perceptions that skill and capacity development is an important factor in promoting SD. That is, participants' beliefs in their capability versus inability impact their self-determined behaviours. In addition to the difficulties related to their disability, individuals with ASD face additional limitations in their environments due to the barriers that others create. This is consistent with the perceived factors that facilitate or hinder the SD of adults with physical disabilities (Stoner et al., 2006), demonstrating the potency of the social construct of disability. Moreover, Thoma, Nathanson, Baker, and Tamura (2002) noted that it is important to remember that the attainment of SD requires not only that people with disabilities develop their SD capacity, but that society support and respond to them as well.

Historically, individuals with disabilities have had less power in society, and have been forced to take lower paying jobs, live in less desirable situations, and accept lower social statuses than those without disabilities (Clark et al., 2004). Although catalysts such as the normalization and self-advocacy movements influenced these perceptions and provisions, further changes in regards to our beliefs, attitudes, and organization of systems in the field of ASD could aid in promoting SD, by enabling more choices, positive behaviour supports, and opportunities to practice SD-related skills. Although this seems like a rational and reasonable solution, there remains much education to be taught about providing support to or working with young adults with ASD across multiple environments (e.g., education, employment).

For instance, research has shown that teachers believed that their students with more severe disabilities would not benefit from instruction to promote SD because they lacked the capacity to learn and practice self-determined behaviours (Carter, Lane, Pierson, & Glaeser, 2006; Shogren et al., 2007; Wehmeyer, Agran, & Hughes, 2000). Angell, Stoner, and Fulk (2010) examined the views of 12 adults with physical disabilities and their experiences of SD in the education system. These adults noted many attitudinal barriers such as low expectations of education professionals contributing to feelings of isolation, insufficient accommodations, or inadequate educational planning and perceptions of isolation. Furthermore, Hogansen, Powers, Geenan, Gil-Kashiwabara, and Powers (2008) have identified factors such as self-perception, mentors, peers, family, and exposure to opportunities that shape students with disabilities' transition goals and influence their attainment of these goals. Even those with ASD without an ID have recounted that having a "non-obvious diagnosis" is associated with numerous daily and long-term risks that hinder positive outcomes (Portway & Johnson, 2005). Specifically, the subjective experiences of adults with Asperger's syndrome noted that the misunderstanding of others, being misunderstood, isolation and loneliness, exploitation, and being ostracized are daily risks that occur, while more long-term risks included underachievement, prolonged dependency on parents, and mental health problems (Portway & Johnson, 2005).

Similarly, as young adults with ASD transition to adulthood, employers' attitudes will be one of the biggest barriers to successful employment (López & Keenan, 2014). Nesbitt (2000) found that 58% of employers who indicated that they were not hiring individuals with ASD, shared some common reasons including being focused on an employee's ability to work in an established way, emphasis on an employee's ability to adapt, concern for potential negative effects, and less open to new information. Aside from the accommodations needed, employers

have also noted a reluctance involving third parties' support (Richards, 2012). It is suggested that knowledge of ASD and self-reflection of attitudes and biases might mediate the low employment rates, while offering opportunities for young adults with ASD to enhance their SD. Our society could provide more support for mental health services, removing stigma and stereotypes about the disability, and allowing our interactions with individuals with ASD to better serve our judgment of their abilities rather than automatically assume their disabilities. This will enable society including its individuals (i.e., parents, educators, employers) to provide opportunities for this population to become self-determined and have a voice in decisions and choices made about their life.

Limitations

Despite the strengths and potential utility of the results of the current study, the limitations should be highlighted as they might impact the findings as well as the generalizability of these findings. A limitation of the study was the lack of standardized diagnostic assessments of an ASD or confirmation of participants' cognitive functioning (i.e., no intellectual disability). Although the *AQ* was employed to help remedy the accuracy of the sample, the findings may not be representative of young adults with ASD. However, the *AQ* has been shown to have good discriminative validity and good screening properties for those with Asperger Syndrome or high functioning autism at a threshold score of 26 (Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005).

In terms of confirming IQ without the use of standardized assessments, demographic questions were devised to capture level of support needs. Questions included directly asking participants if they had an ID and to report on variables such as level of education, support level, and mental health. In the current sample, the cross-tabulations of these variables indicated that

the higher support levels described might not reflect participants' daily living skills (which are used to indicate an ID), but that these participants might have more complex needs in areas of mental health, education, or learning. Research has shown that individuals with ASD without an ID face a multitude of co-occurring mental health, psychosocial, and functional issues, all of which occur in addition to the core difficulties in ASD (Dillon, 2007; Lake, Perry, & Lunsky, 2014). Furthermore, along with these complex needs, it is possible that adults with ASD without an ID have low adaptive skills (Saulnier & Klin, 2007), which might also explain the higher levels of support expressed.

Another limitation includes the lack of a comparison group of young adults without an ASD. Including a comparison group of young adults who were neurotypical or had another disability (e.g., LD, ID) would have allowed for better understanding of SD. This information would also have enabled a closer examination of how young adults with ASD responded on the importance ratings of the *SDS* may differ from the importance ratings of those without ASD. Differences in ratings would have implications for measurement development and how we conceptualize SD for different disability groups.

Probable limitations related to the generalizability of the findings include non-response bias, sampling bias, and the use of qualitative analysis. The current sample of young adults with ASD without an ID might be frequent Internet users, such that the population and sample is limited to those with ready access to a computer and to an online network. The researcher attempted to remedy this by outlining accommodations available, such as a paper copy of the survey. One participant requested a paper copy but did not return it. Also, participants were made aware of the accessibility features (e.g., read out loud questions) offered when using the survey on Survey Monkey. Sampling bias, or the systematic error due to a non-random sample,

is inherent in survey studies and might have impacted the findings of this study. For instance, a portion of the sample was recruited from Cégep and University Offices for Students with Disabilities, which might explain the differences in SD based on level of education completed. Although a unique contribution of this dissertation was to include the voices of young adults with ASD in furthering our understanding of SD, the qualitative findings are uniquely tied to the participants' experiences and should not be generally applied to other individuals.

The nature of the method, an online survey, may have also restricted or confounded the findings. As such, IP addresses were screened prior to providing compensation as some participants may have attempted to complete the survey more than once. Additionally, participants were also screened for fast completion times. That is, “zoomers”, or individuals who complete the survey in less than 15 minutes, were excluded from the study. There may have also been lower levels of confidentiality. Due to the open nature of most online networks, it is difficult to guarantee anonymity and confidentiality, especially given that an electronic response is never truly anonymous since e-mail addresses were required.

Finally, one of the most important limitations was reduced response rate. Due to the nature of the method, there was potential for technical problems. Such problems may have reduced the response rates, as a significant portion of participants had started the survey but never fully completed it in its entirety.

Implications for Theory

The findings of this research support and corroborate the existing theoretical frameworks of the functional theory of SD (Wehmeyer, 1992; 1995) and the self-determined learning theory (Mithaug et al., 2003; Wolman, Campeau, Dubois, Mithaug, & Stolarski, 1994). Specifically, the qualitative findings allude to the various components or domains of the two theories, as well

as to how we might help young adults with ASD be successful in adulthood. A crucial theme of the self-determined learning theory is that individuals who are more self-determined have a greater ability to learn, deal, adjust, and shape different situations as well as experience opportunities for developing SD. In line with the functional theory of SD, the vast majority of the participants in the current study mentioned one or more of the essential characteristics (e.g., behavioural autonomy, self-regulation, psychological empowerment). For instance, autonomy, goal setting and attainment, and knowledge of strengths and needs were frequently mentioned. Consequently, the current findings support the existing frameworks in that capacities for SD affect prospects for SD.

Despite these consistencies, further research is warranted to better understand how these theoretical models fit the complex and heterogeneous needs of young adults with ASD. There are a multitude of factors that need to be further investigated prior to exploring possible models for intervention. Participants in the current study highlighted the role of supports and perceived control in promoting SD, as well as various individual (e.g., age, education, capacity, mental health) and environmental (e.g., societal perceptions about disability, support network, opportunities, and early educational and life experiences) factors that impact their SD. Given the history of ID and the previous acclaimed deficit model, much of the SD research has focused on understanding the intra-individual factors, with little emphasis on the environmental conditions that foster SD skills. However, individuals with disabilities have discussed the role of others in fostering their SD by setting and maintaining high expectations, modeling SD behaviours, and providing consistent social support with repeated opportunities (Angell, Stoner & Fulk, 2010). A better understanding of how the various layers of a system impacts the SD of individuals with ASD is warranted, especially given the inherent social communication and interaction

difficulties. As such, it is not unforeseen that Bronfenbrenner's ecological model (1977) has played a significant role in the empirical understanding of ASD and the provision of services and supports (Woodman, Smith, Greenberg, & Mailick, 2015). Bronfenbrenner recognized that the developing individual is embedded within multiple layers of context, including family, school, and community (1979, 1992), even those with which the individual may never directly interact might have an influence on the individual. This knowledge would inform theoretical models that could be employed as a foundation to future research, including establishing quality supports at home, school, and the community by changing the ethos and practices to promote SD.

Given the current findings, such models should include not only capacity development and opportunities provided, but incorporate how support should be operationalized within a framework for SD development. That is, we generally define SD as independence, however, given the difficulties young adults with ASD experience, the meaning and milestones of independence versus interdependence need to be understood (Wehmeyer, et al., 2011). For instance, a 17-year-old man in the current study explained, "*A lack of self-determination is frowned upon in this culture. I get criticized a lot for relying on others [...]*". This is especially important given that many young adults with ASD continue to live with and require the support of their parents well into adulthood. Nevertheless, researchers suggest that interdependence can simultaneously emphasize individual autonomy (Rogoff, 2003), implying that the *quality* of the supports is important to developing SD and not the access or lack thereof.

Researchers are beginning to integrate the concept of supports and what those mean in relation to the existing SD frameworks. Wehmeyer and colleagues have published a more recent theoretical framework within a person-environment interaction framework (Shogren, Wehmeyer, Palmer, Forber-Pratt, Little, & Lopez, 2015). This is more relevant to the discussed social-

ecological, as well as to the approaches prevalent in positive psychology. The Causal Agency Theory provides a theoretical framework for developing and enhancing supports for individuals to engage in agentic action through goal setting and attainment to promote SD and QoL across diverse social-contextual contexts (Shogren et al., 2015). Particularly, they emphasize that it is within a person-context interaction that individuals become agents of their own actions.

Nevertheless, further work is needed to examine how this theory and its new essential characteristics apply to individuals with ASD.

Implications for Research

The overall findings, as discussed in Chapter 4, have a direct application to future research. Efforts to refine our understanding of the measurement of SD will be critical to further the development of SD in individuals with ASD across the lifespan, including the factors that impact SD and the interventions to promote it. While the findings in Chapter 4 provided insight into the aspects of SD valuable to individuals with ASD, further work will be needed to enhance our understanding of SD and whether its conceptualization differs from persons with other disabilities.

As indicated, the lack of research on SD and ASD may be attributable to the fact that measures of SD were not normed with students with ASD, and as such, there was uncertainty with regard to their utility with this population (Chou et al., 2016). Recent research investigated the factor structure of the *SDS* with 95 students with ASD, and determined that the measure could be considered useful in measuring SD of students with ASD (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2015). Internal consistencies in the current sample ranged from acceptable to good for both the *SDS* and *AIR*, supporting its use in this population. Given this research, we know that these two commonly used measures are applicable to individuals with ASD.

However, future research should establish if the items on the measures that make up the global construct of SD are important to the lives of these individuals, especially given the volitional nature of SD highlighted in the literature. That is, do the *SDS* and *AIR* fit with individuals with ASD, or do they further hinder or minimize their voice and authentic SD? For instance, a significant portion of the participants in the current research reported that items falling on the autonomy and self-realization domains of the *SDS* were not important to them. If these items are not important to them than it would be expected that they would report lower scores on these items, which would impact their global SD. Consequently, this would under-estimate participants' level of SD despite their volition to not "*use the post office*" or "*keep my own personal items together*", which are items that combine with other to make up the *Autonomy* domain on the *SDS*. Future research could establish how to integrate more objective and subjective measures to combine into a global construct of SD that better reflects the varying needs of young adults with ASD in the area of SD (Flanagan, Nadig, & White, 2016).

Similarly, research has indicated that an individual's personal culture is impacted by multiple factors, such as gender, disability, race/ethnicity, language, and socioeconomic status (Trainor, Lindstrom, Simon-Burroughs, Martin, & Sorrells, 2008). These factors have the potential to affect how individuals express self-determined behaviour, which has relevance not only for intervention design and implementation, but also measurement. In fact, Shogren (2011) reviewed 10 published studies (i.e., empirical, theoretical, and review articles) on the relation between culture and SD. Across the articles, there was consensus that SD, as a construct, had relevance across diverse cultural contexts but the way SD behaviour was operationalized may vary. For instance, Shogren et al. (2013) found that race/ethnicity in combination with disability category impacted youth's relative levels of autonomy, self-realization, and psychological

empowerment. It is probable that ASD in and of itself is a culture that requires a better understanding of how researchers should conceptualize the construct of SD, while incorporating individuals' with ASD importance ratings of SD. For example, Tavernor, Barron, Rodgers, and McConachie (2012) argued that QoL indicators developed and normed across various disability categories may be of less relevance to people with ASD as "their interests and enthusiasms may differ from those of typically developing children, which may affect how they value aspects of QoL identified in conceptual models derived from studies of typically developing young people" (p. 2), or people with other disabilities. Arguably, this perspective also applies to the construct of SD. The identity and experiences of an individual with ASD are diverse, as evidenced by the findings in the current study. Researchers should challenge the normative assumptions that come with having a diagnosis of ASD, as they might experience SD in varying ways across the lifespan.

Implications for Practice

The findings of the current research suggest several practical considerations for practitioners and caregivers supporting individuals with ASD. One of the major findings of this research is that the vast majority of young adults with ASD rate SD as important, but are not satisfied with their current level of SD. Particularly, SD is important to them, yet we don't have the empirically based provisions to support or promote SD. It then becomes imperative for caregivers, educators, and professionals alike to initially recognize the value of SD as a curricular area as they transition into adulthood, and even earlier as many participants noted the impact of early life and educational experiences in promoting SD. As Erwin et al. (2009) noted, "promoting self-determination is an intentional and ongoing process" (p. 28). That is, teaching

and providing opportunities for SD should become the primary focus and embedded across the home, academic, and community settings throughout the lifespan.

Much of the research to date pertains to youth and adults, however, the foundations of SD resides early in life (Lee, Palmer, Turnbull, & Wehmeyer, 2006; Palmer & Wehmeyer, 2003; Shogren & Turnbull, 2006; Wehmeyer & Palmer, 2000). Researchers have recommended that encouraging a supportive social and physical environment as well as active involvement in young children is one of the best ways to promote SD later in life (Erwin et al., 2009). For instance, Erwin and colleagues suggest that practitioners and families collaborate to teach children self-regulate their emotions and activities, be able to make simple choices, engage in problem solving with support, and make decisions about play, friends, and activities that match their interests and capacity.

As children age, the school environment becomes an increasingly salient context for SD development, placing responsibility on teachers and educational staff. Promoting SD in school has been encouraged for many years, and considered the ultimate goal of education (Wehmeyer & Schwartz, 1997). The goals of education for individuals with ASD are the same goals for neurotypical students, that is, to provide opportunities to acquire skills that increase independence and social responsibility (Hendricks & Wehman, 2009). For instance, students with ASD require the acquisition of skills in academics, socialization, language and communication, self-management, SD, daily living, employment, and community (Hendricks & Wehman, 2009). One way to better support SD in the school context is to have students with ASD assume more prominent roles in educational planning. As Carter et al. (2008) suggests that youth with disabilities need to understand and communicate their strengths and needs, setting and working towards self-selected goals, advocating for themselves, and self-assessing their own

progress and outcomes. Nevertheless, the voices of individuals with ASD are least frequently heard or solicited in education. This is adequately illustrated by the current state of affairs regarding student involvement in individual education program (IEP) or transition planning meetings (Wood, Karvonen, Test, Browder, & Algozzine, 2004). The reality for too many individuals with disabilities is that they are often left out of this process. However, researchers and educators are beginning to consider the voice of individuals with disabilities in research (Gilbert, 2004) and education (Arndt, Konrad, & Test, 2006; Pierson et al., 2008; Wehmeyer, Agran, & Hughes, 2000). Arndt et al. (2006) increased the attendance and involvement in the IEP process (self-directed IEP) for five students with developmental disabilities and found a functional relationship between implementation of the self-directed IEP and increases in student participation at IEP meetings (Arndt et al., 2006). Students' voice and involvement in their present and future planning exemplified their increased self-determined behaviour.

Although individualized instructional decisions remain a hallmark of special education services, our descriptive findings call attention to the prospect that young adults with ASD may benefit from additional curricular attention on and explicit instruction on SD components, such as goal setting and attainment. Research has recommended that teachers teach students how to set goals, assist students in self-assessment, support development of an action plan, provide opportunities to practice self-determined behaviour, and guide students in self-reflection (Angell, Stoner, & Fulk, 2010). Evidence-based efficacious interventions are required while considering how implementing SD in educational curriculum may be further complicated by the multitude of other instructional priorities, including the academic, social, and behavioural needs of students with ASD (Wehmeyer, Field, Doren, Jones, & Mason, 2004). As such, it has been recommended that learning opportunities should be infused throughout the day rather than treating it

exclusively as an add-on to the curriculum (Wehmeyer et al., 2004). Therefore making SD instruction an integral part of the general curriculum for all students not just students with ASD, demonstrating a more universal design approach or school-wide positive behaviour supports (Sugai, O'Keefe, & Fallon, 2012). In fact, researchers have suggested that SD interventions move towards a multi-tiered system of supports models that emphasize interventions for all students (Wehmeyer, 2015; Shogren, Wehmeyer, & Lane, 2016).

The supports offered from early childhood into school should be emphasized and fostered as students with ASD transition out of secondary school and into adulthood, as growing older alone does not provide the opportunities to acquire abilities to promote later SD (Erwin et al., 2009). It has been recommended that curriculum focus on increased academic and vocational rigor and functional outcomes, including an increased opportunities for internships and employment (Wehman et al., 2014). In a review of the SD literature, Angell, Stoner, and Fulk (2010) presented a list of traits (e.g., perceived control, perceived competence, assertiveness, autonomy, goal setting and attainment, problem solving, self-regulation) that have been identified throughout the past few decades. They emphasized the importance of promoting these measurable and observable traits would lead to more successful adult outcomes. Caregivers and professionals might best serve as the gateway providers to enhancing SD in the lives of adults with ASD. Family involvement in SD-based interventions is critical, especially given the vast majority of young adults who continue to live with their parents into mid-adulthood (Wehmeyer, 2014). The home environment sets the stage for engaging in choice-making, risk-taking, exploration, and exercising control (Field & Hoffman, 1999; Wehmeyer, 2014). Adults with ASD will require practice to learn confidence and competence in engaging in these self-determined behaviours. For example, adults with physical disabilities reported that observing

and experiencing advocacy was positive and encouraged them to self-advocate (Angell, Stoner, & Fulk, 2010). Consequently, parents can not only provide teaching or coaching but also demonstrate positive modeling on a daily basis.

Another major implication of the findings is that capacity development should not be the only focus when promoting SD. First-hand accounts from young adults with ASD offered valuable insight into the environmental conditions that might facilitate and/or hinder their SD. For this reason, the support network (e.g., parents, educators) of individuals with ASD will require psycho-education and training to respect and honor their decisions and choices across the lifespan. This has also been established in the ID field (Algozzine et al., 2001). Specifically, a two-way paradigm shift was proposed suggesting that the individual with ID and their parents, educators, and professionals undergo training to better encourage and honour the individual's SD behaviours (Algozzine et al., 2001). This two-way paradigm shift would also benefit individuals with ASD and their support network in promoting SD. In fact, researchers have shown the need for more teacher training and support that might increase the likelihood that teachers will implement strategies that promote SD in their students (Lee, Whemeyer, Palmer, Soukoup, & Little, 2008). Further, young adults with ASD would benefit from individualized accommodations and supports in higher education (Smith, 2007), given the impact of education on SD revealed in the current study. Perhaps, enhancing post-secondary or university completion will lead to enhanced SD, which has implications for success in adulthood.

Emphasizing capacity development and enhancing environmental conditions across the lifespan are two important implications of the current findings. The benefits of such supports will not only improve the SD of individuals with ASD, but will have collateral effects on attaining positive adult outcomes, such as employment and relationships; as well as positive

benefits for their well-being and mental health. For these reasons, increasing the SD of individuals with ASD should be an important emphasis of legislative, policy, and research initiatives. For instance, the United States Department of Education, Office of Special Education Programs (OSEP) funded 26 projects to promote SD (Wehmeyer, 1999), in which researchers designed and developed curriculum to promote the SD of adolescents and young adults with ID. In fact, much of the evidence demonstrated the importance of SD as a transition-related practice (Wehmeyer, 2015). Consequently, we need to make significant advances in the area of promoting SD of individuals with all disabilities, including ASD, across the lifespan. Research initiatives such as those provided by OSEP would enable a strong evidence base for the importance of SD to successful school and post-school outcomes within a Canadian context.

Recommendations for Future Research

Given the scarcity of research regarding young adults with ASD in general, and research on SD and ASD in particular, there remains a wide range of possibilities for future research. Larger-scale studies with diverse sample of participants would considerably broaden the perspective on SD. The growing evidence of the value of SD in the lives of individuals with ASD highlights the current need to refine our understanding of SD, and the facilitators and barriers they face with regard to promoting it. A closer examination of the individual and environmental factors that impact SD, in addition to defining a theoretical or conceptual model for identifying factors that influence the development of SD across the lifespan. This knowledge would be an important first step before influencing policy and educational reform legislation in Canada.

Recommendations for Future Practice

There are many practical recommendations that should be considered based on the findings from the current study. First, acknowledge that SD is important to individuals with ASD and their success as they transition into adulthood. Personal accounts from young Canadian adults with ASD revealed the value of SD in achieving success in adulthood. As such, listening to the perspectives of young adults with ASD will better bridge the gap from research to practice while respecting and honoring their voices and values in promoting SD.

Second, it is apparent that advances in research are required to design, implement, and validate strategies that enhance the development of SD for individuals with ASD across the lifespan. Given that research has demonstrated that children learn many aspects of SD over time with the support of others (Erwin & Brown, 2000, 2003; Palmer & Wehmeyer, 2003), it is recommended that adults should facilitate the development of SD during early years (Dolls, Sands, Wehmeyer, & Palmer, 1996; Palmer, 2010; Wehmeyer & Palmer, 2003). In early childhood, families generally make daily decisions regarding the types of experiences and learning opportunities offered, thus mediating and creating opportunities to practice these SD behaviours. However, with age the school becomes increasingly salient in mediating and creating these SD opportunities. Researchers have suggested that general and special education teachers collaborate to infuse instruction in SD into the education of all students, including those without disabilities (Wehmeyer et al., 2004). Families and educators are then encouraged to work together to promote SD skills across the home, school, and community environments (Palmer et al., 2013). Therefore, early intervention in teaching and providing opportunities for SD that match the child's interests and needs should be considered an important practice.

These positive family-professional relationships have been suggested to play an essential role as the mediators of development and vehicles for learning (King, 2009; Turnbull, Turnbull, Erwin, Soodak, & Shogren, 2011). For example, Palmer and colleagues (2013) discussed how children with disabilities benefit from such a collaborative partnership by providing supportive, motivating, and coordinated environments in their Early Childhood Foundations Model of SD. This foundations model suggests that the essential skills for developing SD in adulthood require children with disabilities to develop skills in choice-making, problem-solving, self-regulation, and engagement (Palmer et al., 2013). In accordance with the current study, it is hypothesized that early intervention, based on a model similar to the foundations model, may prevent overdependence, a low sense of self-efficacy, and external locus of control, which all have implications for education, living situation, employment, and mental health in adulthood.

Third, although promoting capacity development across settings is important, the caregivers, educators, employers, and other professionals that support individuals with SD are encouraged to reflect on their own biases and attitudes regarding the capacity of individuals with ASD and undergo in-service or trainings that focus on recognizing SD needs and instruction in ways that make it a part of everyday life and not an add-on. That is, it is recommended that such empirically based interventions not only focus on promoting SD capacity or skills but also center on how to create the environmental conditions that encourage and support opportunities to practice these skills in their day-to-day lives, exemplifying a two-way paradigm shift (Algozzine et al., 2001). This can occur in the context of their home, work, school, or community lives. As voiced by many participants in the current study, societal perceptions about disability or abilities have negatively influenced their perceptions of self, impacting their mental health and well being, including their perceived control and ultimately their SD. Consequently, a model, such as

the Early Childhood Foundations Model of SD (Palmer et al., 2013), that focuses on individual and systemic factors would aid in clarifying service planning and development for children, adolescents, and adults with ASD in Canada.

Recommendations for School Psychologists

School psychologists can play an integral role in enabling the family-professional partnership, and promoting the development of SD among children and adolescents, and even young adults with ASD. This can occur in the context of assessment, interventions and curriculum development, positive behaviour supports, and continued educational reforms and systems change (Clark et al., 2004). Further, implementing more positive psychology approaches to service provisions like multi-tiered supports and universal designs, conducting needs assessments in the areas of SD, offering more choices, and setting aside our biases or perceptions about their abilities would allow for the development of SD.

Researchers have reviewed empirically supported assessment strategies as well as interventions and curricula that have been developed to promote SD in ID populations (Algozzine et al., 2001). These assessments and interventions could be adapted when working with other populations, including individuals with ASD. In regards to assessment, Clark et al. (2004) outlined how school psychologists could conduct preference assessments as well as directly assess SD. Research has shown that incorporating preferences into activities of daily living increases positive behaviours; particularly, choices among a variety of options can help to facilitate the development of autonomy and SD (Clark et al., 2004). Assessing SD directly using standardized measures, such as the *SDS* and *AIR* could be help to identify goals for an IEP. This assessment of SD should also take into account environmental factors including the match

between skills and environment, as well as social, cultural, and familial expectations (Baker, Horner, Sappington, & Ard, 2000).

Interventions promoting SD skills should occur in environments that provide many opportunities for practice and reinforcement (Sands & Doll, 1996), such as in home and school settings. For instance, school psychologists could help support educational staff develop SD intervention strategies and include them in IEP goals. Clark et al. (2004) suggests that school psychologists can help families and other professionals understand how children with disabilities might benefit from opportunities to develop SD. Through these opportunities, students with ASD can learn to communicate preferences, set and attain goals, manage their time, identify solutions to daily problems, self-advocate for accommodations and needs, as well as develop a greater self-awareness (Wehmeyer, Martin, & Sands, 1998). These self-determined behaviours will in turn help to promote feelings of self-esteem, self-efficacy, self-control, and perseverance, which will enable a more active participation in decision making about their learning and demonstrate greater motivation to learn (Clark et al., 2004).

Further, school psychologists can play an imperative role in advocating or supporting educational reforms and system changes. As noted earlier, individuals with ASD without an ID have limited access to services, especially as they transition into adulthood. As such, these individuals will continue to require advocacy to ensure that SD is addressed at home, school and community settings (Clark et al., 2004). With this being said, school psychologists are required to stay informed of the growing literature of evidence-based practice designed to develop, enhance, and support SD across the lifespan (Clark et al., 2004).

Conclusions

Research continues to target diagnosis and early intervention for children, despite the increased need to emphasize on those entering adulthood, especially with respect to promoting SD. SD is hard to develop, as it requires understanding and responding to the expectations of individuals in your life, while also asserting your own ideas and decisions. Irrespective of the core difficulties in ASD, individuals with ASD are able to continually gain skills across various areas throughout adolescence when appropriate supports are provided (Smith, Maenner, & Seltzer, 2012). Once these young adults have completed secondary school, such early provisions are terminated. Specifically, the mandate for school intervention is completed and young adults turn to their communities to receive services, which are often non-existent or limited to those with ID. Concerns arise as they enter early adulthood and are faced with the expectation to act independently (Taylor & Seltzer, 2011). In fact, researchers have shown that functional independence for those with ASD begin to plateau and eventually decline in young adulthood (Smith et al., 2012). The current literature suggests that promoting SD has positive adult outcomes, including independence, education, employment, and interpersonal relationships.

The findings from the current study made several contributions to the literature addressing SD among young adults with ASD. Young adults with ASD reported lower mean levels of SD relative to their peers with other disabilities in the literature. A closer examination of the demographic variables associated with SD revealed that young adults above 23 years of age with ASD who were more educated reported higher levels of SD. This suggests that age and education play a significant role in the promotion of SD, whereas gender, living situation, and employment status were not significant in the current study. A hierarchical multiple regression analysis indicated that a person's age, SD capacity, and importance rating predicted higher levels

of SD. Furthermore, mean SD satisfaction scores were lower than their mean SD importance scores, implicating the need for intervention. A thematic analysis demonstrated major SD-related themes associated to success in adulthood, including capacity, control, knowledge of strengths and weaknesses, attaining adult outcomes, and support. Whereas factors that facilitated or hindered participants' SD included SD skills, mental health, societal perceptions about disability, support network, opportunities, and early educational and life experiences. These findings together demonstrate the complex picture of variables that should be considered when designing and implementing SD interventions.

In conclusion, the provision of services should incorporate SD as individuals with ASD embark upon their adult years. This original contribution to the SD literature captures the current movement towards embracing and promoting positive psychology within the field of ID, while ascertaining that a better understanding of SD for individuals with ASD can inform us about the supports required to teach SD skills or create opportunities for SD in educational contexts and supporting them to get the things they want and need out of life.

References

- Abery, B., Rudrud, L., Arndt, K., Schauben, L., & Eggebeen, A. (1995). Evaluating a multicomponent program for enhancing the self-determination of youth with disabilities. *Intervention in School and Clinic, 30*(3), 170–179. doi: 10.1177/105345129503000307
- Abery, B. H., Stancliffe, R. J., Smith, J., McGrew, K., & Eggebeen, A. (1995a). *Minnesota Opportunities and Exercise of Self-Determination Scale—Adult edition*. Minneapolis: University of Minnesota, Institute on Community Integration.
- Abery, B. H., Stancliffe, R. J., Smith, J., McGrew, K., & Eggebeen, A. (1995b). *Minnesota Self-Determination Skills, Attitudes, and Knowledge Evaluation Scale—Adult edition*. Minneapolis: University of Minnesota, Institute on Community Integration.
- Agran, M., Blanchard, C., & Wehmeyer, M. L. (2000). Promoting transition goals and self-determination through student self-directed learning: The self-determined learning model of instruction. *Education and Training in mental retardation and developmental disabilities, 35*(4), 351-364. Retrieved from <http://www.jstor.org/stable/23879857>
- Agran, M., Sinclair, T., Alper, S., Cavin, M., Wehmeyer, M. L., & Hughes, C. (2005). Using self-monitoring to increase following-direction skills of students with moderate to severe disabilities in general education. *Education and Training in Developmental Disabilities, 40* (1), 3-13. Retrieved from <http://www.jstor.org/stable/23879767>
- Agran, M. Storey, K. & Krupp, M. (2010). Choosing and choice making are not the same: Asking “what do you want for lunch?” is not self-determination. *Journal of Vocational Rehabilitation, 33*(2), 77-88. doi: 10.3233/JVR-2010-0517

- Algozzine, B., Browder, D., Karvonen, M., Test, D. W., & Wood, W. M. (2001). Effects of interventions to promote self-determination for individuals with disabilities. *Review of Educational Research, 71*(2), 219–277. doi: 10.3102/00346543071002219
- Altman, D. G. (1999). *Practical statistics for medical research*. New York, NY: Chapman & Hall/CRC Press.
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.
- Angell, M. E., Stoner, J. B., & Fulk, B. M. (2010). Advice from adults with physical disabilities on fostering self-determination during the school years. *Teaching Exceptional Children, 42*(3), 64-75. Retrieved from <http://search.proquest.com/openview/262a117e6a24f1390448347536e6d080/1?pq-origsite=gscholar>
- Angyal, A. (1941). *Foundations for a science of personality*. Cambridge, MA: Harvard University Press.
- Arndt, S. A., Konrad, M., & Test, D. W. (2006). Effects of the self-directed IEP on student participation in planning meeting. *Remedial and Special Education, 27*(4), 194-207. doi: 10.1177/07419325060270040101
- Aspis, S. (2000). Researching our history: Who is in charge? In L. Brigham, D. Atkinson, M. Jackson, S. Rolph and J. Walmsley (Eds.), *Crossing boundaries: Change and continuity in the history of learning disability* (1-5). Kidderminster, UK: Bild Publications.
- Atkinson, D. & Walmsley, J. (2010). History from the inside: Towards an inclusive history of intellectual disability. *Scandinavian Journal of Disability Research, 12*(4), 273-286. doi: 10.1080/15017410903581205

- Ballaban-Gil, K., Rapin, I., Tuchman, R. & Shinnar, S. (1996). Longitudinal examination of the behavioural, language, and social changes in a population of adolescents and young adults with autistic disorder. *Pediatric Neurology*, *15*(3), 217-223.
[http://dx.doi.org/10.1016/S0887-8994\(96\)00219-6](http://dx.doi.org/10.1016/S0887-8994(96)00219-6)
- Baker, D.J., Horner, R.H., Sappington, G., & Ard, W.R. (2000). A response to Wehmeyer (1999) and a challenge to the field regarding self-determination. *Focus on Autism and Other Developmental Disabilities*, *15*(3), 154-156. doi: 10.1177/108835760001500304
- Baron-Cohen, S., Hoekstra, R., Knickmeyer, R., & Wheelwright, S. (2006). The Autism-Spectrum Quotient (AQ)—adolescent version. *Journal of Autism and Developmental Disorders*, *36*(3), 343–350. doi: 10.1007/s10803-006-0073-6
- Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/High-Functioning Autism, Males and Females, Scientists and Mathematicians. *Journal of Autism and Developmental Disorders*, *31*(1), 5–17. doi: 10.1023/A:1005653411471
- Barnhill, G. P. (2007). Outcomes in adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, *22*(2), 116-126. doi: 10.1177/10883576070220020301
- Beaumont, R., & Sofronoff, K. (2008). A multi-component social skills intervention for children with Asperger syndrome: The junior detective training program. *Journal of Child Psychology and Psychiatry*, *49*(7), 743-753. doi: 10.1111/j.1469-7610.2008.01920.x
- Bellini, S., Peters, J., Benner, L., & Hopf, A. (2007). A meta-analysis of school-based social skill interventions for children with autism spectrum disorders. *Remedial and Special Education*, *28*(3), 153-162. doi: 10.1177/07419325070280030401
- Billstedt, E., Gillberg, C., & Gillberg, C. (2005). Autism after adolescence: Population-based

- 13to 22-year follow-up study of 120 individuals with autism diagnosed in childhood. *Journal of Autism and Developmental Disorders*, 35, 351–360. doi:10.1007/s10803-005-3302-5
- Bradley, V. G., Agosta, J. M., Smith, G., Taub, S., Ashbaugh, J., Silver, J., & Heaviland, M. (2001). The Robert Wood Johnson Foundation self-determination initiative: Final impact assessment report. Cambridge, MA: Human Services Research Institute.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77-101. doi: 10.1191/1478088706qp063oa
- Braun, V., & Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners*. London: Sage Publications.
- Bronfenbrenner, U. (1977). Toward an experimental ecology of human development. *American Psychologist*, 32(7), 513–531. doi: 10.1037//0003-066X.32.7.513
- Bronfenbrenner, U. (1979). *The ecology of human development: Experiments by nature and design*. Cambridge, MA: Harvard University Press.
- Bronfenbrenner, U. (1992). *Ecological systems theory*. London: Jessica Kingsley.
- Browder, D. M., Wood, W. M., Test, D. W., Karvonen, M. & Algozzine, B. (2001). Reviewing resources on self-determination: A map for teachers. *Remedial and Special Education*, 22(4), 233-244. doi: 10.1177/074193250102200407
- Brown, R. I. (1996). People with developmental disabilities: Applying quality of life to assessment and intervention. In R. Renwick, I. Brown, & M. Nagler (Eds.), *Quality of life in health promotion and rehabilitation: Conceptual approaches, issues, and applications* (pp. 253– 267). Thousand Oaks, CA: Sage.
- Brown, R. I., & Brown, I. (2005). The application of quality of life. *Journal of Intellectual*

- Disability Research*, 49(10), 718-727. doi : 10.1111/j.1365-2788.2005.00740.x
- Brown, I. & Brown, R. I. (2009). Choice as an aspect of quality of life for individuals with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 6(1), 11-18. doi: 10.1111/j.1741-1130.2008.00198.x
- Brown, I, Brown, R. I., Cummins, R. A., Felce, D., Matikka, L., Keith, K. et al. (2000). *Quality of life: It's conceptualization, measurement and application: A consensus document*. (WHOIASSID Work Plan). Retrieved from http://www.beachcenter.org/Books%5CFullPublications%5CPDF%5CFQLI_Quality%20of%20Life%20Consensus%20Document.pdf
- Brugha, T.S., McManus, S., Bankart, J., Scott, F., Purdon, S., Smith, J., Metlzer, H. (2011). The epidemiology of autism spectrum disorders in adults in the community in England. *Archives of General Psychiatry*, 68(5), 459-466. doi: 10.1001/archgenpsychiatry.2011.38.
- Buntinx, W. H. E. & Schalock, R. L. (2010). Models of disability, quality of life, and individualized supports: Implications for professional practice in intellectual disability. *Journal of Policy and Practice in Intellectual Disabilities*, 7(4), 283-294. doi: 10.1111/j.1741-1130.2010.00278.x
- Burgess, A. F. & Gutstein, S. E. (2007). Quality of life for people with Autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health*, 12(2), 80-86. doi: 10.1111/j.1475-3588.2006.00432.x
- Casas, F. (1997). Children's rights and children's quality of life: Conceptual and practical issues. *Social Indicators Research*, 42(3), 283-298. doi: 10.1023/A:1006836909395
- Carr, E. G. (1996). The transfiguration of behavior analysis: Strategies for survival. *Journal of Behavioral Education*, 6(3), 263-270. doi: 10.1007/BF02110128

- Carr, E. G., Dunlap, G., Horner, R. H., Koegel, R. L., Turnbull, A. P., Sailor, W., ...& Fox, L. (2002). Positive behaviour support: Evolution of an applied science. *Journal of Positive Behaviour Intervention*, 4(1), 4-16. doi: 10.1177/109830070200400102
- Carter, E. W., Lane, K. L., Cooney, M., Weir, K., Moss, K. C., & Machalicek, W. (2013). Parent assessments of self-determination importance and performance for students with autism or intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 118(1), 16-31. doi: 10.1352/1944-7558-118.1.16
- Carter, E. W., Lane, K. L., Pierson, M. R., & Glaeser, B. (2006). Self-determination skills and opportunities of transition-age youth with emotional disturbance and learning disabilities. *Exceptional Children*, 72(3), 333-346. doi: 10.1177/001440290607200305
- Carter, E. W., Lane, K. L., Pierson, M. R., & Stang, K. K. (2008). Promoting self-determination for transition-age youth: Views of high school general and special educators. *Exceptional Children*, 75(1), 55–70. doi: 10.1177/001440290807500103
- Carter, E. W., Sisco, L. G., & Lane, K. L. (2011). Paraprofessional perspectives on promoting self-determination among elementary and secondary students with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 36(1-2), 1–10. doi: 10.2511/rpself-determination.36.1- 2.1
- Carver, C. S., & Scheier, M. F. (2002). Optimism. In C. R. Snyder & S. J. Lopez (Eds), *Handbook of positive psychology* (pp. 231–243). London: Oxford University Press.
- Carver, C. S., & Scheier, M. F. (2003). Optimism. In C. R. Snyder & S. J. Lopez (Eds), *Positive psychological assessment: A handbook of models and measures* (pp. 75–89). Washington, DC: American Psychological Association.
- Centers for Disease Control and Prevention (2007). Prevalence of autism spectrum disorders:

- Autism and developmental disabilities monitoring network, six sites, United States, 2000, *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*, 56(SS-1), 1–28. Retrieved from <http://www.cdc.gov/mmwr/PDF/ss/ss5601.pdf>
- Centers for Disease Control and Prevention (2009). Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network, United States, 2006. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*, 58(10), 1–20. Retrieved from <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>
- Centers for Disease Control and Prevention (2012). Prevalence of autism spectrum disorders: autism and developmental disabilities monitoring network, 14 sites, United States, 2008. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*, 61(3), 1–19. Retrieved from <https://www.cdc.gov/mmwr/pdf/ss/ss6103.pdf>
- Centers for Disease Control and Prevention (2014). Prevalence of autism spectrum disorders among children aged 8 years: Autism and developmental disabilities monitoring network, 11 sites, United States, 2010. *Morbidity and Mortality Weekly Report (MMWR) Surveillance Summaries*, 63(2), 1–22. Retrieved from <https://www.cdc.gov/mmwr/pdf/ss/ss6302.pdf>
- Chambers, C. R., Wehmeyer, M.L., Saito, Y., Lida, K.M., Lee, Y., & Singth, V. (2007). Self-determination: What do we know? Where do we go? *Exceptionality*, 15(1), 3-15. doi: 10.1080/09362830709336922
- Chou, H. J., Wehmeyer, M., & Kingston, N. (2010). Elementary teachers' knowledge and use of interventions and barriers to promoting student self-determination. *The Journal of Special Education*, 45, 3, 149-156. doi: 10.1177/0022466910362588
- Chou, Y., Wehmeyer, M. L., Shogren, K. A., Palmer, S. B., & Lee, J. (2015). Autism and self-

determination: Factor analysis of two measures of self-determination. *Focus on Autism and Other Developmental Disabilities*, 1088357615611391, 1-13. doi:

10.1177/1088357615611391

Chou, Y. C., Wehmeyer, M. L., Palmer, S. B., & Lee, J. (2016). Comparisons of Self-Determination Among Students With Autism, Intellectual Disability, and Learning Disabilities: A Multivariate Analysis. *Focus on Autism and Other Developmental Disabilities*, 1088357615625059. doi: 10.1177/1088357615625059

Christensen, D. L., Baio, J., Braun, K. V., Bilder, D., Charles, J., Constantino, J.N.... Yeargin-Allsopp, M. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years-autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *Morbidity and Mortality Weekly Report Surveillance Summaries*, 65(3), 1-23. doi: 10.15585/mmwr.ss6503a1

Clark, E., Olympia, D. E., Jensen, J., Heathfield, L. T., & Jenson, W.R. (2004). Striving for autonomy in a contingency-governed world: Another challenge for individuals with developmental disabilities. *Psychology in the Schools*, 41(1), 143-153. doi: 10.1002/pits.10146

Cobb, B., Lehmann, J., Newman-Gonchar, R., & Alwell, M. (2009). Self-determination for students with disabilities: A narrative metasynthesis. *Career Development for Exceptional Individuals*, 32, 108–114. doi:10.1177/0885728809336654

Cohen, J. (1988). *Statistical power analysis for the behavioural sciences* (2nd ed.). Hillsdale, NJ: Erlbaum.

Cook, R. D., & Weisberg, S. (1982). *Residuals and Influence in Regression*. New York: Chapman and Hall. Retrieved from <http://conservancy.umn.edu/handle/11299/37076>

- Cooney, B. F. (2002). Exploring Perspectives on Transition of Youth With Disabilities: Voices of Young Adults, Parents, and Professionals. *Mental Retardation*, 40(6), 425-435. doi: 10.1352/0047-6765(2002)040<0425:EPOTOY>2.0.CO;2
- Costanza, R., Fisher, B., Ali, S., Beer, C., Bond, L., Boumans, R., ... & Gayer, D. E. (2007). Quality of life: An approach integrating opportunities, human needs, and subjective well-being. *Ecological Economics*, 61(2), 267-276. doi:10.1016/j.ecolecon.2006.02.023
- Cronbach, L. J. (1951). Coefficient alpha and the internal structure of the tests. *Psychometrika*, 16(3), 297-334. doi: 10.1007/BF02310555
- Cummins, R. A. (1996). The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research*, 38(3), 303-328. doi: 10.1007/BF00292050
- Cummins, R. (2005). Moving from the quality of life concept to a theory. *Journal of Intellectual Disability Research*, 49(10), 699– 706. doi: 10.1111/j.1365-2788.2005.00738.x
- Deci, E. L., & Ryan, R. M. (1980). Self-Determination theory: When mind mediates behavior. *Journal of Mind and Behavior*, 1(1), 33-43.
- Deci, E. L., & Ryan, R. M. (1985). *Intrinsic motivation and self-determination in human behavior*. New York: Plenum.
- Deci, E. L., & Ryan, R. M. (1994). Promoting self-determined education. *Scandinavian Journal of Educational Research*, 38(1), 3-14. doi: 10.1080/0031383940380101
- Deci, E. L., & Ryan, R. M. (2002a). Overview of Self-determination theory. In E. L. Deci & R. M. Ryan (Eds.), *Handbook of Self-Determination research* (pp. 3- 33). Rochester, NY: University of Rochester Press.
- Deci, E. L., & Ryan, R. M. (Eds.). (2002b). *Handbook of Self-Determination research*. Rochester, NY: University of Rochester Press.

- De Vries, A.L., Noens, I.L., Cohen-Kettenis, P.T., van Berchelaer Onnes, I.A., Doreleijers, T.A. (2010). Autism spectrum disorders in gender dysphoric children and adolescents. *Journal of Autism and Developmental Disorders*, 40(8), 930-936. doi: 10.1007/s10803-010-0935-9.
- Dillman, D. A. (2000). *Mail and internet surveys: The tailored design method* (2nd Ed.). New York: Wiley.
- Dillon, M. R. (2007). Creating supports for college students with Asperger syndrome through collaboration. *College Student Journal*, 41(2), 499–504.
- Doll, B., Sands, D., Wehmeyer, M., & Palmer, S. B. (1996). Promoting the development and acquisition of self-determined behavior. In D. Sands & M. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for individuals with disabilities* (pp. 65–90). Baltimore, MD: Brookes.
- Dunn, T. J., Baguley, T. and Brunsdon, V. (2014), From alpha to omega: A practical solution to the pervasive problem of internal consistency estimation. *British Journal of Psychology*, 105(3), 399–412. doi: 10.1111/bjop.12046
- Eaves, L. C., & Ho, H. H. (2008). Young adult outcome of autism spectrum disorders. *Journal of Autism and Developmental Disorders*, 38(4), 739-747. doi:10.1007/s10803-007-0441-x
- Edgerton, R.B. (1996). A longitudinal-ethnographic research perspective on quality of life. In R.L. Schalock & G.N. Siperstein (Eds.), *Quality of Life: Conceptualization and measurement*. Washington, DC: American Association on Mental Retardation.
- Edwards, J. (1982). *We are individuals first: Our handicaps are secondary*. Portland, OR: Ednick.
- Edwards, T. L., Watkins, E. E., Lotfizadeh, A. D. & Poling, A. (2012). Intervention research to benefit people with autism: How old are the participants? *Research in Autism Spectrum*

- Disorders*, 6(3), 996–999. doi: 10.1016/j.rasd.2011.11.002
- Enders, C. K. (2010). *Applied missing data analysis*. New York: Guilford Press.
- Engstrom, I., Ekstrom, L., & Emilsson, B. (2003). Psychosocial functioning in a group of Swedish adults with asperger syndrome or high-functioning autism. *Autism*, 7(1), 99–110. doi: 10.1177/1362361303007001008
- Erwin, E. J., Brotherson, M. J., Palmer, S. B., Cook, C. C., Weigel, C. J., & Summers, J. A. (2009). How to promote self-determination for young children with disabilities. *Young Exceptional Children*, 12(2), 27–37. doi: 10.1177/1096250608329611
- Erwin, E. J., & Brown, F. (2000). Variables that contribute to self-determination in early childhood. *Association for Persons With Severe Handicaps Newsletter*, 26(3), 8–10.
- Erwin, E. J., & Brown, F. (2003). From theory to practice a contextual framework for understanding self-determination in early childhood environments. *Infants & Young Children*, 16(1), 77–87.
- Esbensen, A. J., Bishop, S., Seltzer, M. M., Greenberg, J. S., & Taylor, J. L. (2010). Comparisons between individuals with autism spectrum disorders and individuals with down syndrome in adulthood. *American Journal of Intellectual and Developmental Disabilities*, 115(4), 277–290. doi:10.1352/1944-7558-115.4.277
- Faherty, C. (2000). *What does it mean? A workbook explaining self-awareness and life lessons to the child or youth with high functioning autism or aspergers*. Arlington, TX: Future Horizons.
- Farley, M. A., McMahon, W. M., Fombonne, E., Jenson, W. R., Miller, J., Gardner, M., ... & Coon, H. (2009). Twenty-year outcome for individuals with autism and average or near-average cognitive abilities. *Autism Research: Official Journal of the International Society*

for Autism Research, 2(2), 109–18. doi:10.1002/aur.69

Faul, F., Erdfelder, E., Lang, A. G., & Buchner, A. (2007). GPower-3: A flexible statistical Power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, 39(2), 175-191. doi: 10.3758/BF03193146

Felce, D., & Perry, J. (1996). Assessment of quality of life. In R. L. Schalock (Ed.), *Quality of life: Vol. 1. Conceptualization and measurement* (pp. 63-72). Washington, DC: American Association on Mental Retardation.

Felce, D. & Perry, J. (1997). A PASS 3 evaluation of community residences in Wales. *Mental Retardation*, 35(3), 170-176. doi: 10.1352/0047-6765(1997)035<0170:APEOCR>2.0.CO;2

Field, A. P. (2009). *Discovering statistics using SPSS: And sex and drugs and rock 'n' roll* (3rd ed.). Thousand Oaks, California: SAGE Publications Inc.

Field, S., & Hoffman, A. (1994). Development of a model for self-determination. *Career Development for Exceptional Individuals*, 17(2), 159-169.

Field, S., & Hoffman, A. (1999). The importance of family involvement for promoting self-determination in adolescents with autism and other developmental disabilities. *Focus on Autism and Other Developmental Disabilities*, 14(1), 36-41.
doi: 10.1177/108835769901400105

Field, S., Martin, J., Miller, R., Ward, M., & Wehmeyer, M. (1998). Self-Determination for Persons With Disabilities: A Position Statement of the Division on Career Development and Transition. *Career Development and Transition for Exceptional Individuals*, 21(2), 113–128. doi:10.1177/088572889802100202

Field, S., Sarver, M. D., & Shaw, S.F. (2003). Self-determination: A key to success in postsecondary education for students with learning disabilities. *Remedial and Special*

Education, 24(6), 339-349. doi: 10.1177/07419325030240060501

Flanagan, T., Nadig, A. & White, K. (2016). Incorporating needs assessments in program design:

Results from a Transition Support Program for young adults with Autism Spectrum Disorder. Manuscript in preparation.

Fowler, C. H., Konrad, M., Walker, A. R., Test, D. W., & Wood, W. M. (2007). Self-

determination interventions' effects on the academic performance of students with developmental disabilities. *Education and Training in Developmental Disabilities*, 42(3), 270–285. Retrieved from <http://www.jstor.org/stable/23879622>

Fullerton, A. & Coyne, P. (1999). Developing skills and concepts for self-determination in young

adults with Autism. *Focus on Autism and Other Developmental Disabilities*, 14(1), 42-52. doi: 10.1177/108835769901400106

Gerhardt, P. F., & Lainer, I. (2011). Addressing the Needs of Adolescents and Adults with

Autism: A Crisis on the Horizon. *Journal of Contemporary Psychotherapy*, 41(1), 37–45. doi:10.1007/s10879-010-9160-2

Gillberg, C., & Billstedt, E. (2000). Autism and Asperger syndrome: Coexistence with other

clinical disorders. *Acta Psychiatrica Scandinavica*, 102(5), 321–330. doi:10.1034/j.1600-0447.2000.102005321.x

Gilbert, T. (2004). Involving individuals with learning disabilities in research: Issues and

possibilities. *Health and Social Care in the Community*, 12(4), 298-308. doi: 10.1111/j.1365-2524.2004.00499.x

Glennon, T. J. (2001). The stress of the university experience for students with Asperger

syndrome. *Work*, 17(3), 183–190. Retrieved from <http://www.iospress.nl/journal/work/>

Graetz, J. E. (2010). Autism grows up: Opportunities for adults with autism. *Disability &*

- Society*, 25(1), 33-47. doi: 10.1080/09687590903363324
- Gray, D. E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability*, 27(3), 215-222. doi: 10.1080/1366825021000008639
- Halpern, A. S., Herr, C. M., Wolf, N. K., Lawson, J. D., Doren, B., Johnson, M. D. & Lawson, J.D. (1997). *Next S.T.E.P.: Student transition and educational planning*. Austin, TX: PRO-ED.
- Hanson, W. E., Creswell, J. W., Clark, V. L. P., Petska, K. S., & Creswell, J. D. (2005). Mixed methods research designs in counseling psychology. *Journal of Counseling Psychology*, 52(2), 224-235. doi: 10.1037/0022-0167.52.2.224
- Hendricks, D. R., & Wehman, P. (2009). Transition From School to Adulthood for Youth With Autism Spectrum Disorders: Review and recommendations. *Focus on Autism and Other Developmental Disabilities*, 24(2), 77-88. doi: 10.1177/1088357608329827
- Hergenhahn, B. R. (2008). *An introduction to the history of psychology*. Belmont, CA: Wadsworth Publishing.
- Hoffman, A., Field, S., & Sawilowsky, S. (1996). *Self-determination knowledge scale*. Austin, TX: PRO-ED.
- Hogansen, J. M., Powers, K., Geenen, S., Gil-Kashiwabara, E., & Powers, L. (2008). Transition goals and experiences of females with disabilities: Youth, parents, and professionals. *Exceptional Children*, 74, 215-234. doi: 10.1177/001440290807400205
- Howlin, P. (2000). Outcome in adult life for more able individuals with autism or asperger syndrome. *Autism*, 4(1), 63-83. doi: 10.1177/1362361300004001005
- Howlin, P. (2003). Outcome in high-functioning adults with autism with and without early

language delays: Implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 33(1), 3–13.

doi:10.1023/A:1022270118899

Howlin, P., Alcock, J., & Burkin, C. (2005). An 8 year follow-up of a specialist supported employment service for high-ability adults with autism or Asperger syndrome. *Autism*, 9(5), 533-549. doi: 10.1177/1362361305057871

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry, and Allied Disciplines*, 45(2), 212–229.

Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/14982237>

Howlin, P. & Moss, P. (2012). Adults with autism spectrum disorders. *Canadian Journal of Psychiatry*, 57(5), 275-283. doi: 10.1177/070674371205700502

Hume, K., Boyd, B. A., Hamm, J. V., & Kucharczyk, S. (2014). Supporting independence in adolescents on the autism spectrum. *Remedial and Special Education*, 35(2), 102-113. doi: 10.1177/0741932513514617

Hume, K., Loftin, R., & Lantz, J. (2009). Increasing independence in autism spectrum disorders: A review of three focused interventions. *Journal of Autism and Developmental Disorders*, 39(9), 1329–1338. doi:10.1007/s10803-009-0751-2

Hutchison, T. (1995). The classification of disability. *Archives of disease in childhood*, 73(2), 91-93. Retrieved from

<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC1511184/pdf/archdisch00622-0007.pdf>

Janssen, A., Huang, H., & Duncan, C. (2016). Gender variance among youth with autism spectrum disorders: A retrospective chart review. *Transgender Health*, 1(1), 63-68.

doi:10.1089/trgh.2015.0007

- Jobe, L. E., & White, S. W. (2007). Loneliness, social relationships and a broader autism phenotype in college students. *Personality and Individual Differences, 42*(8), 1479–1489. doi:10.1016/j.paid.2006.10.021
- Johnson, M. (1996). Models of disability. *Physiotherapy Theory and Practice: An International Journal of Physical Therapy, 12*(3), 131-141.
- Johnson, R. B., Onwuegbuzie, A. J., & Turner, L. A. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*(2), 112-133. doi: 10.1177/1558689806298224
- Jones, R. S. P., Zahl, A., & Huws, J. C. (2001). First-hand accounts of emotional experiences in Autism: A qualitative analysis. *Disability & Society, 16*(3), 393-401. doi: 10.1080/09687590120045950
- Karvonen, M., Test, D. W., Wood, W. M., Browder, D., & Algozzine, B. (2004). Putting self-determination into practice. *Exceptional Children, 71*(1), 23–41. doi: 10.1177/001440290407100102
- King, G. (2009). A relational goal-oriented model of optimal service delivery to children and families. *Physical & Occupational Therapy in Pediatrics, 29*(4), 384–408. doi:10.3109/01942630903222118
- Kline, R. B. (2005). *Principles and practice of structural equation modeling* (2nd ed.). New York: Guilford.
- Konrad, M., Fowler, C. H., Walker, A. R., Test, D. W., & Wood, W. M. (2007). Effects of self-determination interventions on the academic skills of students with learning disabilities. *Learning Disability Quarterly, 30*(2), 89–113. doi: 10.2307/30035545
- Krasny, L., Williams, B. J., Provencal, S., & Ozonoff, S. (2003). Social skills interventions for

- the autism spectrum: Essential ingredients and a model curriculum. *Child and Adolescent Psychiatric Clinics of North America*, 12(1), 107–122. doi: 10.1016/S1056-4993(02)00051-2
- Krauss, M. W., Seltzer, M. M., & Jacobson, H. T. (2005). Adults with autism living at home or in non-family settings: positive and negative aspects of residential status. *Journal of Intellectual Disability Research*, 49(2), 111-124. doi: 10.1111/j.1365-2788.2004.00599.x
- Lachapelle, Y., Wehmeyer, M. L., Haeleqyck, M. C., Courbois, Y., Keith, K.D., Schalock, R., Verdugo, M.A. & Walsh, P.N. (2005). The relationship between quality of life and self-determination: An international study. *Journal of Intellectual Disability Research*, 49(10), 740-744. doi: 10.1111/j.1365-2788.2005.00743.x
- Laerd Statistics (2015). *Statistical tutorials and software guides*. Retrieved from <https://statistics.laerd.com/>
- Lake, J. K., Perry, A., & Lunskey, Y. (2014). Mental health services for individuals with high functioning autism spectrum disorder. *Autism Research and Treatment*, Article ID 502420, 1-9. doi: 10.1155/2014/502420
- Lance, C.E., Butts, M.M., & Michels, L.C. (2006). The sources of four commonly reported cut-off criteria: What did they really say? *Organizational Research Methods*, 9(2), 202-220. doi: 10.1177/1094428105284919
- Landis, J. R., & Koch, G. G. (1977). The measurement of observer agreement for categorical data. *Biometrics*, 33(1), 159-174. doi: 10.2307/2529310
- Lee, S.H., Palmer, S.B., Turnbull, & Wehmeyer, M.L. (2006). A model for parent-teacher collaboration to promote self-determination in young children with disabilities. *Teaching Exceptional Children*, 38(3), 36-41. Retrieved from

https://kuscholarworks.ku.edu/bitstream/handle/1808/10988/Turnbull_a%20model%20for%20parent%20teacher%20collaboration.pdf?sequence=1&isAllowed=y

- Lee, Y., Wehmeyer, M.L., Palmer, S.B., Diehm, K. W., Davies, D. K., & Stock, S. E. (2012). Examining individual and instruction-related predictors of the self-determination of students with disabilities: Multiple regression analyses. *Remedial and Special Education, 33*(3), 150-161. doi: 10.1177/0741932510392053
- Lee, S., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., & Little, T. D. (2008). Self-determination and access to the general education curriculum. *The Journal of Special Education, 42*(2), 91-107.
- Lee, S. H., Wehmeyer, M. L., Soukup, J. H., & Palmer, S. B. (2010). Impact of curriculum modifications on access to the general education curriculum for students with disabilities. *Exceptional Children, 76*(2), 213–233. doi: 10.1177/001440291007600205
- Leech, N. L., & Onwuegbuzie, A. J. (2009). A typology of mixed methods research designs. *Quality & Quantity, 43*(2), 265–275. <http://doi.org/10.1007/s11135-007-9105-3>
- Lehr, G., Johnson, D., Bremer, C, Cusió, A., & Thompson, M. (2004). Increasing rates of school completion: Moving from policy to practice. Minneapolis: University of Minnesota. National Center on Secondary Education and Translation. Retrieved from http://www.ncset.org/teleconferences/transcripts/2004_01.asp
- Levy, A., & Perry, A. (2011). Outcomes in adolescents and adults with autism: A review of the literature. *Research in Autism Spectrum Disorders, 5*(4), 1271–1282. doi:10.1016/j.raself-determination.2011.01.023
- Little, R. J. A. (1988). A test of missing completely at random for multivariate data with missing values. *Journal of the American Statistical Association, 83*(404), 1198-1202. doi:

10.1080/01621459.1988.10478722

- Llewellyn, A. & Hogan, K. (2000). The use and abuse of models of disability. *Disability & Society, 15*(1), 157-165. doi: 10.1080/09687590025829
- López, B., & Keenan, L. (2014). Barriers to employment in autism: Future challenges to implementing the adult autism strategy. *Autism Research Network: University of Portsmouth, Portsmouth*. Retrieved from http://www.autismrpphub.org/sites/default/files/articles/employment_report.pdf
- Lopez, S. J., Snyder, C. R., & Teramoto-Pedrotti, J. (2003). Hope: Many definitions, many measures. In S. J. Lopez & C. R. Snyder (Eds), *Positive psychological assessment: A handbook of models and measures* (pp. 91–107). Washington, DC: American Psychological Association.
- Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Reeve, A., et al. (2002). *Mental retardation: Definition, classification, and systems of support* (10th ed.). Washington, DC: American Association on Mental Retardation.
- Luckasson, R., Coulter, D. L., Polloway, E. A., Reiss, S., Schalock, R. L., Snell, M. E., et al. (1992). *Mental retardation: Definition, classification, and systems of supports* (9th ed.). Washington, DC: American Association on Mental Retardation.
- Malian, I. & Nevin, A. (2002). A review of self-determination literature: Implications for practitioners. *Remedial and Special Education, 23*(2), 68–74.
doi:10.1177/074193250202300202
- Martin, J. E., & Marshall, L. H. (1995). ChoiceMaker: A comprehensive self-determination transition program. *Intervention in School and Clinic, 30*(3), 147–156. doi:
doi: 10.1177/105345129503000304

- Martorell, A., Gutierrez-Recacha, P., Perda, A., & Ayuso-Mateos, J.L. (2008). Identification of personal factors that determine work outcome for adults with intellectual disability. *Journal of Intellectual Disability Research*, 52(12), 1091–1101. doi: 10.1111/j.1365-2788.2008.01098.x
- Matson, J. L., & Horovitz, M. (2010). Stability of autism spectrum disorders symptoms over time. *Journal of Developmental and Physical Disabilities*, 22(4), 331–342. doi: 10.1007/s10882-010-9188-y
- Matson, J., & Rivet, T. (2007). A validity study of the autism spectrum disorders - behavior problems for adults (ASD-BPA) scale. *Journal of Developmental & Physical Disabilities*, 19(6), 557-564. doi: 10.1007/s10882-007-9069-1
- Matson, J. L., & Shoemaker, M. (2009). Intellectual disability and its relationship to autism spectrum disorders. *Research in Developmental Disabilities*, 30(6), 1107-1114. doi:10.1016/j.ridd.2009.06.003
- McConnell, S. R. (2002). Interventions to facilitate social interaction for young children with autism: Review of available research and recommendations for educational intervention and future research. *Journal of Autism and Developmental Disorders*, 32(5), 351-372. doi: 10.1023/A:1020537805154
- McGuire, J., & McDonnell, J. (2008). Relationships between recreation and levels of self-determination for adolescents and young adults with disabilities. *Career Development and Transition for Exceptional Individuals*, 31(3), 154–163. doi: 10.1177/0885728808315333
- Minshew, N. J., Meyer, J., & Goldstein, G. (2002). Abstract reasoning in autism: A disassociation between concept formation and concept identification. *Neuropsychology*, 16(3), 327–334. doi:10.1037//0894-4105.16.3.327

- Mithaug, D. E. (1993). *Self-regulation theory: How optimal adjustment maximizes gain*. Westport, CT: Praeger.
- Mithaug, D. E. (1996). The optimal prospects principle: A theoretical basis for rethinking instructional practices for self-determination. In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the lifespan: Independence and choice for individuals with disabilities* (pp. 147–165). Baltimore: Brooks.
- Mithaug, D. E. (1998). Invited commentary: Your right, my obligation? *Journal of the Association for Persons with Severe Handicaps*, 23(1), 41-43. doi: 10.2511/rpsd.23.1.41
- Mithaug, D. E., Campeau, P. L., & Wolman, J. M. (2003). Assessing self-determination prospects among students with and without disabilities. In D. E. Mithaug, D. K. Mithaug, M. Agran, J. E. Martin, & M. L. Wehmeyer (Eds.), *Self determined learning theory: Construction, verification, and evaluation* (pp. 61–76). Mahwah, NJ: Lawrence Erlbaum.
- Mithaug, D. E., Mithaug, D. K., Agran, M., Martin, J. E., & Wehmeyer, M. L. (Eds.). (2003). *Self-determined learning theory: Construction, verification, and evaluation*. Mahwah, NJ: Lawrence Erlbaum.
- Mithaug, D., Wehmeyer, M. L., Agran, M., Martin, J., & Palmer, S. (1998). The self-determined learning model of instruction: Engaging students to solve their learning problems. In M. L. Wehmeyer & D. J. Sands (Eds.), *Making it happen: Student involvement in educational planning, decision-making and instruction* (pp. 299–328). Baltimore: Brookes.
- Nesbitt, S. (2000). Why and why not? Factors influencing employment for individuals with asperger syndrome. *Autism*, 4(4), 357–369. doi:10. 1177/1362361300004004002.
- Nirje, B. (1969). The normalization principle and its human management implications. In R. B. Kugel & W. Wolfensberger (Eds.), *Changing residential patterns for the mentally*

- retarded*. Washington, DC: President's Committee on Mental Retardation.
- Nirje, B. (1972). The right to self-determination. In W. Wolfensberger (Ed.), *Normalization: The principle of normalization in human services* (pp. 176- 193). Toronto: National Institute on Mental Retardation.
- Nirje, B. (1999). How I came to formulate the Normalization principle. In R. J. Flynn & R. Lemay (Eds.), *A Quarter-century of normalization and social role valorization: Evolution and impact*. Ottawa, ON: University of Ottawa Press.
- Nonnemacher, S. L., & Bambara, L. M. (2011). “I’m supposed to be in charge”: Self-advocates’ perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities, 49*(5), 327–340. doi: 10.1352/1934-9556-49.5.327
- Norusis, M. (2008). *SPSS 16.0 statistical procedures companion*. Prentice Hall Press.
- Nota, L., Ferrari, L., Soresi, A., & Wehmeyer, M. L. (2007). Self-determination, social abilities, and the quality of life of individuals with intellectual disabilities. *Journal of Intellectual Disability Research, 51*(11), 850-865. doi: 10.1111/j.1365-2788.2006.00939.x
- Orsmond, G. L., Krauss, M. W., & Selzter, M. M. (2004). Peer relationships and social and recreational activities among adolescents and adults with autism. *Journal of Autism and Developmental Disorders, 34*(3), 1-16. doi: 10.1023/B:JADD.0000029547.96610.df
- Ouellette-Kuntz, H., Coo, H., Lam, M., Breitenbach, M. M., Hennessey, P. E., Jackman, P. D., ... & Chung, A. M. (2014). The changing prevalence of autism in three regions of Canada. *Journal of Autism and Developmental Disorders, 44*(1), 120-136. doi: 10.1007/s10803-013-1856-1
- Ouellette-Kuntz, H. M., Coo, H., Lam, M., Yu, C. T., Breitenbach, M. M., Hennessey, P. E., ... & Crews, L. R. (2009). Age at diagnosis of autism spectrum disorders in four regions of

- Canada. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, 268-273. Retrieved from <http://www.jstor.org/stable/41995266>
- Ouellette-Kuntz, H., Coo, H., Yu, C. T., & Lewis, M. E. (2012). Status report - national epidemiologic database for the study of autism in Canada (NEDSAC). *Chronic diseases and injuries in Canada*, 32(2). Retrieved from <http://www.phac-aspc.gc.ca/publicat/hpcdp-pspmc/32-2/ar-04-eng.php>
- Ozonoff, S., & Schetter, P. L. (2007). Executive dysfunction in autism spectrum disorders: From research to practice. In L. Meltzer (Ed.), *Understanding executive function: Implications and opportunities for the classroom* (pp. 133–160). New York, NY: Guilford.
- Palmer, S. B. (2010). Self-determination—A life-span perspective. *Focus on Exceptional Children*, 42(6), 1–16. Retrieved from <http://hdl.handle.net/1808/8642>
- Palmer, S. B., Summers, J. A., Brotherson, M. J., Erwin, E. J., Maude, S. P., Stroup-Rentier, V., ...Haines, S. J. (2013). Foundations for self-determination in early childhood: An inclusive model for children with disabilities. *Topics in Early Childhood Special Education*, 33(1), 38–47. doi: 10.1177/0271121412445288
- Palmer, S. B., & Wehmeyer, M. L. (2003). Promoting self-determination in early elementary school teaching self-regulated problem-solving and goal-setting skills. *Remedial and Special Education*, 24(2), 115-126. doi: 10.1177/07419325030240020601
- Palmer, S. B., Wehmeyer, M. L., Gibson, K., & Agran, M. (2004). Promoting access to the general curriculum by teaching self-determination skills. *Exceptional Children*, 70(4), 427-439. doi: 10.1177/001440290407000403
- Parsons, S. (2014). “Why are we an ignored group?” Mainstream educational experiences and current life satisfaction of adults on the autism spectrum from an online survey.

- International Journal of Inclusive Education*, 19(4), 397–421. doi:
10.1080/13603116.2014.935814
- Pellicano, E., Dinsmore, A. & Charman, T. (2013). A future made together: Shaping autism research in the UK. London: Centre for Research in Autism and Education (CRAE), Institute of Education, University of London. Retrieved from
http://newsletters.ioe.ac.uk/A_Future_Made_Together_2013.pdf
- Pierson, M. R., Carter, E. W., Lane, K. L. & Glaeser, B. C. (2008). Factors influencing the self-determination of transition-age youth with high-incidence disabilities. *Career Development and Transition for Exceptional Individuals*, 31(2), 115-125.
doi: 10.1177/0885728808317659
- Piven, J., Rabins, P. & Autism-in-Older Adults Working Group. (2011). Autism spectrum disorders in older adults: Toward defining a research agenda. *Journal of American Geriatric Society*, 59(11), 2151-2155. doi: 10.1111/j.1532-5415.2011.03632.x
- Plimley, L. A. (2007). A review of quality of life issues and people with autism spectrum disorders. *British Journal of Learning Disabilities*, 35(4), 205–213. doi: 10.1111/j.1468-3156.2007.00448.x
- Portway, S. M., & Johnson, B. (2005). Do you know I have Asperger's syndrome? Risks of a non-obvious disability. *Health, Risk & Society*, 7(1), 73-83. doi:
10.1080/09500830500042086
- Punch, K. F. (2013). Introduction to social research: Quantitative and qualitative approaches. (3rd ed.). Thousand Oaks, California: SAGE Publications Inc.
- Reamer, F. G. (1998). *The Evolution of Social Work Ethics*. Faculty Publications. Pare 170.
<http://digitalcommons.ric.edu/facultypublications/170>

- Richards, J. (2012). Examining the exclusion of employees with asperger syndrome from the workplace. *Personnel Review*, *41*(5), 630–646. doi:10.1108/00483481211249148.
- Rogoff, B. (2003). *The cultural nature of human development*. New York, NY: Oxford University Press.
- Rotter, J. B. (1966). Generalized expectancies for internal versus external control of reinforcement. *Psychological Monographs: General and Applied*, *80*(1), 1-28. doi: 10.1037/h0092976
- Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, *55*(1), 68-78. doi: 10.1037/0003-066X.55.1.68
- Ruble, L. A., & Scott, M. M. (2002). Executive functions and the natural habitat behaviors of children with autism. *Autism*, *6*(4), 365-381. doi: 10.1177/1362361302006004004
- Sands, D., & Doll, B. (1996). Fostering self-determination is a developmental task. *The Journal of Special Education*, *30*(1), 58–76. doi: 10.1177/002246699603000104
- Sansosti, F. J., & Powell-Smith, K. A. (2008). Using computer-presented social stories and video models to increase the social communication skills of children with high-functioning autism spectrum disorders. *Journal of Positive Behavior Interventions*, *10*(3), 162-178. doi: 10.1177/1098300708316259
- Saulnier, C. A., & Klin, A. (2007). Brief report: Social and communication abilities and disabilities in higher functioning individuals with autism and asperger syndrome. *Journal of Autism and Developmental Disorders*, *37*(4), 788–793. doi:10.1007/s10803-006-0288-6
- Schalock R. L. (1996). Reconsidering the conceptualization and measurement of quality of life. In R. L. Schalock (Eds.), *Quality of Life: Conceptualization and Measurement*, Vol. 1 (pp.

- 123–39). Washington, DC: American Association on Mental Retardation.
- Schalock, R. L. (2000). Three decades of quality of life. *Focus on Autism and Other Developmental Disabilities, 15*(2), 116-127. doi: 10.1177/108835760001500207
- Schalock, R. L. (2004a). The concept of quality of life: what we know and do not know. *Journal of Intellectual Disability Research, 48*(3), 203-216. doi: 10.1111/j.1365-2788.2003.00558.x
- Schalock, R. L. (2004b). The emerging disability paradigm and its implications for policy and practice. *Journal of Disability Policy Studies, 14*(4), 204–215.
doi: 10.1177/10442073040140040201
- Schalock, R. L. (2011). The evolving understanding of the construct of intellectual disability. *Journal of Intellectual and Developmental Disability, 36*(4), 227-237. doi: 10.3109/13668250.2011.624087
- Schalock, R. L., Borthwick-Duffy, S., Bradley, V., Buntix, W. H. E., Coulter, D. L., Craig, E. P. M., et al. (2010). Intellectual disability: Definition, classification, and systems of support (11th ed.). Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Schalock R. L., Brown I., Brown R., Cummins R. A., Felce D., Matikka L., Keith K. D. & Parmenter T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: Results of an international panel of experts. *Mental Retardation, 40*(6), 457-470. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- Schalock, R. L., Coulter, D. L., Polloway, E. A., Reiss, S., Snell, M. E., & Spitalnick, D. M. (1994). The changing conception of mental retardation: Implications for the field. *Mental*

- Retardation*, 32(3), 181-193. Retrieved from <http://search.proquest.com/openview/3f1f5f5028266f098b32bbe6e9aaa7bc/1?pq-origsite=gscholar&cbl=1976608>
- Schalock R. L. & Keith K. D. (1993) *Quality of Life Questionnaire*. IDS Publishers, Worthington, OH.
- Schalock, R.L., Luckasson, R., Shogren, K., Borthwick-Duffy, S., Bradley, V., Buntinx, W...Yeager, M. H. (2007). The renaming of mental retardation: Understanding the change to the term intellectual disability. *Intellectual and Developmental Disabilities*, 45(2), 116–124. doi: 10.1352/1934-9556(2007)45[116:TROMRU]2.0.CO;2
- Schalock, R. L., Verdugo, M. Jenaro, C., Wang, M., Wehmeyer, M., Jiancheng, X. & Lachapelle, Y. (2005). Cross-cultural study of core quality of life indicators. *American Journal of Mental Retardation*, 110(4), 298-311. doi: 10.1352/0895-8017(2005)110[298:CSOQOL]2.0.CO;2
- Seltzer, M. M., Greenberg, J. S., Taylor, J. L., Smith, L. E., Orsmond, G. I., Esbensen, A., & Hong, J. (2011). *Adolescents and adults with autism spectrum disorder*. In D. G. Amaral, G. Dawson & D. Geschwind (Eds.), *Autism spectrum disorders* (pp. 241–252). New York, NY: Oxford.
- Shattuck, P. T., Narendorf, S. C., Cooper, B., Sterzing, P. R., Wagner, M., & Taylor, J. L. (2012). Post-secondary education and employment among youth with an autism spectrum disorder. *Pediatrics*, 129(6), 1042–1049. doi: 10.1542/peds.2011-2864
- Shogren, K. A. (2002). *Examining the measurement of self-determination and its individual and ecological predictors in students with disabilities* (Doctoral dissertation). Retrieved from Proquest Dissertations & Theses.

- Shogren, K. A. (2011). Culture and self-determination: A synthesis of the literature and directions for future research and practice. *Career Development and Transition for Exceptional Individuals, 34*(2), 115–127. doi:10.1177/0885728811398271
- Shogren, K. A. (2013). A social-ecological analysis of the self-determination literature. *Intellectual and Developmental Disabilities, 51*(6), 496-511. doi: 10.1352/1934-9556-51.6.496
- Shogren, K., Faggella-Luby, M., Bae, S. J., & Wehmeyer, M. L. (2004). The effect of Choice-Making as an intervention for problem behavior: A meta-analysis. *Journal of Positive Behavior Interventions, 6*(4), 228-237. doi: 10.1177/10983007040060040401
- Shogren, K. A., Kennedy, W., Dowsett, C., Garnier Villarreal, M., & Little, T. D. (2014). Exploring essential characteristics of self-determination for diverse students using data from NLTS2. *Career Development and Transition for Exceptional Individuals, 37*(3), 168–176. doi: 10.1177/2165143413486927
- Shogren, K. A., Kennedy, W., Dowsett, C., & Little, T. D. (2014). Autonomy, psychological empowerment, and self-realization: Exploring data on self-determination from NLTS2. *Exceptional Children, 80*(2), 221-235. doi: 10.1177/001440291408000206
- Shogren, K. A., Lopez, S. J., Wehmeyer, M. L., Little, T. D., & Pressgrove, C. L. (2006). The role of positive psychology constructs in predicting life satisfaction in adolescents with and without cognitive disabilities: An exploratory study. *The Journal of Positive Psychology, 1*(1), 37–52. doi:10.1080/17439760500373174
- Shogren, K. A., Palmer, S. B., Wehmeyer, M. L., Williams-Diehm, K., & Little, T. D. (2012). Effect of intervention with the self-determined learning model of instruction on access and goal attainment. *Remedial and Special Education, 33*(5), 320-330. doi:

10.1177/0741932511410072

- Shogren, K. A., & Turnbull, A. P. (2006). Promoting self-determination in young children with disabilities: The critical role of families. *Infants and Young Children, 19*(4), 338-352.
- Shogren, K. A., Wehmeyer, M. L., Buchanan, C. L., & Lopez, S. J. (2006). The application of positive psychology and self-determination to research in intellectual disability: A content analysis of 30 years of literature. *Research and Practice for Persons with Severe Disabilities, 31*(4), 338-345. doi: 10.1177/154079690603100408
- Shogren, K. A., Wehmeyer, M. L., & Lane, K. L. (2016). Embedding interventions to promote self-determination within multi-tiered systems of supports. *Exceptionality, 1*-12 doi: 10.1080/09362835.2015.1064421
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Forber-Pratt, A. J., Little, T. J., & Lopez, S. (2015). Causal agency theory: Re-conceptualizing a functional model of self-determination. *Education and Training in Autism and Developmental Disabilities, 50*(3), 251-263. Retrieved from [http://daddcec.org/Portals/0/CEC/Autism_Disabilities/Research/Publications/Education_Training_Development_Disabilities/2015v50/ETADD_50\(3\)_251-263.pdf](http://daddcec.org/Portals/0/CEC/Autism_Disabilities/Research/Publications/Education_Training_Development_Disabilities/2015v50/ETADD_50(3)_251-263.pdf)
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T.D., Garner, N., & Lawrence, M. (2007). Examining individual and ecological predictors of the self-determination of students with disabilities. *Exceptional Children, 73*(4), 488-509. doi: 10.1177/001440290707300406
- Shogren, K. A., Wehmeyer, M.L., Palmer, S.B., Soukup, J. H., Little, T.D., Garner, N., & Lawrence, M. (2008). Understanding the construct of self-determination: Examining the relationships between the Arc's self-determination scale and the American institutes for

- research self-determination. *Assessment for Effective Intervention*, 33(2), 94-107.
doi: 10.1177/1534508407311395
- Shogren, K. A., Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Little, T. D., Garner, N., & Lawrence, M. (2007). Examining individual and ecological predictors of the self-determination of students with disabilities. *Exceptional Children*, 73(4), 488–509.
doi: 10.1177/001440290707300406
- Shogren, K.A., Wehmeyer, M.L., Palmer, S.B., Rifenbark, G. & Little, T. (2015). Relationships between self-determination and post-school outcomes for youth with disabilities. *Journal of Special Education*, 48(4), 256-267. doi: 10.1177/0022466913489733
- Smith, C. P. (2007). Support services for students with asperger's syndrome in higher education. *College Student Journal*, 41(3), 515-531. Retrieved from <http://search.proquest.com/openview/ae7f3da39f30779353fe2eb1c9edefb2/1?pq-origsite=gscholar>
- Smith, L. E., Maenner, M. J., & Seltzer, M. M. (2012). Developmental trajectories in adolescents and adults with autism: The case of daily living skills. *Journal of the American Academy of Child and Adolescent Psychiatry*, 51(6), 622–631. doi:10.1016/j.jaac.2012.03.001
- Snyder, C. R., Shorey, H. S., Cheavens, J., Pulvers, K. M., Adams, V. H. III, & Wiklund, C. (2002). Hope and academic success in college. *Journal of Educational Psychology*, 94(4), 820–826. doi: 10.1037/0022-0663.94.4.820
- Soresi S., Nota L. & Ferrari L. (2004) Autodeterminazione e scelte scolastico-professionali: uno strumento per l'assessment [Self-determination and school-career choices: an instrument for the assessment]. *Giornale Italiano di Psicologia dell'Orientamento* 5(1), 26–42.
- Stancliffe, R. J., Avery, B.H., & Smith, J. (2000). Personal control and the ecology of

- community living settings: Beyond living-unit size and type. *American Journal on Mental Retardation*, 105(6), 431-454. doi: 10.1352/0895-8017(2000)105<0431:PCATEO>2.0.CO;2
- Stang, K. K., Carter, E. W., Lane, K. L., & Pierson, M. R. (2009). Perspectives of general and special educators on fostering self-determination in elementary and middle schools. *The Journal of Special Education*, 43(2), 94–106. doi:10.1177/0022466907313452
- Sterling, L., Dawson, G., Estes, A., & Greenson, J. (2008). Characteristics associated with presence of depressive symptoms in adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 38(6), 1011-1018. doi: 10.1007/s10803-007-0477-y
- Stoner, J., Angell, M. E., House, J. J., & Goins, K. (2006). Self-determination: Hearing the voices of adults with physical disabilities. *Physical Disabilities: Education and Related Services*, 25, 3–35. Retrieved from <http://files.eric.ed.gov/fulltext/EJ795392.pdf>
- Sugai, G., O’Keefe, B. V., & Fallon, L. M. (2012). A contextual consideration of culture and school-wide positive behavior support. *Journal of Positive Behavior Interventions*, 14(4), 197– 208. doi:10.1177/109830070000200302
- Szymanski, E. M., & Trueba, H. T. (1994). Castification of individuals with disabilities: Potential disempowering aspects of classification in disability services. *Journal of Rehabilitation*, 60(3), 12-20. Retrieved from <http://search.proquest.com/openview/9cb9743616b05fcf0e86939c81d96fb2/1?pq-origsite=gscholar&cbl=1819158>
- Tabachnick, B. G., & Fidell, L. S. (2013). *Using Multivariate Statistics (6th Edition)*. Upper Saddle River, New Jersey: Pearson Education Inc.
- Tavernor, L., Barron, E., & Rodgers, J., McConachie, H. (2012). Finding out what matters:

Validity of quality of life measurement in young people with autism spectrum disorder.

Child: Care, Health and Development, 39(4), 1-10. doi:10.1111/j.1365-2214.2012.01377.x

Taylor, S.E., Kemeny, M.E., Reed, G.M., Bower, J.E., & Gruenewald, T.L. (2000).

Psychological resources, positive illusions, and health. *American Psychologist*, 55(1), 99–109. doi:10.1037/0003-066X.55.1.99

Taylor, J.L., & Seltzer, M. M. (2010). Changes in the autism behavioral phenotype during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 40(12), 1431-1446. doi: 10.1007/s10803-010-1005-z

Taylor, J. L. & Seltzer, M. M. (2011). Employment and postsecondary educational activities for young adults with autism spectrum disorders during the transition to adulthood. *Journal of Autism and Developmental Disorders*, 41(5), 566–574. doi:10.1007/s10803-010-1070-3

Terzi, L. (2004). The social model of disability: A philosophical critique. *Journal of Applied Philosophy*, 21(2), 141-157. doi: 10.1111/j.0264-3758.2004.00269.x

Test, D. W. & Neale, M. (2004). Using the self-advocacy strategy to increase middle graders' IEP participation. *Journal of Behavioral Education*, 13(2), 135–145. doi: 10.1023/B:JOB.0000023660.21195.c2

Thoma, C. A. & Gretzel, E. E. (2005). “Self-determination is what it’s all about”: What post-secondary students with disabilities tell us are important considerations for success. *Education and Training in Developmental Disabilities*, 40(3), 234-242.

<http://www.jstor.org/stable/23879718>

Thoma, G. A., Nathanson, R., Baker, S. R., & Tamura, R. (2002). Self-determination: What do special educators know and where do they learn it? *Remedial and Special Education*, 23(4), 242-248. doi: 10.1177/07419325020230040701

- Trainor, A. A. (2007). Perceptions of adolescent girls with LD regarding self-determination and post-secondary transition planning. *Learning Disability Quarterly*, 30(1), 31-45.
doi: 10.2307/30035514
- Trainor, A., Lindstrom, L., Simon-Burroughs, M., Martin, J. E., & Sorrells, A. M. (2008). From marginalized to maximized opportunities for diverse youths with disabilities: A position paper of the division on career development and transition. *Career Development and Transition for Exceptional Individuals*, 31(1), 56-64. doi: 10.1177/0885728807313777
- Tsatsanis, K. (2003). Outcome research in asperger syndrome and autism. *Child and Adolescent Psychiatric Clinics of North America*, 12(1), 47-63. doi: 10.1016/S1056-4993(02)00056-1
- Trivette, C. M., Dunst, C. J., & Hamby, D. W. (2010). Influence of family-systems intervention practices on parent-child interactions and child development. *Topics in Early Childhood Special Education*, 30(1), 3-19. doi: 10.1177/0271121410364250
- Turnbull, A., Turnbull, R., Erwin, E., & Soodak, L., Shorgen, K. (2011). Families, professionals, and exceptionality: Positive outcomes through partnerships and trust (6th ed.). Upper Saddle River, NJ: Pearson.
- Uberti, H. Z., Mastopieri, M., & Scruggs, T. (2004). Check it off: Individualizing a math algorithm for students with disabilities via self-monitoring checklist. *Intervention in School and Clinic*, 39(5), 269-275. doi: 10.1177/10534512040390050301
- United Nations (2006). *Convention on the Rights of Persons with Disabilities*. Retrieved from <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Van Bergeijk, E., Klin, A., & Volkmar, F. (2008). Supporting more able students on the autism spectrum: College and beyond. *Journal of Autism and Developmental Disorders*, 38(7), 1359-1370. doi: 10.1007/s10803-007-0524-8

Walker, H. M., Calkins, C., Wehmeyer, M. L., Walker, L., Bacon, A., Palmer, S. B., . . .

Johnson, D. R. (2011). A social-ecological approach to promote self-determination.

Exceptionality, 19(1), 6–18. doi:10.1080 /09362835.2011.537220

Ward, M. J. (1988). The many facets of self-determination. *National Information Center for*

Children and Youth with Handicaps transition summary, 5(1), 2-3.

Ward, M.J. (1996). Coming of age in the age of self-determination: A historical perspective on

self-determination. In D. Sands & M.L. Wehmeyer (Eds.), *Self-determination across the life span: Theory and practice*. Baltimore: Brookes.

Ward, M. J., & Meyer, R. N. (1999). Self-Determination for Individuals with Developmental

Disabilities and Autism: Two Self-Advocates' Perspectives. *Focus on Autism and Other Developmental Disabilities*, 14(3), 133–139. doi:10.1177/108835769901400302

Wagner, M., Newman, L., Cameto, R., Levine, P., & Marder, C. (2007). *Perceptions and*

expectations of youth with disabilities. A special topic report of findings from the National Longitudinal Transition Study-2 (NLTS2) (NCSE 2007- 3006). Washington, DC:

National Center for Special Education Research.

Wehman, P., Schall, C., Carr, S., Targett, P., West, M., & Cifu, G. (2014). Transition from

school to adulthood for youth with autism spectrum disorder: What we know and what we need to know. *Journal of Disability Policy Studies*, 25(1), 30-40. doi:

10.1177/1044207313518071

Wehmeyer, M. L. (1992), Self-determination and the education of students with mental

retardation. *Education and Training of the Mentally Retarded*, 27(4), 302-314.

<http://www.jstor.org/stable/23878861>

Wehmeyer, M. L. (1995). The Arc's self-determination scale: Procedural guidelines. Arc,

Arlington, TX.

- Wehmeyer, M. L. (1996a). Self-determination as an educational outcome: Why is it important to children, youth and adults with disabilities? In D. J. Sands & M. L. Wehmeyer (Eds.), *Self-determination across the life span: Independence and choice for individuals with disabilities* (pp. 15–34). Baltimore: Brookes.
- Wehmeyer, M. L. (1996b). Student self-report measure of self-determination for students with cognitive disabilities. *Education and Training in Mental Retardation and Developmental Disabilities*, 31(4), 282–293. <http://www.jstor.org/stable/23879103>
- Wehmeyer, M. L. (1997). Self-determination as an educational outcome: A definitional framework and implications for intervention. *Journal of Developmental and Physical Disabilities*, 9(3), 175–209. doi: 10.1023/A:1024981820074
- Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, 14(1), 53–61. doi: 10.1177/108835769901400107
- Wehmeyer, M. L. (2001). Self-determination and mental retardation. In L. M. Glidden (Ed.), *International review of research in mental retardation* (Vol. 24, pp. 1–48). San Diego, CA: Academic Press.
- Wehmeyer, M. L. (2004). Self-determination and the empowerment of individuals with disabilities. *American Rehabilitation*, 28(1), 22–29. Retrieved from <http://hdl.handle.net/1808/10942>
- Wehmeyer, M. L. (2005). Self-determination and individuals with severe disabilities: Re-examining meanings and misinterpretations. *Research and Practice for Persons with Severe Disabilities*, 30(3), 113–120. doi: 10.2511/rpsd.30.3.113

- Wehmeyer, M. L. (2013). *The story of intellectual disability: An evolution of meaning, understanding, and public perception*. Baltimore, MD: Paul H. Brookes Publishing.
- Wehmeyer, M. L. (2014). Self-Determination: A Family Affair. *Family Relations*, 63(1), 178–184. doi: 10.1111/fare.12052
- Wehmeyer, M. L. (2015). Framing the future: self-determination. *Remedial and Special Education*, 36(1), 20–23. doi: 10.1177/0741932514551281
- Wehmeyer, M. L., Abery, B., Mithaug, D. E., & Stancliffe, R. (2003). *Theory in self-determination: Foundations for educational practice*. Springfield, IL: Charles C. Thomas Publishing Company.
- Wehmeyer, M. L., Abery, B. H., Zhang, D., Ward, K., Willis, D., Hossain, W. A., . . . Walker, H. M. (2011). Personal self-determination and moderating variables that impact efforts to promote self-determination. *Exceptionality*, 19(1), 19–30. doi:10.1080/09362835.2011.537225
- Wehmeyer, M. L., Agran, M., & Hughes, C. (2000). A national survey of teachers' promotion of self-determination and student directed learning. *Journal of Special Education*, 34(2), 58–68. doi: 10.1177/002246690003400201
- Wehmeyer, M. L., Agran, M., Hughes, C., Martin, J., Mithaug, D. E., & Palmer, S. (2007). *Promoting self-determination in students with intellectual and developmental disabilities*. New York: Guilfor Press.
- Wehmeyer, M. L., Bersani, H., Jr., & Gagne, R. (2000). Riding the third wave: Self-determination and self-advocacy in the 21st century. *Focus on Autism and Other Developmental Disabilities*, 15(2), 106-115. doi: 10.1177/108835760001500206
- Wehmeyer, M. L., & Bolding, N. (1999). *Self-determination across living and working*

- environments: A matched-samples study of adults with mental retardation. *Mental Retardation*, 37(5), 353–63. doi:10.1352/0047-6765(1999)037<0353:SALAWE>2.0.CO.2
- Wehmeyer, M. L. & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research*, 45(5), 371-383. doi: 10.1046/j.1365-2788.2001.00342.x
- Wehmeyer, M. L., Buntinx, W. H. E., Lachapelle, Y., Luckasson, R. A., Schalock, R. L., Verdugo, M. A., ... & Yeager, M. H. (2008). The intellectual disability construct and its relation to human functioning. *Intellectual and Developmental Disabilities*, 46(4), 311–318. doi: 10.1352/1934-9556(2008)46[311:TIDCAI]2.0.CO;2
- Wehmeyer, M. L., & Garner, N. W. (2003). The impact of personal characteristics of individuals with intellectual and developmental disability on self-determination and autonomous functioning. *Journal of Applied Research in Intellectual Disabilities*, 16(4), 255–265. doi:10.1046/j.1468-3148.2003.00161.x
- Wehmeyer, M. L., Field, S., Doren, B., Jones, B., & Mason, C. (2004). Self-determination and student involvement in standards-based reform. *Exceptional Children*, 70(4), 413-425. doi: 10.1177/001440290407000402
- Wehmeyer, M. L., & Kelchner, K. (1995). *The Arc's Self-determination Scale*. Arlington, TX: Arc National Headquarters.
- Wehmeyer, M. L., Kelchner, K., & Richards, S. (1996). Essential characteristics of selfdetermined behavior of individuals with mental retardation. *American Journal on Mental Retardation*, 100(6), 632 – 642. Retrieved from http://supporteddecisionmaking.com/sites/default/files/essential_characteristics_self_deter

mined_behavior.pdf

Wehmeyer, M.L., Martin, J., & Sands, D. (1998). Self-determination for children and youth with developmental disabilities. In A. Hilton & R. Ringlaben (Eds.), *Best and promising practices in developmental disabilities* (pp. 191–204). Austin, TX: Pro-Ed.

Wehmeyer, M. L., & Metzler, C. (1995). How self-determined are individuals with mental retardation? The National Consumer Survey. *Mental Retardation*, 33(2), 111–119.

Retrieved from

<http://search.proquest.com/openview/0799b4ebd8aefb0ab3376680f5fcd115/1?pq-origsite=gscholar&cbl=1976608>

Wehmeyer, M. L., & Mithaug, D. (2006). Self-determination, causal agency, and mental retardation. In H. Switzky (Ed.), *Current perspectives on individual differences in personality and motivation in persons with mental retardation and other developmental disabilities* (Vol. 31, pp. 37–71). San Diego, CA: Academic Press.

Wehmeyer, M. L., & Palmer, S. B. (2000). Promoting the acquisition and development of self-determination in young children with disabilities. *Early Education and Development*, 4, 465-481. doi: 10.1207/s15566935eed1104_6

Wehmeyer, M. L., & Palmer, S.B. (2003). Adult outcomes for students with cognitive disabilities three years after high school: The impact of self-determination. *Education and Training in Developmental Disabilities*, 38(2), 131-144.

<http://www.jstor.org/stable/23879591>

Wehmeyer, M. L., Palmer, S. B., Lee, Y., Williams-Diehm, K., & Shogren, K. (2011). A randomized-trial evaluation of the effect of Whose Future Is It Anyway? On self-determination. *Career Development for Exceptional Individuals*, 34(1), 45–56.

doi:10.1177/0885728810383559

Wehmeyer, M. L., Palmer, S., Shogren, K. A., Williams-Diehm, K., & Soukup, J. (2012).

Establishing a causal relationship between interventions to promote self-determination and enhanced student self-determination. *Journal of Special Education, 46*, 195–210. doi: 10.1177/0022466910392377

Wehmeyer, M. L., Palmer, S. B., Soukup, J. H., Garner, N. W., & Lawrence, M. (2007). Self-determination and student transition planning knowledge and skills: Predicting involvement. *Exceptionality: A Special Education Journal, 15*(1), 31-44. doi: 10.1080/09362830709336924

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*(4), 305–328. doi: 10.1080/0156655970440403

Wehmeyer, M. L., & Schalock, R. L. (2001). Self-determination and quality of life: Implications for special education services and supports. *Focus on Exceptional Children, 33*(8) 1-16. Retrieved from http://supporteddecisionmaking.org/sites/default/files/self-determination_quality_of_life_implications_special_education.pdf

Wehmeyer, M. L., & Schwartz, M. (1997). Self-determination and positive adult outcomes: A follow up study of youth with mental retardation or learning disabilities. *Exceptional Children, 63*(2), 245– 255. doi: 10.1177/001440299706300207

Wehmeyer, W. & Schwartz, M. (1998). The relationship between self-determination and quality of life for adults with mental retardation. *Education and Training in Mental Retardation and Developmental Disabilities, 33*(1), 3-12. <http://www.jstor.org/stable/23879037>

- Wehmeyer, M. L., & Shogren, K. A. (2008). Self-determination and learners with autism spectrum disorders. In R. L. Simpson & B. S. Myles (Eds.), *Educating children and youth with autism* (2nd ed., pp. 433–476). Austin, TX: Pro-Ed.
- Wehmeyer, M. L., Shogren, K. A., Palmer, S. B., Williams-Diehm, K., Little, T. D., & Boulton, A. (2012). Impact of the self-determined learning model of instruction on student self-determination: A randomized-trial placebo control group study. *Exceptional Children*, 78(2), 135–153. doi: 10.1177/001440291207800201
- Wehmeyer, M. L., Shogren, K. A., Zager, D., Smith, T.E.C., & Simpson, R. (2010). Research-based principles and practices for educating students with autism: Self-determination and social interactions. *Education and Training in Autism and Developmental Disabilities*, 45(4), 475–486. <http://www.jstor.org/stable/23879754>
- Wei, X., Yu, J. W., Shattuck, P., McCracken, M., & Blackorby, J. (2013). Science, technology, engineering, and mathematics (STEM) participation among college students with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 43(7), 1539–1546. doi: 10.1007/s10803-012-1700-z
- Williams-Diehm, K., Wehmeyer, M. L., Palmer, S., Soukup, J. H., & Garner, N. (2008). Self-determination and student involvement in transition planning: A multivariate analysis. *Journal on Developmental Disabilities*, 14(1), 25–36. Retrieved from <http://www.oadd.org/docs/williamsdiehmEtAl.pdf>
- Wolfensberger, W. (1972). *Normalization: The principle of normalization*. Toronto: National Institute on Mental Retardation.
- Wolman, J., Campeau, P., Dubois, P., Mithaug, D., & Stolarski, V. (1994). *AIR self-determination Scale and user guide*. Palo Alto, CA: American Institute for Research.

- Wood, W. M., Karvonen, M., Test, D. W., Browder, D., & Algozzine, B. (2004). Promoting student self-determination skills in IEP planning. *Teaching Exceptional Children, 36*(3), 8-16. doi: 10.1177/004005990403600301
- Woodbury-Smith, M. R., Robinson, J., Wheelwright, S., & Baron-Cohen, S. (2005). Screening adults for asperger syndrome using the AQ: A preliminary study of its diagnostic validity in clinical practice. *Journal of Autism and Developmental Disorders, 35*(3), 331–335. doi: 10.1007/s10803-005-3300-7
- Woodman, A. C., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2015). Contextual factors predict patterns of change in functioning over 10 years among adolescents and adults with autism spectrum disorders. *Journal of Autism and Developmental Disorders, 46*(1), 176-189. doi: 10.1007/s10803-015-2561-z
- Wright, K. B. (2005). Researching internet-based populations: Advantages and disadvantages of online survey research, online questionnaire authoring software packages, and web based survey services. *Journal of Computer-Mediated Communication, 10*(3), 00-00
doi: 10.1111/j.1083-6101.2005.tb00259.x
- Zhang, D. (2001). Self-determination and inclusion: Are students with mild mental retardation more self-determined in regular classrooms? *Education and Training in Mental Retardation and Developmental Disabilities, 36*(4), 357–362. Retrieved from <http://www.jstor.org/stable/23879897>
- Zimmerman, M. A. (1990). Toward a theory of learned hopefulness: A structural model analysis of participation and empowerment. *Journal of Research in Personality, 24*(1), 71-86. doi: 10.1016/0092-6566(90)90007-S
- Zinbarg, R. E., Revelle, W., Yovel, I., & Li, W. (2005). Cronbach's α , Revelle's β , and

McDonald's ω_H): Their relations with each other and two alternative conceptualizations of reliability. *Psychometrika*, 70(1), 123-133. doi: 10.1007/s11336-003-0974-7

Table 1

Phases of Thematic Analysis

Phase	Description of the process
1. Familiarizing yourself with your data:	Reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2) generating a thematic “map” of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Note. Taken from Braun and Clark (2006)

Table 2

Descriptive Statistics of the Demographic Variables (n = 125)

Variable	n (%)
Country of Birth	
Canada	110 (88%)
United States	3 (2.4%)
China	3 (2.4%)
Russia	3 (2.4%)
United Kingdom	2 (1.6%)
Sri Lanka	2 (1.6%)
Iran	1 (.8%)
El Salvador	1 (.8%)
Years living in Canada	
Less than 4 years	3 (2.4%)
5-9 years	1 (.8%)
10-14 years	11 (8.8%)
15-19 years	5 (4%)
20 years or more	8 (6.4%)
All my life	97 (77.6%)
Canadian Province or Territory	
Ontario	54 (43.2%)
Quebec	19 (15.2%)
Alberta	14 (11.2%)
British Columbia	13 (10.4%)
Manitoba	9 (7.2%)
New Brunswick	6 (4.8%)
Prince Edward Island	5 (4.0%)
Newfoundland and Labrador	2 (1.6%)
Nova Scotia	3 (2.4%)
Community Size	
Remote area	1 (.8%)
Rural area	21 (16.8%)
Suburban area	40 (32.0%)
Urban area	63 (50.4%)
First language	
English	111 (88.8%)
French	6 (4.8%)
Russian	2 (1.6%)
Vietnamese	1 (.8%)
Spanish	1 (.8%)
Korean	1 (.8%)
Chinese	1 (.8%)
Cantonese	1 (.8%)
Farsi	1 (.8%)
Highest Level of Education Completed	

Junior high/middle school (9 th grade)	2 (1.6%)
Partial high school (10 th or 11 th grade)	9 (7.2%)
High school graduate	29 (23.2%)
Partial college (at least one year)	44 (35.2%)
College/university graduate	34 (27.2%)
Graduate degree	7 (5.6%)
Occupation (n = 46)	
General Labour	5 (4.0%)
Restaurant-Food service	5 (4.0%)
Education	4 (3.2%)
Sales	4 (3.2%)
Retail	3 (2.4%)
Professional Services	3 (2.4%)
Research	2 (1.6%)
Skilled Labour	2 (1.6%)
Computer and IT	1 (.8%)
Engineering	1 (.8%)
Administration	1 (.8%)
Management	1 (.8%)
Not reported	14 (11.2%)
Ethnicity	
White/Canadian	99 (79.2%)
Asian, Asian Canadian or Pacific Islander (e.g., Chinese, Japanese)	10 (8.0%)
Multi-ethnic	9 (7.2%)
First Nations/Aboriginal	4 (3.2%)
Hispanic	2 (1.6%)
Black/African-Canadian	1 (.8%)
Current Living Situation	
With my parent/caregiver(s)	68 (54.4%)
Independently with some financial assistance	18 (14.4%)
Independently with roommates (you pay your share)	18 (14.4%)
Independently (you pay for all of your own bills)	17 (13.6%)
With another family member	4 (3.2%)

Table 3

Frequency of Services/Programs Currently and Ever Utilized (n = 125)

	<i>Current</i>			<i>Ever</i>		
	<i>M (SD)</i>	<i>Minimum</i>	<i>Maximum</i>	<i>M (SD)</i>	<i>Minimum</i>	<i>Maximum</i>
	1.79 (1.52)	0	7	3.80 (2.24)	0	9
<i>Service/Program</i>	<i>n (%)</i>			<i>n (%)</i>		
Employment or day programs	15 (12%)			50 (40%)		
Life skills training	19 (15.2%)			42 (33.6%)		
Social skills programs	20 (16.0%)			50 (40.0%)		
Recreational or leisure program (e.g., swimming)	17 (13.6%)			75 (60%)		
Post-secondary educational programs (e.g., CEGEP, university)	56 (44.8%)			75 (60%)		
Diagnostic, developmental, and/or skills assessment services	12 (9.6%)			-		
Mental health treatment (e.g., counseling therapy)	49 (39.2%)			81 (64.8%)		
Employment services (i.e., help to find a job)	17 (13.6%)			54 (43.2%)		
Housing or residential options	7 (5.6%)			13 (10.4%)		
Community safety training	3 (2.4%)			6 (4.8%)		
Transition support program	9 (7.2%)			29 (23.2%)		
I am not currently receiving or participating	23 (18.4%)			7 (5.6%)		

Note. Diagnostic, developmental, and/or skills assessment services were not listed in the Ever list

Table 4

Definitions of support levels typically required on a daily basis

Support Level	Definition
Infrequent or No support	You require infrequent or no support. For example, you may possess the ability to live and work independently with occasional advice or assistance from others.
Intermittent	You require intermittent or periodic support and supervision. For example, you may be able to manage most daily activities independently, but may sometimes need periodic advice, support, assistance, or supervision.
Limited	You require limited but consistent support and supervision. For example, you may be independent in some personal care skills, but may require help, support or supervision with many daily activities.
Frequent	You require frequent or close support and supervision with most daily activities. For example, your personal care skills range from beginning to intermediate levels, but still require assistance with most daily activities.
Extensive	You require extensive or continuous support and supervision. For example, you may attain beginning self-care skills but may still require almost total personal care.
Pervasive	You require pervasive or highly intense levels of support and supervision in all circumstances. For example special life support measures or personal care similar to that required by a newborn.

Note. Definitions are based on the *Scales of Independent Behavior – Revised (SIB-R)* support levels.

Table 5

Official and Unofficial Self-Perceived Mental Health Issues

Dx	Official <i>n</i> (%)	Unofficial <i>n</i> (%)
Depression	56 (44.8%)	11 (8.8%)
Anxiety	74 (59.2%)	14 (11.2%)
Schizophrenia/psychosis	7 (5.6%)	1 (.8%)
Personality disorder	6 (4.8%)	5 (4.0%)
Obsessive compulsive disorder	27 (21.6%)	11 (8.8%)
Bipolar disorder	11 (8.8%)	5 (4.0%)
Eating disorder	11 (8.8%)	3 (2.4%)
Tourette syndrome or Tic disorder	5 (4%)	3 (2.4%)
ADHD	27 (21.6%)	5 (4.0%)
Learning Disability	39 (31.2%)	6 (4.8%)
PTSD	2 (1.6%)	5 (4.0%)
Trichotillomania	2 (1.6%)	-
Sensory processing disorder	1 (.8%)	-
Prefer not to self-disclose		1 (.8%)

Note. Dx = Diagnosis

Table 6

Descriptive Statistics (n = 125)

Variable	Mean	SD	Minimum	Maximum
Age	23.15	3.65	18	30
Total AQ score	33.45	5.82	26	46
AQ social skills	6.54	1.85	2	10
AQ attention	8.26	1.74	4	10
Switching				
AQ communication	6.94	1.91	1	10
AQ imagination	5.03	2.20	0	10
AQ attention to	6.69	1.90	2	10
Detail				
SDS Total Score	83.19	19.40	29	125
Autonomy	52.49	14.04	12	91
Self-regulation	10.94	4.81	0	19
Psychological	10.96	3.49	1	16
Empowerment				
Self-realization	8.81	3.17	1	15
AIR Total Score	80.37	17.86	24	120
Capacity	41.00	9.65	12	60
Opportunity	39.38	10.90	12	60
SDS autonomy	107.55	18.50	48	158
importance				
SDS psychological	62.57	10.50	23	79
empowerment				
importance				
SDS self-realization	53.94	9.96	20	75
importance				

Note. AQ = Autism Spectrum Quotient. SDS = Arc's Self-Determination Scale. AIR-S = AIR Self-Determination Scale – Student form

Table 7

Correlations AQ and SDS (n = 125)

Variable	1	2	3	4	5	6	7	8	9	10	11
1. Total AQ score	-	.707**	.632**	.668**	.673**	.361**	-.026	.015	.135	-.171	-.241**
2. AQ social skills		-	.401**	.403**	.337**	.040	-.219*	-.138	-.063	-.340**	-.259**
3. AQ attention switching			-	.270**	.263**	.067	-.022	-.043	.176*	-.010	-.203*
4. AQ communication				-	.331**	.019	-.018	-.011	.212*	-.166	-.200*
5. AQ imagination					-	.006	-.118	-.026	-.039	-.211*	-.318**
6. AQ attention to detail						-	-.318**	.267**	.152	.234**	.274**
7. SDS Total Score							-	.902**	.540**	.662**	.576**
8. SDS Autonomy								-	.242**	.370**	.320**
9. SDS Self-regulation									-	.426**	.247**
10. SDS Psychological Empowerment										-	.666**
11. SDS Self-realization											-

Note. **. p < .01 and * p < .05

Table 8

Correlations AQ and AIR

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13
1. Total AQ score	-	.707**	.632**	.668**	.673**	.361**	-.312**	-.201*	-.182*	-.204*	-.333**	-.345**	-.240**
2. AQ social skills		-	.401**	.403**	.337**	.040	-.313**	-.278**	-.274**	-.261**	-.267**	-.296**	-.172
3. AQ attention switching			-	.270**	.263**	.067	-.174	-.074	-.038	-.102	-.220*	-.251**	-.135
4. AQ communication				-	.331**	.019	-.165	-.160	-.159	-.150	-.129	-.185*	-.040
5. AQ imagination					-	.006	-.297**	-.222*	-.230**	-.198*	-.290**	-.258**	-.251**
6. AQ attention to detail						-	.020	.145	.178*	.101	-.096	-.052	-.116
7. AIR Total Score							-	.851**	.799**	.836**	.885**	.813**	.741**
8. AIR Capacity								-	.960**	.962**	.509**	.512**	.380**
9. AIR things I do									-	.847**	.459**	.459**	.346**
10. AIR how I feel										-	.518**	.525**	.384**
11. Opportunity											-	.878**	.877**
12. AIR school												-	.541**
13. AIR home													-

Note. **. $p < .01$ and * $p < .05$

Table 9

Correlations SDS and AIR

Variable	1	2	3	4	5	6	7	8	9	10	11	12
1. SDS Total Score	-	.902**	.540**	.662**	.576**	.521**	.616**	.582**	.603**	.308**	.300**	.241**
2. Autonomy		-	.242**	.370**	.320**	.342**	.465**	.457**	.438**	.148	.142	.118
3. Self-regulation			-	.426**	.247**	.273**	.305**	.269**	.316**	.178*	.165	.147
4. Psychological Empowerment				-	.666**	.576**	.609**	.536**	.633**	.404**	.416**	.294**
5. Self-realization					-	.627**	.578**	.541**	.571**	.515**	.498**	.405**
6. AIR Total Score						-	.851**	.799**	.836**	.885**	.813**	.741**
7. Capacity							-	.960**	.962**	.509**	.512**	.380**
8. AIR things I do								-	.847**	.459**	.459**	.346**
9. AIR how I feel									-	.518**	.525**	.384**
10. Opportunity										-	.878**	.877**
11. AIR school											-	.541**
12. AIR home												-

Note. **. p < .01 and * p < .05

SELF-DETERMINATION AND AUTISM SPECTRUM DISORDER

Table 10.

Correlations SD and demographic

Variable	1	2	3	4	5	6
1. Age	-	.526**	.025	.356**	.035	.116
2. Education		-	.036	.289**	.063	.140
3. Support			-	-.223*	-.023	.073
4. SDS total				-	.521**	-.026
5. AIR total					-	-.312**
6. AQ total						-

Note. ** $p < .01$ and * $p < .05$

Table 11

Descriptive Statistics for Regression Analysis

Variable	Mean	SD	Minimum	Maximum
Age	23.15	3.65	18	30
Gender	1.60	.62	1	3
Education	4.96	1.08	2	7
Capacity	41.00	9.65	12	60
Importance	4.38	.85	2	5
SDS Total Score	83.19	19.40	29	125

Table 12

Correlations of IVs in Hierarchical Multiple Regression

Variable	1	2	3	4	5	6
1. Age	-	.526**	-.162	.119	.119	-.048
2. Education		-	-.204*	.105	.073	.038
3. Gender			-	-.049	.029	-.076
4. Importance				-	.464**	.249**
5. AIR Capacity					-	.509**
6. AIR Opportunity						-

Note. ** $p < .01$ and * $p < .05$

Table 13

Hierarchical Regression Analysis

Variable	<i>R</i>	<i>R</i> ²	<i>B</i>	<i>SE</i>	β
Step 1	.696	.484			
Age			1.093	.415	.205*
Gender			-3.029	2.102	-.097
Education			1.947	1.391	.108
Capacity			1.035	.169	.515*
Step 2	.696	.484			
Opportunity			.015	.137	.009
Step 3	.708	.501			
Importance			.146	1.686	.146*

Note. *B* = unstandardized regression coefficient; *SE* = standard error of the coefficient; β = standardized coefficient. $R^2 = .484$; $F(4, 120) = 28.16, p = .000$ for Step 1: $\Delta R^2 = .000$; $F(5, 119) = 22.35, p = .000$ for Step 2: $\Delta R^2 = .017$; $F(6, 118) = 19.74, p = .000$ for Step 3.

* $p < .05$

Table 14

SDS self-perceived value or importance across domains (n = 125)

Variable					Not Import ant	A Little Important	Somewhat Important	Important	Very Important
	<i>M</i>	<i>SD</i>	<i>Min</i>	<i>Max</i>	<i>n (%)</i>				
Autonomy	4.496	.736	2	5	0 (0%)	4 (3.2%)	6 (4.8%)	39 (31.2%)	76 (60.8%)
Social Problem Solving	4.064	.895	1	5	2 (1.6%)	3 (2.4%)	25 (20%)	50 (40%)	45 (36.0%)
Goal Setting an Attainment	3.912	1.12 1	1	5	6 (4.8%)	10 (8.0%)	18 (14.4%)	46 (36.8%)	45 (36.0%)
Psychological Empowerment	4.230	.862	2	5	0 (0%)	6 (4.8%)	17 (13.6%)	44 (35.2%)	58 (46.4%)
Self- Realization	4.216	.866	2	5	0 (0%)	7 (5.6%)	15 (12.0%)	47 (37.6%)	56 (44.8%)
SD Satisfaction	3.280	1.23 5	1	5	17 (13.6 %)	10 (8.0%)	40 (32.0%)	37 (29.6%)	21 (16.8%)
SD Importance	4.384	.849	2	5	0 (0%)	5 (4.0%)	15 (12.0%)	32 (25.6%)	73 (58.4%)

Note. SD = Self-Determination

Table 15

Cross-tabulation of Satisfaction vs. Importance SD scores (i.e., How Satisfied are you with your current level of self-determined behaviour? X How important is it for you to be a self-determined individual?)

Variable	Not Important	A Little Important	Somewhat Important	Important	Very Important	Total
Not Satisfied	-	1	2	2	12	17
A Little Satisfied	-	2	1	3	4	10
Somewhat Satisfied	-	1	10	12	17	40
Satisfied	-	1	2	14	20	37
Very Satisfied	-	0	0	1	20	21
Total	-	5	15	32	73	125

N = 50, 40% not satisfied, but important

N = 55, 44% satisfied and important

N = 17, 13.6% not satisfied, not important

N = 3, 2.4% satisfied, but not important

Table 16

Item level analysis of the importance ratings added to the SDS scale

Variable	%
Autonomy (32 items)	
Don't Act Autonomous; Important	12.925
Don't Act Autonomous; Not Important	36.15
Autonomous; Important	37.5
Autonomous; Not Important	13.425
Psychological Empowerment (16 items)	
Not Psychological Empowered; Important	15
Not Psychological Empowered; Not Important	16.5
Psychological Empowered; Important	53.8
Psychological Empowered; Not Important	14.7
Self-Realization (15 items)	
Not Self-Realized; Important	19.95
Not Self-Realized; Not Important	21.33
Self-Realized; Important	37.44
Self-Realized; Not Important	21.28

Table 17

Inductive and deductive codes that emerged from the thematic analysis

Deductive	Inductive
Wehmeyer's Self-Determination Theory	Positive, future-oriented or forward thinking
Autonomy	Negative, pessimistic thinking
Self-Regulation (interpersonal cognitive problem solving & goal setting and task performance)	Adult Outcomes (education, employment, social relationships, adaptive functioning, social communication, mental health, independent living)
Psychological Empowerment (internal locus of control, self-efficacy, & outcome expectancy/expectations)	Motivation, or drive
Self-Realization (self-awareness, self-acceptance, self-confidence, self-esteem, self-actualization)	Mental health (barrier)
Wehmeyer's Causal Agency Theory	External locus of control
Volitional Action (self-initiation)	Interpersonal
Agentic Action (self-direction & pathways thinking)	System, society (barrier)
Action-Control Beliefs (control expectancy, capacity beliefs, & causality beliefs)	Other's attitudes (barrier)
Doll et al.'s Component Elements	Progress
Choice making, decision-making, problem-solving, goal setting and attainment, self-observations, evaluation, and reinforcement, internal locus of control, positive attributions of efficacy and outcome expectancy, self-awareness, & self-knowledge	Static
Wehmen's SD theory	Independence
Capacity	Dependence
Opportunity	Learned helplessness
Deci and Ryan's Basic Psychological Needs	Learned hopefulness
Autonomy	Self-advocacy, rights
Competence	
Relatedness	

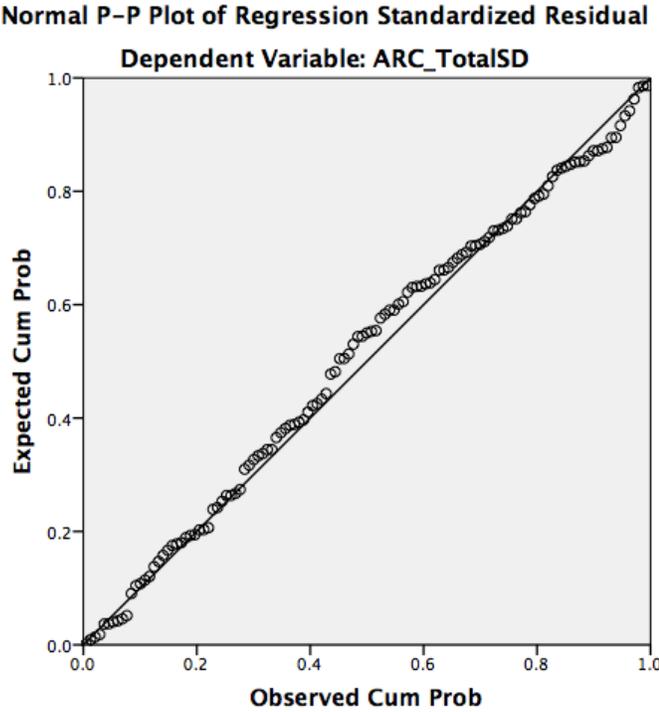


Figure 1. P-P Plot of Regression Standardized Residual

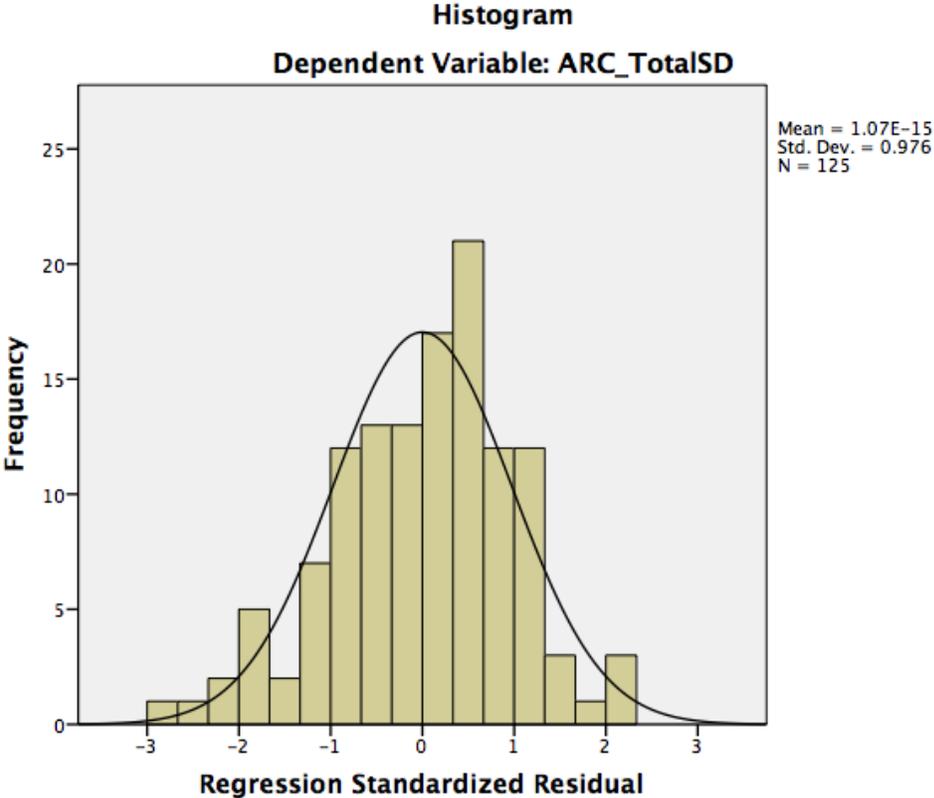


Figure 2. Regression Standardized Residuals

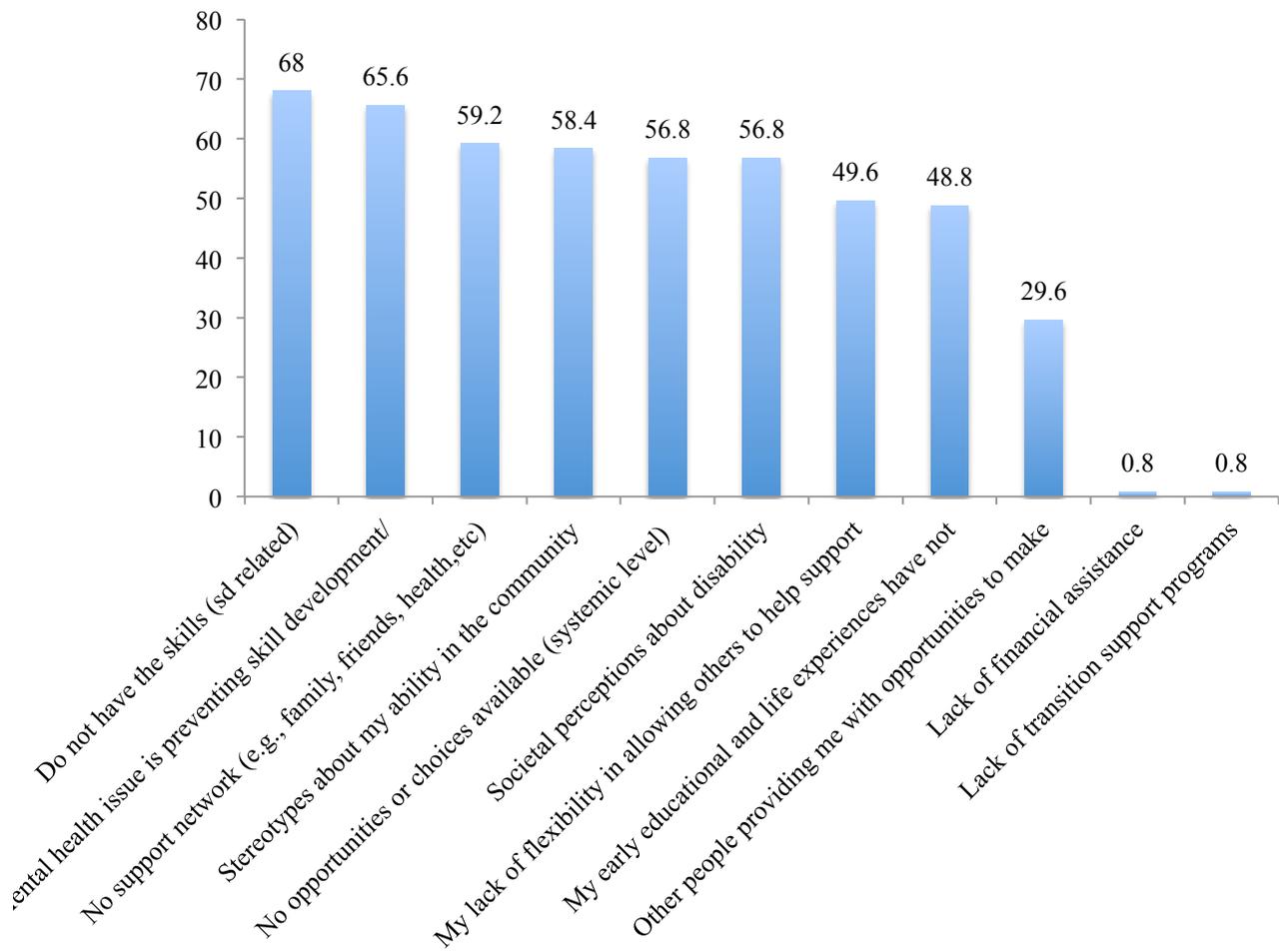


Figure 3. Barriers to SD

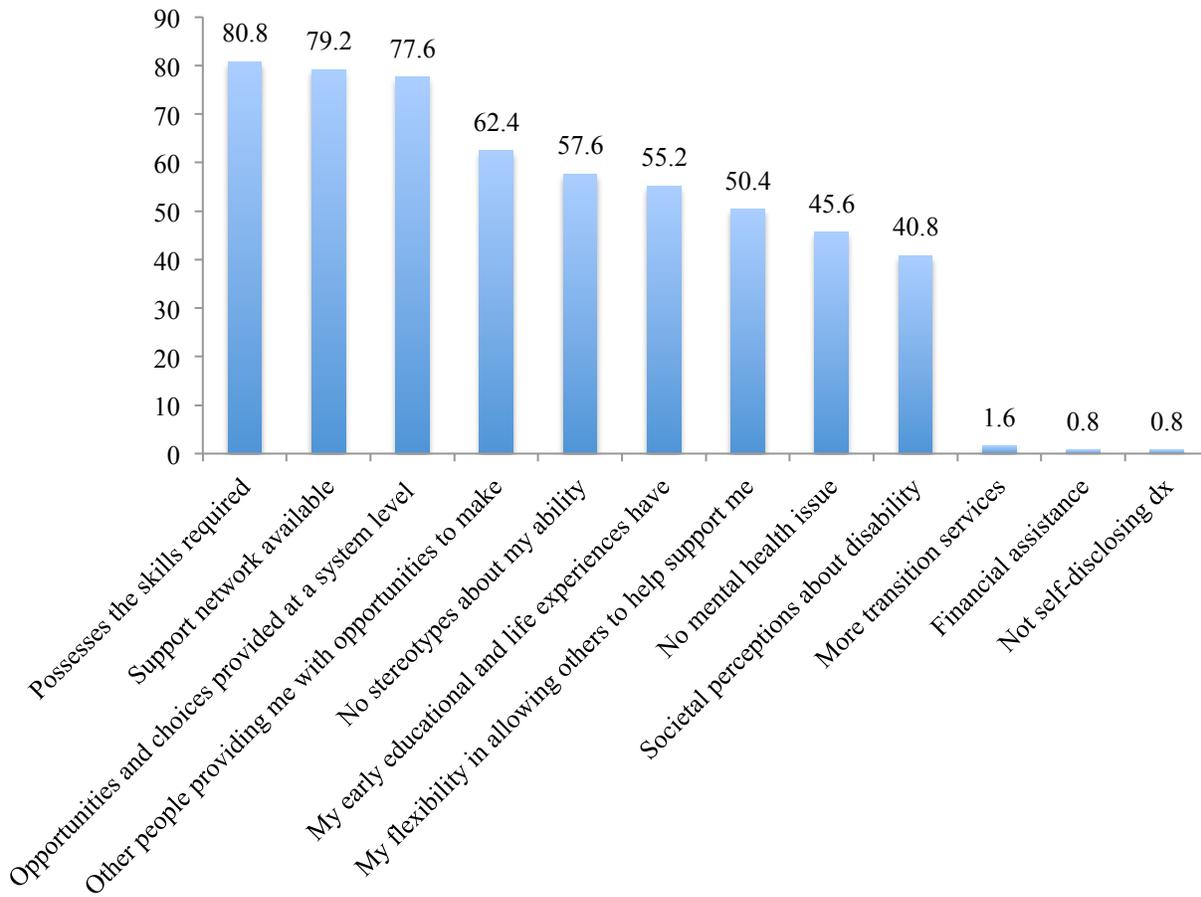


Figure 4. Facilitators to SD

Appendices

- A INFORMATION LETTER
- B INFORMED CONSENT FORM
- C ONLINE SURVEY

Appendix A: Information Letter



Educational & Counselling Psychology
Room 614, Education Building
3700 McTavish Street
Montreal, Quebec H3A 1Y2

Student Researcher

Keeley White, MA, PhD candidate
School/Applied Child Psychology
McGill University
Email: mcgillSDinASD@gmail.com
Phone: (514) 398-2765

Supervisor

Tara Dawn Flanagan, PhD
Department of Educational and Counselling Psychology
McGill University
Email: taradawn.flanagan@mcgill.ca
Phone: (514) 368-3441

LETTER OF INVITATION TO PARTICIPATE IN RESEARCH

Project Title: Finding out what matters: Self-determination in young adults with Autism Spectrum Disorders

My name is Keeley White. I am a doctoral candidate in the School/Applied Child Psychology Program at McGill University. I am conducting a research study as part of the requirements of my Doctoral degree, and would like to invite you to participate. This study is funded in part by the Fonds de Recherche sur la Société et la Culture (FRQSC).

The purpose of this study is to help gain descriptive insight into self-determination of young adults (between 18 and 30 years old) with Autism Spectrum Disorders (ASD) without an intellectual disability in Canada. In particular, the study will attempt to better understand the construct of self-determination for young adults with ASD. If you decide to participate, you will be asked to complete an anonymous online survey that will take approximately 30 to 45 minutes to complete. As a small token of their appreciation, the researcher is offering a \$15 gift certificate to participants who complete the full survey.

Participation is confidential. Study information will be kept in a secure location at McGill University. The results of the study may be published or presented at professional meetings, but your identity will not be revealed.

This information is very important for informing transition planning, and will inform future efforts to understand the construct of self-determination, to create environmental conditions that are supportive of the development of self-determination, and to inform efforts to promote self-determination.

If you have any questions about the McGill Self-Determination in Autism Spectrum Disorders (SD in ASD) Survey, please email mcgillsdinasd@gmail.com. For general information, Keeley White may be contacted at (514) 398-1765.

Thank you,

Keeley White, MA
PhD Candidate
School Applied Child Psychology
McGill University
mcgillsdinasd@gmail.com

Note: If you do not meet the requirements to participate in this research project, please feel free to pass this information on to other young adults with ASD.

This study has been reviewed and received ethics clearance through McGill University's Research Ethics Board (file # XXXXX)

Appendix B: Informed Consent Form



Educational & Counselling Psychology
Room 614, Education Building
3700 McTavish Street
Montreal, Quebec H3A 1Y2

Student Researcher

Keeley White, MA, PhD candidate
School/Applied Child Psychology
McGill University
Email: mcgillSDinASD@gmail.com
Phone: (514) 398-2765

Supervisor

Tara Dawn Flanagan, PhD
Department of Educational and Counselling Psychology
McGill University
Email: taradawn.flanagan@mcgill.ca
Phone: (514) 368-3441

CONSENT FORM

Project Title: Finding out what matters: Self-determination in young adults with Autism Spectrum Disorders

Purpose of the Study

My name is Keeley White. I am a doctoral candidate in the School/Applied Child Psychology Program at McGill University. I am conducting a research study as part of the requirements of my Doctoral degree, and would like to invite you to participate. This study is funded in part by the Fonds de Recherche sur la Société et la Culture (FRQSC). If you have any questions about the McGill Self-Determination in Autism Spectrum Disorders (SD in ASD) Survey, please email at mcgillsdinasd@gmail.com or phone at (514) 398-1765.

The purpose of this SD in ASD study is to help gain descriptive insight of self-determination for young adults with Autism Spectrum Disorders (without an intellectual disability) between 18 and 30 years old in Canada. In particular, the study will attempt to understand the individuals's current levels of self-determination, their capacity and opportunity to become self-determined individuals, their rated value or importance of self-determination, and the predictors and perceived barriers and facilitators that impact the development of self-determination. This information is very important for informing transition planning after school, and will inform future efforts to understand the construct of self-determination, to create environmental conditions that are supportive of the development of self-determination, and to inform efforts to promote self-determination.

Involvement

My involvement would consist of completing an anonymous online survey. Some of the questions will be about my current situation (e.g., age, living situation, education), and some of the questions will be about my self-determined behaviours, my perceived value or importance of these behaviours, and the factors that impact their development. The Survey will take approximately 30 to 45 minutes to complete.

Risks and Benefits

I realize that there are no appreciable risks to participating in this study although answering some of the questions may raise feelings of distress or frustration. If this does occur, I understand I may refer to the researcher, Keeley White for a list of supportive resources.

An indirect benefit to me will be that my responses will be contributing to knowledge about this group of young adults with ASD. I understand that the researchers hope to use this knowledge to help raise

awareness of the needs of these young adults and to improve the services being offered across Canada. As a small token of their appreciation, the researchers are offering a \$15 gift certificate to participants who complete the full survey.

Confidentiality

I understand that the Survey information will be kept confidential, unless you are legally required to disclose information such as in the case where there are reasonable ground to raise concerns about maltreatment, abuse, or neglect. Once collected, information will be stored on a password protected electronic database on computers housed in locked offices at McGill University. Data will be stored for 5 years after publication of the study per publication standards. The researcher will undertake analyses themselves. The information provided will be combined with that of other participants and analyzed as a group. I understand that I will never be identified by name or in any way in any report or publication from the study.

In addition, an optional form will appear at the end of the Survey which I may print and send in, asking me to provide contact information for one or more of the following reason(s): if I would like a copy of the results of the overall study, if I agree that the researchers may contact me for more in-depth studies later, and if I choose to request the \$15 honorarium. For any of these three reasons, I understand that I would need to provide contact information. However, I understand that this information will not be used for any other reason than the ones stated and cannot be linked to my survey answers.

Ethical Approval

I understand that this study has been reviewed and approved for compliance with McGill University Research Ethics Boards, Montreal, Qc, Canada, and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions or concerns regarding your rights or welfare as a participant in this research study, please contact the McGill Ethics Officer at 514-398-6831 or lynda.mcneil@mcgill.ca. This study has been reviewed and received ethics clearance through the Research Ethics Board (REB) at McGill University (**File#XXX**).

Voluntary Consent

I am aware that participation is entirely voluntary and that if I choose not to participate, it will have no impact whatsoever on my child or family receiving service from the researchers, McGill University or any organization or group associated with this project in the future. I have the right to complete some parts of the study and not others and to withdraw from participation at any time by clicking the exit button. If I choose to do so, my responses will be erased and the researchers will not have access to them.

Participant name: _____ Signature: _____

Date: _____

Appendix C: Online Survey



McGill

Educational & Counselling Psychology
Room 614, Education Building
3700 McTavish Street
Montreal, Quebec H3A 1Y2

Contact: Keeley White, PhD candidate
Email: mcgillSDinASD@gmail.com
Phone: (514) 398-2765

Finding out what matters: Self-determination in young adults with high functioning Autism Spectrum Disorders

Instructions:

- Complete as many of the questions as possible
- Keep in mind that questions are mainly multiple choice for speed of completion
- Note that some sections refer to a different time range, such as within the last 6 months. These are underlined, and the listed time frame should be kept in mind when answering the questions for that sections.
- Call us at the phone number above, or email us at mcgillSDinASD@gmail.com if you have any questions

Finding out what matters: Self-determination in young adults with high functioning Autism Spectrum Disorders Online survey (30 to 45 minutes)

A. Please answer the following background questions

A1. What gender are you?

- a. Male
- b. Female
- c. Transgender

A2. What is your year and month of birth (MM/YY)? _____

A3. How old are you? _____

A4. What is your Country of birth? _____

A5. Do you currently live in Canada? Y/N What Canadian province/territory do you live in? _____

A6. If born outside of Canada, how many years have you lived in Canada?

- a. Less than 4 years
- b. 5-9 years
- c. 10-14 years
- d. 15-19 years
- e. 20 years or more
- f. All my life

A7. What is the best way to describe the size of your community:

- a. Remote area of Canada
- b. Rural area of Canada
- c. Suburban area of Canada
- d. Urban area of Canada

A8. What is your first language? _____

A9. What is the highest level of education that you completed?

- a. Less than 7th grade
- b. Junior high/middle school (9th grade)
- c. Partial high school (10th or 11th grade)
- d. High school graduate
- e. Partial college (at least one year)
- f. College/University graduate
- g. Graduate degree

A10. Are you currently employed? Yes/No What is your occupation? Please be specific (e.g., secretary, banker, trucker) _____

Full time? Part time? No employment?

A11. What is your family's ethnic background?

- a. Asian, Asian Canadian or Pacific Islander (e.g., Chinese, Japanese)
- b. Black/African-Canadian
- c. Hispanic
- d. White/Canadian
- e. First Nations/Aboriginal
- f. Multi-ethnic
- g. Other: _____

A12. Describe your current living situation

- a. At home, with my parent(s) or caregiver(s)
- b. With another family member
- c. Independently with some financial assistance (e.g., reduced rent apartment funded by the government)
- d. Independently, but with roommates (e.g., you pay for your share of the bills)
- e. Independently (e.g., you pay for all of your own bills)

A13. Are you currently receiving or participating in any of the following services/programs?

- a. Employment of day programs
 - b. Life skills training
 - c. Social skills programs
 - d. Recreational or leisure program (e.g., swimming)
 - e. Post-secondary educational programs (e.g., CEGEP, university)
 - f. Diagnostic/developmental/skill assessment services (including ASD diagnoses)
 - g. Mental health treatment (e.g., counseling, therapy)
 - h. Employment services (i.e., help to find a job)
 - i. Housing or residential options
 - j. Community safety training
 - k. Transition support program
 - l. I am not currently receiving or participating in any of the above mentioned services or programs
 - m. Other services or programs not listed here (please specify)
- _____

A14. Have you ever received or participated in any of the following services/programs?

- a. Employment of day programs
 - b. Life skills training
 - c. Social skills programs
 - d. Recreational or leisure program (e.g., swimming)
 - e. Post-secondary educational programs (e.g., CEGEP, university)
 - f. Diagnostic/developmental/skill assessment services (including ASD diagnoses)
 - g. Mental health treatment (e.g., counseling, therapy)
 - h. Employment services (i.e., help to find a job)
 - i. Housing or residential options
 - j. Community safety training
 - k. Transition support program
 - l. I am not currently receiving or participating in any of the above mentioned services or programs
 - m. Other services or programs not listed here (please specify)
- _____

A15. Do you have an official diagnosis of an Autism Spectrum Disorder (i.e., Autism, Asperger Syndrome,

Pervasive Developmental Disorder (PDD), PDD-Not Otherwise Specified, or Autism Spectrum Disorder)?

An official diagnosis is provided by a regulated professional qualifies to provide the diagnosis (e.g., psychologist, psychiatrist). Yes/No

If you do not have an official diagnosis, do you identify as having an Autism Spectrum Disorder?
Yes/No

A16. Do you have an intellectual disability? (i.e., IQ lower than 70) Yes/No

A17. How much support do you typically need on a daily basis? (Based on SIB-R descriptions)

Infrequent or No support: You require infrequent or no support. For example, you may possess the ability to live and work independently with occasional advice or assistance from others.

Intermittent: You require intermittent or periodic support and supervision. For example, you may be able to manage most daily activities independently, but may sometimes need periodic advice, support, assistance, or supervision.

Limited: You require limited but consistent support and supervision. For example, you may be independent in some personal care skills, but may require help, support or supervision with many daily activities.

Frequent: You require frequent or close support and supervision with most daily activities. For example, your personal care skills range from beginning to intermediate levels, but still require assistance with most daily activities.

Extensive: You require extensive or continuous support and supervision. For example, you may attain beginning self-care skills but may still require almost total personal care.

Pervasive: You require pervasive or highly intense levels of support and supervision in all circumstances. For example special life support measures or personal care similar to that required by a newborn.

A18. Have you ever been accurately diagnosed by a professional with the following?

Depression
Anxiety
Schizophrenia/Psychosis
Personality Disorder
Obsessive Compulsive Disorder
Bipolar disorder
Eating Disorder
Tourette Syndrome or Tic Disorder
Attention Deficit Hyperactivity Disorder
Learning Disability

A19. Do you feel like you have an undiagnosed mental health disorder? Yes/No

If Yes, please select one (or more) of the following:

Depression
Anxiety
Schizophrenia/Psychosis
Personality Disorder
Obsessive Compulsive Disorder
Bipolar disorder
Eating Disorder
Tourette Syndrome or Tic Disorder
Attention Deficit Hyperactivity Disorder
Learning Disability

ASD Diagnosis: Autism Quotient (Baron-Cohen, S., Wheelwright, S., Skinner, R., Martin, J., & Clubley, E. (2001). The Autism-Spectrum Quotient (AQ): Evidence from Asperger Syndrome/high-functioning Autism, males and females, scientists and mathematicians. *Journal of Autism and Developmental Disorders*, 31, 5-17.

To what extent do you agree or disagree with each of the following statements?

1. I prefer to do things with others rather than on my own.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
2. I prefer to do things the same way over and over again.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
3. If I try to imagine something, I find it very easy to create a picture in my mind.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
4. I frequently get so strongly absorbed in one thing that I lose sight of other things.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
5. I often notice small sounds when others do not.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
6. I usually notice car number plates or similar strings of information.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
7. Other individuals frequently tell me that what I've said is impolite, even though I think it is polite.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
8. When I'm reading a story, I can easily imagine what the characters might look like.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
9. I am fascinated by dates.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
10. In a social group, I can easily keep track of several different individuals's conversations.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
11. I find social situations easy.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
12. I tend to notice details that others do not.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
13. I would rather go to a library than a party.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
14. I find making up stories easy.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
15. I find myself drawn more strongly to individuals than to things.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
16. I tend to have very strong interests, which I get upset about if I can't pursue.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
17. I enjoy social chit-chat.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
18. When I talk, it isn't always easy for others to get a word in edgeways.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
19. I am fascinated by numbers.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
20. When I'm reading a story, I find it difficult to work out the characters' intentions.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree

21. I don't particularly enjoy reading fiction.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
22. I find it hard to make new friends.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
23. I notice patterns in things all the time.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
24. I would rather go to the theatre than a museum.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
25. It does not upset me if my daily routine is disturbed.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
26. I frequently find that I don't know how to keep a conversation going.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
27. I find it easy to "read between the lines" when someone is talking to me.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
28. I usually concentrate more on the whole picture, rather than the small details.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
29. I am not very good at remembering phone numbers.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
31. I know how to tell if someone listening to me is getting bored.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
32. I find it easy to do more than one thing at once.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
33. when I talk on the phone, I'm not sure when it's my turn to speak.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
34. I enjoy doing things spontaneously.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
35. I am often the last to understand the point of a joke.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
38. I am good at social chit-chat.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
39. Individuals often tell me that I keep going on and on about the same thing.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
40. When I was young, I used to enjoy playing games involving pretending with other children.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
41. I like to collect information about categories of things (e.g., types of car, types of bird, types of train, types of plant, etc.).	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
42. I find it difficult to imagine what it would be like to be someone else.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
43. I like to plan any activities I participate in carefully.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
44. I enjoy social occasions.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree

45. I find it difficult to work out individuals's intentions.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
46. New situations make me anxious.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
47. I enjoy meeting new individuals.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
48. I am a good diplomat.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
49. I am not very good at remembering individuals's date of birth.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
50. I find it very easy to play games with children that involve pretending.	Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree

Self-Determination: The Arc's Self-Determination Scale: Adult Version					
<p>B. Section I – Check the answer on each question that BEST tells how you act in that situation. There are no right or wrong answers. (If your disability limits you from actually performing the activity, but you have control over the activity (such as a personal care attendant), answer like you performed the activity.)</p>					<p>In this column, please rate how important this skill or ability is for you.</p>
<p>Questions 1-32 reflect the Autonomy of the person with ASD (i.e., acting independently and acting on the basis of preferences, beliefs, values and abilities). Pg. 68 of manual</p> <p>(Low scores represent low levels of autonomy; higher scores indicate higher levels of autonomy.)</p>					
1. I make my own meals or snacks.	<input type="checkbox"/> I do not do even if I have the chance.	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	
2. I care for my own clothes.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
3. I do chores in my home.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
4. I keep my own personal items	<input type="checkbox"/> I do not do even if I have	<input type="checkbox"/> I do sometimes	<input type="checkbox"/> I do most of the time I	<input type="checkbox"/> I do every time I	1. Not Important 2. A little Important

together.	a chance	when I have the chance.	have the chance.	have the chance.	3. Somewhat important 4. Important 5. Very Important
5. I do simple first aid or medical care for myself	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
6. I keep good personal care and grooming.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
7. I make friends with others my age.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
8. I use the post office.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
9. I keep my appointments and meetings.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
10. I deal with sales individuals at stores and restaurants.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
11. I do free time activities based on my interests.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
12. I plan weekend activities that I like to do.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have	<input type="checkbox"/> I do most of the time I have the	<input type="checkbox"/> I do every time I have the	1. Not Important 2. A little Important

		the chance.	chance.	chance.	3. Somewhat important 4. Important 5. Very Important
13. I am involved in community activities.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
14. My friends and I choose activities that we want to do.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
15. I write letters, notes or talk on the phone to friends and family.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
16. I listen to music that I like.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
17. I volunteer in things that I am interested in.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
18. I go to restaurants that I like.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
19. I go to movies, concerts, and dances.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
20. I go shopping or spend time at shopping centers	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have	<input type="checkbox"/> I do most of the time I have the	<input type="checkbox"/> I do every time I have the	1. Not Important 2. A little Important

or shopping malls.		the chance.	chance.	chance.	3. Somewhat important 4. Important 5. Very Important
21. I take part in community groups (like YMCA/YWCA and church).	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
22. I do free time activities based on my career interests.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
23. I work on activities that will improve my career chances.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
24. I make long-range career plans.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
25. I work or have worked to earn money.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
26. I am in or have been in career or job classes or training.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
27. I have looked into job interests by visiting work sites or talking to individuals in that job.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
28. I choose my clothes and the personal items I	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have	<input type="checkbox"/> I do most of the time I have the	<input type="checkbox"/> I do every time I have the	1. Not Important 2. A little Important

use every day.		the chance.	chance.	chance.	3. Somewhat important 4. Important 5. Very Important
29. I choose my own hairstyle.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
30. I choose gifts to give to family and friends.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
31. I decorate my own room.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
32. I choose how to spend my personal money.	<input type="checkbox"/> I do not do even if I have a chance	<input type="checkbox"/> I do sometimes when I have the chance.	<input type="checkbox"/> I do most of the time I have the chance.	<input type="checkbox"/> I do every time I have the chance.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
Total Autonomy score					Total Autonomy Importance score
Autonomy is when a person acts independently and acts on the basis of preferences, beliefs, values, and abilities. How important is Autonomy to you?					1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important

B. Section II – Each of the following questions tell the beginning of a story and how the story ends. Your job is to tell what happened in the middle of the story, to connect the beginning and the end. Read the beginning and ending of each question, then fill in the BEST answer for the middle of the story. There are no right or wrong answers. Remember, fill in the answer you think BEST completes the story.

Self-Regulation – Interpersonal Cognitive Problem-Solving (higher scores representing more effective interpersonal cognitive problem-solving).

33. **Beginning** – You are sitting in a planning meeting with your boss. You want to learn to work the computer. Your boss wants you to learn to work a cash register. You can only learn one of them.

Middle –

<hr/> <hr/> <hr/> <p>Ending – The story ends with you learning to work a computer.</p>					
<p>34. Beginning – You hear a friend talking about a new job opening at the local bookstore. You love books and want a job. You decide you would like to work at the bookstore.</p> <p>Middle –</p> <hr/> <hr/> <hr/>					
<p>Ending – The story ends with you working at the bookstore.</p>					
<p>35. Beginning – Your friends are acting like they are mad at you. You are upset about this.</p> <p>Middle –</p> <hr/> <hr/> <hr/>					
<p>Ending – The story ends with you and your friends getting along just fine.</p>					
<p>36. Beginning – You go to your job one morning and discover you do not have some of the papers you need. You are upset because you need those papers to do your job.</p> <p>Middle –</p> <hr/> <hr/> <hr/>					
<p>Ending – The story ends with you using the papers to do your job.</p>					
<p>37. Beginning – You are in a committee at work. The committee chair announces that the members will need to elect new officers at the next meeting. You want to be the chair person of the committee.</p> <p>Middle –</p> <hr/> <hr/> <hr/>					
<p>Ending – The story ends with you being elected as the committee chairperson.</p>					
<p>38. Beginning – You are at a new job and you don't know anyone. You want to have friends.</p> <p>Middle –</p> <hr/> <hr/> <hr/>					
<p>Ending – The story ends with you having many friends at the new job.</p>					
<p>How important is social problem solving to you? Social problem solving refers to the cognitive-behavioral process in which one works to find adaptive ways of coping with everyday situations that are considered problematic.</p>	<p>Not Important 1</p>	<p>A little important 2</p>	<p>Somewhat Important 3</p>	<p>Important 4</p>	<p>Very Important 5</p>

Total Self-Regulation Importance Social Problem Solving Score

B. Section III – The next three questions ask about your plans for the future. Again, there are no right or wrong answers. For each question, tell if you have made plans for that outcome and, if so, what those plans are and how to meet them.

Self-Regulation – Goal-Setting and Task Performance (*Note. Goals are not judged on the probability that the student can achieve them, but simply on their presence or absence. Steps to achieve the goal are, however, judged based on whether they are viable steps in the process or unrelated to achieving the goal.*) (Higher scores represent more effective goal-setting and task attainment skills)

<p>39. Where do you want to live in five years?</p>	<p><input type="checkbox"/> I have not planned for that yet</p>	<p><input type="checkbox"/> I want to live: _____ List four things you should do to meet this goal: 1. _____ 2. _____ 3. _____ 4. _____</p>
<p>40. Where do you want to work in five years? (i.e., employment)</p>	<p><input type="checkbox"/> I have not planned for that yet</p>	<p><input type="checkbox"/> I want to live: _____ List four things you should do to meet this goal: 1. _____ 2. _____ 3. _____ 4. _____</p>
<p>41. What type of transportation do you plan to use in five years?</p>	<p><input type="checkbox"/> I have not planned for that yet</p>	<p><input type="checkbox"/> I want to live: _____ List four things you should do to meet this goal: 1. _____ 2. _____ 3. _____ 4. _____</p>

<p>How important is goal setting and attainment to you? Goal setting & attainment: an object or aim of an action by which progress can be mapped</p>	<p align="center">Not Important 1</p>	<p align="center">A little important 2</p>	<p align="center">Somewhat Important 3</p>	<p align="center">Important 4</p>	<p align="center">Very Important 5</p>
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Total Self-Regulation Importance Goal Setting and Task Performance Score

**Total Self-Regulation Importance Score
 (Total Social Problem Solving + Goal Setting/Task Performance Importance Scores)**

B. Section IV – Check the answer that BEST describes you. There are no wrong answers.		In this column, please rate how important this skill or ability is for you.	
Psychological Empowerment – refers to the related constructs of locus of control, self-efficacy and outcomes expectancy (three constructs that provide an overall indicator of perceived control). i.e., beliefs in ability, perceptions of control, and expectation of success (higher scores indicate that students are more psychologically empowered)			
42. <input type="checkbox"/> I usually do what my friends want.	or	<input type="checkbox"/> I tell my friends if they are doing something I don't want to do.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
43. <input type="checkbox"/> I tell others when I have new or different ideas of opinions.	or	<input type="checkbox"/> I usually agree with other individuals' opinions or ideas.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
44. <input type="checkbox"/> I usually agree with individuals when they tell me I can't do something.	or	<input type="checkbox"/> I tell individuals when I think I can do something that they tell me I can't.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
45. <input type="checkbox"/> I tell individuals when they have hurt my feelings.	or	<input type="checkbox"/> I am afraid to tell individuals when they have hurt my feelings.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
46. <input type="checkbox"/> I can make my own decisions.	or	<input type="checkbox"/> Other individuals make decisions for me.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
47. <input type="checkbox"/> Trying hard at work doesn't do much good.	or	<input type="checkbox"/> Trying hard at work will help me get a good job.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
48. <input type="checkbox"/> I can get what I want by working hard.	or	<input type="checkbox"/> I need good luck to get what I want.	1. Not Important 2. A little Important 3. Somewhat

			important 4. Important 5. Very Important
49. <input type="checkbox"/> It is no use to keep trying because that won't change things.	or	<input type="checkbox"/> I keep trying even after I get something wrong.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
50. <input type="checkbox"/> I have the ability to do the job I want.	or	<input type="checkbox"/> I cannot do what it takes to do the job I want.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
51. <input type="checkbox"/> I don't know how to make friends.	or	<input type="checkbox"/> I know how to make friends.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
52. <input type="checkbox"/> I am able to work with others.	or	<input type="checkbox"/> I cannot work well with others.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
53. <input type="checkbox"/> I do not make good choices.	or	<input type="checkbox"/> I can make good choices.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
54. <input type="checkbox"/> If I have the ability, I will be able to get the job I want.	or	<input type="checkbox"/> I probably will not get the job I want even if I have the ability.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
55. <input type="checkbox"/> I will have a hard time making new friends.	or	<input type="checkbox"/> I will be able to make friends in new situations.	1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
56. <input type="checkbox"/> I will be able to work with others if I need to.	or	<input type="checkbox"/> I will not be able to work with others if I need to.	1. Not Important 2. A little Important 3. Somewhat

		important 4. Important 5. Very Important
57. <input type="checkbox"/> My choices will not be honoured.	or	<input type="checkbox"/> I will be able to make choices that are important to me.
		1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
Total Psychological Empowerment score		Total Psychological Empowerment Importance score
<p>Psychological Empowerment is related to locus of control (the extent to which you believe you can control events affecting your life), self-efficacy and outcomes expectancy (i.e., beliefs in ability, perceptions of control, and expectation of success). How important is psychological empowerment to you?</p>		1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
B. Section V – Tell whether each of these questions describes you or not. There are not right or wrong answers. Choose the one that BEST fits you.		
Self-Realization – includes self-awareness, self-acceptance, self-confidence, self-esteem and self-actualization. (Higher scores reflect greater self-realization)		
58. I do not feel ashamed of any of my emotions.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
59. I feel free to be angry at individuals I care for.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
60. I can show my feelings even when individuals might see me.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
61. I can like individuals even if I don't agree with them.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
62. I am afraid of doing things wrong.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
63. It is better to be yourself than to be popular.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
64. I am loved because I give love.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
65. I know what I do best.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
66. I don't accept my own limitations.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
67. I feel I cannot do many things.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
68. I like myself.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
69. I am not an important person	<input type="checkbox"/> YES	<input type="checkbox"/> NO
70. I know how to make up for my limitations.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
71. Other individuals like me.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
72. I am confident in my abilities.	<input type="checkbox"/> YES	<input type="checkbox"/> NO
Total Self-Realization score		Total Self-Realization Importance score
<p>Self-Realization includes self-awareness, self-acceptance, self-confidence, self-esteem, and self-actualization. How important is self-realization to you?</p>		1. Not Important 2. A little Important 3. Somewhat important 4. Important 5. Very Important
OVERALL TOTAL SCORE (Autonomy + Self-Regulation +		OVERALL TOTAL

Psychological Empowerment + Self-Realization Total Scores)	IMPORTANCE SCORES (Autonomy + Self-Regulation + Psychological Empowerment + Self-Realization Total Importance Scores)
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Self-Determination: Air Self-Determination Scale – Student Version

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

This is not a test. There are no right or wrong answers. The questions will help you learn about what you do well and where you may need help.

Goal – You may not be sure what some of the words in the question mean. For example, the word **goal** is used a lot. A **goal is something you want to get or achieve**, either now or next week or in the distant future, like when you are an adult. You can have many different kinds of goals. You could have a goal that has to do with school (like getting a good grade on a test or graduating from high school). You could have a goal of saving money to buy something (a new iPod or new sneakers), or doing better in sports (getting on the basketball team). Each person’s goals are different because each person has different things that they want or need or that they are good at.

Plan – Another word that is used in some of the questions is **plan**. A **plan is the way you decide to meet your goal, or the steps you need to take in order to get what you want or need**. Like goals, you can have many different kinds of plans. An example of a plan to meet the goal of getting on the basketball team would be: to get better by shooting more baskets at home after school, to play basketball with friends on the weekend, to listen to the coach when the team practices, and to watch the pros play basketball on TV.

Capacity = Things I Do + How I Feel

Capacity refers to students’ knowledge, abilities, and perceptions that enable them to be self-determined and feel good about it.

Things I Do:

1. I know what I need, what I like, and what I’m good at.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
2. I set goals to get what I want or need. I think about what I am good at when I do this.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
3. I figure out how to meet my goals. I make plans and decide what I should do.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
4. I begin working on my plans to meet my goals as soon as	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>

possible.				<input type="checkbox"/>	
5. I check how I'm doing when I'm working on my plan. If I need to, I ask others what they think of how I'm doing.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
6. If my plan doesn't work, I try another one to meet my goals.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
How I Feel:					
1. I feel good about what I like, what I want, and what I need to do.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
2. I believe that I can set goals to get what I want.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
3. I like to make plans to meet my goals.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
4. I like to begin working on my plans right away.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
5. I like to check on how well I'm doing in meeting my goals.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
6. I am willing to try another way if it helps me to meet my goals.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
Opportunity = What Happens at School + What Happens at Home Opportunity refers to students' chances to use their knowledge and abilities					
What Happens at School:					
1. Individuals at school listen to me when I talk about what I want, what I need, or what I'm good at.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
2. Individuals at school let me know that I can set my own goals to get what I want or need.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
3. At school, I have learned how to make plans to meet my goals and to feel good about them.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
4. Individuals at school encourage me to start working on my plans right away.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
5. I have someone at school who can tell me if I am meeting my goals.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
6. Individuals at school understand when I have to change my plan to meet my goals. They offer advice and encourage me when I'm doing this.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
What Happens at Home:					
1. Individuals at home listen to me when I talk about what I want,	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>

what I need, or what I'm good at.				<input type="checkbox"/>	
2. Individuals at home let me know that I can set my own goals to get what I want or need.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
3. At home, I have learned how to make plans to meet my goals and to feel good about them.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
4. Individuals at home encourage me to start working on my plans right away.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
5. I have someone at home who can tell me if I am meeting my goals.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>
6. Individuals at home understand when I have to change my plan to meet my goals. They offer advice and encourage me when I'm doing this.	Never <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Almost Always <input type="checkbox"/>	Always <input type="checkbox"/>

Please write your answers to the following questions...

1. Give an example of a goal you are working on.
2. What are you doing to reach this goal?
3. How well are you doing in reaching this goal?

Self-Determination Discrepancy Analysis (i.e., Importance – Satisfaction)

“**Self-determined behaviour** refers to volitional actions that enable one to act as the primary causal agent in one’s life and to maintain or improve one’s quality of life” (Wehmeyer, 2005, p. 117). More specifically, self-determined behaviour refers to human behaviour that is caused or determined by the person as opposed to being caused by someone or something else.

For example these may include: choice-making, decision making, problem-solving, goal setting and attainment, self-monitoring, self-advocacy, an internal locus of control, perceptions of self-efficacy and outcome expectancy, self-awareness and self-knowledge

How satisfied are you with your current level of self-determined behaviour?	Not Satisfied 1	A little Satisfied 2	Somewhat Satisfied 3	Satisfied 4	Very Satisfied 5
How important is it for you to be a self-determined individual?	Not Important 1	A little important 2	Somewhat Important 3	Important 4	Very Important 5

Do you think that being self-determined would help or have helped you succeed in adulthood?

For example, gain employment, succeed in post-education opportunities and development and maintain relationships. Yes or No

Explain. _____

Barriers and Facilitators to becoming a self-determined individual

If you would like to better your self-determination skills, what are the barriers to becoming a self-determined individual? Please select all the ones that apply to you.

No support network (e.g., family, friends, health and mental health professionals)

No opportunities or choices available at a systemic level

Do not have the skills (e.g., poor choice-making, decision-making, problem-solving, goal setting & attainment, self-monitoring, self-advocacy, self-awareness...)

A mental health issue is preventing skill development or opportunities

Stereotypes about my ability

My early educational and life experiences have not prepared me for life after school

Other individuals providing me with opportunities to make decisions about my life

Societal perceptions about disability

My lack of flexibility in allowing others to help support me

Other: _____

If you are a self-determined individual, what are the facilitators that have helped you become self-determined individual? Please select all the ones that apply to you.

Support network available

Opportunities and choices provided at a system level (e.g., community, services)

Possesses the skills required (e.g., adequate choice-making, decision-making, problem-solving, goal setting & attainment, self-monitoring, self-advocacy, self-awareness...)

No mental health issue

No stereotypes about my ability

My early educational and life experiences have prepared me for life after school

Other individuals providing me with opportunities to make my own decisions about my life

Societal perceptions about disability

My flexibility in allowing others to help support me

Other: _____

Thank you for taking the time to complete the McGill SD in ASD National Survey!

The information you provided is invaluable to our research and will help us understand the lives of young adults with Autism Spectrum Disorders

Please indicate your interest in the following by checking the appropriate box(es) and providing the relevant contact information

I would like to receive a summary of the research results

I may be contacted to participate in other research studies and for which I am eligible, at which time I can accept or decline involvement

None of the above

If you have checked any of the above, please provide us with the following information:

Name: _____

Address: _____

City/Town: _____

Province: _____

Postal Code: _____

Email Address: _____

If you would like to receive the \$15 honorarium, please provide us with the following contact information. Your compensation will be emailed to you once you've completed the survey.

Name:

Email Address:

Gift Card option: iTunes, Amazon, Chapters

Thank you for your time and participation!!!