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A Participatory Action Research using Photovoice to Explore Well-Being in Young Adults with Autism

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A Participatory Action Research using Photovoice to Explore

Well-Being in Young Adults with Autism

by

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ABSTRACT

Young adults with autism transitioning from school to adulthood are commonly described as exhibiting poor outcomes. Although there has been research efforts measuring quality of life and life satisfaction in individuals with autism, these conceptualizations of well-being are still predominantly deficit-focused and based on normalizing ideals of the dominant culture. Only by incorporating individuals with autism's perspectives and involving their meaningful participation in research can we better understand and promote well-being among individuals with autism. The present study aims to explore young adults with autism's ideas about well-being. I conducted a Photovoice project using a participatory action research approach with 14 young adults with autism in a post-school transition program and their three instructors. Results revealed a broad sense of young adults with autism expressing their differences while having a strong desire to be connected with others. Specifically, three themes depicted young adults' ideas of well-being in terms of (1) showing their self-expression, understanding, and strengths as well as exhibiting personal growth and learning, (2) having close relationships with their family, friends, and animals, and (3) developing different ways of engagement and connections with the community and environment. The research process itself also supported their experiencing of self-expression and forming connections with other people, which were integral to their well-being. The young adults intended to use the project results to present their personhood in a positive manner and to promote better understanding of autism in society. I drew from critical disability studies to discuss the findings in relation to the academic literature and inform advocacy work at a broader sociocultural level. This study has implications

for researchers to conduct research that is ethically appropriate and sensitive to the needs of the autism community. Practitioners working with transition-age youth with autism can also draw upon from this study to reflect on their relationships and engagement with these youth to better support their well-being.

CHAPTER 1

INTRODUCTION

When I was an undergraduate at the Chinese University of Hong Kong, I enrolled in a

practicum course where I assisted in a local special school, where it was the first time that I met

students with intellectual and developmental disabilities, including autism. One day, the class

teachers and I brought our students to the McDonald's to practice the social skills they learned in

class. While we were so happy watching our students order meals successfully, the cashier

looked at them with a disdainful gaze and made a comment in a sarcastic tone, "How *normal*

they are," meaning that the students given the features of their disabilities were not expected to

behave in such a socially appropriate manner. After this experience, I realized teaching them to

act *normal* is simply not good enough for them.

Since then, I have had the opportunity to interact with individuals with autism in different

capacities, from being a therapist, a mentor, a colleague, to a friend. Throughout graduate

training, I also learned about different "best practices" and "evidence-based interventions" to

support individuals with autism to *lead a better life*. However, the more I learned about these

strategies and techniques, the less I found other researchers and practitioners described them in

terms of the strengths and abilities I saw in them. Capturing more and more moments of

wondering, I started asking myself many questions: "If there exist best strategies to help them to

be better, then what makes autism *less than better* that needs to be helped? As *a non-autistic

person*, based on what grounds I am entitled to help them? What am I helping them to achieve, a

normal life, a good life, based on whose definitions? If becoming *normal* is not the only way, what are other possibilities?" Looking at the academic literature, I found numerous accounts that described the lives of individuals with autism as fraught with challenges and problems. Beyond childhood, youth with autism transitioning from school to the adult world were said to exhibit even poorer outcomes. In contrast, little is known about their strengths and positive experiences. It is almost unknown how they actually perceive and define a good life that they desire.

It is my personal encounter with individuals with autism and my reflection on these experiences that brought me to this inquiry. In this introductory chapter, I provide an overview of my study. I begin the chapter with a brief overview of the current status of post-school transition and well-being research in individuals with autism. I then describe the purpose of research and the significance of this study to research and practice. This is followed by a discussion of the definitions of terms that are used throughout this document.

Background

Post-School Transition in Autism

There is a plethora of educational and clinical interventions available to support youths with autism from early childhood through adolescence. However, once these students complete formal education, structured supports that assist them to meet their developmental needs are less often available in the community (Shattuck, Wagner, Narendorf, Sterzing, & Hensley, 2011). The literature thus far has been focusing primarily on the challenges they face during emerging adulthood. Specifically, research has consistently shown unpromising outcomes in adults with autism in the areas of, for example, employment, postsecondary education, living arrangement, behavioral functioning, community participation, and social relationships (e.g., Hendricks & Wehman, 2009; Shattuck et al., 2011; Taylor & Seltzer, 2011; Wehman et al., 2013). Such

exclusive focus on the negative aspects of individuals with autism has, intentionally or not, equated the presence of such neurological difference to a vulnerable, less-than-normal status of being, such that these individuals are excluded from, and almost discriminated against, the opportunity to express positive life experiences in terms of, for example, resiliency, thriving, and well-being (Runswick-Cole & Goodley, 2013).

Well-Being in Autism

Within the disability literature, the concept of quality of life (QoL) has predominantly been used to describe what a good life is and what good outcomes look like in individuals with disabilities. Although the conceptualization of this construct began with a primary emphasis on one's subjective appraisal (i.e., satisfaction), its development gradually incorporated measurement of objective indicators and functional assessment to assess individuals' performance and skills according to certain standards (Schalock, 2000). However, the added objective components did not accrue to the advancement of epistemological and methodological rigor in QoL studies (Hunt, 1997; Moons, Budts, & De Geest, 2006). Based on the current literature on quantitative measurement of QoL and life satisfaction (LS), our understanding of well-being in individuals with autism is problematic as we do not take into account their unique perspectives and needs. To fully understand what is considered "quality" to one's life, we should look into the qualitative aspects of well-being and the relative importance of different life domains as defined by the person (Whitney-Thomas, 1997). Investigation of well-being in individuals with autism should take into accounts their first-person perspective and their unique but diverse neurological profiles in order to formulate a conceptualization that is meaningful and appropriate to individuals with autism (Robertson, 2009; Rodogno, Krause-Jense, & Ashcroft, 2016).

The Need for Participants' Perspective and Engagement

Since the initial introduction and application of QoL and other well-being constructs, it has been argued that one's subjective appraisal should supplement, if not altogether replace, objective indicators when evaluating the quality and wellness of one's life (Whitney-Thomas, 1997). Although practitioners might have already, or hopefully, embraced the idea of directly inquiring about a person's subjective experience and understanding about his or her own life (see Brown & Brown, 2003), this line of research, however, has not gained much traction in the literature. One of the barriers would be the lack of understanding of how to invite individuals with intellectual and/or developmental disabilities to provide input and be actively involved in research (Haas et al., 2016; Pellicano, Dinsmore, & Charman, 2014). With the advancement of technology and its application in research, participatory action research (PAR) that facilitates participants' alternative modes of expression and involvement allows individuals with autism who have different needs and abilities to provide meaningful input into research and advocacy work. One such example is Photovoice, which allows participants to use cameras to capture photographs on things that are relevant to their lives and to express their ideas around a certain topic (Wang & Burris, 1997). Individuals with autism can take advantage of this technique to document and show their own ideas of well-being.

<div align="center">

Purpose of Study

</div>

I argue that well-being research in autism has suffered from problems of poor conceptualization of wellness constructs and misrepresentation of the perspective of individuals with autism. The purpose of the current study was to understand well-being as perceived and defined by young adults with autism. This project took a participatory action research (PAR) approach and used a photography-based method, Photovoice, to encourage participants' active,

meaningful participation and allow their voice to be expressed and heard throughout the research processes. My primary research question that gave impetus to this research was to understand young adults with autism's ideas about their own well-being. Additionally, I was also interested in different ways that may influence (promote or limit) their well-being, as well as any actions could be taken to promote their well-being.

Significance to Research

Inviting the perspective of individuals with autism to formulate an understanding of what a good life is to them has potential implications for the fundamental conceptualization of well-being for this population. As current definitions of well-being constructs are mostly determined by expert researchers and clinicians in the field, their formulations were based on either expert judgement or quantitative data that aggregated inputs from individuals' in the general population or other types of disability. To my best knowledge, this study is the first research to have individuals with autism provide their first-person accounts to answer the question of what represents their well-being. This endeavor can help researchers to critically reflect on the cultural responsiveness, in terms of neurodiversity and autism-sensitivity, of well-being conceptualizations in contemporary research. Only if the unique needs and profiles of autism are taken into account will conceptualizations of well-being be meaningfully and ethically useful to these individuals (Rodogno et al., 2016). Applications of such conceptualizations in future measurement and intervention efforts will have more solid theoretical ground and be more ethically and culturally appropriate.

The use of PAR is consistent with the call for autism research to increase involvement and collaboration with individuals with autism to address their real-life concerns (Pellicano et al., 2018). The experience of this project can inform how future researchers can better facilitate

active research participation of these individuals. Moreover, the application of Photovoice in autism research is relatively new, initial success of which was shown in children (e.g., Ha & Whittaker, 2016) and young adults (e.g., Cheak-Zamora, Teti, & Maurer-Batjer, 2018). The experience of this project can further our understanding on how Photovoice is received by and can be adapted to be used with individuals with autism.

Significance to Practice

Findings from this study pointed to a neurodiverse, autism-sensitive conceptualization of well-being. The transition from adolescence to adulthood is a period that individuals can have various ways to meet their own developmental needs, which can have profound impacts on their long-term psychological well-being, mental health, and psychopathology (Cohen, Kasen, Chen, Hartmark, & Gordon, 2003; Schulenberg, Sameroff, & Cicchetit, 2004). Practitioners can benefit from acknowledging individuals with autism's first-person account and adopting this autism-sensitive way to understand what is good and important for them from these individuals' perspectives. More specifically, findings from this project can inform how practitioners and researchers should view well-being and good outcomes in individuals with autism. From an advocacy perspective, practitioners and policy-makers can also take into consideration the input from individuals with autism to review current practices and policies and critically reflect on what "best practices" are to serve this population. Furthermore, the experience from this community-based PAR project can serve as an example of how school-based practitioners, such as school psychologists, can promote service learning and community engagement activities of similar kinds to support successful post-school transition in students with autism, and other disabilities in general (Wilczenski, Sotnik, & Vanderberg, 2014).

Definition of Terms

As most of the literature I reviewed are from education, psychology, and medicine, they tended to use the clinical termed, **Autism Spectrum Disorder (ASD)**, to refer autism as a neurodevelopmental disorder characterized by deficits in social interaction and communication coupled with restrictive interests and repetitive behaviors (American Psychiatric Association [APA], 2013). A person who has these symptoms and meets the clinical criteria for this condition can be given a diagnosis of ASD by psychologists, psychiatrists, or other medical or educational professionals. It is noteworthy that in the previous version of the diagnostic manual, ASD was referred to by a range of different diagnoses, including Autistic Disorder, Asperger's Disorder, Rett's Disorder, Childhood Disintegrative Disorder, and Pervasive Development Disorders-Not Otherwise Specified (PDDNOS; APA, 2000). More importantly, despite the widespread influence of the clinical definition, however, whether autism is a "disorder" that an individual possesses is not a universally accepted truth (Goodley, 2017). Other perspectives generally emphasize that the social world plays a critical, if not more important, role in affecting the life of individuals with a disability, thus a *disabled* person. For example, instead of a "disorder," autism can be described as a "disability" or a "condition" as people with autism in an autism-friendly environment can thrive as well as, or even better than people without autism (Baron-Cohen, 2017). Other disability studies scholars have analyzed and interrogated the social meanings and cultural representations constructed around the idea of autism (Osteen, 2008).

With an effort to avoid labeling, and consistent with the ethical guideline suggested by the American Psychological Association (2010), I adopted person-first language to acknowledge individuals who have a diagnosis of autism (i.e., **individuals with autism**). However, recognizing the fact that while some individuals may have a preference for an alternative identity

of autism (Sinclair, 2013), such as autistic person, individuals on the spectrum Aspie, there is no universal agreement as to how autism should be endorsed and described even among members in the autism community (Kenny et al., 2016). Although the use of first-person language may evoke a sense of fixity that autism is an objectively-known condition that a person possesses, I acknowledged the differences (e.g., neurological, behavioral) individuals with autism bring to the table as real, while being mindful of the fact that, beyond biological components, the power of social and cultural constructions around the idea of autism also has important implications for one's ways of being, such as values, identities, and material effects in lives.

Transition is considered as a time period in life in which individuals move from one stage to another. This study was focused on the **post-school transition** or the **adolescence-to-adulthood transition**, as defined by the period of time after one completes formal secondary education and enters adulthood. The concept of emerging adulthood (Arnett, 2000) from the developmental psychology literature is useful here to help understand this period of post-school transition. Emerging adulthood is described as "a distinct period of the life course, characterized by change and exploration of possible life directions" (Arnett, 2000, p.469). While this time period roughly describes people of ages 18 to 25, emerging adults vary in the degree of exploration they pursue before achieving a more stable adulthood, and so there is not a definite age marker for this life period (Arnett, 2000). Although Arnett (2000) distinguished the term emerging adulthood from young adulthood, and he favored the former to describe the transition period described above, the term **young adults** was used in this study for the sake of consistency with how this term denoted this age group in the field of disability and school psychology literature (e.g., Meyer, Hinton, & Derzis, 2015). Considering the context of TLA, I also used

students with autism interchangeably when appropriate to refer to the young adults with autism in TLA participating in this study.

Well-being research stems from the positive psychology movement that has brought the field of psychology from a sole focus on psychopathology to the attention of optimal experience and functioning in people's lives (Seligman & Csikszentmihalyi, 2000). The concept of well-being has never had a unifying definition, but instead it has been theorized in multiple ways based on different ontological orientations. Discussion of what constitutes one's good life is dominant by two major conceptualizations of well-being, including hedonic (i.e., the presence of happiness as indicated by current status of good feelings and emotions) and eudaimonic (i.e., striving for excellence and positive functioning in life) traditions (Ryan & Deci, 2001). For example, the former has coined terms such as subjective well-being (SWB) to equate well-being with happiness in terms of one's satisfaction in life and the presence of positive emotions as well as the absence of negative emotions (Diener, Suh, Lucas, & Smith, 1999). The latter has advocated for the considerations of how individuals meet basic needs, attain optimal functioning, and realize one's potential, as exemplified by the construct of psychological well-being that includes concepts such as personal growth, life purpose, and relatedness (Ryff & Singer, 1998). Recognizing the distinct yet interrelated nature of hedonic and eudaimonic components, contemporary theories and applications tend to attend to both aspects of well-being (e.g., Seligman, 2011). As the purpose of the study was to understand what well-being is like in young adults with autism, the question of how to define well-being is indeed a research question per se.

Before I turn to the specific details of the development and design of this study, it is important to clarify my epistemological stance in deciding the terminology to describe this "**research**." Because of my deliberate choice of the **participatory action research (PAR)**

paradigm (also see Chapter 3), while I acknowledged the significance and legitimacy of doing research, I sided with McTaggart, Nixon, and Kemmis (2017) that PAR distinguishes itself from more traditional research in its collaborative nature of studying practices and understanding knowledges in highly local contexts:

> We do not regard the "research" part of critical participatory action research as employing or applying some "correct" set of research "techniques" borrowed from other fields like agriculture (where experimental statistics were originally developed). In our view, critical participatory action research is not a technique or a set of techniques for generating the kinds of "generalizations" that positivist social research aims to produce. Rather, critical participatory action research aims to help people to understand in order to transform "the way we do things around here"—what happens here, in this single case—not what goes on anywhere or everywhere. (p.29)

Therefore, I deliberately stayed away from using the term "research" to describe my study as a critical gesture to avoid the connotations of a fixed set of *a priori* research tactics. Instead, I referred to this current PAR initiative as "**project**" and "**study**" throughout this report, while using "**research**" as a generic term to describe other research in general.

CHAPTER 2

LITERATURE REVIEW

This chapter is divided into two sections. The first half paints a broad picture of the status quo of autism research as related to this topic of interest. It begins with a brief review of the current trend of post-school transition in young adults with disabilities. This is followed by descriptions of the clinical characteristics of autism. The review then focuses on the outcomes in young adults with autism as described in the literature, which leads to the discussion of promoting transition and lifelong wellness in individuals with autism. In the second half, I argue that the current status of well-being research in autism, which is dominated by quantitative studies using constructs of quality of life (QoL) and life satisfaction (LS), has suffered a series of conceptual and methodological problems. I present further arguments for the need to understand well-being of individuals with autism from their first-person perspective and through their meaningful involvement in research. I conclude the chapter by discussing the use of the participatory action research approach and the Photovoice method to understand well-being in young adults with autism.

Post-School Transition in Young Adults with Disabilities

Student, with or without disabilities, spend the majority of childhood and adolescence learning at schools. While education is to prepare students to become future generations of successful and educated members in society, it is a considerable loss if any young adults coming out of school are not able to life meaningful lives and contribute to their communities. As

students exit secondary education and enter the adulthood, they are faced with numerous life possibilities and challenges. The transition from formal schooling to the adult world is particularly difficult for students with disabilities (Halpern, 1994). Not only do they stop receiving structured supports at school, but also are loaded with different expectations to navigate different life circumstances as an adult, such as gaining employment, making living arrangement, and pursuing postsecondary education. Early reports showed that students with disabilities, 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 gradually expanded to better understand the experiences of students with disabilities as they transition out of high school.

Since the enactment of the Individuals with Disabilities Education Act (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 in the United States (Blackorby & Wagner, 1996). In a more recent report (NLTS-2, 2001) that traced students' post-school outcomes within eight years after leaving high school, students with disabilities were shown to lag 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). Regarding their perceived competencies and strengths, youth with disabilities were found to rate themselves as high as their non-disabled peers 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" (e.g., Gresham, Lane, MacMillan, Bocian, & Ward, 2000; Klassen, 2006) and tended to overestimate their own strengths and limitations, thus calling into question the consistency between their self-report ratings and their real-life competencies.

Large-scale national studies such as the NLTS-2 painted a rather dismal picture of unsatisfactory transition experiences and outcomes of students with disabilities. As noted by Wagner et al. (2007), some subgroups of students reported extremely negative experiences and views across different domains of life. For individuals with autism, who were described as having more complicated symptomatology that affects functioning more pervasively, 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 autism, 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 is provided to acquaint the reader with the dominant clinical conceptualizations of autism. This section also includes a summary of common areas of strengths and challenges individuals with autism are said to experience in everyday life. Subsequently, I describe what is currently known in the literature about the post-secondary transition for youth with autism in different life domains.

Clinical Characteristics and Experiences of Autism during the School Age

Autism, or Autism Spectrum Disorder (ASD) in clinical terms, is described as 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 or interests manifest differently across individuals, 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 approximately 1 in 59 children in the United States (Baio et al., 2018) and, on average, 1 in 132 (Baxter et al., 2015) to 161 (Elsabbagh et al., 2012) children globally have autism. Individuals identified on the autism spectrum exhibit a wide range of clinical symptoms, developmental trajectories, as well as overall functioning (Jensen & Spannagel, 2011). The autism diagnosis encompasses a broad continuum of individuals who, for example, 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.

Clinical symptoms of autism 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 even late adulthood (Geurts & Jansen, 2011). In general, the level of functional impairments of individuals with autism 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 autism were documented to 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 were described to have excellent rote memory and attention to details (Happé & Frith, 2006; Meilleur et al., 2015). Some 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 autism (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 emotion regulation (Samson, Huber, & Gross, 2012).

In educational settings, students with autism face numerous challenges in many aspects of school. With regard to academics, 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 autism exhibit challenging behaviors in school, including non-compliance, aggression, self-injury, and stereotypy (Machalicek, O'Reilly, Beretvas, Sigafoos, & Lancioni, 2007). Compared with their peers, students with autism are described as lacking appropriate social skills (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 autism (Baranek, Parham, & Bodfish, 2005; Simonoff et al., 2009). Common special education services that students with autism receive include speech and 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 usually seek additional community-based services and interventions for their children, such as child care, medication, comprehensive treatment program, parent support group, and different alternative therapies (Thomas et al., 2007). Overall, common features associated with effective educational interventions and programs for school-age children with autism are highly individualized, specialized, systematic, and structured support (Iovannone, Dunlap, Huber, & Kincaid, 2003).

Post-School Transition in Young Adults with Autism

Given the unique characteristics of youth with autism, 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 high school, young adults with autism 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 autism leave school (Taylor & Seltzer, 2010). Findings from the NLTS-2 also painted an overall negative picture of poorer social, vocational, educational, and quality-of-life outcomes in youth with

autism compared to youth with other disabilities, especially during this transition period (Roux et al., 2013; Shattuck, Orsmond, Wagner, & Cooper, 2011; Wagner et al., 2007). Overall, post-school transition has been shown to be a stressful period for young adults with autism, 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, I review the literature on transition outcomes of youth with autism in various life domains.

Vocational Experiences

The employment trends of youth with autism transitioning out of school are generally described as poor. Secondary analyses of the NLTS-2 data revealed that only 55.1% of youth with autism 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 such other disability groups as emotional disability, learning disability, speech/language impairment, and intellectual disability (Roux et al., 2013). Eaves and Ho (2008) followed 76 Canadian families with children diagnosed with autism in the 1970's and 1980's. Of the 48 parents of young adults with autism (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 autism (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 autism over a 10-year period immediately after they exited high school. The longitudinal data revealed significant declines in their 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 autism remained similarly high (Howlin, Goode, Hutton, & Rutter, 2004; Wagner, Newman, Cameto, Garza, & Levine, 2005). In studies that included a wide age range of adults with autism (Cedurland, Hagberg, Billstedt, Gillberg, & Gillberg, 2008; Howlin et al., 2004), individuals with higher intellectual functioning had somewhat higher employment rates than those with lower intelligence, but the majority of those who were employed held jobs in sheltered employment instead of competitive employment. Compared to non-disabled peers, adults with autism 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).

Educational Experiences

Upon the completion of high school, adolescents with autism 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 autism 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 autism had attended college during the first six years after exiting high school (Shattuck et al., 2012). Other reports (Cedurland et al., 2008; Taylor & Seltzer, 2011) generally found that about 10% of individuals with high-functioning autism had attended a college or university, although only a minority eventually received a degree. The incidence of college or university attendance was also extremely rare for those with lower intelligence. Concerns for 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 autism with varying abilities now have more opportunities to participate in post-secondary education (Hart, Grigal, & Weir, 2010).

Living Arrangement

In a population-based study conducted in the Sweden that involved 120 adults diagnosed with autism aged 17 to 40, only four individuals were identified as living independently (Billstedt, Gillberg, & Gillberg, 2005). Other studies reported less than 10% of adults with autism lived independently, one-third lived in a residential placement, and half lived with their parents (Cedurland et al., 2008; Howlin et al., 2004). Secondary analyses of the NLTS-2 data showed that young adults with autism had the highest rates of staying with parents for longer periods of time, residing in supervised living arrangements, and not living independently, compared with students with emotional disabilities, learning disabilities, and intellectual disabilities, even after controlling for functional abilities and demographic characteristics (Anderson, Shattuck, Cooper, Roux, & Wagner, 2014). Some consistent findings suggested

individuals with higher intellectual functioning were more likely to achieve residential independence than their counterparts with lower intellectual functioning (Gray et al., 2014; Howlin et al., 2004), while other factors such as being Caucasian, having better language and function abilities, and having higher socioeconomic status were also reported (Anderson et al., 2014). Regarding subtypes of autism, Cedurland et al. (2008) found a discrepancy between 64% of adults with Asperger's syndrome and 8% of adults with autism who 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, although active participation can also mean other regular, on-going activities in the community. Overall, community disengagement is not uncommon among youth with autism. Shattuck et al. (2012) analyzed the NLTS-2 data and found that half of the youth with autism 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 autism (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 community disengagement.

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

In contrast to what is known about community engagement, relatively less is known about adaptive behaviors and functioning among youth with autism 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), these researchers reported an overall improvement of autism symptoms and internalizing maladaptive behaviors throughout the school age, 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 autism to those with Down syndrome using the Waisman Activities of Daily Living Scale (W-ADL; Maenner et al., 2013). In the autism group, although daily living skills improved during adolescence through 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 although students with autism with average or above intelligence improved more while in school than their counterparts with intellectual disabilities, the former experienced a greater rate of slowdown in improvement after leaving high school, suggesting that post-school transition have more pronounced adverse effects on their autism and behavioral symptoms over time (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 autism, Matthews et al. (2015) compared individuals' adaptive and intellectual functioning using the Vineland Adaptive Behavior Scales, Second Edition (BobBS-II; Sparrow, Cicchetti, & Balla, 2005) and the Kaufman Brief Intelligence Test, Second Edition (KBIT-2; Kaufman & Kaufman, 2004). All individuals with autism showed consistently lower adaptive functioning that what was expected based on their cognitive profiles. While the adolescent group possessed comparable levels of skills in daily living, communication, and socialization, the latter two skill domains were observed to be of 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 autism.

Social Experiences

Social relationships are one of the hallmark challenges for individuals with autism. In adolescence, there is a widening gap in social experiences between individuals with autism and their non-disabled peers (Church et al., 2000). Secondary analyses of the NLTS-2 data showed that half of the youth with autism never saw friends out of school, were called by friends, or were 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 autism reported having at least one friend, but nearly half did not identify any peer relationships (Billstedt et al., 2011; Eaves & Ho, 2008; Howlin et al., 2004; Mawhood, Howlin, & Rutter, 2000; Orsmond, Krauss, & Seltzer, 2004). These trends do 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. Only few cases and anecdotal reports have documented individuals with autism 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 individuals with autism was found to be associated with feelings of loneliness (Bauminger & Kasari, 2000; Bauminger, Schulman, & Agam, 2003). Many individuals with autism reported to 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 lacked the knowledge about how to interact effectively in social and intimate relationships (Stokes, Newton, & Kaur, 2007; Van Bourgondien, Reichle, & Palmer, 1997).

In sum, the review above showed that the field has been almost exclusively focused on the deficits and challenges faced by individuals with autism. However, relatively less is known about the positive experiences in their lives. Such questions as whether individuals with autism have a good life or what a good life is to them are rarely explored in the literature. This line of inquiry indeed possesses crucial theoretical and practical values, which serves as the impetus for the current study.

Well-being in Autism

Every individual has the right to live a good, quality, and satisfied life. However, the matter of how to define it can be subjected to discussions. Over the past century, the field of psychology in the United States tended to focus primarily on eliminating symptoms of psychopathology. Starting from 1980s, social service and welfare providers have been increasingly called on to provide quality services and produce better outcomes to enhance individuals' well-being (Schalock, 2000; Wood-Dauphinee, 1999). With the rise of positive psychology, more attention has been put on optimizing individuals' experience and functioning as well as how to support individuals to become successful, satisfied, and happy in life (Seligman & Csikszentmihalyi, 2000). Contemporary view of complete mental health supports equal emphasis on both the absence of psychopathology and the presence of wellness in children (Suldo & Shaffer, 2008; Suldo, Thalji-Raitano, Kiefer, & Ferron, 2016) and adults (Westerhof & Keyes, 2010).

A variety of psychological concepts have been used to study and measure an individual's well-being, such as quality of life (QoL), subjective well-being (SWB), and life satisfaction (LS). Below I briefly review the different conceptualizations of these constructs in order to provide the context for the development of this study to understand well-being in individuals with ASD.

The World Health Organization WHOQOL Group (1995) first broadly defined QoL as "individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (p.1405). Since then, numerous definitions and models have been proposed to describe and study this multidimensional construct. For example, Schalock (2004) described eight domains of QoL, including emotional well-being, interpersonal relations, material well-being, personal development, physical well-being, self-determination, social inclusion, and rights. Models of similar kinds were proposed in an attempt to address the questions of (a) what comprises quality of life, (b) what predicts quality of life, and (c) what factors are more, or less, important (e.g., Cummins, 2005; Schalock et al., 2002). However, researchers have focused primarily on the latter two areas than the very meaning of QoL, leaving this undefined construct inevitably broad and vague (Keith, 2001). Consequently, numerous definitions of QoL exist in the literature. Some measures of QoL are generic while others are condition-specific (e.g., cerebral palsy; Waters, Maher, Salmon, Reddihough, & Boyd, 2005). Others focus on a certain domain of QoL, such as health-related QoL (Sherman et al., 2002).

Another commonly studied indicator of well-being is subjective well-being (SWB). As stated in the name of the construct, SWB describes one's subjective feelings of wellness, which is consistent with the hedonic tradition of well-being that focuses on one's experience of pleasure (Keyes, Shmotkin, & Ryff, 2002). SWB is operationalized as having two component domains, namely cognitive and emotional (Diener, Suh, & Oishi, 1997). The cognitive component, commonly known as life satisfaction (LS), entails an individual's cognitive appraisal of one's life quality in different areas, such as love, marriage, friendship, and job. The emotional component includes the frequency with which individuals experience positive affect (e.g., joyful,

excited, cheerful) and negative affect (e.g., sad, scared, guilty). While affect represents a more temporary state of well-being and is easily influenced by different factors and contexts, LS is believed to be a relatively more stable construct that can reflect the overall level of enjoyment, contentment, and fulfilment in one's life (e.g., Helm, 2000; Veenhoven, 1996).

Autism research has not been catching up with the development of positive psychology research for the general population. Research operating from the medical model that focuses on eliminating symptoms and minimizing co-occurring problems still dominates the field of disability study, although more authors recently have called for the attention to the study of well-being and other positive psychological constructs as an equally important research agenda to improve the lives of individuals with disabilities (Runswick-Cole & Goodley, 2013; Wehmeyer & Shogren, 2014). Pioneer efforts in this line of research has primarily focused in QoL of individuals with autism, which was developed from research on intellectual disability (Schalock et al., 2002; Schalock & Verdugo, 2012). Below I argue that the current status of QoL research has not been successful in gaining an authentic understanding of well-being in individuals with autism.

Quality of Life in Autism

Despite its widespread applications in research and clinical practice, the construct of QoL has long been criticized for its lack of scientific rigor and technical adequacy (Gill & Feinstein, 1994; Hunt, 1997; Wolfensberger, 1994). A decade later, Moons et al. (2006) conducted a critical review on different conceptualizations of QoL and found six major problems associated with these conceptualizations. Below I briefly review their critiques of these methodological problems and underlying conceptual issues in QoL research. I argue that, even though another

decade has passed, the six common problems of QoL conceptualizations identified by Moons et al. (2006) are similarly prevalent in QoL research among the autism population.

Problem 1: QoL versus Health Status and Functioning

The definitions of QoL that include health and functioning immediately assume that a person can only achieve a high QoL if he or she can function a "normal" life comparable to a healthy person. This notion can be challenged because individuals with autism who have significant health and functional problems do not necessarily have low QoL (e.g., Clark, Magill-Evans, & Koning, 2015; Renty & Roeyers, 2006). The Pediatric Quality of Life Inventory (Varni, Seid, & Rode, 1999) used in most of the studies with youth with autism has been criticized for focusing on functioning and what the child can or cannot do instead of well-being (Waters et al., 2009). Although youth with autism using this instrument reported lower QoL scores than that of the general pediatric population (Potvin, Snider, Prelock, Wood-Dauphinee, & Kehayia, 2015; Shipman, Sheldrick, & Perrin, 2011; Tavernor, Barron, Rodgers, & McConachie, 2013), it is conceptually inconclusive whether these youth truly perceive their life as poorer than others or they live with more functional impairments while having intact QoL. Similarly, the Quality of Life Questionnaire (Schalock & Keith, 1993) aggregated items on functional impairments into the assessment of QoL in adults with autism (e.g., Gal, Selanikyo, Erez, & Katz, 2015; Renty & Roeyers, 2006). For example, an item in the domain of satisfaction asks, "Do you have more or fewer problems than other people?" Including functioning level in the composite score of QoL measure is problematic as disability characteristics were found to be unrelated to self-report QoL of adults with autism (Renty & Roeyers, 2006). Although it is defensible that health or functional statuses might have an impact on QoL, in fact, accumulating evidence from studies among adult populations with different medical illnesses substantiated that

these two concepts are distinctly different and are not synonymous with each other (Moons, Van Deyk, De Geest, Gewillig, & Budts, 2005; Smith, Avis, & Assmann, 1999).

Problem 2: Objective versus Subjective Dimensions

It has long been debatable whether QoL constitutes objective indicators, subjective indicators, or both. Some early proposals of QoL argued that subjective and personal perceptions are more important as the evaluation of objective indicators should be based on how individuals perceive their different life domains (Halpern, 1993). Ruble and Dalrymple (1996) also distinguished the concept of QoL from competence: While QoL denotes one's subjective perceptions of life quality, competence is the evaluation or judgement of one's performance based on external, and usually normative, criteria. These two concepts both have important implications for enhancing outcomes in transition-age students with autism (Ruble & Dalrymple, 1996).

Recognizing the problem that no unified definitions of QoL can be reached, however, Schalock (1999) proposed to instead treat QoL as an organizing concept without a need for a solid definition and moved on to discuss dimensions of QoL and how to measure them. The trend of measurement also moved gradually from assessing only personal values and satisfaction to combining both subjective and objective variables (Cummins, 2000; Keith, 2001; Schalock, 1999). Unfortunately, this was "a rush to measurement" (p.208) despite unresolved theoretical and philosophical issues (Hunt, 1999). One impetus for such a hype for measuring objective standards, in addition to the core subjective evaluations, could be attributed to the "quality revolution" (p.117) occurred during the late 20th century, which placed heavy emphasis on fitting resources and providing supports in service delivery as well as assessing the effectiveness of program to inform service development in a more person-centered manner (Schalock, 2000).

Although measuring objective indicators can best serve the purpose of informing service and policy development, subjective dimensions are more able to reflect the extent to which an individual is satisfied with life (Schalock & Felce, 2004). Some other reasons why researchers turned to objective measurement may stem from the inherent challenges of assessing subjective aspects of QoL, including the difficulty in interviewing individuals with language and communication deficits, the different meanings attributed to QoL by different individuals, and the influence of personality differences on QoL (Hatton, 1998).

However, the need for measuring objective standards and the difficulties in assessing subjective satisfaction should not be the argument for merging objective indicators with the subjective appraisal of QoL. In fact, there is meaningful and significant distinction between objective standards (e.g., living environment, income) and subjective evaluation of life quality (e.g., life satisfaction; Cummins, 2000). Further, it has been repeatedly reiterated that QoL "may mean different things to different people" (p.459) and "is primarily the perception of the individual that reflects the quality of life he or she experiences" (Schalock et al., 2002, p. 460; also see Schalock et al., 1990). Cummins (2000) also cautioned that objective indicators can only be defensibly applicable at a population level, if not only to the Western, middle-class population, as he cited examples of the exceptionally high LS of Hong Kong people living in extremely dense housing (Mitchell, 1971) and a man with intellectual disability residing in a neighborhood with high crime rates and AIDS prevalence (Edgerton, 1990). This also calls into question the cultural appropriateness of the use of standardized objective measurements of QoL.

In the context of transition-age students with disabilities, Halpern (1993) proposed the use of QoL as a framework to evaluate transition outcomes, while cautioning that individual students should be asked and guided to choose their own desired outcomes before any subjective

assessments of individual QoL dimensions can provide meaningful value to the respective dimensions of objective standards. However, it is not uncommon to see professionals and researchers used expert judgment to define *for* individuals with autism what a quality life is. For example, Bishop-Fitzpatrick et al. (2016) used criteria determined by researchers to define "positive normative outcomes" (e.g., competitive employment, independent living) and "good objective QoL" (e.g., good mental health, frequent contact with family members) in adults with autism, while results indicated only two out of 180 individuals in their sample achieved all the normative markers. Barneveld, Swaab, Fagel, Engeland, and Sonneville (2014) compared adults with autism with other psychiatric conditions and found implicated objective QoL in the autism group in areas of marital status, living arrangement, educational level, employment status, mental health care, and medication usage; however, such findings failed to explain why these adults with autism were less content about their work, education, relationships, and future prospects, while more content about their physical condition. These examples show that not only is the perspective of individuals with autism being ignored, it is also uncertain whether these "successful outcome" indicators truly influence the subjective feelings of individuals with autism towards their QoL. In fact, problems may not always be negatively perceived by individuals with disabilities, a phenomenon described as "the disability paradox" (Albrecht & Devlieger, 1999). More recently, Helles, Gillberg, Gillberg, and Billstedt (2017) surveyed 50 adults with autism (mean age 30 years old) with average intelligence quotient and found a high prevalence of social and employment concerns. Forty-eight percent of participants never had a romantic partner, 70% were currently single and had only one or no friend, and 48% were either unemployed or engaged in specialized employment provided by the government. Nonetheless, over 70% of participants rated themselves having average and above sense of coherence, which predicted

lower stress and tension and better coping strategies. It was argued that individuals with autism's subjective well-being does not seem to be based upon living up to the objective standards valued by society (Helles et al., 2017).

Problem 3: Distinction between Indicators and Determinants

Another important yet often overlooked conceptual issue is the distinction between what *refers to* QoL and what *influences* QoL. While subjective perceptions of well-being and LS are the important defining indicators of QoL, factors that influence QoL (i.e., correlates, determinants) are usually objective criteria that can be observed and measured. The decision to include correlates in the measurement of QoL is made based on the challenge, or perhaps implicit assumption, that individuals with communication and cognitive disabilities may not be able to provide accurate appraisal of their life circumstances based on their reports of satisfaction level. For example, Gardner and Carran (2005) found high satisfaction with services and life situations in adults with intellectual disabilities, despite their limited abilities to make choice regarding their living conditions, work, and social roles, which led to the researchers' conclusion that these adults did not evaluate their satisfaction based on the services and supports received.

Current QoL models tend to include both indicators and correlates of well-being, which intend to let individuals "decide the trade-off between competing aspects of their own personal welfare" based on "the weight a person gives to the constituent concerns" (Felce & Perry, 1997, p. 63). However, available QoL instruments usually include categories of life domains that were determined by researchers based on pragmatic reasons such as availability of data (Diener & Suh, 1997). Unfortunately, this practice violates the emancipatory notion of QoL, as it ignores whether individuals indeed value the preselected domains and stifle the possibility for individuals to select idiosyncratic elements that can represent their life quality.

Similar problems can be found in QoL research in autism. Burgess and Gutstein (2007) cited research in other pediatric populations to support the idea that social support, academic success, preparation for future employment, family life, and self-determination are "several aspects of QoL that are possible predictors of QoL in autism" (p. 81). If these categories are truly *aspects* or *indicators* of QoL, it is conceptually flawed to say they are, at the same time, *predictors* of QoL. For instance, self-determination is defined as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117). It is clear that self-determination can only influence (i.e., maintain, improve) QoL, but is not a defining component of QoL. For example, in an empirical study, Lee, Harrington, Louie, and Newschaffer (2008) assessed QoL in children with autism using parents' responses to survey questions that asked about parental stress and children's participation in daily activities, which appeared to be correlates rather than indicators of the children's personal well-being.

Problem 4: Changes over Time

It is argued that one's QoL would change over time as the environment and developmental needs also change. In a recent meta-analysis that included 10 studies that compared QoL in individuals with autism with typically developing or other clinical control groups, age was found to be a non-significant moderator between autism diagnosis and QoL (van Heijst & Geurts, 2015). This may be due to the underrepresentation of older age groups, as there were only four studies that included adult participants (mean age 20.3 to 40.7) and no studies on older adults were available. Similarly, a metasynthesis of qualitative research on individuals with autism indicated a lack of studies focusing on positive lived experience and how age and other

socio-demographic factors influence their positive life (DePape & Lindsay, 2016). Clearly, qualitative research exploring well-being in individuals with autism is much needed.

Problem 5: Negative versus Positive Components

Van Steensel, Bögels, and Dirksen (2012) asked a Dutch sample of youth with autism and their parents to rate their HRQoL using the EuroQol-5D (EuroQol group, 1990), which focused exclusively on the presence and severity of problems in life instead of well-being. This practice completely ignores the positive aspect of well-being that is different from negative symptomatology, both of which account for a distinct aspect of one's complete mental health (Suldo & Shaffer, 2008). A metasynthesis also revealed individuals with autism's diverse views on their identity in both positive and negative terms (DePape & Lindsay, 2016). While some individuals were indifferent to their autism conditions, some were indeed proud of having autism as an integral part of their self-concept. Some viewed their restricted and repetitive interests as inherent talents and personality, while others thought these behaviors could lead to stigma. These observations clearly pointed to the need to understand the positive experiences and the meaning making processes in individuals with autism, which were an underexplored but important area in autism research.

Problem 6: Health-related QoL

To date, almost all studies that included children and adolescents diagnosed with autism investigated QoL from the perspective of health-related quality of life (HRQoL), which focused on the components of QoL related to health conditions and healthcare services (Wood-Dauphinee, 1999). As discussed above, the Pediatric Quality of Life Inventory (Varni et al., 1999) used in the majority of QoL research among children with autism focused exclusively on

their problems in physical, emotional, social, and school functioning, thus ignoring the evaluation of one's QoL from a positive, strength-based perspective (Waters et al., 2009).

Another common pitfall is the faulty conceptualization of HRQoL as perceived health, which may be a correlate of QoL, but does not necessarily indicates one's life quality (Moons, 2004). For example, Helles et al. (2017) operationalized subjective QoL using the SF-36 Health Questionnaire (Sullivan et al., 2002), a health survey that asked participants to rate their functional health in physical and mental domains, which mistakenly combined perceived symptoms and subjective well-being into an aggregate assessment of QoL. In fact, although the participants with more psychiatric comorbidity rated themselves having significantly worse functioning in social activities, physical roles, mental health, and general health, they reported a similar level of vitality (e.g., "feel full of life," "have a lot of energy") compared to all other adults with autism who had less clinical symptoms and without any psychiatric comorbidities (Helles et al., 2017).

Life Satisfaction in Autism

Current literature on QoL has employed a wide variety of ways to define and measure QoL, which in turns created numerous problems and confusions to the conceptual understanding of the construct itself. Following the analysis by Moons et al. (2006), it was found that only life satisfaction (LS) can arguably address the six major conceptual problems found in previous QoL research. Specifically, LS is a subjective evaluation of one's personal life that is distinguished from objective health or normal functioning. Although these objective indicators may be useful to assess one's achievement of normative outcomes in various QoL domains, these outcomes are distinctly different from one's subjective appraisal of fulfilment in respective QoL domains that individuals view as important (Halpern, 1993; Ruble & Dalrymple, 1996). Furthermore, LS also

has an explicit focus on positive aspects in life, which has implications for identifying strengths and resources to enhance a person's life quality. While most of the available empirical literature on QoL focused on the evaluation of functioning problems, impairment reduction, and preferences for certain health states, it was proposed that LS is the most appropriate conceptualization for well-being (Moons et al., 2006). However, literature on LS in autism population is scant. To the author's best knowledge, only three empirical studies have investigated subjective evaluation of LS in adults with autism.

Mazurek (2014) surveyed 108 adults with autism with age ranging from 18 to 62 years about their self-reported autism symptoms, loneliness, and friendship. Well-being was conceptualized as LS, self-esteem, depression, and anxiety. Findings indicated that loneliness negatively predicts LS even after controlling for autism symptoms. Friendship, as measured by the status of having any friends and close friends, as well as the closeness of existing friendship, did not have significant mediation effects between loneliness and LS. This study suggested that different factors at both intrapersonal (i.e., autism symptoms, self-concept, psychopathology) and interpersonal (i.e., friendship) levels have certain impacts on one's perception of LS.

Another similar study using a sample of 104 young adults (15 to 27 years old), 41 with autism and 61 without, investigated the interrelationships between LS and other psychological constructs, including loneliness, stress, and self-efficacy (Feldhaus, Koglin, Devermann, Logemann, & Lorenz, 2015). Young adults with autism reported significantly lower levels of LS and self-efficacy and higher levels of loneliness, while their stress level was comparable to neurotypical adults. The association between self-efficacy and LS was significantly stronger in individuals with autism than control. The authors suggested any assessments and interventions of LS tailored to the autism population should be developed based on the unique perspectives of

these individuals. This points to the needs of exploring their perceptions and understanding of well-being using a qualitative inquiry.

Schmidt et al. (2015) attempted to identify domains of psychosocial functioning that best predict LS in 43 adults with autism (mean age 31 years old, average mean intellectual quotient). Psychosocial functioning was assessed using the German version of the World Health Organization Disability Assessment Schedule 2.0 (Üstün, Kostanjsek, Chatterji, & Rehm, 2010). LS was evaluated using participants' rating of satisfaction in 10 domains of life on the German Quality of Life questionnaire "Fragebogen zur Lebenszufriedenheit" (Fahrenberg, Myrtek, Schumacher, & Brähler, 2000). Compared with neurotypical control, adults with autism indicated more difficulties in overall functioning, as well as in domains of understanding and communication, getting along with people, school or work, and participation in society. They also reported lower overall LS, and in subscales of health, self, sexuality, friends, and relatives. More importantly, having less difficulties with participation in society was found to be the largest predictor of overall LS in adults with autism (accounted for 49% of variance). In contrast, the largest predictor for neurotypical adults was communication functioning (accounted for 53% of variance), while social participation only accounted for additional 6% of variance of their LS. While LS in neurotypical adults was influenced more by interpersonal communication and social interaction, the ability for adults with autism to participate and be included in society appeared to be more important for them to experience a satisfied life. It is strikingly important to consider the perspective of individuals with autism if we are to cater to their unique needs to enhance their well-being.

Problems in Well-being Research in Autism

Despite the use of LS as a QoL indicator, the studies reviewed above shed light on the inadequacy of using psychological measures to understand well-being in individuals with autism. Behind this methodological difficulty lies the epistemological pitfall of missing the perspective and input of individuals with autism in conceptualizing their well-being. As pointed out by the Center for Disease Control and Prevention (2000), a well-being construct without conceptual and theoretical clarity would have profound repercussions on research outcomes and applications. Any measurement or assessment efforts are bound to be flawed if the fundamental conceptualization of well-being is inappropriate, invalid, or incomplete.

One contributing factor is that current well-being research fails to recruit the first-person perspective of individuals with autism, despite the well-established finding that an target individual and his or her significant others indeed provide different, but equally valuable, input regarding the individual's QoL (Saldaña et al., 2009). It is not uncommon to find past studies relied on proxies, such as parents and clinicians, to report QoL of adults with autism, especially when the participants had a wide range of intellectual and/or verbal functioning (e.g., Billstedt et al., 2011; Gerber et al., 2011). This problem is more prevalent in research with younger populations with autism. When parents were selected as the informant for their children's QoL, they typically reported a much lower QoL than their children with autism did (Potvin et al., 2015; Shipman et al., 2011; Tavernor et al., 2013; van Steensel et al., 2012). In fact, low agreement has been found between QoL scores reported by children and parents in both typically developing (Potvin et al., 2015) and autism (Clark et al., 2015; Potvin et al., 2015; Sheldrick, Neger, Shipman, & Perrin, 2012) populations. For example, in one study that asked both adolescents with autism and their parents completed the KIDSCREEN (KIDSCREEN Group

Europe, 2006), adolescents with autism perceived having the highest QoL in their school environment and lowest in social support, while their parents rated them the highest in financial resources and lowest in moods, social support, and social acceptance (Clark et al., 2015). Another study conducted by Sheldrick et al. (2012) showed that when parents were explicitly asked to reflect on their children with autism's QoL and reported based on their children's perspective, a smaller discrepancy was found between the reports by parents and their children. This further suggests a valid perspective from the individuals with autism that should be taken into consideration. It is also important to note that youth with autism's self-report was found to have sufficient variability across different QoL domains and that they also rated themselves lower than typically developing and chronically ill youth, which provide evidence that individuals with autism were aware of the different areas of life that are either more satisfied or challenging for them (Clark et al., 2015).

A mixed-method study conducted by Tavernor et al. (2013) demonstrated the invalidity of using measurement systems and supported the need for incorporating qualitative methods in understanding well-being in autism. They asked 10 children with autism and their 11 parents in the United Kingdom to complete two most commonly used QoL measures, Pediatric Quality of Life Inventory (Varni et al., 1999) and KIDSCREEN (Ravens-Sieberer et al., 2005), followed by a semi-structured interview to describe their thought processes when filling out the measures and to express things they considered actually influencing their QoL. Their findings revealed that the underlying reasons of children with autism experiencing certain challenges in life were not accurately reflected in the QoL domains of the measures. For example, items that were meant to tap QoL in the areas of physical health asked about respondents' abilities to take a bath independently and to do sports, but children with autism may have difficulties performing these

tasks because of psychological, social, and sensory concerns, but not physical per se.

Misinterpretation of items could also be due to these children's idiosyncratic use and

understanding of language and emotional vocabulary. Another problem discussed was the

tendency for children with autism to base their judgements on the effects of isolated events while

psychological measures in general expect informants to give a more generalized perspective.

More importantly, many children with autism and their parents expressed that the QoL measures

failed to consider the idiosyncratic profile and functioning of autism. In other words, the items

did not adequately capture what these children valued in lives. For example, low scores in social

domains were common, but many children with autism reported their preference for being alone,

and their parents also agreed that they could let them by themselves instead of pushing them to

be social. Moreover, special interests were considered an integral part of children with autism's

daily life, but these were not mentioned in the measures as these were originally developed for

the general population. Taken together, these observations did not only challenge the content and

face validity of existing QoL measures as applied to the autism population, but also stressed the

importance of increasing meaningful involvement and gathering first-person perspectives of

individuals with autism (Tavernor et al., 2013).

Another problem contributing to the invalid conceptualization of QoL is that well-being

research has rarely considered the unique contributions of the perspectives and knowledges of

individuals with autism. Their ideas about well-being were rarely acknowledged or considered

legitimate by researchers. Instead, operating from a rigid and narrow conception of disability and

its meanings, these "expert" researchers and practitioners posit that individuals with autism are

less than optimal and require fixing, and define what is good *for* them, with an aim to enable

them to function normally in society (Bagatell, 2010; Wolgemuth et al., 2016). It is not

uncommon to see researchers operationalized QoL or well-being as "good outcomes" based on the normality notion that individuals with autism are successful insofar as they achieve the desired outcomes valued by neurotypicals in the majority of society (e.g., Bishop-Fitzpatrick et al., 2016; Helles et al., 2017; Jennes-Coussens et al., 2006; Kamio, Inada, & Koyama, 2013; Lin, 2014). This practice is completely at odd with the neurodiversity movement that views autism (and also other forms of neurodevelopmental differences, such as ADHD) as a variation of human diversity that comprises different combinations of strengths and weaknesses (Fenton & Krahn, 2007). This fundamentally changes how we value and celebrate the differences of neurology and personhood of individuals with autism. More importantly, the neurodiverse perspective re-conceptualizes the difficulties experienced by individuals with autism from something intrapersonal needed to be fixed to the roles an environment has in meeting the needs of individuals with diverse neurological profiles (Kapp, Gillespie-Lynch, Sherman, & Hutman, 2013; Silberman, 2015). This further empowers individuals with autism with the rights to be accommodated or change their environment in order to achieve desirable outcomes that match their innate differences and needs (Baker, 2006; Fenton & Krahn, 2007).

Qualitative Research on Well-being among Individuals with Autism

The degree to which individuals with autism participate in and contribute to the research processes can vary to a considerable extent. For instance, they can be involved in the creation and collection of data to represent their voice in the outcomes of research. Two recent qualitative inquiries conducted in the United Kingdom exemplified how individuals with autism gave input into their own perspectives of well-being. Milton and Sims (2016) searched for the meaning of well-being and social belonging as narrated by individuals with autism in "Asperger United", a magazine run by and for adults with autism. A thematic analysis of textual materials from the

magazine revealed themes that described different ways adults with autism used to reduce stress, fulfil personal needs, and define their own personal identities. Across all the themes identified, adults with autism expressed a strong desire to use their own perspectives to identify ways to meet their personal needs. They also desired to be understood, valued, and acknowledged as an individual on their own terms, instead of being forced to adopt the normalized notion of well-being defined by the neurotypical society. Moreover, they expressed the importance of engaging in self-advocacy work by actively participating in and contributing to different processes of research. Milton and Sims (2016) asserted that:

> … thinking of autistic well-being purely in terms of efforts to remediate the challenges faced by autistic people as if they are a set of 'deficits' is highly limited and potentially counterproductive (as many accounts spoke of needs unrecognised or misinterpreted by professionals). (p. 531)

They suggested interventions that aim to enhance well-being of individuals with autism need to "focus on the personal constructions and interests of the autistic person, rather than being based on normative assumptions" (p. 532).

Parsons (2015) conducted an online survey that asked 55 adults with autism (17 to 59 years old; mean age 34) about their past educational experiences in school and current LS. Among all the categories of questions related to LS (i.e., employment, housing, personal and social relationships, medical, impact of autism, and school), adults with autism rated the lowest satisfaction in employment, followed by their school experiences. Specifically, they were least satisfied with their work situation and the support they received to help them find and stay in a job. In terms of education, they were not satisfied with the amount of information and options given to them to help them with post-school transition as well as the qualifications they earned at

school. A significant correlation was also found between satisfaction with post-school experiences and mean ratings for current LS. Furthermore, despite the fact that about 70% of adults with autism indicated not having friends who they met regularly, they reported relatively high satisfaction in the subscale of personal and social relationships. A closer examination of individual profiles suggested most of these adults had some forms of involvement in at least one social setting (e.g., work, school, community club), rather than having a wide social network. Moreover, 58% indicated that they had friends on the Internet. These findings suggested that "outcomes are very personal, nuanced and context specific" (p. 418). Citing studies conducted by renowned "experts" of autism research, Parsons (2015) urged practitioners and researchers "[not to] assume a normative stance where typical outcomes are judged according to what may be valued as a 'good outcome' by people without autism" (p. 415), but rather to inquire and understand the personal views and experiences of individuals with autism in order to meaningfully enhance their well-being.

Photovoice Research in Autism

Despite the success of the above qualitative studies in gaining the perspective and voice of individuals with autism, one of the biggest limitations was the overreliance on verbal and written language as the media for these individuals to communicate their thoughts and ideas. Individuals with autism exhibit a wide range of abilities and functioning, who at one end, for example, may possess intact language and communication skills, while individuals at the other end of the spectrum may exhibit minimal or emergent verbal and intellectual abilities (Jensen & Spannagel, 2011). Furthermore, individuals with autism are frequently described as "visual learners" and appear to benefit from visual supports for learning and communication (e.g., Tissot & Evans, 2003). There is evidence for superior visual-spatial abilities in individuals with autism

(Samson et al., 2012). Emerging applied research also demonstrated the effectiveness of using multimodal support (e.g., visual aids) to engage individuals with autism in providing input in goal setting and service development (Hodgetts & Park, 2016). Photovoice (Wang & Burris, 1997), an action research tool that involves participants photographing personally relevant things in life around a certain topic and engaging in discussions about the photographs, is potentially promising in capitalizing on their strengths in visual domain and allowing more individuals with various degrees of abilities to express their voice.

Carnahan (2006) reported the use of Photovoice by teachers and students to improve the inclusion experience of students with autism in general education. During the first phase of the research, five kindergarten teachers took pictures about their students with disabilities. Results from four discussion meetings over the period of eight weeks revealed that participation in Photovoice did not only allow teachers to voice their needs and concerns on how to effectively include students with autism in general education settings, but also provided teachers opportunities to reflect on these students' meaningful contributions to the classroom environment and to commit to learning using more strategies to support the inclusion of these students. In the second phase, the teachers recruited two students with autism, who had minimal verbal communication skills and participated only partially in general education classrooms, and five typically developing peers to photograph objects or activities of their interests. Observation by the teachers during the group sessions revealed that the two students with autism demonstrated sustained attention and active engagement in the Photovoice activities, possibly due to the use of structured guidelines and visual materials of their interests. More importantly, these students were indeed interested in interacting with their typically developing peers without the need of adult prompting. The use of Photovoice in this study did not only promote teachers' ownership

and empathy towards their students with autism participating in inclusive settings, but also created a suitable learning environment in which these students were able to showcase their potentials to learn.

Obrusnikova and Cavalier (2011) used Photovoice to explore factors that promote and prevent after-school participation in physical activity from the perspective of children with autism. Fourteen children of ages 8 to 14 years with autism and adequate communication ability participated in the study, which involved data collection using accelerometers and Photovoice procedures. Children with autism were asked to photograph things that made it easy or hard for them to exercise after school in a two-week period. They then participated in an online survey and an in-person individual interview to provide input about the reasons for taking their photographs and to identify motivation to exercise in their daily environments. Descriptions and interpretations of photos were categorized as either barriers or facilitators in intrapersonal, interpersonal, physical, and community/institutional levels. The most common perceived factors that influenced their exercise level were intrapersonal in nature, such as their preference for technology-based activities over physical exercise. However, such technology as games was also identified to be a potential medium to engage children with autism in exercise. Another oft-cited barrier was their difficulties in motor skills. Children with autism also identified social support and resources for exercise as important to them. This Photovoice project allowed children with autism to directly represent their voice in the findings, which had practical implications for practitioners and policy-makers to develop health-promotion exercise interventions and obesity prevention programs that tailor to the needs and interests of youth with autism.

Recognizing the powerful applicability and potential implications of Photovoice to give voice to and empower individuals with autism, albeit without explicit discussions of its

adaptations to this population (Carnahan, 2006; Obrusnikova & Cavalier, 2011), Ha and Whittaker (2016) examined the challenges in conducting Photovoice with youth with autism and described how this tool was modified to be appropriate and responsive to their unique needs. Nine youth with autism of ages from 10 to 17 years old with a wide range of verbal abilities participated in a Photovoice project that aimed to understand the lived experiences and well-being of children with autism and their families in Vietnam. To support these children to follow through all the procedures structured by the researchers, the photographing processes, for example, were modified to allow them to take pictures according to their own interests. The most important adaptation occurred in the data analysis stage, in which discussion questions were flexibly adapted to shorter questions and simple prompts, and additional information were collected through direct observations and parent interviews to help contextualize and triangulate with the data from child interviews. It was shown that initial interpretations of photographs by researchers or parents might not resemble what the children intended to communicate, but using multiple data sources from different informants likely increased the accuracy of analysis. For example, a photo that captured an empty space was perceived by the first author and the child's mother as not immediately interesting, until they later found out from the child that she wanted to show the sense of emptiness after a school party. Ha and Whittaker (2016) cautioned future endeavor of Photovoice with individuals with autism:

> … not to make assumptions about the photographs. The intention with which these photographs were taken and their aesthetic values remind us that these are artistic expressions and forms of communication, not only photographs by children with autism or products of their disabilities. Children with ASD had their own perspectives and often

surprised us with what they were trying to express. The challenge was how to give them

opportunities to explain what they thought to us. (p.559)

Past Photovoice research applied in the autism population have almost exclusively

focused on children and adolescents. Only one group of researchers has recently extended this

line of research to individuals with autism in early adulthood (Cheak-Zamora et al., 2018;

Cheak-Zamora, Teti, & Maurer-Batjer, & Halloran, 2016; Teti, Cheak-Zamora, Lolli, & Maurer-

Batjer, 2016). Eleven young adults with ASD of ages 18 to 23 and a wide range of intelligence

functioning participated in a Photovoice project to explore their experiences as young adults with

ASD transitioning to adulthood. Thematic analysis based on the photographs taken by the

participants and the discussions in group and individual sessions revealed issues that they

deemed important, including different challenges and resources in post-school transition and

socialization (Cheak-Zamora et al., 2018), transitioning into adulthood (Cheak-Zamora et al.,

2016), and the discovery of their strengths and resilience (Teti et al., 2016). Regarding

difficulties in transition and social life (Cheak-Zamora et al., 2018), young adults with autism

described feeling nervous and worried about transitioning to adulthood as they perceived

numerous challenges in such tasks as getting a job and living independently. They expressed a

strong desire for friendship and social life, while being cognizant of their own differences and

challenges because of their autism. A majority of these individuals also identified their pets and

animals in general as a means for coping with emotional distress and a source of companionship.

Regarding their descriptions of transition to adulthood (Cheak-Zamora et al., 2016), young adults

with autism posited that they were still in the progress of becoming an adult, while perceiving

the meanings of adulthood in terms of having control in life, accepting responsibilities, and

acquiring working and earning capacities. Most of them expressed a strong desire for

independent living, despite the need for continued assistance. They also identified different goals in their future jobs and careers. In terms of strengths and resilience (Teti et al., 2016), young adults with autism described their special interests that cultivated positive emotions and helped them cope with negative emotions. They also showed a variety of skills and activities that they were proud of, such as cooking, animal care, and awards. Most importantly, through their participation in the Photovoice project, young adults with autism wanted others to know their important attributes, saw their past challenges from a new perspective, and discovered in themselves their own abilities, strengths, and possibilities, all of which conveyed a message to reframe autism as their unique self versus a deficit.

The three manuscripts discussed above provided initial evidence that Photovoice can be a promising tool in eliciting the perspectives of young adults with autism about their lived experiences. What was different in the Photovoice project by this group of researchers was their use of group discussion sessions, which were reportedly enjoyed by the participants with autism because of the opportunities for them to be around people who shared similar situations and to form relationships with each other (Cheak-Zamora et al., 2018; Cheak-Zamora et al., 2016; Teti et al., 2016). More importantly, the group of young adults with autism and research facilitators together planned and organized a public photo exhibit, which provided a powerful means for advocacy through communicating their perspectives and raising awareness in the general public.

Purpose of Study

The literature reviewed above suggested that well-being research in the autism population suffers from the problems of poor conceptualization of wellness constructs and misrepresentation of the perspective of individuals with autism. I adopted a participatory action research (PAR) approach in this Photovoice project encouraged their active participation and allowed their voice

to be meaningfully expressed and heard through the research processes. The primary purpose of this study was to understand well-being as perceived and defined by young adults with autism. I was also interested in learning what things, events, and/or situations enhance their well-being. I made an intentional choice to approach my participants with this broad research purpose at the beginning of the project, so I could remain open to their ideas of well-being and what they wanted to learn about through this study. As described in the following chapters, this research purpose was constantly discussed and negotiated with the participants, and gradually morphed into several specific research questions driven by their input.

CHAPTER 3

METHOD

In the previous chapter, I reviewed the literature on well-being in the context of post-school transition in young adults with autism. The lack of autism-sensitive conceptualization of well-being argues for the need to explore the first-person perspective and definition of well-being with active input and involvement of individuals with autism. The current chapter first presents the research paradigm that informed the design of the study. I describe the setting and participants, followed by data collection and analysis procedures. Then, I delineate different ethical considerations throughout the development and implementation of the study, on which the evaluation of validity and quality of this project should be based.

Research Paradigm

A research paradigm is a set of beliefs that describes the overarching worldview and beliefs that guide considerations and practices in a research. In this current study, I adopted the premises of participatory orientation as my primary theoretical paradigm, while basing my ontological and epistemological assumptions on constructivist traditions. According to Denzin and Lincoln (2011), researchers can draw from multiple paradigms that are compatible to guide the development of a qualitative research. In fact, Howell (2013) recognized the similarities in the ontological and epistemological stance of these two approaches and described them as a single paradigm of inquiry that involves close collaboration between researchers and participants to create locally constructed knowledge with emancipatory and transformative purposes.

Constructivism posits that reality is subjective and is locally constructed within the social context in which people are situated (Crotty, 1998). There is no one single truth, but are multiple realities, which produce different understandings of knowledge that exist among people and their contexts in a relational manner. Constructivism seeks to understand a phenomenon from the multiple perspectives and realities of the people experiencing the situation. This study aligns with constructivism as the inquiry focused on how young adults with autism subjectively constructed their understanding of well-being as they saw and experienced in their immediate contexts and environments. I reflected on my own worldview and became aware of how it influenced how I described the participants' own experiences and meanings as related to them. Kemmis (2012) also reminded researchers of the potential danger of imposing one's own self-interests onto participants'. Recognizing that I myself am *not* a neutral or value-free subject in the study, I constantly reflected on my assumptions and beliefs and described how my perspective contributed to the realities constructed in this research to make explicit my roles in the knowledge production processes.

Acknowledging my role as an inquirer in the process of co-constructing knowledge with my participants, I did not position myself as a data miner who entered the young adults' world to gather and repackage their experiences as a research product. Hence, my reflective practices did not intend to privilege myself in an objective status alleging to achieving a complete understanding of my participants' knowledge. Rather, I adopted critical feminist Donna Haraway's (1988) version of objectivity that "turns out to be about particular and specific embodiment and definitely not about the false vision promising transcendence of all limits and responsibility. … It allows us to become answerable for what we learn how to see" (pp. 582-583). Therefore, I adopted a more radical form of constructivist paradigm in this study that deals

with situated knowledge that is positioned, partial, and engaged, instead of single, universal, or deterministic (Haraway, 1988). It is from this standpoint epistemology that I took into consideration the agency of my participants as well as the ethics and politics being negotiated in the producing/product of knowledge (Harding, 1992).

Drawing from the orientation of participatory action research (PAR), this study was conducted *with* the participants rather than *on* them (Kemmis & Wilkinson, 1998). According to Kemmis and McTaggart (2005), PAR is a collaborative learning process involving cycles of self-reflection that begin with planning, acting, observing, reflecting, to replanning and subsequent recursive reflection, discussion, and reconstruction that lead to transformation of social practices. More specifically, PAR is distinctive in terms of seven characteristics: (1) PAR is *a social process* that explores the relationships between individuals and their social environment; (2) PAR is *participatory*, engaging people in examining their understandings, skills, and values in the social world where they make meaning, interact with, and have influence on each other; (3) PAR is *practical and collaborative*, exploring the practices that involve people's social interaction; (4) PAR is *emancipatory*, aiming to help liberate people from the constraints of social structures and practices that stifle self-determination; (5) PAR is *critical,* helping people to contest social discourses, power struggles, and ways of work that applied on them; (6) PAR is *reflexive*, involving recursive actions of investigation and transformation; and (7) PAR aims to *transform both theory and practice* by placing both theory and practice on an equal emphasis that informs each other to ultimately influence the life of people in their local contexts. In this study, participants were engaged in the research processes at various degrees. Although I encouraged their involvement as much as possible, recognizing the different motivation and

comfort levels among individual participants, I deferred to their individual discretions with regards to the degree of involvement they desired in different phases of the study.

As outlined in the next section, it is clear that the general methodology and philosophical underpinnings of Photovoice are consistent with the critical constructivist and participatory paradigms of this study. As described by Wang and Redwood-Jones (2001), the development of Photovoice drew from three major orientations, namely critical education, feminism, and community-based photography. Not only did I draw from feminist traditions to understand people with autism as a disenfranchised group overpowered by the dominant culture, but also shared Freire's (1970) commitment to dialogue and consciousness-raising by creating a research opportunity to think critically about claims and questions of reality and knowledge that have meaningful contributions to their lives. By using Photovoice, "[because] virtually anyone can learn to use a camera, … people with socially stigmatized health conditions or status … often have an expertise and insight into their own communities and worlds that professionals and outsiders lack" (Wang & Redwood-Jones, 2001, p. 370). Using the technique of photography, Photovoice served to promote active citizen participation to reflect the interests of the community with which participants identified, instead of fulfilling the agenda of researchers. Taken together, this study shared explicit connections with critical autism studies (Davidson & Orsini, 2013), and critical disability studies in general (Goodley, 2013), to interrogate the power relations that shape the field of autism and the ideologies of the dominant constructions by using inclusive and non-reductive epistemological stances and methodological frameworks, altogether of which challenges the dominant discourse that violently pathologizes the autism community and naturalizes the assumption of a non-autistic worldview (O'Dell, Rosqvist, Ortega, Brownlow, & Orsini, 2016).

Research Design

The primary design of the study involved the methodology of Photovoice, which is characterized by participants carrying a camera with them for a period of time and taking pictures in everyday life that represent the issues or problems identified as the focus of the study. It is a methodology originally developed by Wang and colleagues to improve health conditions and promote healthcare services among women in a rural Chinese community (Wang & Burris, 1997). Broadly speaking, Photovoice aims to (a) enable participants to document and reflect their resources and barriers in their immediate community; (b) use the photos to engender critical dialogue and generate knowledge to solve social issues; and (c) produce findings that can effect change and reach policy makers (Wang & Burris, 1997).

Discussing the photographs taken is as important as photo-taking itself. It is therefore important to discern the design of the discussion process. As outlined by Wang and Burris (1997), photo discussion aims to let participants reflect on the photographs they produce and understand how they use the photographs to represent the identified issue, here as the meaning of well-being to young adults with autism. Consistent with the paradigms of the study, the knowledge generated through the discussions among participants and I was viewed as "produced", "relational", "conversational", "contextual", "linguistic", "narrative", and "pragmatic" (Brinkmann & Kvale, 2015). I treated participants' photos as an integral, but not exclusive, source of data. Using photographs as a conversation starter, participants also talked about their ideas of well-being that were not necessarily captured in the visual elements.

It is important to discuss the meaning of "participation" in this PAR. As warned by McIntyre (2008) and Patton (2015), participants in PAR need to be involved in a meaningful manner rather than merely using the term "participatory" without an authentic quality of

participation. It is therefore of paramount importance to delineate the parameters of

"participation" in the study. As pointed out by veteran PAR researchers (e.g., McIntyre, 2008;

Wang, Yi, Tao, & Carovano, 1998), there could be various levels of involvement of participants

in different stages of study. As cited in Wang et al. (1998), Biggs (1989) described four levels of

participant involvement, namely contractual, consultative, collaborative, and collegiate (in the

order of increasing levels of participation). In this study, I was the primary researcher who

initiated the research idea and suggested the broad goal to explore well-being in young adults

with autism, while the participants were recruited to participate on a voluntary basis (i.e.,

contractual). They were encouraged to speak for their own data and suggest how their data

should be interpreted (i.e., consultative). Moreover, they were invited to have a high degree of

active participation and ownership in the entire research process (i.e., collaborative). For

example, I regularly asked the participants to provide input as to what they want to explore about

their well-being and how to improve how I ran the sessions. In the data collection and analysis

stage, at least some participants were involved in processing data, producing results, and

interpreting findings, which acknowledged their knowledge and skills brought to the PAR

process (i.e., collegiate). As described in the sections below, in the current project, I did explain

these concepts of participation to the participants and encouraged them to be actively involved in

the PAR process to the fullest extent as possible. However, it was the discretion of individual

participants to decide how and to what extent they wanted to participate in each stage of the

research.

Sample

Setting

The Learning Academy (TLA) at the University of South Florida is a post-school transition program designed for young adults with ASD between the ages of 18 and 25. Students admitted to TLA were all screened for either a clinical diagnosis or an educational classification of autism. TLA is a 30-week program housed in the University of South Florida (USF) where students attend classes following the university academic calendar and have access to campus facilities. TLA provides services, supports, and experiential opportunities that enable students to achieve independence and meet their personal goals in the workplace and postsecondary education settings. Students engage in self-discovery and career exploration through classwork, internship, and mentoring activities. Examples of topics include self-knowledge, organization, time management, goal setting, conflict resolution, and community participation.

Throughout the school year, TLA students attend classes Monday through Thursday from 9am to 12pm. In the Spring semester, they also spend additional four hours per week either completing a job internship in the community or attending a college preparation class. Each TLA student is also matched to a mentor, who is a USF student. Throughout the year, individual students and mentors meet four hours per week to practice concepts and skills learned in class as well as engage in social activities.

Participant Recruitment

Purposeful sampling was used to recruit participants for this study. I contacted TLA and presented my project ideas to the staff. The instructor of TLA, Ms. Maria, agreed to incorporate this project into the regular class time of TLA. She described this project as a natural extension of what they had done in class earlier in the school year. Ms. Maria also led a photography

activity before in which TLA students went across the university campus and took pictures to familiarize themselves with the environment. Ms. Maria indicated that the students do well with language, writing, and group work, so she did not foresee any difficulties for them to participate in photography and discussion activities.

In February 2017, I visited two TLA classes across two weeks to introduce myself and the project idea. Most of the students expressed interest and enthusiasm in participating in the project. A few students were more hesitant but could go along with the class. Therefore, all young adults with autism in TLA were considered "participating" in the project, albeit in various degrees, as detailed in the next chapter. I encouraged all of them to talk to their families and trusted adults to help them make more informed decisions. Despite their different comfort levels and readiness, all 14 young adults signed the informed consent forms at different times of the project and formally agreed to participate in this study.

Later in the project, the students were also interested in learning about well-being from the perspectives of people without autism. They collectively decided that TLA instructors (Ms. Maria, Ms. Carmen, and Ms. Smith) and I should also participate in the project activities. Ms. Maria, Ms. Carmen, and Ms. Smith agreed to participate and signed the informed consent forms.

Inclusion Criteria

1. Individuals had a diagnosis or classification of autism.

Students admitted to TLA were all screened for either a clinical diagnosis or an educational classification of autism. No record review was conducted to verify the participants' diagnoses.

2. Individuals had exited secondary school within the past seven years.

Participants should have either graduated from or terminated their secondary education within the past seven years. Participants who were currently enrolled in postsecondary education or

training, such as college or university education, vocational training, and transition program, were also eligible for the study.

3. Individuals were 18 years old or above.

Participants of age 18 or above were able to give full consent on their own behalf for their research participation. No participants reported guardianship by their parents or caregivers.

4. Individuals must have an identified functional communication system.

Due to the demand of communication abilities in the Photovoice discussion, participants must have an identified means for communication to participate. All participants were able to use verbal language to communicate and participate in conversations and discussions.

Participant Descriptions

Fourteen students in TLA participated in the project. This sample size was comparable to past Photovoice research with general community participants (Catalani & Minkler, 2010) and with individuals with autism (Cheak-Zamora et al., 2018; Ha & Whittaker, 2016; Obrusnikova & Cavalier, 2011), as well as the scope of qualitative research projects in general (Baker & Edwards, 2012).

TLA students self-reported their demographic information (Table 1). In this group of TLA students, 9 (64%) were male. Their ages ranged from 19 to 25. Majority identified themselves as Caucasian/White (57%), followed by Hispanic/Latino (21%), Other: Mixed (14%), and Asian (7%). Majority were high school graduates (86%), and some had college experience (14%). All of them graduated from high school within the past six years. With regard to current living condition, majority lived with their family or caregivers (86%), and some lived with roommates (14%). As a part of TLA program, majority decided to complete a job internship (71%) while others attended the college prep class (29%).

Table 1.
Demographic Information of TLA Students.

Pseudonym[a]	Age	Gender	Race/Ethnicity	Highest level of education	Number of years post-high school	Current living condition	Internship/College option in TLA
JC	19	Male	Caucasian/White	High school	1	With family/caregivers	Internship
Roy	24	Male	Other (Mixed)	High school	5	With family/caregivers	Internship
Luka	20	Female	Caucasian/White	High school	2	With family/caregivers	Internship
Taiki	24	Male	Asian	High school	6	With family/caregivers	Internship
Darth	21	Female	Caucasian/White	High school	1	With family/caregivers	College
Alan	19	Male	Caucasian/White	High school	1	With family/caregivers	College
Christopher	21	Male	Hispanic/Latino	High school	2	With family/caregivers	Internship
John	20	Male	Hispanic/Latino	High school	2	With family/caregivers	Internship
Janiquaa	19	Female	Other: Caucasian/White & African American/Black	High school	1	With family/caregivers	College
Ace	25	Male	Caucasian/White	High school	6	With family/caregivers	Internship
Scarlet	20	Female	Caucasian/White	High school	2	With roommates	Internship
Bob	21	Male	Caucasian/White	Some college	3	With roommates	Internship
Nick	21	Male	Hispanic/Latino	High school	3	With family/caregivers	Internship
Micheal	20	Female	Caucasian/White	High school	1	With family/caregivers	College

[a] Students selected their own choice of pseudonyms.

Later in the research process, the students decided to also include the three instructors of TLA and I in taking part in the project. Therefore, here I also presented the background information of these three instructors.

Ms. Maria was the primary instructor of TLA and had been working for TLA for 7 years. She provided both instructional and employment services to TLA students. She had over 15 years of experience working with children and adults with developmental disabilities. She held a Master of Social Work and had a Bachelor's degree in Music Therapy.

At the time of the project, Ms. Carmen was preparing to become an instructor for TLA in another University campus. Prior to coming to TLA, she was a certified special education teacher and had worked with students from a variety of backgrounds since 2004.

For the duration of the project, Ms. Smith was a master's level student completing her internship as a part of the program in Rehabilitation and Mental Health Counseling. She had an undergraduate degree in Human Development and has been working with individuals with disabilities as a volunteer for the last six years. She also achieved national certification as a rehabilitation counselor. Ms. Smith used a guide dog for mobility, who came to class with her every day and became quite fond of all the students at TLA.

<div align="center">**Data Collection**</div>

Below I describe how I prepared and conducted the Photovoice sessions to collect different sources of data.

Introductory Session

Training. The training covered topics on the rules and ethics of camera use and photography, consent form, and initial project ideas. I conducted a didactic lecture to present on these topics. I used many photo examples to illustrate the scope of the project and different

ethical considerations. I also used a variety of instructional strategies, including questions, discussions, and role play, to actively engage the participants and assess their understanding of the contents.

Below I described the contents of the training in details. I introduced the use of camera and photography by posting the following questions: (1) How do people use camera and photos in everyday life? (2) What can a camera do that is so powerful? (3) What are some good and bad intentions of taking pictures using a camera? These questions were to illustrate the power and authority that come with the use of camera and photos. I stressed the importance to take personal responsibility and build trust with people in the community while participating in this project. I then gave more in-depth explanations of three ethical principles, namely safety, respect, and justice (Wang & Redwood-Jones, 2001). Regarding safety, participants were reminded to make sure they are not in an unsafe or inappropriate situation to use a camera (e.g., crossing a road, in a bathroom, involving in a police investigation). When in doubt of any kinds, they were told to not take any risks, and no photograph should be taken. Regarding respect, participants were taught the ethics involved in taking pictures as related to privacy law (Gross, Katz, & Ruby, 1988 as cited in Wang & Redwood-Jones, 2001). Pictures taken by participants (1) must not intrude into one's privacy even in a public space; (2) must not disclose embarrassing facts about individuals; (3) must not place individuals in a false light; and (4) must not be taken advantage of for profit. Participants were instructed to make every possible effort to obtain permission from their photo targets using a consent form that gives brief information about the project and explains their rights to refuse to participate (Appendix A). Regarding justice, participants were reminded to not take pictures that are illegal, obscene, unsafe, or disrespectful. Participants were shown examples and non-examples of appropriate photos to illustrate these ethical principles. At

the end of the training, I led a practice activity by asking the students to form pairs and go around to take photos using their cellphone.

      Consent process. At the end of the introductory session, I distributed the informed consent forms approved by USF IRB (Pro # 29276) to the participants (Appendix A). I explained the information on the consent forms with the participants, stressing the importance of confidentiality and voluntary participation, and the considerations of potential costs, benefits, and risks. I also reviewed the different levels of involvement participants can choose to participate, ranging from sitting back and listening to actively discussing and contributing their ideas to the project. I especially highlighted the fact that participants have the right to decide and change their level of participation anytime throughout the project. I also encouraged them to discuss their participation with their family and teachers. Participants later signed their consent forms and were given a copy of their forms. Ten students submitted their signed the consent forms after the first discussion session. The remaining four students (Ace, Alan, Scarlet, and Taiki) signed their forms in later sessions.

Subsequent Sessions

      Here I describe the general data collection procedures for photo-taking and photo discussions. The data collection period lasted for six weeks. I asked participants to use the camera function on their cellphones to take photos in daily lives to represent their well-being. All participants and I reconvened weekly to discuss the photos we captured. In every session, participants took turn presenting their photos to the group and discussed how the photos show their well-being. I adopted the following discussion procedures based on the literature of the original Photovoice (Wang et al., 1998) and its application with young adults with autism (Cheak-Zamora et al., 2018). First, participants reviewed and selected one or more photos they

found most important for them to discuss. Second, discussions were focused on delineating the meaning as to how the photos captured the participants' well-being. Specifically, I facilitated the discussions using open-ended, root-cause questions guided by the "SHOWeD" acronym (Wallerstein, 1987). Examples of questions were: What do you <u>S</u>ee in the pictures? What is <u>H</u>appening here? How does it relate to <u>O</u>ur well-being (i.e., participants' well-being)? <u>W</u>hy does this problem/challenge/strength <u>e</u>xist? What can we <u>D</u>o about it? The purpose of using these questioning techniques is "to identify the problem or the asset, critically discuss the roots of the situation, and develop strategies for changing the situation" (Wang et al., 1998, p. 80). Applied to this study, the goals of the discussions were to explore the meanings of well-being to the participants, to identify their community assets and strengths, and to explore what changes they want to see in their lives.

All the weekly sessions were audio-recorded. Each session lasted approximately one hour. After every session, I collected feedback from all participants using verbal (i.e., directly asked about their experience) and written formats (i.e., using a feedback form). Specifically, I asked them about something they like or did not like about the sessions and encouraged them to raise additional questions or concerns that were not addressed during the sessions. I used their feedback to identify themes and issues came up during the discussions to inform my plan for subsequent sessions. I also kept a reflective journal that recorded my observations, thoughts, and ideas throughout the entire research processes to inform data analysis.

While the photo discussions were held regularly in every session, participants and I also spent time talking about different design and analysis issues about the project. For example, in sessions one and two, I reviewed and practiced with the students about the steps to ask other people's permission to be photographed. Specifically, I asked them to (1) introduce themselves,

(2) give a brief description of the project using a photo target consent form (Appendix B) or its pocket-size version (Appendix C), (3) ask if the person would like to be photographed, and (4) obtain a signed consent form from the person and take a photo or discontinue the activity if no permission can be obtained.

In session three, I introduced an online Photovoice platform, PhotovoiceKit (http://photovoicekit.org/; Strack et al., 2015), to facilitate the collection of photos from the participants. Due to technical difficulties and ongoing consultation with the original developer, this platform was not available earlier in the project. I instructed participants to (1) sign up and activate an account, (2) watch training videos to learn to use the platform, (3) upload their photos onto the platform, and (4) add titles and captions. Thereafter, participants were able to upload photos anytime using their own electronic devices. I served as the platform manager to monitor and organize the process. For any photos uploaded, I had to approve the submissions before the photos could be displayed in the gallery of this project platform. Following this session, I was able to show their photos in front of the group while facilitating the discussions.

In sessions four and five, I reviewed some of the comments I received in the feedback forms. The students, the instructors, and I collectively discussed and addressed some lingering questions and concerns about the project, such as ways to structure individuals' speaking time and what should be considered on or off topic. The group also discussed the specifics about our research questions as related to their well-being. More detailed descriptions of these discussions were presented in Chapter 4.

At the end of session six (i.e., the last session), I prepared the printed copies of the photos and handed them back to the young adults and instructors. I suggested them give these photos

back to the people they photographed. They also had different ideas about how to deal with these photos, such as sharing with others and keeping them in a photo album.

Data Analysis

Research Questions

      I invited interested students to meet with me to discuss the plan for data analysis. One student, Luka, attended the meeting and provided input. We discussed what participants wanted to know and achieve from the project, how we wanted to make sense of the data collected, and ways to disseminate the project results. We reviewed transcripts to recall what ideas participants had suggested previously. I later reviewed all the photos, session transcripts, and my reflection journals to identify important themes and questions emerged from the project. After I came up with a list of research questions, Luka and Ms. Maria also provided feedback to finalize the questions. Here are the final research questions that guided the data analysis of this project:

1. How do young adults with autism communicate their understandings of well-being?

2. How similarly or differently do people without autism understand well-being in autism?

3. What understandings of well-being and autism do young adults with autism want to challenge?

4. How do young adults with autism want to share their understandings about well-being and autism with people outside TLA?

      It is also noteworthy that the data processing and analysis processes described below (other than transcription) took placed in a six-month period, during which Luka, Ms. Maria, and I met regularly on phone to discuss progress and decisions about research issues and findings.

Data Sources

I audio-recorded all the sessions and later transcribed them into texts. Identifiable information was removed and pseudonyms were used in the transcripts. I conducted member check with some of the participants to clarify inaudible passages of the recordings.

To answer the question of how young adults with autism showed their understanding of well-being, the major sources of data were: (1) photos submitted to the PhotovoiceKit platform (including the titles and captions), (2) transcripts corresponding to the discussions of the photos, (3) transcripts or written responses of the individual interviews about well-being, and (4) additional photos students submitted for the graduation PowerPoint presentation.

Regarding the Photovoice process, the following data sources were used: (1) transcripts corresponding to the discussions of the project, (2) my reflection journals, (3) an analysis trail that I documented how participants and I engaged in the data analysis processes and made different decisions, and (4) feedback forms I collected from the participants after each session.

Research Ethics Training

Since I anticipated the prolonged and extensive involvement of Luka and Ms. Maria in processing and analyzing data of other participants in the project, I conducted a research ethics training to enhance their understanding of research and ensure their adherence to ethical principles in research. I conducted the ethics training using the Community-Partnered Research Ethics Training and Certification (CPRET, http://www.ctsi.pitt.edu/research-community-cpret.html; see Yonas et al., 2016). It was designed for academic researchers to train community partners of basic research ethics by defining and reviewing principles and ethical considerations in conducting research. Topics included definition of research, historical development of ethical guidelines and IRB, qualities of good and bad research ethics, community partners' roles in

research, informed consent process, and confidentiality. I also adapted the scenarios provided in the CPRET to illustrate the application of different ethical principles in the current project. I provided Luka and Ms. Maria with the CPRET package and reviewed the contents with them individually via phone. I frequently checked their understanding of the materials throughout the training by soliciting their verbal feedback and answering their clarifying questions. Since most of the topics were already covered in the training during the introductory session of the project (e.g., consent process, risks and benefits, ethical research), they had no difficulty understanding the contents of the training. At the end of the training, I reviewed and asked them to voluntarily sign a pledge statement and a confidentiality agreement to document their completion of the training and their consent to comply with the ethical principles.

Coding

The coding process was primarily informed by Saldaña (2016). Taking into considerations factors such as access to computer programs, level of computer knowledge, and the ease of participation, I decided to perform the coding and analysis using the comment function in Microsoft Word, Microsoft PowerPoint, and Adobe Acrobat Reader DC for ease of participation.

Luka, Ms. Maria, and I closely read and studied the data (i.e., photos, session discussions, well-being interviews, and graduation presentation) to familiarize ourselves with the contents. While keeping the research questions in mind, we individually jotted down our initial thoughts on how the data answered each of the questions. Although no formal structures were determined for this initial jotting activity, the majority of notes resembled descriptive codes, *in vivo* codes, process codes, concept codes, and value codes (Saldaña, 2016). We then reconvened to discuss our initial comments and identify emerging patterns from the data. We decided that we needed a

more focused method to organize the data into more manageable units that would be more easily understandable. I introduced the methods of coding and visual analysis. We collectively decided to perform coding to help us see the pattern among the data. We reviewed our initial comments and suggested codes based on the common themes of how we described the participants' ideas of well-being. I then reviewed all the data to revise the codes and develop a codebook. The codes in the codebook included: (A) Family, (B) Friends, (C) Animals, (D) Art, (E) Nature, (F) Community, (G) Self, (H) Favorite time and space, (I) Interests and entertainment, and (N) Others. All of us reviewed the codebook, discussed the definitions and meanings of the codes, and practiced the coding process with samples of the data. We then individually coded all the data (i.e., photos and transcripts), and periodically reviewed the codebook to ensure the codes can adequately capture all the data. Furthermore, we recognized that it was important to pay attention to the reasons why certain thing represents one's well-being, so we decided to also describe the values and meanings of every code we assigned. After the initial round of coding, we compared our codes and resolved any inconsistency to arrive at a final set of coded data.

I then trained Luka and Ms. Maria in writing analytic memos using the descriptions by Saldaña (2016, pp. 44-54). We individually wrote memos to document our reflections on our coded data, the coding processes, and this research project in general. We also drew from the comments we made during our initial jotting to elaborate our memos.

Content Analysis of Visual Images

Content analysis of visual images is an easily understandable and communicable method to engage participants with autism in analyzing photos into meaningful units (Ha & Whittaker, 2016). Based on the codes assigned to the photos, Luka and I sorted all the photos into categories based on their visual characteristics (Bell, 2010; Bock, Isermann, & Knieper, 2011). For lost

photos that were mentioned during the discussions, we inferred the visual contents from the students' descriptions. While this analysis primarily focused on the visual elements of participants' photos, we contextualized our analysis with participants' intended meanings to avoid literal interpretation of their photos. For example, a photo of a stuffed animal was categorized as "family" instead of "art" or "interests" because the participant expressed that the stuffed animal was a symbolic representation of her grandmother.

Thematic Analysis

A thematic analysis was conducted to generate overall findings of the project (Braun & Clarke, 2006; Saldaña, 2016). Based on the coded data and the categories of visual images, Luka and I identified overall patterns and themes that meaningfully represent and organize the codes as a coherent whole to answer the research questions. Luka and I continually reviewed and reorganized the themes generated from the coded data to best capture the meanings of the data. I created this written report that presents the findings to answer the research questions within the contexts of this project and the broader literature. Luka also regularly reviewed the report and provided feedback to ensure my writing accurately represented the points of view of the students. Later, Ms. Maria and Roy also reviewed the final themes and endorsed our analysis.

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Ethical Considerations and Validity Criteria

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Different ethical issues were considered and discussed throughout the descriptions of the study design. Below I presented some broad ethical principles in guiding the implementation of this Photovoice project as related to its procedural integrity. I described the costs and benefits incurred to the participants and me that I observed throughout the project. These ethical considerations comprised the foundation on which the validity quality of this study was to be

established. I also drew from the validity criteria described in other PAR projects as a basis

against which the current study should be evaluated.

Ethics in Photovoice Procedures

Based on their experiences in conducting Photovoice with youths and adults for

community-based violence prevention, Wang and Redwood-Jones (2001) offered a rich

discussion of the ethics involved in carrying out Photovoice procedures as related to privacy and

the use of camera. Below were considered "minimum best practices" (pp. 569-570) that I

implemented to protect both participants and other people in the community.

To protect both the safety of the participants and the privacy of individuals being

photographed, I trained the participants to use two different consent forms that served different

purposes (Wang & Redwood-Jones, 2001). As described in the "Training" section, a traditional

research consent form (Appendix A) was used to detail the information about the research

project and to ask participants to give consent for their voluntary participation. Specifically, the

protocol specified that the participants' private information would be deidentified before being

turned into publications. The consent form was designed to include a range of potential activities

instead of predetermined procedures to allow flexibility for participants and me to collectively

decide a research plan that best fit our circumstances. For example, it explicitly stated,

"Depending on your willingness, you may participate in <u>some or all</u> [original emphasis] of the

following processes," and included activities from designing the study, analyzing data, to

disseminating project results.

A second consent form (Appendixes B and C) was given to participants to obtain

voluntary consent from the people they chose to photograph. This consent form served to protect

the privacy of photo targets by explaining their rights to refuse to participate. Participants needed

to obtain consent before they took any photos that target specific people. Throughout the project, I reviewed all the photos submitted and provided feedback to the participants on ethical adherence. In some cases, participants who failed to document the consent were sent back to obtain signatures from the people captured. On this consent form, there was no mentioning of autism to protect the privacy of the participants. I respect their right to choose to or not to disclose their disability status at their own discretion. I also created a "pocket" version so that participants could carry these around more easily. In one case, a student submitted a photo of his deceased family members, who were not able to provide consents. The student was allowed to use this photo and share about his family as this was not considered disclosing private information beyond his right to do so.

In terms of ethics trainings for the participants, I conducted a training session at the beginning of the project delineating different ethical considerations of participating in this project, including ethical use of camera, personal safety, and respect for other people's privacy. Considering the learning needs and information processing style of individuals with autism, I presented these concepts in easy languages and concrete examples using different instructional strategies (e.g., multiple exemplars, visual presentations, role play, discussions). I also frequently assessed, reviewed, and reinforced their understanding during the training and throughout the project. Later in the data analysis phase, I recognized the needs for additional ethics training to equip Luka and Ms. Maria with more in-depth knowledge of research so that they would be able to understand a broader picture of conducting research and to make more informed decisions in their processing of data (McIntyre, 2008).

In cases when participants shared emotional topics, such as their lost family members, the participants were more susceptible to emotional distress. However, participants were observed to

show only brief moments of sadness. More importantly, when two participants explained how their lost family members contributed to their well-being, they described them as sources of inspiration and encouragement for them to live in the present. This seemed to be a positive meaning making moment rather than an enduringly negative emotional experience.

Validity Evaluation in PAR

The effort to establish "valid" PAR recalls the deliberate commitment of developing such methodology as a poststructural approach to challenge the reductionist nature of validity dominated in the discourse of positivist research (McTaggart, 1998; van der Riet, 2008). As PAR being a versatile research paradigm can take different forms and achieve different purposes, the literature does not prescribe a list of set criteria that are considered best indicators of a valid PAR. Indeed, researchers need to draw from multiple sources of writings about its epistemology and methodology to evaluate whether the project achieves what it claims and supposes to achieve (e.g., McIntyre, 2008; McTaggart, 1998; van der Riet, 2008). In the following evaluation, validity is established through the philosophical and epistemological foundations from which this project drew, including critical theory, feminist theory, and social constructivism. Specifically, the concept of trustworthiness is useful here in discerning the validity evaluation of the analysis and results of this project (Guba & Lincoln, 1989; Lincoln, 1995).

One of the validity features of PAR entails highly contextualized descriptions of the phenomenon of interest so that local knowledge of the community can be documented (McTaggart, 1998; van der Riet, 2008). As multiple perspectives were expressed on different issues, knowledge about well-being was socially constructed and negotiated throughout the sessions. This was evidenced in the detailed descriptions of the Photovoice processes (Chapter 4) and the results of the thematic analysis (Chapter 5), which delineated how the research and

analysis processes unfolded to arrive at the results. I drew extensively from the discussion transcripts, interviews, feedback forms, and reflection journals in providing contexts to the interpretations of the photos.

As far as data processing is concerned, I kept an audit trail to document the discussions and decision-making of analysis so that different data interpretations could be referenced throughout the processes (McTaggart, 1998). Differences in interpretations of the data were "recognised, expressed, and understood" (McTaggart, 1998, p. 224) and negotiated to best fit the position of the research with the help of various perspectives shared by the participants as well as Luka and Ms. Maria while they assisted in data analysis. This clearly demonstrates the significance of insider knowledge within a community that is crucial to the production of knowledge. Member checks with participants regarding the accuracy of data representations were also important to produce trustworthy findings. Recognizing my own role and influence in the project, I strived to be an "ethical, honest, and forthright" (McIntyre, 2008, p. 12) person by constantly reflecting on different issues at hand and used the session reflection journals and audit trail to document my thought process.

Apart from defensible research processes and results, the educative value and political efficacy of PAR are also central to its validity evaluation (McTaggart, 1998). Although there is no guarantee, the most valid expression of PAR should strive for its empowering, liberating, emancipatory power (McTaggart, 1994). Catalytic validity calls for the attention to research praxis that turns into social change and political transformation (Lather, 1986, 1993; also see Guba & Lincoln, 1989). Central to this idea is the notion of practice in and through research that confers transformatory potential on individuals and in social contexts. Through engagement in critical reflection in research brings about changes in how researchers and participants view and

act differently in the real world, which collectively effects social activism and political empowerment (van der Riet, 2008). There is also a critical need and ethical responsibility to recognize participants' voices in public space and academic discourses and to give primacy to their knowledge in data representations (McIntyre, 2008). Devising change effort while recognizing the boundary of research and practical considerations beyond our control is also considered a valid practice (i.e., pragmatic validity; Brinkmann & Kvale, 2015).

In response to this call for broader socio-cultural-political implications beyond the immediate research context (i.e., TLA), I also need to focus my validity evaluation on the impact this project has on different registers of culture. McTaggart (1998) warned researchers to bring the social practice and phenomenon of the central subject of inquiry to a broader level, as "[thinking] about organisational and broader societal cultures helps us to move on to a still more comprehensive view of validity" (p. 230). He further elucidated the conceptual referents for validity in PAR:

> The focus of participatory action research remains as enhancement of educational practices of communication (discourse and other symbolic forms), production (practices and forms of educational work) and forms of organisation (relationships and reciprocity). However these are now seen in the context of the changing individual and the changing social conditions which constrain and enable the enhancement of productive work. (p. 231)

CHAPTER 4

PARTICIPATORY ACTION RESEARCH PROCESS

Participation in PAR distinguishes from participant involvement in other research

methodologies in the quality of engagement with the participants and their experience in

influencing the research process (McIntyre, 2008). Kemmis and McTaggart (2005) talked about

PAR as a space of communicative action where people can engage in open, genuine conversation

to help reach intersubjective agreement that forms a basis for mutual understanding and unforced

consensus of decisions and actions. Based on the spirit of participation in PAR, engaging

participants in research demands the joining of human beings in a trusting relationship (Cahill,

2007). Research consent cannot occur in an abstracted and decontextualized manner, without

considering the relationships between the researcher and the researched (Ellis, 2007). This shift

in power dynamic also helps break down the insider/outsider tension that deals with the issue of

researchers representing the voice of the other, the failure of which illuminates a space where

knowledge (to know and to be known) can be positioned within the negotiating and practicing of

ethics and responsibilities (Lather, 2002).

I utilize this postmodern, critical, feminist understanding of participation to theorize an

ethic of care in engaging the young adults with autism in this PAR study. Recognizing the

continuous dominance of biomedical professionals and, at times, family members that

marginalizes people with autism themselves in research agenda and policy decision-making

(Milton, Mills, & Pellicano, 2014), I, as a non-autistic person assuming the researcher role, am

loaded with both ethical and political responsibilities to encompass the autistic perspectives and to overcome the power differentials inherent in my relationships with my participants. While acknowledging the potential in using the *outcomes* of PAR in guiding ethically informed autism research at a system level (Pellicano, Dinsmore, & Charman, 2014; Pellicano, Ne'eman, & Stear, 2011), there is no reporting on the *process* of which people with autism are actively engaged in co-producing research knowledge. Using the current Photovoice project as a case in point, I show that the basis for participant engagement is a continuous relationship-building process between the young adults and me, with the instructors, and among the young adults themselves. Through the engagement process, we also simultaneously developed our negotiating of research practices and mutual understanding of research questions. I further illustrate how the co-production of knowledge and subsequent community actions with the young adults provide a new framework to negotiate the power dynamic within and outside the Photovoice project. In the following sections, I extract data from the discussion transcripts, audit trail, and my reflection journals to compose the following narratives to describe how the unfolding of the respective elements of PAR (i.e., "participatory," "action," and "research") sheds light on the above issues.

Participation and Engagement of Young Adults with Autism

Following my presentation of the project idea to Ms. Maria, she invited me to the TLA class to talk about my idea. Before going to the class meeting, I asked myself how I should present myself in the meeting. There were moments of struggling whether I should go in with a blank slate and let the students tell me what they want to do, or I should prepare a presentation to structure my introduction. Eventually, I chose to present myself as an "engaging" person, as I wanted to meet and know these young adults as individual persons and to engage them with me in collaborative relationships.

In the second week of February 2017, I went to the class and met with the group of young adults with autism in TLA. I introduced myself by talking about my background in school psychology as well as my experience and interests in working with individuals with autism. I invited the young adults to introduce themselves, and about half of them volunteered to do so. They not only told their names, but some of them also talked about their future goals, such as learning to be social and independent, getting a job, and hoping to change the society. I guessed they did so because they practiced job interviews earlier that day, but more importantly, I got to hear some of their aspirations. Then, I passed on a recruitment flyer (Appendix D) and introduced the project by explaining the key words, "well-being," "Participatory Action Research," and "Photovoice," in simple terms. I also used the term "project" throughout to refer to this study in a less formal and intimidating manner, while maintaining my deliberate choice of terminology that distinguishes from traditional positivist "research" (McTaggart, Nixon, & Kemmis, 2017). Many young adults showed interest and excitement about this project. For example, some expressed that they wanted to use their artistic skills in the project. Others also indicated that the project could be a good learning experience or could be a part of their portfolios.

In the following week, I gave a more formal introduction of the project by discussing the purpose, potential costs and benefits, and activities involved. I adopted the Incredible 5-Point Scale (Buron & Curtis, 2012) to visually represent different levels of participation: (1) Just watch and listen; (2) Respond to questions; (3) Chime in, speak up; (4) Actively discuss; (5) Contribute your ideas, skills and knowledge. I emphasized that they could change their level of commitment throughout the project, the idea of which I reiterated many times to ensure they felt at ease to participate and contribute in their capacity. Most of the young adults verbally expressed interest

in the project and actively participated during my presentations and in the discussions. They even suggested other data collection ideas, such as taking videos, making posters, drawing pictures, using a drone, and making PowerPoint slides. Their positive reactions were also captured in the feedback forms: "I'm on board with this project hopefully we'll get you an A+. Nothing much more just ready for the project" (Christopher); "A fantastic project! It will go far. And speak many volumes, I am willing to participate fully" (Janiquaa). Their understanding of the training materials was also shown by their reactions to my presentations (e.g., laughed at inappropriate picture examples) and rephrasing of lecture contents (e.g., "A picture is worth thousand words"; "We're not paparazzi"). We also collectively decided to change the seating arrangement from sitting in rows facing the whiteboard to sitting in a circle while I circulated around to facilitate discussions among the students.

For a few students who were more quiet and did not indicate their preferences, I talked to them individually and found out that they were not particularly interested, although they could stay in class and observe. This led me to collaborate closely with the instructors as they understood their students better and knew how to facilitate their participation. For example, Ms. Maria once openly addressed her students' off-task behaviors during her class by asking them to reflect on whether their own behaviors met the classroom expectations. Not only did her feedback remind the young adults to show basic respect and participation by listening, but also showed the consistency of expectations carried over from her lessons to my Photovoice sessions. I supposed this helped me set up more structured classroom management to promote students' engagement. Another example was Ms. Carmen's idea to "modify the activities or instructions" so that students with different skills and comfort levels would be similarly able to participate and provide input. Ms. Smith also asked a lot of insightful questions during discussions to elicit

students' responses. For example, after Ms. Smith talked about her fear of novel experience, Scarlet also disclosed that she does not like new things and tends to be rigid, which sparked a rich discussion about trying new things. Furthermore, understanding the young adults' preferences for different ways of expressions, I remained open to various ways as to how they communicated their ideas of well-being throughout the project. Later in the project, while collecting their responses for the PowerPoint slideshow, we also considered students' different preferences and incorporated both modalities of verbal and written responses into the individual interviews. Indeed, I intended to avoid a paternalistic approach to the ethics of care and strived to make every effort to access the perspectives of these young adults with autism (Milton, Mills, & Pellicano, 2014).

With these supports in place, all of us together created a space that encouraged participation and expression. Over the course of the project, I observed remarkable changes in attitudes and behaviors of some students from the beginning to the end. For example, Scarlet was one of the most anxious students who showed obvious signs of anxiety as she put her head down and looked distressed on her face in the initial few sessions. She once even verbally expressed she did not want to participate. I consulted with Ms. Maria and she indicated that Scarlet was generally anxious to most of the class activities and it usually took her a long time to warm up to people. We encouraged her to stay with the rest of the class without the pressure to do anything. Later, Ms. Maria and Ms. Carmen also talked to her individually about things that she really likes and are easy for her that she could contribute. After several sessions, she gradually opened up and found a more comfortable way for her to express her ideas by creating a poster, which she eventually cared so much that she did not want to be missed out in the graduation presentation. When other students talked about showing their photos, Scarlet asked, "How about my poster? I

want to present my poster." When asked what she wanted to achieve through this project, she expressed that, "I guess from this project, I want to show people how creative I am."

Besides the instructors' support, feedback from the young adults was indispensable to facilitate their successful participation. One obvious beneficial outcome of this project was that most, if not all, young adults enjoyed the Photovoice process. When asked to write about what they liked about the sessions on the feedback forms, they overwhelmingly expressed positive reactions about different activities: "Talk about the photovoice;" "Getting to work on project;" "The chance to take pictures that are meaningful;" "Sharing pictures that are meaningful to us and discussing each one;" "Doing the http://Photovoicekit.org activity;" "Uploading picture;" "That we discussed what we will [actually] going to do;" and "I liked the activity we did. It was very fun." Some students also expressed enthusiasm about the project overall: "It's a change of scenery I mean seeing how we can take pictures and to use them as voice. [It's] incredible," Darth indicated she liked "[Gary's] personality," which could potentially mean my overall success in building rapport and joining with the participants to engage them in the PAR processes. Other unintended benefits mentioned by the students included: "I would say, get the pictures that I can remember them, like have memories of them" (Ace). Micheal also described:

> In a way, it kind of helps us like, even though we may not get a job related to this, like we can maybe turn, kind of, if somebody wants to, maybe in an interview, maybe somebody would ask us, like what did you do? What skills that you think help you? And then somebody might say, I did a Photovoice project. "Um, that sounds interesting!" And then they may want you for their company or whatever like takes photos and explain how somebody wants.

These comments pointed to the evidence for a positive atmosphere and trusting relationships between the participants and me, which served as the basis for a higher level of mutual commitment to the project goals (McTaggart, 1998; van der Riet, 2008).

Beyond a positive experience, the young adults with autism both showed their local understanding of the procedures of PAR that contributed to the knowledge production processes per se and provided rich descriptions of their ideas of well-being. As to the former (i.e., methodologically), participants were responsive to my instructions and the process of PAR in general. For example, some students gave positive feedback on my use of effective instructional strategies: "He is [using] powerpoint;" "… told specific instructions to get the project going." More importantly, the young adults attended to how the Photovoice process was run had an impact on their participation. As mentioned above, I collected formal and informal feedback from participants during and after each session. Although most of their feedback were positive in nature, some feedback was useful in improving the procedures. For example, during the discussion sessions, some students expressed concerns about getting off topic. On the feedback form, Micheal wrote, "I think we should not talk as long when describing a picture, so more people have time to talk also." Having heard the feedback, I discussed with the students what they expected to talk about and achieve through the project. We also decided to have students take turn to talk about their photos and keep track of the time each student used so everyone can have a chance to speak.

It was evident that the young adults, the instructors, and I collectively built credibility that brought about constructive changes in addition to serving the purpose of doing research per se (McTaggart, 1998). As PAR and Photovoice was a completely new idea to these young adults, the fact that they bought into this new idea and were willing to learn from this project was related

to their self-reflection. As Janiquaa mentioned, "Guinea pigs are autistic's therapist pigs." Luka also suggested that learning from new things is a maturing experience, which is directly related to the dynamic and ever-evolving nature of students' well-being. Other students' written comments also served as evidence for the process-oriented spirit of Photovoice and an overall meaningful experience of their participation: "This project is about getting to know people on the ASD;" "How we can project our voice with picture;" "Learning about wellbeing and how to understand it by pictures;" "I liked the way everyone was sharing their thoughts about wellbeing and autism;" "Taking pictures is a great way to communicate our feelings." As reiterated by JC, the project goal was to "for everyone here The Learning Academy to really talk about our well-being, and use our pictures to really convey that message." Micheal put it even more eloquently, "[This project] gets you questioning and pondering." It was apparent that participation, engagement, and critical reflections all came into play to effect changes in these individual young adults.

What is most powerful about the young adults' engagement in the project is their mutual empowerment *among* themselves. The students, who supposedly assumed the least power, indeed took on the most powerful position as change agency at local (i.e., individual and interpersonal) level as they recognized their own knowledges and influenced each other's behaviors, and thus promoting mutual intelligibility. For example, while the instructors on multiple occasions advocated that every student should participate in some ways in the final presentation for their own sakes, it was Luka and JC that eventually talked to Alan individually and they together figured out what photos Alan wanted to use to represent himself in the final presentation. This was a huge success considering Alan's chronic reluctance to show any active participation. Similarly, Luka and JC took on leadership roles in helping collect data from

individual students and creating the presentation, which again showed the transformative power of knowledge they brought to the group. As a criterion to evaluate the effectiveness of this project, catalytic validity can be considered established at the internal working of the project. However, without a true experiment to prove whether this project sufficed as an "effective intervention" per se (and this was not the aim), the project's validity and legitimacy should be judged based on the space it created that facilitated the observed students' transformation and any potential community actions.

Negotiation of Research Questions and Practices

In the first Photovoice discussion session, I spent a lot of time discussing with the young adults with autism about the goals and contents of the project. For example, what about "well-being" they wanted to know and what they wanted to achieve through the project. We also brainstormed future photo ideas and discussed different types of data sources. Some students suggested collecting data other than photos, such as drawings, videos, and visuals collected using a drone and from the Internet. I stressed the importance to collect data that are relevant to our project goals while being creative. I also reviewed safety and ethical considerations with using other visual methods. For example, I talked to a student about how using a drone could easily run into the issue of privacy. As these ideas seemed to come from individual students, we decided to discuss the appropriateness of specific methods on an individual basis as they would come up in future sessions.

I further discussed with the young adults and the instructors the definition of participants in the project. Many students expressed interests in learning about the perspectives of people without autism, while some were concerned about the potential risks of changing the project focus. The instructors pointed out the importance of showing the similarities and differences, if

any, between people with and without autism. The group collectively decided that the students, the instructors, and I would be considered "participants" and participate in the photographing and discussion activities.

I intended to leave the answers to these research design questions broad and open-ended for several reasons. First, because of the participatory nature of this project, the young adults' perspectives and expertise were intentionally privileged over my agenda. For example, even though I intended to use photography to document existing community resources that enhance their well-being, these young adults were not interested in pursuing this goal, so I better listened to what they had to say about things that were more meaningful to them. Second, these young adults were so creative in expressing their ideas and looking for different ways to participate. At the initial stage of the project, I wanted to build trust and relationships with them, rather than giving them "corrective" feedback that stifled their creativity or deterred their motivation to participate. Lastly, I emphasized the importance of ongoing discussions of these issues. These decisions were all tentative, which could be changed as the project played out in different ways.

At the beginning of session four, I found a good timing to revisit these issues since I had received some feedback about the project design from the young adults. For example, some students were wary of getting off topic as people shared too much about things outside of their photos. We collectively discussed what was and was not relevant to our discussions. We went on discussing what the goals of our project were and what we wanted to achieve through this project. As shown in the quotes below, their ideas were to (1) share and learn about each other's ideas on well-being, (2) show what is important in their well-being, (3) increase other people's understanding and awareness of autism, and (4) advocate for community and social changes.

Reflected in their ideas was a sense of subjectivity that is personal and critical, as well as a desire

for connections with other people:

> I believe posting pictures about yourself that you represent like saying something sharing
>
> your emotions to everybody. Share yourself basically. (Darth)
>
> Well, it can be. But if you want to show well-being, we at least have to describe, in this
>
> case we have to describe why the pictures represent our well-being. (Luka)
>
> Then you will also have to have a question about what your well-being is, because if it
>
> can vary that much in length, then it could be pretty much anything. (Bob)
>
> Well, for me, since I like learning about different people, it's rather interesting to see
>
> other people's perspectives on their well-being, so it's just interesting to look at how
>
> other people see things differently than I do. (Luka)
>
> And one thing also, that could also come out of this project and would be very good if it
>
> did, would be to increase other people's understanding of how people with autism
>
> perceive their own well-being as well. (JC)
>
> I think, like with that sharing, JC was saying, with us having autism, with that sharing
>
> what our, what autism to a person with autism, what it means to them, what kind of, let
>
> people outside of this circle come to better understand what autism means, and how to
>
> better treat the people that come across with autism. (Roy)
>
> I would say, get the pictures that I can remember them, like have memories of them. … A
>
> picture is worth a thousand words. (Ace)

Regarding the decision about data sources, it was important to note that, although I

originally asked the young adults to take photos in real life, they actually submitted different

types of pictures, such as drawings, images from the Internet, and old photos. From the photos

they showed and described throughout the project, they expressed a strong desire to want more people to understand their perspectives. Instead of documenting community resources that I thought could "improve" their well-being, expressing themselves and having their knowledges recognized were perhaps more important for them to promote their well-being. This was captured by Micheal's comment:

> Well, I mean, I like everyone's ideas. I find these to be very very interesting. Like you know, the fact that you know they are going to do a PowerPoint, some have ideas of a poster, and I like it, because some people, they are not good at taking pictures, they don't like pictures, maybe they don't care about pictures, so, having a new way to do it because everybody has a different way of expressing themselves. And you know, I might be sitting here right now, uploading a couple good pictures that I like. Somebody might say, "I don't like taking that picture, but if I draw it out, it conveys what I want to say about well-being much more better." And I feel to me like this thing that we are doing is not kind of a right or wrong, so it's kind of more an opinion thing, where everybody's opinions can be included. Like there's no excluding like… Nobody is gonna tell him that's wrong. Any which way can be right. It's how you perceive and want to do it.

These collective decision-making experiences also served as a reminder to reinforce the students' intended goals in subsequent analysis and dissemination, which were reflected in the research questions that guided the processes and future community actions. Implicit in the conversations also conveyed the need to recognize students' voices in public space and academic discourses, and to give primacy to their first-person perspectives and realities in data representation.

Throughout data processing and analysis, the participants' input was integrated into the processes and the final products. For example, the PowerPoint presentation at the commencement was the young adults' original idea and created by themselves. I asked some young adults to review the transcripts for transcription accuracy. Luka, Roy, and Ms. Maria also reviewed the results of the thematic analysis to make sure the themes accurately capture their ideas of well-being. As novice researchers, Luka and Ms. Maria were both extremely committed in learning the research methods and invested in the data processing. I frequently collected feedback from them to make sure they have adequate understanding of the research processes. For example, following the research ethics training, Luka expressed her new understanding of the term "ethics" as she previously confused it with "ethnic." When asked to reflect on the use of codebook in data coding, while Ms. Maria expressed feeling "overwhelmed" at the beginning but gradually became more comfortable with repeated practices, Luka found it "easy" to use the codebook as a reference as she was more "detail-oriented." I reassured them that their feelings are common among novice researchers. The fact that they wrestled with the coding procedures provided evidence for their active learning and practicing the research method. Similarly, Luka and Ms. Maria asked me to clarify concepts that are difficult. For example, Ms. Maria once asked whether they should "exclude our interpretations" when doing memos and coding the data, after which I explained the inevitable influence of our own perspectives in constructing our understanding of the data, while also stressing the importance of member checks and triangulation. On another occasion, Luka asked for examples "to visualize how to write a memo," so I provided them with the resources by Saldaña (2016, pp. 44-54) and instructed them to start small by gathering their notes from the jotting activity to compose initial memos.

Luka and Ms. Maria also shared important information that provided new insight or helped verify the analysis. For example, while I initially interpreted a photo as depicting an art piece, Luka recognized that the artifact was the product of a class activity about teamwork. Both Luka and Ms. Maria at different points shared about their personal interactions with different TLA students, which was extremely helpful in contextualizing our interpretations of the data. For example, their knowledge about individual students' personality and preferences were invaluable, which would otherwise be inaccessible if they did not participate in the analysis processes.

The Making of Action

In session four, after we talked about the research goals, I asked the young adults what they wanted to do to achieve those goals. JC was the first one who shared his idea that was eventually turned into our project outcome:

> Well, one way to increase people's awareness of well-being and people with autism would be to generally be open and share our thoughts to the people outside of this place as well as sharing in this room like we are right now. We can also share our opinions and stuff like this outside of this room, outside of this campus even.

The young adults had different ideas about how they wanted to communicate the project findings to the community. Some suggested presenting at an Autism Awareness Month event, but due to time and workload considerations, they found it more feasible to create a presentation at the TLA graduation commencement, which was a natural opportunity for them to showcase their work to their parents and community members. They decided that making a presentation was the best way to represent their work and convey their message to the audience, while considering what was practically feasible and achievable under their circumstances. The conversations below not

only showed how the students developed this idea, but also reiterated the fact that their well-being is best to be understood as situated yet relational, subjective yet engaged, and intentionally critical:

Micheal: And some of the photos have been taken around the Learning Academy, so some of those photos show how we've grown and how we improve. And I thought it would be kind of cool maybe possibly to do a PowerPoint like we did last semester to where, instead of us talking, instead of us just doing PowerPoint, we would do pictures and talk about our pictures. And maybe we can talk about how the Learning Academy has affected our well-being and what we are going to do the next year or so after we graduate. And tell them, this is how it has affected us, this is what we have been doing in the Learning Academy, whether it's outside, inside, what the pictures mean to me. And this is what I'm going to do the next couple months or next year. And thank you, I would like you to come over me and enjoy, blah blah blah.

Gary: So this is an idea for graduation. How about Roy?

Roy: I kind of like that idea, whoever said about presenting. I like that idea because of course, Ms. Maria, Ms. Carmen, Ms. Smith, and everybody in here knows what our well-being knows to us, because they are front in the line. Maybe between it would be a good idea to do our graduation that way. The people who are behind the scene get to see what we do in the Learning Academy, can see this is what well-being means to a person with Autism Spectrum Disorder. It kind of gives them a different light than what well-being means to, like I said, somebody with a disability versus somebody without.

JC: (Clapping hands) I can't agree more with Roy and Micheal because I think presenting these at the graduation would give people out in the community a better

understanding of what well-being is to us with autism. So I think if we should go with

presenting outside of our little group here, then we should do it during graduation,

because I just think that's the best event to do that. What do you guys opinions on this?

Scarlet: Oh, definitely. That's a good idea.

Luka: Graduation would probably be the best time to do it. Everybody will be

there.

Micheal: Because I think it will fit well with graduation, the pictures and

everything. I mean, the idea of the Fiesta thing is great, but I don't see that working out,

because it's something CARD has put together, and they already ran. It's so close to the

event. It would be kind of hard to put this in the event.

Five students volunteered to form a committee to work on the presentation. The

committee held a separate meeting in the following week, in which two students (Luka and JC),

two instructors (Ms. Maria and Ms. Carmen), and I attended. The meeting was mainly focused

on how to create the contents of the PowerPoint slides and logistical issues about the

presentation. Based on the meeting discussions, next steps were to (1) design a PowerPoint

presentation that includes photos and quotes of all the young adults and instructors, (2) interview

them about their ideas on well-being, (3) ask them to identify three photos to be shown in the

presentation, and (4) seek their approval on the presentation design (e.g., format, background

music). Besides photos, we also wanted to include a quote from every person to help explain

their well-being ideas. We decided to interview everyone on (1) what well-being means to

him/her, (2) one thing that can represent his/her well-being, (3) how he/she could improve well-

being, and (4) what photos to be shown in the presentation.

In the next Photovoice session (i.e., session 5), Luka, JC, and I interviewed all the young adults and instructors for their responses and asked about their preference for photos to be shown. (These data were also included in the thematic analysis described below.) Afterwards, Luka and JC took the lead to organize all the materials and created a PowerPoint presentation within the following week. In the final session, they played the presentation in front of the class to seek approval from everyone.

The evening of the same day, the presentation was played at the TLA graduation ceremony at the University campus. The majority of the attendees were students' family members. Others included several of students' internship hosts, mentors, friends, teachers, University representatives, and all the TLA staff. The graduation ceremony usually had a set rundown that included speech by the Director of the program and the University representative, individual TLA students' speeches, and awarding of their certificates. The Photovoice presentation was scheduled to be the last item before the closing comments. Luka and JC went to the stage and Luka introduced the presentation:

> Hello, good evening. I hope you all are excited as we are. I would like to talk about a project that we have been doing this semester here at TLA. This project is called the Photovoice project. We've been working, with Mr. Gary, on uploading photos that represent our well-being. The Photovoice project is a chance to represent our voices through pictures. We took pictures about our well-being in our daily lives. This project is exciting as it expresses our voices. We hope you all the families here will hear our voices through the pictures and the slideshow. Thank you!

They then played the slideshow on a big screen on the stage. Each slide featured the photos and quotes of a student or an instructor. Each slide was shown for about 10 seconds, and

the entire slideshow lasted for around 3 minutes. During the presentation, the audience was very focused and appeared to enjoy the presentation. I saw faces lighted up in the audience and heard laughter throughout. However, for a variety of reasons, the presentation of the slideshow per se did not appear to effect meaningful changes: The slideshow was only shown for a few minutes within the hour of the commencement; the quality of the projection was not very clear and some texts were too small to read; no discussions about this presentation or the students' photos were conducted after the presentation. At the very least, I did not have a chance to collect data on whether the presentation had influenced how the audience viewed these young adults with autism. Since this was the only action step successfully implemented, its effects on community change might be minimal, not immediately observable at best. In other words, the catalytic validity of this project, at best, could only be evaluated based on the inferences I made about the outcomes of this presentation.

Despite these limitations, I think the fact that this presentation was featured in the commencement was significant in several ways. From the perspectives of the young adults with autism and their families, this was an opportunity for the former to speak for themselves and show their knowledge and understanding to the latter. While each young adult did a mid-term individual presentation about themselves and their goals in a similar setting, which was a core program element of TLA, this Photovoice presentation served to reinforce the importance of the young adults' perspectives at the end of the program. Similarly, TLA itself benefited from hosting this project and sharing the results to the community. Although TLA did not plan to adopt this Photovoice activity into their regular curriculum, the nature of this one-time project might have reinforced the program's emphasis in self-discovery and meaningful participation of its students. For example, In the process of developing the graduation presentation, Ms. Maria on

multiple occasions recalled her experience with organizing student-led projects in previous years. Hopefully, this could plant the seed for future program initiative to incorporate more participatory projects.

Before the end of the final discussion session, I extended my invitation to all the young adults to continue working with me on data analysis and community advocacy work. Some students expressed interests in this idea. The group also identified some potential audiences for disseminating the results of this project, such as academic conferences, the USF President, disability services, and Special Olympics. Unfortunately, my efforts to follow up with these young adults were faced with various barriers and setbacks, and thus no community actions were successfully implemented so far. However, I presented preliminary findings of this project at professional conferences. Some researchers and practitioners came to me and expressed that this project's perspective is something needed in the academia, and this has changed how they view their students with autism in their practice. Albeit anecdotal, these comments showed the considerable potential of this project to change the discourse and practice among academic and mental health professionals. These observed impacts of this Photovoice project are tentative at best, as more data need to be collected to document such changes. There are also future conference presentations that I co-author with a young adult and an instructor. It is hoped that this one-time research project can continue to effect changes in the long run.

CHAPTER 5

PHOTOVOICE RESULTS

The previous chapter gave detailed descriptions of how this PAR was conducted to engage young adults with autism in constructing knowledges and negotiating research decisions. In the current chapter, I focus on our understanding of the ideas well-being as expressed by the students' photos, which directly answers the research question: *How do young adults with autism communicate their understandings of well-being?* This chapter presents the analyses of the photos collected through the Photovoice activities. First, a content analysis of all the photos yields different broad categories of visual elements depicted in the photos. Second, a thematic analysis of photos, transcripts, and interviews reveals three themes that capture the ideas of well-being as seen from the perspectives of the young adults with autism in TLA. I also present examples of photos and quotes to illustrate the meanings and contexts of individual themes and subthemes.

Content Analysis of Photos

A total of 88 photos by the young adults were used for the analysis, of which 62 were submitted to the PhotovoiceKit and 19 were additional photos used in the graduation presentation. Another nine photos were mentioned and discussed in the sessions, but the students did not submit a copy of the photos. Table 2 shows the number of photos contributed by each TLA student. Results of the content analysis yielded 10 categories that represent the themes of the visual elements expressed in the photos. Table 3 shows the number and percentage of photos

in each category of visual focus. Below I briefly describe the visual contents of these photos in each category. I organize the descriptions in descending order from the category with the largest number of photos to the smallest.

Table 2.
Number of Photos Contributed by Students.

Student	Number of photos on PhotovoiceKit	Additional photos in presentation	Photos discussed but not submitted	Total
JC	0	3	3	6
Roy	5	3	0	8
Luka	7	1	2	10
Taiki	10	3	0	13
Darth	6	0	0	6
Alan	0	3	0	3
Christopher	3	0	1	4
John	3	0	1 (a video)	4
Janiquaa	7	3	0	10
Ace	1	0	0	1
Scarlet	1	0	0	1
Bob	1	0	0	1
Nick	3	0	1	4
Micheal	15	3	1	19
Total	62	19	9	90

Table 3.
Number and Percentage of Photos in Different Visual Categories.

Category	Number	Percentage
Animals	15	17%
Art	15	17%
Family	14	16%
Friends	11	12%
Education	9	10%
Interests	8	9%
Nature	8	9%
Self	6	7%
Traveling	5	6%
Community	3	3%

*The total number of photos is more than 90 and the total percentage is larger than 100% since some photos were coded in multiple categories.

Animals

Fifteen photos contributed by seven students have a focus on animals, which accounted for the largest category. Dogs and cats were featured in ten and six of these photos, respectively. Janiquaa also had a photo of a guinea pig. Eleven of these photos showed the pets of these students. The other four photos captured animals found in their neighborhood, an instructor's guide dog, and a cartoon dog.

Art

Another biggest category is art. Fifteen photos by seven students showed a wide variety of "art," including drawing, calligraphy, airbrush art, poster, sand model, performing art, culinary art, cartoon, and anime.

Family

Fourteen photos submitted by six students were in the category of "family." Family members targeted in the photos included parents, grandparents, siblings, uncles, and cousins. Students themselves were also present in most of these photos.

Friends

Eleven photos submitted by fix students were grouped under the category of "friends." In six of these photos, TLA students took photos on each other. A TLA mentor appeared in one photo of Luka. Nick and Micheal also submitted four photos of friends they knew since they were little.

Education

Nine photos by five students were focused on themes education. Taiki and Micheal respectively contributed four and one of these photos, which featured different classroom

activities of TLA, including the Photovoice project. Other four photos captured important memories while the students were in grade school.

Interests

Eight photos by six students were categorized as interests. These photos captured students' hobbies (e.g., swimming, reading, computer games, soccer) and objects of interest (e.g., mobile phone, train).

Nature

Eight photos by five students were categorized as nature. Natural sceneries captured include trees, flowers, the sea, the sky, and the moon.

Self

Six photos submitted by three students were categorized as self. Five of these photos featured the portraits of the students themselves (Micheal, Luka, and Roy). Micheal also had a photo of her favorite clothing brand that she considered an important part of herself.

Traveling

John and Luka respectively submitted two and three photos that were categorized as traveling. These photos featured their experiences traveling to New York, Georgia, Virginia, and Canada.

Community

Roy submitted three photos that were categorized as community. Two of these captured the Orlando Eye and the third one captured a community event featuring the navy.

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Thematic Analysis

</div>

Thematic analysis of all the data sources (i.e., photos, transcripts, and interviews) yielded three broad themes that describe the young adults with autism's ideas on well-being, namely

"self and personal growth," "close relationships," and "community connections." Below I described each of these themes and subthemes. I also presented their corresponding data, including quotes and photos.

Theme 1: Self and Personal Growth

      Identity and self-expression. Through the Photovoice activities, students sought to use different ways to express themselves and represent their self-identities. Explicit references to self-identity were evidenced in Micheal's photos of "Aéropostal cloths" and "Me thinking" (Figure 5.1). In the former, she showed that "These are [a part] of my wellbeing because I love this clothing brand and wear [it] a lot. It describes who I am." In the latter, she also took a self-portrait to show "me thinking about something important and I captured that moment so my friends and others can see what wellbeing means to me." Roy's description of the meaning of well-being to him in the graduation presentation also resonated with this theme: "Being able to love who you are."

Figure 5.1. Micheal's photo entitled "Me thinking."
*Caption: This represents my wellbeing because it shows me thinking about something important and I captured that moment so my friends and others can see what wellbeing means to me.

Another salient theme is the students' creative use of alternative media to express themselves. Four students at different points used drawing to convey their ideas of well-being. Luka drew a funny anecdote about her brother. Scarlet did not take any photos, but instead created a hand-drawn poster that included things that showed her well-being. When asked what she wanted to achieve from this project in one session, she expressed, "I want to show people how creative I am." On the interview form, Darth drew a logo of her dog to represent her well-being. Alan took photos on several of his drawings that appeared to express his funny and creative side (Figure 5.2). It was unclear whether the drawing process itself or the contents of his actual drawings matter more to Alan's well-being, but this visual method definitely served important values in his self-expression.
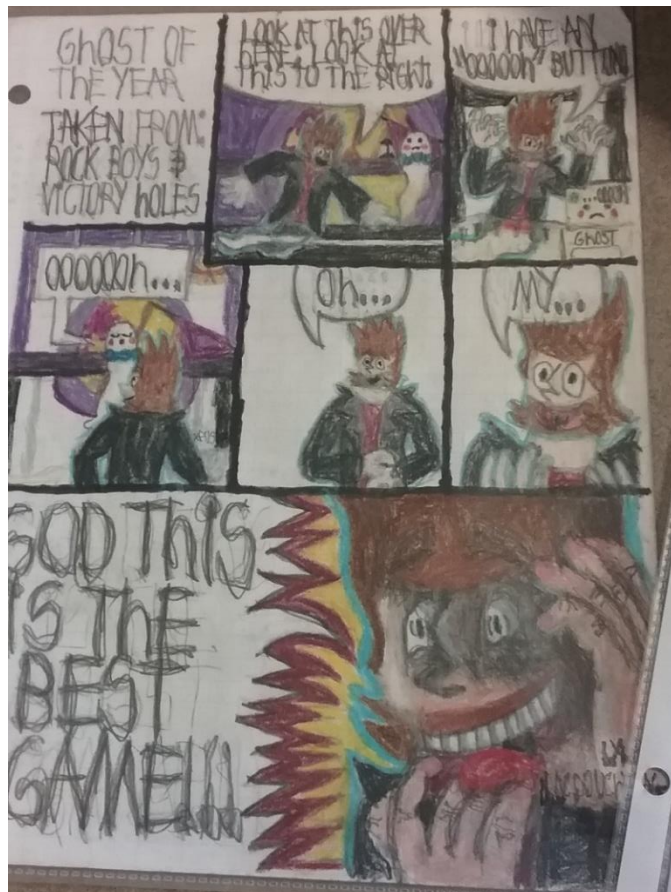
Figure 5.2. Alan's photo.
No title or caption.

Besides drawing, John took a video of a moving train he saw in his internship site to show his interest in the train horn sound. Furthermore, two students made extra efforts to edit their photos. Micheal described her use of the smartphone: "I use it everyday and I keep it close to my side and heart." She further used the Screen Write function of her phone to write and drew on a photo to express her love of her cat. Janiquaa submitted a photo of flowers with a caption written in the format of a poem that read, "Blue and blooming every which way, blown in the breeze each and every day. I walk past you morning and afternoon, you remind me to stay strong and always stay in bloom." She explained:

> I'm better at writing stuff down here on a paper than saying them. So I have something, pictures about flowers. I have a picture of [the name of the guide dog]. I am working on a story. A caption for that photo. I am good at captions with photos. Short stories.

Darth submitted three pictures she found in different anime series. She seemed to express her understandings about the world and find connections with the messages conveyed through the anime. In the "Full metal Alchemist," she learned that "When anything is lost and can never gain something back, never give up in life, move forward." In the "Fairy Tale," she wrote "even though we aren't related, even though we don't get along very well, even though we were enemies once, anybody is welcome to be part of this family." In "Black Butler II," she was amazed by the artistic decision to use topics such as mannerism and law in anime. Similarly, Taiki also reflected on the meanings he learned through various types of expressive arts, including performing and culinary arts. For example, he saw creativity in different food and dishes that he found in everyday life. He also reflected on a show that he attended (Figure 5.3): "It takes heart to have talent. If you believe in yourself, you will show your true talent."

Figure 5.3. Taiki's photo entitled "True Talent."
Caption: It takes heart to have talent. If you believe in yourself, you will show your true talent.

Preferences and interests. The students identified different interests and hobbies they considered as their well-being. John showed a photo of a freight train and a video with its horn sound (Figure 5.4). He explained: "It's something that I love. It also makes this sound that I love to hear." He identified, "Railroads would be the one thing that represents my well-being" and "I would improve my well-being by travelling across the country by train."

Figure 5.4. John's photo entitled "CSX Freight Tampa."
Caption: This is my wellbeing.

Ace indicated "Just play games and read on my tablet" helped him relax. Scarlet drew a poster

(Figure 5.5) that included all her interests and hobbies. "I guess it's just like, I just like them.

Watching movies, browsing internet, playing videogames. I like reading books, I like listening to

music."

Figure 5.5. Scarlet's photo.
No title or caption.

In terms of sports, Christopher identified swimming is a big part of his well-being (Figure

5.6):

I took that picture because of the pool I live with. You know, that is myself in the picture.

We have a pool. And I took that picture like that because that pool represents my well-

being. It relaxes me and refreshes me, you know, my spirit and my mind. It's a, you

know, just jump into the water, freezing cold water. Your body just adapts to the

temperature. The pool, definitely is some parts of me, I guess. I love swimming.

Figure 5.6. Christopher's photo entitled "Pool."
Caption: Whenever [I] swim in a [pool] it makes me relaxed and so refreshing.

Nick showed a photo of the flag of United Manchester that was his "Second Favorite Soccer

Team", while he was "now a Barcelona fan." He loved playing baseball and showed another

photo with the number of Yogi Berra from the New York Yankee:

> I usually played baseball back then. Yogi Berra, he inspired me a lot. I remember
>
> watching him when I was a kid I used to play baseball. I remember he was a really good
>
> baseball player. You know, my dad saw him play baseball before, cuz you know, I used
>
> to live in New York, he did too. So, Yogi Berra was actually the guy who inspired me. I
>
> used to watch his videos too. This is his number.

He also described another incident where he got hit by a baseball that left him a bruise, but this

became an important memory of him.

Self-knowledge, learning, and reflection. Education plays an important role in students'

well-being in different ways. Taiki and Micheal submitted photos they took in class to show

what they learned. A quote written down on the white board reminded Micheal "to control

myself with joy and ease." Taiki used to take a lot of photos on the teacher's presentations, and

he showed one that was about how to be a good speaker and listener. Taiki explained,

"Education will always be around even after schools. And it teaches something you do in the

future, like math, science, history, and more. Without them, you won't have a better future. …

Something to do with your future occupation." Other students elaborated on how they were

going about to apply the knowledge to the real world. For example, Luka related that to her

career goal in teaching:

> Speaking and listening. For me, that sounds like teaching. Because you are speaking to a
>
> kid, but at the same time, you are listening to like, if there's an issue, you listen to what
>
> they have to say. So, sometimes kids have some interesting things to say. You need to not
>
> speak, and listen.

Taiki also submitted three other photos of different class activities that reminded him of what he

learned.

Figure 5.7. Taiki's photo entitled "Creativity."
Caption: Creativity always has no limit on what you do. Always show creativity in order for your dreams to become a reality.

For example, he shared a photo of a tower made up of marshmallows and spaghetti that he and his classmates created during a team building activity in class (Figure 5.7), which reminded him that "Creativity always has no limit on what you do. Always show creativity in order for your dreams to become a reality." In addition, he took a photo of the consent form of the Photovoice project and explained, "Even if you disagree with someone, you must always respect someone. There are opportunities that you can do with." He also showed a photo of a drink he got as "Rewards" as he "helped the office to clean, do this, clean the school yards." The expression of achievements and strengths was best exemplified by several photos Roy submitted for the graduation presentation, two of which featured himself in high school graduation and another photo showed that he won a prize in Special Olympics (Figure 5.8).

Figure 5.8. Roy's photo.
No title or caption.

Luka and Ace submitted two photos that remind them of the good times they had in grade school. Ace took a photo of him wearing his class ring (Figure 5.9) and explained "It's of sentimental value to me. I got it back when I was still a sophomore in high school." He further

stated after graduated from high school, "More important is to make a better choice, that I am going to make better choices."

Figure 5.9. Ace's photo.
No title or caption.

Luka's photo that showed "me going to [kindergarten] while my brother at the time was going to pre-school" recalled her good memory of kindergarten and the fact that she learned to overcome some challenges getting adjusted to the school. She also shared about a picture of "herself as A cute 3 yr. old me" (Figure 5.10) and reflected on "Looking at myself then and looking now, I've really changed. I especially matured in handling my Asperger's." These photos showed the students' reflections of their past experiences and how these shaped their present self.

Figure 5.10. Luka's photo entitled "A cute 3 yr. old me."
Caption: This is a photo of me when I was 3. Looking at myself then and looking now, I've really changed. I especially matured in handling my Asperger's. Time sure flies.

Growth. Inspired by Luka's photo "Trying New Foods" (Figure 5.11) that depicted "a fun experience" of "trying Korean BBQ for the first time in Georgia," where she was "eating in this picture is a pickled relish, which taste a lot like coleslaw," students had a debate on trying new things related to their well-being. For Luka:

… to try something different that I've never tried it before show that I am a little

adventurous. But, also, it's, if you don't try anything, how do you know if you would like

it or not, so I feel a little bit interested and decided I would try it.

Figure 5.11. Luka's photo entitled "Trying New Foods."
*Caption: This is me trying Korean BBQ for the first time in Georgia. The food I am eating in this picture is a pickled relish, which taste a lot like coleslaw. This was a fun experience.

The majority of students recalled that although trying something new might not always be comfortable or pleasant at that moment, this brought them new learning experiences and change in perspectives:

> For me, when it comes to a lot of things, actually. New food, new hobbies. I always try to try out at least one thing new each week. Like for example, recently I went into, trying to use a different style of drawing than I normally use. Because normally I usually drawing like pen, but instead of doing that, which is in my normal comfort zone, I use something completely different. (JC)

> I know for me, the other day I went to a sushi place with my friend. I have never tried sushi, I thought I am not doing this, this is going to be nasty, I am not going to like this! I tried it because how I did in the sushi place is before you buy something, they give you a sample of it, and I tried, and I am like, I like, give me more! (Roy)

Trying something new allows students to grow and mature in the long run:

> Well, if you don't try new things, you are not going to go very far. Because if you won't
>
> step out of your comfort zone, you're too afraid, you are having that feeling holding you
>
> back, so you're not going to be successful if you don't step out and try it at least. And if
>
> you don't like it, you can just taste it, it's maturing experience, it's learning experience.
>
> (Luka)
>
> The thing is, trying new thing is, at first, it may seem a little overwhelming, but once you
>
> try it, you really end up most of the time being happy you did. … I usually for the most
>
> part to a set routine, it's always good to go out of your comfort zone every once in a
>
> while and try something else. Because if you don't try something new every now and
>
> then, you are really really limiting yourself. It's like you have a big round of world that
>
> you can explore and you are just staying in your one little, one-room apartment. (JC)

These descriptions recalled Janiquaa's reaction to the very beginning of this project: "Guinea

pigs are autistic's therapist pigs."

> Trying new things also brought different cultural experiences to these students:
>
> Here's one thing I've never thought about trying something like new food. Trying a new
>
> food is also like trying a different culture. (Roy)
>
> Trying new things is something that's like exploring something exciting, especially with
>
> traveling. Because I mean, yes, you might be a little uncomfortable at first, but you have
>
> fun afterwards though. Because you expose yourself in different cultures, new food, what
>
> kind of ornaments. (Darth)

Although the overwhelming and anxiety-provoking feelings could deter some students from

trying new things, most students tended to be willing to tolerate the uncomfortable feeling to a

certain extent. Scarlet expressed that, "I really don't like doing new stuff. I am really very rigid and very you know, I am just like what I am used to." As a case in point, although Scarlet was clearly anxious and disengaged at the beginning of the project, as the instructors and I encouraged her to stay with the group, learned about her interests and preferences, and capitalized on her abilities and strengths, she later created a poster on her own that depicted her hobbies and interests, and eventually cared so much about representing her work at the graduation presentation.

While more adventurous students were more likely to actively seek out new experiences, this kind of excitement was tempered by other students alluding to the struggle between tolerating uncomfortable feeling about new things coming to them as a surprise versus feeling comfortable until they became ready to try new things:

> I am more neutral. Sometimes things can be a bother but I am willing to try. When I try new things I may like it. … Yea, I will do things, or I will make sure, I would prefer to try something that I make sure I like than doing something I doubt I would like. (Bob)
>
> Trying new things gets on uncomfortable to most people, but also being a relief, because probably end up you very much liking it. … When I first ever have turkey sandwich from Subway. … Very good. … Well, I actually tried it on accident. (John)
>
> You know sometimes to leave, being in your comfort zone, you start doing it on your own. … It's best to leave your comfort zone when you are ready. … Like trying to, grocery shopping, and cooking for my own. (Taiki)

Theme 2: Close Relationships

Family. Family was frequently described as an integral part of the students' well-being. "Family is a big part of my life" (Luka), "… families always been there for me for a long time"

(Nick), "well-being is … just my love to my family and the people I care about" (Scarlet), and "My family and friends because they are the people I spend the most time with, so they are the best thing I can think of to represent my wellbeing" (JC; Figure 5.12).

Figure 5.12. JC's photo.
No title or caption.

Family relationship is everlasting and transcends time and space. This was best illustrated by Christopher and Micheal who described the long-term impact of losing their parents.

> I feel like what is also part of my well-being, and what has helped me grow is from losses. Like there's always time when you lose something important to you, family member. It's hard, it's hard, when you, it's hard when you lose extended family member, but it's even harder, when you lose both of your, of your parents that gave birth to you. So, for me, losing both my mom and my dad was very very hard. (Micheal)
>
> That I be with them. You know, it just represents that I did have parents. I look at that picture every time I wake up. … That's why there are three of us eternally forever. I have

mourned in my mind, but I mean it was too long. I'm not going to write a poem.

(Christopher; Figure 5.13)

Figure 5.13. Christopher's photo entitled "The three of us eternally forever"
Caption: Family.

The bonding between them and their parents were undoubtedly strong and everlasting. Even if

their parents were no longer with them, the relationship and its impact were still present.

Family exerted both direct and indirect impacts on students' well-being. For example,

Bob mentioned his family helped him through a lot of things in daily life. As Micheal summed

up very eloquently, "I think they help you grow, and they help you like learn new things, teach

you new things and. The world is, well, it can be difficult, and having a family helps you

navigate." "Without family, I would [have] never gone anywhere and never had the hope to

dream big" (Luka). For example, Roy described his younger brother as his "little hero" (Figure

5.14) who gave him inspiration and pride. While Roy was very invested in coaching his brother

in football, he also needed to wake up very early on weekends to attend his training. The responsibility brought Roy stress and joy at the same time.

Figure 5.14. Roy's photo entitled "my little hero."
Caption: My little brother is my hero because he plays sports and gets good grades in school and is there for me when [I] need him.

Family members were also at the backdrop of students' well-being. As JC put it eloquently, "most of what represents my well-being is situated in and comes up with my family. That's what makes up the bulk of like my, represents my well-being." Examples ranged from everyday trifles (e.g., Luka's brother accidentally drank rotten milk, which brought unexpected humor and laughter to her) to significant family event (e.g., Roy's family attended his high school graduation).

On multiple occasions, students expressed that they cared about their family, but they might not always show or communicate it. Scarlet found it difficult to express her love and care to her family. She was not good at expressing it, but did care about and want to communicate her

love for her family. "I mean it's not I won't, I never show it. Just that it's not exactly my strong point." Scarlet noted that she would "like [to] be able to be more generous and not think of myself a lot," meaning she wanted to communicate her love and care to her family more.

More importantly, even if the love was not explicitly communicated, this did not mean it was not reciprocated. As Scarlet described, "I am not very good at expressing my love to my family. They know it's there." Micheal recalled her difficulties with opening up herself to her grandmother after she lost her parents, but despite this, her grandmother's unconditional love and care for her eventually helped her get through the difficult time and form a closer relationship:

And it's very difficult moving here, and trying to communicate with my grandmother. It was difficult and very boring. I don't want to talk to her. I want to know heart of her at all. I want to separate myself and be somewhere else. But my grandmother kept telling me there's no other choice. You can't go back to the state where you came from. Then you have, then I took you because no one else could take you. And I will care for you the best I know to how. So, to have my grandmother, who knew nothing about autism, go online and research everything about it, and have a case worker help find me a program, and then enroll me in school and keep me busy, is really amazing. And now that I think about it, I have a better relationship with my grandmother. Like me and my grandmother now are closer.

After all, Micheal seemed to have a great time with her grandma and enjoy each other's company, as reflected in her photo of a stuffed animal that represents their happy moments being together in everyday life (Figure 5.15).

Figure 5.15. Micheal's photo entitled "My grandma's stuffed Ty monkey Moocher."
*Caption: I love grandma's Moocher a lot and he makes us happy. It's funny when grandma is driving me around and she talks to him a lot. That's why it's [a part] of wellbeing.

Friends. Friends serve an important role in students' well-being. Students shared many photos of their friends and memorable moments with them. Micheal described her friends as "makes me happy", "is always there for me", "really inspires". "They are awesome and hold a special place in my heart. They play a vital role to my wellbeing in many ways I can't understand and describe" (Micheal). Janiquaa treated her friends as "brothers" (Figure 5.16) and "sisters," "not literally, but of the heart," suggesting friends play extremely significant roles in her life. Her male friends "put a smile on my face, and encourage me to do my best", while her female friends were "the ones you share secrets with, trust in, love, and are sisters for life." Of note, the friends Janiquaa photographed were her classmates in TLA.

Figure 5.16. Janiquaa's photo entitled "Brothers."
Caption: Not literally. But of the heart. They put a smile on my face, and encourage me to do my best.

Besides Janiquaa, Micheal and Roy also featured different students in the program in their

photos to describe their friendships as a part of their well-being.

Students and their friends "have fun" (Luka), "love to talk" (Micheal), and do things

together, such as go to events, go fishing, and invite each other to birthday parties. Micheal

showed a photo of "Me in my blue dress" and explained that "I fit into my wellbeing because if

it wasn't for me getting up that day and getting ready for my [friend's] senior prom, I wouldn't

have went and had such a great time." As shown in the photo "My friends and I" (Figure 5.17),

Micheal had a great time with her friends at a special event, which was one of the memories that

shows her friends "have both been there for me and really inspires."

Figure 5.17. Micheal's photo entitled "My friends and I."
*Caption: My friends, [friend's name], [friend's name], and I took a selfie at Red Carpet a
dance for special needs because they had a selfie booth at the dance. They have both been there
for me and really inspires.

Although Darth and Nick no longer hanged out with their friends as much as before, their

friendships seemed to last for a long time. Their friends would be there for them when they need

them (Figure 5.18):

> Because we did not talk that much. We stopped talking to each other for long time. We
>
> go to school. I go to here. He goes to a high school. And he goes to baseball sometimes
>
> too. I don't talk to him that much. When we don't have baseball, we do hang out
>
> sometimes. But basically we by ourselves. We just don't talk that much. We stop
>
> communicating. And then when I called him up to sign the picture, he was like, alright,
>
> yeah. (Nick)

Figure 5.18. Nick's photo entitled "My friend [friend's name] and I went fishing."
Caption: My friend [friend's name] caught a 1LB bass in my neighborhood. It was so much fun.

He also identified his weakness in communicating with his friends.

> I have to be like a really good person to be… like my friend I have, I am a really good
>
> person. Like I respect. I will do whatever. If they have a baseball game or a soccer game,
>
> I will be there for them. Or, I need like, because, I did this to [mentor's name], my
>
> mentor. I accidentally did not call him. When I texted him, this is what I need, like
>
> communication, is actually the best thing to like, to improve my well-being right now.
>
> Like I don't text anybody.

Many students described animals as their friends (more descriptions in the "Animals"

section). For example, Bob posted a photo of his "Silly Dog," which he described as "My best

[friend]" (Figure 5.19).

Figure 5.19. Bob's photo entitled "Silly Dog."
Caption: My best [friend].

Taiki took a photo of Clifford the Big Red Dog and Emily Elizabeth to express his understanding

of "True Friendship" (Figure 5.20):

> They are staying by their sides. So it's loyalty to your friends. You treat your friends with
>
> dignity. Clifford treats Elizabeth with dignity. … It's related to Digimon I like. Because
>
> they help … better than being a slave. They have their own freewill, rather than being
>
> kept.

Figure 5.20. Taiki's photo entitled "True Friendship."
*Caption: If you understand people's feelings, and stay by their side, you will understand true
friendship.*

Many other students also resonated with the story and agreed that friendship should entail respect, loyalty, and trust. "In terms of that friendship topic, the three most important things that I see in a friendship are dignity, honesty, and respect" (JC). Of equal importance is the mutual, reciprocal nature of these values within friendship. As Taiki illustrated in his photo's caption, "If you understand people's feelings, and stay by their side, you will understand true friendship," the bonds of friendship are realized in mutual empathy and loyalty. Roy made a similar point about mutual respect, "Honestly, I think respect and friendship kind of go hand in hand. Because how do you expect to be friend with somebody who can't respect each other." Bob also further reflected on the equally giving and receiving nature of friendship:

> Friendship is difficult to me, but a lot of time I see people expecting a lot from friendship. And they think they give a lot but not necessarily giving what they say they will, so it's pretty much they expect more from a friend than they probably give to a friend.

Furthermore, although most students do not seem to have many friends, they expressed that friendship was important to them. More importantly, they were aware of the need to be selective and careful in making friends:

> We think friendship is necessary, and also, as I said before, some people, you can try, but if it won't work, my advice is to avoid them. It's also the best for them to learn that not everyone can be there for them. (Bob)

> There are some people that just, they're not going to change, you know. No matter you are trying to be their friend, they just don't want to be your friend. It's kind of that. You can't really make them want to be your friend. (Scarlet)

> And lots of people don't really understand what it means to be a real friend. And in this generation, we're straining from that, it's like if you really do find a real friend, you have

to keep them, because you will never find that friend again. It's that friend gonna be a needle in a haystack kind of thing. And I try to be that kind of person, because to me, relationship and friendship are very important to me. And it's like, I want to be everybody's friend, but I know I can't. Some people I know, I have to walk away from, because they are hurting me, or they are being mean, socially, spiritually, and mentally. But I can only, I have to take care of myself. I always make more friends, but I still, in that sense not always a real friend. It's better to have few friends than many friends, which I don't have many friends at the first place, if you have a few that you can trust well. (Luka)

Animals. Animals play a big role in students' lives in many different ways. Students described their own pets most of the time, while also mentioning animals they came across in the community. They described these animals as "adorable", "handsome", "cute", "beautiful", and expressed that "I really love them to death" (Darth) and "They have a lot to offer" (Micheal). Their pets "make me happy when I am with her" (JC) and "bring me love and joy every day" (Micheal). Indeed, when asked what represented their well-being, Christopher and Darth named their dogs as the first important thing to their well-being. For example, Darth described how her dogs are a big part of her life and well-being (Figure 5.21):

It's basically a picture of my two small dogs, and one big bed together. It's really cute, I really love them to death. I always play with them, at least every day. And, I love them to death, and I always hang around with them, and sleep with them too. I sleep them on the bed sometimes.

Figure 5.21. Darth's photo entitled "My Dogs."
Caption: These are my super cute dogs at home.

Animals were always there not only to make students happy, but also provided company when they felt down. Animals "give me company when there's no someone else, so that's very valuable to me" (Bob). Christopher also described his dog as "my soul and the only animal that is always by my side anywhere I go." In addition to being a good company, pets spent time with the students in their everyday lives. JC, Darth, and Bob mentioned playing with their pets a lot, such as tug of war. Their pets also did "silly stuff" (Bob) and "random stuff" (Janiquaa) that students recorded and recalled, which seemed to contribute to students' well-being. For example, Bob captured a moment of his dog "going out to the patio after him and he [the dog] was barking and he was pulling around this big clump of, well, mud pretty much, because he wants to play tug of war with it."

Animals were described to be able to sense how the students felt and provided comfort to them. Luka's puppy is very "comforting" to her. Micheal's cat "keeps me calm," and is also "comforting" and "soothing" (Figure 5.22).

Figure 5.22. Micheal's photo entitled "Miss Lizzy my cat."
*Caption: I love my cat so much and she inspires me in so many ways I can't imagine. She keeps me calm and brings me love and joy [every day].

Both Christopher and JC described their dogs knew when they felt sick and would jump on their

bed, sit next to them, and cuddle them. Darth and Janiquaa further explained their shared

emotions and understanding with their pets:

> Well also dogs can also sense if you have a bad mood more than people. They sense like
>
> that. Somehow they tell what your emotions. And they comfort you always. They come
>
> up to lick your face. (Darth)
>
> My cat, knows what I am saying, or, how I am feelings. And she wants to seek my
>
> attention and I give it to her. And when that goes back and forth, she knows that I am
>
> loyal to her, and she is loyal to me by giving back, by being in my room, crying, or
>
> something that she comes by, and she lays on my lap. So sharing. (Janiquaa)
>
> Beyond a sense of shared understanding, some students even drew inspiration from their

pets. Micheal described that she "gains knowledge and understanding from my cat in everyday

life" as "my cat happened to show me curiosity, and I find that interesting because I love the way cats and animals operate." Janiquaa reflected on what one of her pets showed her and related to what she learned about herself growing up (Figure 5.23):

> She's like, "Okay I'm going to do this. I need to do this. I am independent." She is pretty independent for a guinea pig. Most independent guinea pig I have ever met. She's special. She reminds me to stay independent and, do your own thing. More be confident yourself. And when I see her, you know, she gives big hugs. She runs around. She loves to run around the house. She wants to stay strong. … Because, even though she has neuro problems, well, so do I. I kind of, we kind of work with each other in a way that we both have problems of course, but yea, we both love each other, and, we support each other, you know, in different ways, because she is an animal. … She is special, and we are special together in our own way. We share with each other.

Figure 5.23. Janiquaa's photo entitled "Pandora."
Caption: Fuzzy like a panda.

While animals have a lot to offer, young adults also show care for animals in different ways. Darth showed a photo of three kittens she found in one of her potted plants during Easter (Figure 5.24). "That represents my well-being because that just makes me feel like, I just love animals. Any animal is welcome here. But this represents my well-being because I like to get to know as many animals as possible."

Figure 5.24. Darth's photo entitled "Happy Easter."
Caption: We found three kittens in one of the potted plants, so cute<3.

Christopher and Micheal shared their experiences with rescuing dogs from the street and how they eventually developed relationships and attachment with them:

> She grew up from a puppy. I found her in the middle of the road. When I found her, she got an arrow on her leg. You know that? An arrow on her leg. So I took her to the vet. They said, "do you want to take her home, or want her to be put down?" I took her home. And within a year or two. I got her when she was 20 months or something. Within two years, she healed. She is walking on all four legs. … You can tell the moment when she is smiling. She runs all around. … She is a little tiger. So she is very happy. (Christopher)

Rufus is a dog I rescued with my grandma and my uncle Greg and I took care of him and loved him for some of the day. It was very nice to take care of an animal I love and that dog stole my heart. I miss him so much. (Micheal)

Another salient theme that came up in the discussions of animals was that students saw genuine friendship in their relationships with animals. As Luka described, "Dogs are really man's best friend. That saying, that it doesn't take it lightly, it's pretty true." As mentioned earlier, Bob described his dog as his "best friend." Taiki understood friendship from the story of Clifford the Big Red Dog and Elizabeth, which taught him about "dignity," "loyalty," and to respect that animals "have their own freewill." Other students agreed with the nature of friendship portrayed in this cartoon:

I grew up watching Clifford. And, it really taught me as I grew older. I watched it as little kid. I would say, girl and her dog, it's so cute. As I kept watching it, and I get older, I start to understand the meaning that she can trust her dog and the dog is loyal to her and respects her. She respects the dog. And, she is very trusting in the dog. And they have a very beautiful friendship. (Janiquaa)

Students also described other qualities of friends that they realized in their daily interactions with animals. "I think dogs are part of our well-being because no matter what you do to them, or to a certain extent, no matter how we treat them, they always love us, they are always there for us" (Roy). "Animals have souls and feelings. And they can be your best friend. They can be royal to you. They share their thoughts and feelings with you without talking to you obviously" (Janiquaa). In their relationships with their pets and other animals, students could feel trust, mutual respect, unconditional care, and shared understanding, which are essential characteristics of friendship they described. Even though animals could not talk, students seemed to feel the

sense of reciprocity in their animals as if they also knew how much people love them and appreciate their company. Micheal said that "even animals can be a part of family," suggesting an even higher degree of closeness and significance in the relationships between these students and animals.

Related to the topic of animals as friends, students discussed their fond of animals in comparison to human beings. Whereas people "can be dishonest" (JC), "not always going to be there for us" (Luka), "with people, I have to go to like place where I have my hobbies," "plus I moved a couple times" (Bob), their pets are "always there for me" (Bob), "in general can't like say anything to hurt your feelings, and dogs are very loyal" (JC), "they care about them" (Taiki), and "can also sense if you have a bad mood more than people" (Darth). Luka summed up what animals could offer compared to people:

> Animal is really good for my well-being because sometimes we just need some comfort and people not always going to be there for us. So, just having an animal, just being by our side. Some animals can be very loyal. And having them be with you can be very comforting.

Theme 3: Community Connections

Students described their different forms of engagement and connections with the community, society and the environment at large. John and Luka described their travelling experiences as a part of their well-being. John submitted two photos of him visiting New York City for the first time (Figure 5.25):

> I just love the scene. Because it has everything. I mean. Have you heard of a saying, "if you can make it there, you can make it anywhere"? … I love seeing all the landmark of attractions, as well as riding the subway. … It's exciting, because two years ago when I

went there, it was my first time ever, so it was exciting to see these things in person, instead of on TV or in pictures.

Figure 5.25. John's photo entitled "The City."
*Caption: I love the city because it just has, everything.

On the interview form, John further elaborated on his ideas of well-being. Related to his interest in trains, he reiterated, "Railroads would be the one thing that represents my well-being" and "I would improve my well-being by traveling across the country by train." Indeed, John connected his interest to his work by completing an internship at the local railroad company: "I intern at [a local railway company]. And across the time I conduct passenger train surveys. I count how many people get on and off at each stop."

Similarly, Darth saw traveling as opportunities to try new and exciting things. She expressed that "Going out at the mall, restaurant, or a place outside of my home" can improve her well-being. Luka described her positive feelings with traveling to the Niagara Falls, Georgia, and Virginia as she enjoyed exploring new experiences. In her trip to Williamsburg in Virginia,

she visited the "America's first Capital building" (Figure 5.26) and reflected on her interests in

learning about history that contributes to her "well-being just to dig a little deeper why this

country was founded and how I can be proud of this country, and the representation of what this

country is like." Luka made clear that her interest in traveling was connected to a broader sense

of belonging to the community and even patriotism.

Figure 5.26. Luka's photo entitled "America's first Capital building."
*Caption: This picture I took 2 summers ago was in Williamsburg, Bob. Williamsburg was the capital of colonial America before the American Revolution.

Some student described their connections with different communities that contributed to

their well-being. Roy submitted two photos of the Orlando Eye that showed support for different

groups of people. The first photo showed the Ferris wheel in blue (Figure 5.27). Roy further

reflected on that:

… as a person with autism it made me feel so good that, a company I should say, that

doesn't know me, I don't know, it doesn't know that I have autism, that they change the

body on supporting individuals with autism like you. And now you know that, even

though you have autism, you still have voice in the community.

Figure 5.27. Roy's photo entitled "Autism Awareness Month."
Caption: The Orlando eye Ferris wheel in Orlando changed the coloring of the Ferris wheel lights for autism awareness which [I] thought was really nice of them since they do not know how proud it makes me that they care about people with autism.

In another photo, Roy described his fondness of Alex Morgen, a player in the U.S. women's

national soccer team, and recalled participating in drills with the team while he was in the

Special Olympics. "I am sure [the team] has a busy schedule, and they took time out of their

busy schedule to spend on Special Olympics. And to me that means a lot. They do something

that's small for the organization, like the Special Olympics." The fact that the broader

community showed care to the minority groups to which Roy belongs brought him a sense of

connectedness and pride of being a part in society. In return, Roy already represented his county

in the Special Olympics at the state level. He aspired to represent the United States in the World

Special Olympics Games and to be a coach for the athletes in the long run.

Other groups in society showing care to each other also contributed to students' well-being. Another Roy's photo showed the Orlando Eye lighting up in the color of the flag of the United Kingdom after the suicide bomb attack in Manchester: "To me, it's all about solidarity. And it makes, in a part of my well-being, it makes me feel good that the city of Orlando cares, cares so much about what happened in London, that they would do that." There were some discussions about the students' respect to law enforcements who "don't know us from Adam, but they wake up every day and put on their uniform and going to work, not knowing if they are going to go home to their family after their shift" (Roy). Roy discussed a photo of "the SUN N' FUN at the Lakeland airport. That's the US Navy Blue Angel team flying over my home." Even though they do not fight, their performance reminds him that "it makes me feel good that as a branch in the military, somebody in the navy that doesn't know me or know us would be willing to put their lives on the line for our freedom" (Figure 5.28).

Figure 5.28. Roy's photo.
No title or caption.

Indeed, Christopher alluded to the fact that an unsafe neighborhood and dangerous people hurt his well-being:

> And for me, where I live, for me is having people come approach you and asking for a fight. That's really stressing me out, because I don't really want to fight them. I don't want to fight them. Trust me. If they want to fight with me, I will fight them, but no. I want to try to avoid them, just ignore them.

Other students also related to Roy's comments and described their respect to, for example, the navy, the police, and the air force. Luka respected her brother "because he got to be protecting a country that values him the most." JC showed his appreciation by leaving money at the cashier for an officer at the campus cafeteria. Nick recalled that during a baseball game where the air force visited, he "said thank you for flying on your service for all. They all came down. I did it three times, and I said thank you very much for your work." These students were not only passive recipients of services, but they also showed their respect and care to these community organizations. Indeed, Roy aspired to pay back to the military and law enforcement:

> I was gonna say, with the amount of respect I have both to the military and law enforcement, I am going to go to college, and get a business degree. That way I can start a non-profit organization that helps those who, veterans. … Whether it be being like, what I could do is they have big brothers and big sisters, but I kind of want to do something like that, but gears towards the military and their families, and gears towards law enforcement.

Five students submitted photos of natural sceneries that depicted their well-being. They described the beauty of nature and expressed their appreciation of peacefulness that nature brought to them. For example, in Luka's "Fire in the sky," she described that "The colors in the

sky makes the sky look like fire." Going beyond describing, the students reflected on the

inspirations they gained in nature. In Taiki's photo "Serenity", he stated "It's best for people to

live in harmony" (Figure 5.29).

Figure 5.29. Taiki's photo entitled "Serenity."
Caption: It's best for people to live in harmony.

As Janiquaa walked past some blue "Flowers" (Figure 5.30) every day, they "remind me to stay

strong and always stay in bloom."

Figure 5.30. Janiquaa's photo entitled "Flowers."
*Caption: Blue and blooming every which way, blown in the breeze each and every day. I walk
past you morning and afternoon, you remind me to stay strong and always stay in bloom.*

Micheal showed a photo of "The full moon" as "[it] helps me see at night and gives me light in a dark world." She also commented on another photo that:

> I like nature. I like trees, and I like wildness. … If I could live in the nature all my life, if I could live in the woods all my life, I would live there in the woods and not be a human being. But I can't live in the woods. I have to live in a city and I have to buy a car, but if I could live in the woods, and be like wild people, I would.

To JC, he also enjoyed the natural scenery around his neighborhood, such as "the coastlines near my house." He further explained the nature was very important to him because "if we don't treat our environment well, and everything that's around us, what is the next generation going to do, you know? Because without a good environment, we won't have any sustainable place to live." He hoped to contribute back to the environment and "spread the word about like, the fact that we have to work harder to decrease our pollution and, get the environment clean again."

CHAPTER 6

DISCUSSION

Both the process and the results of this Photovoice PAR have offered a sheer amount of rich information that is worth intellectual pondering. In this chapter, I extract relevant findings from previous chapters to focus my discussions on directly addressing the four research questions developed based on the participants' input. I discuss the themes about the young adults' ideas of well-being using relevant literature on Photovoice and other qualitative research. I also present a reflexivity narrative about my and the instructors' roles in the research processes that describe our negotiated and relational understanding of the young adults' perspectives in well-being. In response to the young adults' call for a better understanding of autism in society, I then draw from the literature on critical disability studies and other critical works to critique the dominant constructions of autism's well-being and to (re)imagine alternative possibilities for autism. I conclude the chapter by discussing the project's implications for research and practice as well as its limitations.

Research Question 1:

How Do Young Adults with Autism Communicate their Understandings of Well-being?

The current research explored how a group of young adults with autism understand their own well-being. Using a PAR approach, these young adults participated in a Photovoice project in which individuals were engaged in research design, data collection, data analysis, and dissemination. Specifically, they took photos in daily life to represent their ideas about well-

being. Thematic analysis of different data sources, including photos, group discussions, individual interviews, and permanent products (e.g., questionnaires, presentation), yielded three major themes that captured their understanding of well-being: (1) Self and personal growth; (2) Close relationships; and (3) Community connections. Overall, the results depicted a well-being account that expressed their differences while conveying a strong desire to be connected with others.

Theme 1: Self and Personal Growth

Young adults with autism described how they saw themselves and how they grew personally in relation to their well-being. In the first sub-finding, their self-expression in identity terms or through creative media (e.g., drawing, poem) showed who they are, what they like, what they are good at, and something other people do not necessarily see in them. Research investigating the use of creative art in individuals with autism was surprisingly limited in scope, perhaps because the field has been taking advantage of the instrumental value of art as a window into autistic (dis)abilities, either in terms of an island of savant talents (e.g., Pring, Hermelin, & Heavey, 1995) or their deficits in representational and creative capacity (e.g., Charman & Baron-Cohen, 1993), instead of the immense expressive power of art and its role in serving one's well-being. In an exceptional example, Groden, Kantor, Woodard, and Lipsitt (2011) explicitly linked concepts of positive psychology to the use of photography in nurturing unique capabilities to increase their resilience in a group of children and adults with autism. They recognized this less structured approach in promoting artistic freedom and providing alternative expressive outlets for these individuals' ideas, emotions, and competencies that are not easily observed by others.

Young adults with autism identified a range of interests and hobbies they like to do that contribute to their positive emotions and overall well-being. A similar theme of personal interests

as sources of positive emotions and coping was also found in a similar Photovoice project with young adults with autism (Teti et al., 2016). Milton and Sims (2016) also found adult authors with autism described their experience engaging in activities of interest as a state of flow, which also helps with stress reduction. In reviewing the applicability of a QoL questionnaire in children with autism, parents suggested that "should their child's special interest be limited or removed, then this would definitely have a negative impact upon their QoL" (Tavernor et al., 2012, p.598). A survey study also found recreational activities, among other demographic and program variables, to be the only significant correlate with adults with autism's satisfaction with their residential facilities (Billstedt et al., 2011). Adults with autism perceived their "restricted" interests as a source of validation, a sign of mastery, and a sense of identity (Mercier, Mottron, & Belleville, 2000). Personal interests have been found to play a significant role in enhancing a sense of well-being among young adults with autism.

Young adults with autism showed photos related to their education and schooling, in which they reflected on what they have learned and how they could apply the knowledge in lives. These young adults also discussed the process of personal growth as they seek out new experience to expand their comfort zone and overcome uncomfortable feelings. In a past Photovoice study (Cheak-Zamora et al., 2018; Cheak-Zamora et al., 2016; Teti et al., 2016), researchers found that among young adults with autism expression of their strengths and resilience was influential on their transition to adulthood (Teti et al., 2016). For example, they used photos to express their knowledge, abilities, and achievements that gave them a sense of pride. One of their participants described taking pictures helped him get out of his comfort zone and showed people how he got through challenges in life. Although quantitative research suggested the importance of self in autism's well-being, citing strong correlations of well-being

measures with self-efficacy (Feldhaus et al., 2015) and self-esteem (Shipman et al., 2011), and attempting to measure "meaningfulness" in terms of health-promoting and health-protecting behaviors (Helles et al., 2017), the essence of well-being at the intrapersonal level found in this study was realized in these young adults' exuberant, ever-evolving self. The way in which young adults with autism described their engagement in self-realization and self-actualization was not captured by any existing well-being measures.

Theme 2: Close Relationships

The second theme describes the close relationships valued by young adults with autism that play significant roles in their well-being. In the first subtheme, young adults showed that their family members both directly and indirectly supported these young adults' well-being in their lives. They did very much care and love their family members, although they might not communicate well to their family members. Despite short-lived negative emotions triggered by daily hassles or at times traumatic experiences, after all, family still loved these young adults and helped them learn, grow, and get through difficult times. The young adults' feeling of bittersweet is understandable as they strive for independence and self-determination transitioning to adulthood, while their parents might be uncertain about their changing roles and levels of involvement in their adult children's lives (Anderson, Sosnowy, Kuo, & Shattuck, 2018). Cheak-Zamora et al. (2018) similarly captured a mixture of their positive and negative feelings as they expressed love and admiration for their family members, while sometimes feeling sad and jealous when comparing themselves with them. When asked to formulate one piece of advice for other families, parents living with adult children with autism (majority with below average cognitive functioning) stressed the importance of accepting their children and focusing on the positive aspects of their children's differences (Billstedt et al., 2011). Although in the literature it

is far more common that parents spoke about their experiences living with their adult children with autism, but not the vice versa, this study adds to the perspective of the young adults with autism, who recognize the significance of their families' unconditional love and continuous support in their well-being.

In terms of friendship, young adults with autism identified friends with whom they shared important moments and supported each other. Although they recalled past experiences with difficult friendships, nor did they appear to currently have large social circles or regular social gatherings, the friends they showed in their photos were close to them, always there for them when they needed them, and special. In other words, they described the importance of the quality of friendships that is significant to their well-being. The present findings share similar observations with Parsons (2015) that although many adults with autism did not meet with friends regularly or have a wide social network, they were satisfied with interpersonal relationships with only a handful of social outlets, such as community clubs and the Internet. Cheak-Zamora et al. (2018) found that while young adults with autism recognized their own difficulties in understanding social situations and experienced social rejection in the past, they had a strong desire for more and better friendships. While the majority of quantitative literature that found lower satisfaction in social life or less frequent social contacts among young adults with autism often attributed these "deficits" to their poor social understanding and lack of appropriate social skills (Helles et al., 2017; Jennes-Coussens et al., 2006; Lin, 2014), these studies failed to recognize the agency of individuals with autism, and more specifically, the meaning of social motivation and relationships as seen in these individuals' eyes. The young adults with autism in this study elucidated a nuanced understanding of the dynamic nature of friendship, which entails mutual respect, loyalty, and trust reciprocated between two individuals.

From their first-person perspective, although they were not strong in communicating and expressing themselves, the fact that they were wary and selective in making friends reflected the problem of how other people were also not sensitive and accepting enough when interacting with people on the spectrum ("double empathy problem", Milton, 2012). As people find it difficult to empathize with people on the spectrum and become "dyspathic" (Cameron, 2012) by blocking empathy and distancing themselves from the latter altogether, people with autism experience frequent setback in building trusting relationships with the majority population, and thus hurting their well-being (Milton & Sims, 2016). Although it is not always easy to tell whether a person with autism is not socially motivated or is frustrated by negative social experiences, after all, the fact that some individuals with autism may prefer time alone and not appear to care about social life should be accepted and respected (e.g., Tavernor et al., 2012).

Closely related to the nature of friendship, many young adults with autism described their pets as friends. While their pets gave them comfort and company, these young adults also showed care for and spent time with these animals. That animals account for the largest category of photos may be attributed to the fact that animals were readily accessible and always present in the young adults' daily lives. Young adults with autism viewed the mutual understanding and reciprocal relationships with their pets as genuine friendship that even excels human relationships. Contrary to a common misconception that young adults with autism struggle with communicating and expressing themselves to their families and friends, animals essentially broke down the communication barriers with these young adults, as Janiquaa noted, "They share their thoughts and feelings with you without talking to you obviously." While past research found people with autism who have low incidence of social relationships commonly felt lonely (Bauminger & Kasari, 2000; Bauminger et al., 2003; Mazurek, 2014), friendship (among human

beings) did not appear to mitigate the effect of loneliness on life satisfaction (Mazurek, 2014). In current study, it is fascinating to note that the role of animals in countering loneliness and improving well-being in these young adults with autism. This finding is strikingly similar to the descriptions by young adults with autism in Cheak-Zamora et al. (2018) that animals helped them cope with negative feelings, provided companionship, and share a sense of understanding with the young adults. In essence, animals are non-judgmental, sensitive, and always available to provide comfort and support. This sense of unconditional positive regard serves as the basis for connections and relationships that lead to feelings of acceptance and being understood in people with autism (Milton & Sims, 2016). In fact, the benefits of pets and animals in promoting well-being in people with autism and providing them a complementary social support were previously reported (e.g., Byström & Persson, 2015). Observations of people with autism in this study push the boundary of the concept of "relationships" beyond human beings. A human-nonhuman relationship is as valuable as a human-human relationship insofar as an individual is being acknowledged, accepted, and understood, instead of being judged or disapproved.

Theme 3: Community Connections

The third theme captures a sense of connection with the community, society, and nature surrounding the young adults with autism. They described their engagement in the community through different kinds of activities, ranging from one-time community events, ad hoc leisure activities, occasional traveling experiences, to regular sports practices and job internships, through which they experienced different positive emotions (e.g., joy, excitement, pride, calmness). Knowing the environment is safe and the people around are caring and respectful, these young adults also found meanings in terms of a sense of connectedness and belonging to the broader environment. In a German study, Schmidt et al. (2015) found that having less

difficulties with participating in family, social, and community activities was the largest predictor of overall LS in adults with autism, while satisfaction in neurotypical adults was influenced more by interpersonal communication and social interaction. Parents have also noted the importance of sense of belonging for their children with autism that was not mentioned in common measures of well-being (Ikeda, Krägeloh, Water, & Hinckson, 2016). Cheak-Zamora et al. (2018) asked young adults with autism what scared them about becoming an adult and found that they were worried about losing connection and support they used to have. Using a strength-based approach, the current study shed light on the importance of having close, meaningful connections and feeling supported by the environment that promote these young adults' well-being.

Well-Being as Expressed in Research Processes

Besides the contents of what the participants had to say about their understandings of well-being, the very experience of engaging in the research process (described in Chapter 4) also reflected a sense of well-being of these young adults. By the nature of the research topic, this project offered the opportunity for them to depict themselves in a positive light, which captured their initial interests and excitement about participating in this project. Throughout the development of the project, I respected their different personal preferences in communication and self-expressions, which created a safe space to facilitate their engagement. At the same time, I attempted to elicit their feedback about how the project should be run to ensure that individuals' well-being was considered while the group was making progress. Overall, many young adults described this project as a "fun" and "meaningful" experience. To learn to use pictures to express their well-being, talk about their feelings, and show how they had grown and matured was meaningful to their wellness enhancement. In other words, their sense of self and

personal development (i.e., Theme 1) were integral to their core well-being, while experiencing growth and self-expression was also important. Similarly, conducting and participating in this project itself facilitated these young adults' sharing their ideas to other people and helped eliminate misunderstandings in people in the community, which also resonated with their sense of well-being in terms of forming relationships and connections with people around them (i.e., Themes 2 and 3). It is particularly insightful to witness both the contents and processes of this research achieve its central purpose – to promote well-being among individuals with autism. This current research shares with other Photovoice initiatives to promote accessibility, engagement, communication, skills development, and empowerment among individuals with autism (e.g., Danker, Strnadová, & Cumming, 2017). These documented benefits of Photovoice are strikingly similar to the conceptual components of well-being theories (e.g., Seligman, 2011).

Research Question 2:

How Similarly or Differently do People without Autism Understand Well-Being in Autism?

To answer this question in the context of the current project, I must turn to the Photovoice processes in which the young adults with autism, the TLA instructors, and I constantly negotiated and constructed our understanding around this issue. To be clear, this study did not intend to produce generalizable findings and thus the approach to answering this question was not to compare the conceptions of well-being by the young adults in TLA to the general population. Instead, the knowledge generated in this study was intended to be partial, situated, and engaged (Haraway, 1988). Reading closely and reflecting critically on my journal entries, coupled with quotes from the discussion transcripts, I presented here a reflexivity narrative that shows the multiplicity of understanding around this research question. To theorize this reflexivity piece, I engaged in an "intersubjective reflection" (Finlay, 2002, p. 215) exercise

where I explored the emerging knowledge that was negotiated and situated within the relationships between me, the young adults with autism, and the instructors in the context of TLA. I deployed the technique of reflexive inquiry as an ongoing and relational introspection in the moment during the Photovoice processes, as well as an after-the-fact critical examination of my research positionality, which are mutually contributive to how self and self-in-relation impact my understanding of others in my research (Ellis & Bochner, 2000; Lyle, 2009). In other words, I engage in reflexivity not intending to assert authority in representing reality, to abuse identity labels for political correctness, or to preoccupy with self-representations. Instead, I hope to better understand the system on which I researched and the complex relationships involved in the research processes, while witnessing how these reflections transformed my self-knowledge and my negotiated meanings with others.

At the beginning of the project, I invited Ms. Maria, Ms. Carmen, and Ms. Smith to also participate in the photography activity, hoping that their participation could be a model to promote active engagement of their students. But soon after they discussed how they would like to take photos and discuss their well-being ideas, I realized this practice had so much influence on the research itself: *Why do I want the instructors to participate? What should I do with their photos? If this project aims to put the autism perspective in the foreground, what is the role of the instructors' perspectives?*

My pondering with these questions led me to ask the young adults with autism in the first session, "Who are the participants in this research?" Perhaps because of the inherently abstract nature of this question, philosophically and methodologically, the group first received this question by discussing their photo targets as participants, describing that these people were an important source of inspiration for their well-being. Then, I clarified my question, and asked

explicitly whether the TLA instructors and I should be a part of the project. As different opinions

emerged, some young adults said it was "our choice" as long as we did it "independently," while

others suggested including us could help them "take others' shoes" and see "the perspectives of

how people without autism see autism." Some also cautioned whether this move "would change

the project." Ms. Smith added that people with different disabilities probably see well-being very

differently from people with autism. The young adults elaborated on that idea, describing people

with and without autism have different challenges in life. They continued going back and forth

between documenting experience specific to autism and the risk of being misrepresented by

people without autism.

In the midst of these heated discussions, Ms. Smith assertively asked, "Why don't you

hear what we (instructors) have to say?" Ms. Maria proposed a "compromise" to include

instructors' photos in the discussions, but not in data analysis. Their photos could also be used to

show their "differences" with autism, and how it was like "being around people with autism."

Ms. Carmen suggested that there may be "common human experience" between people with and

without autism, and would be "interesting to look at neurotypical's day and ASD's day." It was

indeed an aha moment to me as I was too focused on the young adults' opinions, but totally

oblivious of the fact that the instructors (and I) were also active agents in the project. Indeed, no

matter we (instructors and I) engaged in photo-taking activities or not, we were still

"participants" as we were integral members of the TLA program who observed and facilitated

students' participation and discussions in the Photovoice project. To wrap up the discussions, I

proposed to try out having the instructors and me participate and take photos, which could add to

the perspective of how people without autism see the life of autism. Both the young adults and

instructors seemed to like this idea. I emphasized that the plan was tentative and could be

changed in the future. I suggested the group continue to discuss and think about the instructors'

roles in this project. In hindsight, I had hesitation about this idea as I worried that including the

neurotypical perspective would recreate the power differential between the researcher and the

researched in the autism field. *Why do we (or I) want to see commonality or difference between*

autistic and neurotypical? What do these decisions tell about our epistemological assumptions?

What is the epistemological value of an autistic standpoint? Is this standpoint only

comprehensible and legitimate when subsumed under the worldview of the dominant paradigm?

Indeed, as described below, when the instructors and I attempted to speak from the autistic

perspective, the moment immediately turned into a crisis of representation (Lather, 2002), which

rendered our critical reflections on this research practice.

From sessions one to three, the instructors were more like observers in the group and did

not insert themselves into the discussions among the young adults. There were only few

instances where the instructors made comments and asked questions, which sometimes helped

clarify students' ideas and facilitate the discussions. After session three, I approached the

instructors to check in whether they were taking any photos. To my surprise, Ms. Carmen

expressed that she was only taking photos about *her own* well-being. I was surprised because I

thought (or I assumed) our participation was to document our views on people with autism's

well-being. After I explained my intention, however, I was faced with skepticism from all the

three instructors. Ms. Carmen quickly envisioned the challenge for her to see well-being from

her students' perspectives as she could not always be around them. Ms. Maria also expressed

hesitation in using this perspective to take photos. Ms. Smith rightfully described the focus of her

photos was "my well-being *in relation to* the students," citing an example of her experience with

using the public transportation. Ms. Maria suggested we address this important issue with the rest

of the students. *Within the context of TLA, what are our roles in this study (e.g., instructor, professional, or neurotypical)? What is our relationship with the students and their well-being (e.g., observer, contributor, interventionist)? Do we intend to situate the knowledge claims about their well-being at a local (i.e., TLA) or more global (i.e., autism community, academia) level?*

Since I received some feedback commenting about some off-topic discussions, I thought that would be a good opportunity for me to revisit the project goals with the young adults. I started session four by asking the students what they wanted to achieve from the project. Their responses coincidentally answered most of the questions from the instructors and me: "…sharing your emotions to everybody" (Darth), "…to see other people's perspectives on their well-being, so it's just interesting to look at how other people see things differently than I do" (Luka), "…to increase other people's understanding of how people with autism perceive their own well-being as well" (JC), "…let people outside of this circle come to better understand what autism means, and how to better treat the people that come across with autism" (Roy). Asking the young adults to speak about their goals indeed offered much insight about how instructors and I should position ourselves in this project. At the end of session four, I directly asked the young adults to comment on how the instructors and I should take photos and engage in the project. A few students suggested "you should say that you aren't people with autism, that you don't have it, so just to make sure we are not confused" (Bob), and "since this project is more about autism and well-being, you could take pictures neurotypical's perspectives on what autism looks like from your point of view" (Luka). Later in the analysis stage, Luka also suggested that "Their [Ms. Maria and I] point of view might line up with, for example, my point of view, someone with ASD, because they are constantly working with those people." Overall, the young adults seemed to be interested to see how we understood well-being in autism.

Despite the students' curiosity, Ms. Maria, Ms. Smith, and Ms. Carmen did not quite agree with this proposition. In other words, they did not think they should or were able to take photos using the perspective of autism. They found it difficult or even inappropriate to say anything about well-being on behalf of their students with autism. More importantly, they always emphasized "every individual is different," so it was hard for them to say what "autism's well-being" actually is. On multiple occasions, I felt their strong sense of hesitation to represent their students with autism.

Below I presented the photos submitted by the instructors and analyzed how they could answer this research question. As explained above, these photos were not, and did not intend to be, encompassing of how well-being in people with autism should look like. Nor did they represent what the instructors and I saw people with autism. Instead, these photos exemplified how the instructors and I negotiated the meaning of "shared well-being" that gave rise to the common ground for relationships and empathy between us and the students.

Both Ms. Maria and Ms. Carmen repeatedly expressed difficulties in taking photos using the perspective of their students with autism. Instead, they captured things that represent their own well-being. Among the five photos Ms. Maria submitted, four of them were related to nature ("Mini snowman," "Huge tree," "Squirrel!" and "Serenity") and the other one was a picture of a Christmas tree. In "Serenity" (Figure 6.1), Ms. Maria expressed her love of nature, which brings her happiness, calmness, and reminds her of home:

> Saint Leo is this little town about 20 miles away from Tampa that I discovered last fall.
> First time I went there I was shocked that it was so close to Tampa like to the city,
> because it feels so far away. I like to be out to the nature. I am from Kentucky, so I grew
> up with lots of hills, and trees, and grass, and it just makes me calm. Makes me feel good

when I am around that. So, this is, um, kind of remind me of home, minus the palm trees. There are no palm trees in Kentucky, but, um, it just, I just think it sounds relaxing. It's just beautiful. It reminds me of the beauty and everything in nature on the Earth. I am always appreciating when I see something in nature that is naturally, beautiful. Or a piece of art or music or something. I just appreciate kind of beauty in things. And, just brings me a lot of happiness.

Figure 6.1. Ms. Maria's photo entitled "Huge tree."
*Caption: Nature is amazing, isn't it?

After hearing Ms. Maria describe her photo, Micheal expressed a similar kind of affinity for nature, "It is really peaceful. Like I like nature. I like trees, and I like wildness. And walking around the campus, it was quiet and peaceful." Roy also commented that "it can help you calm down to an extent." Luka resonated with Ms. Maria's experience as she recalled visiting Mount Dora, during which "I don't think I am in Florida anymore."

For Ms. Carmen, she submitted a photo of "The beach" and another titled "Sprinkles." Ms. Carmen described how she took care of and built relationship with her cat, which reminded her to find happiness in the present (Figure 6.2):

This is my cat. Her name is Sprinkles. … When I first got her, it was so hard for her to trust, because she lives in PetSmart, she lives with different people. And she really never got adjusted. And I remembered one time I took her to the vet, she was very playful when I put her in the car, and then she almost suddenly stopped, being very very still. And I realized that she probably was thinking, in my mind, she was thinking, "you are going to get rid of me too." And it broke my heart. And I remembered getting very very upset that day. … We all have things whether it's an animal or like a person, we all have things that make us feel sad. We've left them in the past and it can still make us feel happy. So, I chose to focus on something that would make us still happy. … So to me, well-being is just reminding yourself doesn't matter what happened in the past, does not matter. Because your friends will become the family that maybe you don't have. And being able to find one and being in happiness of who you are. That is the more important thing to do.

Figure 6.2. Ms. Carmen's photo entitled "Sprinkles."
Caption: Sprinkles is a rescue kitty that someone brought to my classroom many years ago. She was so tiny and scared when I got her. She has grown and is a very loving kitty. I am happy to have her!

The photos of both Ms. Maria and Ms. Carmen captured animals and nature, which shared common themes with the students' photos. Common threads across their quotes were their experiencing of positive emotions, a sense of connectedness, and the relationships they formed with the environment and different animals. Juxtaposing the interpretative accounts of the photos by Ms. Maria and Ms. Carmen with those by the young adults reveals strikingly common meanings created in their accounts of well-being.

For Ms. Smith, she submitted 3 photos, which included a dog, a sign of the University campus where TLA was housed, and a scene of two of her students working in front of computers. Ms. Smith described her well-being in terms of "working with you guys in the Learning Academy, I learned a lot, and learning always helps my well-being." She further explained the reason why her service dog represented her well-being was that "I feel like I share him with you guys, and, so that, that would be something that we have done together to represent my well-being" (Figure 6.3). She also recalled:

> You guys have all told me in one time or another how much you like the dog, or you think the dog is pretty. … you guys have all, you know, kind of looked at the dog, or smiled at the dog, or some. I think that dogs do represent well-being in some of you. Some of you I know brought up, could you keep it as your dog. … So, dogs in general I think represent well-being.

Figure 6.3. Ms. Smith's photo.
No title or caption.

Ms. Smith identified a similar sense of connection and relationship when describing the college

sign (Figure 6.4):

Figure 6.4. Ms. Smith's photo.
No title or caption.

I think that the picture I took of the sign that said the University of South Florida, really

represents my connections with you guys, because I would not have had the opportunity

to meet any of you if I hadn't been, for me being here the school, and you guys here at

the school, so that the University of South Florida represents my connection with you and

my well-being.

It is clear that the common experience in the interactions between Ms. Smith and her students

formed the basis of their shared sense of well-being.

In the three photos I submitted (discussed in details in the next section), I described my

conceptions of well-being in people with autism in terms of their strengths, knowledge, and

possibilities to offer. I saw them as similar to art as they both "can show many different

possibilities in life." When I gave presentations about autism, I found people with autism "have

so much to contribute" and "inspire me." In conducting research, their "perspectives and

knowledge they share with us" always "teach me something."

The original goal of asking this Research Question 2 was a response to the young adults

with autism's curious mind to "take others' shoes," understand "the perspectives of how people

without autism see autism," and "increase other people's understanding of how people with

autism perceive their own well-being as well." The instructors experienced tension between

understanding their own well-being and apprehending that of their students. Reflecting on this

"crisis of representation" (Lather, 2002) reveals an intersubjective space co-created by the

instructors and the young adults with autism. Using the term coined by both Ms. Maria and Ms.

Smith, "shared well-being" is an ethically appropriate and pragmatically informative concept that

could adequately answer this research question in the context of the social relationality formed

within TLA. The instructors and I were looking for commonality between us and people with

autism not because we needed them to "teach" us, or vice versa, about the truth of well-being. It

was not the goal of the present study or this particular research question to search for a singular

way of well-being. In other words, a person's own account of well-being is intelligible in its own

terms, and any attempts to subsume one's personal understanding of wellness under an

incompatible paradigm risk being misconstrued as acts of appropriation or colonization. Instead,

this Photovoice project opened up a space for individuals to explore one's well-being, through

which the young adults with autism, the instructors, and I found similar meanings in each other's

accounts of well-being. Within this intersubjective space of "shared well-being" lay the common

human experiences of building relationships and forming connections with each other, as

exemplified in Ms. Carmen's critical reflections:

> I would prefer positioning myself from a place in what brings us together, versus,
>
> because I can't make that [representing what people with autism think well-being is].
>
> That's like saying, what does she like, she's black? What does he like, he has blonde
>
> hair? You can't make that assumptions. We have things that bring us together as people. I
>
> would prefer to respond to it without feeling like a prejudice, being prejudiced. … I kind
>
> of feel like I don't really have a weight to say what it feels like to have autism because it
>
> is something I can't imagine what it is like to have.

Aligning with the PAR paradigm, Ms. Maria, Ms. Carmen, and Ms. Smith all indicated that

forming relationships with their students indeed enhanced the instructors' own well-being.

Although less obvious in the young adults with autism, they also benefited from the space in

TLA and this Photovoice project to allow them to explore and express their ideas on well-being.

The concept of "shared well-being" captures the intersubjectivity and the dynamics

among the young adults with autism and the instructors (and me). Implications for creating

common ground for empathy and relationships are profound. People have different concepts about their own well-being, but what they share with each other would be an important common ground that could foster mutual understanding and positive change. Recalling the dilemma of the "double empathy problem" between people with and without autism that commonly results in othering, oppressing, and silencing individuals with autism, Milton (2012) argued that "good autism practice" should be "an ongoing imperfect process of interaction and should never be seen as a given" (p. 886). The nature of "shared well-being" being constantly deferred to the understanding within the space co-created among the students with autism and with the instructors in TLA seems to be an exemplary antidote that could foster mutual understanding and relationships.

Postlude: My Reflexivity Statement

In the course of this PAR study, I, as both a researcher and neurotypical, intended to deliberately relinquish my power, control, and privilege that were accrued to me by norms, traditions, and expectations from society. Reading the research proposal I prepared, I previously had imagined myself going into this study being "a powerless researcher and a non-judgmental neurotypical," who would be "in a vulnerable position where I will become a minority among a group of individuals with ASD who hold the power to express their voice and perspectives." In hindsight, this was such a naïve claim. *How possibly could my privilege and power be instantaneously disarmed when I crossed from the social reality occupied by the dominant culture into the research space co-created by me and my participants? However, if this was not the case, then what was (meant to be) different for me stepping into this research space?*

Power is indeed everywhere. In the context of research, I as a researcher and a neurotypical made me by default an outsider of this group of young adults with autism, which

also set up a natural power barrier between us as we are socialized to perform within the boundary of our identities. However, what was different between the social world and this PAR study was the deliberate shift in power dynamic, which positioned knowledge as a relational process and on-going negotiation. Even though I was not an insider to any of their identity categories, I did not have to be them, because it was not my intention to represent them in identity terms. Instead, I engaged the differences between me and my participants in my understanding of their well-being. These differences included differences in worldviews and power. I paid special attention to the differences in my interpretations of the data versus theirs, and brought these differences to my critique of the dominant paradigms in the autism community created by the socio-cultural and scientific regimes.
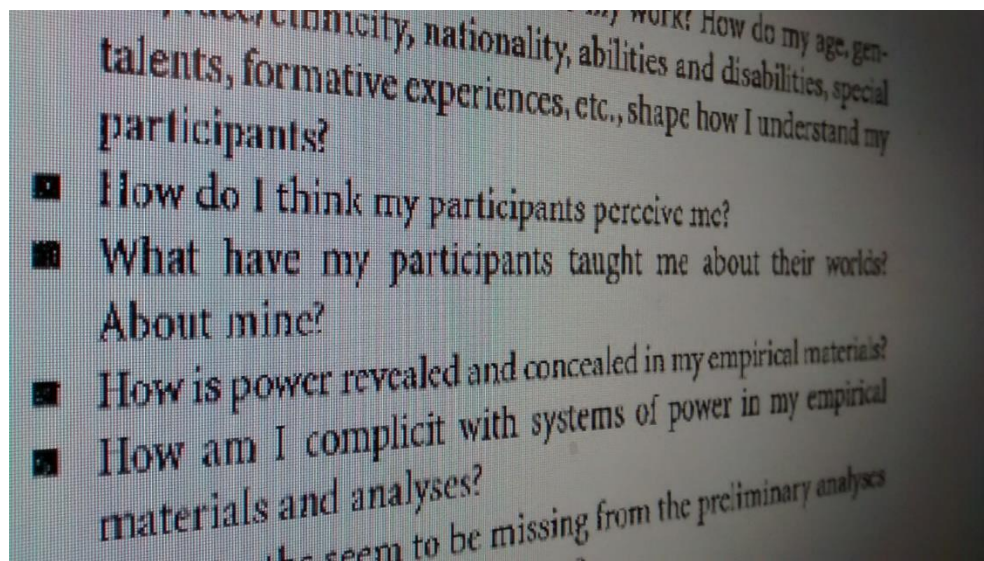
Figure 6.5. Gary's photo entitled "You teach me many things!"
*Caption: This is a picture I took while in class reflecting on how I conduct research. I am especially touched by thinking about working with people with autism, and other (dis)abilities, that they always teach me something. I think the perspectives and knowledge they share with us are part of how they show their well-being.

In this photo I submitted in the Photovoice activity, I captured a portion of a book chapter I read in class (Ellingson, 2011) to reflect on my ideas on well-being in the young adults with autism (Figure 6.5). In the caption, I wrote, "I am especially touched by thinking about working

with people with autism, and other (dis)abilities, that they always teach me something. I think the perspectives and knowledge they share with us are part of how they show their well-being." Evident here was my partial understanding of their well-being in relation to what they presented to and shared with me. While "my participants taught me about their worlds," at the same time I was learning "about mine." This relationality was further implicated in the field of power differential where my participants and I were situated, which necessitated a further analysis of self in my research positionality.

Entering this research space, I brought with me a baggage of privilege and power that directly or indirectly impacted my ability to influence how research could be conducted and results be produced. Besides being a neurotypical and a researcher as mentioned above, being a man in the field of helping profession working with the autism community is an interesting experience for me. On one hand, I could not deny the privilege accrued to me by the patriarchal society, at least in the United States. On the other hand, men are often the minority in this field and thus have to learn how to navigate in a professional culture dominated by women. I use this observation to highlight the importance of intersectionality, and more importantly, how my intersectional identities and/or identifications outside of being a man have influenced my scholarship in research and practice (see McKearney, 2014). For example, I clearly have an accent speaking English, and this shows another facet of myself that I have experienced power in a very different way. Although my accent does not affect my communication ability, it has made me easier to be singled out and spotted on, overtly or covertly, for good or bad reasons. Through this intersectional space in my self-identity, I have experienced both the vulnerability in being different and the embodied reactions to grappling with the issue of power in my personal and professional lives, as manifested in race, ability, and cultural terms. On a positive note, this has

helped me gain self-awareness and cultural humility that inform my motivation to engage in social justice and diversity research. It is these relational accounts with individuals with autism from my professional and personal experiences (also mentioned in the Introduction chapter) that have driven me to continue pursuing inquiry *with* this population. Not only do I want to understand them more, but I also have a constant desire to actually do something to help this group of individuals, all of which have informed my deliberate choice of a PAR paradigm. Consistent with my practice to stay close in order to understand them, I choose not to intervene *on* them but to research *with* them.

It was interesting to witness how Research Question 2 morphed from its original intention into these reflectivity narratives. Initially, some young adults with autism were curious to know the differences in neurotypicals' perspectives about well-being. In the search of this answer, the three instructors experienced a crisis of representation in their negotiation of how they related to and understood their students. Finally, I myself also reflected on my relationships with these young adults and my positionality in my scholarship. This reflexivity does not only provide another angle to answer the research question per se, but also helps bring it altogether the questioning and pondering that hit home to me personally.

Research Question 3: What Understandings of Well-being and Autism do Young Adults with Autism Want to Challenge?

Research Question 4: How do Young Adults with Autism Want to Share their Understandings about Well-being and Autism with people outside TLA?

At the end of TLA program, the young adults with autism decided to create a presentation for the graduation ceremony. As evidenced in the discussions of this presentation and along the

Photovoice processes, there were two messages these young adults wanted to convey through this project.

First, they wanted to show others the positive aspects of their lives. This is not surprising since the main goal of this project was to explore young adults with autism's ideas on their well-being, which is itself a concept about wellness. Micheal elaborated on this idea by contextualizing the project results within TLA and also expanded the implications for improving their well-being in terms of long-term growth and development:

> And maybe we can talk about how the Learning Academy has affected our well-being and what we are going to do the next year or so after we graduate. And tell them, this is how it has affected us, this is what we have been doing in the Learning Academy, whether it's outside, inside, what the pictures mean to me. And this is what I'm going to do the next couple months or next year.

During the discussions about the presentation design, Luka selected an "upbeat and energetic" background music as "we are energetic for graduation, so I feel like it would be appropriate to have such an upbeat song in the slideshow, to show our excitement." JC commented, "And it also puts a positive tone on the PowerPoint overall too."

Second, the young adults with autism wanted to use this project to help other people better understand what well-being means to them: "I think presenting these at the graduation would give people out in the community a better understanding of what well-being is to us with autism" (JC). More specifically, the project results offered "a *different* [emphasis added] light than what well-being means to, like I said, somebody with a disability versus somebody without" (Roy). This called for an explicit move to privilege these young adults' perspectives and knowledges that could potentially add to, counter, and reject the mainstream worldview of

people without a disability or autism. While working on data analysis and thematization, Luka also pointed out that the themes found in this project were like "myth busters" that served to dispel common misconceptions about people with autism, such as their disinterest in communicating with and forming relationships with other people.

These two messages not only resonate with the theoretical bases that undergird the development of this project, but also align the project outcomes with some broader sociopolitical implications for academic scholarship and sociopolitical advocacy. In the following, I use these two messages to formulate my theoretical standpoints in my discussions of the literature on autism's well-being. Recalling the theoretical underpinnings of Photovoice in critical education, feminist theory, and community-based participatory photography (Wang & Burris, 1997), I center my discussions using a critical disability studies lens, drawing extensively from writings of critical feminist, queer, and crip theories to inform my analysis. While well-being research about autism derives knowledge predominantly from positivist empirical paradigms that map its constructs onto external reality, I recognize that reality may be multilayered in nature (i.e., critical realism, Bhaskar, 1998). The task of criticality is to unveil the social meaning and power of the hegemonic dominant ideology that mediates social reality and human agency. I acknowledge that "science" can offer knowledge about the determinants of well-being in human beings who have certain innate needs and (in)capacities, but to understand certain human beliefs that form oppressive social structures and practices can illuminate the dynamic interactions between fact and value, as well as potentially generate action and change (Bhaskar, 1986; Gorski, 2013). Recognizing that language has the power to create knowledge, construct reality, and regulate human activities (Foucault, 1991; Gee, 2000; Potter, 1996), I shared similar concerns of other authors (e.g., Lester & Paulus, 2012; O'Neil, 2008; Osteen, 2008; Solomon &

Bagatell, 2010; Wolgemuth et al., 2016) that academic and scholarly writings have powerful influence in legitimizing knowledge and disciplining practices that foreclose rather than expand our understanding of autism.

Although the academic literature in recent years has reported more research and interventions that claimed to support individuals with autism to achieve a better quality of life, it is unclear on what basis these efforts draw to support their seemingly altruistic and humanist gestures. As shown in the literature review, not only did the *definition* of well-being remain inconsistent and problematic, but its dominant *ideological framework* also worked to perpetuate values with underlying assumptions largely unquestioned. In the following, as I engage with the scientific literature in my discussions of the project results, I critically analyze the literary materials and discursive practices of these existing literature. I am concerned that the cultural practices of the academia have homogenized knowledge around autism and essentialized a narrow understanding of their well-being. I argue that existing research has constructed the ideals of well-being in autism based on the ideologies of normalization, neoliberalism, and heteronormativity, which contradict what I learned from my and other instructors' interactions with the young adults with autism as well as what they advocated for in this project.

Autism's Well-being as Described in the Dominant Literature

Autism was traditionally described as a condition that equates a wide range of deficits, which necessitate different remedial interventions. Literature reporting on assessments and interventions of well-being in individuals with autism also framed autism as a disordered entity. The majority of literature introduced autism as a disability or disorder associated with "difficulties", "impairments", "deficits", "problems", and "inability". Commonly, authors cited the diagnostic criteria of Autism Spectrum Disorder (ASD) in terms of deficits in communication

and social reciprocity and the presence of restricted interests and repetitive behaviors (American Psychiatric Association, 2000, 2013). Moreover, autism was portrayed as an entity different and separate from the body, and exerts negative impact on the otherwise intact body. In other words, autism is extra, disembodied, and potentially harmful to being of a human. This is evident from the following descriptions: "Asperger syndrome occurs" (Jennes-Coussens et al., 2006), "the effects of Asperger syndrome" (Jennes-Coussens et al., 2006), and "be affected by their autism" (van Heijst & Geurts, 2015). Following the logic of biological determinism, these authors asserted that autism as a neurodevelopmental condition brings social and communicative impairments to a person who would otherwise deserve unaffected functioning, whose deficits are to be blamed for their poor QoL. For example, Jennes-Coussens et al. (2006) asked teachers to nominate students "who had average social skills and peer relationships but *were not particularly socially skilled* [emphasis added]" (p. 405), which was intended to find control individuals who function exactly like the clinical group, with the only difference of a diagnostic label of Asperger syndrome. Later in the results section, the authors found lower social and physical quality of life in the group of men with Asperger syndrome and attributed these observations to their diagnostic characteristics of "social skills deficits" (p. 411), "clumsiness of movements" (p. 410) and "sensory hypersensitivity" (p. 410), and concluded that "Asperger syndrome has an impact on quality of life" (p. 412). All these descriptions recalled the prevalence of the medical model of disability and its functionalist view towards people with disability (Barnes, 1998; Gabel & Peters, 2004). From this worldview, autism is an inherently pathological condition needed to be treated, if not completely ameliorated.

Although the claim to promote well-being among individuals with autism sounds liberating, however much this line of works intends to stay away from the deficit-based model,

its working principles has continued to marginalize and discipline these individuals. While Schalock (1999) admitted that a unified definition of QoL cannot be achieved, he proposed to use it as an organizing framework to assess individuals' well-being. Against this backdrop of murky terminology, researchers continued to conduct studies measuring individuals with autism's well-being as if there was a set of criteria that could help them achieve the state of ultimate wellness, however narrowly defined. Subsequently, Renty and Roeyers (2006) concluded that, "Internationally, there is broad consensus about the fact that the term 'quality of life' refers to a set of factors comprising personal wellbeing" (p. 512). In fact, the process of arriving at a "broad consensus" of such definition involves a politically and ethically violent elimination of the voice of individuals with autism. Interviewing children with autism and their parents about their thinking processes when filling out common well-being questionnaires, Tavernor et al. (2012) showed that measurement systems originally developed for the general population do not sufficiently capture how children with autism understand the world and what they value. Formulation of well-being without considering the worldviews of individuals with autism is bound to continue othering and pathologizing this population. Recalling a famous saying by disability activists, "Nothing about us without us," I wonder what the different ways of well-being operationalizations and measurements tell us about the underlying assumptions at work that shape the ideas of autism's well-being. What are the ideologies underpin the regime of well-being interventions (defined broadly, clinical and socio-cultural) insofar as people with autism are being governed to achieve certain outcomes?

As evident in the majority of empirical articles, their operationalizations of well-being constructs failed to dissipate with the notion of normalization. In this dominant discourse, achieving a quality, a good life means turning a person with autism to a normative figure as close

as possible based on a set of fixed standards. Jennes-Coussens et al. (2006) explicated that their "results were *very encouraging* [emphasis added] because there are a number of similarities between the young men with and without Asperger syndrome" (p. 410). In other words, individuals with autism are better worth without the autism symptoms. As described by Sheldrick et al. (2012),

> … comparison between PedsQL subscale scores for adolescents with ASDs and adolescents in the general population showed lower QoL for adolescents with ASDs in all domains. This discrepancy suggests that adolescents with ASDs are aware of and can accurately report on the deficits associated with their ASD, especially in the realms of social and emotional functioning. (p. 54)

If the defining features of autism are the only factors contributing to a lower QoL, then the only way to enhance well-being is to eradicate autism, so that these individuals could match up to the standard of the norm. In the literature, it is pervasive that measurement systems were developed and used to evaluate people with autism's well-being in comparison to the general population. Individuals are considered "positive" and "desirable" if they achieve the "average" or "normal" range of well-being standards of the majority in society. For example, Helles et al. (2017) compared adults with autism to adult males in the general population and found "better objective and subjective QoL" than other studies of similar kinds, which they attributed to the fact that "our study not only includes individuals with a current ASD but also individuals with an 'optimal outcome'" (p. 466), defined by "individuals who at follow-up no longer fulfill criteria for ASD and who function quite well" (p. 459), directly colluding QoL with one's functional outcomes defined by the dominant majority without autism. Van Heijst and Geurts (2015) "[described] the magnitude of difference between QoL of people (i.e., children, adolescents and

adults) with and without autism" (p. 159) and found "a large difference in QoL between people with and without autism" (p. 165), which they further asserted that "much work needs to be done to help people with autism reach a higher level of QoL" (p. 165), suggesting environmental support should eventually make people with autism "learn to compensate, accept impairments and follow successful treatment (García-Villamisar, Wehman, & Navarro, 2002)" (p. 159). Similarly, Kuhlthat et al. (2010) suggested "[comparison] of HRQoL across diagnostic groups might help clinicians and families understand their experience with ASD in the context of other chronic medical conditions" and proposed "greater collaboration among advocacy groups for improving HRQoL for children with chronic medical conditions" (p. 726). Drawing such a parallel with other pediatric medical populations, such as diabetes and cardiac diseases, further reinstates the idea that autism is viewed as a pathological condition better off being cured. Moons et al. (2006) suggested that "most empirical studies assess quality of life in terms of normal life or in terms of a utility measure. This may be due to the fact that no explicit comparison of the respective conceptualisations has been undertaken thus far" (p. 899). Functioning to perpetuate the hegemony of the dominant culture, the power of this status quo is constituted through legitimizing the unquestioned notions of the norm and naturalizing the oppression of the minorities. As Black feminist Bailey (2016) revealed, "'Normal' is aggregated through some bodies and not others, creating a standard that does not include all who will be measured against the rubric" (p. 14). Consequently, differences outside the norm are rendered undesirable, inferior, and unintelligible, which are being marginalized, ignored, and eliminated, and thus people with autism are construed as incompetent, maladaptive, and unintelligent (Goodley, 2001).

One prominent ideology that ran across almost all of the literature is the subjection of autism's well-being to neoliberal ideals. At the outset, many authors subscribed to conceptualizations of well-being as maximizing productivity while minimizing resource consumption. For example, Renty and Roeyers (2006) adopted the Quality of Life Questionnaire by Schalock and Keith (1993), which included questions that ask about an individual's sense of competence and productivity as defined only in job contexts. Achievement outside job, such as volunteerism, did not seem to be valued as a person's competency or productivity. This argument was highlighted again in a review by van Heijst and Geurts (2015), which found the majority of studies looked for outcomes in autism only in limited number of domains. Specifically, "poor outcome" were commonly defined as "remain dependent on their parents or others, are either unemployed or underemployed and lead fairly isolated lives (Howlin et al., 2004, 2013)" (p. 158). Some authors even equated financial directly with well-being, as evident by that "[information] about income can be viewed as a more objective measure of quality of life" (p.406, Jennes-Coussens et al., 2006). Individuals who had "good intellectual resources" are to be pitied, if not blamed, for "not able to finish their academic studies" (Helles et al., 2017, p. 466). In the case of children and adolescents, the pediatric inventory (i.e., PedsQL) used by Kuhlthat et al. (2010) regarded "paying attention in school, and keeping up with school work" (p. 723) as indicators of school functioning that are representative of well-being in school-age youth. Clearly, youth with autism are being harvested for investing maximum focus and producing maximum amount of work in order to be passed as having high QoL.

Mallett and Runswick-Cole (2012) illustrated the commodification of autism joined by professionals, academicians, and individuals with autism and their families, such that autism became an "information-thing," a market product of which was being mutually constituted by the

constant laboring of all the parties, and being fetishized through the circulation of a promise of coherent explanations and useful knowledge around autism. Their caution that "[inevitably] many of the symptoms and behaviours of individuals with the label of autism remain unexplained and this dissatisfaction leads to the further production, trading and consumption of autism as consumers search for a better product" (p. 47) was realized in, for example, the advocating the use of QoL measures in evaluation of treatment outcomes (e.g., Gerber et al., 2011; Kamio et al., 2012). This was unfortunately a camouflaged effort to justify their labor invested in the exchange of information about program implementation and evaluation said to promote well-being in people with autism, but without scrutinizing the fact that the QoL measures used were inherently value-laden and that they alienated the lived experience of people with autism, thus further privatizing the knowledge about what a quality life is to be defined by experts, maintaining the self-sustaining commodity chain.

Outside the academia, the effect of commodification can be similarly observed in the labor market. In recent years there has been an increasing trend for companies to hire people with autism, but only if they have the "right qualities" that fit certain job nature. This recalls Puar's (2015) concept of piecing, which is useful in identifying the commodification and trading of body parts as neoliberal goods. For example, Gal et al. (2015) designed a vocational program that demands skills in interpreting aerial photography, which seems to take advantage of "the good visual perception and analytic skills that characterize many people with ASD" (p. 10828). They explicitly stated that "they [eligible participants] also went through extensive screening testing to define their language, writing and visual processing abilities, and were accepted to the program, only upon passing these tests" (p. 10823) and reaffirmed that "individuals with ASD *who are cognitively able* [emphasis added], can work successfully in community businesses" (p.

10827). Puar (2015) cited Snyder and Mitchell (2010) to describe the trans and disabled body as "a multi-sectional market" (p. 190). The autistic body can be said to be pieced into "definable localities, each colonized by its particular pathologies dictated by the medicalized marketplace" (Snyder & Mitchell, 2010, p. 191), such that different body parts are extracted for productive capacities and market values, and (dis)abilities turned into materials for neoliberal exchange for financial income and corporal interests. "In the economy of alienated parts, piecing becomes a prized capacity" (Puar, 2015, p. 54), which leads to the success of people with autism being defined based on what the market economy likes or does not like.

Scientists have claimed to have arrived at consensus as to how people with autism should live a good life. The rest is left to individuals to choose whether to go on board and follow this standard of wellness. However, is it a free choice? Here I borrow the concept of "compulsory heterosexuality" (Rich, 1980) and "compulsory able-bodiedness" (McRuer, 2006) to argue that the standard of well-being is a prescription of "compulsory wellness" for people with autism. The construction of a normative body desires the elimination of symptoms, pathologies, and disorders in individuals with autism. Similarly, a normative body is successful insofar as it strives to fulfill neoliberal ideals. Goodley's (2011) synthesis of queer and disability studies showed that individuals, queer or disabled, who fall outside the social norm are bound to be subjected to treatment and rehabilitation, as "compulsory ablebodiedness functions by covering over, with the appearance of choice, a system in which there is actually no choice" (p. 41). In free market economy (i.e., neoliberalism), not only do individuals with autism and their families provide bodies, behaviors, and experiences as labor for medicalization and commodification, but professionals, practitioners, and researchers are also subjected to the production of academic information about autism readily consumed by other parties (Mallett & Runswick-Cole, 2012).

Both parties mutually constitute the production of autism as a capitalist commodity that fuels the formation of agreed upon knowledge and naturalized standard of practices that perpetuates the value-laden neoliberal ideology. For example, Wolgemuth, Agosto, Lam, Riley, Jones, and Hicks (2016) showed that the academic literature in the United States predominately "depicted youth (situated) on the autism spectrum as becoming good neoliberal subjects who would gain value when they performed independently and according to expectations" (p. 785). Well-being promotion or intervention targeting people with autism is only a forced choice of either being a devalued citizen or fulfilling the normative standard.

Not only does this capitalist logic do no service to interrogate the boundary of normalcy in workplace, but it also assists in legitimizing an idealized autistic subject who can perform as high productivity and efficiency as workers without autism, which further marginalizes individuals who may not be capable of measuring up to this norm. To further expound on this critical analysis of well-being accounts in autism, I must turn to Foucault's (1984, 2000) analysis of power and knowledge (power/knowledge), which theorized that knowledge claims and truth are intricately linked with power, and the analysis of power is fundamental to the examination of the truth. Based on a latent class analysis that grouped adults with autism according to some hierarchies of functioning indicators, Bishop-Fitzpatrick et al. (2016) classified their participants into three distinctive categories, namely "Greater Dependence," "Good Physical and Mental Health," and "Greater Independence," which were characterized by their different combinations of "poor outcomes," such as working only few hours, living with family or caregivers, infrequent contact with friends or family members, and having a comorbid mental health condition. Although the authors acknowledged that "there are many ways in which adults with ASD can have a good life" and "the bigger picture of outcomes and QoL for adults with ASD is more

nuanced than expected" (p. 2717), their act of citing these facts does no service to help queer the possibilities for individuals to enhance well-being. In fact, the techniques of classification and prediction functioned as a system of differentiation that further legitimized the need for "research and practice in the development of treatments and interventions designed to improve outcomes" (p. 2717). The choice of these *outcomes* was indeed not a choice, but rather an institutionalized regime of "normative standards" acted upon by the power of the objective authority of the expert and their practices within a system, altogether of which brings power relations into being (Foucault, 1984). Bishop-Fitzpatrick et al. (2016) even asserted to speak for the individuals with autism by claiming that their choice of outcome indicators "represents the desires of many adults with ASD and their families" (p. 2717) without clear evidence to support this claim. This blatant attempt to manipulate the power relations in the making of a "good" autistic subject in turns persuades individuals with autism to take up the being of good (versus bad) as a rationalized form of true, linear, and nomothetic standards that forecloses multiplicities and possibilities of well-being.

It is interesting to note that Bishop-Fitzpatrick et al. (2016) found "only two individuals (1.11%) achieved all seven markers of good normative outcomes and objective QoL" (p. 2711), and then they reflected on the fact that they "may set the bar too high for adults with ASD" (p. 2717). They even backed this reflection citing two qualitative studies, which seems to be at odd with the latter's emphasis on the variation of how well-being should be understood in different individuals, as one of the authors stressed "the inability to recognize diverse perspectives seriously impeded the quality of the [school-to-adulthood] transition process" (Cooney, 2002, p. 425). While recognizing individuals' idiosyncratic ideas of well-being, to ask the very questions of why certain indicators matter versus other do not exposes the tension created by "the

discontinuity of its shifting forms, in the different interrogations to which it is submitted"

(Gillan, 1987, p. 37). This is just one among many examples in the literature that the shows

arbitrary but systematic construction of a quality life as an idealized autistic object for which the

discursively constituted formations speak. In other words, the pursuit of the seven outcomes

prescribed to the other 98.89% of individuals with autism with the help of expert interventions

does not necessarily signify the truth of well-being, but instead are non-ahistorical practices that

essentialize the ideals of autism and how its ways of living are to be judged as good or bad. It is

obvious the disciplinary power deployed by healthcare professionals and researchers in the forms

of measurement techniques and interventions are crystalized around the knowledge about this

seemingly fixed, knowable good autistic subject.

Also related to the regimes of neoliberalism and individuation is an indoctrinated form of

intimate relationships. Jennes-Coussens et al. (2006) acclaimed the idea that people with "more

sophistical abilities" to "share feelings and ideas with social partners" will have "more satisfying,

supportive and intimate relationships" (p. 412). They equated social functioning with romantic

relationship and further enforced compulsory dating as a hallmark of social well-being, putting a

heavy emphasis on individual responsibility while ignoring how other people instead also need

to understand how to interact with people with autism. Similarly, Barneveld et al. (2014) found

that "relatively many adults with ASD were single and few were cohabiting or married" and

concluded "the QoL remained to be more unfavourable in adults with ASD" (p. 309).

If social relationships can be graded in a hierarchy of sophistication, then what kind of

relationships is prized as an ideal goal for well-being? In a survey conducted by Renty and

Roeyers (2006), desirable intimate relationships were defined as "married or had an intimate

relationship with a (heterosexual) partner" (original parentheses, p. 515), reinstating both

explicitly and implicitly (in case that non-heterosexual marriages are not recognized, or illegal) a form of heteronormativity. In Helles et al. (2017), the fact that the group who no longer met criteria for a diagnosis of autism still showed similar "objective QoL" in marital status (i.e., percentage of people who have a partner or are married) as other groups who retained an autism diagnosis was attributed to that "the area of romantic relationships demand more subtle understanding of social norms that still might be difficult for some individuals with a previous ASD" (p. 466). Overcoming one's disability by learning to perform like a "normal" person enough to pass as ridded of a diagnostic label is just not enough to become a "supercrip," as non-disabled still does not measure up to the normative standards, which can be elusive and ever-changing. Wiley, Subramaniam, Hamilton, and Couperus (2015) cited examples of news and social media touting personal stories of romantic relationships in autism, the cultural narrative of which helped change the idea that people with autism are unable to love, while also simultaneously producing a new autistic subject that reinforced the naturalization of normative heterosexuality. "The naturalization of a universal disposition toward pair bonding has implications for those various queer subjects for whom this is not a desirable or achievable possibility" (p. 383). Arguably, irrespective of whether one is abled, disabled, autistic, or queer, the universalization of love, especially in its narrowly defined forms, is disconcerting.

Alternative Accounts of Autism's Well-being

The critical analysis above exposed a dominant hegemony in the academic literature that forwarded a limited understanding of autism and prescribed a normalizing, neoliberal, and heteronormative account of personhood as an ideal state of well-being. In this study, when directly asked their ideas about well-being, young adults with autism offered rich descriptions of their self-identity and personal growth, depicted their close relationships with families, friends,

and animals, and described their connections with community and environment. More significantly, they intended to use these results to convey the messages that they wanted to be shown in a positive light and use this understanding to counter the views of the dominant culture. Both the first-person accounts of the young adults with autism in this study and my literary analysis of the literature rejected the idea that the dominant account of well-being is a definitively scientific truth. By exposing the discontinuity of the discourse of well-being formulations, I called into question the legitimacy of the dominant idea while looking for space in the foregrounding of heterogenous ways to see well-being. To bring this critique to the next level, I used the concept of "crip" as an action verb to "unsettle" and "make strange or twisted" of our understanding of bodies, minds, and (dis)abilities (McRuer, 2018, p. 23). Important is to actively resist taken-for-granted systems and to see "what it might potentially become (as a process) than by what is it" as if there was a fixity of being (p. 22). To directly contrast the young adults with autism's accounts with the discourse in the academia, one could find multiple possibilities of well-being. Indeed, the themes from the Photovoice project corroborate other emerging research, primarily qualitative, to suggest alternative ways of being that is currently misconstrued or misrepresented in the field.

First, well-being, by nature, should be understood in positive instead of negative terms. As shown in the first theme, the young adults with autism in this study provided rich accounts of their self-identity, self-expression, and personal growth. With an explicit focus on well-being, the present study focused their attention to the positive aspects in their lives. Even in studies that did not explicitly focus on the concept of well-being, simply interviewing or observing what people with autism had to say and express revealed a powerful common theme that they wanted to be seen as having strengths and positive attributes instead of a disorder or disability (Bagatell, 2010;

O'Neil, 2008; Teti et al., 2016). Furthermore, the young adults with autism in this project expressed ideas of growth, development, and learning in their accounts of well-being instead of only focusing on problems and the ways to eliminate them. Their narratives of strengths, resources, and resilience provided an alternative framework to understand their difficulties and weaknesses. These young adults with autism showed a strong sense of agency in achieving their states of well-being by reflecting on their past, drawing on their own inner strength, and seeking growth and new experience in ways that meet where they are. In essence, they drew motivation to grow and change by comparing their present self to their past self instead of other people or external standards.

Another closely related observation was them expressing their uniqueness and differences. Young adults with autism in this study found well-being through a variety of experiences: They saw friendship in animals, challenged themselves to try new food, found interests in railroad and comic books, expressed themselves in different art forms, and found their personalities in class activities. From a philosophical point of view, Rodogno et al. (2016) argued that, due to the pervasive nature of autism that substantially influences an individual's way of being, one cannot assume that the standard of goodness perceived by the mainstream society can apply to individuals with autism, and more importantly, there is a need to recruit the perspective of individuals with autism "to understand what kind of things, events, feelings, activities or pursuits, persons, and so on make a positive contribution to the lives of individuals with autism and what kinds of things do not" (p. 4). From the perspective of neurodiversity, Silberman (2015) eloquently put, "instead of viewing this gift as an error of nature … society should regard it as a valuable part of humanity's genetic legacy while ameliorating the aspects of autism that can be profoundly disabling without adequate forms of support" (p. 470). The

differences in experiencing wellness arguably can be viewed as a form of embodied differences: People with certain concentration of genetic differences may have a different thinking system and repertoire of behaviors, whom we put on different diagnostic labels.

It is common for people to suggest acceptance as a way to increase awareness and promote inclusion of people with autism and other disabilities. This is evident in the messages the young adults with autism in the current study wanted to convey. Individuals with autism in other studies also identified that accepting social networks in family, the workplace, and the community were crucial to promote social participation and increase QoL (Pfeiffer, Piller, Giazzoni-Fialko, & Chainani, 2017). Milton and Sims (2016) found writers with autism described the benefits of having structure and routine, but they highlighted "the importance of these structures and routines being devised by individuals and not imposed on them by external forces" (p. 525). This also resonated with the participatory nature of the current study. The environment the TLA students, instructors, and I created was supportive and safe, but not necessarily intrusive and intervening. For example, Scarlet and Alan showed increased participation likely because of peers' and instructors' encouragement and acceptance of their alternative expressions instead of pathologizing them as anxious or reluctant and to fix them.

Acceptance cannot, and should not, only be accommodating in a passive manner. To argue on a more socio-cultural and political term, I borrow queer feminist theorist Eve Sedgwick's (1990) famous axiom, "People are different from each other" (p. 22). She asserted that the impact of looking at human differences depends on "a trust in the self-perception, self-knowledge, or self-report of individuals, in an area that is if anything notoriously resistant to the claims of common sense and introspection" (p. 26), by which she meant to use the standpoint of a person, who naturally houses hundreds and thousands of differences, to interrogate the

legitimacy of categories and labels by asking "how certain categorizations work, what enactments they are performing and what relations they are creating" (p. 27). Fail to see people with autism as a marginalized population within the dominant culture or recognize our (i.e., without autism) privileged position in othering and silencing their voice risks a fixity of understanding and acceptance that perpetuates the self-evident knowledge claims of the hegemonic biomedical and neoliberal discourses. While Luka in this study advocated using the understanding of the differences in people with autism as "myth busters," I expanded on this idea that acceptance has to be negotiated, with its meaning constantly deferred to the need and desire of individual person with autism. Being the frontline actors of the power structure, practitioners, professionals, and researchers in the field of autism ought to practice this form of radical acceptance to be critically cognizant of the regulatory ideal legitimized and naturalized by the dominant culture that could be easily imposed onto their treatments and interactions with any person with autism.

Implications for Future Practice and Research

The current study revealed conceptualizations of well-being in the eyes of young adults with autism. Direct comparison of their ideas of well-being with existing theoretical models and measurements revealed stark contrasts in the focuses and assumptions between these conceptualizations. Well-being is arguably a subjective experience, and it should be understood based on the first-person perspectives of how a person sees his or her own values and worldviews (WHOQOL Group, 1995). Well-being is conceptually more compatible with the search for personally meaningful experience instead of subscribing to a finite number of objectively defined behaviors and normative functional outcomes (Moons et al., 2006). Similarly, Seligman (2011) advocated shifting the understanding of well-being from authentic

happiness to a more holistic, encompassing model that considers not only one's positive

emotions, but also engagement, relationships, meaning, and accomplishment (i.e., PERMA

model), the domains of which can also be identified in the themes of the current study. In the

field of autism research, practitioners and theorists argued for a similar approach in

understanding autism's well-being in terms of capabilities (i.e., access to opportunities or

freedoms to realize one's values) rather than functionalities (i.e., actual achievements or

outcomes) to avoid paternalism and respect human agency (Robeyns, 2016; Runswick-Cole &

Goodley, 2013). Applying this conceptual framework in practices and research has implications

for promoting well-being among people with autism.

First, understanding well-being in individuals with autism should start from their own

worldviews, perspectives, and experiences. There are no existing measures of well-being

designed specifically for use with the autism population (Tavernor et al., 2010). To understand,

evaluate, or assess their well-being, the basic is "to understand what kind of things, events,

feelings, activities or pursuits, persons, and so on make a positive contribution to the lives of

individuals with autism" (Rodogno et al., 2016, p. 4), but this autism-centered account of well-

being is still largely absent in the literature. I understand there are many practical barriers that

could prevent us from accessing the autistic perspective, such as time and communication

challenges, but the current study provides an example of using PAR and Photovoice to learn

about individuals with autism's ideas about well-being and different real-life issues faced by

them. This approach is valuable in helping us "to start from the complexities, ambiguities and

challenges of the lives of people with autism," which "makes sure our notion of well-being

reflects the realities of those lives" (Robeyns, 2016, p. 389). Taking the conceptual framework of

critical (disability/feminist/queer) theories to real-world applications, practitioners working with

transition-age youth with autism should constantly reflect on their relationships with these youth and evaluate how this reflective practice can help them achieve a better understanding of how to promote their well-being.

Second, wellness promotion among individuals with autism should focus on its meanings and values *in addition to* the functional and behavioral aspects. Results from this study clearly show that people with autism are capable of making meanings and are willing to express these ideas when provided opportunities to respond and encouraged diverse modes of expressions. Looking through the data for common themes, Luka asserted, "When you ask us personal questions, then you gonna be surprised at our core being." While ignoring the contribution of people with autism's perspective and the legitimacy of their knowledge is disrespectful, depriving them of the opportunities to express their understanding of the world can be a covert form of discrimination in research and practice (Gillespie-Lynch, Kapp, Brooks, Pickens, & Schwartzman, 2017; Pellicano & Stears, 2011; Shriberg & Moy, 2014). Intervention efforts focusing on their inner traits, character strengths, and values can help them develop and achieve long-term goals that are personally meaningful to them (Groden et al., 2011).

This approach of well-being conceptualization is not without challenges. Robeyns (2016) discussed that when individuals with autism engage in self-injurious behaviors or have debilitating comorbid conditions, other people may need to intervene at the expense of autistic agency. Another common dilemma is that caregivers find themselves gently forcing their children with autism to do things that cause immediate distress for the sake of their long-term benefits. This struggle was similarly identified by the group of young adults with autism in this study, as they sometimes found it difficult to push themselves to seek out and learn from new experience in the expense of immediate discomfort. Robeyns (2016) cautioned that one needs to

consider individual differences, as some individuals with autism are naturally more sensitive to distress and vulnerable to the experience of being constrained in freedom. It is understandable that ideally, we should strike a balance between providing total freedom and influencing the choice of an individual, but I argue that the status quo of autism research is obviously far from being fully inclusive and fails to recognize that the first-person perspectives of people with autism have an integral part in their own well-being. Therefore, not only interventions and supports have to be well-intended, but also be well-informed by our genuine understanding of the autistic perspectives (Robeyns, 2016). The field still has a lot to learn from the autistic subjectivity through raising the critical consciousness of practitioners, researchers and other stakeholders within the autism community.

As applied to research, the academic community should embrace a more critical and ethical framework in conducting autism research. By superimposing the young adults' first-person perspective of well-being onto a critique of the dominant research in the field, this current study provides an alternative account of well-being that represents the complexities of personhood of individuals with autism, which further denaturalizes and reformulates the assumptions about autism (O'Dell et al., 2016), and (dis)ability in general (Goodley, 2017). This joins the emerging research in "critical autism studies" that take into consideration the power relations in the field of autism and interrogates its dominant ideologies by using inclusive and non-reductive epistemological stances and methodological frameworks to study the nature and culture of autism as well as their complex interplay (Davidson & Orsini, 2013; see also Milton et al., 2014). From this perspective, academic research and clinical practice are inherently interconnected, as the truth of disorders is produced by the effects of disciplinary power and at the same time the truth allows the manifestation of regulatory power through institutional agents

(e.g., psychologists in schools) administering expert knowledge to subjugate individuals to a disordered truth (Harwood, 2006). For example, "evidence-based" autism interventions are neither self-evident truth nor value-free facts, but instead are carriers of dominant ideologies in society that continue to reinforce their own power status while marginalizing the complex personhood and life possibilities of individuals with autism (Wolgemuth et al., 2016). Similarly, the neurodiversity movement views autism as a variation of human neurodevelopmental differences (versus disorders) and acknowledges the distinct profiles of strengths and weaknesses in people, which recognizes agency in individuals with autism to pursue personally meaningful outcomes (Baker, 2006; Baron-Cohen, 2017; Fenton & Krahn, 2007; Silberman, 2015). The tenets of neurodiversity also allow the recognition of diverse well-being accounts among individuals with autism (Robeyns, 2016; Rodogno et al., 2016). As researchers and practitioners historically assume a higher power status than individuals with autism and other stakeholders participating in research, we have to critically analyze our own privilege and take intentional steps to circumvent the impact of differential power dynamics on research processes and outcomes. For example, researchers should attend to their ways of writing in research products, especially when it comes to (re)presenting ideas about autism, to avoid discursive practices that marginalize or pathologize certain individuals.

Another approach is to conduct inclusive research that is sensitive to the needs of the autism community using participatory paradigms, an umbrella term for different methods such as participatory action research (PAR; e.g., Kemmis & McTaggart, 2005) and community-based participatory research (CBPR; e.g., Israel, Eng, Schulz, & Parker, 2005; Nicolaidis & Raymaker, 2015). These methodologies have more similarities than differences, which they all have philosophical roots in social constructivism and critical theory (Lincoln & Guba, 2000; van der

Riet, 2008). More importantly, their goals are to engage participants in the research process to effect social changes and produce outcomes that are meaningful to them. Recognizing the unmet needs of the autism community, researchers in this field have gradually taken up this idea (Pellicano & Stears, 2011), although the quality of participation and collaboration varies widely, largely depending on the goals, overt or covert, of the researchers. For example, intervention research typically involved a range of stakeholders, including individuals with an identified condition, their families, and practitioners, but participation usually entailed time-limited engagement in technical aspects of research, such as assisting with participant recruitment and providing feedback on treatment protocols (Brookman-Frazee et al., 2016; Powers, 2017). However, I side with Milton and Bracher (2013) to argue that by "meaningful" participation, individuals with autism should be actively involved in the knowledge production process to increase representation of their lived experiences and eschew the imposition of problematic narratives on autistic worldviews. One notable example of exception is the Academic Autistic Spectrum Partnership in Research and Education (AASPIRE), an ongoing CBPR initiative that brought together autistic self-advocates, family members, academic researchers, and practitioners to work collaboratively to address healthcare needs of individuals with autism (Nicolaidis et al., 2011; Nicolaidis et al., 2016). Participatory research with other disability groups also provides insight for conducting emancipatory and collaborative research using other methodologies (e.g., Beresford, 2012; Danker et al., 2017). The current study serves as another example of using Photovoice to engage young adults with autism in representing their ideas of well-being in the community. To improve well-being of the autism community, more PAR with individuals with autism's genuine participation are needed to produce research and practice that are epistemologically, ethically, pragmatically, and politically appropriate.

Limitations

Participant engagement was not consistent throughout the study. Although all young adults participated in the photo-taking and discussion activities, after the graduation presentation and the closing of TLA, only Luka and Ms. Maria continued to collaborate with me in subsequent analysis work. Although several other young adults had expressed interests in continued involvement, they eventually dropped out without explicit reasons. Anecdotally, I suspected their varied schedules and other responsibilities (e.g., job seeking, family duties) might be the biggest barriers that prevented them from devoting extra time and efforts to this project. The lack of monetary incentives also did not support the sustainment of motivation. The final analysis represented what Luka, Ms. Maria, and I interpreted the data based on our understanding of other young adults. Also, dissemination efforts proposed during the discussion sessions were not actually implemented due to lack of continued support and involvement of the participants. Future research can explore the feasibility of building the data analysis and dissemination phases into an existing program, which may provide more structures to promote participants' sustained engagement throughout the research and action processes.

Selection bias might have contributed to the relatively successful experience of the PAR process in the context of TLA. Students admitted to TLA were screened for their motivation to learn and be successful in their adult lives. For example, students who drop out from high school and do not have a high school diploma are not eligible for the program. Also, as the Photovoice project began at the time when the young adults had already been halfway through the program, they had already been exposed to various curricular experiences (e.g., individual presentations, mentoring, internship) and didactic instructions on different topics (e.g., self-exploration, self-determination, community resources). Students also had already formed relationships with each

other and built rapport with the instructors. Individuals with autism in the community without such rich learning experience might have different motivations and backgrounds that influence how they conceptualize well-being and involve in research activities.

Due to the nature of the topic, I focused the Photovoice processes and discussions on strengths, resources, and positive aspects in life. I did not ask about the young adults' negative experience unless they brought up themselves (e.g., lost family members, unpleasant feelings of completing work). However, eliminating negative feelings and life difficulties may be important considerations that could also influence their well-being (e.g., Cheak-Zamora et al., 2018). Future research can explore how different negative experiences also contribute to individuals' understanding and pursuit of well-being.

Conclusion

This PAR explored how a group of young adults with autism in TLA understood the ideas of well-being as perceived by themselves. Using the Photovoice methodology, the young adults with autism used photos to show their ideas about well-being. They expressed well-being in terms of showing self-understanding and personal growth, developing close relationships, and building connections with their immediate and broader communities. While this project identified categories of people, things, and events that had an impact on their well-being, it was also significant that they actively constructed and reflected on their understanding of how these life circumstances were related to their well-being. These young adults did not only display their knowledges about themselves as meaning-making agents, but also contributed their expertise and perspectives in participating and negotiating research decisions throughout the PAR processes. The findings from both the contents and processes of this project served as a direct rebuttal to how the current literature predominantly described their well-being in problem-focused,

normalizing, and neoliberal terms. The young adults with autism in TLA intended to challenge the dominant worldviews by presenting their positive life experiences and offering a critical account to understanding the personhoods of autism from their first-person perspectives. This applied research on autism well-being adds to the emerging literature of critical autism studies that call for attention to the sociocultural aspects of autism and promote neurodiversity. Researchers in this field should design and conduct ethically informed research that is sensitive to the needs and desires of the autism community. Practitioners can draw insight from this study to reflect on their relationships with and understanding of their clients with autism, and how these can better support their transition to adulthood.

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APPENDIX A:

INFORMED CONSENT FORM

USF
UNIVERSITY OF
SOUTH FLORIDA

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

February 28, 2017

Yu Hin Lam
Educational and Psychological Studies
Tampa, FL 33612

RE: **Expedited Approval for Initial Review**
IRB#: Pro00029276
Title: Well-Being in Young Adults with Autism Spectrum Disorder: A Participatory Action
Research using Photovoice

Study Approval Period: 2/28/2017 to 2/28/2018

Dear Mr. Lam:

On 2/28/2017, 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):
study protocol.docx

Consent/Assent Document(s)*:
SB Adult Minimal Risk.docx.pdf

*Please use only the official IRB stamped informed consent/assent document(s) found under the
"Attachments" tab. Please note, these consent/assent documents are valid until the consent
document is amended and approved.

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 45CFR46.110. 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

USF
UNIVERSITY OF
SOUTH FLORIDA

Informed Consent to Participate in Research Involving Minimal Risk

Pro # 29276

You are being asked 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 nature 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:

Well-Being in Young Adults with Autism Spectrum Disorder:
A Participatory Action Research using Photovoice

The person who is in charge of this project 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 project by his Faculty Advisor, Linda Raffaele Mendez, Ph.D., in order to fulfill the requirement for a Doctor of Philosophy (Ph.D.) degree.

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

Purpose of the study

- To explore how you understand and describe your own well-being

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 an initial training session that includes discussions of project goals, the rules and ethics involved in the project, and the logistics of using a camera
- Take pictures in daily lives that can show your own "well-being"
- Participate in weekly/bi-weekly meetings for the time period of 1/2/3 month(s) to discuss the pictures you have taken

The researcher will also invite you to design and implement the research together. This means that the researcher will collaborate with you and other participants to design and carry out the project together. Depending on your willingness, you may participate in some or all of the following processes:

- Develop ways to recruit participants to the project
- Discuss and design how the project is going to be implemented
- Discuss and design how to use the results of the project
- Engage in identified activities that would benefit our group of participants and/or the autism community at large (e.g., advocacy work, presentations)

In addition, the discussion(s) will be audio recorded in a digital format. After the recordings are 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.

Total Number of Participants

Around 12 individuals will take part in this study.

Alternatives / Voluntary Participation / Withdrawal

You do not have to participate in this research project. You should only take part in this project if you want to volunteer. You should not feel that there is any pressure to take part in the project. You are free to participate in this project 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 (organizations with which the participants are affiliated).

Benefits

You will receive no tangible benefit(s) by participating in this project. Some of the potential indirect benefits of participating in this project will be:

- To share your thoughts and feelings with a researcher and/or other group members who are interested in your well-being
- To have an opportunity to express your voice and represent yourself using photographs
- To make changes in society and help people achieve better quality of life

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 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.

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.

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, his faculty advisor and all other research staff.

- Certain government and university people who need to know more about the study, and individuals who provide oversight to ensure that we are doing the study in the right way.

- Any agency of the federal, state, or local government that regulates this research.

- 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, call Gary Yu Hin Lam, M.A. at (813)-502-9674, or contact by email at 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 or contact by email at RSCH-IRB@usf.edu.

Consent to Take Part in this Research Study

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.

_____   _____

Signature of Person Taking Part in Study   Date

_____

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 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. This research subject has provided legally effective informed consent.

_____   _____

Signature of Person obtaining Informed Consent   Date

_____

Printed Name of Person Obtaining Informed Consent

Appendix
Comprehension Check of Informed Consent
[For researcher 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.

(Check if the participant demonstrates comprehension)
- ☐ You were chosen to be in this study because:
    - ☐ You were diagnosed with an Autism Spectrum Disorder.
    - ☐ You exited high school within the past seven years.
- ☐ If you choose to be in this study, you will be asked to:
    - o Participate in a training session.
    - o Take pictures in your daily life.
    - o Participate in regular meetings to talk about your feelings and thoughts about your pictures
- ☐ You are invited to collaborate with the researcher in this project. You may choose to participate in different activities such as designing the project, analyzing results, and/or advocacy work.
- ☐ The discussion process will be audio-recorded.
- ☐ You will not receive any 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 B:

PHOTO TARGET CONSENT FORM

I am inviting you to take a picture!

Please take a minute or two to review the information about our project.

Who are we?

- I and several other young adults are participating in a research project conducted by Gary Lam, a School Psychology doctoral student at the University of South Florida.

What are we doing?

- We are carrying our cameras around and taking pictures of things in daily life that can show <u>our well-being</u>.

What am I asking you to do?

- I want to take a picture on you because you are meaningful to my well-being.

How will we use the pictures?

- We will discuss the pictures in a group.
- We may use the pictures to show our lives to other people (e.g., publishing an article). In this case, your name will not be shared. Your face and other identifiable information will be blurred to protect your identity.
- To show our appreciation, we will offer to give back to you a print of your pictures.

What rights do you have?

- You have ***full right*** to decide whether or not to be photographed, without having any consequences.

Feel free to contact Gary Lam (yuhinlam@mail.usf.edu / 813-502-9674) if you have any questions.

Thank you for your participation and support in our project!

Smile!! ☺

-- Return Slip for photographer --

I **agree / disagree** (please circle) to be photographed as a part of this research project.

Signature: _____   Date & Time: _____

APPENDIX C:

POCKET-SIZED PHOTO TARGET CONSENT FORM

I am inviting you to take a picture!

I and several other young adults are participating in a research project conducted by Gary Lam, a School Psychology doctoral student at the University of South Florida. We are carrying our cameras around and taking pictures of things in daily life that can show our well-being. I want to take a picture on you because you are meaningful to my well-being. We will discuss the pictures in a group and may show them to other people (e.g., publishing an article). In this case, your name will not be shared. Your face and other identifiable information will be blurred to protect your identity. To show our appreciation, we will offer to give back to you a print of your pictures. You have *full right* to decide whether or not to be photographed, without having any consequences.

Feel free to contact Gary Lam (yuhinlam@mail.usf.edu / 813-502-9674) if you have any questions. Thank you!

I **agree / disagree** (please circle) to be photographed as a part of this research project.

Signature: _____

Date & Time: _____

I am inviting you to take a picture!

I and several other young adults are participating in a research project conducted by Gary Lam, a School Psychology doctoral student at the University of South Florida. We are carrying our cameras around and taking pictures of things in daily life that can show our well-being. I want to take a picture on you because you are meaningful to my well-being. We will discuss the pictures in a group and may show them to other people (e.g., publishing an article). In this case, your name will not be shared. Your face and other identifiable information will be blurred to protect your identity. To show our appreciation, we will offer to give back to you a print of your pictures. You have *full right* to decide whether or not to be photographed, without having any consequences.

Feel free to contact Gary Lam (yuhinlam@mail.usf.edu / 813-502-9674) if you have any questions. Thank you!

I **agree / disagree** (please circle) to be photographed as a part of this research project.

Signature: _____

Date & Time: _____

I am inviting you to take a picture!

I and several other young adults are participating in a research project conducted by Gary Lam, a School Psychology doctoral student at the University of South Florida. We are carrying our cameras around and taking pictures of things in daily life that can show our well-being. I want to take a picture on you because you are meaningful to my well-being. We will discuss the pictures in a group and may show them to other people (e.g., publishing an article). In this case, your name will not be shared. Your face and other identifiable information will be blurred to protect your identity. To show our appreciation, we will offer to give back to you a print of your pictures. You have *full right* to decide whether or not to be photographed, without having any consequences.

Feel free to contact Gary Lam (yuhinlam@mail.usf.edu / 813-502-9674) if you have any questions. Thank you!

I **agree / disagree** (please circle) to be photographed as a part of this research project.

Signature: _____

Date & Time: _____

I am inviting you to take a picture!

I and several other young adults are participating in a research project conducted by Gary Lam, a School Psychology doctoral student at the University of South Florida. We are carrying our cameras around and taking pictures of things in daily life that can show our well-being. I want to take a picture on you because you are meaningful to my well-being. We will discuss the pictures in a group and may show them to other people (e.g., publishing an article). In this case, your name will not be shared. Your face and other identifiable information will be blurred to protect your identity. To show our appreciation, we will offer to give back to you a print of your pictures. You have *full right* to decide whether or not to be photographed, without having any consequences.

Feel free to contact Gary Lam (yuhinlam@mail.usf.edu / 813-502-9674) if you have any questions. Thank you!

I **agree / disagree** (please circle) to be photographed as a part of this research project.

Signature: _____

Date & Time: _____

APPENDIX D:

RECRUITMENT FLYER

USF
UNIVERSITY OF
SOUTH FLORIDA

Pro # 29276

Are you an adult with Autism Spectrum Disorder (ASD)?
Did you leave high school within the past 7 years?
We'd like you to join our research project!

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 life experiences.

When?

- ✓ Whatever time works best for you.
- ✓ We will meet several times in the Spring semester (February to May).

Where?

- ✓ This project will take place in a private location agreed upon with the researcher.

Why?

- ✓ We want to explore what a good life is for young adults with autism.

What?

- ✓ You will be invited to take pictures in daily life and discuss about them.
- ✓ You may also join us to plan and run the project together. We want you to have a say!

Interested?

If you want to learn more about or join this project, please contact:

Gary Yu Hin Lam	(813) 502-9674/yuhinlam@mail.usf.edu
Dr. Linda Raffaele Mendez	(813) 974-1255/raffaele@usf.edu

~ Thank you! ~