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# Self-Determination during School-to-Adulthood Transition in Young Adults with Autism Spectrum Disorder from the United States and Hong Kong

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Self-Determination during School-to-Adulthood Transition  
in Young Adults with Autism Spectrum Disorder from the United States and Hong Kong

by

Gary Yu Hin Lam

A thesis submitted in partial fulfillment  
of the requirements for the degree of  
Educational Specialist in School Psychology  
Department of Educational and Psychological Studies  
College of Education  
University of South Florida

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## ABSTRACT

There is an increasing population of students with ASD graduating from schools and entering adulthood. Post-school transition is particularly challenging for these young adults and they tend to exhibit unfavorable outcomes in various domains in life. The concept of self-determination has been identified to promote successful transition and adult outcomes. With its root stemming from Western ideologies, the conceptualizations and manifestations of self-determination have rarely been examined across cultures. The present study aims to examine the experiences of self-determination in young adults with ASD during their school-to-adulthood transition and directly compare their experiences across American and Chinese contexts. Individual interviews were conducted with 11 young adults with ASD in the United States and Hong Kong who exited high school within the past seven years. Results from thematic analysis revealed themes about participants' experiences of self-determination in areas of autonomy, attainment of goals, psychological empowerment, and self-realization. Contextual factors in family, work, postsecondary education, community-based settings, and early school-age experiences were identified to influence participants' development and expression of self-determination. Cross-cultural similarities and differences in self-determination among American and Chinese young adults with ASD were discussed in relation to various factors associated with their ecological systems. Implications of cultural-responsive understanding of self-determination for research and practice are discussed to promote better outcomes and quality of life in individuals with ASD transitioning from school to the adulthood.

## CHAPTER 1

### INTRODUCTION

Individuals with Autism Spectrum Disorder (ASD) face numerous challenges in life beginning in early childhood. Upon completion of school, they transition into the adult world, which can be very difficult, as this often means losing the educational supports and relationships made with peers and teachers in the school setting. While successful navigation through adulthood demands that individuals with ASD manifest a high degree of self-determination, little is known about how they perceive self-determination and how they lead a self-determined life. Even less is understood about the concept of self-determination among individuals with ASD across different cultures.

The following chapter provides an overview of the study as well as its theoretical underpinnings. I begin the chapter with a brief overview of the issue of disability rights and the history of ASD. This overview is followed by a discussion of the significance of self-determination during the transition to adulthood and the growing needs for culturally-appropriate conceptualizations of self-determination. I then describe the purpose of the study, followed by a discussion of the conceptual framework, the research questions, and the definition of terms of the study.

### **Background**

#### **Human Rights of Individuals with Disabilities**

Over the course of the 20th century, there has been increasing awareness of human rights of individuals with disabilities. The disability field gradually shifted from operating solely

according to a medical model to viewing disability as restrictions caused by bodily impairments, stressing the role of environment in placing individuals at a disadvantage and thus handicapping individuals' abilities (World Health Organization, 1980). This called for increasing recognition of the rights of individuals with disabilities to have access to opportunities afforded to those without disabilities. Since then, numerous social movements and public policies have been established globally to protect and promote the rights of different disability groups (Armstrong & Barton, 1999). One of the examples involves the promotion of self-determination in the field of disability services and special education in the United States (Ward & Kohler, 1996), which was largely informed by the dominant Anglo-European values to strive for basic rights to self-governance and autonomy (Frankland, Turnbull, Wehmeyer, & Blackmountain, 2004). However, human rights policies and disability practices vary within and across cultures, so it is important to acknowledge and understand such cultural variations in order to further advance disability rights globally (Armstrong & Barton, 1999).

### **History of Autism Spectrum Disorder (ASD)**

The present study focuses on individuals with ASD as one example of various disability groups. Autism Spectrum Disorder (ASD) is a neurodevelopmental condition that pervasively affects individuals' social, communication, and cognitive functioning (American Psychiatric Association, 2013). The history of ASD in the medical field is relatively short, with Leo Kanner (1943) and Hans Asperger (Frith, 1991) first describing ASD in the early 1940's. Not until the 80's and 90's was social awareness of this disorder raised. This increased recognition among the general public as well as in the scientific community was accompanied by a surge in prevalence rates (Croen, Grether, Hoogstrate, & Selvin, 2002). As the clinical presentation of ASD usually manifests early in life, research and intervention efforts over the past few decades have focused

on the early childhood population (Piven, Rabins, & on behalf of the Autism-in-Older Adults Working Group, 2011). Due to advances in our understanding of the condition and identification methods, although individuals with more complex needs tend to be diagnosed earlier, it is not uncommon for individuals to first be diagnosed with ASD in adolescence and adulthood (Howlin & Moss, 2012). Since ASD is a lifelong developmental condition, individuals with this diagnosis continue to face different challenges in their lives as they age (Perkins & Berkman, 2012). Therefore, there is a pressing need for interventions and services beyond school age and to support the ASD population across the lifespan.

### **Individuals with ASD during the Transition to Adulthood**

There are a plethora of available educational and clinical interventions supporting youth with ASD from early childhood through adolescence. However, once those with ASD complete formal education, structured supports to meet their developmental needs are less often available in the community (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). In general, although the adolescence-to-adulthood transition is characterized by increased diversity in pathways and timing of different developmental milestones (e.g., Cohen, Kasen, Chen, Hartmark, & Gordon, 2003), this period usually creates significant life changes and has profound impacts on individuals' psychosocial well-being (Schulenberg, Sameroff, & Cicchetti, 2004).

Individuals with ASD continue to face many challenges in different settings in adulthood. Related to the core deficit of ASD, social communication difficulties continue to impact the lives of those with ASD in multiple domains (Wehman, Smith, & Schall, 2009). Adult outcomes for individuals with ASD in the areas of employment, postsecondary education, independent living, and sustained social relationships remain unpromising (e.g., Hendricks & Wehman, 2009; Shattuck et al., 2011; Taylor & Seltzer, 2011; Wehman et al., 2013). Yet, research has not been

able to catch up with the pressing need to understand and intervene in the factors that impact this population during their transition out of school (Wehman et al., 2014).

### **Understanding the Concept of Self-Determination**

Self-determination has been 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, 2006, p.117). It is characterized by individuals exhibiting autonomy, self-regulation, psychological empowerment, and self-realization (Wehmeyer, 1996; Wehmeyer et al., 1996). This psychological construct has been identified in the special education literature as an important concept to promote better transition and adult outcomes in individuals with disabilities (e.g., Thoma, Williams, & Davis, 2005; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998). Teaching the component skills that contribute to self-determination for students with disabilities can result in long-term improvement in transition and adult outcomes, such as quality of life, self-awareness, employment outcomes, and community participation (e.g., Algozzine, Browder, Karvonen, Test, & Wood, 2001; Chambers et al., 2007; Wood, Fowler, Uphold, & Test, 2005). It has been suggested that students with ASD preparing for transition out of school would similarly benefit from the instruction of self-determination skills (Wehmeyer, Shogren, Zanger, Smith, & Simpson, 2010).

### **Culturally-Specific Conceptualizations of Self-Determination**

Despite established evidence pointing to the relationship between self-determination and promising adult outcomes, the concept of self-determination may not be understood the same way in all cultures (Smith & Routel, 2010). The behaviors and attitudes associated with this concept that are defined in the literature are heavily influenced by Western values (Frankland et al., 2004). However, the emphasis of culturally-specific values in different societies has a

significant impact on how self-determination is perceived and manifests across cultures (Shogren, 2011). For example, American culture tends to place higher value on individualism over collectivism while the opposite is true in Chinese culture (Hofstede & Peterson, 2000). Self-determination in the literature traditionally reflects the values of Anglo-European culture, including individualism, personal control, self-help, and goal orientation (Frankland et al., 2004), which appears to contrast directly with the collectivistic worldview. For example, Taiwanese Chinese parents tend to be more involved in children's lives and emphasize independence less (Zhang, Wehmeyer, & Chen, 2005). To support the development of self-determination and subsequent positive life outcomes in individuals with ASD across cultures, much effort is needed to better understand the behaviors and conceptions associated with self-determination in members from different cultural backgrounds (Smith & Routel, 2010; Shogren, 2011).

### **Statement of Problem**

There has been a surge in the number of individuals being identified with ASD, who move through the education system and then transition into their adult lives (Brugha et al., 2011; Howlin & Moss, 2012; Piven, et al., 2011). Given the unique profile of strengths and challenges associated with ASD, many individuals with this disorder struggle to reach their potential in adulthood and show unfavorable outcomes in various life domains, such as low employment rates, low postsecondary education attainment, and disengagement from the community (Howlin & Moss, 2012).

It has been argued that self-determination is an important predictor of successful transition and adult outcomes in individuals with ASD (Wehmeyer & Shogren, 2008). However, little is known about how the concept of self-determination is viewed by young adults with ASD and how it manifests in their lives (Shogren, 2011). Previous research efforts investigated self-

determination mostly through reports from their significant others, such as parents and teachers (Carter, Lane, Pierson, & Stang, 2008; Grigal, Neubert, Moon, & Graham, 2003). Even when the perspectives of individuals with ASD have been studied, most of the research has relied primarily on self-report measures only (e.g., Wagner, Newman, Cameto, Levine, & Marder, 2007), which largely ignore the complexity and the dynamic nature of perceptions and feelings related to one's personal experiences. The use of qualitative interview method is directly contrary to the quantitative tradition dominating this field of inquiry, which tends to document the deficits and weaknesses within individuals using the medical model of disability (Hartley & Muhit, 2003; Wolgemuth et al., in press). Since the core value of self-determination emphasizes how individuals act as the causal agents in their own lives (Wehmeyer et al., 2011), its conceptualization cannot be fully captured without the input from the individual of concern.

The conceptions and behaviors associated with self-determination are specific to the sociocultural values embedded in a society (Shogren, 2011). The Anglo-European view of self-determination has long dominated the research and discussion in the literature. A more culturally-appropriate understanding of self-determination is crucial for successful transition in young adults with ASD from diverse cultural backgrounds (Frankland et al., 2004). To assess how self-determination is defined and applied in different sociocultural contexts, it is necessary to directly compare conceptions of self-determination and experiences in young adults with ASD across two different cultures (i.e., American and Chinese).

### **Purpose of Study**

The present study aims to explore the experiences and contexts of self-determination in young adults with ASD from the United States and Hong Kong. Individual qualitative interviews were used to gather in-depth information about their experiences about self-determination in

respective cultural contexts. Direct comparison of results from the two cultural groups allows for better understanding of how self-determination is conceptualized and manifests in young adults with ASD across two different cultural contexts. This study provides a cross-cultural account of similarities and differences in the construct of self-determination. This culturally-responsive understanding has implications on supporting youth with ASD to navigate the post-school transition into the adulthood.

### **Significance of Study**

This study examined the first-person, subjective experience of self-determination in young adults with ASD. The approach in studying self-determination is novel in that its aim is to gain the perspectives of young adults with ASD through talking with them directly in qualitative interviews. Only by involving the person-centered perspective are we able to understand self-determination in relation to one's immediate ecology (Trainor, 2002). Moreover, the interview process offered individuals from the ASD population a valuable opportunity to express their voice (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005). Although historically individuals with ASD were not viewed as good informants for their own issues, currently more individuals are diagnosed with higher functioning levels in terms of intellectual and language abilities (Howlin, 1997), thus allowing for direct inquiry of their experiences and perceptions. Lastly, the cross-cultural aspect of the study allowed for direct comparisons of how self-determination manifested and was understood by young adults with ASD across the United States and Hong Kong. Practitioners and researchers from both cultures will be able to gain deeper understanding on the conceptualizations and manifestations of self-determination in American and Chinese cultures and engage in more culturally-sensitive practice when

developing self-determination interventions and providing transition services for this population in the future (Shogren, 2013; Wehmeyer et al., 2011).

### **Conceptual Framework**

The concept of self-determination has been recently critiqued as heavily culturally-bound by the Western literature (see Smith & Routel, 2010). However, other cultures may have a different emphasis on different values, and specific behaviors associated with how individuals with self-determination also vary across cultures (Shogren, 2011). A flexible conceptualization of self-determination is needed in order to understand a person's behaviors within his or her own culture. The present study was guided by the proposition that self-determination can be conceptualized and operationalized in different ways across different cultural contexts in relation to one's ecological system (Bronfenbrenner, 1979, 1989).

### **Research Questions**

1. How do young adults with ASD perceive their experience with self-determination during their transition from school to adulthood in the United States?
2. How do young adults with ASD perceive their experience with self-determination during their transition from school to adulthood in Hong Kong?
3. How does the experience and perception of self-determination vary in young adults with ASD across the United States and Hong Kong?

### **Definition of Terms**

**Self-determination**, broadly defined, is a set of volitional behaviors and attitudes that enable individuals to act as the primary causal agent in their lives and to improve quality of life (Wehmeyer, 2005). In other words, self-determination empowers individuals to make conscious choices and decisions intentionally and purposefully to cause one's actions. Self-determination

by itself is a psychological construct, which by definition confers a universally equal function, but its behaviors can be operationalized differently across contexts (Wehmeyer et al., 2011). In the literature available in Western cultures, self-determination is related to concepts such as self-control, decision-making, self-regulation, self-awareness, problem solving, and self-advocacy (Wehmeyer, Agran, & Hughes, 1998).

**Autism Spectrum Disorder (ASD)** is a neurodevelopmental disorder characterized by deficits in social interaction and communication coupled with restrictive interests and repetitive behaviors (American Psychiatric Association [APA], 2013). Symptoms are usually present and affect individuals' functioning since early childhood; however, due to recent scientific advances in understanding and assessing the disorder, there is an exponential increase in individuals diagnosed with ASD, with increasing number of people diagnosed at later stages in life (Howlin & Moss, 2012). In the present study, young adults with ASD were the population of interest.

**Transition** is considered as a time period in life in which individuals are moving from one developmental stage to another. In the present study, the transition period after one exits the formal secondary educational system and enters adulthood was of the central focus.

## CHAPTER 2

### LITERATURE REVIEW

The previous chapter introduced the background and the theoretical framework of the study. In the current chapter, I review the literature on self-determination in relation to individuals with ASD in different cultures. The chapter begins by reviewing the history of human rights movement associated with individuals with disabilities from both local and global perspectives. I then discuss the post-school transition in young adults with disabilities. This is followed by a brief review of characteristics of ASD and their strengths and challenges in childhood and adolescence. The literature review then focuses on the experiences and outcomes of post-school transition in young adults with ASD, which leads to the discussion of the concept of self-determination in response to the need for promoting better transition outcomes in young adults with disabilities in general as well as with ASD specifically. In the context of cross-cultural disability literature, I argue for the need for understanding the concept of self-determination through a culturally-responsive lens. I then review both quantitative and qualitative cross-cultural research on self-determination in individuals with disabilities to inform the study. I conclude the chapter by pointing to the need for an empirical account to investigate the experiences and meanings of self-determination among young adults with ASD in different cultures.

#### **Historical Context: Human Rights of Individuals with Disabilities**

Over the course of the 20<sup>th</sup> century, the issue of human rights among individuals with disabilities has received increasing attention and undergone fundamental change in different

societies around the world (Armstrong & Barton, 1999). In the first half of the century, Western societies often used the terms “disability” and “handicap” interchangeably to refer to individuals with disabilities, in which one’s internal limitations and deficits became the center of focus in the definition of disability (Hahn, 1985). With the efforts of numerous social and political movements throughout the 20<sup>th</sup> century, a paradigm shift has evolved that viewed individuals’ personal traits as something to be valued and respected for instead of a basis for an identity with stigma and discrimination (Hahn, 1997). For example, the World Health Organization (WHO) adopted a new classification in 1980 that acknowledged the shift from a medical approach to a person-environment interaction perspective in defining a disability. Specifically, the International Classification of Impairments, Disabilities, and Handicaps (WHO, 1980) defined a disability as an individual’s restrictive consequences due to the impairments of bodily abnormalities or dysfunctions. A handicap, however, reflected disadvantageous conditions that ensued as a result of barriers or demands in the social environment. Within this new paradigm, the (dis)abilities of individuals were weighed against the societal expectations and environmental conditions, with the recognition that a more accommodating society would not put a person with impairment or disability at a disadvantage.

Following this paradigm shift, considerable progress has been made with regard to recognizing the rights of and promoting equality among individuals with disabilities. At the global level, the United Nations (UN) is one of the most influential organizations supporting the efforts of individuals with disabilities to assert their own abilities and rights (UN, n.d.). In 1982, the UN adopted the World Programme of Action to enhance disability policy in the areas of prevention, rehabilitation, and equalization of opportunities, all of which promote participation of individuals with disabilities in society. A decade later, the Standard Rules on the Equalization

of Opportunities for Persons with Disabilities further encouraged local governments to implement measures and monitoring mechanisms to facilitate the full participation and equality of individuals with disabilities. In 2006, the Convention on the Rights of Persons with Disabilities took an even more proactive stance to clarify the human rights of persons with disabilities and the obligations placed on local bodies to promote, protect, and ensure their equal rights.

At the regional level, numerous public policies were shaped with the intention to intervene in constraining environments that handicap people with impairments or disabilities. In the United States, more than 20 laws prohibiting discrimination against individuals with disabilities were passed between 1973 and 1990 (Burgdorf, 1991). For instance, the Rehabilitation Act of 1973 authorized funding for disability-related services such as vocational rehabilitation and independent living programs; the Air Carrier Access Act of 1986 required air carriers to accommodate the needs of passengers with disabilities; and the Fair Housing Amendments Act of 1988 prohibited housing discrimination on the basis of disability. However, it was not until the Americans with Disabilities Act (ADA) of 1990 that individuals with disabilities were ensured the same civil rights as other minority groups. The ADA is a comprehensive federal statute that guarantees equal opportunity to individuals with disabilities in a wide range of domains, including employment, transportation, education, and public and government services. In the same year, the Education for All Handicapped Children Act of 1975 was renamed the Individuals with Disabilities Education Act (IDEA) with the aim of assuring the rights of children with disabilities to a free and appropriate education. With the term handicap replaced by disability, IDEA and its 2004 amendments serve as a mandate to schools to provide services and supports in the environment in response to the children's disabilities.

Differences in human rights policies and disability practices are not uncommon within and across societies (Armstrong & Barton, 1999). From a cross-cultural perspective, individuals and groups from diverse cultures have different understandings of issues of disability and human rights based on their various values and interpretations. In recognition of this, one of the aims of the current research is to acknowledge and examine these cultural variations, recognizing that there may be areas of overlap in perspectives as well as areas of clear difference (Armstrong & Barton, 1999). Notably, many Eastern countries, contrary to Western societies, have a relatively shorter history of disability policy and law that guides their human rights development (Degener, 2000). Few in the Asian region have anti-discrimination legislation or disability policies that protect the rights of individuals with disabilities (United Nations Economic and Social Commission for Asia and the Pacific, 2012). Hong Kong is one of the governments that has a relatively well-established system for protecting the rights of those with disabilities. In the 1970's, Hong Kong began adopting rehabilitation policies and developing relevant services with the aim of integrating individuals with disabilities into the community. Since the release of the first Hong Kong Rehabilitation Programme Plan in 1976, a variety of services were developed in the areas of education, employment, housing, and community living. In 1995, the Disability Discrimination Ordinance was enacted to ensure equal opportunities for individuals with disabilities in the abovementioned areas.

### **Post-School Transition in Young Adults with Disabilities**

In the area of education, students around the world, with and without disabilities, spend the majority of childhood and adolescence at schools learning a variety of skills and knowledge. One of the goals of modern schooling is to prepare students for becoming future generations of successful and educated members in the society. It is a considerable loss to a society if members

of any group are not able to make meaningful contributions to their communities. As students exit secondary education and prepare to enter the adulthood, they must be prepared to address the next chapter of their lives, such as entering the workforce or pursuing post-secondary education. Unfortunately, the transition from secondary education to the world beyond formal schooling is a difficult time period for students with disabilities (Halpern, 1994). Not only do they stop receiving structured supports from school, they also have to face different challenging life circumstances on their journey towards attaining adulthood, such as employment, postsecondary education, and independent living. Early reports showed that this population of students, compared to their non-disabled peers, consistently exhibited poorer outcomes in high school and after leaving the school system (see Phelps & Hanley-Maxwell, 1997 for a review). In the past two decades, research has expanded to better understand the experiences of students with disabilities as they transition out of high school.

Since the enactment of IDEA (1975), the National Longitudinal Transition Study of Special Education Students (NLTS) has provided the most systematic effort to document the experiences of youth with disabilities transitioning out of school (Blackorby & Wagner, 1996). More recently, the National Longitudinal Transition Study-2 (NLTS-2; 2001) was commissioned to assess the current status of adolescents with disabilities in the United States. Regarding post-school outcomes within eight years after leaving high school, students with disabilities lagged behind their general education peers in numerous life domains, such as poorer postsecondary education attainment and lower employment rates and wages (Newman et al., 2011). Youth with disabilities expressed more negative experiences and views than their peers in general education in terms of poorer experience in high school, lower postsecondary education expectation, and lower peer acceptance, although they were more likely to report receiving attention from

families, enjoying life, and feeling hopeful about the future (Wagner et al., 2007). With regard to perceptions of their competencies and strengths, youth with disabilities generally rated themselves as high on measures such as personal autonomy, self-advocacy, self-realization, and psychological empowerment. However, Wagner et al. (2007) suggested that some of the disability groups possessed “positive illusory bias” (Gresham, Lane, MacMillan, Bocian, & Ward, 2000; Heath & Glen, 2005; Hoza, Pelham, Dobbs, Owens, & Pillow, 2002; Klassen, 2006) and tended to overestimate their own strengths and limitations, thus calling into question the consistency between their self-report measures and their real-life effectiveness in interacting with the environment.

Large-scale national studies such as NLTS paint a rather dismal picture of the unsatisfactory transition experiences and outcomes of students with disabilities. As noted by Wagner et al. (2007), different subgroups of students reported extremely negative experiences and views across different domains of life. For individuals with disabilities with more complicated symptomatology that affects functioning more pervasively, such as Autism Spectrum Disorder (ASD), studies suggest that these individuals experience an even more challenging transition period than other disability groups (e.g., Esbensen, Bishop, Seltzer, Greenberg, & Taylor, 2010). While a lot of research efforts have been devoted to investigating school-age populations with ASD, relatively less is known about their lives after they leave the educational system and enter adulthood (Howlin & Moss, 2012; Hurlbutt & Chalmers, 2002). In the following sections, a brief review of ASD will be provided to acquaint the reader with current conceptualizations of the disorder. This section also will include a summary of common areas of strength and challenge. Subsequently, what is known about the post-secondary transition for youth with ASD in different domains of life will be described.

## **ASD: Characteristics and Experiences during the School Age**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by deficits in social interaction and communication as well as the presence of restricted, repetitive behaviors and interests (American Psychiatric Association, 2013). Common areas of social communication impairments include the lack of social-emotional reciprocity, deficits in nonverbal communication, and weaknesses in developing and maintaining social relationships. Restricted, repetitive patterns of behaviors and activities show a range of manifestations according to individuals' age and ability, which may include motor stereotypies, repetitive speech, excessive adherence to routines or rituals, resistance to change, fixated interests, and hyper- or hyporeactivity to sensory inputs. It is estimated that ASD affects approximately 1 in 68 children in the United States (Autism and Developmental Disabilities Monitoring Network, 2014) and, on average, 1 in 132 (Baxter et al., 2015) to 161 (Elsabbagh et al., 2012) children globally. Individuals identified on the autism spectrum exhibit a wide range of symptoms, developmental trajectories, as well as overall functioning (Jensen & Spannagel, 2011). The ASD diagnosis encompasses a broad continuum of individuals who, at one end, may possess high intelligence but experience difficulties socializing with people, while individuals at the other end of the spectrum may exhibit emergent or minimal verbal abilities and comorbid intellectual disabilities or psychiatric conditions.

Symptoms of ASD usually emerge in the first two years of life (Zwaigenbaum, Bryson, & Garon, 2013). Although symptoms can be reliably detected in early childhood (e.g., Reznick, Baranek, Reavis, Watson, & Crais, 2007; Robins, Fein, Barton, & Green, 2001), many individuals go undiagnosed until school age (Mandell, Novak, & Zubritsky, 2005; Shattuck et al., 2009) or late in adulthood (Geurts & Jansen, 2011). In general, the functioning of individuals

with ASD is associated with their core neuropsychological differences in the areas of theory of mind (Baron-Cohen, 2000; Frith, 1991), executive functioning (Hill, 2004), and global-local processing style (Happé & Frith, 2006; Mottron, Dawson, Soulières, Hubert, & Burack, 2006). With regard to strengths, some individuals with ASD may exhibit a range of splinter skills in areas such as music, art, engineer, and mathematics (Baron-Cohen, Ashwin, Ashwin, Tavassoli, & Chakrabarti, 2009; Heaton, Williams, Cummins, & Happé, 2007; Meilleur, Jelenic, & Mottron, 2015). Some have excellent rote memory and attention to details (Happé & Frith, 2006; Meilleur et al., 2015). They can also possess exceptional cognitive processing abilities in terms of superior perceptual functioning in visual-spatial (Samson, Mottron, Soulières, & Zeffiro, 2012) and auditory (O'Connor, 2012) domains. Regarding weaknesses, language and communication impairments are common in individuals with ASD (Tager-Flusberg, Paul, & Lord, 2005). Many have difficulties processing social-emotional information (Adolphs, Sears, & Piven, 2001; Olson, Plotzker, & Ezzyat, 2007) and understanding pragmatic language in complex social situations (Volden, Coolican, Garon, White, & Bryson, 2009). They also tend to experience challenges in emotion recognition (Berthoz & Hill, 2005) and emotional regulation (Samson, Huber, & Gross, 2012).

In educational settings, students with ASD face numerous challenges in different aspects of school life. With regard to academic, although basic reading skills and rote skills tend to be intact, they generally experience difficulties in tasks requiring higher order skills, such as listening and reading comprehension, writing, and mathematical problem-solving (Nation, Clarke, Wright, & Williams, 2006; Whitby & Mancil, 2009). Some students with ASD exhibit challenging behaviors in school, including noncompliance, aggression, self-injury, and stereotypy (Machalicek, O'Reilly, Beretvas, Sigafos, & Lancioni, 2007). They also lack

appropriate social skills interacting with others (Church, Alisanski, & Amanullah, 2000). They tend to have less friends and social interactions with peers (Wainscot, Naylor, Sutcliffe, Tantam, & Williams, 2008). Prevalence of bullying and victimization is high in this group of students (van Roekel, Scholte, & Didden, 2010). Other concerns including delay in motor skills development, sensory processing dysfunction, and psychiatric comorbidities have various degrees of negative impact on the educational experience of students with ASD (Baranek, Parham, & Bodfish, 2005; Simonoff et al., 2009). Common special education services that students with ASD receive in school include speech/language therapy, occupational therapy, social skills training, behavior management plan, academic skills support, case management, and special transportation (Thomas, Morrissey, & McLaurin, 2007; Wei, Wagner, Christiano, Shattuck, & Jennifer, 2014), while families also seek additional community-based services and interventions for their children, such as child care, medication, comprehensive treatment program, parent support group, and different kinds of alternative therapies (Thomas et al., 2007). Overall, common features associated with effective educational interventions and programs for children and adolescents with ASD are highly individualized, specialized, systematic, and structured (Iovannone, Dunlap, Huber, & Kincaid, 2003).

### **Post-school Transition in Young Adults with ASD**

Given the unique characteristics of youth with ASD, the task of transitioning from formal education to life beyond secondary school (Lee & Carter, 2012) as well as to late adulthood (Perkins & Berkman, 2012) tends to be fraught with challenges. Beyond the high school environment, young adults with ASD no longer receive the structured supports and formalized services they used to have in educational settings (Lee & Carter, 2012). In fact, the potential benefits gained from schooling and interventions in early years are easily lost after students with

ASD leave school (Taylor & Seltzer, 2010). Findings from NLTS-2 also revealed overall poorer social, vocational, educational, and quality-of-life outcomes in youth with ASD during the transition period compared to youth with other disabilities as well as when compared to other times in life (Roux et al., 2013; Shattuck, Orsmond, Wagner, & Cooper, 2011; Wagner et al., 2007). Overall, the post-school transition has been shown to be a stressful period for young adults with ASD, who struggle to adapt to the drastic changes and contextual demands in this developmental stage (Schall, Wehman, & McDonough, 2012; Wehman, 2013). In the following section, research documenting the school-to-adulthood transition of youth with ASD will be reviewed to provide an overall picture on their transition outcomes in various life domains.

### **Vocational Experiences**

For youth with ASD transitioning out of school, employment trends are poor. Secondary analyses of the NLTS-2 data revealed that only 55.1% of youth with ASD had paid employment experiences during the first six years after high school (Shattuck, Narendorf, Cooper, Sterzing, Wagner, & Taylor, 2012). They also had the worst overall postsecondary employment outcomes compared with other disability groups (Roux et al., 2013). Eaves and Ho (2008) followed 76 Canadian families with children diagnosed with ASD in the 1970's and 1980's. Of the 48 parents of young adults with ASD (mean age of 24), 56% reported their children had ever been employed. The majority were employed in volunteer, sheltered, or part-time work, while only 4% were competitively employed. Taylor and Seltzer (2011) surveyed 66 caregivers of young adults with ASD (mean age of 22.98) who had exited high school two years previously. Over half of the young adults worked in sheltered workshops or attended day activity centers, while less than 20% were engaged in competitive or supported employment. Analyzing subgroups with different intellectual abilities showed that those with an intellectual disability were less likely to

attain post-secondary education or employment; however, a significantly larger proportion of individuals with average range intelligence (compared to those with an intellectual disability) had no or minimal daily activities. The same group of researchers (Taylor & Mailick, 2014) followed 161 youth with ASD over a 10-year period immediately after they exited high school. The longitudinal data revealed significant declines in levels of vocational independence and engagement over time, which points to their deteriorating vocational functioning from late adolescence through adulthood.

Looking beyond the transition years, unemployment rates among adults with ASD remained similarly high (Howlin, Goode, Hutton, & Rutter, 2004; Wagner, Newman, Cameto, Garze, & Levine, 2005). In studies that included a wide age range of adults with ASD (Cedurland, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Howlin et al., 2004), individuals with high functioning autism had somewhat higher employment rates than those with lower intelligence, but the majority who were employed held jobs in sheltered employment instead of competitive employment. Compared with peers without disabilities, adults with ASD were more likely to be unemployed or underemployed, earn less, switch jobs frequently, and have difficulty adjusting to new job settings (Howlin, 2000; Hurlbutt & Chalmers, 2004; Jennes-Coussens, Magill-Evans, & Koning, 2006; Müller, Schuler, Burton, & Yates, 2003).

### **Education Experiences**

Upon the completion of high school, adolescents with ASD may choose to pursue further education in post-secondary settings. Traditionally, due to the high academic demands, the pathway to traditional college and university programs may be more accessible to only a small proportion of individuals with higher levels of functioning, while posing difficulties to those with comorbid intellectual disability (Hart & Grigal, 2009). Reviewing a number of studies conducted

in the 1980's and 1990's that followed individuals with high-functioning ASD from childhood to adulthood, Howlin (2000) reported a wide range of 7% to 50% of individuals who had ever received a college or university education. Secondary analyses of the NLTS-2 data revealed that less than 35% of youth with ASD had attended college during the first six years after exiting high school (Shattuck, Narendorf, Cooper, Sterzing, Wagner, & Taylor, 2012). Other reports (Cedurland et al., 2008; Taylor & Seltzer, 2011) generally found that about 10% of individuals with high-functioning ASD had attended college or university, although only a minority eventually received a degree and the incidence of college or university attendance was extremely rare for those with lower intelligence. Concerns of social disengagement and social anxiety were also found to be the major challenges for this group of college attendees (Camarena & Sarigiani, 2009; White, Ollendick, & Bray, 2011). However, with the emergence of many new possibilities and non-traditional alternatives in enrollment options, programs of study, and disability services and accommodations, individuals with ASD with varying abilities now have more opportunities to participate in post-secondary education (Hart, Grigal, & Weir, 2010).

### **Independent Living**

In a population-based study conducted in the Sweden that involved 120 adults diagnosed with ASD (ranging in age from 17 to 40), only four individuals were identified as living independently (Billstedt, Gillberg, & Gillberg, 2005). Other studies reported less than 10% of adults with ASD lived independently, one-third lived in a residential placement, and half lived with their parents (Cedurland et al., 2008; Howlin et al., 2004). Individuals with higher intelligence generally achieved higher levels of independence than their counterparts with lower intellectual functioning (Howlin et al., 2004). Cedurland et al. (2008) compared adults (ages 16-38) with Asperger's syndrome and those with autism and found 64% and 8% of the respective

groups lived independently, although both groups were described by their parents as dependent on parental support.

### **Community Engagement**

Community engagement after high school exit is commonly described in the literature as participation in employment or post-secondary education. The primary issue is whether an individual has regular, on-going activities involving active participation in the community. Overall, community disengagement is not uncommon among youth with ASD. Shattuck et al. (2012) analyzed the NLTS-2 data and found that half of the youth with ASD were disengaged from any kind of vocational or educational activities in the first two years after high school, which was the highest among the various disability categories. Higher household income and higher intellectual functioning were associated with higher probability of community participation. However, in a small sample of 66 young adults (mean age of 22.98) with ASD (Taylor & Seltzer, 2011), three-quarters of whom had a comorbid intellectual disability, 8% of mothers of those with an intellectual disability and 24% of mothers of those without an intellectual disability reported no regular daily activities. As such, in Taylor & Seltzer's study (2011), having an intellectual disability was associated with greater community engagement whereas in Shattuck et al.'s study (2012), having an intellectual disability was associated with lesser community involvement. In short, these two studies reported contrasting findings with regard to the association between individual's functioning level and the odds of no community participation.

Regarding leisure activities, the NLTS-2 study revealed a high involvement of isolated activities, such as playing video games and watching television, in young adults with ASD transitioning out of high school (Wagner et al., 2005). Compared with age- and intelligence-

matched typically developing peers, significantly more young adults with Asperger's syndrome (mean age of 20.3) preferred solitary (e.g., TV, internet, video games, reading) than social activities (e.g., sports; Jennes-Coussens et al., 2006). In a sample of adults with ASD (ranging in age from 17 to 40), over 80% of whom had below average intelligence, only 30% participated regularly in recreational activities, such as horseback riding, bowling, and swimming (Billstedt, Gillberg, & Gillberg, 2011). Listening to music was one of the most common interests among 44% of the adults, although almost all participants reported some other specific topics of interests, such as airplanes, computers, and food.

### **Behavioral Functioning and Symptoms**

In contrast to what is known about community engagement, relatively less is known about adaptive behaviors and functioning among youth with ASD transitioning to adulthood. In one study, Taylor and Seltzer (2010) examined the longitudinal change in autism symptoms and behavior problems over a 10-year period. Using the Autism Diagnostic Interview-Revised (ADI-R; Lord, Rutter, & Le Couteur, 1994) and the Behavior Problems subscale of the Scales of Independent Behaviors-Revised (SIB-R; Bruininks, Woodcock, Weatherman, & Hill, 1996), the researchers reported an overall improvement of autism symptoms and internalized maladaptive behaviors when adolescents with ASD were in secondary schools compared to earlier in life, but the rates of improvement slowed down significantly after high school exit. Drawing from the same community-based sample, Smith, Maenner, and Seltzer (2012) compared the longitudinal change in daily living skills of individuals with ASD to those with Down syndrome using the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013). In the ASD group, although daily living skills improved during adolescence and the early 20's, they plateaued during the late 20's and showed signs of decline during the early 30's. In contrast, individuals

with Down syndrome displayed a stable trend of improvement over time. Both studies showed that individuals with ASD who did not have an intellectual disability experienced a greater decline in rates of improvement over the school-to-adulthood transition (Smith et al., 2012; Taylor & Seltzer, 2010).

In another cross-sectional study with samples of adolescents (mean age of 17.52 years old), young adults (22.22 years old), and adults (35.04 years old) with ASD, Matthews et al. (2015) compared individuals' adaptive and intellectual functioning using the Vineland Adaptive Behavior Scales, Second Edition (VABS-II; Sparrow, Cicchetti, & Balla, 2005) and the Kaufman Brief Intelligence Test, Second Edition (KBIT-2; Kaufman & Kaufman, 2004). All individuals with ASD showed consistently lower adaptive functioning than cognitive abilities. While the adolescent group possessed comparable levels of skills in daily living, communication, and socialization, the latter two skill domains were observed to be the relative weaknesses in the adult group. Across all age and intellectual ability groups, writing skills appeared to be a relative strength while interpersonal relationship skills were a relative weakness for individuals with ASD.

### **Social Experiences**

Social relationships are one of the most oft-cited challenges for individuals with ASD. During adolescence, there is a widening gap in social experiences between these individuals and typically developing peers (Church et al., 2000). Secondary analyses of NLTS-2 data showed that half of youth with ASD never see friends out of school, get called by friends, or are invited to social activities (Shattuck et al., 2011). Across multiple reports of other small-scale studies, about 10 to 30% of adolescents and adults with ASD reported having at least one friend, but nearly half had no peer relationships (Billstedt et al., 2011; Eaves & Ho, 2008; Howlin et al.,

2004; Mawhood, Howlin, & Rutter, 2000; Orsmond, Krauss, & Seltzer, 2004). These trends did not seem to differ among individuals with different levels of intellectual functioning. Not surprisingly, the prevalence of intimate relationships is much lower than ordinary social relationships. Few cases or anecdotal reports have documented individuals with ASD engaging in romantic relations (Eaves & Ho, 2008; Jennes-Coussens et al., 2006), sexual relations (Hellemans, Colson, Verbraeken, Vermeiren, & Deboutte, 2006), and long-term or marital relations (Billstedt et al., 2005; Cedurland et al., 2008; Howlin, 2000). The low incidence of social relationships among these individuals often is associated with feelings of loneliness (Bauminger & Kasari, 2000; Bauminger, Schulman, & Agam, 2003). Indeed, the majority of individuals with ASD have interest and desire in social relationships (Billstedt et al., 2011; Hellemans et al., 2006; Jennes-Coussens et al., 2006; Marks, Schrader, Longaker, & Levine, 2000). However, they often lack the knowledge of how to interact effectively in social relationships (Billstedt et al., 2011; Stokes, Newton, & Kaur, 2007; Van Bourgondien, Reichle, & Palmer, 1997).

In short, research to date has demonstrated emerging evidence in search of the predictors related to successful outcomes during the transition from school to adulthood in youth with disabilities in general (Landmark, Ju, & Zhang, 2010; Test et al., 2009) as well as with ASD specifically (Wehman et al., 2014; Migliore, Timmons, Butterworth, & Lugas, 2012). The majority of predictors identified are related to strengthening context-specific skills in preparation for the three most common post-school environments: (a) predictors for success in post-secondary education include inclusion in general education, vigorous academic standards, and planning the program of study during high school; (b) predictors for success in employment include vocational education, work study, and job skills training; (c) predictors for success in

community living include self-care skills and social skills training. Other generic predictive factors include participation in structured exposure to real-life settings, such as transition programs, work/internship experiences, and community experiences. Supports and collaboration among significant parties, including family, social network, and community agencies, are also important in predicting students' transition outcomes.

Despite structured support in place, youth with ASD are not likely to show active participation in planning their transition and future life (Shogren & Plotner, 2012). Although they tend to be directed by others to learn and perform certain behaviors and tasks, the process of internalizing such external demands is no less important, which involves linking the expectations in the environment to intrinsic motivation and subsequently to their engagement in actions to produce the ultimate outcomes (Ryan & Deci, 2000). Indeed, self-determination is the only identified predictor for successful transition outcomes that can potentially facilitate this internalization process to produce more autonomous functioning across different life domains (Wehman et al., 2014).

### **Concept of Self-Determination**

The concept of self-determination has been identified in the special education literature as an important psychological construct (e.g., Thoma, Williams, & Davis, 2005; Wehmeyer & Palmer, 2003; Wehmeyer & Schwartz, 1998). Wehmeyer (2005) defined self-determination 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). Instead of prescribing power and control, self-determination serves to empower individuals to make conscious choices and decisions to intentionally and purposefully cause one’s actions. Its notion is closely related to the disability rights movement in a way that assumes self-determination as a universal phenomenon and

proclaims self-determination as the basic human right in all people, including individuals with or without disabilities (Wehmeyer, 2005). From a functional perspective (Wehmeyer, 1998, 1999), behaviors with the following four essential characteristics are identified to serve the functions of self-determination: (a) a behavior is *autonomous* when a person acts according to their preferences, interests, or abilities, and acts independently without much external influence; (b) a behavior is *self-regulated* if a person make decisions about his/her behaviors in a situation, examines the task demand and available resources, and plans, enacts, evaluates, and adjusts his/her action; (c) a person acts in a *psychologically empowered* manner if he/she has the beliefs that he/she has the capacity to behave in a way to produce and influence the expected outcomes in the environment; and (d) a *self-realized* person has a reasonably comprehensive and accurate understanding of him-/herself, including strengths and weaknesses, and capitalizes on this knowledge in an adaptive and beneficial way (Wehmeyer et al., 1996).

Operationally, self-determination entails a constellation of skills, knowledge, and beliefs that enable individuals to “engage in goal-directed, self-regulated, autonomous behavior” (Field, Martin, Miller, Ward, & Wehmeyer, 1998, p. 2). The four essential characteristics that define self-determined behaviors manifest as a range of subcomponent skills and attitudes, including (a) choice-making; (b) decision-making; (c) problem-solving; (d) goal-setting and attainment; (e) independence; (f) self-management; (g) self-instruction; (h) self-advocacy; (i) internal locus of control; (j) self-efficacy; (k) self-awareness; and (l) self-knowledge (Wehmeyer et al., 1998). These altogether characterize how self-determined behaviors look like in a person as suggested by the Western literature.

The functional theory of self-determination provides a pragmatic account of how to understand self-determination across different contexts. This theory suggests that behaviors are

considered to be self-determined based on the function they serve for the individuals while taking into consideration the context in which a person is situated as well as the interaction between the person and the context (Wehmeyer, Kelchner, & Richards, 1996). The role of environment is further emphasized in the ecological model of self-determination (Abery & Stancliffe, 1996; Wehmeyer, Abery, Mithaug, & Stancliffe, 2003), which was derived from the ecological model of human development by Bronfenbrenner (1979, 1989). According to this model, self-determination is a product of both the person and the environment, with the person interacting with the environment to determine to what extent and in what contexts the self-determined behaviors are exhibited. These two theories together argue for the need for considering contextual and cultural variables in the environment in order to understand individuals' self-determination behaviors. Despite a similar focus on the person-environment interaction, theories of self-determination are not to be confused with positive behavioral interventions and supports (PBIS; Sugai & Horner, 2002; see also Carr, Dunlap, et al., 2002; Carr, Horner, et al., 1999). While the latter focuses on structuring the environment to support the learning of positive behaviors and to prevent problem behaviors, the former focuses on the development of one's internal dispositional self-determined characteristic and external behavioral expressions of such characteristic that allow individuals to become the causal agent in one's environment (Shogren et al., 2015).

### **Self-Determination in Young Adults with Disabilities**

Empirical research has demonstrated the relationship between self-determination and positive outcomes in young adults with disabilities transitioning to adulthood. Following students with learning disabilities or intellectual disabilities one year after high school exit, Wehmeyer and Schwartz (1997) found that the group that reported higher on a self-determination measure at

graduation had a higher employment rate and salary. In another study using a similar follow-up methodology, those with higher levels of self-determination were found to do better than their peers with lower self-determination in various life domains three years after graduation, including employment, job benefits, financial independence, and independent living (Wehmeyer & Palmer, 2003). After controlling for intellectual functioning and living settings, adults with intellectual disabilities who are more self-determined experienced a higher quality of life (Wehmeyer & Schwartz, 1998). The similar benefit of self-determination to quality of life was also demonstrated using an international samples from four Western countries (Lachapelle et al., 2005).

Accumulating evidence has begun to show that interventions targeting the subcomponent skills of self-determination are effective in promoting better functioning in individuals with disabilities across the lifespan (e.g., Algozzine et al., 2001; Chambers et al., 2007; Wood et al., 2005). In a narrative metasynthesis that summarizes meta-analyses on the self-determination literature in students with different types of disabilities, Cobb, Lehmann, Newman-Gonchar, and Morgen (2009) concluded that (a) self-determination is a multifaceted and complex construct; (b) interventions with multiple components are more promising in producing positive outcomes; (c) self-determination interventions are not effective in enhancing academic achievement; and (d) subcomponent skills of self-determination can be enhanced by targeted curricular and instructional interventions.

More recently, rigorous research designs have been applied to evaluate interventions specifically targeting self-determination in secondary-age students with disabilities in relation to their effectiveness on transition and post-school outcomes. Powers et al. (2012) reported a randomized control trial of a self-determination intervention, *TAKE CHARGE*, in 69 adolescents

who are enrolled in both foster care and special education. Students randomly assigned to the program received coaching in applying self-determination skills to achieve self-identified transition goals and mentoring workshops with foster care alumni, while the control group participated in an independent living program. Across pre-intervention, post-intervention, and one year follow-up, students in the intervention group showed notable gains in self-determination, quality of life, and utilization of community services. They also showed better transition outcomes in high school completion, employment, and independent living. In a randomized trial with placebo control group design, Wehmeyer, Palmer, Lee, Williams-Diehm, and Shogren (2011) evaluated an intervention, *Whose Future Is It Anyway?* (Wehmeyer et al., 2004), that aims to promote student involvement in transition planning. The 36-session curriculum covers contents related to (a) awareness of self and disability, (b) making decisions about transition, (c) identifying community resources, (d) developing transition goals, (e) communication skills, and (f) participation as a team member, leader, or self-advocate. Over a one-year period, in comparison to the control group with teachers promoting family involvement in transition planning, the intervention group (n=119) showed larger positive gain in self-determination as well as knowledge and skills in transition. A similar randomized control trial was conducted using different evidence-based self-determination curricula of teachers' choice (Wehmeyer, Palmer, Shogren, Williams-Diehm, & Soukup, 2013). Compared with the control group, students with intellectual disabilities and learning disabilities in the intervention group demonstrated significantly greater growth in self-determination over a 3-year period. In a follow-up study of the participants in the Wehmeyer et al. (2011) and Wehmeyer et al. (2013) studies, students with higher self-determination upon high school exit were found to have more positive outcomes in employment and community access one year post-school (Shogren, Wehmeyer,

Palmer, Rifenbark, & Little, 2015). More importantly, students who received self-determination interventions in school showed less regression in adult outcomes over time.

### **Self-Determination in Young Adults with ASD**

Compared with other disability groups, not only is the post-school transition more difficult for individuals with ASD, the development of their self-determination is also a challenging task. Their characteristic deficits in social communication and idiosyncratic patterns of cognition (American Psychiatric Association, 2013) may impact the development of self-determined behaviors, such as communicating needs, expressing preferences, exercising decision-making skills, and understanding personal strengths and weaknesses. Due to the high prevalence of behavioral and mental health challenges in this population, they often require substantial support and contingencies to function in different daily environments, which further undermines their opportunities to practice self-determination and reinforces their dependence to others (Clark, Olympia, Jensen, Tuesday-Heathfield, & Jenson, 2004). However, with educational supports and accommodations targeting the unique needs of students with ASD, research suggests they can acquire skills to enable them to function more autonomously and benefit from self-determined behaviors (see Wehmeyer & Shogren, 2008). As suggested by Wehmeyer, Shogren, Zager, Smith, and Simpson (2010), students with ASD preparing for the transition out of school would similarly benefit from instruction in self-determination skills. For example, with the assistance of multimodal support (e.g., visual aids), children and youth with ASD can be meaningfully involved in setting goals for their use of services (Hodgetts & Park, 2016). Practitioners should therefore take into consideration both person-centered factors and environment-based ecological variables, as well as their complex interactions, to enhance the

capacity of individuals with ASD and modify their immediate environment in order to support their success in acquiring self-determination (Wehmeyer et al., 2010).

When the entire ecology is recruited to support the development of self-determined behaviors, it is important to consider important individuals in the life of young adults with ASD. Research consistently indicates that significant others support the development of self-determination among youth adults with ASD. For example, parents of children with ASD or developmental disabilities highly value the component behaviors of self-determination (Carter, Lane, Conney, Weir, Moss, & Machalicek, 2013). Teachers in both general and special education perceive the instruction of self-determination skills as important to transition-age youth with disabilities (Carter, Lane, Pierson, & Stang, 2008). Both parents and teachers indicate adequate opportunities available at home and school for students to engage in self-determined behaviors (Carter et al., 2008; Carter, Owens, Trainor, Sun, & Swedeen, 2009), although they may hold different views on self-determination and different beliefs in the ability of students to exercise it (Carter et al., 2009; Grigal et al., 2003). However, in these reports, parents and teachers consistently suggested an overall low level of self-determination in students with ASD. Importantly, however, none of the research in this area has surveyed students with ASD with respect to their own perspectives on their self-determination. Individuals with ASD, despite being served and supported by multiple stakeholders in different environments, are indeed at the center of the ecology. With only a few exceptions of self-advocates speaking about their firsthand accounts (e.g., Cesaroni & Garber, 1991; Grandin, 1995; Volkmar & Cohen, 1985), the voices of individuals with ASD go almost unheard in the literature. The essence of “self” in self-determination is also belittled and the first-person experiences and meanings of self-determination in individuals with ASD remain unknown.

## **Cross-Cultural Perspective in Understanding Disability**

To take a social-ecological approach when considering contextual factors that affect self-determination (Shogren, 2013; Wehmeyer et al., 2010), individuals with ASD centered in two different ecologies with contrasting macro-level cultural backgrounds may have different experiences and understandings of self-determination. Broadly speaking, cross-cultural research is a valuable tool for us to understand the issues regarding mental disabilities in different socio-cultural contexts (Daley, 2002). With better understanding of disability as well as culture, researchers will eventually be able to devise interventions to enhance the well-being of individuals with disabilities that are compatible to the cultural values of specific ecology. As discussed by Bernier, Mao, and Yen (2010), although biologically-based disorders may have similar symptoms across cultures, how the symptoms are processed within different value systems all boils down to the variations in how people interpret, accept, and intervene in the disorders. They noted that among dominant interventions for the ASD populations, those with a focus on facilitating independence and autonomy may fit more into the values of individualism in Anglo-American culture but may clash with other cultures with a more collectivist orientation that prioritizes group over individual. For young adults with ASD transitioning to adulthood, the goals of this developmental period could vary from increasing independence to fostering family interaction, depending on the cultural expectations and family values (Bernier et al., 2010).

Cross-cultural research indeed suggests meaningful differences between Western and Eastern cultures. Anglo cultures dominant in Europe and America can be described as individualistic and low-context, emphasizing equality of all human beings, personal achievement, and individual rights (Hofstede & Peterson, 2000). Eastern societies influenced by the Confucian frameworks of understanding, such as China, Japan, and Korea, tend to value

more the mutual relationships between oneself and others within a network of societal hierarchy (Yang, 2011). Individuals from these collectivistic and high-context cultures tend to interact with the environment in a manner that emphasizes groups more than individuals and tends to adjust the self to meet group needs. Despite sharing the similar Confucian heritage ideology with other Chinese societies, Hong Kong has a distinct social and educational development due to its history of British colonization that results in an earlier exposure to Western influences in its institutional structures (Yang, 2011). It is of great value for cross-cultural research comparing the West and the East to examine the possibility of transferring educational practices across the contextual boundaries (Evers, King, & Katyal, 2011).

Within the self-determination literature, the self-determination construct has been recently critiqued as heavily culturally-bound. Originally rooted in the philosophical debate between determinism and free will in late 17<sup>th</sup> Century Europe, the concept of self-determination has been strongly influencing the European and American history in multiple disciplines, including the theological debate between human free will and the determinism by religious figures and the political movements of native tribes and minorities proclaiming the rights for self-governance and autonomy (Frankland et al., 2004). Its widespread adoption and usage in applied fields, such as psychology, education, and social work, was preceded by numerous social movements in the Western societies, namely disability rights, self-advocacy movement, and equal opportunities movement (Ward, 1996), which reflected the central tenets of individualism, normalization, autonomy, independence, and equity (Harry, Rueda, & Kalyanpur, 1999). As such, consensus of the defining features of self-determination has emerged exclusively from the discussion by researchers from the Western background. For example, Wehmeyer and Shogren (2008) pointed out that the promotion of self-determination was grounded in “the conviction

about the rights of people with disabilities to control their own lives” (p. 437), which highlights the sociocultural significance of personal control evidenced in Western societies. However, these values may seem unfamiliar or inappropriate to people who are not European American and middle class (deFur & Williams, 2002; Kalyanpur & Harry, 1999).

### **Cross-cultural Conceptualizations of Self-determination in Individuals with Disabilities**

From the functional perspective of self-determination (Wehmeyer, 1999), it can be argued that the behaviors that defined self-determination may look different across cultures but they may all serve the same functions of autonomy, self-regulation, psychological empowerment, and self-realization. In other words, culture can be considered a moderating variable that impacts how self-determination operationalizes and decides what behaviors express this psychological construct (Wehmeyer et al., 2011). In the following paragraphs, a number of theoretical as well as empirical research will be reviewed to discuss how members from diverse cultures understand the concept of self-determination.

Frankland et al. (2004) discussed the influence of the culture of Diné (Navajo) traditions on transition and self-determination, including traditional family structure, expectations of child development, and perceptions of disability. For example, the Diné family holds a view that children with disabilities can attain self-governance when provided family guidance and support, thus allowing the immediate and extended family networks to be involved in their children’s development. Borrowing from relevant cross-cultural literature and qualitative reports, the authors illustrated how the four essential characteristics of self-determination (i.e., autonomy, self-regulation, psychological empowerment, and self-realization) are compatible to the traditional beliefs and practices of Diné culture, but with a heavier emphasis on interdependence and group cohesion (Frankland et al., 2004). For example, although Diné students are expected

to acquire skills to make decisions and regulate their own behaviors, they tend to place their family's needs above their own. Autonomy in Diné students may mean fulfilling expected family roles through a group-oriented decision-making processes within the communal value system.

With an aim to adopt self-determination instruction into Japanese culture, Ohtake and Wehmeyer (2004) explored how the central tenets of self-determination can be related to the values embedded in the nationally recognized exemplary instructional practices in Japanese special education. For example, students with disabilities are empowered by teachers who recognize their hard work at both an individual level and an interdependent-group level. Instead of “self” determination, the authors suggested “corporate” determination as a better term in delineating the collectivistic processes involved in decision-making, choice-making, and problem-solving for individual students.

More recently, Marfull-Jensen and Flanagan (2014) discussed the conception of self-determination in the context of the enactment of the National Disability Law in Chile. The authors argued that the efforts to promote individuals' independence and autonomy in collectivistic societies are likely to be discouraged due to the fact that the cultures and values of such societies do not provide and promote opportunities for people to do so. Instead, to foster the four characteristic functions of self-determination within a collectivistic context, practitioners and policy makers should inquire about the cultural values and beliefs of individuals with disabilities and take these factors into consideration using a person-centered approach. It is of utmost important that we recruit the perspectives of individuals with disabilities when assisting them in the transition and self-determination processes.

Conceptually, there are various levels of similarities and differences in the self-determination conceptions and manifestations in people with disabilities between individualistic

and collectivistic societies. Despite this conceptual argument, cross-cultural empirical research of this kind is relatively scant. Seo (2014) conducted a survey research to investigate the perceived importance and the reported instruction of specific skills of self-determination by teachers who teach students with disabilities in Korea. Although 70% of general and special education Korean teachers were not familiar with the concept, 80% indicated high importance on most of the components skills of self-determination, with the exception of self-advocacy and leadership skills. This research provides an idiographic account of educators' perspectives on self-determination in a non-Western context. However, a limitation of this research is the absence of direct comparison of findings across different cultures.

In one study that did examine differences across cultures, Zhang et al. (2005) recruited 627 American and 268 Taiwanese parents and teachers to rate on a questionnaire how frequently they engaged in the recommended practices for fostering self-determination of school-age students with disabilities (e.g., providing opportunities to choose from several different strategies for a task; leading the student through planning activities to determine the steps to take to progress toward goals; assisting the student in requesting academic and social supports from teacher). While no significant differences were found between teachers' practices in the United States and Taiwan, American parents rated their involvement in self-determination-fostering behaviors higher than their Taiwanese counterparts. However, as noted by the authors, it is important to detail the complex contexts in which the behaviors occur when interpreting the findings. For example, Asian Americans tend to emphasize family priorities more and believe in exercising parental authority less than Caucasian parents (Zhang, 2005). Despite the quantitative difference evidenced in the unidimensional self-determination questionnaire, there may be qualitative differences in how the process of self-determination is cultivated in different cultures.

With an effort to explore the cross-cultural operationalization of self-determination, Ginevra, Nota, Soresi, Shogren, Wehmeyer, and Little (2013) recruited 237 Italian and 285 American typically developing adolescents to respond to *The Adolescent Self-Determination Assessment* (Wehmeyer, Lopez, & Shogren, 2007). Analyses using structural equation modeling revealed an invariant factor structure in the two groups of participants, indicating that the four essential characteristics of self-determination (i.e., autonomy, self-regulation, psychological empowerment, and self-realization) hold up across Italian and American cultures. However, on individual item level, substantial differences were found as to how adolescents from these two cultures exhibit self-determined behaviors in specific situations and activities. For example, compared with American adolescents, Italian adolescents were more likely to express autonomy in household activities but less likely in activities outside home that are away from parents' supervision. Italian adolescents were also more likely than their American peers to make choices that are important to them, which may be attributed to their early experience of making important decisions associated with the streaming system in the Italian high school educational system.

A number of preliminary studies reviewed above have used quantitative methods to demonstrate cross-cultural differences in conceptualizing self-determination. These studies show that the functions and characteristics that define self-determination (i.e., autonomy, empowerment) need to be considered separately from the developmental tasks that are used to present it in a particular culture (e.g., residential independence, competitive employment) (Taylor, 2009). However, there is still a lack of understanding on how different cultural values and social processes lead to the multiple manifestations of self-determined behaviors across cultures. No qualitative inquiry has been done to investigate this issue by comparing individuals with disabilities across countries with different cultural backgrounds. Insights need to be drawn

from qualitative studies that investigate self-determination experiences among different ethnic groups in the United States.

In one of the few qualitative studies on self-determination among youth with disabilities, Trainor (2005) examined the perceptions and behaviors of self-determination in a culturally-diverse sample of American students with learning disabilities. The author used a qualitative approach to collect data from multiple sources, including interviews, focus groups, observations, and record reviews, to illustrate students' perspectives during the transition planning process in high school. Despite this multi-source approach, the results failed to reveal diverse self-determination perspectives across cultural groups because the educators in the research site tended to take charge of and control students' transition planning processes. Specifically, even if students from diverse backgrounds may hold different values about self-determination, they appeared to be unaware of, unknowledgeable of, and disengaged from the transition expectations and requirements, which were already structured by adults in schools. However, interestingly, the author found subtle cultural differences in self-determination manifestations outside of the formal transition planning procedures. For instance, Hispanic students tended to express a preference for living at home after high school and sharing about their self-determination efforts with teachers.

Leake and Boone (2007) investigated the influence of culture on self-determination in students with emotional and/or behavioral disabilities by conducting focus groups with multiple stakeholders (i.e., youths, parents, and teachers) from a wide range of culturally and linguistically diverse ethnic groups (i.e., White, Black, Hispanic, East Asian, Filipino, Hawaiian, and Pacific Islander) in Washington, DC, and Hawaii. The qualitative data revealed that members across all non-White cultural groups adopted a broader conception of family system

and a greater focus on interdependence than the mainstream American culture. As such, family is a crucial determinant that needs to be taken into consideration in the development of self-determination in the post-school transition of youth from culturally-diverse cultures. Moreover, a clear contrast of individualism and collectivism was found in participants from White and East Asian backgrounds. For example, the latter placed value on education in a way that youth would pursue post-secondary education because of their family expectations. However, as most participants were identified as bicultural or multicultural as well as acculturated to the mainstream culture to various degrees, overall, there was a mix of individualistic and collectivistic characteristics within and across cultural groups, thus posing challenges in interpreting the cross-cultural findings. Instead, it would be methodologically sounder to compare two cultures in a single study.

More recently, 20 parents of high school students with a wide range of disabilities from different ethnic groups (European American, African American, Hispanic American, and Asian American) were interviewed by phone about how they understood and promoted self-determination (Zhang, Landmark, Grenwelge, & Montoya, 2010). European American parents were found to be more able to articulate the definition of self-determination (i.e., individuals being the primary decision-makers in their lives). They were also more proactive in promoting independent living in their children. In contrast, more parents from other diverse cultures did not know the meaning of self-determination. They also tended not to discuss their children's strengths and weaknesses. However, one of the limitations of the study was that the vast diversity of culturally-specific parent responses on self-determination cannot be solely attributed to cultural factors due to the heterogeneity of students' disability types. The author suggested

limiting participants to one disability category, such as ASD, in order to systematically compare the differences in cultural values.

### **Summary**

The literature reviewed above reveals a growing interest in investigating culturally-appropriate conceptualizations of self-determination across different ethnicities or nations. On a conceptual level, self-determination, despite its roots in European and American ideologies, is valued in other cultures but is associated with different meanings and behaviors that are influenced by the particular cultural beliefs and customs (Frankland et al., 2004; Ohtake & Wehmeyer, 2004). Preliminary studies conducted using quantitative methodologies support such meaningful cross-cultural differences between Western and Eastern cultures (Zhang et al., 2005) as well as among different countries in Western society (Ginevra et al., 2013). While there is a need to use qualitative methodology for deeper understanding of the socio-cultural contexts and meanings of such cross-cultural differences (Trainor, 2002), all available qualitative literature was focused on comparing ethnic groups only within the United States (Leake & Boone, 2007; Trainor, 2005; Zhang et al., 2010). However, the global initiative of disability movement, and more specifically, the promotion of self-determination to enhance the quality of life in individuals with disabilities, calls for a qualitative comparative study at the international level.

### **Purpose of Study**

The present research aims to explore the experiences and meanings of self-determination in young adults with ASD from the United States and Hong Kong. Research including the voices and perspectives of individuals with ASD from diverse backgrounds is crucial in understanding how self-determination is operationalized in different cultures. By using qualitative methodology, in-depth information were collected about the experiences of young adults with

ASD in their respective cultural contexts. Direct comparison of the two cultural groups served to reveal how self-determination behaviors manifest in the two different cultural contexts. The cross-cultural qualitative design provides the first empirical account in the literature on how cultural factors play a role in how individuals with ASD interact with their environment to express self-determination. Specifically, American culture was directly compared against the Chinese, which helped elucidate context-specific self-determination experiences and conceptualizations. This paves the way for future research to apply self-determination interventions in a culturally-responsive manner and to promote better post-school transition and adult outcomes in individuals with ASD across different cultural contexts.

## CHAPTER 3

### METHOD

In the previous chapter, I reviewed the literature on self-determination and its relation to post-school transition in young adults with ASD. The lack of culturally-specific conceptualizations of self-determination provides evidence for the need to explore the experiences and perceptions of self-determination among young adults with ASD in both Western and non-Western cultures. The current chapter will first present the research questions that are central to the study. I will then detail the research design and the theoretical orientation. The selection of settings and participants, data collection procedures, pilot study, and data analysis plan will be presented next. I will also discuss the concept of trustworthiness in evaluating the quality of the study. My role in the research study will be detailed in the reflexivity section. Finally, I will discuss some ethical considerations of the study.

#### **Research Questions**

1. How do young adults with ASD perceive their experience with self-determination during their transition from school to adulthood in the United States?
2. How do young adults with ASD perceive their experience with self-determination during their transition from school to adulthood in Hong Kong?
3. How does the experience and perception of self-determination vary in young adults with ASD across the United States and Hong Kong?

## **Research Design**

The purpose of the current study was to compare cross-culturally how young adults with ASD experience and understand self-determination during the period of the school-to-adulthood transition. Individual qualitative interviews were the primary data source to answer the research questions. The interviews conducted in this study employed an emic perspective and ensured that participants described their experiences and expressed their thoughts and perceptions from their perspectives of interpretation and minimize judgment from me (Brinkman & Kvale, 2014). Specifically, the use of individual interviews enabled the collection of rich, in-depth data from individuals with ASD about their self-determination experience. The present study involved individual interviews with young adults with ASD in the United States and Hong Kong to explore their experiences and perceptions of self-determination. The USF Institutional Review Board (IRB) approved the study to be conducted between July 21, 2015 and July 21, 2016.

## **Research Paradigm**

As it adopts a cross-cultural approach, it is important to explicate how culture is conceptualized in the current study. Traditionally, the discipline of psychology adopts a post-positivist approach to investigate human behaviors and their interrelationships in a linear, causal, and objective manner (Kim, 1999; Koch & Leary, 1985). Culturally-related variables, such as state of consciousness, meaning, and intentions, are mostly considered unobservable and unamendable, so that they are treated as mere background extraneous factors and are ignored in the majority of research (Kim, Park, & Park, 2000). However, there is no denying that context and culture has a significant impact on human behavior within one's community (e.g., Berry, 1980; Berry, Poortinga, Segall, & Dasen, 1992; Segall, Dasen, Berry, & Poortinga, 1990). Using the natural and human resources available in one's immediate environment, individuals achieve

desired outcomes in a certain way of life as a group, in a period, or as part of humanity in general (Williams, 1985). The pattern of how individuals interact with their environments constitutes a particular culture, which in turn provides shared symbolic meanings, directions, and coherence to its members within groups (Bocock, 1992). In short, culture can be understood as “shared meanings and ways of life” as well as “the practices which produce meaning”, which respectively focus on the content and meaning aspects of a culture (Bocock, 1992, p.234). Kim et al. (2000) further postulated that the understanding of culture has to be investigated through the examination of: (a) context, (b) epistemology, and (c) phenomenology. In short, culture was understood as the contexts in which a person situate, which may include the intersections of multiple systems within a person’s immediate ecology (Bronfenbrenner, 1979). With this background understanding of culture, the research questions were focused on the phenomenology and epistemology of the experience of self-determination by revealing its manifestations, meanings, and significance in participants from American and Chinese cultures. The contexts of self-determination were also thoroughly examined to better understand the connections and relationships with the broader sociocultural values.

Regarding the specific orientation adopted for the research methodology, I conceptualized the qualitative interviews in the current study as both “neo-positivist” and “romantic” using the terminology of Roulston (2010). Neo-positivism (or post-positivism) assumes that there is an objective truth out there that is readily accessible and investigable by an outsider. Consistent with the neo-positivist tradition, the formulation of interviews and data analysis procedures were approached with a clearly defined research topic using a set of guiding questions that aim to access participants’ information, which then can be meaningfully combined within cultural groups and be compared among the groups (Alvesson, 2003; Foddy, 1993). On

the other hand, the processes of conducting the qualitative interviews and interpreting the data were approached with a “romantic” orientation. Knowledge we learned during interview is produced in the context of a conversation relation where the interviewer or researcher is also actively involved alongside interviewee’s contribution (Brinkmann & Kvale, 2015). During the interview process, I as the interviewer was aware of the rapport and empathic connections built with the participants. Interview questions were also carefully formed and sequenced to accommodate the situations of individual participants (Hermanowicz, 2002). These are important when working with the ASD populations considering their challenges in social communication and idiosyncratic use of language. Throughout the interview and research processes, I was cognizant of my role in engaging the participants in revealing their experiences and perceptions of their life-worlds. I was constantly engaged in reflections regarding my own personal assumptions and presuppositions that might influence participants’ accounts. This was achieved by writing interview notes and keeping reflective journals throughout the interview and data analysis processes (discussed below).

To explore the experiences and meanings of self-determination in young adults with ASD, qualitative interviews and subsequent data analysis will be conducted in a classical phenomenological approach to yield rich and in-depth findings (Brinkmann & Kvale, 2014). More importantly, the use of qualitative methodology in cross-cultural comparative research provides an opportunity to understand individuals’ psychological and educational processes within the contexts of their local cultural, political, and social environments (Fairbrother, 2014).

### **Settings**

This study took place in two cities in two countries, namely Tampa, Florida in the United States and Hong Kong in China, to provide data from the perspectives of American and Chinese

cultures respectively. The Center for Autism and Related Disabilities (CARD) and The Learning Academy (TLA) at the University of South Florida (USF) were the sites chosen for the part of the study conducted in the United States. CARD is a community-based project that provides services and consultation to individuals with ASD and other related disabilities. It serves the ASD population at all ages as well as their families, educators, and professionals in 14 counties in the southwest region of Florida. TLA is a customized transition program that specifically serves young adults with ASD to prepare them for employment and independence.

The Spastics Association of Hong Kong (SAHK) was chosen for the site for the Chinese part of the study. SAHK is a non-government organization (NGO) providing comprehensive rehabilitation and educational services for individuals in all age groups with neurological impairments, including ASD. It consists of variety of service units, such as preschool centers, special schools, sheltered workshops, and adult training centers, which are located in different districts around Hong Kong and serve the clientele in the city.

## **Sample**

### **Participant Recruitment**

Purposeful sampling was used to select suitable participants who were able to participate in the research. First, potential participants of young adults with ASD meeting the selection criteria (listed below) were shortlisted by the staff in the respective sites. A recruitment flyer with brief information about the research was disseminated to the potential participants by the staff of the organizations. Potential participants who were informed and interested in participation were allowed to contact me or the staff of the organizations. I further explained the details of the research to the interested young adults before they gave full consent to participate in the study. In addition to the participant recruitment through the two identified organizations, I

also distributed the recruitment flyer to people with whom I have personal or professional relationships (e.g., friends, colleagues, practitioners), who are able to identify more potential participants for the research.

During the period of the study, five individuals from the United States and eight individuals from Hong Kong were informed of the research and expressed interest in participation. However, one individual from the United States did not meet the inclusion criteria (i.e., he exited high school more than seven years ago). One individual from Hong Kong was not able to be contacted following an initial conversation. As a result, four young adults from the United States and seven young adults from Hong Kong who met the criteria for the study consented to participate in the study.

Based on the guidance by expert qualitative researchers (see Baker & Edwards, 2012) as well as practical considerations, it was proposed that at least six young adults would be recruited from the United States and Hong Kong, respectively. However, due to the limited timeframe to conduct the study, more participants were not able to be recruited before the end of the study period. The data present in this report were gathered from the individual interviews conducted with these 11 young adults with ASD (four from the United States and seven from Hong Kong). These data represented rich, in-depth descriptions of participants' experiences. The degree of data saturation as indicated by the recurrence and coherence of themes was sufficient in answering the three proposed research questions. Specifically, the data enabled me to compare and contrast between the sociocultural values in American and Chinese cultures regarding the self-determination experiences in young adults with ASD. Therefore, the current number of participants were deemed to be adequately appropriate for the scope of this study.

## Inclusion Criteria

Participants must meet the following criteria in order to be included in the study:

1. Individuals must have been diagnosed with ASD.

A formal diagnosis of ASD was provided by a licensed medical professional or psychologist by using the *Diagnostic and Statistical Manual of Mental Disorders*, either with the 4<sup>th</sup> edition text revision (DSM-IV-TR; American Psychiatric Association, 2000) or the 5<sup>th</sup> edition (DSM-V; American Psychiatric Association, 2013). Alternatively, individuals who were determined by school districts as eligible for the ASD category could also participate in the study. These diagnostic information were verified verbally by the participants (i.e., no medical or psychological reports were obtained).

2. Individuals must have exited secondary educational system within the past seven years.

The present study aimed to document the current or recent experience of transition from school to adulthood in young adults with ASD. Participants should have either graduated from or terminated their secondary education in order to be considered eligible. In general, expectation of secondary education in the public education system is completing 12<sup>th</sup> grade in high school in the United States. Considering the recent changes in school structure in Hong Kong, expectation for different cohorts of students are slightly different. For secondary school students graduated before 2012, they were expected to complete at least 5 years of junior secondary education (i.e., equivalent to 11<sup>th</sup> grade) and take the Hong Kong Certificate of Education Examination (HKCEE), followed by an optional 2 years of senior secondary education (i.e., 13<sup>th</sup> grade) and the matriculation with the Hong Kong Advanced Level Examination (HKALE). For students graduated after 2012, they were expected to complete altogether 6 years of secondary education

(i.e., 12<sup>th</sup> grade) before taking the Hong Kong Diploma of Secondary Education Examination (HKDSE). Participants who completed or discontinued secondary education and continued to pursue further education or training, such as college or university education, vocational training, and transition program, were also eligible for the study.

3. Individuals must have adequate language and communication abilities.

Due to the use of qualitative interview in this research, participants must possess adequate language and reasoning skills in order to produce meaningful output through the expression of personal thoughts and ideas in a way that can be understood by others.

Participants can either identify themselves or be identified by the staff in the research sites as having adequate verbal and communication abilities to participate in the research.

4. Individuals must be 18 years old or above.

No participants in the study had their parents assume legal guardianship. As such, all the consent procedures were conducted with the young adults with ASD. In the case of Isaac, his mother was also contacted to provide verbal agreement of his participation because she was the guardian advocate of Isaac.

### **Exclusion Criteria**

1. Individuals must not have identified comorbid diagnosis of other psychiatric (e.g., schizophrenia, personality disorder) or developmental disorders (e.g., Down's syndrome, Rett syndrome).

### **Participant Descriptions**

There were 11 young adults with ASD participating in the study. Four participants from the United States were all male with age from 19 to 21. Seven participants (six males, one

female) from Hong Kong were of ages between 19 and 24. To familiarize readers with the background information of the participants, below I included a brief description for each participant that summarizes their background information, significant events after high school, my interview observations, and my reflections interacting with the participants.

### **Participants in the United States.**

**Terry.** Terry was a 21-year-old Caucasian male. He graduated from a local Florida high school in 2014 with a regular diploma. Following the recommendation of an Exceptional Student Education (ESE) teacher, Terry participated in a transition program for young adults with ASD during the 2014/2015 school year, where I served as his student mentor. Since the second semester in the program, he has been working part-time as a bagger in a local grocery store. At the time of the interview, Terry was living with his parents. He has already enrolled in a local community college and will begin his study for an associate degree in Spring 2016. I conducted the interview with Terry in his house. Terry presented himself well with his verbal language. However, the interview did not flow as smoothly as I expected. It may be because Terry was sitting on his bed during the interview and appeared to me too relaxed, or even a bit languid. In fact, I suggested taking a break in the middle of the interview and we came back after dinner. He seemed to have better energy at the second half of the interview.

**Justin.** Justin was a 20-year-old Caucasian male. He graduated from a local Florida high school in 2014 with a regular diploma. After, he went to a local community college but dropped out in the first year. He was then admitted to a transition program for young adults with ASD and has been in the program for two months. Justin was currently living independently in an apartment close to the college campus where the transition program is located. His parents, together with his two younger sisters and one younger brother, lived at their home approximately

one-hour away from the college campus. The interview was conducted in the facility of the transition program. Justin appeared enthusiastically willing to share his stories with me to help “raise awareness” of autism. Even before the interview started, Justin did not hesitate to share with me his personal experience and opinions. He presented himself as a cheerful, approachable young man who enjoyed talking. Although he often went off on a tangent throughout the interview, he sometimes caught himself and would apologize for such acts.

**Gabriel.** Gabriel was a 20-year-old Caucasian male. He finished a local Florida high school in 2013 with a regular diploma. With a big scholarship, Gabriel then left his immediate family in Florida for pursuing an undergraduate degree in a reputable private college in a Midwest state. After a semester, he dropped out from the college and went back to live with his family (parents and three siblings of ages 10 years younger than him). In the following 2014/2015 school year, he participated in a transition program for young adults with ASD where he also started living independently with a roommate in an apartment close to the college campus. I knew Gabriel through the transition program as he was a friend of Terry. At the time of the interview, he was working as an editor for a university-based program that provides services to individuals with ASD and their families. During the interview at his workplace, Gabriel was forthcoming answering my questions. As an editor who also had experience interviewing individuals with ASD and writing about their stories, Gabriel expressed interests in learning about “how people in Hong Kong would respond to these questions.”

**Isaac.** Isaac was a 19-year-old second-generation South Asian male. Isaac speaks fluent English without any accent. He also speaks a South Asian native language at home with his mother and other relatives. He graduated from a local Florida high school in 2014 with a regular diploma. At the time of the interview, he was a sophomore in a public state college obtaining his

undergraduate degree in a science subject. I first knew Isaac when his mother came to me and looked for academic tutoring. He was living with his mother at home approximately half-hour drive from the college campus. During the interview conducted on the college campus, Isaac was extremely fluent and insightful in describing his experience. He gave serious thoughts into my interview questions. However, Isaac appeared a bit distressed whenever he talked about negotiating independence with his mother, who has been his guardian advocate since he turned 18. Of note, Isaac's mother also called and texted me several times to make sure Isaac knew his way and arrived at the interview venue safe.

### **Participants in Hong Kong.**

**York.** York was a 19-year-old Chinese male. At the time of the interview, he lived with his parents and a 15-year-old brother in the same household. York graduated from secondary school in 2014 after finishing Form 6 (equivalent to Grade 12) with the Hong Kong Diploma of Secondary Education (HKDSE). York obtained a foundational diploma in Information Technology after studying for one year full-time in a local institute that provides vocational education. Since graduation, he has been working part-time as a kitchen staff in a fast food chain restaurant. He usually goes to work three to four days a week, 8-10 hours per work day. York's mother was aware of this project because of her active involvement in a parent advocacy group that connects her with different professionals. York preferred to have his mother accompany him to participate in the interview in a coffee shop with few customers. York appeared willing to share about his thoughts, although his responses tended to be short and concrete. In several instances, he was reluctant to discuss certain topics that he found too sensitive (e.g., arguments with colleagues). Although York's mother was present during the entire interview, she let York do most of the talking. She occasionally chimed in rephrasing questions for York and providing

additional information following York's account. When talking to me, she mentioned "I let him make his decisions" a number of times.

**Aaron.** Aaron is a 24-year-old Chinese male who graduated from secondary school in 2008 after completing the Hong Kong Certificate of Education Examination (HKCEE) in Form 5 (Grade 11). After that, he enrolled in a two-year vocational education program, during which he also reattempted the HKCEE. He then completed a one-year alternative program that aimed to equip students with the same standard as passing the HKCEE. Upon graduation, Aaron was introduced by his mother to a non-government organization (NGO) where he worked as a clerk for six months. He was then referred by SAHK to work in a local university for one month, where I met him as a colleague in the same research laboratory. He was then introduced by his mother again to work as an activity assistant in the same NGO for the past two years. At the time of the interview, he lived with his parents and his older brother has already married and moved out. Aaron was interviewed in the NGO where he works. He showed willingness to collaborate with me and share his experience. In some instances, he frowned a number of times and seemed unhappy when talking about his past negative school experience and his wish for parents to accept his interest in cosplaying. Aaron also showed me the accommodations (e.g., visual work schedule) he received in his job.

**Michelle.** Michelle was a 24-year-old Chinese female who lived with her parents and a younger sister at the time of the interview. After graduating from Form 5 (Grade 11) in 2008, she was admitted to a two-year higher diploma program that focused on designing animation. She then took half year time off to take care of her sick mother. After that, she worked in several different jobs for around one month each, where she encountered mismatches between the work demand and her own emotional control, physical abilities, and personal values. She then worked

as a research assistant in a local university for more than a year, where I met her as a colleague in the same research team. As her employment status on that job was shifting between full-time, part-time, and temporary, she also sought other part-time jobs, such as graphic design and typing. In recent months, she worked as a freelance librarian assistant in public libraries. Although Michelle was interviewed in a busy coffee shop with people walking by around us, she appeared comfortable talking about her experience with me. Her tone of voice can vary a lot depending on the emotions she was describing (e.g., she sounded angry when talking about her challenges at work and political issues, but at times she had a soft, gentle voice when she described her affections for her family). However, she was not completely willing to disclose the details of some emotional incidents. It is interesting to note that Michelle offered a piece of candy to me after she heard me coughing, which I think reflecting her caring and considerate personality.

**Derek.** Derek was a 26-year-old Chinese male. He was graduated from secondary school in 2009 after completing the Hong Kong Advanced Level Examination (HKALE) in Form 7 (Grade 13). He was then admitted to a three-year bachelor program in a local university doing a major related to health science. After graduation, he worked as both full-time and part-time research assistant for several different groups in another local university, where I met him as a colleague on the same research team. At the time of the interview, he was looking forward to his potential new employment as a full-time office assistant in a government organization. He was also living with his parents and a younger sister in the same household. During the interview in a restaurant, Derek sounded a bit reserved to me. He tended to use negation in his responses to my questions. For example, he frequently said “無乜野[nothing]” or “無架[no such things]”. Although he indicated that these are usually his verbal fillers, it may be possible that Derek truly wanted to go with the flow and did not have preferences. It may also be possible that he was

cognizant of the perceptions of other people on him, thus feeling hesitant to speak about his opinions in front of me.

**Kenny.** Kenny was a 19-year-old Chinese male who dropped out from secondary school in 2012 in the middle of Form 4 (Grade 10) because he was disinterested in school at that time. Since leaving school, he had experience with different short-term (i.e., from few weeks to one year) vocational courses in areas such as cookery, construction, and bakery. However, Kenny found himself not interested in any of these occupations that he either discontinued his enrollment from a course or quitted a job after trying it for only a short period of time. At the time of the interview, he was working part-time in a factory folding towels. He was living with his parents in the same household. I met Kenny when I volunteered at a social skills group in SAHK. Kenny was interviewed in a restaurant where he felt very comfortable chatting. However, he usually gave short answers and laughed following his responses, as if he did not know what he was actually talking about. He also used a lot of words “求其/是但[perfunctory]” and “重覆[repeated]” when describing his vocational experience, which resonated with his feelings of helpless, bored, and low motivation. Nevertheless, he was honest with revealing his low self-esteem to me.

**Michael.** Michael was a 23-year-old Chinese male who completed Form 5 (Grade 11) in a local secondary school and took part in the HKCEE in 2009. He then went to New Zealand for further secondary education and preparation courses for college. Due to some mental health concerns, he went back to Hong Kong after two years. Afterwards, he went to his relatives in the United States, where he studied in a college and worked part-time in the relatives' restaurant. However, after one and half year, Michael came back to Hong Kong again due to another mental health crisis. Since then, he had worked several jobs in grocery stores and convenient stores. At

the time of the interview, he worked as a part-time staff in a coffee shop. During the interview conducted in a center of SAHK, Michael presented himself as very talkative and very willing to express his thoughts and opinions. In fact, the interview went longer than expected, so we had to move to a restaurant nearby to finish the interview after the center was closed. Michael seemed to have in his mind a clear way to narrate his experience that I sometimes failed to interrupt with my questions. Overall, Michael was a reflective individual who offered a lot of insights.

**Joshua.** Joshua was a 23-year-old Chinese male who completed Form 5 (Grade 11) in a local secondary school and participated in the HKCEE in 2009. He then went to the United Kingdom for further secondary education and preparation for the General Certificate of Education Advanced Level (GCE A-level). During this period of time, Joshua experienced the death of his mother. He also developed some serious mental health crises later. He went back to Hong Kong for a two-year associate degree in Journalism. He was then admitted to a top-up program organized by a Hong Kong local community college and a British university. As a recent graduate from the program, Joshua indicated the possibility of getting a full-time job as a journalist for a religious organization in Macau, a neighboring city of Hong Kong. During the interview conducted in a SAHK center, Joshua was sad and cried when he talked about his mother's passing away. Nonetheless, he was able to talk about his other experience without becoming distressed. Overall, Joshua was very verbally fluent and was able to share a lot of feelings and thoughts.

### **Data Collection**

The current study employed semi-structured individual interviews as the primary means of data collection. An interview protocol (described below) was used to guide the topics to be

covered in the interview, while the semi-structured nature of the interview also allowed flexibility to explore any emerging issues by asking follow-up questions in more depth.

I as the primary researcher was responsible for conducting all interviews at both sites in the United States and Hong Kong. Potential participants contacted me to consent to their voluntary participation. A date and time for the interview was arranged for each participant at their convenience. Interviews venues were also chosen by the participants, which included CARD or SAHK, school, home, workplace, and local restaurants. Participants were also allowed to have a family member or staff member accompany them during the interview.

All the interviews were conducted within the period between July 2015 and February 2016. Interviews were conducted in English and Cantonese Chinese for participants in the United States and Hong Kong respectively. The interview process began with a brief introduction about the purpose and context of the interview. Participants were screened for the abovementioned inclusion and exclusion criteria. With the aid of the consent forms approved by the USF IRB, informed consent was obtained after discussing issues such as recording and transcribing procedures; voluntary nature of participation; potential risk and benefit; and confidentiality agreement. I then conducted the main interview with the help of the interview protocol and topic guide. The length of the main interview process varied across participants with the range from one to two and a half hours. Throughout the interview process, I audio-recorded all the interviews and took notes for later reference. After the interview process, I debriefed the participants about the next step and the potential implications of the study as well as encouraged them to raise any questions or concerns. Participants were also asked to volunteer for the possibility of reviewing the data and results to ensure my interpretations would accurately represent their perspectives.

In addition to the main interviews with the individuals with ASD, data from other sources were also gathered to triangulate findings from the interviews. I encouraged participants to bring artifacts to the interview that they think can help others understand their transition experience. During the interview, I took notes regarding the interview process and observations of the participants. I also kept a journal to document my personal reflections on the perceptions and feelings of conducting the interviews as well as issues that came up during the interview and research processes.

### **Interview Protocol**

Interviews were conducted using an interview protocol (see Appendix B) with the aid of a topic guide (see Appendix A). Broadly speaking, the interviews covered the four domains of component characteristics of self-determination, namely autonomy, self-regulation, psychological empowerment, and self-realization (Wehmeyer, 1996; Wehmeyer et al., 1996). Under each domain, a number of subdomains were also identified in the Wehmeyer's model to further elucidate the conceptual characteristics. The list of domains and subdomains (see Appendix A) was used to guide the development of interview questions. This list also served as a reference for the topic areas of interest during the interview to ensure adequate coverage of the discussion of self-determination and to further elicit participants' responses if necessary.

The interview questions were developed based on the domains and subdomains of Wehmeyer's self-determination model as well as the interview protocols of relevant literature (e.g., Leake & Boone, 2007; Trainor, 2005; Zhang et al., 2010). The questions on the interview protocol (see Appendix B) served as prompts to explore the different facets of self-determination in participants' lives in terms of their (a) experience, (b) meaning, and (c) importance of self-determination as well as the contexts in which these occurred.

The interview protocol was first developed in English. The English interview protocol was shared with the thesis committee to gather their input on the development of interview questions. The protocol was also presented to a young adult with ASD, who is associated with CARD but not involved in the study, for specific feedback about the wordings and appropriateness of the questions. The final version of the English interview protocol was translated into Chinese for the use in Hong Kong, which was also shared with the staff of SAHK to ensure the cultural-appropriateness of the translated interview questions.

The English and Chinese interview protocols were also piloted with two young adults with ASD in the United States and Hong Kong, respectively. These young adults were consulted for their perceptions and suggestions of the topic areas, the discussion questions, and the format and duration of the interview. Based on their feedback, the number of questions was reduced to keep the interview in a reasonable duration. Some questions with complex sentence structures and difficult wordings were revised. Changes were also made to ensure construct equivalence between the English and Chinese protocols (i.e., questions presented in both languages are probing for similar concepts). Although the pilot data were not included in current analysis, these two young adults with ASD were later recruited in the main study. As they were not able to recall from the pilot interviews the specific questions they were asked, the pilot interviews did not appear to affect the data collected during the main study.

### **Data Analysis**

All the interview recordings were transcribed verbatim into English and Chinese respectively. Pseudonyms were used to substitute any identifying information in the transcripts. Transcribed interviews were loaded into Atlas.ti, a database management system for qualitative research, to assist in the coding and analysis procedures.

## **Thematic Analysis**

In the current study, the research questions were answered through analyzing the interview data. Thematic analysis was adopted as the method of analysis to provide a rich account of data with patterns or themes. Its strength lies in the flexibility in conducting analyses of qualitative data across different theoretical approaches (Braun & Clarke, 2006). As discussed above, the data analysis processes were approached using both “neo-positivist” and “romantic” perspectives (Roulston, 2010).

As outlined by Braun and Clarke (2006), one of the key considerations of conducting thematic analysis involves the approach to derive codes and themes. The current analysis incorporated both deductive and inductive approaches in processing data. The deductive approach took into considerations the model of self-determination that theorized the development of the research questions and interview processes to understand the experience of young adults with ASD with respect to the central characteristics of self-determination (e.g., autonomy, empowerment; Wehmeyer, 1999). The inductive approach was used at the same time to derive themes that are strongly related to the interview data themselves (Patton, 1990). The combination of both approaches helped answer the proposed theoretical questions while maintaining the openness to novel ideas emerged from the data.

The current thematic analysis followed the six-step guidelines described by Braun and Clarke (2006). First, I came to become familiar with the interviews through generating the interview transcripts by myself. Interview recordings were listened repeatedly throughout the transcription process, in which I was actively involved in considering initial interpretations and meanings and gathering these ideas onto a reflective journal (Lapadat & Lindsay, 1999). All the

interview transcripts were reviewed after the transcription process, which also involved checking the transcripts back against the audio recordings to produce accurate transcriptions.

In the second phase, initial codes were produced by writing comments about short segments of data on the transcripts that appeared interesting and meaningful. Based on the diversity of characteristics (e.g., gender, current status, complexity of experience), three transcripts from the American and Chinese samples, respectively, were selected to be reviewed thoroughly for generating initial codes. Although the coding process focused primarily on the written descriptions of verbal output by the interview participants (i.e., semantic or explicit features), some latent (or interpretative) features of the data were taken into account. For example, some non-verbal features, such as long pauses, inflections, and emotions, were meaningful to contextualize the coding for semantic features. Also, based on my background knowledge of the interviewees and my interactions with them, I actively took into consideration interviewees' use of idiosyncratic language, which, in some cases, demanded me to look beyond their semantic output for meanings that better captured the interviewees' perceptions. After reading and coding six transcripts, I reviewed all the initial codes emerged from the transcripts, and developed initial categorization of different groups of codes and their tentative definitions that contributed to the formulation of a codebook. All of the interviews were coded using the codebook, during which new codes were added and existing codes were revised to encompass all features of the data.

The third phase of thematic analysis consisted of searching for themes. This involved analyzing the codes at a broader level through which the relationship between different levels of codes and themes were formulated. This thematization process was done with an aim to answer the research questions using the codes and themes emerged from the data. Specifically, with

reference to the interview guide (see Appendix B) that originally developed based on the functional model of self-determination (Wehmeyer, 1999), I sorted codes into broader themes that describe the manifestations, meanings, importance, and contexts of self-determination. With an aim to make cross-cultural comparison, it is important to note that the process of creating themes was conducted separately for the data from the American and Chinese participants.

In the fourth phase, themes were reviewed and further refined to produce a coherent whole that tells about the data. The main objective of this phase is to evaluate the data from a holistic perspective where themes were revised, combined, separated, and/or discarded. The data within themes should meaningfully coherent and consistent, while different themes should be distinctive to each other (Braun & Clarke, 2006). The first level of this phase involved ensuring that all codes within a theme hold together as a coherent pattern. The second level involved ensuring that individual themes accurately reflected the data set and the connection among themes reflected the overall meanings as a whole.

Phase five involved defining and refining the themes. The essence of each theme was identified by rereading the data extracts for each theme and organizing them into a meaningfully coherent picture. This process of memo writing was used to help further develop, interpret, and analyze the themes and their connections (Creswell, 1998). Memos are brief narratives that researchers record their reflections of the data, summaries of findings, and any other information that are important to represent the concepts and patterns emerged from the data. Thorough analyses were conducted for each theme with the help of the memos, which were then turned into detailed descriptions of all of the themes and their relations with each other, as well as the story that captured the overall meanings.

The last phase of thematic analysis involved producing the report. It is recommended that the analysis and write-up of the results be “concise, coherent, logical, non-repetitive and interesting” (Braun & Clarke, 2006, p.93). Vivid examples and quotes that represent the essence of themes were included in the report. These extracts are able to provide descriptions of data, as well as to create connections to the research questions and stimulate discussions on the essence of the story tells.

### **Trustworthiness**

In qualitative research, the extent to which data and findings are considered valid is through establishing trustworthiness (Lincoln, Lynham, & Guba, 2011). Credibility and dependability are among the two important parameters.

Credibility involves the truthfulness of the data collected and subsequent analysis process (Guba & Lincoln, 2005). First, member checks were conducted by inviting participants to provide input in the data analysis process. Participants were asked to indicate if they would like to consent voluntarily for reviewing the data after the interviews were completed. Some of the participants who consented were contacted to provide input and clarify information obtained in the interviews. This also helped prevent misinterpreting idiosyncratic use of language specific to the individuals with ASD or to the particular cultural groups. Second, triangulation of multiple data sources and methods was employed to check the credibility of the interview data.

Information such as artifacts collected from participants, interview observation notes, and reflective journals were used to provide additional perspectives other than the interview transcripts, thus strengthening the credibility of the research data and findings (Koch, 1995; Shih, 1998). Third, to minimize the influence of my presuppositions on the data analysis process, I kept a reflective journal throughout the research process. I continuously engaged in reflecting on

my own worldview, perceptions, and judgments and keeping them consciously aware in the processes of data collection and analysis.

Concerning the consistency and reliability of data and results, dependability is another important aspect to consider so as to ensure similar results if the study is to be repeated or replicated (Guba & Lincoln, 2005). First, two members in the research group of the major professor were recruited to check excerpts (without identifiable information) of the English interview transcripts against the audio recordings to ensure participants' verbal responses were accurately recorded and represented. In addition, translation in cross-cultural research may pose challenges to the validity of data interpretation (Hennink, 2008; Larkin, 2007). It is argued that the exact equivalence of linguistic terms and their concepts may not exist across languages and cultures (e.g., Michaud, Blum, & Slap, 2001; Tsai et al., 2004). It is of utmost importance to ensure that translations retain the same meaning and relevance in both the cultures of the interview language and the analysis language (Regni, Naidoo, Pilkington, 2010; Squires, 2009). To prevent the loss of important information in the translation process, when translating quotes from Chinese to English, in addition to literal translation, I also included in the footnotes some contextual information and cultural considerations to help readers understand the interpretations of the translated data.

### **Reflexivity**

My role as the primary researcher in this qualitative study was closely examined. As one of the instruments in the research process, I used my interpretation in analyzing data and generating findings. Throughout the entire research process, I was engaged in this form of constant, thorough reflexivity to help make my preconceptions transparent to the audience. The section below exemplifies how I identified my own experiences and preconceptions about the

phenomenon of self-determination in young adults with ASD transitioning to adulthood in a cross-cultural context.

In conducting a cross-cultural comparative research, it is important for me to explore my own worldviews and preconceptions about the cultures in the United States and Hong Kong. I used to think I am an extremely agreeable person in terms of being highly adaptable to different people with different values and cultures. Having spent some time studying, working, and traveling in different countries around Southeast Asia and Europe, I had no problem in navigating through different cultures. Not until I came to the United States for study did I discover the core of my value system. My experience of the ways people operate in the United States clashed so much with how I used to view the world. For example, I felt that people have very little interests in relating to others as a group; everyone has to speak up for your own self or else no one is there for you; people operate in their own ways instead of following group or social norms; and there is almost no hierarchical order within a network of social relationships. In other words, without experiencing such cultural shock, I would not have realized what I value indeed stems from my Chinese background in a relatively collectivistic society, compared to an individualistic American society at the other extreme.

Growing up in a Chinese society for more than 20 years, I now have had a chance to step out from it and reflect on my past experience so I can understand how my worldview is shaped. Throughout my development, I was reared in a culture that values relating oneself to others, in matters as big as making an important life decision or as small as expressing our preferences or interests in front of others. My family upbringing can also be considered conventional in a Chinese society. Both or one of the parents, mother in my case, usually occupy the authoritarian position in a family and take control over the issues of the rest of the family. This leaves little

room for children to “self-determine” in an absolutely autonomous sense. Even if we want to do so, we would have to make so much effort or even sacrifice and disobey the authority figures in order to realize our will. For example, I remembered having a heated argument with my parents before they gave in to my decision of choosing my major in Psychology instead of Medicine.

Noticing this cultural difference between American and Chinese societies, I think a similar pattern could be seen in individuals with ASD across the two cultures. In my previous work in Hong Kong, I worked closely with colleagues with ASD and their case workers, witnessing a lot of individuals either displaying low level of self-determination or having difficulties exercising it in their environment. For example, some were placed in jobs decided by their parents and some did not have goals or plans in life. After coming to the United States, I worked for a transition program and realized that individuals with ASD were given more opportunities for self-determination, such as moving out of their childhood home to live independently and selecting career options based on their personal preferences. On the surface, young adults with ASD in Hong Kong look like they are almost not self-determined compared to their American peers. However, after I reflect on the spirit of self-determination, it is the psychological process of individuals acting as the causal agents in their lives that defines self-determination, while the behavior is a form of expressing it. In other words, independent living does not necessarily equate a self-determined life unless individuals engage the actions volitionally (Wehmeyer, 2005). On the other hand, self-determined individuals may not necessarily rely solely on themselves because they may, for example, make an informed, self-realized decision to live with their parents and contribute to the entire families in the households.

I believe young adults with ASD across both cultures, to a greater or lesser extent, do have the desire for autonomy, empowerment, and self-realization. In other words, I think they all

would like to be self-determined and have a higher quality of life. I believe they are able to express self-determination in ways that are compatible with their respective environment and culture. For example, I recalled that a young adult with ASD in Hong Kong expressed his preference for dining place among his colleagues and persuaded them to go with him as a group, while individuals in the United States tend to pick their own preferred food individually. A former colleague of mine with ASD worked in a job assigned by his case worker, but he was able to plan a schedule of reinforcement for staying in the job for a certain duration. Even though individuals with ASD from the United States and Hong Kong may act differently and hold different perspectives about the concept of self-determination, I believe they strive to better their lives by expressing self-determination in culturally-appropriate ways.

### **Ethical Considerations**

Participation in the current study may be associated with certain potential benefits as well as risks to the participants. Measures were taken to maintain the ethical integrity of the study.

One of the immediate benefits to the participants is the opportunity to be heard through participating in the interview process (Wolgemuth et al., 2015). Due to the core symptoms of language and communication deficits in ASD diagnosis, these individuals are generally assumed to be unable to express their thoughts and be deprived of opportunities to speak. However, this is a misconception because individuals with ASD have distinct profiles of strengths and weaknesses, with some possessing exceptionality in verbal language. This is particularly true in individuals at the higher end of the autism spectrum who were the participants in the study. As they are given the opportunities to reflect and be listened to, they may find the interview experience itself rewarding. During the interview process, I allowed participants to explore the general topic of post-school transition and express their ideas even though at times they went off

topic. Indeed, a few participants explicitly acknowledged the opportunities of me listening to their perspectives and agreed on the need for more awareness on their post-school transition.

More importantly, the findings generated from the study serve as a channel to express their voice to a wider audience. As with individuals with disabilities in general, individuals with ASD constitute an underprivileged group in the society who have been historically silenced or marginalized, so the present research did not only ensure their voices were heard, but it also advocated for the group of people sharing the ASD diagnosis as a whole (Brantlinger et al., 2005). Through representing their voices by disseminating the findings of the study, scholars and practitioners working in the area of disability as well as the general public would become more aware of their perspectives and experiences, which could result in a higher level of educative authenticity and alterative validity (Lincoln et al., 2011). In addition, even after the completion of the study, I will still have the ethical responsibility to represent the participants' voice instead of merely owning the data. In the future, I could help facilitate the expressing of their voice to make meaningful changes through discussing research findings with participants who showed interest before, giving presentations in educational and community organizations (e.g., CARD, TLA, SAHK), and disseminating research findings in professional conferences and academic journals. Regarding potential risks, the interview process involved discussions that might evoke psychological stress among interviewees. As the topics covered in the interviews mostly asked about participants' private life and personal feelings, participants might not feel comfortable disclosing everything to the interviewer. In other cases, even though they were willing to disclose sensitive information, talking about these issues would bring up emotions that may cause distress to the participants.

To minimize any potential harm to the participants, the following measures were taken (see American Educational Research Association, 2011). First, participation in the study was strictly voluntary and participants had the rights to withdraw at any time of the study. While some participants did not want to disclose certain information during the interviews, I respected their rights and did not interrogate them further. Secondly, concerning the issues of confidentiality, only I and the research group members involved in transcribing the interviews will be able to access the original interview data. Thereafter, pseudonyms were used to substitute identifying information in the transcripts for data analysis and interpretation. All parties involved in the data process, including members in major professor's research group, agreed on keeping the data strictly confidential. Last but not least, an informed consent was obtained from all the participants before the interview is conducted. The consent procedure ensured that the participants were informed of all of the issues regarding the potential benefits and harms and the measures taken to protect them. A debriefing after the interview was also conducted in some cases to discuss any emotional and psychological reactions caused during the interview to ensure the interview process did not incur unnecessary harm (Brinkmann & Kvale, 2014). For example, participants who disclosed traumatic events (e.g., suicide) during the interviews were followed up immediately to ensure they were currently safe and were being taken care of by family members or professionals, if necessary.

## CHAPTER 4

### RESULTS

This chapter presents the themes that were identified from analyzing the interviews with all participants in this study. The 11 interview transcripts were analyzed thematically using the method outlined by Braun and Clarke (2006). Analysis was focused on answering the proposed research questions to understand the experience of self-determination in young adults with ASD during their transition from school to adulthood. Specifically, it was achieved by exploring the manifestations, meanings, and significance of self-determination as well as the contexts in which these occurred. Analysis was guided by the functional model of self-determination theory (Wehmeyer, 1999) using the socio-ecological model approach (Shogren, 2013; Wehmeyer et al., 2010) as well as other themes that emerged from the contents that the participants chose to discuss. Results included two overarching thematic categories that captured self-determination in young adults with ASD during their transition after high school, namely experiences of self-determination and contexts for self-determination. Under experiences of self-determination, there were 4 themes that described different facets of self-determination, including autonomy, goal attainment, psychological empowerment, and self-realization. Under contexts for self-determination, there were five themes that described how different environments supported the self-determination experiences, including family context, vocational experience, postsecondary education, community-based resources, and early experience in the school-age years. Lastly, a theme that described participants' overall perceptions of the post-school transition was identified

to understand self-determination in relation to this particular timeframe in life. Table 1 summarized the organization of the themes extracted through the data analysis.

**Table 1.** Organization and Descriptions of Themes.

Theme Name	Descriptions of Theme
<u>A. Experiences of Self-Determination</u>	
A1. Autonomy	Behaviors performed and/or decisions made based on one's own judgment without much influence by or reliance on external agents.
A2. Goal attainment	Identification of goals and descriptions of ways through which goals are approached.
A3. Psychological empowerment	The sense of control over oneself and the environment through gaining internal asset, efficacy, and ability to do things.
A4. Self-realization	With the understanding about oneself, achieve a desired state of self through adapting to the environment and developing one's full potential.
<u>B. Contexts for Self-Determination</u>	
B1. Family context	Experiences related to parents, family members, and extended family
B2. Vocational experience	Experiences related to job, workplace, and work experience in general, such as prevocational training, job-

**Table 1 (Continued)**

	searching, as well as interactions with employers, colleagues, and other people at work
B3. Postsecondary education	Experiences with college, university, and other postsecondary educational settings, as well as interactions with peers, teachers, and other educational environments and structures
B4. Community-based resources	Experiences with government bodies, non-government organizations, religious organizations, and other resources in the local community
B5. Early experience in the school-age years	Experiences in school, family, and community before leaving school
C. Overall perceptions of the post-school transition	Reflections and feelings towards life after school exit

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To answer the specific research questions related to cross-cultural comparison, data from the participants in the United States and Hong Kong were analyzed separately using the above thematic structures. It is important to note that the descriptions of the themes in Table 1 were intentionally kept general and broad in order to effectively capture the nuances of the experiences and contexts of self-determination in respective cultures. In the following, results obtained from the analysis of data from the participants in the United States were first presented, followed by the results for the Hong Kong participants. For the sake of simplicity, participants

from the United States were referred to American(s) while participants from Hong Kong were referred to Chinese hereafter.

## Results in the United States

### Thematic Category A: Experiences of Self-Determination

**Theme A1: Autonomy.** Participants described behaviors they performed and decisions they made based on their own judgment, without much influence by or reliance on external agents. They talked about the notion of independence. They also described their basis for autonomous acts.

**Independence.** American participants mostly described independence as doing things either *on their own* or *for themselves*. They did a variety of things *by themselves* at home (e.g., live in their own apartment or dorm; learn to cook), in college (e.g., apply to college; arrange to meet with counselor), and in the community (e.g., get a driver's license in order to drive by themselves; do social activities and meet new people). They also described things that they did *for themselves* as a sign of independence, including doing basic chores for their own living place, managing their own finance and paying for their own expenses, and pursuing their own academic major in college. Some other examples of independence showed participants' abilities and skills in life, such as getting a job and learning a new language.

Although independence might not start out to be a comfortable experience because of, for example, financial pressure and a lack of experience, participants generally described the state of being independent as “fulfilled”, “nice”, and “important.” Isaac best exemplified being in the intermediate stage of struggling to gain more independence while being taken care of by his mother as his guardian advocate, which gave him mixed feelings of “good and bad”. Similarly, Terry described the process of gaining more independence from his parents:

Kind of scary, but also...nice. You know. ... Scary part is that...you know I'm not used to...having to do everything, or do not everything, but certain things by myself. But, um...I'm so used to my parents doing it.

Participants described various pathways of attaining independence. On one hand, Justin and Gabriel described past experiences of parents supporting their attainment of complete independence through gradual release of assistance. For example, their parents began by paying for their apartments before they could eventually afford to pay for themselves. On the other hand, the need for parent support speaks to the consideration of one's readiness for independence. Gabriel asserted that he is currently more ready for independence compared with his time of studying out of state when he was completely overwhelmed living independently without any support. Isaac further explained the significance of explicit instruction and real-life experience to help him do things independently:

...like she might you know be able to advise me in certain things. Like I said I didn't know even how to apply for a job application. She wouldn't help me in those things. She would just like, assume that, I should just do it on my own, even though that's telling someone who doesn't have a driver's license, just go and drive on your own, start driving. So I didn't know how to navigate through those things. ... And I remember in school I also wanted a summer job, like really really badly, but my mom was saying, "No you won't be able to do it" and things like that, and she was like "Oh, if you want a summer job, apply for you know job application", but thing is you know I was during that age, I didn't know how to apply for a job application. Like, the type of analogy that I would give is like, you don't give a person who hasn't driven before a driver's license. You have to help them and teach them, and my mom wasn't there to like really do that, for like the

summer job, or for the job application, to apply to...you know get a job or something.

When asked to reflect on the meaning of attaining independence, participants described meanings that centered on themes of freedom and ownership. For example, Gabriel emphasized he is “paying for this place, like it’s mine.” Isaac considered independence as “the whole thing that your life evolves around” that enables him to clear up “roadblocks in my way” so that he will not be “bound by so many things” and be able to make decisions and act freely in life. Justin related independence to the freedom he acquired that he could choose his living style. Terry used an analogy of playing video games without using cheat codes to describe his attainment of independence:

Just the, the feeling of...um...the feeling of doing stuff on my own. I'm not sure how to explain it, really. I think the best way to explain it is...if you are playing a video game, and, all your life, whole time you've been playing that game, you've been using cheat codes to go through. Then you finally go through it without using any cheat codes. It's just through your skills. You feel more fulfilled, like doing that than you would with cheat codes.

Participants also considered independence as a normative hallmark of adulthood. For example, Gabriel described independence as living independently away from family, and when I expressed my curiosity about his intention of not moving back with his parents, he appeared a little shocked and replied with a laughter, “just cuz, I mean that’s just what adults do.” Similarly, Isaac expressed the desire to become more independent when he turned 18. Contrary to this normative understanding of independence, a more individualized perspective that intersects with individuals’ (dis)abilities was also evident. Recognizing his own disabilities in calculation and numbers in general, Justin decided to let his mother help manage his finance. This idea

challenges the normative (or otherwise, “unhealthy”, as Justin described) expectations of independence in adults held by people in general in American society (e.g., Goldscheider, Thornton, & Yang, 2001):

...it depends, like as far as money is concerned, no, because I know I will never be able to handle it, um, like once I got my own bank account, and once I became an agent or that, one of the first things I did, one of the first thing I did, is, give access to my mother, my mom, because she handles money way better than I do, and I know I can trust her. ... Ah but the...and so it's like, I don't mind at all, some people might think that's unhealthy, you know, the mother's boy and all that, but it's like, she's cool though. I don't, I don't mind. It's like...cuz it's not unhealthy, cuz she's not mothering me. She is helping me.

*Act on the basis of...* American participants described their actions in relation to autonomous decisions they made based on a variety of reasons. Participants engaged in autonomous actions through the cultivation of interests and knowledge in certain areas. Terry decided to make short videos and ultimately films based on his interests in films that he studied a lot himself. Isaac decided to become a medical doctor as he found himself interested in the career of a researcher and the meaningful role of a doctor in a society. Justin was interested in creating story ideas and fanfiction where he could combine characters and plots from different stories, although he expressed the disappointment that it is difficult to make money out of these things.

Participants showed autonomous acts based on their personal beliefs about the world. Terry made a strong statement about how he would like to choose his own life: “I just...think what, think of what I want. And, do what I need to do get there.” He also spoke about his pursuit of a career in film, indicating his desire of earning money out of his strengths and knowledge. He also mentioned the importance of it as his passion:

Ur...well I...to quote one of my favorite characters and comics, the Joker, you know, "If you are good at something, never do it for free." You know, I, you know, not only is that I wanna make money though, I wanna have um, just have something I am passion about and do it anytime.

Similarly, Justin stressed the importance of going to college because he wants more choices and freedom to have more opportunities other than doing manual labor work that he does not like. He also mentioned the significance of personal growth. In another instance, he described his decision to drop out from community college because he was stressed out by his belief that grades should not be used to judge a person's worth.

Well, probably it's necessity. Like what I said, um, having a college degree has a lot doors opened, without a college degree closes a lot of doors. I, may not know what I want to do for career, but I know it's not flipping burgers, [laugh] which is usually lack of a college degree, that's what that leads to usually. Like on the assembly line or something, you know what I mean? Something very manual, very tedious, very, meaningless, right? At least to me, you know it's like, you don't...no one talks about, got to an assembly line to screw a nut, a thousand, two thousand times a day. ... Yes, I want, I want, I want the world to be open for me. I don't want to, enclose myself in, cuz I'm just limiting myself, and it's silly to do, you know? ... Um, again, it's part of necessity, right? It's what we've talked about. The other part is, it's a learning experience. I might be able to get more um, knowledge more, build more character, you know what I mean? That's what I am all for. But it's like the um, I like cuz, I think about stuff, right?

Gabriel described his negative experience going through college because he made a lot of decisions based on affective connections. Specifically, he felt excited receiving a large

scholarship for college; he had the feeling of home in the city where the college is located; he chose a major related to international affairs because of his one-time pleasant experience traveling to China. The inadequacy of basing decisions on feelings is further explicated by his reflections of his first semester in the college. This points to the role of information and knowledge in making individuals “informed” in their decision-making process:

...in hindsight, you know, I realized you shouldn't just choose a college based on where it is. Um, you should really look more, into it. But at the time, I mean, my, it was mostly I wanted to go back to (a northeast city). I really, I have family there, I really enjoyed the city. Um, the cold doesn't bother me as much as most people. Um, and ah, yea, I mean that, that was mostly it, plus I mean, it's, it's, it's a good school, I mean. (A major university in the northeast city) has a lot of really great programs. I don't necessarily regret going there. I feel like anywhere that I had gone at that point, be it in (the northeast city), California, or China, would have been the same, story, um, so, yea. ... Um, it's just cuz, I didn't really know what it entailed. Like it wasn't, I won't say, it wasn't smart necessarily. It's more like it wasn't very informed. I really didn't know what it was. Like, I basically just kind of said, "Oh, international, that relates to traveling. I like traveling, therefore, I should do this." Like, um, it, I just, I didn't know, really what it was all about it. I didn't do much research or anything. Um, and ah, it just ended up not being all that interesting to me.

**Theme A2: Goal attainment.** Participants identified different goals after school exit and discussed how they reached or would approach their goals.

**Goals.** American participants generally discussed their goals in relation to career prospects. Terry would like to finish his novel that he started in high school, which he believes

could help with his goal of becoming a filmmaker in the future. Building on his interests in medicine and research, Isaac wants to become a neurosurgeon. Gabriel described his current goal as pursuing further study in community college that will support his writing career. Justin did not have any specific goals, but he had been pondering his career goal and had some ideas of what he is good at doing, although he did not specify what they are.

Participants also discussed what their goals mean to them. The majority of them discussed the sense of worth their goals give them, either in terms of personal or financial perspectives. Terry wanted to take advantage of his interests and strengths in film making to make money. Isaac considered pursuing further education and his career be more worthy than any other options in life. Justin also would like to make money out of things he likes, such as Star Wars, but in his opinion, these are not something from which he can easily make money.

*Pathways to goals.* All of the American participants, to a certain extent, described their goals as an important source of motivation for them. Terry, Gabriel, and Isaac indicated their goals as their passion that they enjoy, which gives them hopes and motivations to work for the future:

Um, I guess it just feels like uh, something, that I kind of have a passion for I think, that I built something, a passion for? So I kind of just uh, feel like, it's kind of like the thing down the tunnel, like the light down the tunnel, and I wanted to, see if I can you know, get there. (Isaac)

It makes me want to do something. It makes me not lazy. Ah, makes me ah, keeps me on my feet. (Terry)

Terry had a particularly vivid way to understand his source of motivation. He enjoys writing and has created different story characters, which in turns motivated him to develop

bigger ideas of books and movies:

Well when I was in high school, writing was my hobby, and I've always had these characters in my head, you know these people, and I wanna to make a story for them, and with their own world, and that ended up becoming the (title of his novel) with (the two protagonists), and...you know, they...haven't, I mean my own creations very much, they inspired me to keep writing and um, try to make something of it. Over time, after high school, I decided, you know, when my book was finished, I actually wanna make movies too!

As explained clearly by Gabriel, success in achieving goals in adulthood requires more intrinsic motivation than earlier in life:

Also, um, you know, it, at this point, once, once high school ends, you cannot get by on just like intelligence anymore. Like you know I can mostly just go through things in high school with not all that much effort, because I'm just, kind of, not to sound like arrogant or anything, which is kind of naturally intelligent. And just that is not going to fly anymore. Um, you need to have, like uh...hardworking everything, and dedication, determination.

Justin and Isaac also pointed out hard work as a crucial element in their pursuit of goals. Specifically, Justin clearly differentiated goal from dream, the former of which involves multiple steps that he needs to make efforts and build on one another in order to achieve ultimate success.

**Theme A3: Psychological empowerment.** Participants described the sense of control over themselves and their environment. They also described the ways through which they gained internal asset, efficacy, and ability to become empowered to do things.

**Control.** American participants talked about things over which they have or wish to have control. Terry indicated having control to apply to jobs he wants, but he wishes to have the control to work on things directly related to his goal. Both Justin and Isaac described their control with inner thoughts and emotions. Justin did not want his emotion to override his thoughts and actions by having “a lid over a pot of boiling water”. Although he was not always able to hide his feelings in his appearance, he tried to keep the feelings to himself. Similarly, Isaac described his way to control thoughts, but in a more mindful manner. He chose a certain way to deal with his thoughts as it can affect how he feels and acts in certain situations:

Just you know you can control the way you think. You can control how you feel. You can choose to give importance to a certain thought, or you can let that thought flow by, flow by, like a stream of water. Or you can let that thought like, consume you, and kind of like, block off the stream, like you know, with some type of like, you know, something that's blocking the stream, or obstructing your train of thought or something. It just like, for instance, if people get really really mad, it's usually because they are thinking about something. Some type of thought, or some type of situation, that they think about, that gets them really really mad. Invoke that thoughts or reactions from them.

**Pathways to empowerment.** American participants described how they eventually became empowered to have control to do things. Learning was the most commonly cited pathway through which participants became empowered. Learning took several forms, namely acquisition of knowledge or experience and social learning. Both Terry and Gabriel went through a transition program in which they received direct instruction on different skills and knowledge. They were able to practice life skills, gain knowledge about what a college is like, and gain hands-on pre-vocational experience through internship.

Without direct, explicit instruction and practice, participants were also able to learn through real-life experiences in a hard way, however. For example, even though Gabriel's mother suspected that he was failing in the first semester of college, she did not intervene and let him go through this experience. Gabriel described this experience as "I almost needed to hit rock bottom before I could like pick myself back up", but he was glad to have this experience as he would know what to prevent in the future. Terry articulated well the importance of prior knowledge or experience by using an analogy: "...you have to learn how to walk before you can run. ... Walking is like learning what college is about, and running is, actually doing it, going into college, actually talking the classes."

Without prior knowledge or experience, it is crucial for other people to use different strategies to guide the participants through the task in hand. This concept is perhaps best exemplified by how the transition program assisted students in moving from lacking knowledge to becoming empowered by real-life experience. With the knowledge of Terry's interest in film, the program coordinated work opportunities through forging collaborative relationships and liaising with sites and companies in the community related to the film industry. After setting the stage for internship opportunities, more importantly, the program empowered Terry to take the initiative to contact the film organization to set up his internship. Justin indicated that when he lacks prior experience in certain things, he needs to communicate with other people to seek opinions and discuss solutions, but gradually wants them to have their hands off. For example, following his negative experience of studying out of state, Gabriel acquired the experience of living alone, but he still found it helpful to live not too far away from parents and have their support in learning to live independently.

**Theme A4: Self-realization.** Participants described their understanding about themselves. They discussed how they capitalized on this knowledge to achieve a desired state of self through adapting to the environment and developing their full potential.

*Self-awareness.* American participants showed awareness of their interests, preferences, abilities, and knowledge, as well as the lack thereof. More importantly, they acknowledged their own limitations and showed acceptance of their weaknesses or differences. Isaac recognized a drop in his body energy level and concentration since his junior year of high school, which made him unable to quickly accomplish multiple tasks and achieve different learning goals at the same time. Although he would “get mad of myself” initially, he gradually learned that this may be due to the changes in his body conditions and “just learn to accept that unfortunately I guess”. He showed a similar process of learning to accept the fact that he was bound to a local college because his mother did not think he was sufficiently independent to study away from home.

Socially, Isaac once had little confidence in grade school because he was worried about other students’ judgments of his appearance and behaviors. However, he currently acknowledge this awareness as “being aware of your surroundings, that you can also be aware of yourself”. Not only did he critically analyze other people, but also applied the same awareness to his own sensations, thoughts, and feelings.

Although Terry was aware that he is comparatively more independent and does not have those more severe symptoms in individuals with more classic autism, he learned throughout the transition years that he wants to be in a suitable environment where he can learn and work with people with similar functioning “so that I don’t end up going to a wrong place”.

Justin discussed at great length the idea of ASD versus normality in regards to his awareness of his own learning profile:

Well, it's hard, sometimes it's told what's this me being me and or normal human weirdness, and what's a part of spectrum. This is a symptom, this is a thing. You know that. Er, for example, ah I mentioned before we started recording I've never passed a math class. Um, again it's not because I, er, lazy in math class. I always tried my best. It's that, because I have Asperger's syndrome, er, I, er, retained information very poorly, especially about math. Asperger's syndrome plus dyscalculia, um, of course I am diagnosed with both, lucky me, but, so that's doubly, you know, against math. But, um, it has helped me. I'm not saying that it's completely negative. It has helped me um, my humanity classes, art, history, culture, that kind of stuff, I tend to, ah, ah, I don't know if flourish is the right word, but definitely succeed in those classes. Um, because ah, I retained information more. I'm interested in that. It's you know, ah I remember this.

Similarly, Justin acknowledged his love of talking and tendency of going off on tangents.

Although he found it hard to maintain conversation to be on topic, he radically accepted this as “an alternative way of thinking”:

When I try to focus on a specific, um, cuz, you're hearing me now, and when you look at the recording again, you can probably pick up on it too. I go off on tangents, right? I, it's hard for me to stay on topic around stuff. For me, cuz I'm thinking about a lot of stuff. It's like trying to open, it's like trying to close the flood gate, there's only a trickle coming through. You know what I mean? It's hard for me, because immediately, like when I'm trying to focus on something, immediately I like, another thing my mind goes off over here. What about this thing, what about that thing, you know? Which again, I'm used to it. It's not like it gives me headaches or anything like that, that you might think it would. It's not like, I notice it even it's um, not that much, you know? It's just the um, um, how to

say it, it is just, uh, the way my brain works, because I have an alternative way of thinking.

Participants were not always simply aware of their differences and inadequacies. They would turn this awareness into opportunities for learning and practice. Gabriel recognized himself have “a very bad tendency to be lazy” and hoped to improve himself by practicing “the appropriate behavior in certain situations”. He was also aware of his weakness in initiating communication to maintain friendship relative to starting friendships, so as he recently “managed to make a couple of really good friends”, he was “definitely going to try my best to keep on to that”.

Justin expressed an awareness of his own appearance and how other people see him. He did not only “always try to be very friendly and very open-minded”, he did not intend to act but found these traits “admirable”. Even when he got angry, he “tried to keep a lid on it” and not to look ugly. Although he indicated others usually would be able to recognize his anger, he at least would not vent his anger without control.

With the awareness of their own learning profiles and conditions, participants also exhibited various help-seeking behaviors. Terry was aware of his dyscalculia, so he spoke to the disability counselor in community college to advocate for accommodations for classes. With a tendency to shut down communication when things do not go well, Gabriel was eventually aware of his extreme level of stress and physical illness after the first semester of college and recognized a need to come out and communicate to parents about his situation.

***Self-actualization.*** All American participants described a certain degree of actualizing their potential in their own circumstances. Terry used the analogy of “to learn how to walk before you can run” to represent his learning and preparation in the transition program for his

future life in college and beyond. At the time of the interview, Terry was already admitted to a community college and he expressed high hope to thrive in the future:

Um, well, you know I knew that if I were to just say like, I am going to (a community college in his local area) after I, right after I got out of high school, I get there, and I just scratch my head, I wouldn't know where to go, who to talk to, what to say, you have to learn how to walk before you can run. ... Walking is like learning what college is about, and running is, actually doing it, going into college, actually talking the classes, through that you can fly once you graduated.

Similarly, Gabriel went through the transition program in which he also completed an internship and eventually obtained a job. If he would go to college again, he would feel more confident at making informed decisions because he had gained the knowledge and experience to do so:

Um, I mean, I definitely, when I'm picking like a, a class I wanna take and everything, uh, and my major, I'm definitely gonna put a lot more thought into it. Um, there's uh, you know I just, I realize that I control my own fate. Like I, if I put in like the hard work and everything like, I can do what I wanna do. Um, I just have that confidence now, where I didn't before.

He also discovered his interests and passion in life that could be used in his job. Specifically, found writing as his way to “express” and a “form of communication” that he feels comfortable and enjoyable. He contributed his strengths to the autism community around the world by writing blog posts for his worksite of an autism organization:

And uh, I just found that I enjoyed doing it. Like I enjoyed doing uh...the research went in to it, and uh, the actual writing process like. The words just, words just come a lot

easier to me when I am writing them down. Uh, as opposed to speaking, a lot of the times. ... And now that you know I know something that I enjoy doing and I am passionate about. I feel like it would be a lot easier, to put forth that hard work, where it's before there's lack of motivation.

In Isaac's case, he perceived that he has a lot of potential than he is allowed to express in his current circumstances. Although he once felt frustrated by the fact that he was limited by the issue of independence, he tried to convince himself to understand this limitation and to maximize his outcome using the available resources in his current environment:

I am just trying to make the best out of it now, because um, you know, even (the university in the local area he was currently attending) has lots of research opportunities, and things like that, I am just trying to make best out of my time here.

Unlike other participants, Justin's expression of self-actualization is not primarily task-focused. Instead, he showed emerging actualization of self through radical acceptance of his personality and exhibited behaviors that are congruent with his self-knowledge. For example, Justin classified himself as both "an optimist and a realist" by looking for "at least a silver lining to something" and trying "to be careful" at the same time in daily life. This is also consistent with his personal belief "to find the happy medium" in life because "extremes are bad". He recognized these ideals are "that's kind of what I strive for" and "I don't always succeed", citing an example of how he controlled his angry expressions and thoughts while savoring his emotions as a human being. Here is another example showing Justin's realizing his optimist and realist self in not judging people based on their backgrounds.

I look around and I see art, right? And I'm like always seeing there has been artists. When there's art there's artist, laws that dictates. And then I think that's the realism means. The

optimistic me is like, well I could be incredibly depressing, if there isn't an afterlife of some kind. So, there we go. The afterlife that, you know. And I'm from a Christian family, so I'll see that's a safer take. I'm very well aware that I was and raised in let say Hindu family, or a Muslim family, or whatever, I will be Hindu, I'll be Muslim. I don't judge people based on religious beliefs and opinions.

### **Thematic Category B: Contexts for Self-Determination**

**Theme B1: Family context.** All American participants described their family members' extensive involvement in supporting, or adversely impacting in some cases, self-determination in the young adults' transition out of school. Parents have huge influence on all domains of self-determination in these young adults.

In the area of autonomy, participants described their experience with various degrees of autonomy attainment in relation to their parents. The contexts in which autonomy is expressed mostly center around living arrangement and reliance on parents for completing certain tasks. As for the former, although Terry was currently living with his parents in the same household, he indicated his parents “don't really like haul”, although he still perceived receiving emotional support and guidance from them while he “wouldn't say my family is very actively supportive”. To the contrary, Isaac described an overwhelmingly large number of examples that his mother stifled and discouraged his independence. Examples ranged from making excuses for not driving him to buy his preferred food, discouraging him from moving out to college dormitory, to stopping him from attending colleges out of state. Understanding the Benefit of mother as his guardian advocate and acknowledging his own needs for learning to be more independent in the areas of mental health and self-care, Isaac expressed great frustration and disappointment towards his mother's unwillingness to teach him despite his motivation to learn:

You know, then I kind of realize okay maybe you know, it might help me, like she might you know be able to advise me in certain things. Like I said I didn't know even how to apply for a job application. She wouldn't help me in those things. She would just like, assume that, I should just do it on my own, even though that's telling someone who doesn't have a driver's license, just go and drive on your own, start driving. So I didn't know how to navigate through those things.

There was an overarching theme of “lack of trust” between Isaac and his mother. While Isaac’s mother did not believe in his abilities for independence, Isaac felt “no value or meaning to it” for even trying to do or plan things.

For Justin and Gabriel, their parents supported their independence by providing direct assistance in tasks such as paying for the apartment rent and helping manage finance. While enjoying their current state of autonomy and residential independence, Justin and Gabriel stayed close contact with their families and appeared to welcome parents’ assistance before they could ultimately achieve full independence:

I'm still living on my own. Uh, I'm, I'm now, uh, when the first year of my apartment's lease was going on, my parents were paying for it, and now I'm totally paying for it, which, you know, I mean, I don't like that from a financial standpoint, but, but it's good to know like, I'm now almost fully, like, independent. (Gabriel)

I don't mind at all, some people might think that's unhealthy, you know, the mother's boy and all that, but it's like, she's cool though. I don't, I don't mind. It's like, cuz it's not unhealthy, cuz she's not mothering me. She is helping me. (Justin)

Regarding goal attainment, participants identified various ways that their parents provide support to aid their achievement of goals. They mostly described parents offering information

support (e.g., research for post-school options, suggest alternative perspectives, weigh pros and cons), emotional support (e.g., be caring, considerate, and understanding), and tangible support (e.g., introduce useful connection, write notes for him during a phone call). Parents have done all these actions for their young adults with ASD to support their attainment of different educational, vocational, and life goals, which directly or indirectly model and teach them self-regulation and foster empowerment and self-actualization.

Justin and Gabriel also discussed the role of family members in relation to their expression of self-awareness. On one hand, Justin recognized the differences between his beliefs and preferences and those of his parents, siblings, and relatives, which reinforced his awareness of his own personality and emotion expression. Gabriel also looked up to his relatives as models for interpersonal and career decision-making. On the other hand, both acknowledged their inadequacy in self-awareness and indicated that their mothers know them better than they do. With this awareness and knowledge of self in mind, Justin and Gabriel could easily let parents assist in compensating for their insufficient self-awareness and, more importantly, foster the development of their self-determination by supporting them in their real-life learning experience. Overall, Justin and Gabriel painted a more positive picture about how their parents supported their learning about themselves and continued growth in self-determination:

It's just, uh what it's, like mother's intuition I guess. She's just, I mean, she's been around me my entire life. She knows all of my tales, and my, um, like quirks and everything, like, she can look at me and just tell exactly how I'm feeling, even better than I can a lot of the time. ... It's, it's, it's good. I am glad. Um, cuz she's able to help me through a lot of uh, tough, things. Um, uh, yea, it, it can be a little bit disconcerting, um to, know that like uh, someone can pick up on my emotions better than I can. [laugh] (Justin)

Well my mom said afterward she suspect, cuz you know, she knows me better than like I know myself. So, she said she suspected like something was wrong, but she wanna to try to let me figure it out on my own and, you know, just something I needed to experience, like, I, it's like I almost needed to hit rock bottom before I could like pick myself back up. (Gabriel)

**Theme B2: Vocational experience.** American participants in this study were at a relatively early stage in their adulthood (i.e., all exited high school within the past 3 years) that they had not have much work experience. Nevertheless, they showed different emerging signs of vocational development through which self-determination manifested.

Having a job serves as a context for the expression of various self-determination characteristics. For example, Terry treated his job as an obligation both for the workplace and for himself. Although his current part-time job at a local grocery store occupied so much of his time and prevented him from starting community college, he regarded it as “a stepping stone” on the pathway towards his ultimate career goal. Moreover, both Terry and Isaac described the financial independence a job can bring to them because they can secure stable income and pay for their own things:

Um, I ah, only started paying for my own phone bill, and few other things, when I was um, when where I got my job, at (a chain grocery store), cuz before I couldn't pay for anything. Um, but once I had I stable income, I could, buy my own, things. (Terry)

Isaac even described getting a summer job as “my way of proving to her that I am going to be independent”.

For students who are transitioning from high school to adulthood, finding and working a job is a completely novel experience that they hardly have any background knowledge. This idea

was also reiterated by different participants. On one hand, as indicated by Terry, they could control what jobs to apply among many different options. On the other hand, Isaac expressed a lack of prior knowledge or experience with getting a summer job during his high school years. He wish his mother could provide direct instruction on such pre-vocational skills as job application that would capitalize on his motivation to learn and advocate for more independence:

And I remember in school I also wanted a summer job, like really really badly, but my mom was saying, "No you won't be able to do it" and things like that, and she was like "Oh, if you want a summer job, apply for you know job application", but thing is you know I was during that age, I didn't know how to apply for a job application. Like, the type of analogy that I would give is like, you don't give a person who hasn't driven before a driver's license. You have to help them and teach them, and my mom wasn't there to like really do that, for like the summer job, or for the job application, to apply to, you know get a job or something. I was really mad at that because I wanted a summer job, because that was like, in my mind, I felt like that was my way of proving to her that I am going to be independent, that I can make money, that I can get a summer job. You know apply to like, even McDonald's or any place, that will like take me, that I can work at. So then I kind of got mad that, even like, she won't even let me, you know, prove to her that I can get independent. So.

Besides formal working experience, there can be other pathways through which young adults with ASD can develop vocationally and express self-determination. For example, Terry and Gabriel were set up for individualized internship experience through the transition program. Through the internship experience, participants gained hands-on experience in practicing their abilities of interests. They became more aware of their own career interests and passion through

this self-exploration process in real-life settings, which further reinforced their directions in career development and lifelong pursuit. Furthermore, they also gained access to network of colleagues and organizations that may pave their future career opportunities and success as their long-term goals:

And I really learned a lot of film making, and um...how they produced television shows and news and stuff like that. And I made some good contacts there for networking. I still have their email. (Terry)

Uh, well I actually, I interned here at (the organization he currently worked at). Um...and uh, for them, like I basically just did um, like write-up about things. Like I did one thing where I interviewed some of my classmates, and uh, asked them questions, kind of like, kind of like...this [laugh], anyway. And uh, then I would do a write-up on like, my findings and everything, and uh, um, just uh, they had my writing blog post on like various topics related to like um, things going on in the autism community, be it here, in the local area, or like, elsewhere in the country or the world. And uh, I just found that I enjoyed doing it. Like I enjoyed doing uh, the research went in to it, and uh, the actual writing process like. The words just, words just come a lot easier to me when I am writing them down. Uh, as opposed to speaking, a lot of the times. (Gabriel)

**Theme B3: Postsecondary education.** To American participants, studying in college demands a distinctively higher state of independence in students. Reflecting on his past experience failing in college, Gabriel articulated the demands of independence in terms of managing school work and living independently. More importantly, these tasks are to be accomplished without the support from teachers and family that he used to have when he was in school. In fact, one of the main reasons for Isaac not being allowed to attend college away from

home was his mother's concerns about his independent functioning, including taking care of his independent living and managing his mental health.

All participants described many choice-making circumstances throughout their journey of postsecondary education. At the outset, young adults leaving high school have to consider whether to pursue postsecondary education or not. Both Justin and Isaac hold a clear mindset that college education matches their expectations of learning in general (i.e., "I might be able to get more um...knowledge more...build more character"), or specific career goals (i.e., medical doctor).

Making a choice among different options of colleges and major of studies is the next step. Participants have considered a variety of factors to choose their college options, including location, reputation, and career interests. However, based on the experiences of Gabriel and Isaac, they learned that they should have also considered more factors such as family support and their own state of independence. Specifically, Gabriel regretted that he "wasn't very informed" when selecting his major as he "didn't do much research or anything" and decided to do a major related to international affairs simply based on his positive experience of traveling.

Similar to the choice of entering college, students have the freedom to decide to change their studies or drop out, and they have the option to reenter secondary education later in life. Both Justin and Gabriel decided to drop out from college because of their intense stress level. Gabriel indicated wanting to "start off a bit smaller" in the future by first attending a community college, then ultimately going back to a formal university. Students can have different types of educational options that can suit their learning stages, expectations, and needs.

Isaac expressed a clear goal in his college study. With the goal of becoming a neurosurgeon, he described a clear pathway for attaining this goal, from studying on different

biomedical courses, gaining research experience, joining student organizations, to preparing for future entrance exam for medical school. Justin also described a long-term plan to balance his college study with his current job before he could ultimately attend a formal university and develop his career related to writing.

Having the goal to pursue postsecondary education, participants also discussed different ways they were empowered to attain these goals. Justin was nervous to start his study in the community college, but he also stayed “open-minded” to try new things and learn new knowledge. Gabriel learned from his negative experience that he would “need to have, like uh, hardworking everything, and dedication, determination” in addition to mere intelligence to thrive in college. He also was glad that his mother let him experience the hardship when he almost broke down after the first college semester. This in turns empowered him to know what to avoid in the future when he would go to postsecondary education again.

Participants expressed various aspects of self-awareness in the context of postsecondary education. Justin was aware that he has weakness in researching about college information that are not of his interest (contrary with information about Star Wars), which he would need mother’s assistance to discuss college options. During his study in the community college, he realized that his accommodations can be useful, but mostly were too standardized and not helpful to him. He even had a chance to advocate for himself to compensate for a missed exam, although his teacher did not understand his difficulties and did not grant him a second chance. Recognizing his own disability in math, Terry also advocated for himself by talking to a disability specialist in the community college who offered him accommodations in taking alternative classes. Learning from his past experience, Gabriel alleged that in the future “when something's going wrong, I need to tell people, so they can help me find the solutions, instead of

trying to like, uh, like, bear the whole burden by myself.”

**Theme B4: Community-based resources.** Three of the four American participants (Terry, Justin, and Gabriel) had participated or was participating the same transition program for young adults with ASD who exit high school and enter the adulthood. They all felt delighted to have found the program and were happy to participate in it because they felt “directionless”, “lost”, and “know nothing” about life after high school, although they also felt nervous about not knowing what to expect and who would be in the program.

The setting of the transition program was tailored to the specific learning needs of young adults with ASD without intellectual disabilities. As described by Terry, the program is “like a professional learning environment” with students of his similar conditions and level of functioning. It is housed within a college campus so that students can really experience authentic campus environment and interact with college students. Gabriel described this as a perfect environment for such a school-to-adulthood transition program:

I was like, wow, this sounds great, like it's not gonna be, it's not thrown me right back into like full-on school, but it's also, it's gonna be something that is like, nice state, pace that can hopefully teach me the skills that I will need to succeed.

The transition program constitutes a variety of elements that contribute to students’ growth in general, and their self-determination in specifics. Participants emphasized the significance of direct instruction. Students were taught by program instructors and mentors knowledge about post-secondary education, vocation, and adulthood, such as different expectations in respective settings and skills needed to succeed and cope in these environments. Gabriel explained, “it taught you, like, um, you know the essential skills that you would need to transition from like high school into the adult world, which was exactly what I felt I needed.”

Terry also indicated that “I’ve learned a lot about life and, what to expect, and what to do.”

The transition program also promoted students’ discovery of self in various aspects. The program set up a context for interacting and learning with peers and college student mentors. Terry and Isaac gained more awareness and understanding about their own conditions and personalities through social comparison with their peers with ASD. Another significant program element involves students’ discovery of interests. Through program instructors’ guidance and the use of aptitude tests, participants were engaged in continued process of exploration of career interests. Moreover, participants described program staff as empathetic yet firm. They have good understanding of the students and can empower them from different entry points based on individual students’ levels. For example, as Gabriel did not have any specific career preference, the staff helped pick an internship site for him that potentially fits his profile. On the contrary, knowing Terry had a clear interest in the film industry, the program first established relationship with a television station and then empowered Terry to set up his internship with his supervisor (see “Vocational experience” section for details about internship).

The transition program also acted as a catalyst for independent living and future employment. Justin and Gabriel moved to the campus area and lived independently since they participated in the program, which opened up even more opportunities for self-determination in their daily lives. Gabriel was also supported by the program staff to practice self-advocacy skills by proposing a new job position for himself in the same organization where the program operates:

...so then I just kind of bring this idea up to (program staff) and (program staff), and uh, (program staff), and uh, (program staff) and everything. They all told me that like, you know maybe write up a proposal, to give to (the program director), the program director.

And uh, I did, and, seem to like it. And they basically just made a job for me.

Last but not least, parent involvement was evident in the transition program, albeit not extensive. Participants described their parents mostly involved in preparation or the beginning of the program, including searching for program information, helping arrange roommates and living places, and attending orientation on the first day.

**Theme B5: Early experience in the school-age years.** American participants described some experiences during their school age that showed their emerging characteristics of self-determination. Terry, Gabriel, Isaac described their discovery of interests and subsequent involvement in experiences related to their interests in high school. For Terry and Isaac, they have engaged in hands-on experiences either in pastime (i.e., writing a novel) or school curriculum (i.e., biological sciences) through which they explored emerging career interests. In contrast, based on only one experience of traveling to and volunteering in China, Gabriel did not have a comprehensive understanding of his interests or passions, which led him to wrongly pick a major that he did not like:

And back at the time of when I was making that decision, I didn't, I didn't have much of a direction. I don't really know, what my passion was. Like, you know I always got good grades in school and everything, but uh, I didn't know what I really like, wanted to go.

Um, I just kind of saw something that I generally enjoyed in doing, in travelling. And um, I figured, I can do this, and maybe, change my major later, if I don't like it. Um, I don't know. By the time that uh, the first semester was up, I was just so totally done, with uh, that whole thing. Um, yea.

Terry, Gabriel, and Isaac described their early experiences with activities structured by parents or educators. For example, a special education coordinator at high school found the

community resources and suggested Terry to attend the transition program. Isaac mentioned his classroom accommodations were arranged by his mother and teachers. His middle school teacher also helped gradually move him from self-contained special education classroom to general education classroom. However, these structured experiences did not necessarily contribute to their self-determination characteristics later in life. For example, although Terry had experience interacting with children with Tourette syndrome similar to him, he did not have adequate knowledge about his ASD conditions, and he was still nervous attending the transition program with individuals with ASD. Isaac also expressed that his mother wanted to continue her advocacy work for him from high school, thus claiming to be his guardian advocate. Gabriel mentioned that “things aren't always like, super easy in high school, but um, for the most part, I knew what I needed to do. I knew how to do it. And once I did it, it usually turned out well”, but once he transitioned to adulthood with the loss of structure, he could not figure out his directions.

Participants overwhelmingly described numerous negative experiences related to their early school life. Terry, Justin, and Isaac expressed intense dissatisfaction with their school life and identified associated mental health concerns that stemmed from their school experiences. They experienced peer victimization, social isolation, and unfair treatment from teachers, which had differential impacts on different participants. The negative experiences could either serve as an opportunity to learn or a way to punish individuals from developing self-determination. For example, Isaac was repeatedly discouraged by his mother from getting a summer job, which made him become more hopeless in striving for independence and realizing his own capabilities over time:

And I remember in school I also wanted a summer job, like really really badly, but my mom was saying, "No you won't be able to do it" and things like that, and she was like

"Oh, if you want a summer job, apply for you know job application", but thing is you know I was during that age, I didn't know how to apply for a job application. Like, the type of analogy that I would give is like, you don't give a person who hasn't driven before a driver's license. You have to help them and teach them, and my mom wasn't there to like really do that, for like the summer job, or for the job application, to apply to, you know get a job or something. I was really mad at that because I wanted a summer job, because that was like, in my mind, I felt like that was my way of proving to her that I am going to be independent, that I can make money, that I can get a summer job. ... that I couldn't control, so then I kind of like, just gave up on my, hopes and aspirations, swim team, after that coach, and then, you know, gave up on the summer job, but I really wanted to do really badly. So.

On the other hand, although Isaac had difficulty engaging in communication before third grade and was repeatedly teased in middle and high schools that led to his social anxiety, he showed resilience and learned strategies to cope with unfamiliar social situations by, for example, making jokes. Overall, Isaac perceived his life journal as “a success story”:

And I think overall I say that, my whole journey through middle school, even like grade school, elementary school, high school to college like, was just overall, just really a difficult thing. They are just hard to survive. I think I learned a lot of skills along the way, during that time.

Negative experiences in childhood and adolescence could also affect the development of self-image and identity, which may also impact self-awareness and self-realization in adulthood. Justin indicated his experience of being bullied in middle and high schools led him to present a very different self than he supposed to be:

... the me you see now, right? Very friendly, very outgoing that kind of outlet as complete one-hundred eighty from how I was in middle school and high school. Believe me or not, I was very standoff, was very cold, um, when, I was very sarcastic, and not in a ha-ha funny way, in a kind of biting, criticizing way. ... Because I was out of my, I was out of my environment, my environment sucked, to be more accurate.

Similarly, Terry was educated mostly in a self-contained special education classroom with students with psychological disorders other than ASD, which might have contributed to his inaccurate understanding of his ASD conditions:

... imagine being a high-schooler where that doesn't have any real prob, like problems mentally, and they put you into a ESE class with people with mental disorders. Like you feel diff, like you don't, you know you don't belong there. That's how I, that's what I thought it would be like before I started [the transition program].

### **Theme C: Overall Perceptions of the Post-School Transition**

Overall, American participants expressed mixed feelings upon reflecting on their experience transitioning from high school to adulthood. This transition period was described as something ambiguous, uncertain, and not obvious that involves a lot of changes:

I could probably make a short film, some sort to kind of symbolize it. ... It'll be a silent film I think. ... Something that's like not obvious, like not literal. ... Artistic. It makes people think. (Terry)

On one hand, this transition could mean a preparation period before one would experience more growth, attain more independence, and gain more success in adulthood later in life:

Cuz right now not much is going on, just more like learning, you know. Like learning, you know, like, kind of taking a breath from high school, you know, preparing for what's

to come. ... It's like, it's like in a, in a movie, some movies, you know, some books, you know there's the story, and it's the main story, and then it cuts through a break to let you take in everything, but also prepare you for the rest of it. And that's usually even bigger than the first half. And trust me I'm sure college is probably gonna be a lot harder than, high school. (Terry)

I guess it just means like you are able to learn, you become more independent. You are able to uh, finally get into your career, and do your planning that you may or may not have had in high school, the idea of career that you wanted, to be able to achieve that, accomplish that. It also means like being successful, gaining success uh, just like, that's the main thing. (Isaac)

On the other hand, this transition could also mean being forced to step into the adulthood with no explicit guidance and pre-existing structures to follow:

Uh, just means growing up. Like it's something that all we all have to do. It's something that was more of a struggle for me, and continues to be more. Uh, was a struggle for me than say, maybe to say your, typical person. ... Like I didn't know where to go next. ... So, in this, new environment, I was like, lost. (Gabriel)

Of note, Terry and Gabriel who have gone through a transition program expressed a clear sense of ownership and determination towards their future. The transition program seemed to serve as a powerful source of empowerment and hope for supporting them to navigate the contradictory tensions embedded in the ambiguous transition period:

I've my certificate of graduation from the (transition program). ... It shows what I wanted to learn in the (transition program). And it shows that I, am capable of, other things, you know if I can do that, I should be able to, get through college without a problem, too

much of a problem. ... It means, that I've learned a lot about life and, what to expect, and what to do. (Terry)

The best thing to come out of it was, you know, they helped us learn about what our real passions are, cuz a lot of us were just unsure, unclear. ... It just opened my eyes too. You know I really enjoyed doing this. For the first time in my life I feel like, this is something I could do long term. ... It taught you, like, um, you know the essential skills that you would need to transition from like high school into the adult world, which was exactly what I felt I needed. (Gabriel)

Putting these together, the transition from school to adulthood seems to be a mix of both feelings. Justin's analogy speaks to both positives and negatives of approaching this transition:

Um, transition, it's good, it's a good thing, first of all. Cuz change is a good thing, for bad or for worse, eventually come back around is good, you know? ... Change doesn't go to a bed and then stop. It continues. Um, so um, I think it's good. Transitions are good, because that's a change. You know, that's like, you know transition, you need to experience this stuff, cuz that builds your character, that builds who you are as a person. ... It's weird, um, but it's not altogether unwelcome, if that makes sense. It's like, um, a guy you just met who is super friendly, but you don't know that well.

## Results in Hong Kong

### Thematic Category A: Experiences of Self-Determination

**Theme A1: Autonomy.** Participants described behaviors they performed and decisions they made based on their own judgment, without much influence by or reliance on external agents. They talked about the notion of independence. They also described their basis for autonomous acts.

**Independence.** Chinese participants exhibited a range of behaviors that express the notion of independence. Overall, participants endorsed the significance of being independent in life. Although they described some independent behaviors, they also acknowledged their inability to be fully independent at the present stage.

Participants described independence as doing things *by themselves*, *for themselves*, and *for others*. They described a variety of behaviors either *by* or *for themselves*, such as self-care, problem-solving and decision-making, and doing house chores. Moreover, some participants indicated independent as doing things *for others*. Both Michelle and Joshua indicated contributing money to the family as one of the indicators for independence. Michelle expressed a strong desire to “...可以做到全職咁樣,可以,自己獨立D,可以,可以俾家用呀,或者希望自己可以代表自己可以,獨立咁樣. [...can be able to work full-time, can, become more independent, can, can give money for family’s use, or hope myself can represent myself, can, be independent]”. For Joshua:

獨立我諗第二個原因就係因為我呀爸就啱啱尋日退左休,尋日last day架啦,咁就退休啦終於,咁呀,我係大仔啦,我都有個責任,要,不過雖然佢話佢係,佢係公務員啦咁樣,咁但係, ... 我都有番責任,俾少少零用,啫係到我搵,搵到野做嘅時候,都俾少少零用佢囉. 同埋都要供我細佬讀書囉.雖然呀爸話,得架啦,你搞掂你自己先啦咁樣,不過我覺得,遲早如果我嗰份工穩定左就真係要,要做架啦,啫係要開始俾錢呀細佬呀,開始俾錢呀爸呀咁樣囉. [Independence, I think the second reason is because my dad was just retired yesterday, his last day yesterday. Finally he is retired. I am the eldest son, I have a responsibility, to, although he is a public servant ... I have the responsibility to give a little bit pocket money...by the time I will find a job, I will give a little bit pocket money

to him. And I have to help pay my younger brother's education. Although dad said, 'it's okay, you first take care of yourself', but I feel like, it's the matter of time, if my job becomes more stable, I really have to, have to do that. Need to start giving money to brother, to dad.]

Similarly, Michelle and Michael described learning to better deal with interpersonal problems as a way to show independence. Among all participants, Michelle was the only one who mentioned independent living as an indicator for independence, although she made such a cautionary statement that points to the constraint due to socioeconomic factors in Hong Kong:

唔好太,唔好太依賴家人呀. 但係而家香港情況實在太難啦. ...住屋,住屋呢方面你唔使諗啦 ... 根本無辦法供度,我地都搵唔到啱嘅,居住環境,而且好勉強,而家勉強呢都係申請公屋啦. [Don't, don't be too reliant on family members. But nowadays, it's too difficult in the situation in Hong Kong. ... Housing, housing this aspect, it's not even under my consideration. ... At the end of the day, you have no way to pay for the mortgage loan. We can't find a suitable, living environment. And at most, at most I can only apply for public housing.] – Michelle

Participants described a variety of ways to help them gain independence. Almost all participants indicated parents as the agent for their attainment of independence. For example, parents acted as models and provided instruction of independent behaviors. Many participants described their experience with advocating for more independence by initiating to do more or even negotiating more room of independence with their parents. Events ranged from as small as doing dishes (Joshua), cooking for the family, to such big events as going for a trip outside Hong Kong (Aaron) and deciding to study abroad (Joshua). At another extreme, some indicated their parents put them into the state of complete independence abruptly. For example, Michael and

Joshua were sent to study abroad to learn independence. For Michael, his parents decided to send him to New Zealand and put him in an area away from the Chinese community with an intention to force him learn English and grow. Even though Michael's father accompanied him in the first few weeks to help him set up and take care of his self-care needs, this kind of transient support was not effective in reducing Michael's negative emotions about the impending complete independence:

覺得自己好似一個,俾人遺棄左嘅物質,啫係,我嗰時諗,爸爸係咪要趕走我呢? 係咪我讀得唔好書而要趕我扯呢? 有呀,拿呢個第一個,甚至有咁嘅諗法. 甚至覺得啫係,呢個群體係咪唔要我呢? [I feel like I am like a, substance being abandoned. That is, at that time I thought, does dad want to kick me out? Is it that I did not do well in school so he kicked me out? I have, the first, even have such a thought. I even thought that, does this group not want to have me?]

When reflecting on the meaning of independence, most participants did not express any emotions associated with gaining more independence. At best, Michelle described this as “成熟表現問題,唔好,太,ea驚慌 [the problem of behaving maturely, don't be, too, fearful.]”. In fact, most participants described a need to be independent, citing the reason that parents would eventually pass away and leave them.

啫係我唔想一世靠佢地呀嗎.啫係啫係,唔老黎講D呀,佢地終有一日都會離開我架嗎,係囉. [That means I don't want to rely on them for my whole life. That is, that is...talk about the taboo, they will leave me one day. Yes.] (York)

The need to be independent was understood within the frame of facing an indisputable truth and, to a certain extent, a sense of helplessness.

獨立因為好多時,ea父母始終有一日都會離開個世界,但始終你自己都要,ea生活落去嘅,啫係你,點樣由一個中年,去到老年,呢段時間,去到死啦,”...”每個人都要必經呢一個,呢個階段. 唉!就黎到我架啦. [Independence, because in many times, parents in one day will eventually leave the world, but you still have to, live on. That is you, how you live from a middle-age, to old-age, that time, to death. ... Everyone has to go through this, this stage. Urgh, it's almost time for me.] (Kenny)

Michael further explained this sense of external pressure in terms of the sociocultural values in the broader society that laid on his parents, which were ultimately passed down to him as a form of pressure to be independent:

不過我都承認嘅,因為香港個升學主義,或者個,攻利太勁,有D似日本.咁令到好多父母其實都有一種壓力嘍度,佢自己都有個心理壓力嘍度,因為,佢都希望呢自己個仔呢,唔好話望子成龍<sup>1</sup>啦,啫係起碼都,呀,唔好話做一D啫係,啫係無人鐘意見到有個宅男<sup>2</sup>啦,要人地,養佢一世架嗎,啫係你養佢一世,都好麻煩嘅一件事,佢無一個自理能力. [But I have to admit, because the ideology to further study in Hong Kong, or, too utilitarian, is like Japan. This causes many parents actually have a kind of pressure. They also have a kind of psychological pressure, because, they also wish their son, not to say expecting a son to become a dragon<sup>1</sup>, but at least, not to say, no one wants to see an Otaku<sup>2</sup> guy, needing others...to take care of him for the whole life.]

On the other hand, Michelle and Joshua also described the attainment of independence as

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<sup>1</sup> “望子成龍” Chinese can be literally translated as “hope a son will become a dragon” in English, but this proverb actually means “hold high hopes for one’s child” (Lee, 2015).

<sup>2</sup> “Otaku” is a Japanese term that was originally coined by amateur manga artists and fans in the 1980s to describe “weirdo” and “nerd” (Kinsella, 1998). With its original meaning as “your home”, this term is also a common reference to people who are not accustomed to social relationships and spend most of their time alone at home.

meaningful to other people. It served a way to pay back and contribute to their families, financially and emotionally:

欠呀爸太多啦,欠屋企人太多啦,啫係佢俾咁多錢我讀書呀咁樣囉,係時候要還番囉,我覺得. [I owe dad too much, owe family too much. He gave me so much money for my school. It's time to pay back, I think.] (Joshua)

有時我覺得我未盡我,我孝,孝,孝,孝,孝順嘅責任嘅.[Sometimes I think I have not paid my, filial, filial, filial, filial, filial responsibility.] (Joshua)

Joshua also described his concerns with himself being independent before he would be able to handle relationship issues: “自己未ready好,如果你搞掂左自己,頭先厘清個責任呀,ea獨立嘅問題呢,我諗,先至處理感情問題,我諗先叫,會好D.[I am not ready yet. If you first take care of yourself. First to clarify the responsibility, the question of independence. I think, and then deal with relationship problems. I think this is, better.]”

*Act on the basis of....* Participants described a variety of autonomous behaviors they performed based on their interests, preferences, feelings, past experience, and consideration of other people.

In terms of interest, almost all participants indicated making certain decisions based on their personal interests. Their interests influenced their postsecondary options as well as career choice. For example, York decided to do a vocational program related to computer because of his interests in computer; Aaron decided to do a culinary course in Western dessert because he was interested in cooking; Michelle planned her career in librarian after she discovered her interests in reading and organizing things; Joshua was once intrigued by an online news clip and he advocated for a volunteer experience in a net station because he wanted to get a taste of becoming a journalist. Michelle described how the discovery of her interests led to her career

plan:

近來我發現我自己都好鐘意睇書嘅,又有興趣執野,所以我諗做,圖書管理員呀.

[Lately I discovered I myself also like reading, and have interest in tidying, so I am thinking to be a librarian.]

Interests also influenced participants' decisions of daily activities. For instance, Derek enjoyed hiking with a group of psychologists and youths with ASD where he could learn team work and build up stamina; York's interest in numbers in general turned into his hobbies of playing online gambling games and buying Mark Six (a lottery in Hong Kong) regularly. However, acting on the basis of their interests does not necessarily mean interests would not change. Kenny described his interests kept changing over time. After trying a certain vocational program or job out of his current interests, he would soon be disinterested in some aspects of it and discontinued doing it. On the other hand, Joshua also mentioned his personal interests in church activities might sometimes override other important priorities in his regular job.

Participants also showed preferences in daily decision-making. They expressed personal preferences mostly in vocational-related issues. For example, Michelle showed her job preference by quitting a job after she tried and found out she could not stand performing certain tasks that were either too physically demanding or inconsistent with her personal values. York decided to take an afternoon shift at his work in a fast food restaurant because he preferred waking up late. Joshua explained his preference for working in a press with religious background with considerations of his weaknesses in socializing and his passion in religious issues. Even though Kenny presented as unmotivated and expressed a sense of helplessness in the interview, he preferred going to work than “都好過留喺屋企呀[better than staying at home]” because he felt more bored and lonely at home.

Many participants described their experience of making autonomous decisions based on their feelings, negative emotions in most cases. Aaron, Michelle, Kenny, and Michael expressed negative feelings towards their jobs in the past, which made them feel they were not suitable and quit the jobs. Both Michael and Joshua felt their lives in Hong Kong in the past were too stressful and unhappy, which was one of the main reasons why they wanted to study abroad after high school.

Many participants also described some negative consequences following their actions based on feelings. Aaron bought an expensive action figure (around \$1,000 HKD = \$128 USD) to celebrate the completion of his one-year contract, but after his parents explained to him, he understood it was too extravagant. Michelle felt angry about her supervisor cutting back her work hours and spoke to the supervisor in a direct way, which her parents considered too blunt and inappropriate. Kenny started smoking recently to cope with his stress, but he clearly thought “我而家覺得壞左囉[I think I now become bad]” and advised the interviewer “你千其唔好學, 你一學左呢,好似我呢D上,上,上左,上左癮呢,唔掂呀 [don’t learn it from me. In case you are like me, become addicted, that’s bad.]”. Joshua described an interesting example that acting based on feelings may not always lead to outcomes that he desired. As he felt like resonating with some friends he knew from high school, he disclosed his ASD conditions and eventually gained their acceptance. In contrast, he was isolated by some of his classmates in his associate degree program whom he considered “敵人[enemy]”, which made him decide to disclose to them about his conditions just because “真係唔知呀. 我都唔知點解會同佢講, 總之就,可能唔開心咪發洩囉咁樣,咁咪講左出黎囉 [I don’t actually know, I don’t know why I would tell him, but, maybe I was unhappy so I vented it out, so I talked about it.]”. Unfortunately, he was further victimized by the classmates, which made him even more depressed. Joshua learned from this

incident that “真係信得過嘅,我自己覺得信得過嘅人講囉 [really trustworthy, just talk to people I really trust]”.

In some instances, participants identified incidents where they used past knowledge or experience to make decisions. York decided to enroll in a prevocational program major in computer-related subject because he had prior experience with studying computer at high school, which his mother also reiterated that this decision benefited York in practical way and boosted his confidence. Similarly, after volunteering at a net station for a few years, Joshua ultimately decided to pursue formal training and his future career in Journalism. When his father gave him multiple options to choose for studying abroad, Michael spoke about his preference for New Zealand based on his positive experience of a family trip to there when he was in elementary school:

咁,拿紐西蘭呢個地方呢,同樣我都係矛盾架,點解矛盾呢? 好嘅就係其實我真係好鐘意呢個地方,我真係好喜歡呢個地方,矛盾就係,其實都係嗰D野囉,啫係,吓? 咁我啫係點呢? 要離開熟悉我嘅地方、熟悉我嘅生活,同埋最重要係呢樣野呀,我係覺得係俾一大群人遺棄左呀. [New Zealand this place, I was similarly ambivalent. Why ambivalent? Positive is that I actually really like this place, I really like this place. What is ambivalent is, it's actually that thing. That is, huh? What am I? I had to leave the place I know well, the life I used to. And the most important thing is, I think I was abandoned.]

Michael further reinforced his preference for living in New Zealand in the future by mentioning his overall meaningful, positive experience studying abroad in New Zealand, through which he learned about the local cultural value and interpersonal style with which he felt comfortable (i.e., more inclusive instead of holding strong moral judgment).

Many participants explicitly indicated considering others when making decisions for

themselves. Specifically, they showed a considerate mindset by taking serious considerations of others' perspectives and serving others' interests as well as protecting others' feelings while compromising their own preferences. Most examples were related to decision-making out of consideration for family members. In terms of serving the needs and interests of family members, Michelle expressed a clear determination to postpone job hunting for half year in order to take care of her sick mother. York also made the following claim when he was asked to express his desire for earning a small fortune from buying Mark Six.

啫係我唔會話, 我唔會話好大洗咁樣樣囉. 可能, 可能留番俾自己囉, 我D下一代用囉. 可能係咁囉. [I would not, I would not be spending too much. Maybe, maybe to leave it to myself, my next generation to use. It may be the case.]

From the perspective of protecting family members, Michael reasoned that although he personally liked New Zealand, he also envisioned himself being lonely and isolated, but he indicated part of the reason of choosing to go finally is “嗰陣時揀, 好啦, 紐西蘭啦, 咁我嗰陣時只好話好啦, 因為我都無理由逆屋企人意架嗎 [At that time, okay, chose New Zealand. Then at that time I just have to say yes, because I have no reasons to object to my family's wills.]”, expressing a sense of obeying to parents' wills while protecting the efforts and preparation his parents already invested in the options. Similarly, Joshua hid from his father the fact that he was developing severe emotional disturbance because Joshua did not want to “burden” his father.

係呀, 咁然後就, 一一年七月啦, 咁我... 因為你知啦, 你患呢D野, 啫係可能情緒病, 我唔想呀爸, 又擔心呀, 又黎另一個擔心, 我瞞住佢, 得我同呀姨知啫, 咁就去左睇精神科醫生囉 ... 唔想呀, 呀姨, 佢都有三個仔女架嗎, 我又唔想佢負擔囉, 同埋都, 都希望瞞住, 唔想俾爸爸知咁樣 [Yes, then, July 2011, then I, because you know, you have this kind of

thing, maybe emotional disorder. I think want dad, to be worried again, another worry for him. I hid the truth from him, only me and my aunt knew about this, and visited a psychiatrist. ... Don't want, aunt, she has three children. I don't want her to be burdened, and I also want to hide this from, not want to let dad know.]

Family members aside, some examples also indicated participants' considerations of other people in their life when making their own decisions. For example, Joshua decided to continue taking up tasks in his church on top of his full-time job because he considered the church leader his “兄弟[brother]” and did not want to leave him alone, especially that the leader would get married soon and would need Joshua's help so much. Derek also gave several examples how he proactively considered other people's interests when making his own decisions. For instance, he explained why people generally would not talk about the accommodations they received at school because:

一黎私隱啦,二黎你咁樣人地會覺得,對其他正常嘅人好,叫做咩呀,係啦,唔公平. 如果咁樣會唔公平囉. 啫係可能,要識呢D位囉. [One thing is, privacy. Another thing is, other people will feel, to normal people, that's called, yes, unfair. If this is the case, it's unfair. Maybe, have to know these things.]

Another example involved his interactions with colleagues at his job:

點樣講俾你聽呢,講唔到啲,啫係講呀拿,我中,啫係我舉個例啦,我未必係真架啦.啫係例如,我好鐘意去某一間餐廳到食,我日日都要去,咁其他同事都唔鐘意去啲,咁人地次次都咁樣就佢,咪已經係過份遷就囉. [How to describe it? It's hard to explain. It's, me give an example, not necessarily be real. For example, I like to dine in a certain restaurant, I have to go every day. Other colleagues don't like to go. Other people compromise to him every time. That is over accommodating.]

**Theme A2: Goal attainment.** Participants identified different goals after school exit and discussed how they reached or would approach their goals.

*Goals.* When asked about goals or things they would like to achieve in the future, Chinese participants described their goals related to several aspects in life. Five participants mentioned increasing socialization as an important, if not prime, goal for them. While Aaron and Kenny wanted to meet more friends and join more social activities, York, Michael, and Joshua indicated a desire to find a girlfriend or even get married in the future. Getting a job is another oft-cited goal identified by five participants who either have a part-time/temporary job (York, Michelle, Derek, and Kenny) or did not have a job at all (Joshua); however, they would all like to seek for a full-time job or a more suitable job. Joshua also expressed his goal of becoming an amateur organist aside from his career in journalism. Related to their current life goals, Kenny and Michael expressed a strong desire to leave Hong Kong and live in other places.

When asked to reflect on the meanings of their goals, most participants endorsed the importance of getting a job that allows them to earn money and live their lives. More importantly, they expressed a sense of priority and urgency to work. Joshua would like to get a job from wherever and be open to other options in the future. Whereas York found the sense of connectedness in his current job, Michelle also expressed an urge to work more as if having a “工作狂傾向[workaholic tendency]” as she would feel “我唔番工覺得好唔安樂[I feel very annoyed when I don’t go to work]” and “好攞憎[very irritated]” because “而家係兼職,無無話係全職嗎[now it’s part-time, not full-time]” and “想快D做野,想快D,想快D番工之類嘅野呀 [want to quickly go to work, want to quickly, want to quickly have a job and something like that.]”. For Kenny, even if he felt like unmotivated, he found it more meaningful to get a job for whatever purpose:

而家係唔知點解讀完D野,又覺得無咩興趣,又係打動唔到我,都係而家我求其搵份工算啦. 加上學歷,加上我個學歷又低,都搵唔到D咩野工架啦,再加上,我自己又無咩興趣想,做,某一些工種. ...起碼有錢先呀. 有人工先,當你,你喺屋企無,無用,又識唔到人,又自己一條友,日日打機打...打廿四小時又點啫? 喺屋企坐吓,坐廿四小時又點先?

[Now it's like, I don't know why after studying these things, I felt like not interested, can't motivate me. I now just want to find a job perfunctorily. Plus, academic qualification, plus my qualification is low. Can't find any jobs. Plus, I myself don't have much interest to, do, particular kind of job. ... At least I have money. Have salary. When you, you are at home, it's useless, and you can't know people, and you have to be yourself. Play video-game, play...play it 24 hours a day, so what? Just sit at home, sit 24 hours a day, what's the point?]

Some participants cited the contributions of their own goals to their parents and families. Aaron, Michelle, and Joshua indicated earning money not only for themselves, but also to contribute to their families through giving parents money and taking care of financial situations of siblings and relatives. Aaron also indicated wanting to meet more people who share similar interests in cosplaying, so that he could introduce them to his parents,

因為呢,都希望我屋企人接納吓,我呢個朋友,雖然讀得書叻...唔理佢讀得書叻唔叻啦,我係...我鐘意嗰個活動認識嘅,志同道合. [because, I want my family to accept this friend of mine. Although he is good at school work...I don't care if he does well in school. I...I like the activity, where I know him, like minded.]

Aaron further elaborated on the meaning behind knowing a friend, “A嘅coser [Autistic cosplayer]” as his wish to gain parents’ acceptance on his identity with the ASD population while having an interest that is not different from ordinary people:

啫係話代入一個同平,啫係大眾化一般人呀無乜分別囉.我都知道,應該知道,啫係我都係同佢一,啫係正常左之後都係我咁樣啦,啫,做番正常 [That's, to be included in a...a popular, not different from ordinary people. I know, should know, me and him are. after being normal, I. I turn back to normal.]

Some participants found it meaningful to gain a sense of connectedness to people and the broader society. As mentioned above, Aaron would like to prioritize to know more friends because “我覺得應該目,我覺得個目標 (i.e., earn more money, be happy himself, and go for a trip) 應該係,算係,算係其次啦,最緊要係識到朋友. [I think my goal...my goal (i.e., earn more money, be happy himself, and go for a trip) should be, can be, can come after. The most important is to know friends.]”. Similarly, Kenny would like to make more friends so that he could confide with them about unhappy events, seek help, and feel less bored. Moreover, both Kenny and Michael reasoned that living in other places would make their life more meaningful, more being included, and more self-efficacious in trying different things because they felt like in Hong Kong “我生活狀態已經已經生活厭晒,慣晒,已經無無咩人生樂趣 [my life is already, already, already, like fed up, got used to, no longer have much interest in life.]” (Kenny) and “因為我D點子嚟香港,主流社會其實唔係好接納架 [because my ideas in Hong Kong, mainstream society doesn't really accept them.]” (Michael).

**Pathways to goals.** Chinese participants described different ways through which they attained their goals. All participants indicated analyzing resources and barriers of options along their decision-making journey towards their goals. Evaluating different job options is one of the most commonly discussed areas. For example, York expressed that he once thought about being a fireman and a lot of different jobs when he was young, but knowing his own limitations and

abilities more, he now thought working in a restaurant fits him. Wanting to change his job to a postman, Aaron did not only apply and interview for the job, but he also thought through the pros (i.e., higher salary, less complicated work) and cons (i.e., working environment not as comfortable) of this job option and would consider advocating for accommodation for his needs (i.e., to work in areas with less dogs because he is afraid of dogs). Joshua explained his consideration of the social demands of different job options in relation to his ASD condition.

ea, 啫係我個人覺得啦吓, 我個人覺得啦, 啫係佢地都知道我有呢樣野啦, 啫係, 呀AS呢樣野就, 同人相處係... 特別係同老闆相處、同同事相處呢, 一定中招嘅, 但係如果你話相反我係一個穩定嘅機構, 做, work at home 嘅, 咁就問唔中先過吓澳門做嘅, 咁可能, 對我黎講, 舒服D囉. 同埋佢得, 都係得幾個人, 幾個幾個幾個, ea, 同事咋嗎, 準同事啦, 因為我都未未未入架, 啫係就黎入嗰時先啫係叫做同事, 都係得幾個咋嗎, 而且, 中文嗰邊, 中英文嗰邊, 都係得嗰幾個人咋嗎. [I think, I personally think, they know I have this thing, that is, AS (i.e., Asperger's syndrome) this thing. Interacting with people, especially with bosses, interacting with colleagues, must have problems. But if on the contrary, I work in a more stable organization, work, work at home, occasionally travel to Macau for work. This may be more comfortable for me. Also, there are only a few, a few a few a few, ea, colleagues, colleagues-to-be, because I haven't been in the job. When I will be in the job, I call them colleagues. There are only a few. Moreover, Chinese department, Chinese-English department, there are only a few people.]

Derek, Michael, and Joshua also discussed their problem-solving experience in the context of postsecondary education. Similarly, they emphasized the consideration of their limitations such as ASD, academic abilities, and adaptive functioning in making decisions towards their goals.

Some participants described their difficulties in analyzing and problem-solving situations where they did not have prior knowledge about the options. Kenny wanted his parents to guide him through how he could start researching some working holiday programs so that he could plan ahead. Derek was also worried about the “風險[risk]” of making mistakes at his work. Both of them expressed a similar sense of anxiety and low confidence in the face of lack of adequate information. Michael explained his self-blame of being uninformed along the way towards his goals because he “去個目標去得太快呀,唔知道會有咩風險呀揸咁快 [is moving too fast to the goal, don't know what risk of driving that fast]”. He further described his regret about going to the United States without knowing much about it:

嗰陣時都幾難搞掂我自己嘅生活架,最難係唔知去邊度買野,唔知行去邊,人地講D地方我又完全唔知,因為我唔識呢個地方,結果就,好大鑊啦,啫係,又唔知自己做乜野,結果好迷惘,結果覺得自己黎啦,真係個情緒黎啦,覺得自己,啫係又未到想自殺,但係覺得自己係ea,好無用呀,吓? 啫係,點解當初我唔睇多D野先至黎呢度呀,啫係好多責備呀,啫係自己責備自己呀. [At that time, it's quite difficult for me to take care of my own daily living. The most difficult was not knowing where to buy things, not knowing where to go. I completely had no idea the locations people talked about, because I didn't know the place. It turned out, a big trouble. I also don't know what I was doing. It turned out, very perplexed, it turned out, I think, the emotions really came. I think myself, is not yet suicidal, but feel myself is, useless. 'Huh? That is, why didn't I read more about the place before coming here.' Many blames, that is like blaming myself.”]

From his experience of failure in studying abroad, Michael learned the importance of having others to guide him through the pathways towards his goals:

我會.唯一我會做就係我要提醒自己囉,要注意自己.可能有D野你過左,譬如人地咁樣同我傾嘅,可能我要咁諗就係,我要開始喺人地角度去諗.吓我自己做緊D乜野,我係咪真係有D野係過左火呢? 我係咪超左速呢? 咁樣,而唔係同人地嗌,我無做呀,我咁樣做無錯架. [I will, the only thing I will do is to remind myself, to pay attention, maybe there are something you are too. If other people say this to me, maybe I have to think, I have to start thinking from their perspectives to think about, what I am doing. Is there anything that I really go too far? Have I speeded? That is, not to argue with them, ‘I didn’t do it. I’m not wrong to do it this way.]

This idea is further reinforced by the fact that Michael acknowledged he does not know the potential consequences and limitations of his ways of doing things:

我知道自己做緊乜野,我知道我自己係有意識地知嘅,但係問題就係話,我連自己超左速,唔知,自己行錯地方,唔知,自己可能撞緊車架啦已經,都唔知. [I know what I am doing. I know myself is consciously knowing. But the problem is, I don’t even know I have speeded. I don’t know I have gone to some wrong places. Even if I may be crashing my car, I don’t even know.]

All participants expressed they sought help from other people to help them achieve their goals. People in their social networks outside of their immediate families are the most commonly cited sources from which participants sought support. Friends in general, relatives in extended family, classmates in postsecondary course, colleagues at job, and people related to church could provide a variety of support to the participants, such as problems specifically related to academic, vocational, social, and interpersonal areas:

係呀但係問題啫係,啫係你,就算你屋企人都,唔係個個人都識呢D架嗎,變左嘅話可能

我嗰陣時讀書就,有D困難囉.啫係個困難就喺呢個位啦. ... 都係問番教授啦,但係問題你就算問教授,我都唔識點樣問架嗎.同同學傾吓點樣問囉. [Yes, but the problem is, is you, even though your family members, not all of them know these things. That's why maybe I at that time had some difficulties with studying. This is the difficult thing. ... Will ask professors. But the problem is, even though you ask professors, I don't even know how to ask. I talked to classmates how to ask.] (Derek)

Two participants mentioned that they look on the Internet for help and support. Two participants mentioned the use of social organizations (i.e., the Labour Department and political parties) to help reach their goals. Immediate families and parents were rarely referenced as the people whom participants would go to for problems. However, both York and Michelle commented that, outside family, they would only seek help from people whom they think are “可信/信得過[trustworthy/can be trusted]”.

**Theme A3: Psychological empowerment.** Participants described the sense of control over themselves and their environment. They also described the ways through which they gained internal asset, efficacy, and ability to become empowered to do things.

**Control.** Chinese participants described a variety of things they can control in the lives. All participants mentioned exerting control over their daily life, such as food, transportation, leisure, and schedule. Money spending is the most commonly discussed theme. While they could control how they used their money, many indicated that they tried to save up money and spend very frugally, although they would find it challenging to manage their finance. Aaron, Michelle, and Kenny expressed that they sometimes could be big-spenders on cartoons and comic books; however, they would try to control their spending by making a plan for expenditure and saving up more money to pay forward. York and Aaron also indicated their parents' role in helping

them manage money (see “Family context” section). Joshua also expressed that he wish to manage his mother’s inheritance and his family’s finance more effectively.

Four participants described having control in their jobs. York and Michael indicated that they found their jobs by themselves. Many of them also expressed wishes to have more control over their work. Michelle wished that she could find a full-time job. York wished to be employed by future employees. Kenny wished to only work certain positions in his job that he could manage.

Three participants described having control in their postsecondary education life. Both Derek and Joshua expressed that they made the final decisions in college options even though others’ had given them guidance and opinions along the way. Joshua also showed his control in terms of persevering in his associate degree program despite repeated peer rejection. York suggested that he had more control over his daily schedule after high school because the timetable was more flexible and less packed.

Three participants described having different degrees of control over their own emotions. Michelle indicated that when she got angry when talking with her family about some issues, she would leave the discussion and drink some water to calm herself down. Aaron found himself have better emotions at his job, but still wish to control his emotions better and be able to think about consequences more. Similarly, Michael learned from an experience at his job that other people would also get irritated and behave in ways that agitated him. With this insight, he was more able to observe his own behaviors and emotions, although he still wish to regulate emotions better.

***Pathways to empowerment.*** Chinese participants overwhelmingly described different learning processes that made them empowered to do things. Learning can take a variety of forms,

including direct instruction by others and social learning, both of which supply a good source of prior knowledge and experience to the young adults with ASD for their future use. Regarding direct instruction, York, Aaron, and Derek identified different significant people in family, in school, and in job taught and practiced with them task-specific skills as well as life and social skills in general. However, Derek pointed out that parents' teaching and reminding may not help him in the long run due to his weakness in generalizing learning to other contexts, which is likely to be a common concern among individuals with ASD:

我唔記得佢地點教,可能提架咋,但問題你咁樣提完之後你下次呢,可能你轉左第個人,跟住又未必記得喎,呢個先係最大問題呀,啫係我地,可能有時對某D野呢,係無乜咩呀...無乜嗰個叫咩呀,記性呀.因為你學完呢D野,可能資料上面教左你咁樣,但係你第日會唔會轉左第個環境又唔記得呢? 呢個就係最大問題囉. [I forget how they taught me, maybe just remind me. But the problem is after being reminded, the next time, maybe it change to another person, then I don't remember. This is the biggest problem. For us, sometimes maybe for certain things, we don't have, don't have that thing, good memory. Because after you learn about this thing, maybe you are taught about the information, but the next day would it be possible that you don't remember as the environment is changed? This is the biggest problem.]

Michael and Joshua also mentioned the role of community resources, including religious groups and community-based ASD support program, in providing social network for supporting their learning and practicing of life skills such as emotion regulation and social communication skills.

Regarding social learning, many participants described their learning gain following exposure to and/or observation in social situations that empowers them to be more able to behave more appropriately or adaptively. Participants learned from other people sharing their

experiences and observing others directly. Participants also learned from their own experiences of interacting with people and solving real-world problems that, depending on the success or failure in the experiences, would serve to either reinforce or prevent certain behaviors in the future:

咁咁啱就有一個日本人喎,佢[an old lady at the home-stay family]話拿,我俾一個重任你啦,你要照顧佢,啫係我係哥哥,要,要我做哥哥嘅身份去照顧個,弟弟. ... 我居然成功我覺得自己好成功,啫係我做到個大哥哥嘅責任,我照顧到,叫照顧到個弟弟,啫係譬如有陣時見到佢好似唔開心,我開解佢,同佢一齊啦. 咁我地,佢開心我都開心喎,啫係我開始學識到一個同人地相處個基本嘅,嘅野喎,因為以前我,講真係我少有嘅. [What a coincidence, there is a Japanese, she [an old lady at the home-stay family] said, 'I give you an important responsibility. You have to take care of him.' That means I am the older brother, need, need me to take the role of older brother and take care of that, little brother. ... I am actually successful, I feel like I am very successful that I can do the responsibility of an older brother. I can take care of, sort of take care of the little brother. For example, sometimes when I saw him unhappy, I consoled him, but with him. Us, if he felt happy, I felt happy too. That is, I started to learn about a basic thing of interacting with other people. Because in the past, it's rare.]

Participants described a variety of situations in which they received emotional and psychological support from other people, which make them able to do things in the future. The first commonly discussed theme is encouragement. For example, York mentioned his family showed support and encouragement to each other especially during his low time in job, whereas Joshua described his religious belief brings him up in his low time. Kenny's friends encouraged him by acknowledging his effort to try in his job, although he wanted them to give him even

more encouragement and confidence. Michael had a particularly interesting experience while he was studying in New Zealand in which he encountered many people showing him encouragement in different ways than that in Hong Kong, which he perceived as very rejecting and stressful.

Participants also discussed the role of trust with people in empowering them to perform certain activities. York indicated trusting his colleagues so that he would be confident in handing over tasks to colleagues and seek their help in regulating his emotions. Aaron and his colleagues showed a similar kind of camaraderie relationships that made him feel “呀原來我都有好朋友啫 [I actually have good friends]”. Joshua chose to disclose his ASD condition to some friends who he trusts and, subsequently, tried to accommodate his needs, although Joshua asserted that he needed not to be accommodated.

Across many participants, a theme of deliberately relinquishing one’s control by subjecting one’s abilities to external limitations was discussed as a source of empowerment. For Michelle and Joshua, they ascribed their available abilities as well as limitations to the God who created human beings. Derek, Kenny, and Joshua described an attitude of being satisfied with the things they need and not fighting for the best or even better. York, Derek, and Kenny highlighted a similar concept of “順其自然[following its nature]<sup>3</sup>” and going with the flow:

因為,有有野做咪做住先囉,無野做就無架啦,又唔知做咩好.啫係而家只有,船,船到橋頭自然直<sup>4</sup>囉.啫係ea,到時,到時再算咁樣囉,我而家心態係,我都諗唔到. [Because, if I have a job, simply do it. If no job, nothing, I don’t know what to do. Now I can just be,

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<sup>3</sup> “順其自然” in Chinese literally means “following its nature”. It is a common expression that generally refers to an attitude of going with the flow.

<sup>4</sup> “船到橋頭自然直” in Chinese can be literally translated to “when the boat gets to the end of the bridge, it will naturally straighten itself out”. This proverb actually means that there will eventually be a way out for a problem when it comes to the end. It is similar to the English proverb “we will cross the bridge when we come to it”.

boat, when the boat gets to the end of the bridge, it will naturally straighten itself out<sup>4</sup>.

That is, when the time comes, when the time comes, then do something. My thought is, I have no idea.] (Kenny)

When Derek was asked what he wants to request others to help him achieve his desires, he responded:

我唔會貿貿然咁樣做架係架.因為對我黎講做人都未必會幫你,同埋啫係我覺得,唔合理呀嗎呢D野,我都係睇情況架嗎,啫係唔會話,啫係可能我嘅公司,成日都見嘅其實,「我想要買,乜乜牌子嘅機」,手機咁,但係我覺得生活夠又使乜要呢D要求呢? 反而我會咁樣諗囉,就唔會話啫係,話要,啫係一定要指定某D要求咁樣. [I won't do that rashly. Because to me, they may not help you necessarily. Also, I think it's not reasonable. It depends on situation. I won't, in my workplace, I always saw this actually. 'I want to buy, that, that brand of mobile phone.' But I think, why ask for that if your life is already sufficient. In turn I would think like that. I won't say, I need to make certain requests.]

**Theme A4: Self-realization.** Participants described their understanding about themselves. They discussed how they capitalized on this knowledge to achieve a desired state of self through adapting to the environment and developing their full potential.

*Self-awareness.* Chinese participants described their awareness of a variety of interests, preferences, abilities, and knowledge, as well as the lack thereof (referred to the “Independent” section). They acquired knowledge about themselves through different daily experiences, which could be turned into their acceptance of their own abilities and limitations. York explained that although he had a lot of career aspirations when he was young, he currently was more able to consider to decide his suitable career in catering because “職業,同埋打工,要考慮埋自己嘅實際

能力囉 [occupation, and work, need to consider my own actual abilities]”. On a related vein, Joshua was aware that he was too naïve when selecting college programs, so he ultimately listened to his father’s opinions to guide his choice. In contrast, Kenny found out that he was not interested or motivated in almost all jobs and vocational courses he had tried. He pointed out that his low perseverance, low academic qualification, and limited social network limited his career choices. Although at one point he expressed that he could work at home making a few bread a day, he could not handle a larger amount of work in a job at a bakery. In Kenny’s case, his awareness and acceptance of his own (in)abilities does not necessarily provide him a way to meaningfully adapt to the working environment.

Almost all participants described being aware of their ASD conditions, and four of them showed acceptance of their conditions. After learning about their diagnoses in college years, both Michelle and Joshua were eventually relieved and understood why they had been different from other people and had social difficulties. Aaron, Michael and Michelle further expanded their awareness of ASD to their formation of self-identity. Aaron identified himself as similar as a cosplayer with ASD who was reported on the news. Michael described himself as an alien with an adult body but is immature inside who understands and enjoys life differently from other people:

哦,我睇呢樣野呢,我認為我自己係ea,好可能,我係一個外星嘅生物. 好似,異型,嗰類嘅生物. ... 喺呢個,可能喺呢個世界上面搵唔到同類,我,可能都係獨處一角 ... 可能我地嘅目的,可能係造福呢個社會,或者係造福呢個星球,亦都可能係破壞呢個星球嘅秩序. ... 我,睇我呢個身份係,ea,我我我有呢個軀殼,我好可能係,因為人會長大,所以我有呢個軀殼,我廿三歲係因為我活左二十三年,但喺我角度,好多野其實唔係好重要.

喺我生命入面最重要架呢,就係,享受生活. [Oh, I see this thing, I think I myself is, very

possibly, I am a living organism from another planet. It's like, alien, that kind of organism. ... In this world, maybe I can't find anybody similar to me in this world. I, I maybe am alone at the corner. ... Maybe our purpose, maybe is to benefit this society, or to benefit this planet, or maybe to disrupt the order of this planet. ... I, see this identity in myself, ea, I, I, I have this body. It's very possible, because human grows, then I have this body. I am 23 years old, it's because I have lived for 23 years. But from my perspective, many things are not important to me. The most important thing in my life, is to enjoy life.]

Four participants described using their awareness of self to adjust their own behaviors to meet the needs of others or the demands of environment. For example, understanding their deficits in social communication, both Joshua and Derek indicated choosing jobs with less social demands. Michael described his understanding of a customer's perspectives in being difficult to control emotions, so Michael had to hold back from discussing the argument with the customer so as not to irritate the customer again. Similarly, Joshua would try to turn down the volume and pitch of his anxious and irritable voice or otherwise his friends would feel annoyed. Michelle also described her awareness of people's different preferences in cake ingredients, so thereafter she chose to make birthday cakes with chocolate and nuts that are commonly liked by all of her colleagues. She also indicated compromising her involvement in political activities to be more passive as she was alert of her ASD condition and her family's worries.

Almost all participants indicated capitalizing on their self-awareness as opportunities for learning. For example, York indicated not knowing how to socialize with girls, so he wanted to ask female friends and relatives of younger ages about their opinions about dating. Derek treated his weaknesses in social understanding across different educational and vocational contexts as

opportunities for him to learn and practice skills in reading others' intentions and perspectives. Michelle understood the difficulties for her to start her career without any prior experience, so she had a plan to work hard from small steps to her ultimate goal:

不過,我暫時未有經驗去到做ea,ea,喺D學校全職住,所以我而家暫時係打算喺,外判嘅ea,外判嘅嗰度做住跳板,但係要面對住ea,低薪,開工不足嘅煩惱呀. ... 而家就係捱囉,之所以繼續喺,繼續捱嗰個ea,開工不足嘅外判,係因為想儲嗰個有關圖書館理員經驗,然後就喺D,有D國際學校呀、中學、大學嘅圖書館度做野呀. [But, at this stage, I don't have the experience to be, in a school to be full-time, so I now temporarily plan to in, outsourcing, the outsourcing company to treat it as a springboard, but have to face the worries of low wage, and insufficient work hours. ... Now I have to endure. The reason why I keep, keep enduring that, lack of guaranteed work hours in the outsource company, it's because I want to accumulate experience relevant to librarian. Then, I can work in some, some international schools, secondary schools, universities, at their libraries.]

Five participants described their desire to seek help from the environment following their awareness of their own capabilities. This happened in several ways. One way is through their willingness to seek help from other people after understanding their own abilities or limitations. For instance, Michael's analogy of him driving a car too fast without knowing the right directions speaks to his willingness to be helped by his parents and other people during his transition years. Derek described how he came to become more and more aware of his weakness in social understanding and subsequently found it helpful to have parents and psychologists help him learn skills:

原來發現有D野架,啫係呢樣野又係同我地啫係有ASD嘅人嗰D特徵有關囉,因為,第一可能我唔識得點樣去show off啦,唔識唔唔唔係,唔識得,啫係唔識得show off 啦,第

二樣,唔識得點樣去sell自己啦,第三就係話我唔識得點樣去ea,啫係去sell自己啦,同埋可能人地叫你自我介紹,你,可能因為我,唔識得點樣意會人地背後嘅意思,引至到我,啫係嘅interview答問題嘅時候唔知人地想要D咩資料,變左可能你自我介紹嘅時候我唔識篩野囉. ... 有其他嘅,啫係有其他嘅心理學家,啫係有其他心理學家講,我先發現.

[I actually found out that there is something related to us, the characters of people with ASD. It's because, first, it's possible that I don't know how to show off, don't know, don't know, it's I don't know how to show off. Second, don't know how to sell myself. Third, it's that I don't know how to, sell myself, and when other people ask you to introduce yourself, maybe I, don't know how to understand the meaning behind this. That made me, when I answer questions during interview, I don't know what information they want to know. When you introduce yourself, I don't know how to filter information. ... Some other, other psychologists, some other psychologists said that, then I realized.]

Another way to change the environment is through advocating for changes. Aaron understood himself as not abnormal having ASD and playing cosplay, so he would like to introduce his cosplayer friends to his parents so that they could understand him more:

啫係話代入一個同平,啫係大眾化一般人呀無乜分別囉.我都知道,應該知道,啫係我都係同佢一,啫係正常左之後都係我咁樣啦,啫,做番正常. [That's, to be included in a, a popular, not different from ordinary people. I know, should know, me and him are, after being normal, I, I turn back to normal.]

Similarly, Michelle reflected on her personality as being caring for the next generation.

Witnessing the worsening educational environment in Hong Kong, she would like to advocate for societal changes through her participation in political movements and her support in political parties that could potentially help her realize her aspiration.

**Self-actualization.** Some Chinese participants discussed how the realization of their desires and potentials in their job or career. Overall, working does not seem to be a way for them to actualize themselves. York expressed that working and learning things are more important than his dream of becoming a teacher, which he found lacking the abilities to do so. Aaron described his job as nothing special as he feels like “渾渾噩噩[muddle-headed]” going to work and going home repeatedly every day. Similarly, Derek explained that he chose a clerical job with less social demand as he “咪用番有我,我有既定嘅能力去做囉[use my, use the abilities I already have to do the job]”. He further reasoned that he only aimed to work for reaching requirements:

達到要求就得架啦. ... 啫係例如話而家我係點樣諗,做到好嘅野就已經夠架啦,就唔會話太多呀.啫係D,啫係D criteria太高其實唔係太好囉. [Reaching the requirement is good enough. ... For example, now I think, doing something good is enough. Won't be too much. That is, that is, it's not too good to set the criteria too high.]

The phenomenon that job or career is not an avenue for self-actualization can be understood in terms of the interaction between the individuals with ASD and the broader societal and cultural context. Kenny explained his low motivation to work in terms of his long history of trying different jobs but failing to find his career interest. He also described his low sustained motivation and perseverance that contributed to his inability to realize his potentials in work. Similarly, Michael also described his lack of maturity, awareness, and knowledge to effectively navigate his pathways in life:

你而家你會有好多你可以達成嘅目標,但係問題就係,而家我就係好似係,一條就係揸緊一架車喺度,高速公路嗰度,拿,高速公路你應該知啦,可以帶你去唔同嘅地方,你去

屯門公路咪帶你去屯門,你要去大,你要去深圳嘅,你咪揸深圳嗰條咩呀,高速橋囉,就帶左你去深圳. 但係你,我個人完全無諗到就係,公路上有好多牌、有好多野,我就係揸住呢個軀殼,居然,連自己濫用左自己嘅年齡身份都唔知. 啱係,個人,所謂人就大呀,但係個心靈個空間呢,仲係一個十零歲嘅少年,無分別,呢個係我自己睇自己嘅. [At this moment, you have a lot of goals you can achieve. But the problem is, now I am like, driving a car on a highway. Highway, you know, can take you to different places. Tuen Mun Road takes you to Tuen Mum. If you need to go to, you need to go to Shenzhen, you have to go on that Shenzhen what, high-speed bridge. It then takes you to Shenzhen. But you, I completely haven't thought about, there are many road signs, many things on the highway. I am driving my body, but actually, I don't even know I am abusing my age, my identity. That is, myself, my body is like a grown-up, but my soul, is still like a 10-year-old teen, no difference. This is how I see myself.]

Aside from individuals' abilities, the social-cultural environment also has a strong influence on the extent to which individuals with ASD are able to thrive and actualize. Michael and Joshua explicitly pointed out their perceptions of the society in Hong Kong that values academic achievement, emphasizes adherence to social norms, and discourages individual uniqueness outside the norms. These cultural values translate to social processes of parental control, social comparison and marginalization that would ultimately undermine individuals' confidence to do things, the identity of self within the society, and the desire for self-actualization:

以前就成日話想做一個,管風琴嘅,管風琴家囉,但係都無呀,我點有時間啫,同埋,業餘就得,但係我正式就應該機會好微啦. 因為香港嗰個對藝術嗰個比較偏囉,偏門D架,重

視成就比較,呀唔係,係高,但係學術上嘅高囉,就唔係performance上嘅高,就算係performance都係叫做,好難,好麻煩囉其實. ... 我覺得係,好多時都係要睇你有無cert呀,有咩野呀咁樣,啫係好多時都,俾我個impression係咁囉. 但係我呢D有talent,有有有有granted talent 嗰D就,無呀,佢地好似,無呀,唔係太重視囉. 失望囉,失望就有架啦,但係有時,都要接受囉,咁咪業餘嗰度發展囉,唔係點,啫係都無辦法架. [In the past I used to say I want to be an, organ's, an organist. But I didn't, how do I have time. Also, can be an amateur, but the chance is so slim to be a formal one. It's because Hong Kong treats arts as, tends to be non-mainstream. It places heavier importance on achievement, no, high, but it's high achievement on academics, not high achievement on arts performance. Even arts performance, it's difficult, it's so much trouble actually. ... I feel like, it's usually looking at whether you have any certification, you have anything, usually. That gives me an impression of this kind. But for me with talents, with, with, with, with granted talents, not, it's like, not, not too valued. Disappointed, I am disappointed. However, sometimes, you have to accept. Just develop it as an amateur. What can I do? I have no way.] (Joshua)

啫係我覺得好似,唉,我根本唔係呢個社會嘅一份子. 我嘗試過認同呢個社會,但係呢個社會極為,呀,ea,其實其實,所以所以令到我,成日都有種感覺就係話,唉,我根本唔係屬於呢個世界嘅. 可能,可能我嘅,啫係我唔想啦,我唔希望我下半生係喺一個看守,俾人看守嘅環境下過活. [I feel like, sigh, I am indeed not a part of this society. I have tried to identify with this society, but this society is too, uh, ea, actually, actually, so, so, it causes me, always have a kind of feeling, sigh, I indeed do not belong to this world. Maybe, maybe my, I don't want, I hope the rest of my life I won't be monitored, won't

live in an environment being monitored.] (Michael)

我始終都係讀唔到書,我唔同你呀嗎,你個地位一定係比我高架,我個地位係一定比你低,明唔明點解呀? 因為你,你可以讀到碩士呀,而我唔係,我只係一個...普通平民嘅中學畢業生都不如我係,講得衰D,只不過係,面前有工作咪做囉,無咪算囉,好普通呀,無乜特別,無咩光彩無咩樂趣啦,嗰D. [At last I am not able to do well in academics. I am not same as you. Your status must be higher than me. My status is for sure lower than yours. Do you know why? It's because you, you are able to get a Master degree, but I am not, I am only an, ordinary citizen, not even a secondary school graduate. Say it in a more negative way, it's simply just, I work if there's a job in front of me, I'm fine without it. Very ordinary. Nothing special. Not much bright side, not much fun.] (Kenny)

In spite of the desperate picture painted by the participants, most of the participants found different ways through which they could express and actualize themselves in alternative ways. For example, although Michelle's parents did not allow her to participate in political movements, she maximized her contribution by donating daily supplies and drawing encouraging pictures to “默默<sup>5</sup>做保護呀,保護留守者嘅工作[Silently<sup>5</sup> do, protect, protect people who stayed behind in the campaign]” and “默默<sup>5</sup>祝福佢地[Silently<sup>5</sup> wish them well]”. Joshua also described his compromise to become an amateur organist playing in church and teaching lessons, so as not to waste his granted talent. On the other hand, Aaron described that during his lowest time in his life when he found out he failed extremely low in his public exam, he found enjoyment and achievement when he started acting cosplay. More importantly, Aaron found his identity and meaning in this leisure. Specifically, he read a news coverage of a cosplayer with ASD with

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<sup>5</sup> “默默” in Chinese literally means “silent”. Applied to contexts, it usually means doing positive things and making contributions behind someone's back without being acknowledged.

whom he also shared similar background, which made him feel “啫係可能關乎認識吓大家A仔<sup>6</sup>啦,亦都係cos player嗰D啦,佢係,並唔係想像中差啦 [maybe it’s related to knowing each other as A-guy<sup>6</sup>, at the same time is a cos-player. He is not as bad as you would imagine.]” because “意義重大囉,鼓,鼓舞我,我有呢個,呢種可能性囉. [it’s with serious meanings. Encourage...encourage me. I have this...this kind of possibility.]”.

## **Thematic Category B: Contexts for Self-Determination**

**Theme B1: Family context.** Chinese participants identified how their families play different significant roles in their expression of self-determination. Regarding independence, the majority of participants described independence as related to contributing to their families. Specifically, they mentioned giving money to family, sharing house chores, cooking for family members, and helping siblings as signs of independence. While attaining independent does not necessarily mean they have to live independently, participants described different dynamics through which they negotiated independence with parents under the same roof:

通常呢,我係,通常我地番晒工呢,D衫呀,D野都係呀媽,啫係通常D屋企人會拎晒落去洗呀剩架嗎,就唔會自己走去咩架嗎,如果你話獨立嘅話就會自己走去,做呢D野囉.

[Usually, I am, usually, when we’ve all gone to work, those clothes, those things, mom, usually family members would take care of the laundry, so I won’t do it myself. If you are independent, you would go ahead and do it.] (Derek)

有時我覺得我未盡我,我孝,孝,孝,孝,孝順嘅責任嘅,而家好多都係呀爸自己洗. 所以有時我都,我都話,‘唉也唔好啦’,我都,我自己開,開,開洗衣機咁樣囉,自己識洗嘅.

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<sup>6</sup> “A 仔” in Chinese can be literally translated as “an A-guy”. In Hong Kong, it is a fairly common and informal way for practitioners and individuals with ASD themselves to refer to people in the ASD population.

[Sometimes I feel like, I haven't taken my, my filial, filial, filial, filial, filial responsibilities. Now dad usually does the laundry by himself. So sometimes I say, 'don't do that', I will go and turn on the washing machine by myself. I know how to do it.]

(Joshua)

To almost all of the participants, independence is either a need or a responsibility. For the former, participants described the need to be independent ultimately when their parents will be gone one day:

咁因,啫係大個人啦嗎,咁同埋,啫係屋企人唔會跟我一世架嗎,啫係要識囉. ...啫係我唔想一世靠佢地呀嗎. [Because, I am a grown-up. Also, family members won't be with me in my entire life. That means I have to learn. ... That means I don't want to rely on them for my whole life.] (York)

獨立就係當你可能父母唔喺度嘅時候,我要你自己,你要生活架嗎,咁呢樣野咪需要獨立囉,咩都要做嘢事,話嘢事囉,點樣去生活都係要囉. ... 始終呢度呢,就係要完全獨立呢,我覺得,點樣講呢,遲早都要面對嘅,無得避,啫係避無可避嘅野黎添呀我覺得係一個. 啫係,唔可以逃避架. ...啫係任何人都會有呢個諗法架嗎,唔會話淨係,autistic有呢個特別D嘅野. [Independence is when your parents are not here anymore, I need to, yourself, you have to live, so you need independence. Make decisions on everything, decide on everything, how to live your life. ... At the end of the day, have to be fully independent. I think, how to put it, you have to face it at the end of the day. You can't avoid, can't escape from this thing, I think. You can't avoid. ... Anyone would have the same thought. It's not only...autistics [sic] have this special thing.] (Derek)

For the latter, independence means shouldering responsibilities to take care of and protect their

families through, for instance, giving money. For Joshua, he also reasoned achieving independence as his responsibility out of filial piety (also see above), as well as he thought he “欠呀爸太多啦,欠屋企人太多啦 [owe dad too much, owe family too much]”.

Participants overwhelmingly described the role of their families in suggesting goals and analyzing the pros and cons as well as the costs and Benefits for them. Examples included choosing college options, planning for studying abroad, and prioritizing work over school. In some cases, young adults followed parents’ suggestions because they did not have clear preferences, while in other cases, young adults complied despite passively disagreeing with the suggestions or when the environment conditions favored parents’ suggestions over the wishes of the young adults.

It is also noteworthy to understand what family means to the participants so as to contextualize our understanding of their self-determination characteristics with respect to their family contexts. The majority of participants described family as a place for mutual support, encouragement, and adjustment for each other. Family members come together to solve problems and discuss emotional concerns, as well as share each other’s responsibilities. Although a harmonious, argument-free atmosphere seems to be an ideal family environment endorsed by participants, Kenny, Michael, and Joshua indicated having emotional arguments with parents over issues such as academics and jobs. Aaron, Michael, and Joshua also described a sense of normalization conveyed through their parents’ expectations, which stemmed from the societal values rooted in the early experience of their parents growing up from children to adults. The societal values were often passed down from parents to the young adults with ASD through, unfortunately, arguments and conflicts over the tension between normalization and self-determination. Michael detailed how his dad’s expectations were influenced by the process of

## socialization:

如果你問番,佢可能都會答你,'其實我呢一生人嘅呢40,30到40年黎嘅生活就係ea,明白到呢,人際溝通嘅重要性'.係啦,ea,亦都因為呢,我呢個病,啫係呢個情形,令到我,由細到大呢,都可能,入唔到主流社會啦,甚至乎同人地溝通係完全出問題,咁令到佢其實個心理壓力都好大,咁佢同時呢就,都會有D,對我都有少少施壓嘅程度,例如細個嗰陣時都好想我讀好D書啦,ea,除左讀好D書之外仲有,想同,想搵一D方法,令我可以同人可以溝通. ... 我爸爸就都係嗰句啦,對我期望其實都幾,得意架,就係希望我過番一個比較正常、年輕人應該有嘅生活,例如唔好話喺屋企淨係要睇自己要喜歡嘅野,或者沉迷喺自己最喜歡個世界. ... 爸爸就,唔知點講呀,啫係,我唯一唔鐘意佢,就係成日兜口兜面鬧你呀,你讀唔到書呀,你唔得架,你唔好諗呢D野呀,呢D野唔係你架,啫係咁樣批評我我唔鐘意囉. 同埋覺得我玩埋一D野,覺得我無出色呀,睇漫畫呀,無出色呀,覺得我宅男<sup>1</sup>呀,呢個我最憎人講呢樣野,又係一個導火線黎架. [If you ask him, he will tell you, 'actually my life for the past 40, 30 to 40 years of life, I understand the importance of interpersonal communication.' Yes...and it's also because my disorder, this condition, which made me can't enter the mainstream society since childhood until now. There are many problems with me communicating with others. This creates a lot of pressure on him. At the same time, there is...pressure on me. For example, when I was young, he so wanted me to do well in school. Besides doing well in school, he wants to, wants to find some ways to let me able to communicate with others. ... My dad, it's the same thing, his expectations on me are very, interesting. He wishes that I can live a relatively normal life as a teenager. For example, not just stay at home and watch things that I only like, or get adsorbed into the world that I like. ... Dad, I don't know how to

put it. The only thing I don't like about him is that he is always in my face scolding at me. You can't do well in school. You can't do things. You don't even have to think about these things, these things are not yours. That's how he criticizes me, I don't like it. Also, he thinks I am interested in things that he thinks are not outstanding, like reading comic books, not outstanding. He thinks I am an Otaku guy (see Footnote 2, p.108). I hate this the most, this is a trigger for me.]

**Theme B2: Vocational experience.** Chinese participants exhibited a variety of self-determination characteristics throughout different stages of vocational development. In terms of autonomy, the majority of participants described making decisions to terminate or change jobs constantly due to a number of factors, which included completion of short-term contracts, unable to fulfil job responsibilities, unable to cope with emotional demand, and disinterested in jobs after trying. Interestingly, Michelle and Kenny described several experiences in which job titles did not match the exact job duties, which either conflicted with participants' personal values or demanded skills that participants lacked. Moreover, there were a lot of uncertainties happened to their vocational experiences, such as frequent changes in supervisors and long waiting time for job offers. They experienced constant changes in their job conditions and they yet had not had a long-term, stable job. Their vocational experiences can be characterized by Michelle's description of "亂糟糟 [chaotic]".

Overall, it was not common for the participants to identify their jobs as a sign of independence or goals. In fact, for participants who considered independence as a concept defined relative to family, although going for work could provide them with financial independence and the ability to contribute to their families, it might also prevent them from performing independent acts at home. For example, Aaron and Derek mentioned that his parents

would take up his house chores when worked full-time, thus limiting his abilities to exhibit independence.

Nonetheless, participants showed some characteristics of control and empowerment through their engagement in vocational experiences. In terms of having control at their jobs, participants described obtaining jobs that match their interests and abilities and having control over their work schedule. Work experiences also served to empower participants through different ways. For example, Aaron, Michelle, and Kenny indicated having better emotions and feeling better when they were at work. Michael also learned from his interactions with customers how to better regulate his emotions. Aaron and Joshua showed advocacy skills that involved either asking for accommodations for their weaknesses or creating more opportunities for realizing their ideas at work.

Participants discussed the concept of responsibility in the context of their work. They described that they are responsible to do a good job at work, completing tasks assigned without the need for other people to follow up with them and pick up their work. Some participants reiterated the idea that contributing salaries to their families means both responsibility and independence. Some others also indicated showing responsibilities at work through different ways, such as being present to work despite being late and problem-solving to clarify responsibility with coworkers. However, responsibility may sometimes lay too much stress on individuals that Kenny mentioned he coped with the stress with smoking.

In the area of self-realization, participants showed their awareness of social understanding in relation to the tasks and people in their jobs. For instance, Aaron was aware that his colleagues expected him to work more efficiently. Michelle and Derek learned how to take others' perspectives and understand different people through their interactions with colleagues.

Similarly, Derek and Joshua were aware of their weaknesses in social communication as well as the challenges they faced in job selection and job interview, thus informing them to choose jobs with less social demand. The demand for social abilities in workplace could be exemplified by Michelle's experience with her supervisor:

諗吓溝通嘅時候比較直接ea,地講述我嘅感受,但係就往往俾屋企人制止,話要婉轉D講,但係我只係直接講出心入面真正嘅咩感覺呀嗎,例如唔好用「扣減」呢個字眼呀,等等. ... ea我原本嘅工時係番ea咁多個鐘,突然間扣減左咁多個鐘,但係你話你話,應該講為ea,而家有少少調動,可唔可以番番多D,我,但係問題真係「扣減」左呀嗎! ... 係我覺得係ea,呢份ea突然少左,少左工時,我就覺得應該用「扣減」呢個字,但係我屋企人話唔應該用呢個字眼. [When I think about during the time of communication, to directly, express my feelings. But my family members used to stop me, saying that I have to say it more indirectly. But I was only saying my true feelings directly from my heart. For example, don't use "deduct" this kind of word, et cetera. ... Originally my work hours are certain number of hours. Suddenly, many number of hours were deducted. But you say, you say, should say it as, 'with some little adjustments, and can I work more hours?' I, but the problem is it's really 'deducted'! ... I think, this, suddenly reduced, work hours were reduced. I think I should use the word 'deducted', but my family members say I should not use this word.]

Participants also showed different degrees of self-actualization at work. York, Michelle, and Joshua found their strengths, realized their interests, and maximize their own abilities by balancing work and amateur activities. Although both Aaron and Michael indicated a need for them to work because of their poor academic performance, they had different perspectives on the

meaning of their job. Although work is repetitive and not meaningful to Aaron, Michael saw work as an opportunity for him to explore his abilities without limiting himself in academics.

Lastly, it is noteworthy to discuss how participants described their relationships with colleagues. In general, participants treasured the positive relationships, and in some case camaraderie and friendship, developed through positive social interactions among colleagues and them:

喺個 (大學工作地方) 嗰度,識左同事又識朋友,幾好架. ... 因為有朋友交流呀、傾計呀、食飯呀. ... 好開心啦,個記憶梗係開心啦,認識佢地梗係黃色<sup>7</sup>,不得了啦! [In (the workplace at a university), I knew some colleagues and some friends. Quite good. ... Because I have friends, to interact with, to chat with, to have meals together. ... Very happy. The memory is of course happy. Knowing them is of course yellow<sup>7</sup>. So awesome!] (Aaron)

Many participants also mentioned the roles of colleagues in helping them with problem-solving and emotion regulation, acting as learning models, and expanding their social circle. To the contrary, Michelle and Kenny also mentioned that their colleagues and supervisors can cause negative impacts to them, such as emotional distress and maladaptive coping.

**Theme B3: Postsecondary education.** The trajectories of transitioning from secondary school to postsecondary education in Hong Kong seemed to be differentially defined by individuals' academic performance. For Derek, it seems that he passed the first public exam, Hong Kong Certificate of Education Examination (HKCEE), in Form 5 (Grade 11) and continued his studies in Form 6 and 7 (Grade 12 and 13) before taking another public exam,

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<sup>7</sup> Aaron made reference to the movie *Inside Out* when talking about his memories in the past. "Yellow" is a reference to the golden memory ball that symbolizes happy memory. "Headquarter" in the movie refers to the central system in human brain that store long-term memory.

Hong Kong Advanced Level Examination (HKALE). For Derek, he feels like “中學畢業左之後,就係讀大學啦 [after graduating from secondary school, it should be university]”. He further explained that it is compulsory for all students exiting public secondary schools to participate in a centralized mechanism for college entrance called Joint University Programmes Admissions System (JUPAS). This educational policy provides a common procedure for all students to follow without a need for them to take the initiative to apply to individual colleges or universities:

就無乜點樣特別啦,啫係只不過係ea,點樣講呢,啫係只不過係跟住佢地點樣去揀,點樣去揀科呀,跟番正常人咁樣去,去申請番,個渠道去申請番囉 [Nothing special really. It's just something, how to put it. It's only something you follow. How to choose major. Follow how ordinary people do to, to do the application, through the way to do the application.] (Derek)

Moreover, Derek indicated that students with disabilities are accommodated in the JUPAS process for earlier access to admission results. Nonetheless, Derek had his parents and secondary school teachers actively involve in helping him decide options for college major to ensure he would have a good learning experience. In other words, although the JUPAS set up a structure for college entrance, Derek only treated it as a “媒人[matchmaker]” and “過程[process]”, without shunning his ultimate responsibility of making the final decision for college:

啫係最終都係我,我填電腦架嗎,我會自己揀囉,但係問題因為我地自閉症人士<sup>8</sup>,嗰陣時入大學,我見到有興趣就知啦,但係可能我地諗嘅野就比較點呢,單,單方面呀,無諗過你背後嘅支援,可能喂你入到去之後,上堂會唔會有問題呀? 會唔會去到,上堂會唔會唔明呀? D 教授會唔理呀? D成績會唔會差呢? 呢D就可能無諗到囉. [At the end of

the day I, I fill in the computer form. I will make a choice by myself. But the problem is, we autistic people [*sic*]<sup>8</sup>, at that time I went to university, I saw something that interests me and I know, but maybe we tend to think, from only one perspective, not think about the support behind you. It's possible after you got admitted, would going to a class be a problem? Would you not understand the contents in classes? Would professors care? Would your grades turn worse? We may not have thought about these things.]

On the other hand, the release of public exam results seemed to be an extremely stressful event for the majority of other participants who had poorer academic results. Aaron, Michelle, Michael, and Joshua described their experiences with the release of HKCEE results as “唔開心 [unhappy]”, “難受 [unbearable]”, “傷心 [sad]”. This was followed by a variety of choices of postsecondary educational and prevocational training through which individuals with ASD were involved in different choice-making processes. For example, Michelle showed independence by enrolling in a vocational education program and making a backup plan by herself. Aaron decided to retake HKCEE exams and examine the possibility of different prevocational training options. The parents of Michael and Joshua suggested ideas of studying abroad after secondary school, although the onus was on them to decide if they would like to go. Furthermore, this decision-making process was not a one-off event, as their postsecondary education pathways were characterized by a series of short-term enrollments (i.e., from few months to few years) in multiple educational or training options one after another. Consequently, every decision involved the needs for considering many different factors, such as individuals' interests and preferences, their readiness and motivation, the quality of educational options, and many other factors related

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<sup>8</sup> “自閉症人士” in Chinese can be literally translated into “autistic people”, which is a legitimate way to refer to individuals with ASD in Hong Kong and in Chinese context in general.

to the resources in individuals' environments. As such, parents of these participants were actively involved in giving advice and guidance as well as making decisions for them at times when they were not clear about their preferences and goals.

During their time in postsecondary educational programs, participants described their different experiences with learning and interacting with peers. Regarding their learning experience, they encountered a number of difficulties that demanded their self-determination and problem-solving abilities. In general, postsecondary programs involve learning in different courses with different instructors and peers. Michelle found some content may be more difficult and stressful than others. Derek also expressed that he did not know how to ask questions when he did not understand, while he also could not rely on parents. The experiences of Derek and Joshua speak to the variety of class instructors in terms of understanding and accommodating individual students' learning needs. While Derek indicated that different professors provided assistance very differently, Joshua recalled one positive experience:

第二個sem就好搞笑啦,就,無人肯同我一組,咁但係好搞笑呢就話,我同miss講,我可唔可以一個人做呀,都唔計分囉佢話, 'OK,無問題'咁樣,咁我咪一個人做嗰個group project囉. 結果,嗰日present,嗰,嗰ja,啫係之前同我夾嗰個就,杯葛我唔黎,咁呢其他人有黎啲,但其他人呢就見到我,'你present好好啲', 跟住呢,最搞笑係咩呢,佢係,呀miss話我係聽左咁多個人present入面,你個presentation skills係最好嘅,咁呀結果呢,結果D同學喺度擺我電話呀笑鬼死,跟住就問我教,教,點做呀咁樣. [It's so funny in the second semester. No one wanted to form a group with me, but it's so funny. I asked my teacher if I can do it on my own. She said it won't be counted into the grade, and said, 'okay, no problem.' So, I did the group project by myself. It turned out, at the day of presentation, those people who isolated me did not come, but other people did come, but

other people saw me, ‘your presentation is very good’. Then, the funniest thing is, the teacher said I had the best presentation skills among all the presentations she listened to. It turned out, those classmates were coming to me and asking for my numbers. So funny. They then asked me to teach to how to do.]

Regarding peers in postsecondary environments, participants indicated that they could know many people from different courses. Kenny expressed his desire to socialize with more peers in postsecondary courses. However, the great variety of peers in different programs and courses also means that participants would be prone to different challenges. York and Derek indicated seeking help from their peers. On the other hand, Michelle found it challenging to socialize with different people with different values. Joshua experienced peer isolation and victimization across different educational programs.

**Theme B4: Community-based resources.** Many Chinese participants described their involvement in a variety of community-based resources during their transition years. Identified as either a Christian or Catholic, Michelle, Michael, and Joshua described the crucial role of church in their lives. Church served as an avenue for them to seek help and integrate into the local community:

我覺得好似係,啫係有人帶我出黎呢個世界囉,有人帶我去融入呢個世界,令到我鼓起勇氣去融入佢地 (New Zealand) 嘅社會囉. 唔似香港咁樣係,排斥你呀,或者甚至乎推你去壓力邊緣呀. [I think it’s like, someone brings me out to this world. Someone brings me to be included in this world, which encourages me to be courageous and include myself into their society [sic: that is, New Zealand]. It’s not like in Hong Kong, exclude you, or even push you to the extreme pressure.] (Michael)

There are also diverse styles of churches one can join. Michael found one local church in Hong

Kong that has a lot of expats with whom he enjoys hanging out. For Joshua, knowledge about religion and church is of his interests. Moreover, he got a few job offers from religious organizations. He also thought religion can give him directions and guidance in life as well as support him in face of adversity.

Michelle, Michael, and Joshua further described their interactions with people in church that help foster self-determination. They developed good relationships with people in church. These people shared about both positive and negative life experiences from which individuals with ASD could learn. They would give support and opinions to these individuals. They would also teach and support individuals' learning of social communication and emotion regulation skills:

啫係我兄弟<sup>9</sup>前幾日都打俾我,啫係教會個兄弟,最好個兄弟啦吓. 打俾我就同我傾左一陣啦,佢就話,'其實你唔需要太在意D人,啫係話俾你聽,ea,點樣樣,我都無鬧你,我就話,提醒你咋嗎,幫你咋嗎,你唔使咁在意架,你唔使話,啫係發晒老牌話' [My brothers<sup>9</sup> called me few days ago. They are my brothers in church, the best brothers. They called me and talked to me for a while. They said, "actually you don't have to be too bothered by the people...saying to you...I didn't blame you. I said, I reminded you only, helped you only. You don't have to mind it so much. You don't have to be so emotional.]

(Joshua)

有時我地教會都會傾呢D樣野,都會傾呢樣野架,公民責任呀呢D野. [Sometimes we discuss these things in my church. Will discuss things things, civic-mindedness these things.] (Michelle)

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<sup>9</sup> “兄弟” in Chinese literally means “brothers”, which is a common way for people to refer to close male friends without having any familial relationships.

Some participants mentioned their use of a community-based non-government organization (NGO) that houses a program providing support services for adults with ASD. For example, the program helped Kenny find a job and checked in with him regularly. Although Michael enjoyed learning social-communication skills in the program, he spoke about the importance of gaining buy-in by making the program useful and meaningful to service users:

當初黎咪以為係,開頭我拒絕架,開頭真係唔想黎架,但係後尾,ea,ea,因為我以為係,係咪好似係上課嗰D呢,啫係你上課嗰D你使乜黎呢度啫,好煩呀,啫係放假,我梗係去玩啦,你嘅我一個鐘頭時間. 咁後尾,原來唔係嘅,原來黎到嘩係,都有D,我都想聽到嘅野啲. ... 例如好似話同人地見,面對面交流啦,交流呀,因為我鐘意同人地做交流嘅.

[When I came the first time, at first I refused. At first I didn't really want to come. But later, because I thought if it would like lecturing, something like going to a class. You don't have to come, so annoying. I surely want to do something fun in holidays. You waste my time for one hour. But later, it's not the case, there's actually something I really want to listen. ... For example, something face-to-face interaction, interaction, because I enjoy interacting with other people.]

Kenny mentioned his experience of exerting control and making choices in using government-related services. He chose his program of interest when enrolling in a program called the Youth Employment and Training Programmes (YETP), which provides prevocational training for young adults without higher educational experience. On the other hand, he had his case worker in the Labour Department help him find a suitable job when he had low motivation and showed no preferences or goals.

**Theme B5: Early experience in the school-age years.** Chinese participants described some experiences during their school age that showed their emerging characteristics of self-

determination. York, Michael, and Joshua have experiences with their own interests and preferences throughout school age. For example, with his experience of studying Computer Studies in secondary school, York was confident in enrolling in similar courses for his prevocational training. With his father providing choices of countries for secondary education, Michael expressed his preference for studying in New Zealand based on his prior experience and familiarity with this place. Furthermore, York and Michelle identified teachers as highly influential models in their life. York was inspired by his teachers and he once wanted to become a teacher. Michelle described how a teacher in her elementary school helped rebuild her self-confidence and compassion after she was repeatedly bullied by suggesting her read stories about students with various disabilities.

Some participants described their early experiences with activities structured by parents or educators. For example, York had to participate in compulsory camping activities that he did not like, Derek described that his secondary school teachers accommodated his learning needs by using more discussion, put him into a Chinese orchestra to have him learn cooperation, and discussed college choices with his parents before communicating to him. It is clear to Derek that these structured experiences benefited him in the areas of learning and social growth. However, it is not clear whether these structures simply helped the students get through the school tasks or were able to foster self-determination. Regarding the former, Joshua identified that the structured support provided by the educational psychologist (equivalent to school psychologist in the United States) was ineffective in helping him to become more socially adaptable especially in the long run. Derek spoke about the developmental and cultural expectations of decision-making in students, as he reasoned that “你中一可唔可以做決定呀? 都唔得架嗎中一.[You as a Form 1 [equivalent to Grade 7] student, can you make decision? You can’t in Form 1.]” Michelle also

suggested that while one's school has a certain school climate, it is more difficult to deal with so many more challenges when transitioning to the adulthood. Regarding the latter (i.e., fostering self-determination), Michael described his summer learning experience in New Zealand through which he experienced how explicit instruction can empower students' ownership in learning:

我地去學呢樣學個樣囉,但係學呢樣學個樣你係唔知道你自己係,點解要學一樣野.佢地好清楚話俾你聽,你點解要學識呢樣野,你點解呀,呢個先係最重要,咁我個陣時好開心啦啫係,咁樣學,咁呀好多野我學識左呀. [We learn about these things, learn about those things. But when you learn about these and those things, you don't know why you have to learn. They clearly told you why you have to learn these things. The reason, this is the most important. So at that time I was very happy. I learned so much.]

Almost all participants expressed having negative experiences related to their primary and secondary school lives. Aaron, Michelle, Michael, and Joshua experienced victimization and social isolation by peers as well as unfair and harsh treatments by teachers that greatly impacted their emotional and psychological well-being, such as becoming more emotional, aggressive, and socially disengaged. On one hand, Michelle, Michael, and Joshua noted these experiences led them to be more self-aware of differences in their own behaviors and values with other peers, which did not become a relief until they received a diagnosis of ASD later in life that offered an explanation of their differences. On the other hand, Aaron's account could point to the negative long-term impact of such negative schooling experience to his self-concept in specific and self-realization in general.

我真係爆,我爆小學嗰,爆一個小,我喺小學嗰陣時嘅料出黎啦,有個唔知邊個同學呢,喺我食飯期間搞我杯野飲,搞到我無得飲,癲起上黎,拎凳,剪刀追住人黎插,接近呢種情況. ... 係呀真係架,簡直係,嗰個小學簡直係入左個中央系統呀唔使問. ... 嗰個,用

嗰個,睇左個老朋友之後呢,學習嗰D嘅,變左核心呀,大佬! ... 仲有我呀媽話我細細  
個幼稚園,無位坐,我wea人差D,大反應呀,痴線. ... 通常好少黃色囉,唉! [I really  
disclose, disclose primary school, disclose, the event when I was in primary school. A  
classmate messed with my drink when I was eating, that made me can't drink the thing. I  
freaked out, got a chair, a pair of scissors, chased after him and punch him, almost. ...  
Yes it's true, really, that primary school really went into my headquarter (see Footnote  
7). ... And my mom said in Kindergarten, I don't have a seat, I grabbed people, being  
very reactive, crazy. ... Only have so few yellow (see Footnote 7, p.142), sigh!]

Participants also mentioned numerous unpleasant experiences related to academic issues.  
In general, academics seemed to be an extremely important aspect in their life in childhood and  
adolescence as reflected by their descriptions of the behaviors of their parents, classmates, and  
themselves. Michelle and Michael indicated that their classmates bullied and teased them  
because they either performed so well or so poor academically. Joshua mentioned that his mother  
slapped him after knowing that he failed in the public exam, indicating that “嗰左咁多錢補,要  
我補嗰D補習天王嗰D,全部都無效嘅咁 [Waste so much money to have me attend those  
tutorial lessons by famous tutors. Everything is ineffective.]”. Aaron was also extremely upset  
with his public exam results, which he argued to make him become more engaged in cosplay  
activities to get rid of his negative emotions. Ultimately, Aaron also found a sense of  
accomplishment and identity through cosplaying. It is not clear how the high academic pressure  
is related to the formation of self-concept and identity in these adolescents with ASD, which may  
also influence the manifestation of self-awareness and self-actualization in adulthood.

## Theme C: Overall Perceptions of the Post-School Transition

Chinese participants described their experience transitioning from high school to adulthood with mixed feelings. Aaron, Derek, and Michael described this transition period as “階段轉變[a change of life stage]” and “嗰陣時一段時間,慢慢過度[a slowly transitioning process]” for “中學生去諗, 將將來將來條路點行[secondary school students to think about which directions to take in the future]”. This experience of transition full of changes was accompanied by a strong sense of ambivalence. Describing his experiences of moving between Hong Kong, New Zealand, and the United States for various educational and vocational opportunities, Michael expressed both excitement about exploring new things and the feelings of loneliness and anxiety towards the need of facing the uncertain future by himself. Similarly, although Joshua found his passion in working as a journalist, when foreseeing the need to shoulder responsibilities and hand problems in the future, he thought “但有時我就覺得自己未 ready 好, 啱係, 又係嗰句囉, 又想逃, 又好想逃避, 但係, 又唔想逃避, 啱係, 掙扎緊呀其實有 D 位 [sometimes think I am not really yet. That is, it's the thing again, want to escape, so want to escape, but, don't want to escape. That is, struggling at some points.]”.

Despite this sense of ambivalence, participants seemed to express a more negative outlook that pervades the meaning they made out of the school-to-adulthood transition. Michael thought he is not prepared to face adulthood. He further expressed his need of help from people to “俾到我有個安全感, 俾到我有個, 安慰感 [give me a sense of security, give me a sense of, consolation.]” and to let him “安排自己一個好自由呀, 好有安全感嘅空間囉 [arrange myself a very free, a space with a sense of security]”. Similarly, Michelle cited a song, “Rootless” by an American band Youngblood Hawke, to illustrate her feeling of directionless during the transition to adulthood, as if being “canyons in the sea”:

有時我覺得自己係ea,無根,唔知係邊度feel到,有時好似做一份工唔能夠長久呀,好似無根咁樣,經常搬. ... 感覺就好似喺個浮台,喺海上面個獨木舟,唔知去邊度.

[Sometimes I feel like myself is, rootless. Don't know where I got this feeling.

Sometimes it's like I can't stay in a job for long. It's like rootless, have to move constantly. ... The feeling is like on a floating platform, or a canyon in the sea, not knowing where to go.]

Not only does the feeling of “rootless” speak to Michelle’s lack of stability and directions in her vocational pathway during the transition, it also symbolizes her self-identity as an individual with ASD who is different from the rest of the people in this world. While she identified the meaning of her transition as “喺大專嗰陣知道自己嘅,身份呀,咁呀認同呀 ... 自己係ea,點解同人地唔同呀,自閉症人士身份呀,價值觀ea...價值觀呢樣野呀 [in college I know my, identity. ... Me myself, why I am different from other people. The identity as autistic people [sic] (see Footnote 8). Values...values these kinds of thing.]”, she also indicated “我覺得有時聽講過人生係一個ea,有一個只係一個寄居喺呢個世界上嘅人,然後你就等待一個時候,然後過左一段時間之後,你就番去一個美好嘅家鄉. [sometimes, I heard people say life is a, is a person like a hermit living in this world, and then you wait until a time comes, when time passes, you will go back to a beautiful home.]”. To Michelle, rootless also conveys a sense of non-belongingness to the human world.

The overall negative outlook towards school-to-adulthood transition is further evidenced in the worries expressed by different participants. Both Aaron and Michelle reported feeling emotional and irritated when they did not have a stable job. Kenny explicitly expressed feeling stressful about life that made him cope with smoking:

生活上負擔呀.係驚搵唔到咩,搵唔到,工作呀,跟住又諗,ea,自己要做咩野工作呀,個D  
囉. [Burden in daily life. Afraid that I cannot find, cannot find, a job. Then I think, what  
job I have to do, these kinds of things.]

Similarly, Joshua also expressed his worries towards his adult life in the upcoming future:

我比較擔心可能係,ea,自己個財富管理囉,因為都,都係一個疑問黎架,因為其實ea,  
雖然話,我呀媽死左之後都,都好多錢嘅,係留左好多錢俾我嘅,但係我話,我唔想咁囉,  
因為,都要考慮番,我自己個能力,啫係而家買樓又咁貴啦,跟住D物價又,升到不,不  
倫不類咁樣囉,咁其實自己都有諗過,ea,因為驚,驚將來好難搵食呀,啫係話,點講,有D  
野,可能,唔係我控制得到囉,但係預計我未必有咁嘅能力做到囉. ... 啫係例如話頭先  
話搵錢個能力,我話,我雖然話,可能就黎搵到工啦咁樣,但係搵到工之後,你又要諗,  
點樣去處理其他野呢咁樣,啫係例如話,ea,感情唔好講住先啦,啫係講,講自己賺錢個  
能力先啦,咁你你你唔係淨係靠一份工去,搵食架嗎,你仲要去,幫呀爸呀,幫呀細佬呀,  
你仲要可能幫D親戚呀,仲要幫呀婆咁樣呢,啫係好多好多concern囉. [Relatively  
speaking, I am more concerned about, my ability to manage finance. Because, it's a  
question to me. Because, actually, although after my mom passed away she left me a  
large amount of inheritance, but I don't want to waste it, because, I have to consider, my  
own abilities. Nowadays, it's so expensive to buy a house. Living cost is like surging  
crazily. I actually have thought about, because I am afraid it's difficult for me to earn a  
living in the future. How to say, something, maybe, not under my control, but I predict I  
may not have the ability to do that. ... For example, I talked about my ability to earn  
money. I said, although I said, I maybe soon will get a job, but after I get a job, you have  
to think about how to deal with other things. For example, don't even talk about love

issues, let's talk about my own ability to earn money. You, you, you are not only earning for yourself. You have to help dad, help younger brother. You may even have to help relatives, and grandma. So many, so many concerns.]

## CHAPTER 5

### DISCUSSION

The present research aimed to explore the experiences of self-determination in young adults with ASD from the United States and Hong Kong. Direct comparison of the two cultural groups may serve to reveal how self-determination behaviors manifest in the two different cultural contexts. A cross-cultural qualitative design provided the first empirical account in the literature on how cultural factors play a role in how individuals with ASD interact with their environment in their expression of self-determination. Results from the study were discussed in the previous chapter in terms of the manifestations, meanings, and importance of self-determination characteristics relative to American and Chinese contexts. Based on the findings of this study, the discussion in this chapter aims to answer these research questions:

1. How do young adults with ASD perceive their experience with self-determination during their transition from school to adulthood in the United States?
2. How do young adults with ASD perceive their experience with self-determination during their transition from school to adulthood in Hong Kong?
3. How does the experience and perception of self-determination vary in young adults with ASD across the United States and Hong Kong?

Using the organization of themes presented in Table 1, the discussion in this chapter is organized in terms of the experiences of self-determination, the contexts for self-determination, and the overall perceptions of the post-school transition, with a focus on comparing and

contrasting the findings between the United States and Hong Kong. Based on the findings of this cross-cultural study on self-determination in young adults with ASD, implications for research and practice are discussed. Limitations and future directions are also presented.

## **Comparisons between the United States and Hong Kong**

### **Experiences of Self-Determination**

**Autonomy.** In the area of autonomy, young adults with ASD in the United States endorsed both personal motivations and societal expectations of achieving independence in adulthood. They described independence as doing things for and/or by themselves. Parents had major roles in releasing different degrees of independence to these young adults. American young adults with ASD also described their acting of autonomous behaviors based on various reasons, including interests, preferences, beliefs, feelings, and past experiences.

Young adults with ASD in Hong Kong endorsed the significance of independence in their lives and the fact that they were striving to be more independent. They described independence as both doing things for and/or by themselves as well as for other people, such as parents. At the same time, parents were identified as the major ways through which Chinese young adults with ASD developed independence. To these young adults, the attainment of independence is more of a need driven by external environment than an internal motivation. Chinese young adults with ASD also described that their adoption of autonomous behaviors was based on a variety of reasons, namely interests, preferences, feelings, past experience, and consideration of other people.

It is noted that young adults with ASD expressed the notion of independence by doing things *by* themselves and *for* themselves. Underlying this notion entails both the traditional understanding of self-reliance (i.e., doing everything *on their own*) and the concept of autonomy.

In other words, autonomous acts do not necessarily equal self-reliance or self-sufficiency (i.e., doing everything *on their own*; Wehmeyer, 2005). No matter whether they do something with or without the involvement of other people, the autonomous characteristic that contributes to self-determination is defined primarily by the volitional nature of one's acts without external influence rather than one's capacity to perform certain behaviors on their own.

It is clear that both American and Chinese young adults with ASD value autonomy, but they express it in different ways and for different reasons. Consistent with cross-cultural research on individuals with disabilities and their families, compared with European-American culture, collectivistic cultures place a heavier emphasis on group interdependence and cohesion and thus tend to view family's needs above individuals' needs and consider family members more than oneself in making autonomous decisions (Frankland et al., 2004; Leake & Boone, 2007; Ohtake & Wehmeyer, 2004). Similarly, the value that living independently is a sign for independence and a need in adulthood seems to be proactively promoted only by European-American parents (Zhang et al., 2010), which may also explain the stark difference between Daniel's mother (i.e., a first-generation South Asian) and other Caucasian participants' parents in their approaches to the issue of independent living. In short, in the current study, the notion of independence, and autonomy in general, can indeed be realized in both individualistic and collectivistic cultures.

**Goal attainment.** In the area of goal attainment, American young adults with ASD described their goals mostly related to their careers, which contributed to their sense of self-worth and financial assets. They also identified various ways through which they achieved their goals, namely intrinsic motivation and personal effort.

Chinese young adults with ASD described their goals in the areas of socialization and vocational development, which gave them financial and social assets as well as allowed them to

contribute to their families. They also identified different pathways that allowed them to reach their goals, namely analyzing pros and cons and seeking help from others.

As defined in the functional model of self-determination, individuals with characteristics of self-regulation “make decisions about what skills to use in a situation; examine the task at hand and their available repertoire; and formulate, enact, and evaluate a plan of action, with revisions when necessary” (Wehmeyer, 1996, p.633). In the current study, self-regulation is understood within the context of goals identified by the young adults with ASD and how they managed to attain these goals.

Drawing from the psychosocial theory (Erikson, 1968), work and romantic relationships are the salient developmental tasks in the transition to adulthood (Roisman, Masten, Coatsworth, & Tellegen, 2004), at least in Western societies. The young adults with ASD in this study expressed their goals mostly in terms of current or future development of their career, which were perceived as enhancing their personal self-worth and financial status. This observation is consistent with the Social Role Valorization theory (Wolfensberger, 1983; Wolfensberger & Thomas, 2005), which stated that individuals are more likely to gain “good things in life” (i.e., be afforded positive expectations and experience positive circumstances) if they hold social roles that are valued in society. Indeed, an analysis of national datasets in the United States showed that employment for individuals with disabilities is related to their improved financial situation, increased social and community participation, and enhanced sense of respect from others (Schur, 2002).

Increasing socialization and community engagement was identified as a crucial goal in the Chinese participants but not in their American counterparts. This again can be explained in terms of the relatively heavier emphasis on group interdependence and cohesion in collectivistic

cultures. It was found in neurotypical populations that Asian American young adults were more likely than Caucasian Americans to agree that interdependence must be achieved for the transition to adulthood (Arnett, 2003). From the perspective of Social Role Valorization, Chinese participants with ASD in this study also indicated the gains accompanied their striving for social relationships, such as family acceptance and the sense of social connectedness. In contrast, it is unclear why American participants with ASD did not endorse any social goals. It may be possible that socialization does not provide as many “good things” to the young adults with ASD in American society that values less social interdependence.

Related to social relationships, only very few Chinese participants (Cherry, Freddy, and George) expressed the desire to develop intimate relationships. Even if this was mentioned, they expressed a pessimistic attitude towards achieving this goal. Although incidence of romantic relationships in individuals with ASD is low (Eaves & Ho, 2008; Howlin, 2000), most have a desire in engaging in relationships (Billstedt et al., 2011). It is unclear whether participants in the current study have no interests in forming intimate relationships or they consider it of a low priority that was not worth discussing.

While the American young adults with ASD in this study identified personal effort and motivation as their means to help achieve goals, the Chinese counterparts tended to focus on cost-benefit analysis and help-seeking. Cross-cultural research in general populations has established that individuals from individualistic cultures tend to have a greater sense of internal locus of control and influence external environment, whereas individuals from collectivistic cultures tend to have a more external locus of control and adjust oneself to fit in with the environment (e.g., Chun, Moos, & Cronkite, 2006). While the former would more likely to approach goals with the motivation to maximize personal pleasure and fulfil personal needs, the

latter would approach goals with an aim to minimize loss (Aaker & Lee, 2001; Lee, Aaker, & Gardner, 2000).

**Psychological Empowerment.** In the area of psychological empowerment, American young adults with ASD indicated having control over their own emotions and thoughts and wish to have more control over work that is of their preference. They also described different pathways through which they developed sense of empowerment, namely learning processes that include direct instruction or practice and socialization.

Chinese young adults with ASD indicated having control over their finances, at work, in postsecondary education, and over their own emotions. They also described different pathways through which they developed sense of empowerment, namely learning processes, socialization, psychological support, and relinquishing control.

Overall, young adults with ASD in the two cultures described a variety of things they could control in their respective environments. It is important to discuss the conceptual distinction between control and self-determination. As Deci (2003) noted, “One needs to have control over outcomes in order to be self-determining, but personal control does not ensure self-determination” (p.23). For example, when an individual is instructed by others to perform certain behaviors in order to gain reinforcement, although the individual has personal control over whether s/he is going to obtain the reinforcing outcome or not, the individual’s self-determination is said to be undermined because his/her behaviors are dependent solely on the outcome determined by others instead of motivation or intention from his/her own self. The current findings indicated young adults with ASD from both cultures are acquiring emerging control over outcomes that are consistent with their preferences, beliefs, and intentions (i.e., acting volitionally).

It is interesting to contrast the two cultures in their approaches of achieving control and gaining competence internal to oneself. All young adults with ASD acquired psychological empowerment mostly through the processes of learning from experience, which is consistent with the recommendations of providing vigorous learning opportunities to this transition population (Test, Smith, & Carter, 2014). The Chinese young adults identified an additional way to attain empowerment via relinquishing control. As Wong, Wong, and Scott (2006) summarized cross-cultural comparison of values and ideologies, American society is characterized by an attitude of mastery and domination over nature and an instrumental orientation in achieving accomplishments, whereas Chinese society is dominated by Taoist teachings that encourage the practice of a simple, spontaneous, and harmonious life and emphasize non-action and subjugation to nature. The American young adults with ASD clearly explicated different behavioral principles, such as modeling, observation, direct instruction, and practice, in helping them achieve internal competencies. On the other hand, the Chinese participants expressed a sense of going with the flow and letting go to achieve a state of living an authentic and fulfilling life, which resonates with the Taoist teaching of “do nothing” (*wu wei* 無為 in Chinese) and let things to take their own courses (Chen, 2006). However, it is not known whether this relinquishment of control would influence their actual resource-mapping and problem-solving abilities in face of real-life challenges.

**Self-Realization.** In the area of self-realization, American young adults with ASD showed awareness and acceptance of their own conditions (e.g., weaknesses, differences). They took advantage of this self-awareness to create learning opportunities for them to work hard and seek help from others. Individuals described their unique ways of self-actualization that capitalized on their own strengths and/or passion in their work.

Chinese young adults with ASD showed awareness and acceptance of their own conditions. They capitalized on this awareness and acceptance to adjust their behaviors, create learning opportunities, and seek help from others. Although they described various limitations for them to self-actualize in vocational contexts, they were mostly able to actualize their potentials in other areas in life, such as interests in leisure time.

Similar to the discussion above, individuals from individualistic cultures tend to exert their own influences to change the environment so as to achieve personal goals, whereas individuals from collectivistic cultures tend to adjust oneself to fit the environment so as to maintain harmony and minimize conflict. The American young adults with ASD in this study were able to find ways to actualize their own abilities by crafting out their unique career pathways and jobs based on their personal interests and passions. Their Chinese counterparts tended to treat work as a responsibility that does not necessarily realize their true potentials. Their attainment of self-actualization was more likely to be realized in terms of developing their interests in non-vocational settings, such as through active participation in church or leisure activities. Adults with ASD perceived that their restricted interests could be a source of validation, a sign of mastery, and a sense of identity (Mercier, Mottron, & Belleville, 2000). It is possible that the Chinese young adults with ASD found meanings and validation through realizing their potentials in non-vocational activities, which they failed to find in their jobs.

### **Contexts for Self-Determination**

Self-determination does not occur in vacuum, nor does it emerge from an isolated individual. Traditionally, it has been recognized that self-determination is to be understood from an ecological perspective (Abery & Stancliffe, 1996). The important question is to elucidate how individuals achieve self-determination through developing inner resources and interacting with

different opportunities and supports in the environment (Ward, 1988; Wehmeyer, 1999). The present study followed Shogren's (2013) social-ecological approach to contextualize the development and expression of self-determination in young adults with ASD.

**Family context.** Regarding family context, American young adults with ASD identified their living arrangement and physical proximity in relation to their parents as significant factors in fostering or impeding the development of self-determination. With active parental involvement, the young adults acquired a sense of control and empowerment through various ways of support and guidance offered by parents. The young adults mostly welcomed support from parents, depending on the mutual trust and understanding built between the young adults and their parents, which is also deemed as an important consideration when designing transition interventions for this population (Hong, Kim, Abowd, & Arriaga, 2012).

Chinese young adults with ASD identified their family as an important context through which they developed and exhibited self-determination. Independence was perceived as either a need or a responsibility related to the welfare of family members. The young adults' goals were highly influenced by what parents and relatives suggested to them. With active parental involvement, the young adults acquired a sense of control and empowerment through parents' facilitation of practice, guidance, and learning. Overall, parents have been assuming crucial roles in the development and education of these individuals with ASD. Societal expectations were also conveyed to the young adults from parents through intense family dynamics and processes.

It is clear that parents are greatly involved in the development of self-determination in both American and Chinese young adults with ASD. This is consistent with previous findings with students with various disabilities that their families gave important input and support in their transition and could either foster or hinder students' self-determination through many

different ways (Morningstar, Turnbull, & Turnbull III, 1995). In a cross-cultural sample, general college students from both Western (i.e., Germany and the United States) and Eastern (i.e., Hong Kong and Korea) cultures also reported receiving different forms of support from parents at least monthly (Fingerman et al., 2014).

Regarding cultural differences, despite the rapid changes in social structures and family practices in recent years, traditional family values (e.g., filial piety, parent authority) are still pervasive in Chinese society in influencing students' development in emerging adulthood (Nelson & Chen, 2007; Yi, 2013). In terms of parent involvement, neurotypical Asian college students reported receiving more frequent parent support, despite feeling less satisfied with the support, than their counterparts from Western cultures (Fingerman et al., 2014). Although Asian young adults were found to be aversive to others supporting them in explicit ways (Kim, Sherman, & Taylor, 2008), it was postulated that they welcomed the support because they found the support necessary or helpful to deal with their environment (Fingerman et al., 2014). In this study, although a few young adults with ASD from Hong Kong mentioned their negative attitudes towards parents managing their life, the Chinese participants were generally receptive to parental involvement and support, which may be because of their awareness of weaknesses or their lack of directions in some cases.

Another theme emerged from the Chinese participants is the idea of family-oriented independence. It relates to the deeply-ingrained filial piety in East Asian cultures, of which parent-child relationships and social norms are characterized as “close, interdependent family ties, responsibility and sacrifice, harmony, and viewing individuals in relation to the family” (Bengtson & Putney, 2000). This virtue is commonly practiced in young adults from East Asian backgrounds, as evident in college students in Hong Kong contributing more to their families

than their American and German counterparts (Fingerman et al., 2014). Asian American high school students with disabilities were also found to pursue further education to fulfil their family's expectations (Leake & Boone, 2007). For the Chinese young adults with ASD, their shouldering of responsibilities to take care of their families and to sacrifice their own needs for the families' needs is viewed as culturally obligatory behaviors and attitudes that will make their families well (Kim, Cheng, Zarit, & Fingerman, 2015).

**Vocational experience.** American young adults with ASD generally described their vocational experience as important in their development of self-determination. A range of prevocational activities (e.g., volunteer work, internship experience) was identified as the main source of knowledge, practice, and resources for the young adults to acquire hands-on experience in vocational development.

On the other hand, Chinese young adults with ASD did not generally perceive their jobs as their goals or a sign of independence. This could be explained by the postulation by Nelson and Chen (2007) that Chinese young adults feel pressured to move into a job because in general they have limited opportunities to explore different areas of work in and after high school. Their vocational experience was described as full of uncertainties and instabilities. Although they perceived having some degrees of control and empowerment in their jobs, at the same time, they strongly related responsibilities to their work (i.e., they are responsible to do work). Vocational experience also served as an important context for these young adults to build camaraderie with colleagues and supervisors as well as to learn social awareness and practice social and communication skills.

Filial responsibility of employees directed towards superordinates is again evidenced in Chinese workplace (Morris, Podolny, & Sullivan, 2008). Furthermore, social relationships in

workplace appear to serve different purposes across cultures. Whereas Americans view social connections as instrumental to their jobs, Chinese are likely to form close personal relationships with colleagues (Morris et al., 2008). This has implications on young adults with ASD in the workplace. It is possible that Chinese individuals with ASD would face more challenges in their jobs given the high social demand expected in a culture where vocational achievement is valued within the relational system of hierarchy of superiority and inferiority (Parsons, 1951). This is evident in the accounts of Derek, Michelle, and Michael in relation to their social experiences in workplace.

**Postsecondary education.** The postsecondary education environment demands a relatively high status of independence in American young adults with ASD. In the pursuit of post-secondary education, young adults and parents were involved in numerous decision-making opportunities to evaluate different choices. Different postsecondary education environments generally provided different opportunities for these young adults to learn and work towards their goals, with individualized accommodations to support the learning needs of individuals.

The postsecondary education trajectories for Chinese young adults with ASD were largely dependent on individuals' academic performance in secondary school, which created a high level of stress to students and their parents, especially in low-achievers. In the pursuit of multiple prevocational training and higher education options, young adults and parents were involved in numerous decision-making opportunities to evaluate different choices. Different postsecondary education environments generally provided different opportunities for these young adults to learn and socialize.

At least in the American context, college environment is very different from high school that it gives students so much more time and freedom to direct their own studies and plan for

their lives (Brinckerhoff, Shaw, & McGuire, 1992). Students leaving high school for college are laid with responsibility for decision-making, freedom of choice, and expectations of acting independent, which this room for self-determination may or may not fit with young adults with ASD as they have different levels of preparedness (VanBergeijk, Klin, & Volkmar, 2008). Among our American participants and two Chinese participants (Freddy and George) who had college experience in Western countries, they all identified different concerns related to attending college, such as self-care, mental health problems, and college readiness, which tend to put these young adults' into pathways for mental health crises and drop-out rather than to serve as opportunities for them to learn to express self-determination. Although formalized accommodations and supports might be available through disability policies and laws, these protections are not always consistently functional in practice and not universally found across countries (VanBergeijk et al., 2008). Preparation in terms of planning with parents and learning about college as well as self-advocacy seem to be some strategies discussed by both American and Chinese participants that promote college success.

**Community-based resources.** American young adults with ASD identified a customized transition program as their critical community-based resources. The program consisted of classroom instructions, mentorship program, and internship experience that set up different structures for the young adults to learn and practice self-determination with planned degree of support in various settings.

Chinese young adults with ASD identified different community-based resources that helped foster self-determination. Church served to provide guidance and resources for goal attainment, problem-solving, and empowerment to the young adults. Other government or non-

government organizations in the local community in Hong Kong also provided assistance that serves specific areas of needs, such as employment services.

The experience of two American young adults with ASD (Andy and Chris) clearly illustrates the role of a community-based transition program in supporting the development of self-determination and promoting post-school transition outcomes in this population. Although the process of transition for young adults with disabilities has long been identified as an important area in needs of intervention and support, it is not known what practices lead to improved post-school outcomes and how transition programs should be developed and implemented (Test et al., 2009). Given its potential benefit to integrate multiple evidence-based transition components, however, empirical investigations and practical examples of such kind of transition programs are scant. In fact, in a program evaluation study conducted on the transition program Andy and Chris participated, it was found that through gaining knowledge about aptitudes, interests, disabilities, and employment, practicing these knowledge and social skills in practical and relevant ways, as well as being supported by peers and the learning environment, young adults with ASD were able to achieve self-determination in terms of gaining self-awareness, independence, and empowerment (Timmons, Zalewska, & Lam, 2016).

It is surprising to note that support from Catholic or Christian groups was discussed among young adults with ASD in Hong Kong but not in the United States, given the long-established religious tradition in the latter. One possible explanation may be that religion is considered a taboo topic in the American culture. Another possibility would be that religious groups function as social entities with which individuals from collectivistic cultures could be easily identified.

**Early experience in the school-age years.** As far as school-age experience is concerned, both American and Chinese young adults with ASD described some early experience that allowed them to express emerging preferences and interests. However, structures set up by educators and parents for the students with ASD were not always readily translated to the acquisition of self-determination in the young adults. In other words, while some experience (e.g., prescription of support services or resources) were set up to help students with ASD get through certain school tasks, some other structured experience (e.g., engaging students in certain classroom settings or extra-curricular activities) were able to foster students' self-determination. Most young adults identified negative school experience related to academic, behavioral, and social-emotional issues to have long-term impact on the development of their self-concept and identity.

It is interesting to note that both American and Chinese educators seemed to provide qualitatively similar opportunities for the development of self-determination. This is consistent with previous findings that American and Taiwanese teachers reported similar level of self-determination fostering practices (Zhang et al., 2005). It is noteworthy that expressing preferences is evident in most participants' early experience. From a developmental standpoint, understanding and communicating preferences and interests are common rudimentary skills to be addressed early in self-determination instruction before more advanced and abstract skills are introduced (e.g., Palmer & Wehmeyer, 2003). Choice-making in general is one of the most commonly taught areas in interventions that promote self-determination in individuals with disabilities (Algozzine et al., 2001). It is possible that the experiential nature of students exploring their own interests, preferences, and values does not require much instructional support from teachers, thus allowing relatively more opportunities for students with ASD to practice

expressing preferences. On the contrary, this speaks for the needs of explicit, direct instructions on more advanced self-determination areas, such as problem-solving, goal-setting, and self-advocacy.

### **Overall Perceptions of the Post-School Transition**

Regarding the perceptions of the school-to-adulthood transition, American young adults with ASD expressed a sense of ambivalence between achieving higher degrees of independence and success and approaching uncertain changes in life. Some young adults, with the help of a transition program, expressed more hope and determination towards facing future challenges in adulthood.

Chinese young adults with ASD expressed a sense of ambivalence between approaching changes in life and preparing for uncertainties. The young adults indicated having feelings of rootless and directionless that stemmed from the sense of insecurity and instability they experienced in their environment during the transition. A negative outlook was pervasive among the Chinese young adults, who also expressed worries towards their future.

Participants' overall appraisal of their transition after high school can be understood in terms of the characteristics of emerging adulthood proposed by Arnett (2000). Emerging adulthood is a developmental period from late adolescence through the twenties during which individuals experience a prolonged period of exploration of adult roles and social expectations (Arnett, 2000). Common themes of emerging adulthood includes self-exploration as identity development, uncertainty and change, optimism about future, transition in demographics, and attainment of self-sufficiency (Arnett, 2000, 2006). Clearly, young adults with ASD in the current study expressed their experience of self-exploration of their identities, roles, and responsibilities, accompanied by the high rate of changes and uncertain situations happened in

their time after leaving high school, in terms of transitioning among and between different opportunities for school, jobs, living arrangements, and interpersonal relationships. Their accomplishments of and aspirations for making independent decisions, becoming responsible, and achieving financial independence largely resonate with what Arnett (2000) termed “self-sufficient” in a typical emergent adult, although cultural difference emerged as the Chinese participants also considered shouldering responsibility for family as a core value to be a sufficient person. In this regard, it is important to point out that the experience of young adults with ASD striving for self-determination has more overlaps than differences with neurotypical emergent adults developing self-identity and capacity for self-sufficiency (Meyer, Hinton, & Derzis, 2015). It is therefore critical to reconceptualize how we situate our understanding of individuals with ASD with respect to their abilities, possibilities, and potentials of becoming a meaningful member in society (Mallett & Runswick-Cole, 2012; Wolgemuth et al., 2016).

Consistent with the concept of uncertainty in emerging adulthood (Arnett, 2000, 2006), the young adults with ASD in the current study described their experience of going through numerous changes in social roles and responsibilities as well as their subjective feelings of uncertainty about future changes. It is argued that through the high rates of experimenting with various life possibilities in work, education, and relationships, emerging adults in the United States express optimistic views about their future (Arnett, 2000), although this finding may be tempered with the consideration of the heterogeneity of emerging adulthood across individuals with different mental health status and across cultures (Arnett, 2007). Indeed, young adults with ASD were found to have frequent shifts in employment and postsecondary education status, but a large proportion of them actually experienced a relatively suboptimal level of engagement, in terms of extended period of part-time employment or even completely disengaged from school

or work (Wei, Wagner, Hudson, Yu, & Shattuck, 2015). Although only few of the participants in the current study have indicated their community disengagement for a brief period of time, overall, their perceptions of uncertainty during post-school transition entail a flavor of “lost”, “directionless”, and “rootless”. It is possible young adults with ASD lack the skills and knowledge to navigate the lack of structure and stability in emerging adulthood, thus arguing for the needs of more support from family, community, and public policies.

Cultural differences were noted in their overall outlook towards post-school transition and the future. While the American young adults expressed more hope for the future, the Chinese young adults described more worries. There are a number of possible explanations. First, culturally speaking, while the well-being priority in Western cultures is to strive for fulfilment and savor positive emotions, individuals from Eastern cultures tend to focus on the attainment of a meaningful life in relation to others in the social context (Suldo & Lam, in press). Individuals’ perceptions of their life experiences are likely to be influenced by their cultural orientations of life goals and priorities. Second, three of the four participants in the United States had current or past experience with a transition program. The provision of structured learning experience that gradually exposes young adults with ASD to the adult world noticeably empowers them to be prepared for their future (Timmons et al., 2016). Third, the macro-structural environment in Hong Kong has been deemed as worsening in recent years due to the constraints and limited opportunities set forth by policy regimes of the government (e.g., Hu & Chou, 2016). The uncontrollability of socio-political factors may have caused the young adults in Hong Kong to express a more pessimistic and worrisome outlook towards their future.

## Implications for Practice and Research

The current study has clearly shown that individuals with ASD have abilities and motivations to express self-determination in their lives. Self-determination is not only a normative expectation for individuals growing up as adults (Arnett, 2000), it also serves to enhance individuals' quality of life (Wehmeyer, 1999). Through interviewing individuals with ASD about their self-determination experiences, they were able to reflect on their lives and identify intrapersonal and interpersonal resources that foster their development of self-determination. This practice is consistent with the clinical use of motivational interviewing to motivate changes in clients through exploring their needs and goals and identifying discrepancies between their current versus desired status (Miller & Rollnick, 2013). Young adults with ASD who are experiencing a strong sense of ambivalence during post-school transition are excellent candidates for this technique (Meyer et al., 2015). Although the current study was not designed to perform "therapeutic" interviews of any kinds (Kvale, 1999), the questions and techniques used in the interviews could serve as an example for therapists and counselors who are interested in using motivational interviewing to facilitate discussions that support their clients' development of self-determination.

Important in the current findings is that young adults with ASD helped contextualize their expression and development of self-determination with the support they received from the environment, such as parent involvement, teacher instructional support, transition program, and vocational planning. From an ecological perspective, individuals express self-determined characteristics through the interactions between one's own internal abilities and environmental opportunities and supports across different systems (Shogren, 2013). Indeed, the field is moving towards a contemporary conception of disability as a gap created between internal personal

resources and the demands of the environmental context (Shogren, Wehmeyer, Palmer, Forber-Pratt, & Todd, 2015). Practitioners and policy-makers should recognize this framework and create interventions and support services to facilitate individuals with ASD expressing self-determination and showcasing their abilities. For example, educators should teach and practice skills associated with self-determination to students with disabilities in school, not only to support their school-to-adulthood transition processes and adult outcomes (e.g., Shogren et al., 2015; Wehmeyer et al., 2011; Wehmeyer et al., 2013), but also to improve educational outcomes and quality of life in these students (Wehmeyer et al., 2010). Indeed, self-determination interventions should be included within the multi-tiered systems of supports framework and be delivered to all students, including students with and without disabilities, so that they can all benefit from engaging with curriculum and instruction more effectively (Shogren, Wehmeyer, & Lane, 2016; Wehmeyer 2015).

Family is another important ecological system to support young adults with ASD transitioning from school to adulthood. While young adults with ASD are experiencing numerous changes and uncertainties in multiple contexts during their transition, family is supposed to be a relatively stable system in which these young adults can count on for consistent support. It is important to note that receiving support from family does not mean losing self-determination. As argued above, self-dependency and individuation are potential outcomes of self-determination, but these outcomes do not necessarily define how an individual would take volitional actions based on one's own intention (Wehmeyer, 2005). Indeed, current study also found that young adults with ASD across American and Chinese cultures acknowledged their parents' roles in providing guidance and support in their learning and practicing skills related to self-determination. What is of utmost importance is that, instead of providing support in the form

of doing things *for* their children, parents have to ensure young adults are equipped with adequate knowledge and skills and are given suitable opportunities to execute their volitional actions to influence their environment. For example, family-centered transition planning takes into considerations perspectives from both families and individuals with ASD in identifying expectations, resources, and barriers that are specific to one's family context, in order to develop an individualized transition plan that is carried out by the young adult to achieve identified goals with the available support and resources (Hagner et al., 2012).

This cross-cultural, cross-national research is one of the few pioneer initiatives to directly compare the conceptualization and experience of self-determination across different cultural groups. Stemming from Euro-American ideologies, the concept of self-determination is also found to be valuable and meaningful in diverse cultures, despite its different ways of conceptualizations and expressions (Frankland et al., 2004; Ohtake & Wehmeyer, 2004). Consistent with the recommendations by Trainor (2002), American and Chinese young adults with ASD in the present study provided their first-person perspectives of the meaning, significance, and manifestation of self-determination from their respective culturally-relevant worldviews. Current findings do not only support the universal significance of self-determination to individuals with ASD across cultures, but these also provide an empirical account in support of culturally-relative conceptualizations of self-determination, in terms of how different worldviews could influence individuals to act volitionally and be the causal agent in one's life. Research into self-determination should therefore take into account culturally-relevant sociocultural variables in order to meaningfully measure and compare self-determination in different cultural groups. Similarly, while being aware of the Western historical root of self-determination concept, practitioners should adopt a culturally-responsive understanding as well

as consider both inter- and intra-cultural (i.e., individual) differences in assisting individuals with developing self-determination to enhance their quality of life.

### **Limitations and Future Directions**

There are several limitations in this study. First, there is selection bias in the sample. Young adults with ASD who participated in this interview study, by definition, had functional communication. Indeed, all participants were verbally fluent. The experience of individuals with ASD who are non-verbal is not captured in this study. It is therefore important in future research to obtain more information about individuals' profiles (e.g., cognitive abilities, ASD symptoms, mental health conditions) to better contextualize the findings. Another issue related to the sample is that the recruitment process might have been biased by the scope of services provided by the community-based organizations in the United States and Hong Kong, respectively. While TLA provides vocational services and organizes transition programs for individuals with ASD who come from different settings, SAHK mostly serves individuals in their vocational processes. The differences in the findings from the American and Chinese groups might not be solely attributable to cultural factors.

Second, related to the degree of representativeness of the sample, these findings, which are based on participants from Florida and Hong Kong, cannot be generalized to represent the American and Chinese cultures, respectively. Notably, the majority of the American participants are Caucasian, which does not reflect the demographic representation of young adults in the America. Similarly, regional differences are huge within Chinese culture (Nelson & Chen, 2007), while Hong Kong is traditionally considered a city unique from the mainland China.

Third, the present study only considered the perceptions of individuals with ASD. Although it is important to listen to the voices of these individuals, recruiting the perspectives

from their families is also critical, especially considering that family involvement was pervasive in these young adults' life. It is important to involve parents in future research to better understand how individuals with ASD are supported by their families to develop self-determination. Furthermore, obtaining more detailed descriptions of the individuals' family background (e.g., socioeconomic status) would also better contextualize the findings.

Fourth, the current analysis primarily focused on sociocultural factors that are more relevant in the comparison of cross-national, cross-cultural comparisons of participants from the United States and Hong Kong. However, it should be noted that other dimensions of individual differences, such as race and gender, may also play significant roles in shaping the worldviews of individuals. Future research should recruit more participants from diverse backgrounds and examine the experiences of self-determination among different subgroups of individuals with ASD.

### **Conclusion**

With an increasing prevalence of individuals diagnosed with ASD, more children and adolescents with ASD are growing up and entering the adulthood. The transition from school to adulthood is particularly challenging for young adults with ASD due to the loss of structured supports to continue fostering their lifespan development. One way to promote better transition and adult outcomes in individuals with ASD is to foster their self-determination, which is characterized by individuals taking charge of their lives and making things happen by having their own intentions without much influence from others. With its root stemming from Western traditions, the concept of self-determination may not manifest and be perceived in same ways across cultures with different value systems. This calls for the need of a cultural-responsive understanding of self-determination that considers the perspectives of individuals with ASD.

The current study contributed to the literature on self-determination in the ASD population by exploring the experiences of and the contexts for self-determination in young adults with ASD during the school-to-adulthood transition across American and Chinese cultures. Findings from this qualitative interview research indicated that young adults with ASD exhibited characteristics of self-determination in areas of autonomy, goal attainment, psychological empowerment, and self-actualization. They identified several contexts that significantly influenced their self-determination experience, including family, vocational experience, postsecondary education, community-based resources, and early school-age experience. Cultural differences were found between American and Chinese young adults with ASD in their experience with self-determination, including dimensions of independence, priorities of goals, sources of motivation and empowerment, and ways of attaining self-actualization. Young adults with ASD across the United States and Hong Kong also identified several areas of differences in the contexts in relation to their self-determination experience, including the connections with people in workplace and other resources in the local community as well as the demand for independence in college. Consistent across both cultures, parent involvement was pervasive; early experiences with expressing preferences were evident; and negative early schooling experiences were prevalent. Regarding their overall perceptions of the post-school transition, all participants had ambivalent feelings towards the transition as they are preparing for adulthood with positive changes in life while approaching numerous uncertainties. However, young adults with ASD from Hong Kong expressed a more pessimistic worldview towards their future. Cultural similarities and differences identified were discussed in terms of factors that cut across the entire ecological system, including the intersections among psychological, interpersonal, educational, social, economic, political, and historical factors.

Future research and practice should take into consideration this cultural-responsive understanding of self-determination in the development and delivery of interventions, policies, and services to better support individuals with ASD transitioning from school to successful adulthood.

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## APPENDIX A

### DOMAINS AND SUBDOMAINS OF SELF-DETERMINATION

1. Autonomy
  - a. Independence
  - b. Acting on the basis of preferences, beliefs, interests, and abilities
2. Self-regulation
  - a. Interpersonal cognitive problem-solving
  - b. Goal setting and task performance
3. Psychological empowerment
  - a. Locus of control
  - b. Self-efficacy
  - c. Outcome expectancy
4. Self-realization
  - a. Self-awareness
  - b. Self-acceptance
  - c. Self-confidence
  - d. Self-esteem
  - e. Self-actualization

## APPENDIX B

### INTERVIEW PROTOCOL

#### Demographic information:

- Age, gender, educational level, occupation, family status, guardianship status, etc.

#### Introduction

1. I am interested in learning about your experience transitioning out of high/secondary school. Would you mind sharing with me some of the things that happened after you left high/secondary school?

#### Goals

1. What are your goals in life? (e.g., job, marriage, live with parents, etc.)  
(Inquiry: How does it feel/What is it like...to be able to have goals in life?)  
(Probes: What do you want to do in your life? How about dreams? Hopes for the future? Imagine yourself 5 years from now. Where do you see yourself? What do you see in your future?)
2. What are somethings that you could do to help reach your goal?  
(Probes: Tell me what a person has to do to make their future plans become a reality. Tell me how you plan to reach your goals. What do you think you need to do in order to get to a goal or a dream that you have? What kind of things might be in your way, do you think?)
3. Why do you want to do .../ become...? (Probe for motivation for goals)  
(e.g., You want to do ... / become ... because ...? What moves you getting to your goal?)  
How do you talk to others (e.g., parents, teachers) about these dreams or goals? What did they say? How do they think about your goals?  
(Probes: Do you talk to your parents/teachers/others about their goals? Who else do you talk to about your future goals?)

#### Decision making

1. What kind of decisions can you make about your life (e.g., school, home, workplace, community)?  
What decisions did you make about your life?  
Do you make your own decisions, or someone else?  
Do you, or some other people, make the most of the decisions in your life? Can you give me some examples?  
E.g., Can you choose your school? Where you live?  
Are you able to choose your school? Where you live?

(Inquiry if “yes”: How does it feel/What is it like...to be able to make decision?  
E.g., happy, anxious, fearful, empowering, terrified)

2. What decisions would you want to make for yourself that you haven't been able to make?  
(Inquiry if “no” on No.1: Do you want to choose xxxxx?)  
What are some decisions you would like others to make for you?  
(e.g., be ready with a list: work, school, living, relationships with people, and others?)

#### Control over life

1. How do you control over your life? Do you have any control in your life? Do you feel like you are in control of your life?  
(Probes: What skills do you need to direct your own life, or to get what you want? What do you need to be able to shape your own lives? What has helped you at or kept you from shaping your own life?)  
(Are these realistic skills or barriers?)
2. To what extend are you able to choose your own life (a lot, some, a little, not at all)?  
(Inquiry: How does it feel/What is it like...to be able to control/choose your life?)
3. What do you wish that you had control over?

#### Autonomy (e.g., independence, interests, preferences)

1. Tell me how independent you are.  
(Inquiry: How does it feel/What is it like...to be independent?)
2. Tell me about your interests and preferences.  
(Probe: What do you like to do in your leisure time?)  
(Inquiry: How does it feel/What is it like...to have your own interest/preference?)

#### Self-realization

1. How self-confident are you? How much confidence you have in yourself in the future?  
(Inquiry: What does self-confidence/self-esteem/self-acceptance/self-awareness mean to you? How important are these to you?)  
(Probe: How do you view yourself/self-esteem? Do you like yourself? Are you good at xxxxx?)
2. What are your strengths (good at)? Weaknesses (not good at)? What do you need more help with / need to learn more about?  
(Probe: How well do you know yourself?)
3. Where can you go for help (for any specific things)?  
(Probe: Where can you go to, to say that “I have issues”? Why are people scared of admitting that we have a problem?)
4. What does it mean to be responsible?  
(Probe: What is it to face the world?)

#### Influences of others

1. Tell me how other people (peers, family, teachers, cartoon characters, etc.) influence you? How about you influencing others (e.g., does anybody do what you tell them to do? Copy what you do?)?  
(Inquiry: How does it feel/What is it like...to have others influence you/for you to influence others?)

2. What/who do you think influences you the most? What/who are important to you?  
(Probe: How do others influence you to achieve or whatever?)
3. If you could make any request of important persons in your life, how would you want them to help you to reach your future goals?
4. What does family mean to you? How about home?  
(Probe: Who is in your family? Who lives in your house?)
5. What do other people expect from you (e.g., what are the rules at home/school/job, etc.)?  
How do you know what others' expectations of you are?
6. Who are your role models? (e.g., teachers, relatives, spiritual models, celebrities)  
(Probes: Who has inspired you? Why?)

#### Conclusion

1. Do you know what “transition (out of high school)” mean? What does this mean to you?

APPENDIX C  
RECRUITMENT FLYER

**Are you an adult with Autism Spectrum Disorder (ASD)?**

**Did you leave high school in the past 7 years?**

**If so, we'd like to hear your story!**

### **Who?**

- ✓ Young adults with ASD who left high school within the past 7 years.
- ✓ We are looking for people who are willing to share their experiences in a face-to-face interview.

### **When?**

- ✓ Whatever time is best for you. You will participate in one individual interviews lasting approximately 50-60 minutes.

### **Where?**

- ✓ Interviews will take place in a private location agreed upon with the interviewer.

### **Why?**

We are conducting a study of the transition experiences of young adults with Autism Spectrum Disorder from their own perspectives. We are interested in how young adults become an adult after you left high school. This research study is being conducted by a doctoral student researcher, Gary Yu Hin Lam, from the University of South Florida.

\*\*\*Note: What you share with us is confidential. We will use a fake name to refer to you when we write up the study.

## **Interested in sharing your story?**

If you want to learn more about or join this study, please contact **Gary Yu Hin Lam, M.A.** at (813) 502-9674 or [yuhinlam@mail.usf.edu](mailto:yuhinlam@mail.usf.edu) or Dr. Linda Raffaele Mendez at (813) 974-1255 or [raffaele@usf.edu](mailto:raffaele@usf.edu).

APPENDIX D  
INFORMED CONSENT FORM



## **Informed Consent to Participate in Research Involving Minimal Risk**

**Pro # 22751**

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You are being invited to take part in a research study. Research studies include only people who choose to take part. This document is called an informed consent form. Please read this information carefully and take your time making your decision. Ask the researcher or study staff to discuss this consent form with you, please ask him/her to explain any words or information you do not clearly understand. We encourage you to talk with your family and friends before you decide to take part in this research study. The descriptions of the study, risks, inconveniences, discomforts, and other important information about the study are listed below.

We are asking you to take part in a research study called:

### **Self-determination during the transition from school to adulthood in young adults with Autism Spectrum Disorder (ASD) in the USA and Hong Kong**

The person who is in charge of this research study is Gary Yu Hin Lam, M.A. This person is called the Principal Investigator. However, other research staff may be involved and can act on behalf of the person in charge. He is being guided in this research by his Faculty Advisor, Linda Raffaele Mendez, Ph.D., in order to fulfill the requirement for an Educational Specialist (Ed.S.) and a Doctor of Philosophy (Ph.D.) degree.

The research will be conducted at an agreed upon location between yourself and the researcher.

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## **Purpose of the study**

- To explore your feelings and thoughts about self-determination, which is about how your adult life should be determined by yourself during the time after high school exit
- To compare how self-determination looks like and is perceived across the United States and Hong Kong.

## **Why are you being asked to take part?**

We are asking you to take part in this research study because you were diagnosed with an Autism Spectrum Disorder (ASD) and exited high school within the past seven years.

## **Study Procedures:**

If you take part in this study, you will be asked to get involved in these procedures:

- Participate in one interview lasting about an hour that will ask you about personal questions regarding your self-determination experiences. Based on your time schedule and attention span, the interview could also be divided into multiple sessions (no more than four visits within one month). These multiple sessions would not take more than an hour in total.
- During the interview(s), we will ask about your feelings and thoughts about self-determination during the school-to-adulthood transition in topics related to, for example, goals, independence, and decision making.
- Optionally, you will be encouraged to bring and share an artifact (e.g., drawing, story) in order to further demonstrate your transition experiences. Also, you are encouraged to share and give permission for researchers to review other documents (e.g., school record, transition plan, and case record) that are related to the interview(s).
- The interview(s) will take place at an agreed upon time and location by you and the researcher.
- The interview(s) will be audio recorded in a digital format so that other members of the study staff can help turn the interview into written transcripts. After the recordings will be turned into written transcripts, your personal information will be de-identified. The recordings will be maintained until they are converted to transcripts by the research staff. Once the audiotapes have been transcribed, the recordings will be deleted permanently. The transcripts will be kept for a minimum of seven years after the close of the study.
- Optionally, you may be invited to review your written transcripts and the materials for data analysis in order to ensure the accuracy of recording and representing your ideas.

## **Total Number of Participants**

A minimum of 6 and a maximum of 10 individuals will take part in this study in the United States and Hong Kong, respectively. A total of 12 to 20 individuals will participate in the study at all sites.

## **Alternatives / Voluntary Participation / Withdrawal**

You do not have to participate in this research study. You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study. Decision to or not to participate will not affect your services with the Center for Autism and Related Disabilities (CARD) and/or The Learning Academy (TLA).

## **Benefits**

You will receive no benefit(s) by participating in this research study. The potential indirect benefit of participating in this research study is a chance for you to share your thoughts and feelings with a researcher who is interested in documenting your story.

## **Risks or Discomfort**

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

This study will ask you to think about events related to your personal and family lives. There is a possibility that you could become emotional or upset when talking about these subjects. You may choose not to respond to any questions that may make you uncomfortable.

## **Compensation**

You will receive no payment or other compensation for taking part in this study.

## **Costs**

It will not cost you anything to take part in the study other than the possible cost of travel to interview site.

## **Privacy and Confidentiality**

We will keep your study records private and confidential. However, if you tell us that you or someone else is in harm and/or danger, we will share your information with your parents or staff members in the organizations so that they can better help you.

Your study records and data will be kept in a cabinet in an office that are both protected by a password or a key. No one is allowed to access these records without the permission of the Principal Investigator and the Faculty Advisor.

Certain people may need to see your study records. Anyone who looks at your records must keep them confidential. These individuals include:

- The research team, including the Principal Investigator and his faculty advisor.

- Certain government and university people who need to know more about the study, such as individuals who provide oversight to ensure that we are doing the study in the right way and make sure that we are protecting your rights and your safety.
- Any agency of the federal, state, or local government that regulates this research. This includes the Office for Human Research Protection and the Department of Health and Human Services.
- The USF Institutional Review Board (IRB) and related staff who have oversight responsibilities for this study, including staff in USF Research Integrity and Compliance.

We may publish what we learn from this study. If we do, we will not include your name. We will not publish anything that would let people know who you are.

### **You can get the answers to your questions, concerns, or complaints**

If you have any questions, concerns or complaints about this study, or experience an unanticipated problem, please contact Gary Yu Hin Lam, M.A. by phone [USA: (1)813-502-9674; Hong Kong: (852)90301050], or email [[yuhinlam@mail.usf.edu](mailto:yuhinlam@mail.usf.edu)].

If you have questions about your rights as a participant in this study, or have complaints, concerns or issues you want to discuss with someone outside the research, call the USF IRB at 813-974-5638.

## Consent to Take Part in this Research Study

It is up to you to decide whether you want to take part in this study. If you want to take part, please sign the form, if the following statements are true.

**I freely give my consent to take part in this study. I understand that by signing this form I am agreeing to take part in research. I have received a copy of this form to take with me.**

(Please check one of the following)

I **give my permission** for the study staff to use the additional documents I will provide them.

I **do not give my permission** for the study staff to use the additional documents I will share with them or speak about during the interview

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Signature of Person Taking Part in Study

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Date

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Printed Name of Person Taking Part in Study

## Statement of Person Obtaining Informed Consent

I have carefully explained to the person taking part in the study what he or she can expect from their participation. I hereby certify that when this person signs this form, to the best of my knowledge, he or she understands:

- What the study is about;
- What the potential benefits might be; and
- What the known risks might be.

I confirm that this research subject speaks the language that was used to explain this research and is receiving an informed consent form in their primary language. Additionally, this subject reads well enough to understand this document or, if not, this person is able to hear and understand when the form is read to him or her. This subject does not have a medical or psychological problem that would compromise comprehension and therefore makes it hard to understand what is being explained and can, therefore, give legally effective informed consent. This subject is not under any type of anesthesia or analgesic that may cloud their judgment or make it hard to understand what is being explained and, therefore, can be considered competent to give informed consent.

---

Signature of Person obtaining Informed Consent

---

Date

---

Printed Name of Person Obtaining Informed Consent

**Appendix**  
**Comprehension Check of Informed Consent**  
**[For investigator use only]**

After potential participants read the consent form to themselves with the facilitation by the investigator, they will be assessed of their understanding of the following selected aspects of the study by the use of verbal questions. For any misinformation or misunderstanding, participants will be given further explanations and discussions. Upon repeated informed consent process, if participants are not able to demonstrate their understanding of their participation or disagree with any consent or research procedures, research procedures will be terminated and they will not be included in the study. For those who are able to demonstrate their understanding of participating in the study, they will be directed to sign the consent form and proceed to the main interview.

(Check if the participant demonstrates comprehension)

- If you choose to be in this study, you will need to participate in a one-hour interview.
- If you choose to be in this study, you will need to answer some questions about your school-to-adulthood transition experiences.
- If you choose to be in this study, the interview process will be audio-recorded.
- If you choose to be in this study, you may be asked to share artifacts and/or records.
- If you choose to be in this study, you may be asked to review your interview transcripts and/or materials for data analysis.
- You were chosen to be in this study because you were diagnosed with an Autism Spectrum Disorder.
- You were chosen to be in this study because you exited high school within the past seven years.
- You will not receive any benefits/compensation from or spend any costs on participating in this study.
- Your participation or non-participation in this study will not affect your status in (the name of the organization).
- Your information and records provided in the study will be kept strictly confidential, unless you tell us that you or someone else is in danger.
- After you sign the informed consent from, you still have the freedom and rights to withdraw from the study at any time.

APPENDIX E

INSTITUTIONAL REVIEW BOARDS APPROVAL LETTER



RESEARCH INTEGRITY AND COMPLIANCE  
Institutional Review Boards, FWA No. 00001669  
12901 Bruce B. Downs Blvd., MDC035 • Tampa, FL 33612-4799  
(813) 974-5638 • FAX(813)974-7091

7/21/2015

Yu Hin Lam  
USF Department of Educational and Psychological Studies  
4202 E. Fowler Avenue, EDU105  
Tampa, FL 33620

RE: **Expedited Approval for Initial Review**

IRB#: Pro00022751

Title: Self-Determination during the Transition from School to Adulthood in Young Adults with Autism Spectrum Disorder(ASD) in the USA and Hong Kong

Study Approval Period: 7/21/2015 to 7/21/2016

Dear Mr. Lam:

On 7/21/2015, the Institutional Review Board (IRB) reviewed and **APPROVED** the above application and all documents contained within, including those outlined below.

**Approved Item(s):**

**Protocol Document(s):**

[thesis proposal revised after proposal meeting protocol for IRB.docx](#)

**Consent/Assent Document(s)\*:**

[SB Adult Minimal Risk gary for HK.docx.pdf](#)

[SB Adult Minimal Risk gary for US.docx.pdf](#)

\*Please use only the official IRB stamped informed consent/assent document(s) found under the "Attachments" tab. Please note, these consent/assent document(s) are only valid during the approval period indicated at the top of the form(s).

It was the determination of the IRB that your study qualified for expedited review which includes activities that (1) present no more than minimal risk to human subjects, and (2) involve only procedures listed in one or more of the categories outlined below. The IRB may review research through the expedited review procedure authorized by 45CFR.46.110 and 21 CFR. 56.110. The research proposed in this study is categorized under the following expedited review category:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes.

(7) Research on individual or group characteristics or behavior (including, but not limited to, research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices, and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

As the principal investigator of this study, it is your responsibility to conduct this study in accordance with IRB policies and procedures and as approved by the IRB. Any changes to the approved research must be submitted to the IRB for review and approval via an amendment. Additionally, all unanticipated problems must be reported to the USF IRB within five (5) calendar days.

We appreciate your dedication to the ethical conduct of human subject research at the University of South Florida and your continued commitment to human research protections. If you have any questions regarding this matter, please call 813-974-5638.

Sincerely,



John Schinka, Ph.D., Chairperson  
USF Institutional Review Board

## ABOUT THE AUTHOR

Gary Yu Hin Lam is a doctoral student of School Psychology in the University of South Florida. His clinical practice and research work focus on school-based behavioral and mental health. He specializes in working with individuals with Autism Spectrum Disorder and their families in school, clinic, and community-based settings.