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# Well-Being in Adults with High Functioning Autism Characteristics

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UNIVERSITY OF CALGARY

Well-Being in Adults with High Functioning Autism Characteristics

by

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## WELL-BEING IN ADULTS WITH HFAC

### Abstract

This study sought to examine well-being in adults with characteristics of high functioning autism. Drawing on first-, second-, and third-person perspectives, this study explored how autistic traits affect well-being. Integral methodological pluralism (IMP) was employed as a framework towards achieving a more balanced, comprehensive understanding of both background knowledge and issues germane to the topic of well-being in high functioning autism. The themes examined include the role of self in autism, relationships and autism, cognitive science and autism, and the approach to teaching learners with high functioning autism recommended by the Ministry of Education in the province of Alberta.

Autism is a complex developmental disorder that is marked by its heterogeneity of symptoms, severity, and etiology. It has become a major field of research in multiple disciplines. Increased awareness has led to new methods for educating this growing population of learners. In spite of Alberta's movement towards evidence-based teaching, much of our effort currently focuses on managing and controlling symptoms in order to promote positive behavior and immediate academic success. There is evidence that this approach amounts to short-term interventions designed to meet the more immediate needs of the child within the school setting, possibly at the expense of identifying and imparting skills and understandings that will contribute to long-term success and wellness.

In the spirit of backward design models of educational planning, this study investigated understandings of well-being in high functioning autism. By improving the understanding relating to how adults with high functioning autism interpret and experience well-being, the findings can be used to provide curricular direction for youth that are less likely to be able to recognize and articulate the phenomena than adults.

## WELL-BEING IN ADULTS WITH HFAC

*This thesis is dedicated to my family. My husband Kirk pushed me to move forward with my curiosity because he knew before I did that it was something I needed to do. Without his support, none of this could have happened. My sons, Kody and Jared, keep the fire burning in me to contribute what I can to help make the world a better place for our children, our future. My parents have always believed in me, even when I didn't. My siblings have supported me in countless ways including providing me with lodging, asking important questions, making me laugh and always reminding me what really matters.*

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Table of Contents

Abstract..... ii

Chapter 1: Research Problem..... 1

    1.1 Introduction..... 1

    1.2 Background and Context..... 1

    1.3 Problem Statement..... 3

    1.4 Statement of Purpose and Research Questions..... 4

    1.5 Research Approach..... 5

    1.6 Research Design Overview..... 6

    1.7 Definition of Terms..... 7

    1.8 Rationale and Significance..... 13

Chapter 2: Review of the Literature..... 14

    2.1 Introduction..... 14

    2.2 Purpose Statement..... 14

    2.3 Search Terms and Parameters..... 15

    2.4 Conceptual Framework..... 16

    2.5 Integral Methodological Pluralism and Multi-Methods Approach..... 16

    2.6 Ontology, Epistemology, and Enactment..... 18

    2.7 Well-Being..... 21

    2.8 Autism..... 25

    2.9 Identification and Diagnosis..... 27

    2.10 Cognitive Theories of Autism..... 28

    2.11 The Role of Self in Autism..... 37

# WELL-BEING IN ADULTS WITH HFAC

2.12 Interpersonal Relationships and Autism .....	38
2.13 Alberta Education and High Functioning Autism .....	39
2.14 Summary and Conclusion .....	47
Chapter 3: Research Methodology .....	48
3.1 Introduction and Overview .....	48
3.2 Research Paradigm and Methodology .....	48
3.3 Description of Methodologies.....	48
3.4 Setting and Context of Study .....	54
3.5 Research Population.....	57
3.6 Methodology and Research Questions.....	59
3.7 Methods and Procedures .....	61
3.8 Methods for Data Analysis and Synthesis .....	63
3.9 Ethical Considerations .....	65
3.10 Delimitations.....	65
3.11 Limitations .....	67
3.12 Trustworthiness.....	69
3.13 Chapter Summary .....	70
Chapter 4: Findings by Method .....	71
4.1 Introduction.....	71
4.2 IMP and Methods for Study.....	71
4.3 UR Findings: Results from the AQ and PWBS .....	73
4.4 UL Findings: Results from Phenomenological Interviews.....	79

# WELL-BEING IN ADULTS WITH HFAC

4.5 LL Findings: Results from Duo-Ethnographic Conversation.....	80
4.6 Identifying Themes for Deeper Analysis .....	85
4.7 Primary and Integral Themes.....	88
4.8 Conclusion .....	89
Chapter 5: Primary Themes .....	90
5.1 Introduction.....	90
5.2 Advocacy .....	90
5.3 Autonomy .....	92
5.4 Autism Assets .....	94
5.5 Bullying and Abuse.....	97
5.6 Diagnosis.....	99
5.7 Growth and Learning .....	102
5.8 Relationships and Belonging .....	104
5.9 Balance and Environmental Mastery .....	107
5.10 Mental Health.....	109
5.11 Communication.....	110
5.12 Awareness .....	113
5.13 Self-Acceptance .....	114
5.14 Conclusion .....	115
Chapter 6: Narrative Analysis of Integral Themes in Alberta Schools .....	117
6.1 Introduction.....	117
6.2 Personal Growth and Learning .....	118

WELL-BEING IN ADULTS WITH HFAC

6.3 Awareness..... 123

6.4 Balance and Environmental Mastery ..... 128

6.5 Communication..... 131

6.6 Relationships and Belonging ..... 135

6.7 Conclusion ..... 140

Chapter 7: Conclusions..... 142

7.1 Introduction: Research Questions Answered..... 142

7.2 UR: The extent and nature of high functioning autism characteristics as identified and described by participants..... 142

7.3 UR: Well-Being in participants with high functioning autism characteristics ..... 143

7.4 UR: The relationship between characteristics from the Autism Quotient Scale and the dimensions of the Psychological Well-Being Scale ..... 144

7.5 UL and LL: Themes emerging as important to well-being in people with high functioning autism characteristics ..... 146

7.6 LR: Future directions for improving education in Alberta for learners with high functioning autism characteristics..... 148

7.7 Conclusion ..... 151

References..... 153

Appendices..... 162

List of Figures

*Figure 1. All Quadrants model* ..... 12

*Figure 2. IMP framework* ..... 20

*Figure 3. Core dimensions of psychological well-being and their theoretical foundations*..... 25

*Figure 4. Causal model showing three levels of explanation* ..... 30

*Figure 5. Participants involved in research method by quadrant* ..... 58

*Figure 6. Total participant mean autism quotient (AQ) scores* ..... 74

*Figure 7. Total participant mean psychological well-being scale scores* ..... 74

*Figure 8. Participants identifying their strongest well-being assets* ..... 76

*Figure 9. Participants identifying their top two well-being assets* ..... 76

*Figure 10. Dimensions identified as most significant challenge to participants' well-being*..... 77

*Figure 11. Dimensions identified as being in the top two of participants' most significant challenges to well-being* ..... 77

*Figure 12. Comparing autism characteristics with dimensions of well-being* ..... 78

*Figure 13. Results from parents' personal PWBS* ..... 81

*Figure 14. Results from parent-completed PWBS on their adult child* ..... 81

*Figure 15. Template for identifying level of themes by research method*..... 86

*Figure 16. Integral themes by IMP quadrant* ..... 118

*Figure 17. LR recommendations derived from narrative analysis of integral themes* ..... 141

List of Tables

*Table 1. Literature review topics by IMP quadrant ..... 14*

*Table 2. Common learning strengths and challenges in high functioning autism..... 27*

*Table 3. Alignment of research method by quadrant and purpose ..... 72*

*Table 4. Comparing autism characteristics with dimensions of well-being ..... 79*

*Table 5. Participants making reference to themes in interviews ..... 80*

*Table 6. Themes emerging from parent conversations regarding their personal well-being ..... 83*

## **Chapter 1: Research Problem**

### **1.1 Introduction**

As a whole, individuals with high functioning autism do not tend to have better life outcomes than those with more severe forms of autism (Hofvander, et al., 2009). Studies indicate that few individuals with autism live independently and that they experience higher levels of antisocial personality disorder, substance abuse problems, and mood and anxiety disorders. Despite having normal IQs, less than half are generally employed (Eaves & Ho, 2008), the majority have never been in a long-term relationship (Hofvander, et al., 2009), and a higher percentage of this population express suicidal thoughts (Eaves & Ho, 2008). In general, people with high functioning autism are unable to meet their potential and suffer a decreased quality of life (Heijst & Geurts, 2014).

Alberta's education system has seen a significant increase in the number of students diagnosed with, or exhibiting characteristics of, high functioning autism (Clarke, et al., 2014). These students tend to be academically capable, but their prospects beyond school are often bleak. An increased understanding of their condition and strategies to support their needs are more likely to be implemented now than in previous years, but the current approach to accommodating these students' needs lacks consistency and reflects a reactive rather than proactive approach. To shift to a proactive position requires an inclusive, integrated perspective that focuses on the long-term implications of the disorder as well as the symptoms that manifest in the classroom.

### **1.2 Background and Context**

Autism is a difficult topic to research because it is an evolving concept (Roth & Rezaie, Researching the Autism Spectrum, 2011). Variability is present in the full expression of

## WELL-BEING IN ADULTS WITH HFAC

symptoms, the severity of symptoms, and the range of different co-morbid conditions that can accompany autism. In addition, a lack of consistency in diagnosis complicates our ability to study autism. Finally, heterogeneity at both etiological and behavioral levels has led to methodological and interpretative difficulties in research. For these reasons, statistics regarding autism cannot be assumed to be completely reliable or valid. Yet these statistics are important because we must start somewhere.

What we can assert with confidence is that in the past three decades there has been a proliferation in both our understanding of autism and the number of learners identified with the condition. Curriculum and learner support in Alberta have not reflected this change. People with Autism Spectrum Disorders are often quite severely disabled. They require supports and services in the areas of communication, relationships, social care, living skills, housing, education, and employment. However, in assisting students with Autism Spectrum Disorders, the emphasis has traditionally been placed on assisting individuals to cope with their circumstances rather than identifying and teaching the skills required for students to successfully and independently navigate life challenges.

People with high functioning autistic characteristics tend to have strong skills in some areas, while being very low functioning in others. Common strengths often include skills and traits required for school success, including the ability to focus attention, memorize, master basic academic skills quickly and easily, and follow concrete instructions. It is not uncommon for the educational needs of these learners to be overlooked because they are capable of mastering basic curriculum. Important areas of deficit are generally not addressed, as they are not part of any current curriculum, possibly because most neurotypical learners naturally develop these essential skills without instruction. Weaknesses relating to perception, abstract thinking, understanding

## WELL-BEING IN ADULTS WITH HFAC

cause and effect, prioritizing, decision-making, and adapting to change are typical for the diagnosis. These are examples of skills that are pertinent to success, but are not identified as focus points in any particular curriculum that emphasizes supporting the needs of these learners.

Although one can use existing research to speculate about what knowledge, skills, and attitudes need to be addressed for the successful education for these learners, there seems to be little research examining the big picture of autism. This is somewhat ironic considering that a characteristic of high functioning autism is the ability to excel at working with detail, but often at the expense of sacrificing a broader understanding. In addition, there appears to be an absence of work that connects the many disciplines of research active in the study of autism, as well as a rather curious absence of first person perspectives from within the autistic community (Neuman, 2010).

### **1.3 Problem Statement**

Our lack of insight into the causes and mechanisms of autism has engendered a rapidly growing field of research. Between 1971 and 1997 there were three North American journals dedicated specifically to autism. By 2013, five additional journals dedicated to the subject had been established (Autism Journals, 2014). In addition to these journals, a growing number of research articles about autism can be regularly found in other academic, medical, psychological, scientific, and technological research journals.

Educational practice has not kept up with research (Simpson, 2013). Significant numbers of students diagnosed with high functioning autism are not developing the understandings and skills they need to be successful in life (Duncan & Bishop, 2013). Despite their ability and/or academic success, these people are not able to achieve the potential that their education is meant

## WELL-BEING IN ADULTS WITH HFAC

to facilitate (Nova Scotia Department of Education, 2010). There is limited understanding as to how curriculum should be tailored to meet the unique needs of this population.

The expectation remains that Alberta teachers must meet the diverse needs of the growing number of students with high functioning autism in their classrooms, but there has been no serious effort towards compiling our accumulated knowledge into curriculum or formal practice (Gonzalez-Gil et al., 2013). Teachers, often with limited or no training relating to autism, are responsible for developing plans to support these students, typically by creating individualized curriculum. In theory, this sounds ideal. In practice, it often falls short of acceptable. With limited understanding, time, and support, the Individualized Program Planning (IPP) process can quickly become superficial and even mask the fact that important needs are not being met.

To improve our effectiveness in helping these students develop traits and skills necessary for their success, research is needed in order to coordinate our current knowledge of the topic and to establish clear curricular direction for applying this knowledge. A better understanding of well-being, and what well-being looks and feels like for people with high functioning autistic characteristics, can provide valuable information for establishing this direction.

### **1.4 Statement of Purpose and Research Questions**

This research sought to understand well-being in individuals with high functioning autism characteristics (HFAC), and to explore what this insight could reveal about educating Alberta learners on the autism spectrum. It was anticipated that a better understanding of these learners' perceptions of well-being, as well as the challenges they face in pursuing well-being, would have curricular implications. To shed light on the problem, the following research questions were addressed:

## WELL-BEING IN ADULTS WITH HFAC

- 1) What is the nature and extent of high functioning autism characteristics identified and described by study participants?
- 2) How was well-being experienced in people with high functioning autism characteristics (HFAC)?
- 3) How did participants describe these characteristics' influence on well-being?
- 4) What themes emerged as important to well-being for people with HFAC, and how do these themes compare with themes of well-being in people who do not have HFAC?
- 5) How does Alberta Education support the development of well-being in learners with high functioning autistic characteristics?
- 6) What does this study suggest as far as new directions and improvements to our system's capacity for meeting the needs of these learners?

### **1.5 Research Approach**

Elements of multiple methodologies from quantitative and qualitative paradigms were adopted for this research. Scales, questionnaires, phenomenology and narrative analysis were employed. Integral theory provided the framework for study and was used to promote balance in terms of context, methodology and methods.

Neuroscience has revealed that many disorders are in fact the result of impaired connections between otherwise satisfactory operating neural structures (Baron-Cohen, The Cognitive Neuroscience of Autism, 2004). As autism appears to be a disorder marked by impaired neuronal connectivity, the autistic brain is generally a brain not functioning as a cohesive whole (Grandin, 2014). This description is a partial explanation of the curious mixture of ability and disability often accompanying individuals with the diagnosis. The very nature of

## WELL-BEING IN ADULTS WITH HFAC

the disorder mirrors the way in which research in the field seems to have developed in isolation and lacks connectivity.

Using Integral theory to establish and improve connections in the research—with the goal of developing a better practice for educating individuals with high functioning autism—is not only practical, but serves as a wonderful metaphor for the importance of developing practices that enhance connectivity and performance within the autistic brain, mind, and spirit.

### **1.6 Research Design Overview**

With the approval of the university's institutional review board, this research studied perceptions and experiences of well-being in connection with high functioning autistic characteristics. A total of 18 individuals participated in this study. Sixteen participants were adults with high functioning autism, and two were the parents of an adult with high functioning autism characteristics. In the final cycle of this project, the researcher conducted a narrative analysis of key themes uncovered by the study in the context of Alberta schools.

This research was designed to make use of a multi-method approach to exploring the research topic. Different research methods were employed depending on their suitability to individual research questions. This method allowed for multiple dimensions of understanding, and is further described in Chapter Three.

Participants with high functioning autistic characteristics initially completed both the Autism Quotient Questionnaire (Baron-Cohen, 2001) and the Psychological Well-Being Scales (Ryff, 1989). The parents of a young adult male with high functioning autism characteristics also completed the Autism Quotient (AQ) questionnaire and the Psychological Well-Being Scales (PWBS) for both themselves and their son. This information was used to individualize interview

## WELL-BEING IN ADULTS WITH HFAC

questions and initiate conversations regarding perceptions and experiences of well-being in connection with high functioning autism characteristics.

The information described above was used to generate starting points for phenomenological study about well-being. The study concluded with an experienced teacher of students with high functioning autism characteristics undertaking a narrative inquiry that focused on understandings acquired from earlier cycles of study. A chart summarizing the sequence and methods proposed for this study can be found in Appendix H.

### 1.7 Definition of Terms

**High functioning autism (HFA).** High Functioning Autism (HFA) is a neurodevelopment disorder marked by social impairment, communication difficulties, and restrictive, repetitive, and stereotyped patterns of behavior in individuals with average to above average IQs. Prior to the implementation of the newest Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, it was generally synonymous with Asperger's Syndrome.

**High functioning autistic characteristics (HFAC).** High functioning autism characteristics (HFAC) refer to individuals who exhibit the same symptoms as individuals with high functioning autism, but may lack a formal diagnosis. For the purpose of this study, the term is also used interchangeably to describe common traits exhibited by individuals on the spectrum. For the purpose of this study, specific characteristics of high functioning autism are defined by irregularities in conduct related to social skills, communication skills, attention to detail, focus, and imagination (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001).

**Well-being.** Research on well-being stems from two philosophical schools of thought, one that posits a hedonic focus to well-being and the other that emphasizes eudemonism as the path forward to well-being. Hedonic models advocate that the chief goal of a good life is to seek out pleasure and avoid pain. The pursuit of maximizing pleasure and minimizing pain is seen as

## WELL-BEING IN ADULTS WITH HFAC

the purpose of a life well lived. In contrast, Eudemonic models hold that well-being lies in the actualization of human potential. Humans, as individuals and groups, hold final values and purpose in which they pursue and fill. Ryan & Deci (2001) note that both of these philosophical positions alone cannot account for well-being. They describe that “Well-being is a complex construct that concerns optimal experience and functioning. It is composed in varying degrees of both hedonistic and eudemonic experiences.” (p. 144). Six popular models are described below that propose measures of both eudemonia and hedonism for understanding well-being.

### Liking/Wanting/Needing Theory

This theory is composed of three parts. *Liking* embraces the hedonistic elements of well-being, acknowledging the importance of maximizing pleasure while minimizing pain. It focuses on immediate gratification and distinguishing between things that make life pleasant and unpleasant. The *Needing* component of this model acknowledges the importance of balancing physical and psychological aspects of well-being, such as provided by Maslow’s hierarchy of needs. Meeting these also contribute to happiness. Finally, *Wanting* refers to the pursuit of desired goals. It positions itself to acknowledge that the journey towards pursuing desired goals is as important as the destination itself (Durayappah, 2010).

### Multiple Discrepancy Theory

All things are relative to some standard, and all experiences and emotions are evaluated by this standard. If circumstances and experiences fall on the upside of these standards the result will be positive well-being. Poor well-being is the result of circumstances and experiences measuring on the down-side of these standards. Well-being is ultimately evaluated both by the standard that is held and one’s ability to adapt to the standard, or adapt the standard itself (Durayappah, 2010).

## WELL-BEING IN ADULTS WITH HFAC

### Top-Down and Bottom-Up Factors Model

External events and circumstances are referred to as bottom factors. Top factors are composed of an individual's disposition and the filters by which he or she interprets experiences and well-being. Well-being is the result of the unique way in which the top-down and bottom-up factors connect and interact with each other (Merwe, 2015).

### Orientations to Happiness Model of Well-Being

This model, advocated by Seligman, respects that there are different ways of being happy. It is composed of three parts: the *pleasant life*, the *engaged life*, and the *meaningful life*. People will choose different paths and levels of balance between these three, and the most satisfied individuals will be the people who choose all three paths. More emphasis is put towards the value of the engagement, or meaning, path (Durayappah, 2010).

### Mental Health Continuum Model

This model, supported by the work of Keyes, also places emphasis on both positive emotions and psychological and social well-being as the components of subjective well-being. This model proposes a spectrum between languishing, incomplete mental health, and flourishing, complete mental health (Merwe, 2015).

### Past, Present and Prospect Model

Commonly referred to as the 3P model for subjective well-being, focus is given to the temporal determinants of well-being. Like each of the preceding theories, elements from both hedonistic and eudemonic philosophies are recognized. *Present* focuses on positive emotion in the here and now, great value is assigned to the consuming effect of the moment. *Past* refers to positive reminiscing, accompanied by gratitude and ascribing meaning to past experiences and emotions. *Future* (prospect) embraces the optimism and positive anticipation of experiences as a factor in the model, the value of the well-being inherent in purpose for moving into the future

## WELL-BEING IN ADULTS WITH HFAC

(Durayappah, 2010)

### Ryff Model of Psychological Well-Being

This study uses the Ryff model, which conceptualizes *well-being* as an individual's subjective experience relating to self- acceptance, quality ties to others, a sense of autonomy in thought and action, the ability to manage complex environments in order to suit personal needs and values, the pursuit of meaningful goals and a sense of life purpose, and the continued growth and development of the individual (Ryff, 1989). The Psychological Well-Being Scales (PWBS) were developed as a credible method for collecting empirical measures of well-being. The scales were simple for participants to complete and for the researcher to interpret.

The model was developed in effort to address fundamental challenges in studying and understanding well-being, which included a lack of tools for credibly measuring the concept. A review of literature relating to the topic and mental health, self-actualization, optimal functioning and developmental life span converged around the six core constructs of her model.

The model emphasizes an approach to understanding well-being that initially appears to relate more to eudemonic values of well-being. However, as can be seen in the popular models described above, it is fair to note that the connection between the two philosophies of well-being are not at all clear and concrete. They interact with each other in an ongoing swirl of ebb and flow to create the malleable nature of the phenomena.

In addition, it was hypothesized that the autism characteristics that this study's participants would exhibit generally support a stereotype that is less inclined to value hedonistic attributes of well-being. It was acknowledged that this hypothesis would be delimitation if the psychological well-being scales were the only method used for identifying and understanding well-being in this study, but they were not. Phenomenology and duoethnography were also used to collect data.

## WELL-BEING IN ADULTS WITH HFAC

Questions and conversation cues were designed to be openended and were intentionally not developed to focus participant's attention towards the six correlates of Ryff's model, although the structure of the questions allowed for these correlates to emerge if the participants valued them.

**Psychological well-being scales (PWBS).** Carol Ryff's scales have been demonstrated to measure levels of well-being with validity and reliability. These scales measure an individual's well-being based on one's subjective experience of the six core categories of her model for well-being, which are named above and described in more detail in Chapter 2.

**Integral methodological pluralism (IMP).** Integral Methodological Pluralism is a framework for applying Integral theory to research. It seeks to include as many perspectives, styles, and methodologies as possible within one coherent view of the topic. By drawing together already existing approaches into an interrelated network, we are able to move beyond the challenges of traditional research paradigms, which, despite providing useful information and understanding, can be limited in scope. This is a complex undertaking, but is assisted by Ken Wilber's (1995) map of "all quadrants, all levels, all lines, all states, all types" (AQAL). The AQAL Map is a useful tool for integrating diverse perspectives toward the goal of knowledge discovery and creation. Its acronym addresses five essential components of Integral theory: quadrants, levels, lines, states, and types. The quadrants of Integral theory played a significant role in the development of this proposal and are briefly described below. Data connected with Integral Methodological Pluralism's levels, lines, states and types were also collected for future reference, but were not used within the scope of this study.

## WELL-BEING IN ADULTS WITH HFAC

**Quadrants.** In Wilber's AQAL model there are four quadrants that represent irreducible perspectives, or dimensions, of reality. The quadrants consist of subjective, intra-subjective, objective, and inter-objective perspectives, as represented in Figure 1. Each quadrant is required to fully understand any issue or aspect of reality (Wilber, 2007). The *x-axis* represents internal and external perspectives, while the *y-axis* represents individual and group perspectives. The upper left (*UL*) quadrant represents the *interior individual* dimensions connected to the research problem. The lower left (*LL*) quadrant focuses on dimensions of the issue relating to the *interior-collective*. The upper right (*UR*) quadrant examines perspectives representing the *exterior-individual* perspectives, and the lower right (*LR*) examines elements of the research connected with the *exterior collective*. Each of these four quadrants encompasses both inside and outside perspectives (zones) related to the phenomena being examined. IMP zones are described with more detail in section 2.6, Ontology, Epistemology and Enactment.

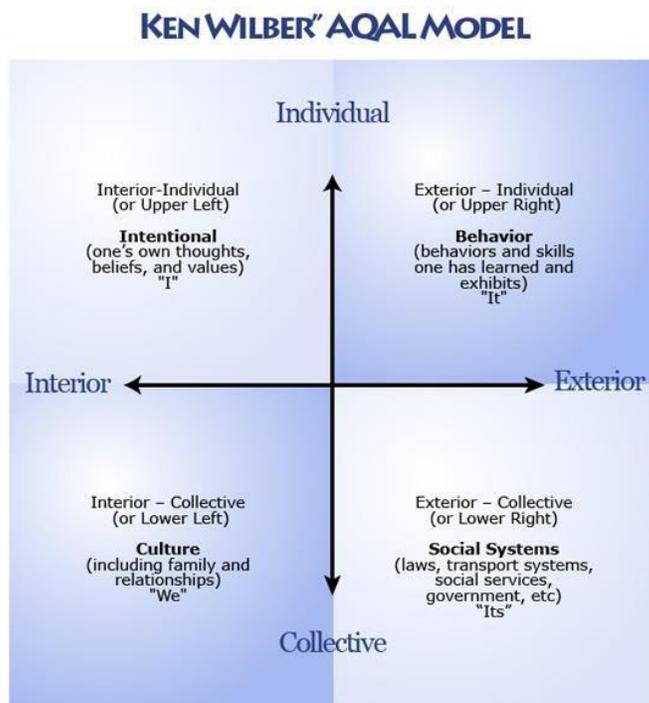


Figure 1. All Quadrants model. Adapted from Wilber (1995).

### **1.8 Rationale and Significance**

An increasing number of families are facing HFA diagnoses; our school systems are reporting record numbers of students experiencing the challenges of autism. Alberta's parents and teachers are facing a new reality in which they are expected to meet the diverse needs of this population who seem to be characterized by paradox, in that autistic individuals often exhibit a mixture of strengths and challenges. Without a clear understanding of their needs, their potential when the needs are met, and a plan for advancing forward, we are essentially being asked to navigate through a maze blindfolded. This study sought to uncover a better understanding of well-being in adults with HFAC, with the intention of improving educational practices in Alberta schools.

**Chapter 2: Review of the Literature**

**2.1 Introduction**

Reviewing literature relating to a topic of study constitutes research in and of itself (Bloomberg & Volpe, 2012). A comprehensive literature search was completed with the goal of conducting a methodological examination of the topics pertinent to this study. Wilber’s quadrants were used to ensure a balanced representation of perspectives for the literature review. Table 1 provides a visual representation of each topic by quadrant.

Table 1.

*Literature review topics by IMP quadrant.*

<b><i>INDIVIDUAL INTERIOR (UL)</i></b>	<b><i>INDIVIDUAL EXTERIOR (UR)</i></b>
Well-Being Role of Self in Autism	Well-Being Cognitive Science and Autism
<b><i>COLLECTIVE INTERIOR (LL)</i></b>	<b><i>COLLECTIVE EXTERIOR (LR)</i></b>
Well-Being Interpersonal Relationships and Autism	Well-Being Alberta Education and High Functioning Autism

**2.2 Purpose Statement**

This study has reviewed research related to concepts of well-being, autism, cognitive theories of autism, the role of self in autism, interpersonal relationships and autism, and Alberta Education’s past and present approach to supporting learners with high functioning forms of autism.

The essence of this study was to explore the concept of improving well-being as a possible curricular direction for learners with high functioning autism characteristics (HFAC). Currently, result-based teaching strategies are being adopted in education settings worldwide, and have fast become key in autism education. This movement has led to an activity-based

## WELL-BEING IN ADULTS WITH HFAC

approach, which may not be the most effective or efficient way to move forward. Reviews suggest that existing research evidence fails to capture the “whole” picture necessary for successful education for people on the spectrum (Howley, 2015). Howley observes that “a critical link is to identify the impact of structured teaching upon outcomes relating to the quality of life and well-being” (p. 111).

The Backward Design Model, highly valued in education, suggests that learning experiences should be planned with the final outcome in mind. This model might be applied successfully to education for the autistic population, if individuals’ well-being is the desired final outcome. Backward Design is a three-stage model. First, desired results are identified. Second, acceptable evidence of learning is determined. Finally, learning experiences and instruction are designed to support the skills and understanding that are necessary for the desired outcome (Wiggins & McTighe, 2005). The intent of this study was to investigate well-being as an educational outcome for learners with HFAC.

### **2.3 Search Terms and Parameters**

Our understanding of autism has evolved considerably over the past 70 years as a result of the increasing quantity of research spanning across fields that include biological science, economics, education, humanities, medicine, nursing, philosophy, public policy, social work, psychology, and sociology. Almost three times as many reports about autism were published between 2000 and 2012 than between 1940 and 1999 (Lai, Lombardo, & Baron-Cohen, 2014). The research landscape for this topic continues to expand, with new studies being released daily.

The databases ERIC, Psych INFO, PubMed, ProQuest, Academic Search Complete, and Google Scholar were used to access references and abstracts for this literature review. In addition, a notification service from Science Daily regarding new publications related to the

## WELL-BEING IN ADULTS WITH HFAC

search term “Autism News” was utilized to keep the researcher aware of recent updates in the thriving field of autism research.

Primary search terms included “autism,” “autism spectrum disorder,” “Asperger’s syndrome,” “high-functioning autism,” “well-being,” and “quality of life.” Other relevant reports were identified by searching reference lists identified through the database search.

### **2.4 Conceptual Framework**

This study made use of a multi-method research paradigm based on Ken Wilber’s Integral theory, using a framework referred to as Integral Methodological Pluralism (IMP). IMP proposes to use All Quadrant (AQ) mapping as the framework for pedagogic research (Wilber, 2007). AQ mapping is an “elegant, infinitely adaptable, and panoramic” stand-alone method for defining a problem (Cook-Greuter, 2005).

### **2.5 Integral Methodological Pluralism and Multi-Methods Approach**

Martin (2008) states that “the primary contribution that Integral Methodological Pluralism and Integral Research make is the creation of a map that extends the awareness of perspectives” (p. 160). IMP allows us to consider our inquiry within a larger perspective. While not all methods are appropriate for our study or discipline, there will be many that are. As Martin states, “There is power in being able to see a larger picture, transcend our typical ways of approaching an inquiry, and consider where and how we can strategically use these elements” (p.160). However, the advantages can be compromised, or even eliminated, by challenges in the process.

A mixed method approach can be viewed as a melting pot where methodologies are combined to enhance understanding through multiple perspectives. However, something can be sacrificed when combining the ingredients into a homogeneous solution. If we are unable to see

## WELL-BEING IN ADULTS WITH HFAC

the quantities and ingredients in the final product, then there is bound to be an unequal combination of methodologies and perspectives, which can create a bias that is not easy to identify.

Varela and Shear (1999) refer to this problem as *degrees of blindness* in their analysis of methodology for studying first-person data. This phenomenon can be present in any form of study, but may be even more significant when applied to mixed-method studies. No methodological approach or experience can be neutral. Every methodology is accompanied by an interpretative framework that can deform or even create the data, a problem that Varela and Shear identify as the *excavation/deconstruction fallacy*. The authors propose that the answer to this fallacy is first to admit that it is present and problematic, and that there is no way to dissipate it *per se*. What we can do is “remain conscious that whatever descriptions we can produce are not pure, solid facts but potentially valid intersubjective items of knowledge, quasi-objects of a mental sort” (p. 14). This approach makes even more sense when we respect that the human experience is fluid and dynamic, not fixed and static.

The methodology for this research therefore attempted to move beyond quantitative, qualitative or mixed methodological communities. It employed a multi-method paradigm in which scales, questionnaires, phenomenology and narrative inquiry were used to understand the research problem. Rather than combining methods into a homogeneous solution where the methods and understanding absorb into each other and are indistinguishable from each other, a virtual mechanical mixture was created within a container focused on understanding well-being for HFAC learners. The excavation/deconstruction fallacy was more successfully avoided by selecting methods of study that were specific and were oriented to the research questions rather than to the methodology itself (Martin, 2008; Varela & Shear, 1999.)

## 2.6 Ontology, Epistemology, and Enactment

What separates IMP from other methodologies embracing the mixed-research paradigm is its pluralistic embrace and integration of ontologies and epistemologies. Epistemology and ontology are viewed as two correlative dimensions of every occasion; they cannot be fragmented or fractured without also dismantling the richness and wholeness of existence. Being (ontology) co-enacts with knowing (epistemology), and is completed through enactment (methodology). Every moment and instant of existence is made of an objective *what* (being), which is perceived by a subjective *who* (knowing), and the union of the two culminates in an enactment that enriches and transforms both the object and the subject, creating a new moment. Each new moment creates a slightly different object, which is completed by the consciousness of a different subject, who enacts each new moment or instant in an ongoing cycle of change and development (Wilber, 2012). An illustration of this concept applied to the context of this study can be found in Appendix H.

With *being* conceived as dependent on and developing from subjective consciousness, *being* will exist in as many different dimensions as there are unique subjects to comprehend it. Not only are ontology and epistemology evolving with each moment, the same occasion is enacted differently depending on the subject comprehending the object. As such, at any given moment infinitely different versions of the same reality are occurring and evolving (Wilber, 2012). Wilber is careful to note that these different versions are not merely perceptions of one reality, but actual *Truth* in itself.

The complex and evolving nature of ontology and epistemology in IMP creates complexity by revealing that it is not possible to understand all of the realities of a moment or occasion. Wilber (2002) has stated that he has “one major rule: Everybody is right. More

## WELL-BEING IN ADULTS WITH HFAC

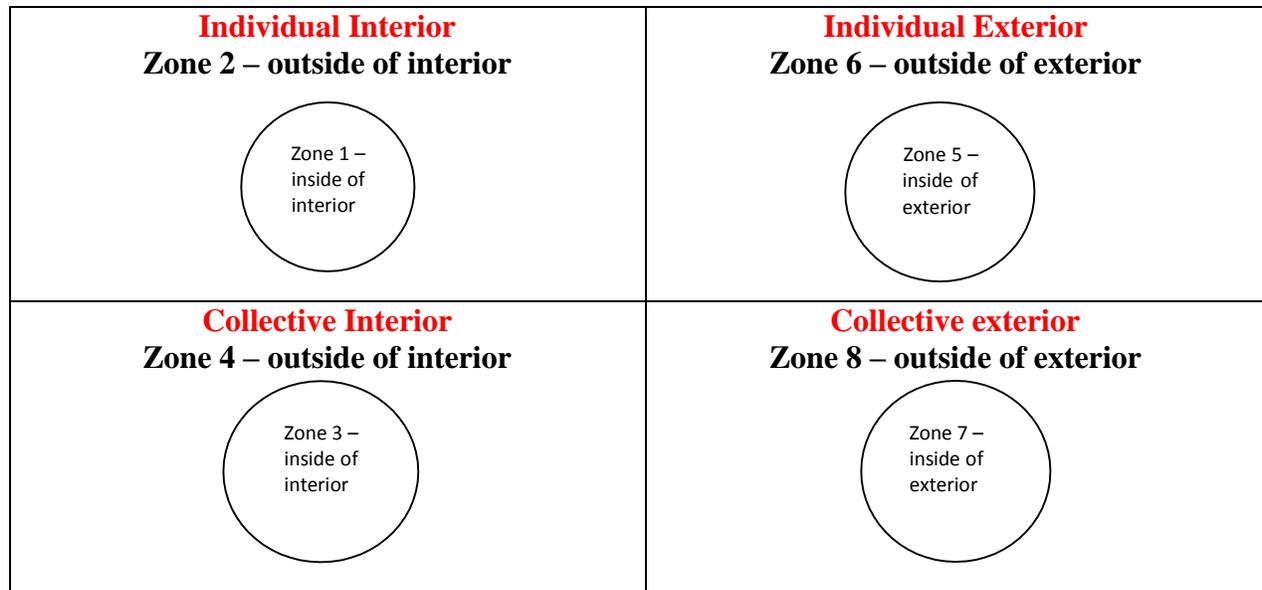
specifically, everybody—including me—has some important pieces of truth, and all of those pieces need to be honored, cherished, and included in a more gracious, spacious, and compassionate embrace” (p. 2). To be clear, when Wilber describes pluralism he does not invoke relativism. While there are multiple dimensions of truth, he elaborates that not all truths are equal or right for the context that they exist within. Rather, it is the juxtaposition of these truths that offers the most accurate picture, which we can use to move forward. The more dimensions that can be embraced in understanding a phenomenon, the more complete and true that understanding can be.

The AQ map is a quadrant that separates four key viewpoints of human experience along two axes: individual or collective, interior or exterior (Wilber, 2007). It is represented below in Figure 2.

The upper left (UL) quadrant, the individual interior, focuses on understanding related to the thoughts, beliefs, feelings, emotions, and values of the individual. This is a subjective, inward view of the self, which can be examined from a first-person perspective (zone 1) or a third-person perspective (zone 2). The lower left (LL) quadrant represents the perspective of the collective interior. In this quadrant, the beliefs, values, and culture of the collective are manifest as intentions and expectations of the group as a whole. It can be examined from the inside (zone 3) or from the outside (zone 4). The upper right (UR) quadrant looks at the perspective of the individual exterior. It is the individual seen from the outside who, from this perspective, is concrete and measurable. The individual can be viewed from the first-person perspective (zone 5) or the third-person perspective (zone 6). The lower right quadrant (LR) represents the experience of the collective exterior. This is a social exterior, and encompasses the external structures of the inter-objective systems of the collective. It can be viewed from within (zone 7)

## WELL-BEING IN ADULTS WITH HFAC

or from the outside (zone 8). It includes the systems that cultures and societies develop to enact the collective interior.



*Figure 2. IMP framework. Adapted from Esbjorn-Hargens (2010).*

This study proposes to employ Wilber’s quadrants and zones as a methodological tool for establishing a more complete and integrated understanding of the issue of well-being in individuals with high functioning autistic characteristics. It is not possible to consider all of the diverse perspectives and knowledge claims existing about autism and well-being, but the quadrants and zones ensure that a more balanced perspective is maintained throughout this study and that the literature review is truer than it would be without this model. Wilber (2007) observes, “the integral (AQAL) Map is just a map, but it is the most complete and accurate map we have at this time” (p. 18). Through the use of the AQAL Map, this study strives toward as complete and accurate understanding of well-being and high functioning autism as possible.

An integral, balanced perspective is especially important for an investigation into well-being and high functioning autism because there may be much discrepancy between first-person and third-person perspectives. The literature is rife with studies identifying poorer life outcomes

## WELL-BEING IN ADULTS WITH HFAC

for people with autism. Many of these studies use quantitative measures to derive data, which are assessed from an outside perspective. Far less subjective data exist regarding the quality of life of people with autism. The lack of first-person accounts from people on the spectrum is significant because there is some evidence that autistic people may perceive their limited social and emotional functioning as less severe of a problem than other people. Perceptual differences between people with and without autism may challenge the validity of research regarding well-being and high-functioning autism (Sheldrick, Neger, Shipman, & Perrin, 2012).

### **2.7 Well-Being**

Questions relating to the meaning of life and what makes life worthwhile have likely existed for as long as the human race has existed. Aristotle stated that the highest of all goods achievable by human action was “eudemonia,” which utilitarian philosophers from the 19<sup>th</sup> century interpreted to mean happiness. Empirical assessments were developed to measure the extent to which people felt good, contented, and satisfied with their lives (Ryff, 1989). These measures were based on a hedonic sense of well-being—specifically, that merely increasing pleasure and decreasing pain would lead to happiness and a good life. However, little thought was given to happiness being a more complex, and dynamic experience. Hedonic well-being is important, but by itself can be a shallow and insufficient form of well-being. In addition, evaluating well-being on the highs and lows of any given moment is bound to produce varied data that are difficult to interpret and even more difficult to move forward from.

In contrast, eudemonic well-being looks to deeper measures of happiness that involve striving toward excellence based on one’s unique potential. Aristotle’s eudemonia described the highest human good as involving activities that are goal-directed, have purpose, and help us to achieve the best that is within us. Eudemonic concepts of well-being have inspired fields of

## WELL-BEING IN ADULTS WITH HFAC

research, whose theories and measures have enriched our understanding of well-being. These advancements include perspectives connecting well-being to maturity, executive processes of personality, basic life tendencies, personal development, will to meaning, mental health, individuation, self-actualization, and fully functioning person theories (Ryff & Singer, 2008). Figure 3 shows the core dimensions and the theoretical underpinnings behind the PWBS.

In the spirit of Integral theory, value and understanding can be garnered from both hedonic and eudemonic understandings. Ryff and Singer (2008) observed that the “central challenge in working with all of the above perspectives was the task of integrating them into some coherent whole” (p. 19). As a solution, they identified recurrent themes or points of convergence in those formulations of positive functioning. Their work revealed six key dimensions of well-being, each of which represent frequently endorsed aspects of what it means to be healthy, well, and fully functioning (Ryff & Singer, 2008). Ryff and Singer’s work in identifying a model of psychological well being (PWB) explored the distinction between hedonic pleasure and eudemonic well-being. They propose a model of six core dimensions of well-being:

1. Autonomy
2. Personal growth
3. Self-acceptance
4. Purpose in life
5. Environmental mastery
6. Positive relations with others.

In addition to a model for psychological well-being, Ryff developed an evaluation of self-report scales to measure the dimensions of well-being, which are based on a psychological theory that specifies the constructs of interest. Although these scales are not without limitation,

## WELL-BEING IN ADULTS WITH HFAC

research findings generally support their use in educational settings. The Ryff scales have since become the most popular instrument employed to assess human positive functioning (Sirigaatti, et al., 2012).

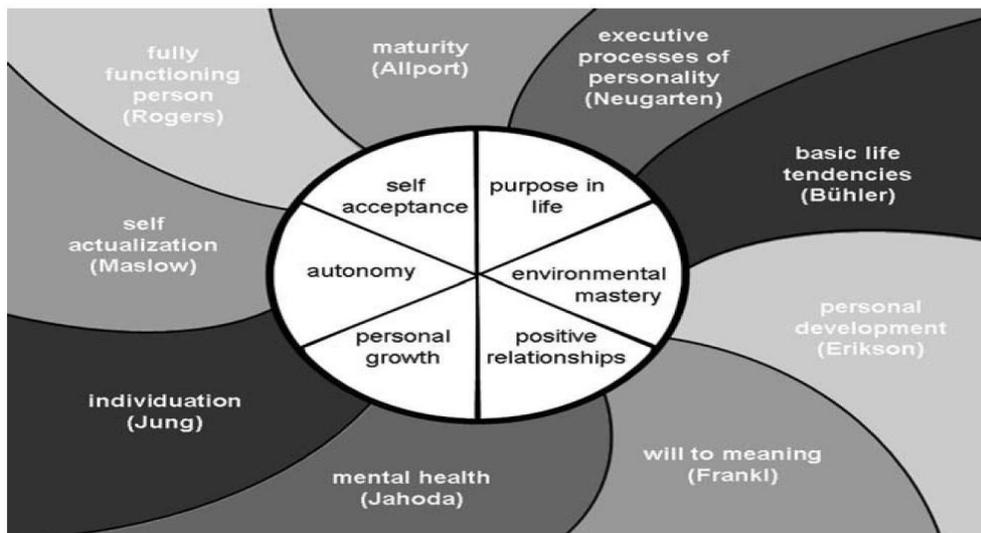
Well-being is often either confused or considered synonymous with *quality of life*, the study of which emerged as an academic discipline in its own right in the 1970s with the establishment of the peer-reviewed scientific journal *Social Indicators Research* (Galloway, 2005). Since then, the volume of academic articles concerned with quality of life and well-being issues have steadily increased. Quality of life, like well-being, is a vague and difficult concept to define, and its use is not consistent. For the purpose of clarity, a distinction and justification for this proposal's focus on the term *well-being* over *quality of life* should be made. Economists make a clear distinction between well-being as pertaining to individuals, and quality of life as being concerned with the comparisons of welfare between individuals (Galloway, 2005). While both terms speak of similar issues, well-being seems to focus more on the UL and LL quadrants while quality of life is more likely to be found in the UR and LR quadrants. While information that is meaningful for this study is found in all four quadrants, the nature of active research described in this proposal remains closer to the individual and collective interior quadrants.

Dr. Abraham Maslow's book *Motivation and Personality* (1954) introduced the term positive psychology, which initiated a movement to focus on the promotion of positive mental health rather than merely treating illness. Martin Seligman further promoted this theme in his 1998 role as president of the American Psychological Association, stating, "for the last half century psychology had been consumed with a single topic only—mental illness" (2005). In the footsteps of pioneers of positive psychology, who include Maslow, Rogers and Fromm, Seligman urged psychologists to push forward in the field by nurturing talent and improving

## WELL-BEING IN ADULTS WITH HFAC

normal life in order to promote happiness and flourishing. The field did indeed move ahead with an emphasis on exploring factors that hold the greatest value in life, that contribute most to a well-lived and fulfilling life. Respect for the personal and subjective nature of the “good life” is fundamental to the movement, as is encouraging signature strengths every day to produce authentic happiness and abundant gratification (Seligman & Csikszentmihalyi, 2000). This movement in positive psychology soon spread to the field of education, which is reflected today in the strength-based planning model predominant in Alberta’s inclusive education movement.

The term well-being in this proposal reflects the spirit of Seligman’s positive psychology, and is promoted as the desired outcome in education for all learners. However, the emphasis on well-being holds even more meaning for learners with characteristics of high functioning autism. It is likely that no other group exhibits such a clear dichotomy between strengths and challenges. The impact of autistic activism has stimulated scholarly discourse on the subject, which is covered in depth in multiple peer-reviewed journals (Caplan, 2005). Yet evidence suggests that the rich nature of talent and ability in this group is generally overlooked and their potential remains underdeveloped in education systems.



*Figure 3. Core dimensions of psychological well-being and their theoretical foundations (Ryff & Singer, 2008, p. 20)*

## 2.8 Autism

Autism is a developmental disorder characterized by impaired social interaction and communication as well as restricted interests and repetitive behavior. About one percent of the worldwide population is affected by the condition, and the proportion of autistic students in Calgary's school population mirrors this statistic (Ghali, et al., 2014). The prevalence of autism has been steadily increasing over the past two decades, especially in individuals without intellectual disability. It is possible that an increase in risk factors are involved, however other factors certainly contribute to the rising prevalence. Improved awareness and recognition of the condition, a rise in diagnoses for funding purposes, an improved cultural acceptance, and changes in how the condition is diagnosed have also contributed to increased diagnoses in autism (Lai, Lombardo, & Baron-Cohen, 2014).

Autism is a spectrum condition that can manifest with mild to severe symptoms. Approximately forty-five percent of autism cases involve intellectual disability. Males are three

## WELL-BEING IN ADULTS WITH HFAC

times more likely to be effected than females. While the broad phenotype is specific to social communication and interaction challenges with restricted and repetitive patterns of behavior, more than seventy percent of individuals with autism have co-occurring medical, developmental, or psychiatric conditions. Sleep disorders, depression, anxiety, ADHD, tic disorders, and obsessive-compulsive disorder are the most common conditions accompanying autism (Lai, Lombardo, & Baron-Cohen, 2014).

A meta-analysis showed that individuals with autism have a mortality risk that is almost three times higher than that of unaffected people of the same age and sex. Up to eighty percent of adults with autism have poor or very poor outcomes in terms of independent living, educational attainment, employment, and peer relationships. Even for individuals without intellectual disability, adult social outcome is often unsatisfactory in terms of quality of life and achievement of occupational potential (Lai, Lombardo, & Baron-Cohen, 2014).

High functioning autism is at one end of the spectrum. Signs and symptoms are less severe, and people with high functioning autism usually have average to above-average intelligence. From an educational perspective, high functioning autism is challenging because of the diversity in intrapersonal strengths and challenges, as summarized in Table 2.

## WELL-BEING IN ADULTS WITH HFAC

Table 2.

*Common learning strengths and challenges in high functioning autism.*

<b>Strengths</b>	<b>Challenges</b>
3.1 Attendance to Detail	3.2 Generalization of skills and Concepts
3.3 Highly Skilled in Particular Areas	3.4 Grasping the Big Picture
3.5 Recognition of Patterns and Ability to Classify	3.6 Uneven Skill Set
3.7 Rote and Visual Memory	3.8 Perceiving Unwritten Rules of Social Interaction
3.9 Vocabulary	3.10 Difficulty Processing in Non-Favorite Modalities
3.11 Logic	3.12 Parsing Out/Summarizing Important Information from Conversation
3.13 Independent Thinking	3.14 Sensory Integration Problems
3.15 Visual Processing	3.16 Expressing Empathy in Ways Others Expect or Understand
3.17 Direct Communication	3.18 Executive Functioning Challenges – Difficulty in Planning Long Term Tasks
3.19 Honesty	3.20 Episodic Memory
3.21 Ability to Quickly Learn and Adhere to Consistent Rules	3.22 Cognitive Flexibility

### **2.9 Identification and Diagnosis**

Autism in Alberta is generally diagnosed by a developmental pediatrician, a neurologist, a psychologist, or a psychiatrist. The Diagnostic and Statistical Manual (DSM) is the primary manual used by clinicians to provide a formal diagnosis of autism. Autism is a disorder characterized by heterogeneity: until 2013, the DSM-IV identified a set of autism spectrum disorders (ASDs) that included Autistic Disorder, Asperger’s Disorder, and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) to categorically distinguish between the range of symptoms and abilities on the broad spectrum.

In 2013 the newly published DSM-V replaced the separate diagnostic labels associated with the spectrum with one umbrella term, Autism Spectrum Disorder (ASD), in an effort to

## WELL-BEING IN ADULTS WITH HFAC

make diagnosis more specific, reliable and valid. The new criteria are more thorough and strict, with diagnosis involving a heavier focus on symptoms within the area of fixated interest and repetitive behavior. Distinctions are now made according to severity levels, which are determined based on the amount of support needed in response to challenges involving social communication, and problems concerning restricted interests and negative patterns of behavior.

Diagnosis of autism generally occurs early in an individual's life, and in many instances is facilitated by one's school or school division psychologists. Alberta has experienced reduced funding in schools for both diagnostic and programming supports in recent years, resulting in many students exhibiting characteristics of autism yet have not been diagnosed, and thus are not being funded. As a result, teachers are less able to meet the diverse needs of autistic learners in Alberta's classrooms.

Simon Baron-Cohen saw the need for a measuring tool to identify the degree to which people with normal or high IQs may have autistic traits connected with "the broad autistic phenotype" (Bailey, et al., 1995). He developed a short, self-administered autistic quotient scale to this end "for both scientific reasons (establishing who is affected and to what degree) and for applied reasons (screening and assessment)" (2001, p. 5). The instrument he devised is utilized in this study, and may prove useful in Alberta schools under current circumstances.

### **2.10 Cognitive Theories of Autism**

Leading the path in autism research has been an effort to elucidate the mechanisms underpinning the behavioral manifestations of autism (Lai, Lombardo, & Baron-Cohen, 2014). Genetics/biology, cognition, behavioral factors and an individual's environment have been implicated to some degree as either having a causal or symptomatic role—although the specific nature or role of each remains uncertain (Frith, Morton, & Leslie, 1991). Initial theories focused

## WELL-BEING IN ADULTS WITH HFAC

on single and primary cognitive deficits, but more recent theories acknowledge that there is likely a complex interplay between explanatory levels, which is represented in Figure 4.

Pellicano (2011) suggests that a successful model of autism needs to address four key criteria:

- 1) The model must be universal; it need address autistic traits in all individuals on the spectrum, not just some of them.
- 2) It should be unique to the characteristics of individuals with autism, to distinguish between it and other developmental disabilities.
- 3) The model should explain causal precedence, addressing how the theory is a cause in the disorder rather than a symptom of the disorder.
- 4) It should provide an explanation that connects the severity of the described deficit to the behavioral symptoms of autism.

A successful cognitive or psychological theory of autism should also be able to integrate neurobiological theories. To date, no theory has been proposed that stands to meet each of the above requirements, although there are prominent theories that contribute to our understanding of autism. Five of these theories will be summarized.

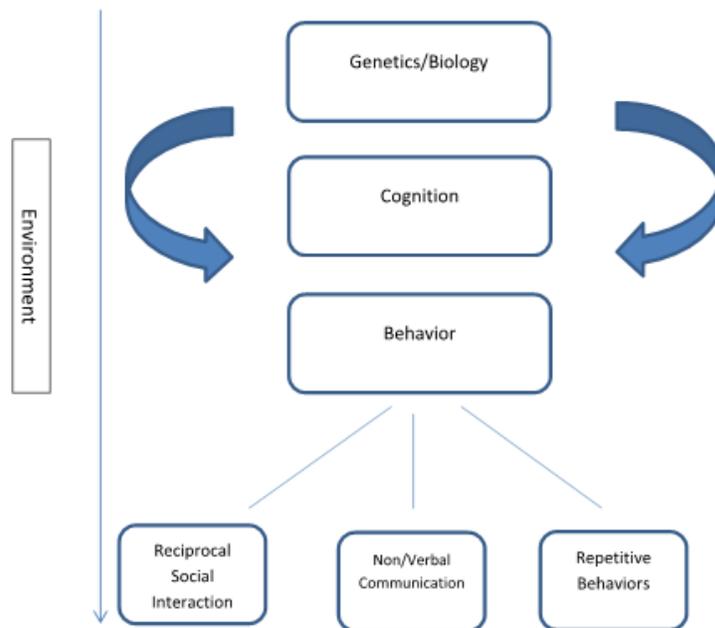


Figure 4. Causal model showing three levels of explanation. Adapted from Frith et al., 1991).

**Theory of mind.** This hypothesis for autism focuses on deficits in the autistic individual’s ability to attribute mental states to self and others (mentalizing), which manifests in challenges to predict or interpret others’ behavior. In 1985 Baron-Cohen showed that the majority of children with autism had difficulties with the false-belief task, which supported the proposal that autism could be explained by a deficit in the ability to understand other minds (Roth & Rezaie, 2011). This theory provided an explanation for communication deficits and social difficulties. It also addressed symptoms including lack of imaginative or pretend play, the isolating sense of “autistic aloneness,” and empathy challenges. This theory provided a causal explanation for autism. Conclusive evidence to date indicates that most individuals with autism show weakness in mentalizing. However, difficulties with theory of mind are not specific to autism: many individuals with learning difficulties who do not have autism also show difficulties with false-belief tasks. Another criticism of Theory of Mind (ToM) is that, while it explains

## WELL-BEING IN ADULTS WITH HFAC

social communication challenges, it fails to address other key aspects of the disorder, including repetitive behavior and stereotyped interests.

**Executive dysfunction.** Executive function skills (EFS) are higher-level thought processes linked to the prefrontal cortex. They assist with guiding flexible, goal-orientated behavior, especially in novel circumstances. A deficiency in EFS could express itself in the inhibition of natural responses, working memory, and the ability to flexibly shift attention focus. Each of these problems are characteristic of autism. Executive dysfunction theory accounts for the inflexible, perseverative behaviors and concreteness in thought and language evident in autism. It can explain the inherent rigidity and invariance in autistic behavior as the result of a reduced ability to generate novel, goal-directed behavior. Evidence to support this claim has been reported in studies that link repetitive behavior with measures of executive dysfunction (Baron-Cohen, 2004).

If dysfunction in EFS is to be used as a causal explanation for autistic symptomology, these deficits should be readily apparent in very young children with autism. However, studies are not conclusive in finding autism-specific executive difficulties in young children. Proponents of the theory suggest that executive difficulties can be missed in young children with autism because assessments are not sensitive enough to detect what might be very subtle difficulties, which only later may shift developmental trajectory and amplify symptoms of dysfunction in EFS. Relative strengths relating to causal precedence lend strength to this theory, but its efficacy remains inconclusive in terms of universality, uniqueness, and causal precedence (Pellicano, 2011).

**Central coherence theory.** The previously described theories were construed based on evidence of deficits in autism. Frith, Morton and Leslie (1991) noted that both theories failed to

## WELL-BEING IN ADULTS WITH HFAC

explain the strengths associated with autism. In addition to their impairments, many people with autism display special talents. The Central Coherence Theory posits that neurotypical individuals display “central coherence,” or, a propensity to process stimuli as Gestalts. Frith suggests that people with autism exhibit “weak” central coherence, which is evident in their preference for processing local elements over the global whole. This theory views central coherence as a domain-general information processing style that pervades all areas of a neurotypical individual’s functioning. It goes on to predict that the relationship between local and global processing is reciprocal in nature. The theory offers an explanation as to why people with autism may demonstrate preserved or enhanced performance in tasks where local processing is beneficial, but perform poorly on those that benefit from a more global integration of information (Roth & Rezaie, 2011).

People with autism demonstrate an impaired ability to draw together complex information from their environment (especially in social environments), which hinders their ability to derive coherent and meaningful interpretations from these environments. This disconnect in experience results in an “incoherent world of fragmented experiences” (Frith, 1989, p. 98). With limitations in ability to attend to the bigger picture, energy and attention can be devoted to smaller pieces of the bigger picture, allowing for stronger abilities in more isolated and specific skill areas (Pellicano, 2011).

Research and evidence has not ultimately supported this theory, but the notion of “weak” central coherence in autism has been very influential in generating interest in local and global processing in autism. Perhaps more importantly, it has informed the researcher’s understanding of autism as a condition with a specific pattern of both strengths and weaknesses.

**Empathizing-systemizing theory.** This promising theory addresses social and communication difficulties in autism from two different perspectives: weaknesses in empathy and strengths in systemizing. The strength in this theory is that it is a two-factor theory that provides a causal explanation for the cluster of social and non-social features in autism (Baron-Cohen, 2004). It addresses both strengths and weaknesses associated with the disorder, moving beyond the focus on repetitive behaviors and narrow interests as a symptom of brain dysfunction (executive dysfunction theory), as well as the view that reduced ability to perceive at a global level is a result of something missing in the brain (weak central coherence theory). This theory looks at the same behaviors through a different lens, viewing them as a result of intelligent behavior.

Empathizing-Systemizing Theory is similar to theory of mind, but extends beyond the cognitive component to include the response element. It suggests that empathy challenges are not only experienced in the receptive domain, but also in the expressive domain. The ability to recognize and register empathy is deemed “cognitive empathy,” which directly relates to theory of mind. By contrast, the ability to appropriately react to another person’s thoughts and feelings is “affective empathy” (Baron-Cohen, 2008).

Systemizing is the drive to analyze or construct any kind of system that follows rules. Systemizing, then, is the ability to identify the rules governing a system and then to predict how that system will behave. It offers a causal explanation for the autistic strengths of excellent attention to detail in perception and memory. This attention to detail is viewed as occurring in the service of achieving an ultimate understanding of a system. The fundamental difference between this and other theories is that this theory maintains an optimistic view of the autistic individual’s integrative capacity. While the former theories predict that people with autism will

## WELL-BEING IN ADULTS WITH HFAC

forever remain lost in detail at the expense of understanding the bigger picture, the latter theory predicts that over time the individual can achieve an excellent understanding of the whole system. It may take longer for them to grasp and control the variables in a system, but once they do, their understanding may exceed that of neurotypical individuals (Baron-Cohen, 2008).

**Intense world theory.** The newest theory of autism is proposed as a unifying theory. It offers the most complete explanation of autism to date, addressing elements of genetics, biology, cognitive and behavioral theories, and an individual's environment. The theory posits that autistic behavior is not the result of cognitive deficits, but rather the opposite. Autistic people are hypersensitive to stimuli, taking in too much and learning too fast. This sensitivity to stimuli overwhelms the autistic individual, causing withdrawal from stimuli (Markram & Markram, 2010).

The Intense World Theory proposes that autistic traits can emerge if a molecular syndrome (stemming from genetic predisposition, epigenetic attack, and/or environmental factors) is activated that sensitizes gene expression pathways such that they respond excessively to environmental stimulation. In normally developing brains, enriched environments nurture brain development. In the autistic brain, these pathways are sensitized such that environmental stimulation may be exaggerated, which accelerates development in the brain. This interpretation is supported by research showing that in early development the autistic brain is larger than in the typically developing brain (Markram & Markram, 2010).

Hyper-reactive and hyper-plastic neural microcircuits may lead to hyper-perception, hyper-attention, hyper-memory, and hyper-emotionality. This theory focuses primarily on the neocortex and the amygdale, but might be applicable to the study of other brain regions as well. If neocortical columns are hyper-reactive and hyper-plastic, there could be significant

## WELL-BEING IN ADULTS WITH HFAC

consequences for perception, attention, and learning, which might further affect the developmental trajectory. This theory offers an explanation of the heterogeneous nature of autism, as well as the curious mixture of strengths and challenges evident in many people with autism (Markram & Markram, 2010).

Intense World Theory, as the newest theory described in this review, is in its early stages of research. It has the potential to amalgamate and/or transcend current theories, and it avoids the piecemeal and unidimensional pitfalls of many popular theories. It bridges neurobiology (plasticity, neural anatomy, and executive functioning) and cognitive theories of autism. It appears to address the criteria of a successful model for autism in that it meets the criteria for universality, unique autistic characteristics, causal precedence, and provides a means to explain the connection between observed behaviors and cognitive functioning.

This is a popular theory in the autistic community because it is generally acknowledged as an accurate reflection of individual experiences. It is also valuable because it reflects “a radical departure from the outdated and socially stigmatizing disease models of the past” (Markham & Markham, 2012). This theory is promising, but scientific theories are not scientific facts that are meant to last indefinitely; theories are meant to lead us forward towards improved understanding. What is exciting about this theory are the new directions it opens in autism research.

This theory, which is to date more of a hypothesis as the scientific community continues to collect a substantiated body of research to support it, stands out because of its ability to align itself with Frith’s causal model (Figure 4). It is an Integral theory with connections firmly rooted to the individual and collective—the subjective and objective. It explains the autistic individual’s sense of being overwhelmed, of having too much rather than

## WELL-BEING IN ADULTS WITH HFAC

too little stimulation—an experience continuously described by participants in this study as part of the subjective experience of high functioning autism. Intense World connects the genetic/biological, cognitive and behavioral aspects of autism to the importance of the environment. It accounts for the unique diversity that characterizes the condition, transforming a significant challenge in the study of autism to an important descriptor of the condition. As Markram (2015) describes Intense World:

The theory was triggered bottom up from neuroscientific studies and the real changing point for us was when we found that fear memories were so quickly acquired, lasted longer, were difficult to erase and over generalized. This put all the results into context because the neocortex could render the world intense, highly fragmented and overly specialized while the amygdala would dial up the emotional component of the intense world making it potentially extremely painful and aversive forcing the autistic child to take refuge in a secure bubble. If they don't succeed to take refuge through repetitive behavior, routines, rocking, and other types of behaviors, then they may display self-injurious behavior – like ants crawling all over your body. The diversity comes from the fact that we are normally diverse and if you add hyper functional circuits to that then naturally each autistic child will be even more different from each other. It is like taking all our normal differences to an extreme. This challenges society to accommodate autists, but diversity is the key to social evolution and so it is a good challenge.

Perhaps most encouraging, this theory formally extends our understanding of autism beyond any one of Wilber's quadrants, connecting them all and encouraging us to work together to transcend the challenges of autism. It has much potential as a unifying theory for autism.

### **2.11 The Role of Self in Autism**

It is established that theory of mind is affected in autism. It is also theorized that the ability to recognize mental states in oneself depends on the same psychological mechanisms (Cheng, Rolls, Gu, Zhang, & Feng, 2015). If this is the case, autism likely involves mechanisms relating to the *theory of own mind*. The combination of weaknesses relating to theory of mind and theory of own mind may be associated with anxiety disorders, which are prevalent in autism (Hare, Wood, Wastell, & Skirrow, 2014). An inability to recognize the intent of others and reconcile it with self-awareness can impair systemizing strengths and create anxiety by contributing to an inability to predict what might occur in a personal environment. Lack of certainty and fear of the unknown are triggers for anxiety in most people. This alone supports the value of focusing on the development of self in autism. Without a strong sense of self, an individual is more likely to interpret experiences as occurring from an external locus of control. People with autism tend to experience difficulty distinguishing between self-controlled and externally-controlled action, indicating that they may exhibit abnormalities in their metacognition of agency (Zalla, Miele, Leboyer, & Metcalfe, 2015).

As Siegel observes, “Few ideas are both as weighty and as slippery as the notion of the self” (Hobson, 2010). Yet for all of its slipperiness, self-experience combines with worldly encounters that facilitate personal development and social engagement. Hobson suggests that we cannot presume that autistic people have the structure of self-experience that most people take for granted (2010).

Facilitating the development of the recognition of self has implications not only for anxiety management and social connections, but for improving communication. Communication itself requires understanding of self. In essence, communication is the connection between self

## WELL-BEING IN ADULTS WITH HFAC

and other. An individual with limited understanding of self will be at a disadvantage in communication, which will impact the developmental trajectory of communication and likely result in further impairment over time (Hobson, 2010).

Research indicates that facilitating development of self through mindfulness practices is promising. It seems that mindfulness-based stress reduction (MBSR) techniques may be an effective intervention for reducing comorbid symptoms of depression, anxiety and distress in high functioning adults with ASD. New techniques that help individuals with autism develop a sense of self will likely have a positive influence on well-being (Bogels, Hoogstad, Dun, deSchutter, & Restifo, 2008).

### **2.12 Interpersonal Relationships and Autism**

At one point, there was an unsubstantiated belief that individuals with autism did not experience or were not affected by loneliness. More recent studies show that loneliness is an associated negative emotional experience for people with autism (Mazurek, 2013). Many building blocks of interpersonal relationships, such as communication, social cognition, and processing of emotional signals, are impaired in autism (Travis & Sigman, 1998). These challenges to developing interpersonal relationships are detrimental to the development of individuals with autism. Loneliness is associated with increased depression and anxiety as well as decreased life satisfaction and self-esteem. Yet we know that people with autism can and do develop meaningful relationships. Increasing social networks to decrease loneliness may have a significant impact on well-being for adults with autism (Mazurek, 2013).

At the core of most educational approaches to autism is the teaching of social skills. This can include encouraging specific social behaviors and social rules, which can be quite effective. However, Baron-Cohen suggests that we need to go further than the rote teaching of skills. By

## WELL-BEING IN ADULTS WITH HFAC

themselves, these approaches tend to impose a rigid use of social skills, which can be detrimental since rules are hard to specify in ways that cover all instances. He argues that it is equally important to teach about mental states (beliefs, thoughts, intentions, desires, and emotions).

Addressing social deficits and enhancing social skills early on seems to be an effective way of improving the quantity and quality of relationships for people with autism. In addition, it is likely to improve the developmental trajectory of people with HFAC, improving well-being outcomes.

### **2.13 Alberta Education and High Functioning Autism**

Inclusive education in Alberta has brought both exciting potential and challenges beyond those normally expected with such changes. The promise of reaching each and every student, to help them grow into the best they can be, is the beacon that guides most of us in the field. Yet the Alberta government, despite its commendable vision, has made decisions that have undermined the promise of inclusion for students with HFAC.

The past four decades have been decades of diversity. In terms of creating an equitable system that supports a variety of learning needs, Alberta schools have experienced a range of philosophical, economic, and social changes as well as changes in practice (Jahnukainen, 2011). These changes have required teachers to push forward into new territory, and some moments have shown more success than others.

Survey data collected by ATA since 2005 show that Alberta teachers believe that support for students with special needs has declined dramatically. In 2005, twenty-five percent of teachers indicated that support had somewhat or significantly declined (Murgatroyd, 2013). By 2013, fifty-seven percent of teachers were expressing these same concerns. Educational professionals in Alberta seem to feel that we are losing what progress we initially made

## WELL-BEING IN ADULTS WITH HFAC

regarding inclusive education, and that we may in fact be moving backwards from where we were at the start of the millennium (Alberta Teachers' Association, 2012).

At the same time, knowledge and understanding in the field of autism has grown at an incredible rate. The condition had originally been associated with a lack of parental love and acceptance. Up until the 1960s autism had been treated aggressively with electric shock therapy, strict behavior modification programming using pain and punishment to correct anti-social behavior, and a variety of medications including LSD. Moving into the 1970s, research began to suggest a genetic basis for the condition and early diagnostic tools were developed. By 2010, the public became aware that the prevalence of autism was skyrocketing. This led to questions about the methods we use to diagnose the condition, as well as widespread concern and fear regarding the causes of the disorder. Most notable was the ungrounded perception that autism might be caused by immunization, resulting in a public backlash that threatened the medical progress made through inoculation programs.

Throughout these changes, Alberta Education remained rather silent in terms of leadership and support for dealing with this growing population of learners. Until 2003, students on the spectrum were supported in the same way other students with disabilities were. Alberta provided funding to support teachers with access to material resources, expertise, human resources, program planning and development. Teachers felt that inclusive education for these students was both appropriate and achievable. However, as we moved forward into more challenging economic times, although inclusive values and expectations remained intact, the supports that were instrumental to the success of HFAC learners began to disappear (Murgatroyd, 2013). Mayton, Wheeler, Menendez, and Zhang (2010) described the impact of insufficient teacher training on learners on the spectrum:

## WELL-BEING IN ADULTS WITH HFAC

For educators attempting to meet the diverse range of learning needs for children with ASD, decisions regarding the types of interventions to implement in the classroom and the limited research on numerous strategies can be both misleading and confusing.

Professionals' and caregivers' reliance on untested methods and dependence on strategies that have limited evidence have resulted in unrealistic and unreasonable expectations for students and have hindered the potential progress of students with ASD. (p. 541)

In Alberta, there are no longer any B.Ed. programs offering a major in special education training and development. Classroom teachers in the system have had to rely on the support of consulting teachers or specialists with knowledge backgrounds and experience relating to autism and other conditions, but the availability of this support is declining. Meanwhile, expectations that teachers independently meet the needs of all learners in their classrooms are increasing.

Of the ten most prevalent factors that teachers felt necessary for teacher training towards inclusion, teachers cited as most important the implementation of new methodological and curricular elements that would transform schools into more inclusive settings (Gonzalez-Gil et al., 2013). Alberta requires curricular guidance specific to the unique needs of learners with characteristics that teachers generally don't have the education, experience, or expertise to support on their own.

**A deficit model.** In Alberta, the 1970s and 1980s were a time of prescriptive teaching. The emphasis was on providing teachers with a list of skills and objectives that needed to be taught in a developmental sequence, with the ultimate goal being the students' "normalization" and attainment of only those skills most pertinent to independence and basic life skill functioning (Alberta Department of Education, 1982). While talk of inclusion was beginning to emerge, the emphasis was on integration. The term *integration* suggests that learners with special needs were

## WELL-BEING IN ADULTS WITH HFAC

to begin in seclusion and ideally progress towards assimilation with peers in a more natural environment. There was a program of studies outlining general objectives for special education, which were further developed into specific curriculum guides for the educable mentally handicapped and the trainable mentally handicapped. The dominant sensibility of this era is best expressed in the *Educable Mentally Handicapped Curriculum Guide* (Alberta Education, 1982):

Because of the diverse nature of school settings in which classes for students with mental handicaps are located, it is impossible and inadvisable to suggest one particular setting over another. It is recommended, however, that wherever possible, students with mental handicaps be integrated into a regular classroom setting. It is imperative that this policy be enacted only after a careful assessment of the student's needs and of the regular classroom setting. (p. 2)

In a search of articles and publications from Alberta Education in the 1980s, no specific mention of ASDs could be found. Outside of the school system, the 1980s saw autism earn recognition as an independent disorder, specifically separated from mental illnesses such as schizophrenia. It was recognized in the DSM II under the diagnosis "Infantile Autism." The DSM III-R in 1989 renamed it "Autism Disorder," and the recognition of Asperger's Disorder signaled in a new era that acknowledged the spectral nature of the condition. It is reasonable to believe that emerging understandings of autism were so new that they were not yet reflected in Alberta Education publications, although this assumption is suspect, considering that no specific reference to autism was made until 2003.

Students on the spectrum at this time were either educated in the regular programs of study or, if "disabled" enough, were served by the special education program of study. There appears to have been little information or support for students who were academically capable,

## WELL-BEING IN ADULTS WITH HFAC

but whose social, communication, and behavioral characteristics created challenges not reflected in any program of study. This inadequacy is still evident in schools today.

**A shift in paradigm.** Between the early 1990s and 2005 the call for integration in Alberta had grown in strength. This approach still worked from the standpoint of the medical model and its emphasis on finding a remedy, or at least controlling deficits. The basic structure of this approach resembled the category used at the federal level in the United States called the “Disability Model” (Jahnukainen, 2011). Only now the model was applied with a single-minded goal to focus all efforts and resources on placing the disadvantaged child in a regular classroom regardless of what would be best for the child or the other students. As one high school teacher in the researcher’s school division observed, this model amounted to “inclusion for the sake of inclusion, with little thought towards meaningful inclusion.”

There was a call for intervention and integration, and for special education to be structured as a supportive system to supplement regular education. This era saw the rise in the importance of the individualized program plan (IPP). Meaningful and substantial resources were dedicated to this cause, and it is worth noting that between 2003 and 2005 Alberta teachers reported their highest satisfaction with their ability to meet the needs of children coded as special education students (Murgatroyd, 2013). This was the era of resource rooms—when most schools had access to special education teachers and were able to employ collaborative team-teaching approaches to meet unique learning needs.

With President Bush’s 1990 proclamation of the Decade of the Brain project, public awareness of brain research brought forward a wealth of new research and understanding relating to autism. The condition was recognized socially and economically as a disability in the United States, and other nations soon followed suit. This era can be identified as the forerunner to the

## WELL-BEING IN ADULTS WITH HFAC

early 2000s commitment to social action and equity. Freire's *Pedagogy of the Oppressed*, published in 1970, had beckoned in a new generation motivated by a passion for justice and equity for all. It was not until the 1990s and early 2000s that these ideals were to become evident in Alberta Education's policies, publications, and practices.

In combination with the scientific insight gathered from the Decade of the Brain, autism benefited from the work of advocacy organizations and social justice fighters. It was here that the philosophy emphasizing a focus on ability over disability was born. This was a philosophy that would spread through the autistic community and facilitate progress in the way society viewed, valued, and worked with this population. In Alberta this change in public consciousness culminated in the 2003 Alberta Education publication, *Teaching Students with Autism Spectrum Disorders*—just one document in a series providing information and strategies for differentiating instruction for students with a wide range of needs influencing their learning. These documents provided valuable support for teachers struggling to help their students achieve success. They remain in frequent use today.

**Breaking the boundaries of the deficit model.** The years 2005 to 2013 saw the emergence of a new way of thinking about challenge. Part of this new way of thinking suggested the transition from the disability model to a strength-based model. Strength-based learning as a process advocates a focus on personal strengths and success in order to encourage the acquisition of knowledge and skills. This promising approach represented a gentler, more respectful philosophy in which all learners could be successful. At its core was the belief that each learner is a unique individual with unique talents and challenges. It further promoted the decentralization of traditional special education services in Alberta schools, and instead emphasized that each and every learner had the right to her development within the dynamics of the regular classroom.

## WELL-BEING IN ADULTS WITH HFAC

Resource rooms as a consistent part of the school geography faded. So too did the idea of a regular education classroom.

All teachers were expected to be special education teachers. Differentiation and inclusive education became concepts that every teacher was expected to exemplify. This adaptation can be seen as a call to move towards 21<sup>st</sup> century learning, and is reflected in Alberta Education documents including *Setting the Direction*, *Action Plan for Education*, and *Inspiring Education*. The promise of this moment shines bright, but our ability to move forward with it remains questionable.

Through this period, new understandings about autism continued to emerge at an impressive rate. Of equal interest was the changing perception of autism in the media and the general public. Public awareness has increased, and it seems that the negative stigma associated with the condition had decreased (Martin, 2008). This is evident with the introduction and popularity of new television series featuring characters with autistic characteristics. Examples include Sheldon from *The Big Bang Theory*, Abed from *Community*, and Brick from *The Middle*.

Despite a growing acceptance of these personalities in our culture, much progress is to be made in terms of connecting our general understandings with our practice. Sadly, the majority of learners identified with ASD do not experience the same acceptance and compassion from others as their counterparts on television. Progress towards a society whose view of people with ASD mirrors the favorable public response to ASD characters depicted in popular media will require careful preparation, support, and education.

**A bump in the road in the journey to inclusion.** In *Rethinking Equity*, Murgatroyd (2013) observes that the efficacy of Alberta's commitment to equity through its focus on inclusivism in schools is predicated on the assumption that Alberta provides the resources

## WELL-BEING IN ADULTS WITH HFAC

necessary to address both the growing and increasingly diverse and complex student population. Sadly, the same article presents research statistics on class sizes in Alberta that clearly indicate deterioration in this area between 2005 and 2013. Data collected by the ATA suggests that teachers are more concerned than ever about student readiness to learn and their ability to facilitate growth:

Despite years of policy reviews, promises of “wraparound services”, learning coaches, digitized student profiling platforms and other commitments outlined in the Action on Inclusion, the realities of roller-coaster funding, including a freeze on increases in special education funding, have taken their toll. (Murgatroyd, 2013, p. 42)

In many ways, we have made great progress in Alberta schools towards meeting the needs of our ASD learners. We are one step closer towards seeing autism through the lens of neurodiversity. Improved recognition of the condition and increased positive social perceptions associated with it are bound to have beneficial effects, as will programs geared towards increasing compassion and tolerance in schools, including anti-bullying programs and gay-straight alliances. The change in our schools’ values, which has instigated a transition from a deficit-based model towards a strength-based model, is also very promising, as in general the ASD population tends to offer as many gifts as challenges.

Alberta teachers are facing growing demands and expectations while also struggling with reduced levels of support. With such discrepancy between expectations on teachers and their ability to meet these expectations, it would be understandable if teachers were to turn a blind eye to the needs of students with HFAC. After all, these learners tend to be intelligent and academically capable. Most are able to meet curricular demands, which at this point is all the teacher is responsible for. Teaching practices that reflect this perspective are bound to be

## WELL-BEING IN ADULTS WITH HFAC

shallow, even hollow, and leave this growing population of learners facing the danger of chronic underachievement or worse. This is a situation that threatens to not only steal from the future of individuals with HFAC, but to rob society of the rich contributions these individuals might otherwise make.

This study proposes that further research is required towards the development of a flexible curriculum that can provide guidance and structure to help learners with HFAC navigate the road to personal success—for their own sake and for the sake of their future valuable contributions to society in general.

### **2.14 Summary and Conclusion**

This chapter began with a description of the purpose of the scholarly review, followed by a review of the search terms and parameters used in development of this research plan. IMP was summarized as a conceptual framework. Topics germane to a study in well-being and HFAC were identified, and literature was reviewed to enhance understanding of pertinent information in order to further develop the context for this study. This review included research relating to well-being, autism, cognitive theories of autism, the role of self in autism, interpersonal relationships and autism, and a review of Alberta Education's journey towards developing the potential of learners with HFAC.

## **Chapter 3: Research Methodology**

### **3.1 Introduction and Overview**

The methodology for this study of well-being in adults with high functioning autistic characteristics (HFAC) is discussed in this chapter. The chapter includes a statement of the study's research purpose and questions. The methodology and rationale is explained and the setting and context of the study are described. An explanation of the methods and tools used for data collection is presented. The chapter concludes with a discussion of ethical considerations germane to this study, including delimitations, limitations and issues of trustworthiness.

### **3.2 Research Paradigm and Methodology**

This study used a multi-method research paradigm based on Ken Wilber's Integral theory, often referred to as Integral Methodological Pluralism (IMP). All Quadrant (AQ) mapping (Wilber, 2007) was used as the framework for developing the research plan.

### **3.3 Description of Methodologies**

This study used research methods representing each of the four IMP quadrants. The upper right (UR) quadrant was represented through the use of two different scales, one measuring autism characteristics and the other measuring subjective well-being. Each scale is supported by solid data confirming the tool's validity and reliability. The upper left (UL) quadrant sought to understand the issue through phenomenological inquiry. The lower left (LL) quadrant utilized duoethnographic conversation. The lower right (LR) quadrant sought to clarify and focus understanding by using narrative analysis to explore themes uncovered by the research methods as they relate to Alberta schools and education. An initial description of the research method, each selected to provide balance in perspectives relating to the research problem, follow below.

## WELL-BEING IN ADULTS WITH HFAC

**The psychological well-being scales (PWBS).** The PWBS scales consist of 84 questions based on a series of statements reflecting six areas of psychological well-being: autonomy, self-acceptance, environmental mastery, personal growth, positive relationships with others, and purpose in life. To complete the questionnaire, participants rated the statements on a scale of 1-6, with one indicating strong disagreement and six indicating strong agreement. Responses were then tallied for each category, with high scores indicating that the subject had mastery of that area in their life, and low scores indicating that the respondent was struggling to feel comfortable with that particular concept. A copy of these scales can be found in Appendix E.

This instrument was developed for the purpose of obtaining a measurement of theoretically-derived constructs of psychological well-being. Developers were guided by theoretical literature relating to literature in mental health, self-actualization, optimal functioning, maturity, and developmental life span (Ryff, 1989).

The scales are generally accepted as valid and reliable measures of psychological well-being. While relying on subjective analysis of an abstract construct, they offer an otherwise sound method of summarizing an individual's sense of general well-being (Ryff, 1989). A search revealed that this model has been used in research to assess the well-being of parents and siblings of people with autism, but no studies were found in which the scale was used to measure first-person perspectives of the topic. This study of well-being in people with HFAC offers valuable insight towards understanding the research problem.

**The autism quotient (AQ).** Participants in this study were required to exhibit HFAC as evident by having a score of 26 or higher on The Autism-Spectrum Quotient (AQ) questionnaire. In addition, participants could have a formal diagnosis from a health care professional, but this condition was not necessary and was not by itself sufficient for participation in this study. Due to

## WELL-BEING IN ADULTS WITH HFAC

inconsistent diagnosis practices in Alberta, many people struggle with autism characteristics without having the knowledge, motivation, or means to diagnose the condition. Limiting participants to those with a formal diagnosis from the health system could potentially inhibit valuable contributions from people struggling with HFAC.

The AQ questionnaire was published by Simon Baron-Cohen in 2001. The instrument uses 50 forced-choice statements to address six key areas identified with the autism spectrum. These involve communication, social skills, imagination, attention switching, tolerance of change, and attention to detail. Each question allows the participant to indicate “*definitely agree*,” “*slightly agree*,” “*slightly disagree*,” or “*definitely disagree*.” About half of the questions were worded to elicit an “*agree*” response from neurotypical individuals, with the other half to elicit a “*disagree*” response (Baron-Cohen, Wheelwright, Skinner, Martin, & Clubley, 2001). A copy of the Adult Autism Quotient questionnaire can be seen in Appendix D.

The AQ was developed to measure the degree to which an adult with normal intelligence has autism traits. Study results indicate that the instrument has good discriminative validity and good screening properties at a threshold score of 26, with scores over 22 indicating autistic tendencies above the population average (Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005). While this tool was initially intended to provide data specific to the quantity and quality of autistic characteristics rather than serve as an assessment of or diagnostic tool for autism, some research indicates that the questionnaire can be used for screening in clinical practice (Woodbury-Smith, Robinson, Wheelwright, & Baron-Cohen, 2005).

**Duoethnography.** Duoethnography is an approach for studying how two or more individuals give similar and different meanings to common phenomena as experienced throughout their lives. The approach combines aspects of storytelling with William Pinar’s

## WELL-BEING IN ADULTS WITH HFAC

concept of *currere* (Norris, 2008). The term refers to the idea that one's history is a composite of learning experiences, and thus stands as an informal curriculum in itself. Personal experiences will shape what and how an individual learns. Duoethnography uses the power of personal story to explore how the life histories of different individuals affect the meaning that they give to experience. Rather than being a prescriptive method for exploration, it remains flexible to the experiences of the participants and the direction of the research. It employs four basic tenets in its framework for study (Norris, 2008), as summarized below:

- 1) The methodology must remain open to adaptation according to the needs of the research.
- 2) Each participant's voice must be made explicit, true to the voice of the participant and easily distinguished from other voices by the reader.
- 3) Central to duoethnography is that existing meaning is not only being revealed or uncovered, but that new meanings may be created through the conversation or combination of viewpoints in the conversation.
- 4) Differences between the researchers' and writers' points of view are viewed as strengths, not weaknesses. It is through embracing differences that new understanding can evolve.

Duoethnography, conducted through a series of conversations between the mother and father of an adult with HFAC, was used to explore how the parents personally interpreted and experienced their own well-being as well as the well-being of their adult child. In addition to valuable information collected from a second-person point of view, a third-person perspective of well-being was employed for their son. Valuable understanding was uncovered relating to the

parents' personal understanding and experiences regarding well-being, and the extent to which this understanding influenced how they interpreted the well-being of their son.

**Phenomenology.** The intent of a qualitative phenomenological study is to describe the lived experience of a phenomenon. Participants can intimate their lived phenomenal experiences in many ways, including interviews, self-reports, or aesthetic expressions. Regardless of the method, the researcher must work to ensure that the responses are genuine. As such, the researcher does not suggest or direct descriptions in any way. Participants are encouraged to give full stream of consciousness descriptions of their thoughts, images, sensations, and memories in order to provide as detailed a presentation as possible (Groenewald, 2004).

In phenomenological research the method of data analysis must follow the nature of the data itself, maintaining focus on understanding the meaning of the description. Themes should be identified which convey the essential aspects of the phenomena in terms of similarities and differences that distinguish it from other phenomena. For this study, results were examined through both inter and intra-group comparisons. Two categories of themes were expected to emerge from this study: collective themes that occur across the group of participants, and individual themes that are unique to an individual or to a subgroup within the larger collective of participants.

The method for phenomenological study in this study was that of the interview, however the process is more complex than the term suggests. In this process, it is important to “bring the subject to the point where he describes what he really does, and not what he thinks or imagines he does” (Varela & Shear, 1999, p. 46). This explicatory interview unfolds through a process in which the researcher brings the participant to the point of reliving the experience being explored,

guides the participant to engage in a “thinking through” of the experience, and enables him to use words to clarify and represent the experience.

**Narrative inquiry and analysis.** Narrative inquiry is the study of experience understood in narrative terms, with *narrative* being the study of the way humans experience the world (Connely & Clandinin, 1990). This approach is different from phenomenology in that phenomenology studies an issue through descriptions provided by participants concerning a given topic. Narrative inquiry puts less focus on the topic directly, and instead emphasizes the subjective experiences of the participant.

One educational theory holds that humans are storytelling organisms who, individually and socially, lead storied lives (Clandinin & Huber, 2010). People by nature live lives full of stories, which hold valuable information. It is the role of the narrative researcher to describe such lives, collect and tell their stories, and write narratives of the experience. The particular form of narrative inquiry employed in this study is that of autobiographical writing.

In this study, narrative analysis is employed as a method of making sense of the themes identified by UR, UL, and LR methods of inquiry. This form of analysis views narratives as social products produced by people in the context of specific social, historical and cultural circumstances. The process lends itself more to a social constructionist approach than that of a positivist approach. Narratives are looked upon as devices through which people represent themselves and their world, both to themselves and to others (Lawler, 2002).

The focus of this narrative analysis was built upon the researcher’s personal responses to the study’s themes as she has seen them represented within the Alberta schools where she has been employed as a learning support teacher. Throughout her work on this study, stories that had accumulated over many years of teaching emerged. These stories explore how concepts relating

## WELL-BEING IN ADULTS WITH HFAC

to well-being are addressed within our schools, and the analysis of these stories has culminated in a series of recommendations for improving how Alberta schools meet the needs of learners with HFAC. This narrative analysis is the focus of Chapter 6.

Cresswell (2007) describes narrative research as beginning with the experiences of individuals or cultures, which are then expressed in lived and told stories. Information gleaned from the stories of the study's participants are at times retold, or "restoried," by the researcher into a narrative chronology in order to provide the meaning of the experiences (Creswell, 2007). Ultimately, the narrative will combine views from the participants' lives with those of the researcher's life, forming a collaborative narrative.

### **3.4 Setting and Context of Study**

This study examined concepts of well-being from first, second and third-person perspectives. Well-being is an abstract construct that permeates through all settings and contexts of life. Given the fluidity of the subject of well-being, the setting for this study has dual meanings. The setting of the research collection itself will first be described, and then a broader and more inclusive statement regarding the setting of the research interest will be made.

**Setting for research collection.** Autism is defined by impairments relating to communication skills, social relationships, and restricted and repetitive patterns of behavior and interests. An increased susceptibility to anxiety disorders is associated with the condition. Research suggests that anxiety may be temporarily reduced by maintaining strict control over routines, schedules, and patterns of behavior. But implementing these rigid controls may in turn contribute to the limited flexibility common to the disorder. Each of these impairments bring challenges to traditional methods of understanding and collecting data in this research population.

## WELL-BEING IN ADULTS WITH HFAC

Irrespective of these potential limitations, the internet shines as a valuable method of collecting information about the research questions. People with autism can maximize their social abilities online. The common language and interactions that take place in synchronous online communication serve the cognitive needs of many people on the spectrum. Where humor or sarcasm may be confusing in face-to face interaction, use of common emoticons and internet jargon can explicitly convey the intentions of the writer (Kidney, 2012). The use of non-verbal communication is eliminated and the field is leveled to the benefit of people with HFAC. It is observed that delayed response is considered appropriate in order to give any individual time to read, understand, and formulate a response. This breathing space is a luxury that many people with HFAC do not have during face-to face interaction, and can serve to alleviate stress, creating an environment more conducive to introspection—an environment that can mediate communication challenges.

For this reason, the research setting in which data was collected from participants representing views from the UL and UR quadrants occurred in a digital setting. Participants dialogued with the researcher regularly through email interviews and conversations that extended anywhere between a week and six weeks. Pace was determined by participants.

There were a few notable exceptions to the information contributed through email. Two participants requested follow-up phone conversations to supplement email exchanges. In one instance, the participant described severe learning challenges that impaired her ability to express herself in writing. In fact, it was the participant had sought assistance from a colleague to record responses to the AQ and PWBS questions and to scribe her responses in email exchanges. Another participant, who provided very detailed and elaborate descriptions of her perceptions through email exchanges, requested telephone follow-ups because she was concerned with her

## WELL-BEING IN ADULTS WITH HFAC

ability to stay on topic without direct verbal cues from the person she was conversing with. Phone conversations were recorded and transcribed. A third participant supplemented the information he provided by allowing the researcher to access his personal electronic journals, in which he had recorded his experiences over many years.

Information from the LL quadrant, collected through duoethnographic conversation, was gathered in settings where the participants could discuss their views on the topic in privacy and comfort. Each conversation was recorded for later transcription and analysis.

**Setting of research interest.** Well-being is a complex, and often times messy, topic for research. It lacks clear and concrete attributes that a positivist approach for study might enjoy. The PWBS provides a somewhat defined structure for investigating well-being, but the topic itself cannot be understood from a limited perspective of a given place and time. Well-being should not be examined as occurring in one moment, or as being contained within the parameter of one location or experience. The concept of well-being is messy because it bleeds out from and into different times, places and ways of being and knowing. Early experiences carry forward to influence our understanding of well-being.

A challenge to acquiring information on the topic of study was finding a way to give enough structure so that participants could understand what information was being sought, but to collect that information in a manner that did not lead, limit, or define the concept itself. Interview questions were developed with this challenge in mind, and are included in Appendix I. The initial question proposed a structure for, or definition of, well-being. Participants were asked if they agreed or not, and asked to elaborate. This provided a starting point for defining the topic, but allowed the individual to reshape the question to reflect her own experience and understanding. Questions were included that required participants to reflect on both early

## WELL-BEING IN ADULTS WITH HFAC

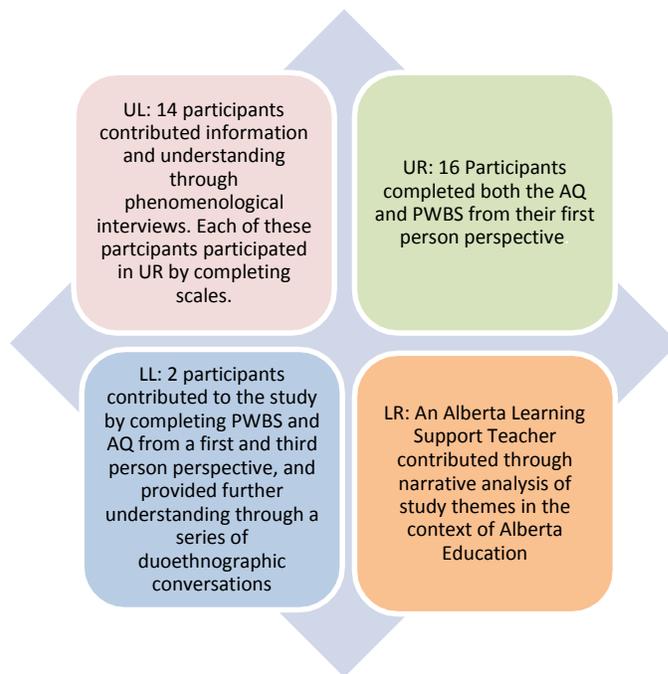
experiences that might have contributed to the shaping of their current experiences and understandings of the topic, as well as questions that encouraged them to think of how the topic might be experienced in their future.

The setting of the research interest is then extended beyond the confines of precise time and location. Well-being is not a concrete thing to be studied, but an experience to be understood. While our research setting is concretely defined by the time and place in which the data were collected, the topic itself is cumulative. Well-being is unique for each individual, and extends beyond the time and place of the setting itself.

### **3.5 Research Population**

This research proposal, based on IMP, employs multiple perspectives and methods for gathering information. A total of 18 participants contributed to this study, with all of them completing AQs and PWBS for the UR quadrant. The upper quadrants gathered information from individuals exhibiting HFAC. The researcher contributed understanding from her perspective as a learning support teacher in the LR quadrant. Further detail regarding the participant group is described below in Figure 5.

## WELL-BEING IN ADULTS WITH HFAC



*Figure 5. Participants involved in research method by quadrant.*

**Participants with HFAC.** All participants in this study were Canadian, with the majority currently residing in Alberta. Ten males and six females with HFAC, between the ages of 19 and 58, participated in the study. Aside from exhibiting HFAC, the individuals comprising this group represented a diverse range of demographics. Of the 16 participants, eight had received a formal Autism Spectrum Disorder diagnosis. All participants had an AQ score of over 26.

Two were unemployed, while some individuals described themselves as underemployed and others as successfully employed, self-employed, or being near or at the top of their professional careers. Eight participants were pursuing or had completed some form of post-secondary education, with accomplishments ranging from diploma to post-doctoral degrees.

Four participants were involved in a relationship with a significant other; three of these participants were female. Three individuals had a child or children. Of the three participants with children, each had at least one child identified as being on the autism spectrum.

## WELL-BEING IN ADULTS WITH HFAC

**Duoethnography participants.** The mother and father of an adult with HFAC—both 46 years old at the time of conversation—provided information relating to well-being and HFAC. Both are residents of Alberta and have completed post-secondary education. Each is professionally employed. In addition to sharing thoughts and experiences relating to their own personal well-being, they also discussed their perceptions of the well-being of their adult child with HFAC. As such, their adult child became an indirect focus of the study as a subject. Their child was 22 years old at the time of their conversations. He had obtained a post-secondary degree and was employed in his field of study. He resided at home with his parents.

**Narrative analysis participant.** Narrative analysis was contributed by the researcher, and reflected her personal experiences in Alberta schools as a learning support teacher working with students with HFAC. She was employed full time as a learning support teacher in a middle school. She had worked with children with HFAC, aged between preschool and grade 12 in seven different Alberta schools in five different Alberta school divisions. She will celebrate 25 years of working as an educator in the 2016/17 school year.

### 3.6 Methodology and Research Questions

The ability to view the research problem from multiple dimensions enhances and enriches comprehension, engendering a more complete understanding of the problem. When planning for multi-method research, it is important to orient the project such that the most essential and relevant understandings are collected. Each specific question in the research proposal was matched to the best possible method for researching it. This section connects each research method with the specific research question it is meant to serve.

**The autism quotient questionnaire (AQ).** The AQ Questionnaire was used to answer the research question, “What is the nature and extent of high functioning autism characteristics

## WELL-BEING IN ADULTS WITH HFAC

identified and described by study participants?” Each participant with HFAC completed the AQ questionnaire about themselves at the beginning of the study. Results from these questionnaires were collected and evaluated to identify the autistic characteristics of both individual participants and the participant group in general.

**The psychological well-being scales (PWBS).** The Ryff Scales were used to gain understanding relating to the question, “What themes emerged as being important to well-being for people with HFAC, and how do these themes compare to themes of well-being in people who do not have HFAC?” A subjective measure of the well-being of participants exhibiting HFAC was gathered by having each participant complete a self-assessment using these scales.

**Duoethnography.** This research method was applied to gather different perspectives on how well-being is experienced by people with HFAC. Insight was sought regarding how individual characteristics of autism contribute to the experience of well-being. Additional insight was gained regarding the ways in which personal understandings and experiences of well-being influence the ability to understand well-being in other people.

**Phenomenology.** Phenomenological interviews provided insight regarding how well-being is perceived and experienced in the lives of people who have HFAC. In addition to revealing important themes relating to the topic, these interviews provided insight into the interaction between characteristics of autism and perceptions and experiences of well-being. This methodology contributed data towards answering research questions three and four: How do specific autism traits influence well-being? and How do well-being themes for people with HFAC compare to those without?

**Narrative analysis.** Narrative analysis was employed to provide insight into the connections between the study themes and future educational direction in Alberta, specifically its ability to meet the needs of learners with HFAC, which was research question number six. This analysis followed the rules of narrative inquiry, but was used to take an inside (lower right quadrant) perspective for understanding themes that emerged from the scales, phenomenology and duoethnographic conversation.

**Researcher's IMP Position.** Data do not assume meaning until they have been analyzed and interpreted. Analysis and interpretation cannot be objective, no matter the safeguards applied to promote reliability. The whole process rests on the filters and lenses used by the researcher. It is therefore worth describing the integral address inhabited by the researcher.

The primary locations that the researcher worked from is situated in the UL quadrant, zone two and the UR quadrant, zone six – from the outside looking in. Her comfort zone favors a positivist approach to problem solving because it posits a simpler, cleaner and more concrete way of answering questions. However, the researcher is also aware of the limitations of such an approach. She has a strong predisposition towards inhabiting zone one in the UL quadrant, a position that once manifested with a tendency towards absolute relativism. Aware of the challenges inherent in such a position, she consciously focused on balancing it with zones two and six. She is working towards developing skills and traits that will allow her to move between quadrants and zones as required towards more complete understanding of phenomena.

### **3.7 Methods and Procedures**

A multi-method design was chosen for this study in order to utilize both qualitative and quantitative methods for answering research questions. This approach was conducive to understanding complexities, and allowed for the pursuit of both confirmatory and exploratory questions at the same time. It offered the ability to both construct and confirm theory in the same

## WELL-BEING IN ADULTS WITH HFAC

study, providing explanations to seemingly contrary results emerging from different research methods (Creswell, Clark, Gutmann, & Hanson, 2003).

Some features from design-based research (McKenney & Reeves, 2012) were also incorporated into the methodological design of this study, including the collaboration between researcher and participants in a natural setting, the iterative nature of the research, and being responsively grounded. Flexibility imbedded in the design plan was utilized.

Study revisions included:

- 1) Participants in the duoethnography were asked to complete AQ questionnaires if their personal PWBS shared more similarity to the PWBS results of participants with HFAC than a control group from another study. It was necessary to investigate whether the parents themselves exhibited traits common to high functioning autism characteristics.
- 2) At times, details in personal email conversations with some participants with HFAC needed to be directed back to the information provided by the AQs or PWBS in order to provide deeper insight and understanding.

**Flexible communication between quadrants for data collection and analysis.** Wilber describes the interaction of perspectives from the quadrants as simultaneous “tetra-arising.” However, in conducting the research, this interaction was pragmatically reflected as a “cycling” from one quadrant to the next, as the information from one informed inquiry in the next quadrant.

Each research method represented a quadratic cycle in data collection. Occasionally, as new understanding emerged, it was necessary to revisit a previous cycle. Cycles were connected, emerging alongside and shaping one another. A diagram illustrating the connection between ontology, epistemology, methodology, and study design can be found in the appendix.

This connection between quadrants is illustrated clearly by the quadratic cycle involved in the collection of information in the LR quadrant through narrative analysis. From the beginning, it was anticipated that themes of well-being and HFAC would emerge that would have implications for education. An illustration representing this quadratic cycling can be found in Appendix H.

### **3.8 Methods for Data Analysis and Synthesis**

The challenge in data collection and analysis for any multi-method research rests in making sense of large amounts of data, reducing the volume of information, identifying significant patterns, and constructing a framework. To increase organizational efficiency and to benefit from the flexible nature of this research design, data collection and first-level data analysis occurred simultaneously. This resulted in a more focused questioning approach and an easy clarification of answers, which reduced the risk of repetitious, unfocused, and overwhelming data (Merriam, 2009).

## WELL-BEING IN ADULTS WITH HFAC

All data, including transcriptions of interviews, conversation transcripts, raw data from scales and questionnaires, as well as notes for narrative inquiry, were kept for future reference and to serve as a safety measure for checking data.

Participants were recruited over a four-month period of time, with each participant beginning at a different time. Not all participants had been recruited when the study began. At any given point during that four-month time span, between one and four participants would be engaging with the researcher to answer questions and provide insight relating to the research topic.

Results from participant-completed AQs and PWBS were assessed and calculated quickly after each participant completed the assessments. Information regarding the individual's autism characteristics and self-assessment of well-being were recorded on an excel spread-sheet. Interview questions were then enhanced with questions to reflect the individual nature of each participant's results. Email interviews and conversations began soon after their completion of scales.

Results from email conversations and transcriptions were kept until the end of the data collection cycle, when they were transferred into NVIVO for coding. Each participant's comments were read and identified according to the theme or themes they represented. NVIVO was a valuable tool because it clearly displayed the number of times participants commented on each theme. After the data collection cycle was completed, analysis could commence regarding how the information contributed to the UL, UR and LL quadrant's research method. A method for identifying and organizing important themes emerging from each quadrant was devised, as described in Chapter 5. This process contributed to a more integrated and clearer understanding of the bigger picture.

### **3.9 Ethical Considerations**

This study was approved by the Conjoint Faculties Research Ethics Board, in accordance with the University of Calgary's guidelines and *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2010*. A copy of the ethics certification is included in Appendix A.

In any research study, ethical issues relating to the protection of subjects and participants is a primary concern. Participation in this study was voluntary and participants were informed about the purpose of the study and the way in which the information would be handled. Safeguards to ensure the protection and rights of the participants were taken.

Informed consent is important and was described at the beginning of and throughout the study. Information was provided through email, with follow up conversations via telephone calls if participants wanted further information or clarification. Written consent to proceed with the study was received from each participant at the beginning of the study, and it was made clear that volunteers could withdraw from the study at any point.

Participant rights and interests were considered of primary importance when making choices about reporting and disseminating data. Names and other significant identity characteristics of participants remain confidential. Measures were taken to secure the storage of research-related records and data, with nobody other than the researcher having access to this material.

### **3.10 Delimitations**

Decisions were made throughout the design process of this research plan that clearly defined the boundaries for this work. This was necessary to ensure that the goals identified in the

## WELL-BEING IN ADULTS WITH HFAC

research problem would not become too large to manage and complete. These delimitations were strongly related to the methodological theory and the research questions.

Understanding should be inclusive and open, but this condition can quickly become a challenge of scale. How deep should we dig? How many perspectives should we strive toward knowing? There is no easy answer for these questions, and a good rule is generally *the more the better*. The design for this research worked to embrace different perspectives within the scope of the research, but it was necessary to define boundaries to fit the research within the scope of a doctoral thesis.

Two main delimitations were identified. A choice was made to use the first element of the Integral model only, which comprises the quadrants and the multiple methodological pluralism. As explained above, this was a decision motivated by pragmatics. Data emerged from the study that could support a more detailed integral analysis of high functioning autism and well-being. Incorporating the lines, levels, types and states that comprise Wilber's AQAL map would have enhanced the understanding of the topic, but would have broadened the scope of the study beyond that of a doctoral thesis.

The other choice was to focus analysis only on the data/information that was available, even if other or additional analytical methods became available. Examples of this delimitation emerged in two different instances. The first was when data from the AQs and PWBS did not indicate any connection between communication and social skills and satisfaction with personal relationships. The second was when it became apparent that participants AQ scores, beyond the clinically significant level identified for study, did not seem directly connected with PWBS. Participants with higher scores did not evaluate their well-being as necessarily being better or worse than people with lower scores.

### **3.11 Limitations**

The study's issues of limitation and trustworthiness are described below, as they are part of the standard academic treatise. When viewed through an integral lens, however, it is worth noting that both of these sections are reminiscent of a perspective firmly rooted in the UR sensibility. Every other quadrant recognizes and respects that knowledge obtained from its methodologies is partial. By contrast, the UR quadrant strives to present its truths as being complete and independent, which requires the articulation of limitations and issues of trustworthiness to explain possible discrepancies in results.

So, following the above disclosure, the UR sensibility is presently assumed and used to examine limitations and trustworthiness. This study contains certain limiting conditions, some of which are common to the critiques of multi-method research in general, while others are inherent to the topic of study. Careful thought was given to ways of accounting for these limitations and minimizing their impact.

Relying on the subjective data provided by a relatively small group of participants offers the ability to uncover deeper, richer levels of understanding relating to concepts of well-being. However, the nature of the size and scope of this study limits the ability to make generalized assertions regarding the larger group of people with high functioning autistic characteristics. Rather, it is hoped that the insight derived from this study be viewed as a "snapshot" of well-being in the autistic population, and that this glimpse into their well-being can be used as a step forward for future studies that may continue to illuminate understanding relating to the topic.

Participants who responded to invitations to participate in this research included more females than would normally be expected, while only a quarter of people diagnosed were female. While the group represents impressive diversity, as a whole they demonstrated a level of

## WELL-BEING IN ADULTS WITH HFAC

introspection and communication skills that might not normally be expected in people with characteristics of high functioning autism. It is possible that the type of individual this study attracted as participants may not be a normal representation of the group as a whole.

The AQ and PWBS are qualitative assessment tools used in this study. However, these instruments were not always used in their intended manner. In addition to the procurement of quantifiable data, each instrument was used as a springboard for entering into deeper exchanges modeled on phenomenology and duoethnography. These instruments were developed and referenced for use in self-assessment. For one part of this study (the LL), the parents of the adult with HFAC completed both the AQ and the PWBS on behalf of their adult child, representing a third-person perspective of his autism characteristics and well-being. This information was used to initiate and enhance the conversations between the participants on the topic, with reliability and validity measures not being mitigating factors for this part of the study.

Among the most significant limitations of this study is the nature of the autistic characteristics that participants exhibit. Autism is defined by challenges relating to communication, social relationships, theory of mind, introspection, and repetitive and restricted behaviors and thought patterns. The fact that there has been no study addressing well-being in autistic adults themselves is not so surprising when considering that the challenges of collecting subjective data are amplified by the nature of autism.

These limitations were addressed in two ways. The group of participants exhibiting high functioning autistic characteristics participated in the study primarily through electronic media. This was intended to reduce anxiety experienced through person-to-person contact. It allowed for shorter, more frequent and less formal means of communication so that the researcher could tailor questions and discussion to the needs of the participants. Participants chose when they

wanted to connect and share information, which allowed them autonomy and flexibility. In addition, language challenges were mediated because the medium embraced straight-forward and explicit language while eliminating non-verbal receptive communication skills.

### **3.12 Trustworthiness**

While empirical studies have traditionally been derived from either quantitative or qualitative methods, there has more recently been a call to triangulate methods to suit the needs of the research questions being addressed (Eriksson & Kovalainen, 2008). Multi-method research shines with potential to combine the benefits of both paradigms; however, it is marred by the challenge of avoiding the pitfalls of each. This concern is especially relevant when considering the issue of trustworthiness in research.

Trustworthiness refers to the efforts of the research to address issues of validity (the degree to which something measures what it purports to measure) and reliability (the consistency with which it measures over time). Credibility relates directly to validity, and dependability is synonymous with reliability (Bloomberg & Volpe, 2012).

Measures were taken to ensure that information derived from quantitative and qualitative designs worked cohesively and in accordance with the research questions (Ihantola & Kihn, 2011). The research design was chosen with the intention of selecting methods that supported the gathering and understanding of data relating to the well-being of people with high functioning autistic characteristics. A balanced approach was developed with the intent of minimizing the weaknesses inherent to specific methods by integrating them with the strengths inherent to other methods. For example, completion of scales or a phenomenological study of well-being alone can each provide valuable and reliable data, but using the methods to complement each other facilitates an exploration of the topic that holds potential for deeper and richer understanding.

## WELL-BEING IN ADULTS WITH HFAC

Measures were also taken in the design process to encompass a more faithful representation of the insider and outsider views of the topic (Ihantola & Kihn, 2011). Information is taken from the perspective of people with high functioning autistic characteristics and from the perspective of a learning support teacher in Alberta. Outside views on the topic were collected through a detailed literature review, the AQ and the PWBS, and through duoethnographic conversation. The researcher had an informed knowledge of earlier studies and theories connected to the topic, which, in combination with her personal experiences, allowed for the integration of inside and outside perspectives.

### **3.13 Chapter Summary**

In summary, this chapter provided a detailed description of the study's proposed research methodology. Multi-method methodology was employed in the design of the study to explore well-being in people with high functioning autistic characteristics. The data gathered from this undertaking should prove useful towards understanding how Alberta's education system might move forward to meet the needs of this growing population of learners. The participant sample, comprised of 18 purposefully selected individuals, was described. Four cycles of research were described, which implemented diverse data collection methods including scales, questionnaires, interviews, conversations, and narrative analysis. Methods for data analysis and synthesis were described. The chapter concluded with an examination of the potential limitations in this study, ethical issues, and a reflection on issues of trustworthiness.

## **Chapter 4: Findings by Method**

### **4.1 Introduction**

Mixed-method research focuses on collecting, analyzing and mixing quantitative and qualitative data in a single study (Creswell, 2007). Integral Methodological Pluralism (IMP) was chosen as methodology and guided the selection of particular research methods for this study. This chapter will begin by reviewing the IMP model and describing the research methods that represented each of the four quadrants. After gathering the data, the results from each method of study used in this research were presented by quadrant. Later in the chapter, the process of selecting primary and integral themes for further analysis is described, and then the themes will be presented. The chapter concludes with a summary of the significance of primary and integral themes.

### **4.2 IMP and Methods for Study**

IMP was selected as methodology in order to allow a richer and more comprehensive means of understanding the research problem than any one method by itself. As initially described in Chapter 1, Wilber's quadrants were used to promote awareness of and inquiry into the unique way in which the individual and the collective arise together. A visual representation showing the alignment of research method with its purpose and quadrant is provided in Table 3 below.

Baron-Cohen's Autism Quotient (AQ) Questionnaire and Ryff's Psychological Well-Being Scales (PWBS) were employed in the UR quadrant as tools to establish a quantitative perspective based on the participants' assessment of their own autism characteristics and personal well-being. This understanding was enhanced by a UL quadrant perspective, represented by phenomenology, using interview questions through an electronic medium.

## WELL-BEING IN ADULTS WITH HFAC

The LL quadrant perspective was represented through a series of duo-ethnographic conversations between the mother and father of an adult with HFAC, during which they discussed their own thoughts and experiences relating to well-being as well as thoughts and observations regarding their son's well-being. Finally, the LR quadrant was addressed through an analysis of study themes in the context of Alberta schools. The researcher, a special education teacher with 24 years of professional experience relating to the topic in seven different Alberta schools, provided an analysis of the themes from inside the education system.

The results summarized in this chapter will follow Wilber's quadrants in a counter clockwise direction, beginning with the UR quadrant. This chapter will conclude with an explanation and description of how the findings were pulled together and organized for deeper analysis.

Table 3.

*Alignment of research method by quadrant and purpose*

	<b>INTERIOR</b>	<b>EXTERIOR</b>
	<i>What meaning is being made?</i> <i>Interpretive</i>	<i>What is happening here?</i> <i>Descriptive</i>
<b>INDIVIDUAL</b>	Subjective	Objective
	Phenomenology	Autism Quotient (AQ) and Psychological Well-Being Scales (PWBS)
<b>COLLECTIVE</b>	Inter-subjective	Inter-Objective (Systems)
	Duo-Ethnographic Conversations	Narrative Analysis

### 4.3 UR Findings: Results from the AQ and PWBS

Sixteen participants with HFAC completed the Autism Quotient Questionnaire and the Psychological Well-Being Scales at the beginning of the study. Three participants were wary of completing the questionnaires, feeling that these tools might engender a shallow and unreliable description of their experience. One participant reported that the questionnaires represented previous negative experiences she had endured throughout the diagnosis process. Nevertheless, each participant agreed to participate in this part of the research, assured that they would have the opportunity to discuss their experiences and perceptions through email interviews.

The individual participants' AQ scores, which measured the extent of their own autism characteristics, and their subjective assessments of well-being, quantified using PWBS, were calculated and graphed. Individual results were used to provide mean scores for the total group, which were correlated with both the five categories in the autistic phenotype and the six dimensions of well-being. These are represented in Figures 6 and 7.

**Autism quotient (AQ) scores.** Scores of 26 or above were set as the criteria for establishing characteristics of high functioning autism. Total scores ranged between 26 and 44. Each category of the phenotype was measured on a scale of one through ten, with higher scores indicating more significant characteristics of that particular autism trait. As a group, the participants in the study described their most severe autism characteristics as relating to the ability to shift their attention. Their second most severe characteristics involved challenges relating to social skills. Participants in this study identified imagination as the least impaired trait of the five subscales of the Autism Quotient. This finding is consistent with other studies that have identified difficulties involving attention shifting as being the most significant challenge, and imagination as being the least. This study's participants indicated social skills as being more

## WELL-BEING IN ADULTS WITH HFAC

of an issue than communication, which is the reverse of what other studies have suggested (Broadbent, Galic, & Stakes, 2013). It is important to note that all scores, regardless of relative highs and lows, were clinically significant.

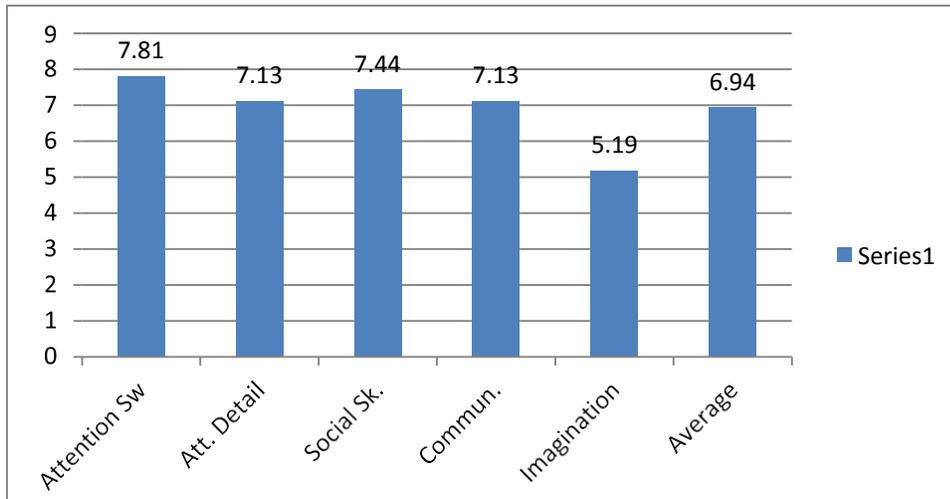


Figure 6. Total participant mean autism quotient (AQ) scores.

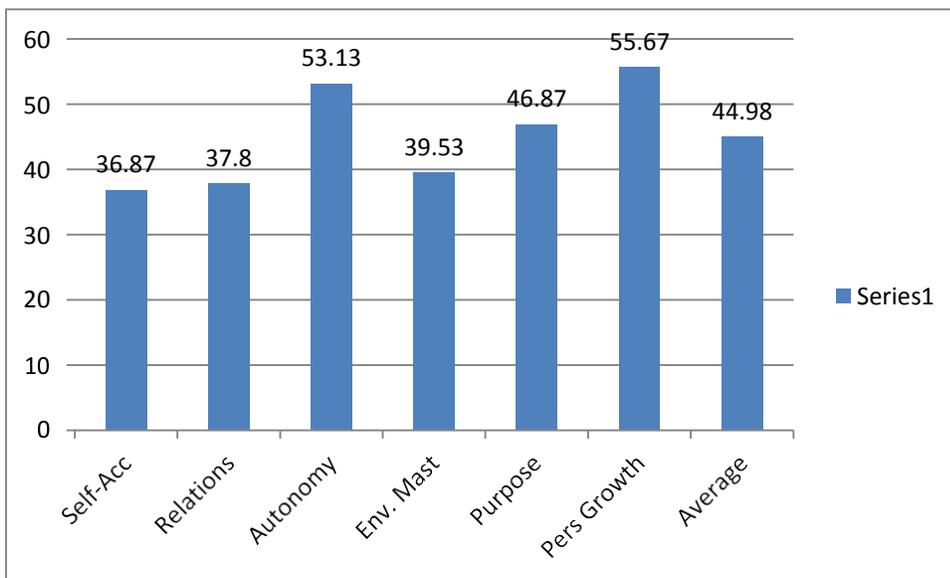


Figure 7. Total participant mean psychological well-being scale scores.

**Psychological well-being (PWBS) scores.** PWBS are not designed to provide a cut-off score for good or bad well-being. The focus is on balance, with higher scores representing relative strengths and lower scores pointing to areas of dissatisfaction or deficit in the

## WELL-BEING IN ADULTS WITH HFAC

individual's overall profile. These results are subjective and vary according to the nature of the individuals and groups completing it. There was far greater discrepancy between dimensions in this study than in other studies. For example, the discrepancy between high and low dimensions in this study is a full 18.80 raw points, compared to a control group in a study of 243 adults, which showed a discrepancy of 7.20 between dimensions in raw scores (Mahmoudzadeh, Mohameadhani, Dolatshani, & Moradi, 2015).

**Relative well-being strengths.** As a group, participants clearly identified personal growth as their single top asset (53%), followed by autonomy (33%) and purpose in life (7%). An interesting shift occurs when we looked at participants' top two identified assets. While the rank order remained the same, the percentage changed dramatically. Personal Growth remained the top asset at 39%, followed closely by autonomy at 36%, with purpose in life more than doubling its performance in the single top asset category at 16%.

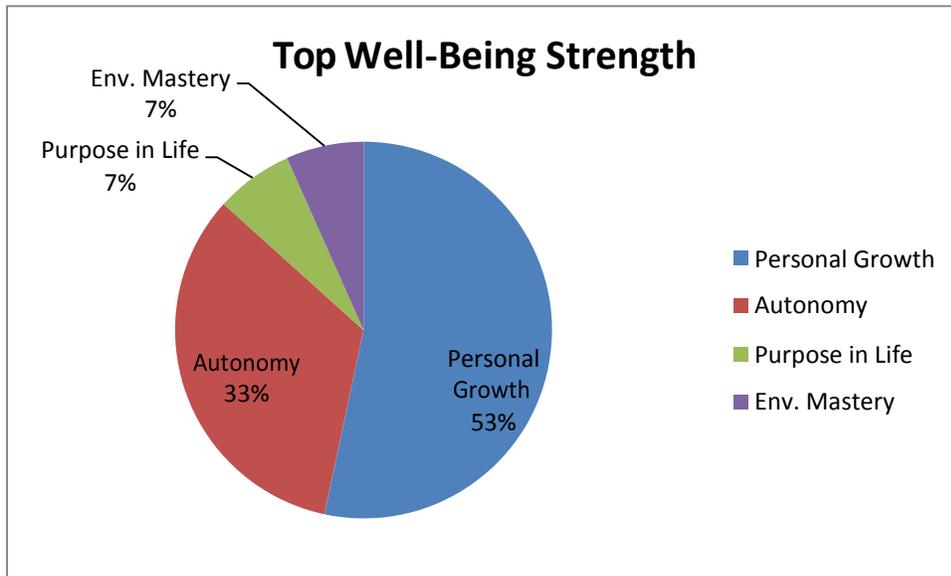


Figure 8. Participants identifying their strongest well-being asset.

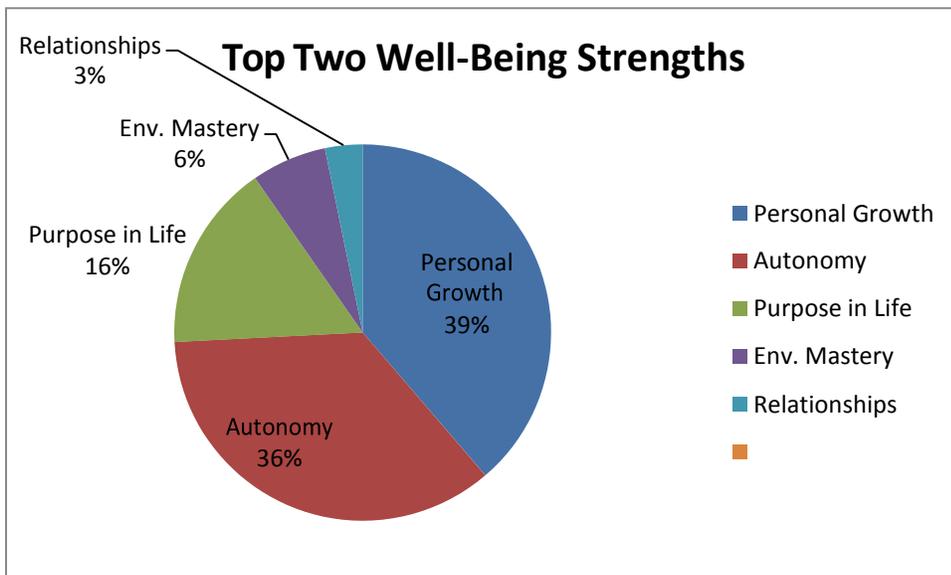


Figure 9. Participants identifying their top two well-being assets.

**Relative well-being challenges.** When participants were asked to cite their single greatest challenge to well-being, relationships were clearly the biggest concern, as reported by 43% of participants. Self-acceptance followed at 29%, with autonomy and environmental mastery tying at 14%. While the differences between the top and top-two well-being strengths

## WELL-BEING IN ADULTS WITH HFAC

were worth noting, the differences between the top and top two well-being challenges were even more significant. Relationships fell from the most significant challenge to well-being (29%), being replaced by self-acceptance (39%). Environmental mastery as a challenge ranked higher, at 18%. The emphasis the participants placed on challenges involving self-acceptance was clearly reflected and supported by the other two methods of research in this study.

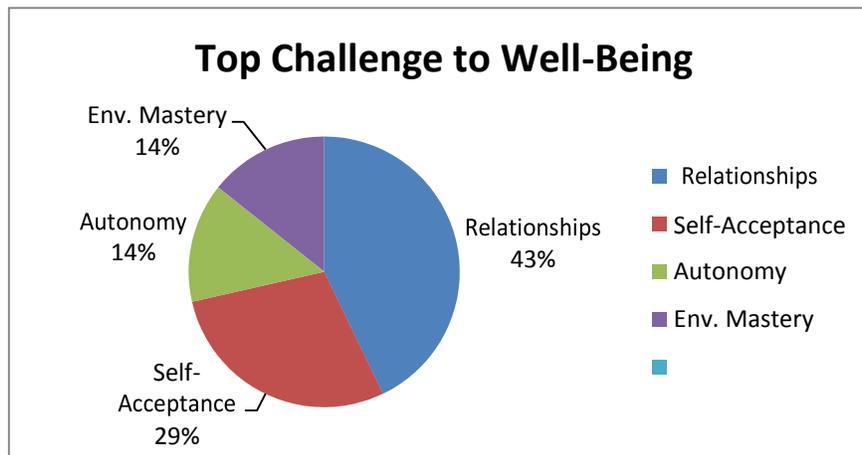


Figure 10. Dimensions identified as the most significant challenges to well-being.

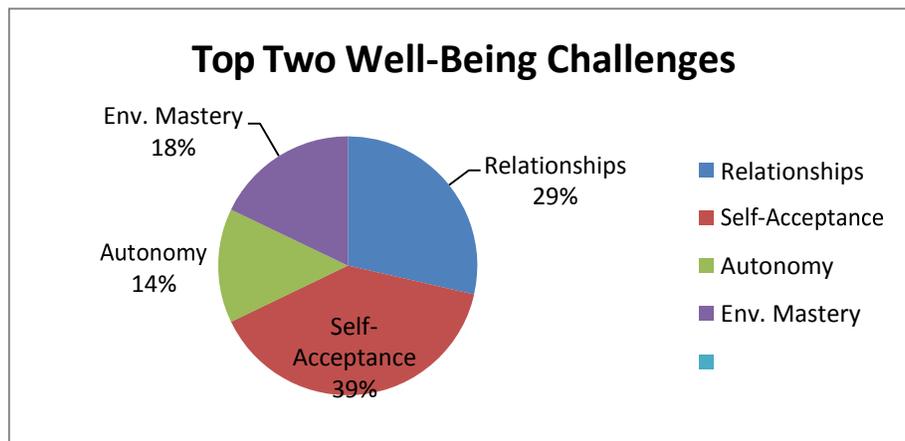


Figure 11. Dimensions identified as being in the top two of participants' most significant challenges to well-being.

**Connecting characteristics of high functioning autism with subjective well-being.** To identify potential connections between the degree of one’s autism characteristics and her subjective dimensions of well-being, each individual’s data was examined to identify strengths and weaknesses on both rating scales. Relative strengths were rated as “+” and relative challenges were rated as “-”. Each participant’s identified strengths and challenges were plotted on a table with the *x*-axis representing well-being dimensions and the *y*-axis showing autism characteristics. Possible correlations were identified when all participants’ strengths and challenges were plotted, seen in Figure 12. Cells colored red indicate a strong pattern of relationship. Cells colored and bolded in red indicate a definite pattern of relationship between the autism characteristic and well-being dimension. These relationships are summarized in Table 4.

	Self-Acc		Relations		Autonomy		Env Mast		Purp		Pers Growth		
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	(-,-)(-,-)		(-,-)(+,-)		(+,-)		(+,-)				(-,-)		
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Figure 12. Comparing autism characteristics with dimensions of well-being.

## WELL-BEING IN ADULTS WITH HFAC

Table 4.

*Summary of relationship between individual HFACs and dimensions of PWBS.*

<b>Autism Characteristic (as identified by the AQ)</b>	<b>Well-Being Dimensions (as identified by the PWBS)</b>
Poor Attention Shifting Skills	Poor Self-acceptance Poor Environmental Mastery Strong Autonomy Strong Personal Growth
Poor Attention to Detail	Poor Relationships Strong Purpose in Life
Poor Social Skills	Poor Self-Acceptance Strong Purpose in Life
Strong Communication Skills	Strong Purpose in Life
Strong Imagination Skills	Poor Self-Acceptance Stronger Autonomy Stronger Purpose in Life

In this case, what the scales show is of equal interest as what they do *not* show. There was no apparent connection between participant satisfaction with personal relationships and either communication skills or social skills. The researcher does not purport that this data is conclusive, but that it offers a glimpse into possible connections between autism and well-being. It may be useful for pointing toward future research directions.

### **4.4 UL Findings: Results from Phenomenological Interviews**

Fourteen participants engaged in a series of email conversations, responding to interview questions regarding their perceptions of and experiences relating to well-being. Two participants did not participate in the email interviews. One reported that she wanted to participate, but the pressure was overwhelming and she was struggling with mental health issues. Another participant, enthusiastic to complete the scales and questionnaires, failed to respond to a series of requests to do so. Two participants provided additional information to the email conversations through telephone calls.

Email exchanges were reviewed statement by statement, with themes being identified and coded using NVIVO. Table 5 identifies these themes and summarizes the number of participants

## WELL-BEING IN ADULTS WITH HFAC

that referred to each theme throughout the interview process. Primary themes will be elaborated on in Chapter 5.

Table 5. *Participants making reference to themes in interviews (n=14).*

# of Participants Making Reference to Theme	
Self-acceptance	14
Communication	14
Relationships	14
Perceptions of Me	14
Self-Awareness	13
Autism Assets	13
Prev. Shaping Exp	12
Goals/Purpose	12
Mental Health	12
Advocacy	12
Parental/Family	11
Educational System	11
Social Expect.	11
Work	11
Physiological	10
Bullying/Abuse	10
Diagnosis	10
Passion/Interests	9
Significant Other	9
Sensory	7
Social System	6
Resilience	5
Mimic/Mask	5

### 4.5 LL Findings: Results from Duo-Ethnographic Conversation

Conversations between the parents of an adult with HFAC were recorded over a period of six weeks. They were transcribed and imported into NVIVO, where each statement was analyzed and coded by themes emerging from those conversations. Initially, each parent completed a

## WELL-BEING IN ADULTS WITH HFAC

PWBS for themselves and for their son. The results of each participant's PWBS were clearly reflected throughout their conversations and are summarized in Figures 13 and 14.

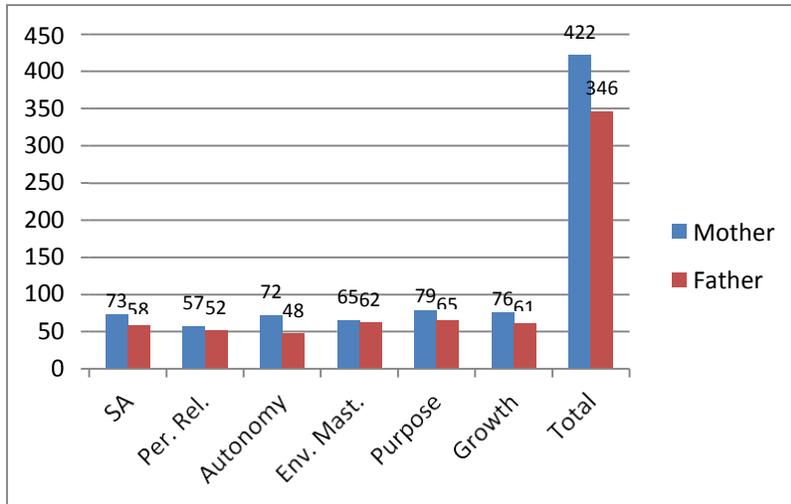


Figure 13. Results from parents' personal PWBS.

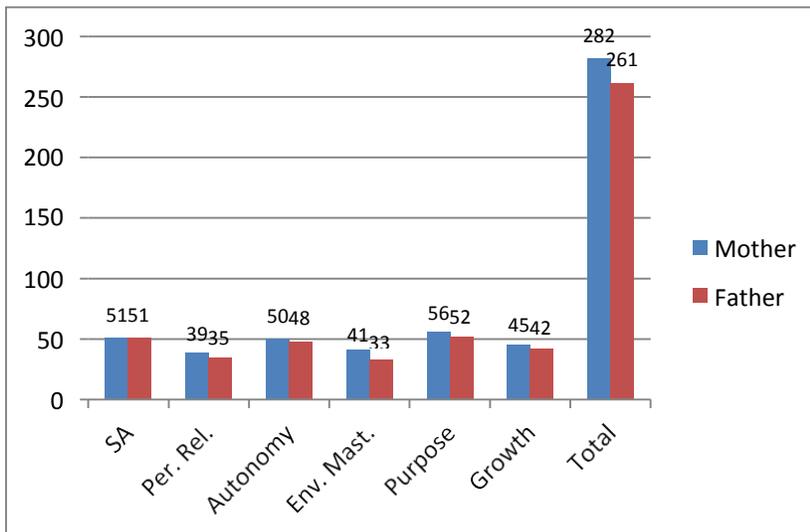


Figure 14. Results from parent completed PWBS on their adult child.

Both parents assessed their own dimensions of well-being as having an overall balance, with one notable exception for each. The mother showed a significantly weaker score regarding her weakest dimension, relationships, with a difference of 22 between that and her life purpose.

## WELL-BEING IN ADULTS WITH HFAC

The father rated his most significant concern as autonomy, with a discrepancy of 17 between this and his strongest dimension, life purpose.

The discrepancies described above, while less pervasive than those identified in the participants PWBS, were greater than what might normally be expected in the general population. Given autism's genetic link, it seemed fitting that each parent should complete an AQ questionnaire to ensure that they were not also exhibiting HFAC. Both parents, while scoring slightly higher than average, were well below the AQ cut-off score for this study.

According to the parents' responses in their third-person completion of the PWBS, they ranked their adult son's well-being in a similar order. They agreed that life purpose was the most important asset to his well-being, followed by self-acceptance, autonomy and then personal growth. Both also agreed that relationships and environmental mastery were roadblocks for his overall well-being, but the father ranked environmental mastery as the biggest challenge while the mother felt that relationships were the most significant challenge. Their assessment of their son's level of self-acceptance as a strength was in sharp contrast to the HFAC participants in this study, who cited self-acceptance as posing a challenge to their well-being. It is not certain whether this discrepancy amounts to an actual difference between the well-being of the subject and the other participants, or whether this difference is a result of the third-person assessment of the subject's well-being.

The conversations were rich and consisted of varying perspectives between the two parents. The themes identified as important to personal well-being, in order of the frequency they arose in conversation, from most to least, are indicated below in Table 6.

## WELL-BEING IN ADULTS WITH HFAC

Table 6.

*Themes emerging from parent conversations regarding their personal well-being*

Mother	Father
1. Goals and Achievement	1. Respect and Reciprocity in Relationships
2. Close Relationships	2. Happiness of Others
3. Purpose and Meaning in Life	3. Interests and Hobbies
4. Autonomy and Independence	4. Personal Happiness
5. Learning	5. Children

The conversations about their son and his well-being presented a range of themes that the parents agreed were important, indicated below by the frequency they were addressed in discussion:

1. Relationships
2. Empathy
3. Belonging
4. Communication
5. Happiness
6. Growth and Learning
7. Repetition and Routine
8. Autism Challenges and Limitations, Family, Interests & Hobbies, Emotional Maturity
9. Intelligence & Academics and Diagnosis

### 10. Purpose and Meaning

While there were many issues that both parents agreed upon as being important to their son's well-being, there were also some differences in their perspectives regarding their son's well-being. The father tended to focus far more on his son's limitations and interests and hobbies than the mother did. The mother emphasized the role of strengths, balance, awareness, and mental health as influencing her son's well-being. While both parents expressed concern for their son's well-being, the mother tended to take a more optimistic and proactive perspective, while the father was less positive about the state of his son's well-being, and was less confident in how to support his progress into the future.

These differences reflected the ways each parent perceived and experienced their own personal well-being. While the father emphasized the value of relationships and factors that facilitate, enhance, and detract from satisfaction in relationships, the mother put more emphasis on growth, achievement, learning and purpose. The father's lower assessment of his son's well-being can be explained by his personal values, and his belief in what makes a good life. Autism is characterized by deficits in relationships and challenges relating to patterns of thought and behavior—two areas that were described as being very important to the father's personal sense of well-being.

The mother's personal values for well-being were strongly connected to notions of achievement, growth and purpose. Her focus on these matters may provide some insight as to why she assessed her son's well-being more favorably than her husband, and why she is more optimistic regarding the development of his future well-being. The very characteristics of autism that can hinder the development of personal relationships and limit areas of interests can also enhance achievement when one's skills are focused in the right context. For example, her son's

## WELL-BEING IN ADULTS WITH HFAC

deficit in social relationships has encouraged him to focus on his academic achievement. His tendency towards routine patterns of thinking and behavior has also enhanced his work ethic and school performance. Characteristics of autism that can be viewed as deficits in one context may actually appear as strengths in another. Stereotypical characteristics of high functioning autism have contributed to significant growth and achievement for both individuals and society as a whole. The mother's personal leaning towards values that are associated with growth and achievement allow her to view autism as an asset, not just a challenge. In contrast, the father's personal values aligned more with the natural tendency to focus only on the challenges associated with common autism traits rather than the assets.

The conversations allowed both parties to see how their assessment of their son's well-being was a reflection of their own personal understandings and values associated with well-being. The mother was finally able to understand the father's lack of enthusiasm and acknowledgement of their son's high functioning autism condition earlier in his life. It was not that he didn't believe it or didn't care, but because the implications of his son's condition conflicted so much with his own values for well-being. He desperately "didn't want it to be true," for the sake of his son. The mother was equally concerned and upset about the added challenges her son would likely face, but, in accordance with her own values for well-being, she was able to position herself to see the challenge as something to be identified and overcome—something that she could "learn about and turn around." She believed that by "viewing them from a different perspective the challenges could be minimized, and the assets developed."

### **4.6 Identifying Themes for Deeper Analysis**

In total, the three methods employed in this study produced 23 themes, which were organized into four categories. These categories were developed using Wilber's quadrant model.

## WELL-BEING IN ADULTS WITH HFAC

Research methods were assigned to the quadrant they were selected to represent. Themes emerging from each method quadrant were plotted on another quadrant model located within that quadrant (see Figure 15). For each method of inquiry, themes were identified by the quadrant or quadrants they inhabited. Themes from each quadrant were then combined by level and are stated below.

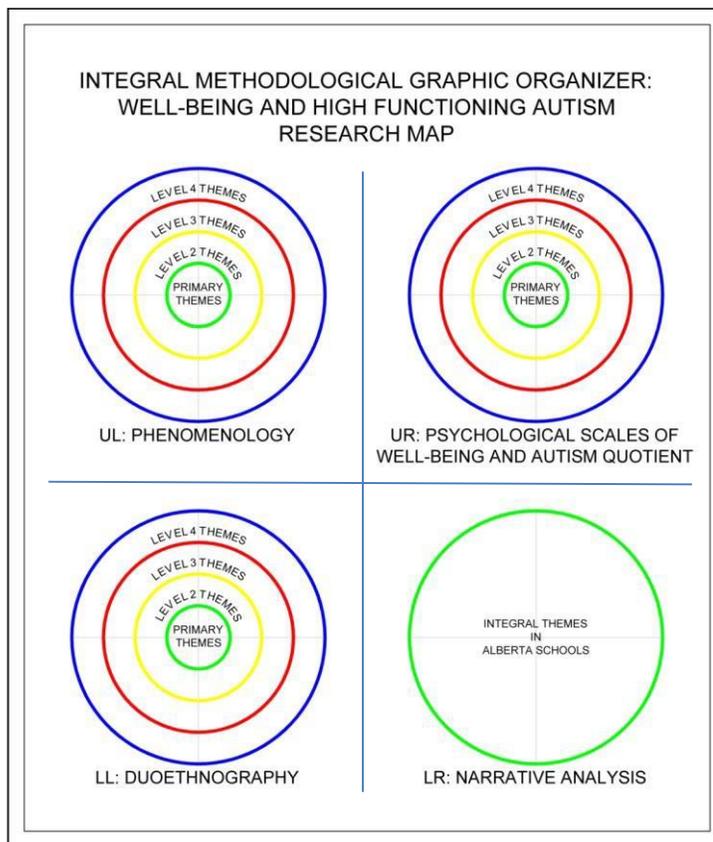


Figure 15. Template for identifying level of themes by research method.

**Primary themes.** To be included in this category, themes needed to either be situated in each of the four quadrants and/or be revealed by each of the three methods employed in the study. These themes were:

## WELL-BEING IN ADULTS WITH HFAC

### ***Level I Category.***

1. Personal Growth and Learning
2. Balance and Environmental
3. Awareness
4. Communication
5. Autism Assets
6. Relationships and Belonging
7. Advocacy
8. Bullying and Abuse
9. Diagnosis
10. Self-Acceptance
11. Autonomy
12. Mental Health

### ***Level II Category.*** (These themes connected in three of the quadrants):

13. Diagnosis
14. Mimicking and Masking

### ***Level III Category.*** (These themes touch in two quadrants):

15. Empathy and Understanding
16. Sensory and Physical
17. Work and School
18. Perceptions of Me
19. Social Expectations

*Level IV Category.* (These themes were specific to one quadrant):

20. Personal Happiness
21. Emotional Maturity
22. Work Environment
23. Systems (Educational, Medical and Social)

#### **4.7 Primary and Integral Themes**

Primary themes, selected for more detailed analysis, were chosen if they proved significant to each of the three research methods and/or they could be clearly viewed as situated in each of the four quadrants. In Chapter 5, each primary theme is illustrated using the voice of participants through personal quotes relating to the topic, which are then followed by a clear definition and description of the theme.

##### **Primary themes.**

1. Advocacy
2. Autonomy
3. Autism Assets
4. Bullying and Abuse
5. Diagnosis
6. Growth and Learning
7. Relationships and Belonging
8. Balance and Environmental Mastery
9. Mental Health
10. Communication
11. Awareness

### 12. Self-Acceptance

Five of these primary themes were identified as being integral, since they were uncovered as important to each of the three research methods *and* they could be comfortably situated in each of the four quadrants of IMP. These integral themes are further explored from the perspective of education in Alberta in Chapter 7's narrative analysis and recommendations.

#### **Integral themes.**

1. Growth and Learning
2. Balance and Environmental Mastery
3. Awareness
4. Communication
5. Relationships and Belonging

### **4.8 Conclusion**

The data collected from each quadrant was allowed to speak for itself, which gave rise to many themes useful for understanding well-being in relation to high functioning autism characteristics. Regardless of the research method employed, even qualitative data analysis comes down to quantitative judgment. An approach for identifying key themes was developed, which shares traits of quantitative research. The process of identifying themes was confirmatory and deductive in nature. However, the final step consisted in the qualitative selection of important key themes, which were investigated in an exploratory and inductive manner. Chapter 5 focuses on the analysis of primary themes and Chapter 6 further explores integral themes.

## Chapter 5: Primary Themes

### 5.1 Introduction

Participants in this study shared that they were motivated to contribute to this research for two important reasons: the desire to understand themselves better as well as the desire to be better understood by other people. They hoped that sharing their thoughts and experiences could improve the world for other people facing similar challenges. Qualitative research methods hold that a person can be defined by the stories he tells about himself, as well as by the stories that are told about him (Ashby, 2011). Too often, stories are told only *about* or *for* people with autism. In this study, people with autism are given a voice.

This chapter describes, defines and analyzes each of the primary themes that emerged from this study. Each theme is deliberately introduced through a series of quotes from the individual participants. The quotes were selected because they accurately reflected the spirit of the theme represented by the participants and resonated with the researcher's experiences with the theme from her perspective as an educator. This method of presentation was chosen, not only to better represent the ideas embedded within the themes, but also to honor the participants who contributed their voices to this research.

### 5.2 Advocacy

*"I want to contribute for kids who grew up alienated because of circumstances like my own."*

*"I just feel like many people don't understand how autism affects adults and many of the resources are for children."*

*"It wasn't until around 23 that I began to realize that I needed to take control of my well-being, because your parents aren't there to mold you anymore, and frankly, people in society don't care as much as you think."*

*"I have a lot of resource for growth in this way, to get shit shaken up."*

*"When I was 31 I was asked by the Autism Society of PEI to do a speaking tour because I had learned to use my voice."*

## WELL-BEING IN ADULTS WITH HFAC

*“My effort will only be cathartic if, and ONLY if, it makes an objective difference. Otherwise, I may as well be scribbling on the walls of a dungeon that no one else may ever see.*”

*“I frequently encounter barriers to services designed to prevent NTs (neurotypicals) from “working the system.” Particularly as a low income family, many of the services that are designed for low income people come with gate keepers – mainly social workers whose mandate is to deter people from accessing resources rather than ensure qualified individuals or families get the help they should be entitled for. As a result, I frequently require advocacy in order to access services I should be entitled to.”*

*“I think I have started the slow process of beginning to educate the rest of my family about the challenges I have and how to help me.”*

Advocacy refers to the process of informing people about autism in order to influence how individuals and groups understand and interact with people on the spectrum. It was identified as a primary theme because it can be situated in each of the four quadrants. It is important in that it connects the internal subjective perspective (UL) of the condition to the observable behaviors (UR) of autistic people and the individuals and groups (LL) around them, and can also have systematic implications (LR). As a theme, advocacy emerged primarily from the phenomenological interviews, with 86% of participants initiating the topic independently. It is most closely connected to the themes of awareness, relationships, growth and learning, goals, self-acceptance, and systems.

Participants differed greatly in their comments regarding the target group they wanted to focus on. Most felt it was important to advocate for themselves to benefit their personal relationships with family, friends and acquaintances. Approximately half thought that increasing awareness and understanding would improve their ability to be happy and productive in work and school environments. When asked about their reasons for agreeing to participate in this study, every single participant expressed that they wanted their experiences to make a difference for themselves and other people in the future. Four participants focused their advocacy comments on improving systems to be more inclusive and supportive for people on the spectrum,

## WELL-BEING IN ADULTS WITH HFAC

feeling that the structure of the system either excluded them or discouraged them from accessing beneficial services.

Two participants, both female, have found a way to work advocacy into their career paths. Both engage professionally in public speaking for awareness campaigns, one of whom makes her services available for free, advocating for people on the spectrum who don't have the ability to "voice" their own concerns. Both of these participants spoke of the need to advocate with a degree of aggressiveness and some level of anger from previous personal experiences, and the need to fight for respect and understanding.

### **5.3 Autonomy**

*"I have always preferred to do things on my own, but I've started to value spending time with others because I know I need to do this to achieve the things I want to in my life."*

*"I suppose I never got caught up in things like everyone else did – I wasn't into partying, drugs and binge drinking and I was certainly never materialistic. It just didn't make sense to me."*

*"Generally I was happiest when I was alone on the computer doing my thing without the company of others. It was just easier."*

*"Nobody bothers me in my own little world, and I like it".*

*"When most boys my age were interested in hockey, I spent a lot of time drawing pictures of chemical plants and transit systems."*

*"I was very hard headed and would not accept no for an answer. Even as a child, and even if I did it quietly".*

*"Taking the road less traveled can mean not fitting in, not belonging."*

*"My opinions on lots of things are very rational, but in this day are considered fringe and garner frowns."*

*"I feel like I have a greater tendency and enjoyment of keeping myself at least slightly more isolated than normal people."*

*"I have always valued solitude over proper company."*

## WELL-BEING IN ADULTS WITH HFAC

*“Trying to live up to everyone’s expectations is not worth the stress and pain it can bring into your life.”*

*“If I could, I would very much so eliminate my inability to socialize. I often have a very difficult time talking to people and so isolate myself from others.”*

*“I stand for my beliefs, but I tend to come off too strong or not strong enough.”*

In this study autonomy refers to an individual’s ability to self-direct and self-govern. It entails being aware of one’s own person, thoughts and values, and maintaining a loyalty to these when part of a bigger group.

Participants often described autonomy as important for maintaining integrity and being true to one’s own self. It was the second most common well-being strength on the PWBS, with 33% of participants identifying it as their top strength and 36% identifying it in their top two assets. It most closely connects with the other themes of awareness, relationships and belonging, mimicking and masking, and communication. The theme of autonomy also emerged from each of the three research methods.

Autonomy focuses on respect and the rights of the individual. To be considered a strength, one’s autonomy must maintain a delicate balance whereby it nurtures the rights of individuality without sacrificing the importance of social relationships and belonging. This study suggests that participants’ strengths in autonomy often come at the expense of their ability to connect with the world around them, an outcome that has implications for every aspect of well-being. It may be an individual’s greatest strength while also being the source of his or her greatest challenge. Not having enough autonomy leads to a reduced sense of personal worth, while having too much autonomy can segregate and isolate individuals.

A general pattern of this research was that participants reported less of a desire for social connections and relationships. However, it was not clear as to whether this preference was an

## WELL-BEING IN ADULTS WITH HFAC

innate tendency of their personalities or whether it stemmed from a reduced ability to communicate and connect with others. Some participants, proud of their autonomy, were so firmly rooted in their sense of self that they seemed to lack any awareness of the same rights in others. Other participants, aware of their strengths in this area, celebrated their autonomy but worked to balance it so that they could improve the status of their relationships and their ability to function in larger groups.

### 5.4 Autism Assets

*“A trait I consider a big asset to me is my attention to detail.”*

*“I think the amount of arrogance/narcissism I have is at least maybe a little healthy in that I feel as though I can do anything if I get an interest in it.”*

*“I feel my eye for detail and analytical thinking has done a lot for me in terms of problem solving. I found that my troubleshooting ability transferred really well to vehicles, plumbing, circuits and other things that have allowed me to both save money and be useful to people around me.”*

*“I often think that the things I would have liked to change that caused problems for me as a kid in elementary school ended up being some of my biggest strengths and gifts later in life. I am pleased that I didn’t have a magic wand or I might have made some terrible mistakes thinking I was doing a good thing.”*

*“I love having an internal monolog that never stops, and I love that I cannot accept things at face-value.”*

*“Those attracted to academia are typically thinkers. I would not be surprised if a significant percentage of those who go into grad studies had some connection with Asperger’s – it’s the type of world where you can actually excel if you are brainy but not necessarily practically minded or good with people.”*

*“I like to consider myself very open to anything that might help me develop and grow as a person, and I welcome the difficulties or challenges that come with such experiences. Not seeking out and participating in such enlightening experiences would be worse than death for me.”*

*“I am a very good worker and am intelligent in my field.”*

*“I am very observant and see and remember things that many don’t. I feel like this is a way for me to seem very helpful to people and it gives me an opportunity to pipe in.”*

## WELL-BEING IN ADULTS WITH HFAC

*“I am the kind of person who meticulously plans and organizes for every potential variable”.*

*“Being successful depends on my ability to match my strengths to my environment”.*

*“In spite of my limited employment opportunities, I am part of a group that has and will continue to contribute to some of the most brilliant innovations of the 20<sup>th</sup> century.”*

*“I have noticed that autism communities are notably anti-racism, anti-homophobia, trans-positive and logical in their social ideals.”*

Assets of autism were defined using Baron-Cohen’s characteristics of autism as identified by the Autism Quotient. The phenotype is defined by qualities relating to communication, social skills, ability to focus attention (attention shifting), attention to detail, and concrete and literal ways of interpretation (imagination). The theme of autism assets was selected as primary because it was identified by each of the three research methods and was brought forward by 93% of participants. Assets directly connected to characteristics of autism were identified as being:

- Propensity for personal growth and life-long learning.
- Autonomy
- Attention to Detail
- Logic and Analytic Skill
- Intelligence and Learning Skills (ability to excel academically)
- Work Ethic (Routine and Repetition)
- Creativity and Innovation
- Acceptance of Others (Logic over Emotion)

Many participants described the value of being able to use these strengths to navigate around perceived weaknesses. For example, five different participants described incidents in which they were able to use autism traits to contribute to the group and make social connections, thus improving on areas that they generally view as detrimental to their personal well-being. The

## WELL-BEING IN ADULTS WITH HFAC

benefits to autism assets is summarized beautifully by Temple Grandin's, consideration that, if the autism gene were eliminated, we would have people standing around in a cave, chatting and socializing, and not getting anything done (Grandin, 2014).

An overwhelming number of the participants emphasized that it is imperative for them to situate themselves in environments and contexts that cast their autism traits in a positive light, as opposed to environments where their characteristics limit their opportunities and well-being. Strengths and weaknesses are defined according to the context of the situation and environment one finds oneself in. Participants' ideal environments were described as closed, in that they were structured and followed routine patterns of behavior and expectation. Often these included educational settings and work environments with clearly defined responsibilities and expectations. In these environments, participants were able to demonstrate strengths related to strong focusing skills, the ability to attend to detail, and a work ethic enhanced by the desire for routine and repetition.

Creativity and innovation was mentioned with surprising frequency. Participants described their creativity not as arising spontaneously in a flash of insight, but often as a result to a lack of ability to see things in the way most other people around them do. It is as though their autonomy, despite having the potential to inhibit relationships and belonging, promotes an unfettered interpretation of what is in front of the person. An example is illustrated in a story from the duoethnographic conversations: the parents described that their son had artwork displayed in a museum exhibit for a piece he created in kindergarten, and a poem published in a book that he wrote in grade three. Celebration of his works was due to his ability to step outside the circle, to see things from a different perspective. The mother laughed and explained that he wasn't stepping outside a circle to shine light on a different perspective, but rather he was

## WELL-BEING IN ADULTS WITH HFAC

situated outside the circle, only seeing the topic from the perspective he understood, and representing this reality in his creations. Yet the result was remained the same: his unique way of thinking allowed him to produce interesting pieces that merited recognition.

### 5.5 Bullying and Abuse

*“I have too many unhappy memories to list. I was singled out and picked on by physically/emotionally abusive teachers in elementary school because I couldn’t learn in the way they structured their lessons.”*

*“I felt very restricted as a child and not validated.”*

*“My actual environment itself was chaotic, abusive.”*

*“The price of my being allowed to live at all was to live in a world of people who damaged me for not being someone else, someone more convenient and like them.”*

*“I am a 53 year old woman with several neurological disabilities – and I would have liked to be reared as a human being. Instead, I was frequently informed (often by my mother) that I was a monstrosity.”*

*“I am certain that the mindless hell of my childhood has irremediably excised or stunted a great many of my own potential capacities.”*

*“I’ve survived several attempted rapes (no successful rapes) – in late teens and adulthood. The most recent was when I was 29, during a professional conference on a Russian cruise ship.”*

*“I don’t recall a day as long as I remember living at home when a parent didn’t tell me that I deserved to be locked up.”*

*“Even my husband has experienced bigotry from individuals who learned that his wife is autistic.”*

*“As a teen, while most of my peers were encouraged to marry and have children, I was told that I should pursue sterilization because my children might be like me.”*

*“It is not just stress from living in a body with sensory issues, a seizure disorder and trying to navigate a highly socially structured culture – it is not just the medical challenge of being autistic, it is also having to field countless macroaggressions that wear me down. It’s being confronted with systematic discrimination that borders on abuse.”*

*“I have read that upwards of 90% of autistic people report severe social bullying, not just at the grade school level but continuing into their adult years. This is no surprise to me.”*

## WELL-BEING IN ADULTS WITH HFAC

*“Despite the otherwise hostile environment that autistic people are born into, we can and do experience well-being.”*

*“I used to always see the good in people and that’s got me into trouble because I would go out of my way to help those who would hurt me or my family.”*

*“So it began, six years of bullying and being the outcast in most situations. I remember coming home a lot of times scared and sick from the bullying and harassment.”*

*“I remember feeling the sheer terror of walking through the hallway to my locker and then to my homeroom. I was ‘locker smashed’ a few times – where someone punches you in the back of your head and it bangs your head into the locker tray. I remember walking in the hallway and numerous times people who I never knew would walk up and punch me.”*

*“The fighting and bullying got so bad by the end of grade 7, my parents decided the best thing for me was to get me out of the country. I spent the summer of 1993 in the UK with my grandparents.”*

This study defines bullying and abuse as any behavior by individuals, groups or systems that made a participant feel intimidated or unsafe. This includes physical, psychological, emotional and social trauma. Bullying and abuse was identified as a primary theme, as it is firmly situated in all four quadrants. The theme emerged as significant to 73% of participants, and was uncovered by all three methods of inquiry. As a theme, it is closely connected to relationships and belonging, communication, self-acceptance, mental health, and environmental mastery.

Trauma ranged from feeling unacknowledged, undervalued, and suffering from a lack of nurturing, to full out physical assault. Every participant who initiated discussion concerning this theme described bullying and abuse as having such a negative effect on their sense of self-worth that to this day it continues to hinder their ability to accept themselves. It was described as either causing or contributing to the overwhelming sense of fear and anxiety prevalent in autism, and was also closely associated with depression. Many participants described a process of gradual withdrawing from the world around them to ensure their own physical and safety needs.

## WELL-BEING IN ADULTS WITH HFAC

Much of the abuse described was initiated by a lack of parental understanding and support. Participants described the challenge to achieve the expectations of parents and teachers and their inability to understand the motivations of others. Lack of social skills, along with difficulties in both verbal and non-verbal communication, resulted in encounters that participants were unable to see coming. The lack of ability to understand why the abuse was occurring caused them frustration and hopelessness regarding what to do to protect themselves. Many participants described the world around them as being cruel and questioned the inherent goodness of the people around them. They described problems of trust, which without doubt has contributed to their challenges in developing relationships. Early experiences with bullying and abuse appear to have impacted the overall developmental trajectory of participants, reducing the qualities of well-being associated with personal relationships, self-acceptance and environmental mastery. It is possible that these experiences contribute to a sense of autonomy and life purpose.

### 5.6 Diagnosis

*“After DSM IV, with no more Asperger’s, of course my diagnosis switched to autism. They also found ADHD, which had always been suspected. But all those years ago people would disagree and say you couldn’t be concurrently diagnosed with both. I was told that I didn’t have focus problems. That I could do it if I was interested in it or if I would shift my attention from whatever else I was focusing on. I believe that just as we are learning that autism is not tuning out the world but perceives it too intensely, we are learning that it is not a simple matter of this or that.”*

*“The psychiatrist didn’t want to put it down on paper because nobody wants an autistic kid.”*

*“I would have wanted to know that I had autism. It is something about me. I mean, think about it as with anything else. Think if it were blindness, or diabetes, or a mobility disorder. Wouldn’t you want to know so that you could help yourself? A kid who has diabetes, you would tell him he has diabetes!”*

*“One of my challenges is that I have a number of traits that are not typical of autism; but I wonder how many of them have to do with having a high IQ, being able to figure out how to act in given situations. My academic bent and training has resulted in me being a highly analytical person that should be able to rise above many of these challenges.”*

## WELL-BEING IN ADULTS WITH HFAC

*“My intelligence made it difficult to get our GP to take seriously any possibility that I had autism.”*

*“I have two generations of diagnosed autism above and below me. It was no great surprise.”*

*“I deliberately chose to see different educators and doctors and other fun stuff, I deliberately chose to torture myself to get that first diagnosis.”*

*“It was a lie to say that I didn’t have any issues. A stupid lie. They pretended it wasn’t a big deal and that I should have no excuse for being the way I was. It hurt me.”*

*“I just couldn’t handle not knowing or understanding anymore, thinking I was crazy.”*

*“My disability is not physically visible. This is both a good thing and a bad thing.”*

*“Because I sound reasonably intelligent when I speak, the kinds of challenges I had were often dismissed rather than addressed. I remember a math teacher taking me into the hall and screaming at me for not understanding what he said in the lesson, saying I wasn’t listening or trying.”*

*“In my last two years at University, I started to hear a little bit about ASD. My mother heard about it on the radio and started to talk about it with me. She recorded the radio show, and it sounded like it fit me to a ‘T.’ I was furious, and despite all what I heard about people feeling like they had a weight lifted from their shoulders, I was disgusted and embarrassed that I had a disability. I felt worse than before I knew.”*

Of the 16 participants with characteristics of high functioning autism in this study, 50% had received formal diagnosis. Diagnosis was selected as a primary theme because it touches on each of the quadrants and was brought forward by two of the research methods. A total of 73% of participants identified it as playing a role in their well-being. Diagnosis was a contentious issue among participants, with an approximate equal distribution between people thinking it was a positive thing and people thinking it was not. It is an important issue because diagnosis is often necessary if one is to receive supports and services from a system perspective, yet the process can be long and difficult. It connects closely to the themes of self-acceptance, self-awareness, challenges of autism, assets of autism, personal growth and relationships and belonging.

## WELL-BEING IN ADULTS WITH HFAC

People supporting the process expressed that they were grateful because the diagnosis helped them to understand and accept themselves. It provided an explanation for the challenges they faced, which had often been unrecognized by those in a position to help. Supporters of the diagnosis process described their new understanding as being useful for navigating around challenges, and for helping others accept and understand them. This group clearly accepted their diagnosis, but did not feel it limited them.

Participants who did not support the diagnosis process had a pessimistic view, sometimes focusing on “the hoops” that were necessary to jump through for diagnosis. More often it was because they felt stigmatized and marginalized. They viewed diagnosis as a limitation. While the previous group found that the diagnosis allowed for self-understanding and acceptance, this group felt that it impaired their ability to accept themselves. It was described as being associated with a sense of hopelessness and failure.

Duoethnographic conversation with the parents of the adult with HFAC mirrored this division. The mother, who had attempted to pursue diagnosis early on, felt that the father was not supportive of the diagnosis. Conversations revealed the father’s initial hesitancy toward diagnosis, stemming from his own lack of acceptance and worry; he didn’t want for it to be true. The diagnosis made it real, and he worried that his son would use the diagnosis as an excuse in a way that could hinder him in the future. The mother viewed the diagnosis process as being potentially valuable, in that it would help their son to understand himself and to rise above challenges, to accept, and maybe even celebrate, his differences. She thought it would be useful information to provide others in the development of future relationships, if he chose to share the information. In the end, the son was not diagnosed. He felt the process was excruciating because it required a series of assessments and a process of talk-therapy that the very characteristics of

## WELL-BEING IN ADULTS WITH HFAC

autism made challenging and uncomfortable. Ironically, the mother ended up comfortable with the lack of diagnosis because she came to recognize that the potential she saw in it was not dependent on a piece of paper with a label. The father, however, wondered about potential financial benefits of a diagnosis. He thought that perhaps the son would be eligible for post-secondary grants or scholarships, or other programs and benefits that they might not be aware of.

Diagnosis has become increasingly challenging to pursue. At a time when Alberta schools had enough funding to set up Educational Psychological evaluations, many children received diagnosis and supports early on. As schools become more crowded and financial times have become more challenging, school divisions have cut back funding of assessments for diagnosis, and young adults seeking the diagnosis independently are often hindered by social and communication challenges, as well as a lack of professionals with expertise in diagnosing adults.

### **5.7 Growth and Learning**

*“There were a few months in high school where I absorbed all the information I possibly could on body language, because it occurred to me that I had never even considered the way a person was standing or sitting or looking could give clues as to what was going on.”*

*“My ability to work out other people’s intentions, not just their emotions, has come in time. Learning to understand what drives people to do the things they do has been my most important learning.”*

*“I have constantly, always been interested in learning. Watching shows like ‘How it is Made’ and ‘Daily Planet’ have made me happier.”*

*“If I was given an assignment and told exactly what I needed to know to do it, I could learn that stuff no problem and put it to use right away on the assignment. I feel like the way a lot (not all) of my teachers taught was way too indirect. A 30–40 minute lecture filled with jokes, metaphors, videos, breaks and questions, possibly followed by a booklet where you had to work in groups and do crossword puzzles, was not especially useful to me.”*

*“I think, I feel, that I have a passion for growth”.*

*“Now that I’ve learned how I learn, I learn better.”*

## WELL-BEING IN ADULTS WITH HFAC

*“I was taught how to learn, how to teach, in cadets. The structure of cadets showed me that I could actually learn.”*

*“As much as I have learned, I am for the most part self-educated.”*

*“Everybody would struggle with learning from traditional teaching methods if they had my processing issues.”*

*“The ability to think for myself, with undue influence from the outside, contributes to my learning ability.”*

*“I was lucky to have people around me who would repeat words for me, to define them for me until I understood them.”*

*“I know not to let my emotions get involved, or it affects my ability to think and learn.”*

*“When I was 25 years old I picked up a biology book for the first time ever, then a sociology book. Those two books shook my world up like crazy, and my world has never been the same.”*

*“I actually do have a good sense of humor; I do irony and sarcasm very well. Perhaps too well. I have learned these with time and practice.”*

*“As somebody who spends a lot of time in my head, learning and personal development occupy a great deal of my experience.”*

*“I like to be challenged, and I know that some of these things that are a huge challenge within me, I know that I have the ability to learn and grow beyond them. I am a firm believer that I can change things by learning. Awareness, yes – once you are aware I think you can fly higher than the sky. At least I can!”*

Growth and learning was identified as a top asset by 53% of participants on the PWBS. 90% of participants initiated discussion of this theme during phenomenological interviews or duoethnographic conversations. It is included as a primary theme because, in addition to being identified as important by each research method, it can be clearly situated in each of the four quadrants. It clearly connects to other themes including autonomy, self-awareness, and acceptance, relationships and belonging, communication, environmental mastery, goals, and life purpose.

Participants spoke of the topic itself with overwhelming positivity and optimism. There was some disagreement about the value of the education system and teacher practices, and 29%

## WELL-BEING IN ADULTS WITH HFAC

of participants reported learning disabilities and difficulty learning with traditional practices. Traditional learning environments such as lectures may not be overly effective, and social learning activities can actually detract from learning and development.

The majority of participants identified the development of their ability to self-teach. It seems that many did not come to view learning as a personal strength until their adult years. It was typically described as something slow to develop, but that has continued to pick up steam over time.

Participants generally perceived continuous growth and learning as a personal passion and interest that has contributed greatly to their sense of well-being. There were many instances where participants commented on the ability to target their attention and focus their learning in areas that are traditionally viewed as autism weaknesses. With focus, people have improved their communication skills and social relationships. Their preferred learning style seems to be structured, directed, mechanical and targeted.

### **5.8 Relationships and Belonging**

*“I think that a LARGE number of autistics grow up feeling no real connection to relationships, even with their family.”*

*“When I was growing up I had very few friends. My family did not understand my challenges.”*

*“I grew up in a family environment where both friends and relationships with extended family were viewed as important. These were some of the most treasured relationships I experienced.”*

*“Ever since I moved from the place where I grew up ten years ago, the sense of isolation and emptiness I have been trying to cope with has grown. It has grown to the point of consuming me.”*

*“My parents really did try their best for me, but to no success.”*

## WELL-BEING IN ADULTS WITH HFAC

*“The only place where I felt safe was with my grandparents – I was always very close to my Oma and Opa. They always seemed to encourage my strengths and my interests, and not to focus on what I was not.”*

*“Despite my issue, my home life was relatively okay. I wasn’t abused in the traditional sense, but all I really ever remember was feeling alone.”*

*“My parents really didn’t have a support network. They didn’t know how to parent me. But they made a lot of effort to always do family things – going out to the park together for walks, cross country and downhill skiing, camping. They really did try, and those relationships were the most important I have had in my life.”*

*“My children make my life worth living. I have never been great at anything, so I take pride in being a mother.”*

*“Even with my family, when I do feel relaxed, I am still pretty quiet for the most part. Maybe it’s my lack of activities and interests that make me feel like I have nothing to say.”*

*“I am told that I seem overly rational and cold for most people. I have a very hard time expressing empathy, but an incredibly easy time experiencing it.”*

*“When we fought I would always be heartbroken because I would think of the moments where things were so great and wonderful. As I grew older my mom would often say things like ‘there is something very wrong with you’. I couldn’t comprehend how someone that loved me so much would want to give up on me so easily.”*

*“Until about 23, I was absolutely obsessed with how the world perceived me. I couldn’t make a decision without worrying how other people would react. It was easier to shut other people out.”*

Relationships emerged as among the most important themes for well-being in this research. 100% of participants independently initiated the topic in interviews and conversations. It was a cornerstone of the PWBS, with 43% identifying it as the most important challenge to their well-being. Only 35% of participants reported having a significant other, and of these a full 80% were female. The theme of relationships emerged as important from every research method, and can be seen to influence a person’s well-being in each of the four quadrants. This theme is closely connected with communication, awareness, acceptance, interest and hobbies, and bullying and abuse themes.

## WELL-BEING IN ADULTS WITH HFAC

For every participant, early relationships with parents and family seemed to have a profound effect on their ability to develop subsequent relationships later in life. People who reported a good connection with their families demonstrated more awareness as to the potential value in relationships and the willingness to put in effort and understanding in pursuing them. It is not clear whether this is a cause or effect situation.

Participants who felt poor family connections or experienced early abuse described many experiences in which they tended to assume that other people were bad and would hurt them if given the opportunity. They appeared more inclined to withdraw socially, focusing more on the development of self, goals and achievement.

Most participants indicated a desire to engage in close relationships, specifically to find a significant other. Frustration was expressed in their inability to meet people and develop relationships. Without doubt their prospects in this regard are hindered by their inadequate communication skills, restricted interests, and limited experiences in social situations where they could meet new people. There was also a tendency to refrain from making new connections following bad experiences. Following a relationship that didn't work out, participants were generally reluctant to recover and move forward.

A preference for time spent alone seems to impair the ability to meet and pursue relationships. Participants frequently expressed that the demands of developing and maintain close relationships were both exhausting and anxiety provoking. There was also evidence that participants tended to value and engage more in less involved relationships over more intense relationships. People expressed pleasure in time spent with colleagues, classmates and acquaintances that they saw regularly throughout the course of their day.

## WELL-BEING IN ADULTS WITH HFAC

Relationships require a delicate balance of “me with we.” Balance was often lacking in the experiences participants shared. What was clear is that no participant was completely satisfied with the status of her relationships with others. It appears that, even assuming good social and communication skills, relationships require more effort and energy to initiate and maintain for people with high functioning autism characteristics.

### 5.9 Balance and Environmental Mastery

*“These are issues of need versus want. I would rather go to a library and just read things, but I know that I need to socialize myself because the last thing I want to do is to be a hermit.”*

*“If too much stuff disrupts my daily routine I am bed ridden with thoughts of what’s going to happen.”*

*“I really started striving for optimal health: mental, physical, spiritual, etc... Although I don’t always achieve my goals and feel great about all areas of my life, I know this balance plays a significant role.”*

*“If I am lacking anywhere in my life, it begins to manifest and take over who I am in every aspect.”*

*“If I am in a controlled environment then I am okay. And it helps me, I know I have to socialize and I can do it through work, and if it isn’t for that environment I know I won’t do it at all. I will stick my head in a book and be lost in the world.”*

*“Because you should be able to balance your obligations, no matter what was loaded on your shoulders or poorly communicated. If you can’t balance those obligations, more just continue to come.”*

*“How do I strategize when there are so many variables? I want logical black and white rules for how to navigate life. Not all this ‘must be able to multi-task in a high-stress environment’ pressure just to survive.”*

*“I suppose that this idea that there is a certain way that things ought to be could be a ‘spectrum symptom’. I do believe that this is possible even in an environment that isn’t peaceful, but it is certainly harder in such situations.”*

*“Wellness extends beyond the individual to include relationships with those around us, but it is even more. Again, everything is integrated and so lack of wellness inside is the total balance of the individual, relationships and the surrounding environment.”*

## WELL-BEING IN ADULTS WITH HFAC

*“The big deal for me is that I have a mind which can see a huge number of outcomes for any given decision – I am constantly thinking and analyzing things, constantly in problem-solving mode. Faced with a decision, I go down endless ‘decision trees,’ coming back to the last branching point when a given branch ends up obviously leading to a non-tenable decision. And I do this all the time. Even choosing what I might want from a restaurant menu has come to be a taxing enterprise. Please, just choose for me because this is way bigger in my head than you could ever understand and the thought of it is exhausting and overwhelming!”*

Balance and environmental mastery are primary themes because they influence and are reflected in each of the four quadrants. Every research method uncovered this theme as being very important to the well-being of the participants. It touches on themes relating to mental health, awareness, relationships and belonging, systems, mimicking and masking, and social expectations. It can be traced to the autism characteristics of challenges in shifting attention and emphasizing detail (often at the expense of the bigger picture). This lack of cognitive flexibility is described by participants as impairing their ability to manage the environment around them, and in some cases has prevented participants from living independently. This theme was described, to some degree, by 100% of the participants, with 14% percent indicating it as being their most significant challenge and 18% identifying it in their top two most significant challenges to well-being (PWBS).

Some participants, aware of this particular challenge, make focused efforts to strategically and mechanically incorporate balance into their lives. They described this as a very difficult endeavor, one that does not get easier with time and practice. Some participants described this challenge as becoming increasingly difficult with age.

Autism is characterized by repetitive patterns of thoughts and behavior. Routine and repetition are essential for well-being and success, but it seems easy for participants to become trapped, with the strategy feeding the problem. Anxiety was described by 86% of participants as being a challenge to well-being. Often, coping with anxiety creates a negative cycle. The

## WELL-BEING IN ADULTS WITH HFAC

inability to control anxiety leads to a limited scope of focus and a reduced ability to manage one's own environment. The challenge to manage environment, in turn, increases anxiety with the result of the person reducing their focus and balance even further. This challenge, often resulting in withdrawing from the chaotic world surrounding participants, likely contributes to an increase in autonomy.

### 5.10 Mental Health

*"I was suicidal in 2004 onward to 2009, when I would have been 9 through 13. I started high-school that year. That is why I'm interested in school system reform."*

*"Social anxiety is such a strong feeling when I am around other people. I just can't stand feeling that way, so I avoid it like the plague. It causes me to have an almost feedback loop in my head where I can never think of anything creative or imaginative. I shut down."*

*"I lived with fear, anxiety, depression and related isolation throughout most of my grade school and some of my post-secondary career."*

*"It was only this year that I finally have started to be able to describe for my own self the deep void, and profound sense of loneliness I live with daily."*

*"Dealing with mental clutter and over-stimulation from too many thoughts leads to an inner paralysis."*

*"I am wired to get overwhelmed easily."*

*"My rigidity certainly affects my relationships and how I feel about myself. I have gotten to the point where it is absolutely draining the people around me to reassure me that I am okay to them. I am constantly asking my boyfriend 'do you love me?' even though I know. Or, if my sister teases me, I can handle it for a while but I then need to ask 'you still like me, right?'"*

*"My life is filled with depression, despair and hopelessness."*

*"I fell into a bad depression. I did some digging and eventually found a counselor in Calgary that dealt with ASD issues. I started to feel better about things, and was happy I could finally have someone that didn't have their head up their ass and could understand a little bit of what I went through."*

*"Focusing on personal growth has cultivated and carried me above the anxious, depressed mess I used to be five years ago."*

## WELL-BEING IN ADULTS WITH HFAC

*“Accessing medical and dental care is extremely difficult for me, my anxiety prevents me from accessing services I probably desperately need.”*

Mental health was identified as a primary theme because it is firmly rooted in all four quadrants. Collective exterior may not immediately come to mind when thinking about an individual’s mental health, but challenges associated with autism make it very difficult for participants to find and access required mental health supports in a system that is often difficult to maneuver, even for people without communication challenges and crippling anxiety. 87% of participants described mental health as being problematic to their well-being. This theme connects with balance and environmental mastery, personal growth and learning, relationships and belonging, diagnosis, sensory and physiological challenges, awareness and systems.

Participants vividly described situations of crippling depression and anxiety, as well as an overwhelming sense of loneliness. 33% talked about suicidal intentions. A subtheme was the difficulty participants had in navigating a system that was often described as requiring the same skills to work through as their personal deficits. The lack of professionals aware of the nuances of autism as a condition seemed to be a problem. Even if such professionals were not so difficult to find, accessing them required participants to have strong communication skills as well as the ability to function in an unfamiliar environment far from the structure and routine often relied upon to remain functional.

Mental health issues in the participants were initiated or compounded by autism characteristics relating to loneliness, poor self-acceptance, social anxiety and reduced mental flexibility and the tendency to become easily overwhelmed.

### **5.11 Communication**

*“I struggle to communicate, to appropriately show, empathy; but I feel it very easily.”*

## WELL-BEING IN ADULTS WITH HFAC

*“I try to refrain from getting too personal, but I know why I do every single thing I do. To me, I am just telling you why something is the way it is, so it’s difficult for me to differentiate what might be considered too much information. Hopefully I stay on topic, though.”*

*“If I know when I am going on too much about something, I will put a stop to it and point it out by finishing my sentence with something like ‘...and I could keep going on.’ It’s a combination of being socially/conversationally inept and wanting to go on about certain topics for the rest of my life.”*

*“I’ve learned to enjoy talking to people, even if I am not good at it. Sometimes I’ll see what kind of reactions I can get out of them from showing them my very strange sense of humor.”*

*“I imitate body language and social cues because I don’t ‘get them.’ I tend to flat out tell people I work with closely this. It gets me strange looks.”*

*“I have a very hard time understanding people’s intentions and am sometimes unable to read emotions.”*

*“I have lots of thoughts and ideas in my head, but have a very hard time verbally communicating them.”*

*“I may not like it, but having conversations and helping people open up helps me to understand, and I can then learn.”*

*“Communicating is exhausting, so exhausting! I am almost brain numb, I can feel my mind on fire now and I will need lots of time to recover from this talk.”*

*“Autistic people are often punished/uncomprehended/outcast/damaged because of just ‘not knowing’ the innumerable beliefs, premises and observations that others take as self-evident and base everything else upon.”*

*“I have learned to be a good listener, I just don’t generally enjoy it and when I am in a situation where there is no pressure on me to perform (like talking with my wife), I do things like close my eyes.”*

*“It is really wonderful to be in a group of aspies. The communication dynamics are fluid; their speech is precise and hinges on what is said rather than what is implied. It is very nice.”*

*“There are aspects of my communication style that seem to affect relationships. My husband tells me that I do not have a good sense of cues other people use to navigate conversations. When to let people speak, how to judge if they are receptive, reading body language to know if someone is sick/tired/grieving/agitated, making eye-contact, etc....”*

*“My communication skills and style contribute to an overall sense of personability that shape how likeable people find me”.*

## WELL-BEING IN ADULTS WITH HFAC

At heart, communication is the vehicle that is used to connect the self to the other. It is firmly situated in each of the four quadrants and was a cornerstone theme, emerging from each method for study. 100% of participants identified it as playing an important role to their well-being, which is not surprising considering that autism is classified as a communication disorder.

Most of the participants' descriptions painted a picture of communication as a negative factor in their life experience, with some exceptions. Communication is intricately connected to themes of personal growth, awareness, advocacy, diagnosis, empathy and understanding, social expectations, relationships, and systems.

Descriptions relating to communication emphasized the tendency and preference for concrete and literal language. This is how participants expressed themselves, and the primary way in that they understood others. Non-verbal, abstract and figurative language generally caused frustration, with the ambiguity of such means of communication reducing the effectiveness of communication between participants and the world around them. This difficulty resulted in a disconnect, which was likely to increase autonomy at the expense of relationships. It also appeared as though decreased communication effectiveness, or lack of confidence in it, contributes to the anxiety prevalent in participants in this study.

Some participants explained that, when focused on this area, they were able to improve their communication skills. Communication challenges, while never eliminated, were at times acknowledged and then navigated around. Success in this regard always hinged on the awareness of the participants' own communication style and asking another speaker for help in improving the effectiveness of the communication. This method seemed to reduce social anxiety, improve relationships and environmental mastery, and helped to provide future growth opportunities, in that in this manner participants could learn a bit more about the people around them.

## 5.12 Awareness

*“When I became aware of how I learned best, I used that to my advantage. When I became aware of how I interacted with people differently, I started to learn how to interact. I learned to use what I do have as an advantage. If a class existed to educate the autistic about autism, I wonder what the results would be.”*

*“In my case, learning to bypass a difficulty doesn’t exclude me from being able to draw on it when I find a need for it.”*

*“Knowing that you think differently and process things differently than the people around you might make it difficult to enjoy situations.”*

*“I realized that I was pretty easy to manipulate when I was very young, so I took steps to make sure that wouldn’t be the case as I grew older.”*

*“I have figured myself out. This is a HUGE part of everything, but some of the pieces did not start coming to me until I was 25 years old, and I had to uncover them myself.”*

*“I have chosen to fight myself, to challenge myself. To put myself in situations knowing I was fighting against something.”*

*“Recognizing and learning about myself, what works for me and what doesn’t, have made a big difference to my life in the past ten years. It has triggered that desire to keep learning and keep growing, as well as advocating for myself.”*

*“I was going to play their way, continuously knowing that I wouldn’t wimp out, that I would find what I needed to do and that I would figure it out myself. I had a plan.”*

*“I want to know definitively. I want to understand myself, not to find an excuse, but to be able to get to the place where I know what can be changed and what cannot. I hope that, at some point, with that self-understanding, I might possibly be able to help others ‘like me.’”*

*“I think of hope as having both a better understanding of myself, and the ways I can positively interact with and thus know the world around me.”*

Awareness is a primary theme because it is firmly situated within each quadrant. It was expressed through each research method—although it is only indirectly expressed through the PWBS. It is very closely connected with growth and learning, advocacy and acceptance. While analyzing the data, it was often very difficult to establish where one of these themes ended and the other began. The three themes bled together, almost as though they were being fed by one

## WELL-BEING IN ADULTS WITH HFAC

heart. 93% of participants discussed the concept of awareness, mostly with optimism. Two participants indicated the possibility of awareness having a negative impact on well-being, but the experiences they described did not reflect this perspective.

For the participants, this theme was permeated with a sense of hope, as though awareness were embedded within the strong well-being asset of continuous growth and learning. Many participants described awareness as a first step on a new path towards improving their lives. It was perceived as a tool to help them harness their own strengths and to improve on their weaknesses.

Most participants did not describe a slow and gradual path to awareness. Rather, for most, awareness occurred rapidly at some point in their adult years. Participants described younger lives filled with the challenges and frustrations associated with autism, but it seemed as if they were embedded in the details and unable to connect those details with the bigger picture. It appears that the experience of increased awareness is the impetus for the development of self-acceptance, one of the most significant challenges in the well-being of HFAC.

### **5.13 Self-Acceptance**

*“As a child I tried to be so perfect in school and with friends, but felt like I was never perfect because there was always going to be something else to strive for. I didn’t appreciate my accomplishments. Even though I have come a long way and succeeded in many areas of my life, I still feel like a failure.”*

*“I have an immense fear, a feeling I have been unable to change or vanquish, that I am subhuman and should be rejected by anyone I admire, anyone worth dealing with.”*

*“I may have changed, but really I am the same person on the inside and always will be.”*

*“I still don’t use the terms wellness or well-being very much, but I suppose what it means is to be at peace with myself, satisfied with where I am in life, feeling that I am genuinely being who I am meant to be and doing what I am meant to do.”*

*“It is tough to separate personality traits from autism.”*

## WELL-BEING IN ADULTS WITH HFAC

*“If anything, looking back on my life makes me feel embarrassed.”*

*“I am quite happy with my life and the direction it is taking.”*

*“I have a real problem with anyone who says ASD is a ‘gift’ or ‘something to be proud of’. While it might give a few people very extraordinary useful skills, for most people it is a curse and a disease. It should be treated as such!”*

*“Ever since I was a kid, I have always felt disconnected.”*

*“There is something just not right with me.”*

*“In no way do these things make me feel bad about myself now. I embrace the way these things have turned me into who I am.”*

Self-acceptance was identified by the PWBS as being the second most common single challenge to well-being, with 29% of participants identifying it. When asked to identify the top two biggest challenges to well-being, self-acceptance surpassed relationships as an issue of concern by a full ten percent. Yet, the literature fails to mention self-acceptance as being a significant challenge in autism.

Self-acceptance is a primary theme because it emerged as important to well-being in each of the three research methods and was described by 100% of the participants. It is situated firmly in the UL quadrant and appears to be intricately linked with awareness and growth and learning.

While the majority of experiences described relating to self-awareness were positive and optimistic, many shared experiences regarding self-acceptance were not. Participants either had achieved it or had not, with participants appearing to not see it as an ongoing process. Through these findings an important question emerged: to what extent does the development of self-awareness influence the development of self-acceptance in individuals with HFAC?

### **5.14 Conclusion**

The 12 primary themes described in this chapter were identified as being especially important, either because they emerged from each separate research method or because they

## WELL-BEING IN ADULTS WITH HFAC

connected in each of the four IMP quadrants. Each of these primary themes connected with other themes emerging throughout the study. Analysis of these primary themes illustrated the importance of well-being itself as an integral theme in the lives of participants.

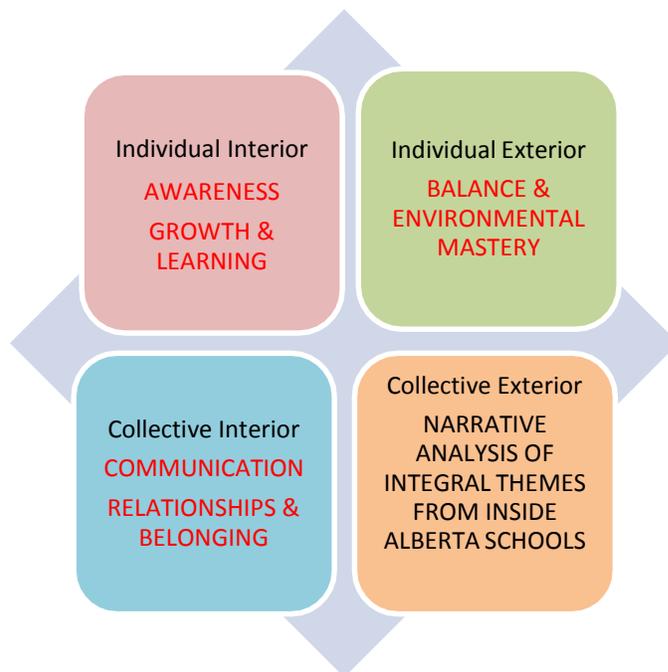
## **Chapter 6: Narrative Analysis of Integral Themes in Alberta Schools**

### **6.1 Introduction**

Of the 12 themes identified as primary, five stand out because they emerged as truly integral themes in the topic of well-being and high functioning autism:

1. Growth and Learning
2. Awareness
3. Balance and Environmental Mastery
4. Communication
5. Relationships and Belonging

These five themes were revealed by each of the three methods of research used for this study, and also clearly connected with each of the four quadrants. Just as the primary themes were emerged out of the many smaller themes uncovered in the study, these integral themes are fed by the primary themes. Integral themes, while fitting into each of the quadrants, can also be seen as being situated more firmly in one quadrant than any other, as illustrated in Figure 16.



*Figure 16. Integral themes by IMP quadrant.*

Surprisingly, the collective exterior remains empty up to this point. While the integral themes clearly connect with the LR quadrant, none inhabit it as a primary residence. By examining integral themes through the lens of the education system, we can assess how we might better support the development of well-being in learners with HFAC, and develop future research directions. This chapter will use a narrative analysis approach to examine these themes as they are currently enacted in Alberta schools. Analysis of each integral theme engendered recommendations for improving our current education practices, which are identified at the end of each theme.

### **6.2 Personal Growth and Learning**

This theme relates most clearly to our education system. Traditionally, curriculum has referred to the planned interaction between the learner and a predefined educational content. A quantifiable curriculum, with clear measures for assessing knowledge and skills, remains important. My experience is that most of my students with HFAC are very successful in this type

## WELL-BEING IN ADULTS WITH HFAC

of learning. While many of my students benefit from accommodations that support learning disorders that are common in autism, these are rather simple accommodations that most Alberta teachers make almost automatically. These small accommodations are effective, and upon implementation, teachers will attest to the ability of most of their students with HFAC to master basic knowledge and content. In fact, this type of performance is often considered among the HFAC student's personal strengths.

As a learning support teacher (LST), I have assessed hundreds of students with HFAC over the years. I regularly use standardized achievement tests to identify strengths and needs, and often contribute to intensive educational psychological assessments to provide better insight into how these students think and learn. In the majority of cases, these students possess relative strengths that contribute to their ability to master concrete learning objectives. These strengths include strong short term and long term memory, good vocabulary, the ability to follow clear directions with surprising accuracy, and good academic skills. Yet these students have been referred to me for a reason. Something is preventing them from achieving their potential, and it isn't a lack of academic skills.

I have counselled countless teachers who are frustrated by their student's obvious potential but seeming unwillingness to use their ability as they should. Teachers often interpret the student's lack of motivation and refusal to cooperate as blatant disrespect of the teacher's authority and person. This often means that, what should be one of the strongest and most important relationships in that student's world is irreparably damaged due to a reciprocal misunderstanding. The teacher is left feeling both helpless and hurt, while the student is often angry and confused. Both teacher and student become firmly rooted, stubbornly adhering to their own position and perspective. The teacher is usually aware of her own position and perspective,

## WELL-BEING IN ADULTS WITH HFAC

but the student has often not yet matured enough to recognize that he or she even has a perspective. The student sees only injustice.

The teacher works with this student for a year with little success and, ideally, recovers herself at the beginning of a fresh new year and a new group of students. In a worst case scenario, the child never becomes aware of what the problem actually was. The problem festers as an unresolved issue that is bound to be repeated again in subsequent years. Over the years this frustration grows into anger and helplessness, born from confusion and a perceived lack of ability to change. It takes a toll. I suspect this student begin to see her experiences of school in the same negative light in which so many study participants described the education system and their school experiences.

While some participants enjoyed the school experience and moved onto post-secondary education, the majority had poor experiences in the educational setting. At first glance this is surprising, considering the overall consensus that growth and learning is a well-being strength for them. On the other hand, I have seen so many students with HFAC who lacked validation during their school years, as it is difficult for an uninitiated teacher to provide sincere validation of a student who seems to insist on behaving in a manner that is in direct opposition to the kinds of conduct we are accustomed to validating.

I have witnessed school as a setting of bullying and abuse. I have been able to step in to protect children, but have found it so difficult to be proactive towards helping to prevent it in the future. I have known school as a place where HFAC students were made to feel like underachievers for not meeting their potential. I have seen school as the setting where these students began to become aware of their differences and first experienced a sense of alienation. I understand that school is the place where many of my HFAC students first experienced anxiety,

## WELL-BEING IN ADULTS WITH HFAC

which, for some, later crippled them and contributed to the depression they still struggle to control.

At heart, I believe the nature of the challenges that many HFAC learners face in school is a direct reflection of how teachers understand and interpret curriculum. When we educators view the mastery of clear cut knowledge and skills as success, and this remains our only criterion, we do these children a disservice. Students will either do it, or they won't; they will be successful, or they won't. If they have the academic skills to be successful but they are not, it must be because they choose not to be successful. And a teacher cannot be held responsible for student choice. That is the responsibility of the student and her parents.

This concrete and literal focus on the hard curriculum sets a dangerous tone. It is too easy for the teacher, the student, and the parents to become divided and even adversaries. The most important tenet of successful teaching and learning—that of good relationship between teacher and student—is so easily broken.

More recently, we have seen a movement towards recognizing the value of soft skills and hidden curriculum. We are seeing programs of study that emphasize the importance of working with other people, critical thinking, and combining and transferring knowledge and skills for innovation and problem-solving. These are bound to remain important outcomes as new curriculums unfold. What is currently missing is a task analysis of the foundational skills needed to meet these outcomes. I can attest that the skills impaired by autism—specifically those centering on communication, the ability to work with other people, and cognitive flexibility—are bound to be important tools for meeting these important outcomes, and these are tools that the majority of our students already possess.

## WELL-BEING IN ADULTS WITH HFAC

In our classrooms we immerse students in opportunities to practice and demonstrate their ability to meet these lofty outcomes, but I am not aware of any teachers who really know what the foundational skills for achieving these outcomes are or how to identify them. We are certainly not confident in our ability to teach these skills. I liken this to handing a four-year-old a book and telling her to read it. It may be that this little girl has never held a book or even been read to, but the teacher still sits by, adhering to the time-honored principle that practice leads to improvement.

Adults with HFAC in this study identified, as an important asset to their well-being, their passion for and ability to grow and learn. Generally, participants described this trait as developing in their mid-twenties. Aside the acquisition of basic literacy and numeracy skills, there didn't seem to be a strong connection between what they learned in school and this important asset.

Participants also described autonomy and purpose as being strong well-being assets, and many of their comments and anecdotes suggested that these traits were present at a young age. How might these traits look in a young student in school? I see two diverse possibilities. If the student understands expectations and the reasons for them, and if the student feels safe and validated, then these traits will be assets. The student will work in alignment with teachers, focusing her talents and skills toward success. This success will beget more success; the student is likely to have a very positive experience in school.

Now, looking at these strengths in a different context, we can see how these traits may instead cause harm to the growth and development of the child. Suppose that the student doesn't understand the expectation or sees no purpose for it. Think about the student not feeling comfortable with her relationships in school, feeling disrespected and not validated. In this case,

## WELL-BEING IN ADULTS WITH HFAC

the student's strengths in autonomy and purpose, which feed her determination and desire for justice, can easily make her into an oppositional learner. Depending on personality, this opposition can manifest as either defiant or unreasonable, or perhaps as passive aggressive. Regardless, without adult intervention, the door to happiness and success in school is likely to begin to close.

### **Recommendations.**

1. Work is done towards identifying the foundational skills that are essential to a student's ability to work in groups, think critically, and to combine and transfer knowledge and skills towards innovation and problem-solving.
2. Knowledge of these foundational skills, organized and accompanied with possible teaching strategies, be systematically presented to teachers in a manner such that this knowledge can supplement existing curriculum instead of becoming new curriculum.
3. Teachers recognize that positive relationships with students with HFAC will be critical for students' growth and well-being, now and into the future.
4. Teachers understand the importance of perspective and context in defining whether autism characteristics will be reflected as strengths or challenges.

### **6.3 Awareness**

The emergence of self-acceptance as perhaps the most significant challenge to well-being experienced by adults with HFAC was a personal surprise to me. I have observed countless examples where the behavior of students with HFAC suggests the opposite. They appear insensitive and uncaring as to how people around perceive them. Not only are they limited in their ability to recognize other perspectives, when these differences are brought to their attention it is not unusual that the student will deny or dismiss them.

## WELL-BEING IN ADULTS WITH HFAC

Their commitment to their own perspectives, to their own self, often manifests as a young person who sees other people and their perspectives as being less important than their own. There is almost always insensitivity, even disrespect, in how these kids value their peers. They become fixated on their own perspective, which persists even when their attention is drawn to how others are impacted. This fixation, often described as being stubborn, unreasonable and unkind, hinders their ability to connect and form relationships.

Restricted ability to recognize and respect the thoughts and feelings of peers is among the first clues I see for recognizing a child on the spectrum when they come to school. Yet these clues can be very subtle. All young children pass through a developmental phase of being focused on self at the expense of others. We work to help them learn to recognize and respect the different perspectives of those around them. It is the classic stage of teaching toddlers and preschoolers to “play nice”, to acknowledge “the golden rule”.

This characteristic emerges around the same time in development that it does for other children. Initially, the only indication that something might be askew is often the greater extent to which it is demonstrated. A child on the spectrum is likely to find the lesson of recognizing and respecting others more difficult to learn, and may respond to this lesson far more dramatically. Temper tantrums, normal in children learning to balance their personal needs and wants with the demands of the outside world, gradually extend into what parents and teachers will later describe as “autistic melt-downs.”

I believe that this phenomenon is predicated by limitations regarding *awareness of self* as well as *awareness of others*. While kids know very clearly what they want and don’t want in any given situation, they often lack the understanding as to why they want it, how their behavior is

## WELL-BEING IN ADULTS WITH HFAC

influencing their ability to achieve what they want, how what they want is interpreted, and how it affects the people around them.

I argue that the ability to know what they want is not a form of self-awareness in the autistic child because this ability to know does not require conscious recognition, but rather is a mere reflection of the child's current state. A baby will cry when he is hungry, but this is a spontaneous response to a condition that does not require conscious awareness. The baby does not think to itself, "I am hungry, I had better cry to let somebody know they should feed me."

With a tendency toward strengths in autonomy and directing behavior to achieve goals for a purpose, students with HFAC will employ their exceptional skills of attention to detail and focusing attention to achieve what they want. With limited awareness of the reasoning behind what they want and challenges in seeing the big picture through the details, their stubborn fixation on what can be viewed as selfish and petty behavior begins to make sense. A pattern of behavior emerges that is characteristic in the profile of a person with HFAC. An adaptive behavior that is often reinforced by getting them what they want at the moment becomes a maladaptive behavior that is costly in the long run.

In schools, staff and students are very aware of this limitation in children and teens with HFAC. We see, from an outside perspective, students who are rigid and stubbornly persist in disregarding and disrespecting people around them. We tend to label these students as willfully engaging in behavior that hinders their ability to form mutually respectful and healthy relationships. We see young people take an active role in cultivating one-way relationships where they are happy to take but not willing to give unless it suits them. From this outside perspective, the young person is not viewed with sympathy and compassion. The tendency is to treat the individual with HFAC the same way that she is treating other people, holding onto the

## WELL-BEING IN ADULTS WITH HFAC

misguided belief that this treatment will make her recognize how her behavior makes other people feel so that she will self-correct it. Again, we fall into that pattern of thinking that practice will improve a skill that doesn't yet exist.

What if we change the way we understand this particular behavior characteristic? As adults in a school system we must work to maintain diligent awareness that this behavior likely stems from (1) a lack of conscious awareness of what and why the student wants something, (2) a limited awareness of the perspectives of others, (3) a lack of awareness of the bigger picture that this moment is a part of, which are all compounded by (4) a severe and biological restriction of the ability to shift attention away from the immediate moment. Indeed, this then becomes a teachable moment of an ability that will be critical to the student's well-being throughout life.

How, then, might this limitation towards self-awareness and awareness of others transform over time into a debilitating state of self-acceptance later in life? Imagine countless instances of being criticized as a selfish and self-centered person, of being told that you behave in a manner that makes people not want to befriend you. Imagine being told, over and over, that you do this to yourself and that, by persisting in this behavior, you don't deserve or are not capable of having good friends and close relationships. Understand that the person receiving these messages struggles with an impairment relating to being able to understand the more abstract *why* implicit in these messages, but possesses a sufficient ability to understand the more concrete *what* of these messages.

HFAC individuals can listen and be aware that people don't like certain parts of who they are, but likely can't truly understand why they are like this or what to do about it. A public form of self-awareness may develop, in which the individual perceives how aspects of his personality, behavior and emotion appear to others. What is lacking is a private sense of self-awareness, of

## WELL-BEING IN ADULTS WITH HFAC

understanding one's own personal motivations and tendencies contributing to this behavior. I have seen evidence that there is a tendency to eventually just accept this as part of oneself. By middle school, many of these students have withdrawn from their peers in favor of pursuing more safe and solitary patterns of behavior that promote autonomy and the development of self, but at the expense of relationships. The damage has the potential to move beyond inhibiting the development of relationships. Left unchecked, it can threaten the sense of self that might initially have been a personal strength for people with HFAC. A poor sense of awareness of self and others threatens to erode the individual's sense of self by sabotaging the individual's self-acceptance.

### **Recommendations.**

1. Recommended future research directions:
  - a) To explore how education focusing on improving self-awareness and awareness of others in young people with HFAC influences self-acceptance later in life.
  - b) To explore possible connections between an improved awareness of self and others and satisfaction in personal relationships for people with HFAC.
2. Strategies to improve metacognition are specifically taught to students with HFAC.
3. Teachers strive to understand that inflexible, self-centered patterns of behavior on the part of students with HFAC are likely the result of combined impairment in the student's awareness of self and others as well as difficulty in shifting attention. Focusing on developing awareness is likely to be more beneficial than attempting to eliminate the undesirable behavior itself.

### **6.4 Balance and Environmental Mastery**

This theme involves the challenge of balancing optimal mental health, emotional well-being, positive relationships, while also meeting the demands of daily living. By stepping back and looking at the issue from the teacher perspective, it becomes clear that this challenge is firmly rooted in two characteristics of autism: propensity to see detail (often at the expense of the big picture) and hyper-focus. As a teacher, I can't say that I readily or easily connected the challenges my HFAC students face with this theme.

However, upon consideration I recognize that my colleagues and I frequently discuss a student's lack of ability to separate detail from big picture or the student's lack of compliance when instructed to redirect her attention. These behavior challenges are most often evident during times of transition in the school day. Problems of all sorts develop when going to or coming from recess and lunch breaks, and in moving from classroom instruction to less structured environments like gym class. Changing from one school subject to another or even shifting attention between learning activities is frequently problematic. A common strategy built into almost every student with HFAC's individualized program plan is to provide visual schedules and plenty of advanced warning ahead of transitions. This requirement is a clear example of HFA challenges in balancing attention and environmental demands. Students often have difficulty flexibly moving away from an established pattern or routine to a different one, even if it is familiar.

This struggle for balance can also be seen in less concrete ways. The idea of connecting the interior individual with the exterior collective—so important in communication and relationships—is also really a matter of balance. Balancing personal awareness with awareness of others is almost always difficult for students with HFAC. The tendency to completely

## WELL-BEING IN ADULTS WITH HFAC

immerse oneself in one way of seeing, thinking and being—which in some contexts is described as an autism asset—crosses over to become weaknesses of balance, which are represented by challenges in transitioning, and rigid restriction to a singular pattern of thought or behavior. Perhaps this lack of ability to balance is implicated in our HFAC students' struggles with empathy, communication and relationships. Even sensory issues take new meaning if observed from the perspective of lack of balance.

When considered from the theme of balance, an ongoing issue that has caused problems for one of my students for many years begins to make sense. As a junior high student, he adamantly and creatively finds ways to sneak or hide small electronic items on his person. Between classes, walking the halls, he obsesses over how these items work, and clearly loses himself in taking them apart and reconstructing them. From the beginning, his interest in and understanding of electronics had been considered an asset. However, it is also the source of many of his problems. As he carries the item between classes, he starts to tinker. Upon arriving at his destination (often late because he stops and becomes completely absorbed in the task), he is unable to redirect his attention away from the item. The result is a complete lack of awareness regarding his classmates and teacher, and the inability to attend to the class lesson. Worse, when the teacher intervenes to redirect him, the young man frequently regresses to temper tantrum like behavior, which damages him emotionally, socially, and occasionally physically.

Another young woman in grade 8, with exceptionally strong academic skills, is regularly at risk for failing academically because of her inability to balance the focus of her attention. In her school, as part of a division-wide focus on literacy, students are expected to carry a personal reading book with them throughout the day. However, this young lady becomes so absorbed in her reading that she refuses to put the book away and attend to the lesson or participate in

## WELL-BEING IN ADULTS WITH HFAC

teacher-directed learning activities. She is the only student in the school who is not encouraged to carry a reading book with her; in fact she is prohibited from it. To her this is a great injustice. She feels segregated and unfairly targeted. While she can understand the reason for this differing expectation for her cognitively, she cannot relate with it personally. In protest, she frequently finds other items or distractions to immerse herself in to the same effect. In recent years, school has become a place that this gifted student does not want to be.

It is possible that this lack of ability to balance attention and focus is also reflected in the tendency for students with HFAC to go on infinitely about a topic in extreme detail with what appears to be a lack of concern for the interest level of their audience. I have witnessed teachers attempt to physically escape or hide from a student with HFAC who is intent on engaging in conversation on a topic that is not appropriate for such intense discussion.

As students with HFAC advance into their high school years we usually see visible progress relating to the overt behavior challenges common at younger ages. However, more difficulties emerge relating to their ability to balance their time and attention to ensure that assignments are completed. Kids with HFAC often tell me that they focus their time and energy specifically on one subject at the expense of others, a challenge that is only mitigated by reducing the quantity of their course load or with the implementation of a strict schedule indicating when they must focus on what.

In the past year, two of my HFAC students have changed school divisions in order to take only two courses at a time. I have known some students to transfer out of traditional high school to an online school where they can reduce the subjects that they must focus on, thereby reducing the need for balancing their time and attention. Even with these accommodations, I frequently hear students say that they find school exhausting and anxiety provoking. When I ask why, these

## WELL-BEING IN ADULTS WITH HFAC

young people struggle for an explanation, they just know that it is. I am certain that challenges in balancing their time and attention to meet the demands of high school life contribute to their perception of school.

### **Recommendations.**

1. Teach children from a young age to distinguish between supporting details and important ideas to help them achieve balance and meet the demands of daily living.
2. Draw student attention to the importance of balance in their lives; teach strategies for promoting balance relating to awareness, attention, and techniques for managing multiple obligations and expectations in their environments.

### **6.5 Communication**

As a LST, one of the most perplexing and challenging tasks I face in understanding and advocating for students with HFAC revolves around language and communication. Autism tends to be a condition represented by a dichotomy of strength and weakness. Language is the one area where skill and challenge swirl together in a paradoxical void. The result can be a gap between the student and the world around them, a gap we sometimes seem to lose kids in.

I have often read about very young children described as ‘little professors,’ with examples of preschool aged children whose passion and interest for a particular topic results in them becoming miniature experts on the subject, possessing an acute memory for even the smallest detail about their beloved interest. This can be accompanied by an impressive vocabulary that sometimes includes terms that many adults have never heard.

With a student’s attention almost always focused on their particular topic of interest, conversation tends to mostly revolve around that subject. The student with HFAC’s impressive, precise and detailed vocabulary skills can easily be mistaken by adults as being transferable to

## WELL-BEING IN ADULTS WITH HFAC

other topics and into other situations. It is understandable that so many of us are surprised and confused to learn that this strong vocabulary often masks a moderate to severe communication disorder.

Effective communication calls on both expressive and receptive language skills, and participants must be able to both send and receive verbal and non-verbal messages. All of the students I have worked with who have HFAC are able to participate successfully in verbal language exchanges, seemingly expressing themselves succinctly and understanding what they hear. However, this can be misleading. They are able to work very well with language on a concrete and literal level, but their ability to recognize and interpret non-verbal cues is almost always lacking. I frequently see impaired comprehension when it comes to skills of listening and interpreting body language, with the intended message being lost on a student with apparent language strengths connected with concrete and literal language.

If this reality were a stage production, the scene would be set for a show where severe miscommunication leads to the development of an interesting problem with funny antics as each important player acts out their role. The resulting irony in the situation is likely to be resolved by the end of the performance, leaving the audience comfortable and satisfied. Sadly, this is not how things usually work out in the real-life communication of students with HFAC.

Too often, participants in the communication exchange will remain unaware that there has even been a breakdown in communication. With each party believing that all messages have been clearly sent and received, the conversation concludes. Working under the assumption that each heard and understood the same thing from the conversation, the parties are perplexed by what appears to be behavior contrary to the intent of the conversation.

## WELL-BEING IN ADULTS WITH HFAC

A grade five student with HFAC started the year adamant to not participate in any assignment or activity involving writing. As the year progressed and a relationship grew between him and the teacher, he began to occasionally engage in writing activities. During a program-planning meeting the teacher discussed her inability to understand why he would participate in some writing activities, but not others. The teacher described situations where he would participate as directed, but upon completion when she would ask nicely if he would please take out his writing journal, he would politely decline. After some discussion, we wondered if the difference might lie in the teacher politely asking him to do something versus the teacher politely telling him to do something. When this theory was put to the test, the young man did participate in writing activities more frequently (although still not consistently). The boy interpreted the direction as a request, which technically it was. Both parties believed that they comprehended the meaning in the exchange the same, but the difference in understanding had a significant effect on the outcome of the exchange. This type of miscommunication occurs far more often than we recognize.

Another example of a communication challenge is illustrated by a parent of a high school student with HFAC. The young man, aware that he frequently missed the larger meaning in communication exchanges, was very anxious about informal conversation in social situations. The mother described how she would sometimes receive multiple phone calls from her son throughout the day where he described social conversations to the smallest detail and asked for confirmation of his interpretation of them. A typical conversation would sound like this:

Son: Hello Mom. In Social class, before we started, Joe said this. Jane then said this. I said this, and then everybody laughed. Was it funny?

Mother: Yes son, I think it was.

## WELL-BEING IN ADULTS WITH HFAC

Son: Good, thank you. Were they laughing with me or at me?

Another parent described his son as having a predilection towards television shows with an element of physical comedy. The boy loved Seinfeld, mostly because of the scenes with Kramer. The father believed it was because the son was more able to see when Kramer is funny because of his lack of physical coordination and his many stumbles, trips and falls. At the same time, when the laugh track came on for more abstract forms of the comedy, the son frequently interrupted with, “Is it funny? Why is it funny?”

An important challenge that I see in communicating with students with HFAC lies in the student’s level of self-awareness. When a student exhibits a limited verbal response, it is sometimes hard to determine whether he is hindered by an inability to communicate his thought or emotion or whether he actually has limited meaning to convey. Many times, when I have not been able to understand the behavior of a student with HFAC, I ask him or her why they are acting in a particular way. The most common response I hear is “I don’t know.” Students quickly become frustrated with my attempts to dig deeper for clues as to what they might be thinking or feeling. My assumption has been that they must know, but do not want to intimate the reason, or are unable to communicate it. But I suppose it is equally possible that they truly don’t know. If this were the case, it is easy to see how my not accepting their clearly communicated response could be frustrating or even disrespectful. This may be an example of authentic communication that conveys a message about the student’s lack of awareness and understanding of her own motivations—in which case the message has effectively communicated the student’s meaning. On the other hand, the student’s response could instead represent a difficulty in articulating the meaning itself. This is a big challenge for adults working with students with HFAC.

## WELL-BEING IN ADULTS WITH HFAC

Throughout my years as a LST, I have found the support of speech and language pathologists (SLP) very helpful towards the development of educational programming for students with HFAC. In more recent years, I have begun to pursue this support as soon as I recognize that a student is exhibiting characteristics of autism. Initially, it was a challenge for me to access this service for students older than grade three. The system tends to focus SLP support on early intervention. With limited funding for such support, students tended to automatically be discharged after division one. However, my efforts to extend this support to older students on the autism spectrum have paid off. Teachers and parents are almost always surprised with the initial assessment results because they truly did not understand the extent of their child's communication challenges. I have found the benchmark assessment useful to help identify where the student sits on the language continuum, at which point it becomes much easier to identify specific areas of deficit and plan for improvement.

### **Recommendations.**

1. Parents and school staffs should recognize the likelihood that communication challenges in students with HFAC are more significant than they appear.
2. SLP support should be made available for students with HFAC as early as possible, and should extend to include the duration of the student's school years if necessary.

### **6.6 Relationships and Belonging**

A desire to understand my student's relationship needs was an initial motivation for this research interest. Intensive literature review and deep investigation were not required to unveil the predominance of unsatisfactory interpersonal relationships in students with HFAC. School staffs often express a concern in both the limited quantity and quality of social connections that our HFAC students seem to make. What is less apparent, and really at the heart of the matter, is

## WELL-BEING IN ADULTS WITH HFAC

any real understanding as to how much of this deficiency in peer interaction is caused by lack in social ability and how much is a reflection of personal preference on the part of the student.

Strong relationships are the underpinning of successful organizations, and I like to think that this assertion is recognized more in the field of education than other systems. Research is rife, as it has been throughout history, with understanding of the vital connection between learning and relationships. Likewise, much focus in autism research is devoted to communication, social skills and relationships. So it may be a surprise to many people that there is limited activity in our schools geared towards supporting the development of relationships between children with HFAC, their peers, and the adults that teach them.

Most students with HFAC are easy to identify, even through the eyes of somebody without any experience. They tend to sit away from other students in the classroom, often initially as part of a seating plan developed by the teacher as a tool for reducing disruptions caused by social challenges and outbursts.

As the student gets older, he or she will often choose to be seated away from other students. This might help to accommodate sensory challenges, but more often it appears to be a manner of establishing a safety zone. With years of negative experiences stemming from failed social interaction, keeping a distance from other kids provides a buffer zone where a student with HFAC is less likely to face unkind words or actions from other kids. The space sends a signal that the HFAC student doesn't care about being accepted by peers and cannot be troubled with the bother of connecting with them. An understanding that they are completely independent develops; that they don't need or want social interaction. The safety zone can become an isolating barrier that permeates other areas of life. It appears as though the HFAC student does not want social connections.

## WELL-BEING IN ADULTS WITH HFAC

In the past, I have frequently identified deficits in skills that contribute to the social challenges of students with HFAC. I have put effort into directly instructing students regarding these skills, helping them to practice these skills around the educators and other adults in the school, then with a safe partner, and finally within small groups in a controlled environment. Then, after a clearly defined plan for implementation, which the students were fully involved with and enthusiastic about, watch as the plan fails. I know that the student wants to befriend a particular peer. I know that the peer will be receptive, and I know that the HFAC student has the skill and ability to successfully initiate a relationship. Yet time after time, I have seen it simply not happen. I have asked students why they don't apply the skills they have towards making a friend, and time after time I hear the same response: *I don't know*.

The closest I have come to even a glimpse of the answer to this puzzle came from an insight shared by a participant in this study. The young man, a student, described a scenario where he might be walking down a hallway in the university alongside a classmate. He described consciously thinking that this seems to be a person he likes and probably has a great deal in common with. He is aware that this person has the potential to be a friend, and that he would really like to cultivate a relationship with this person. He is also consciously aware that he has the required social and communication skills to initiate the relationship. The young man then explained to me that he is likely to make a decision not to pursue this relationship because he knows that the effort required to develop it will be both exhausting and overwhelming. He summarized his choice by explaining that it is simply easier to not bother, to acknowledge the person on a casual basis and to keep walking.

Key to the participant's ability to share this insight was his clearly articulated state of awareness. This study indicates that self-awareness tends to begin to develop later in individuals

## WELL-BEING IN ADULTS WITH HFAC

with HFAC. With this in mind, it is quite possible that my young students' inability to articulate why they do not utilize the skills they have learned towards developing relationships stems from lack of self-awareness. It is equally possible that, regardless of this limited awareness, the underlying reason for not initiating relationships is the same as described by the young man. This suggests the potential value of further exploring the conditions and the process of implementing existing skills and abilities towards the development of personal relationships.

These same phenomena may be core to the study theme of mimicking and masking, which was not identified as a primary theme but is worth summarizing here. 71% of the participants in the phenomenological interviews described situations in which they understood the social expectation and chose to follow the norm, even if they did not agree with it or it came at a personal cost. Participants were often aware of forcing themselves to do something that was much more difficult for them than it appeared to be for others, merely for the sake of conforming. As one participant described:

“Now I am one of those people who has learned to mimic, mask, cope or otherwise—and exceedingly well. Where it is masked and you don't know a lot of things unless you know me well, and of course hardly anybody knows me well; but it isn't easy and I don't think that it is necessarily fair.”

Human interaction is a complex issue, and there aren't any quick and easy answers that can apply to all students with HFAC. There are factors that influence the development of relationships other than social and communication skills. For example, school is often an environment in which HFAC students first encounter bullying and harassment. This should not be surprising considering the tendency to lack prerequisite skills for developing and maintaining relationships. What are less predictable are the long term effects of such encounters on a child,

## WELL-BEING IN ADULTS WITH HFAC

and the future developmental trajectory such experiences launch. It seems logical that early shaping experiences are likely to have serious implications for the development of self-acceptance over time, which in turn affects one's ability or desire to pursue relationships.

My personal assessment is that this critical development walks the fine line between being an educational issue and being a mental health issue. Fine lines, when marked with the rigid flexibility that often characterize bureaucratic systems, become cracks. As money has become tight in both the education and mental health systems, this crack has expanded with too many of students with HFAC being swallowed within.

Ten years ago, my school employed two full-time LSTs, a full time family school liaison counsellor (FSLC) and a child youth care worker (CYW). We are entering the 2016/17 school year with a .5 LST and a .5 FSLC. We have not employed CYCWs in our schools for many years, yet we have more students coded with exceptional needs than ever before.

The typical profile of a HFAC learner does not require intensive academic support within the classroom, as this learner often possesses sufficient academic ability. This is not where the critical support is needed. The help is needed someplace alongside, where skills for understanding and connecting with others can be explicitly taught and then subtly coached in context during less structured moments of the busy school day. Despite my greatest efforts towards advocating for the needs of these kids, the system continues to maintain that such support is a luxury that cannot be accommodated in such challenging financial times. Year after year, I watch too many of these amazing young people fall a little more behind, step a little further outside of the circle of daily interactions, and remove themselves just a little more from the vital connections that are so important to their success and well-being, both now and in the future.

## WELL-BEING IN ADULTS WITH HFAC

While answers are elusive, the problem itself is clear. As a group, students with HFAC are less able to develop the relationship skills that we tend to expect people to naturally and spontaneously acquire. Teaching students the necessary skills and understandings that are the foundations for good relationships, and helping them to develop the ability to navigate a world based on abstract social conventions should not be considered a privilege that we grant students only when times are good. It should be a right within our education system.

### **Recommendations.**

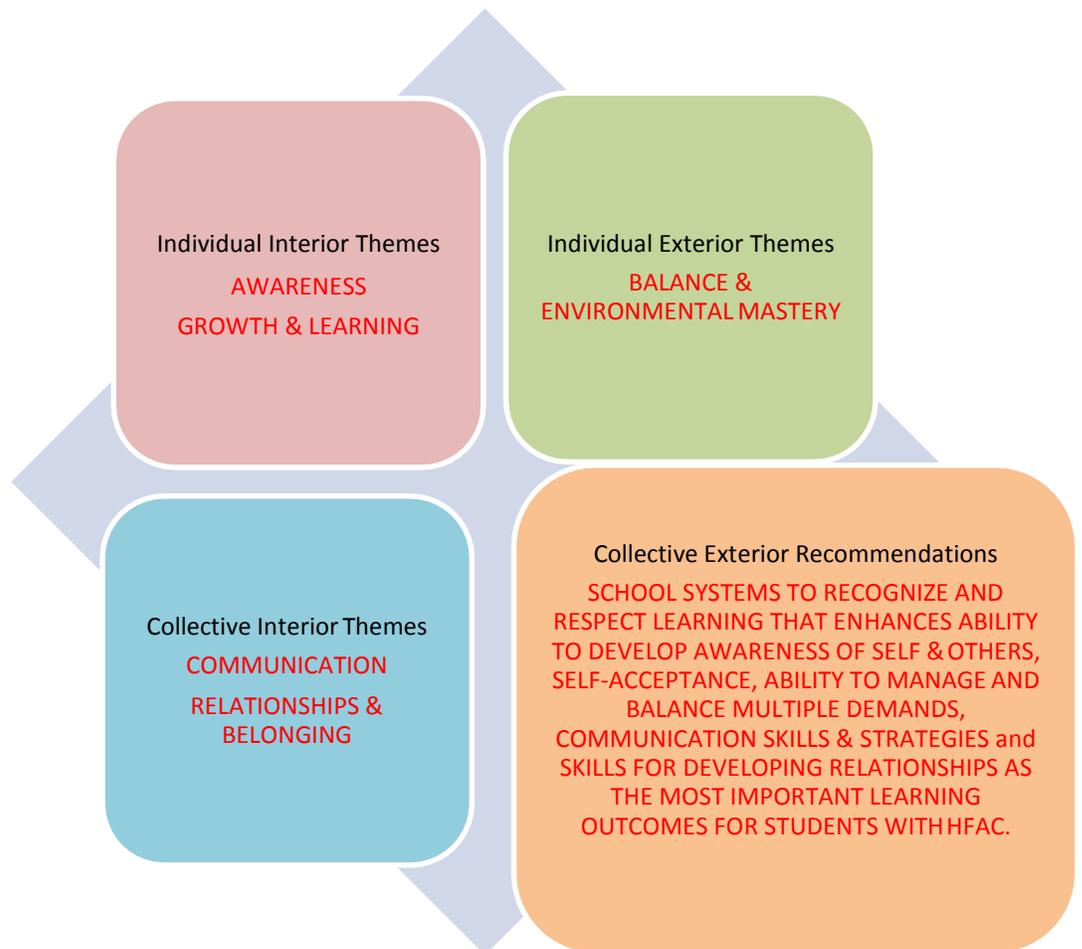
1. Parents and professionals recognize that the unsocial behavior of students with HFAC, who often appear fully capable of developing relationships, does not necessarily reflect a lack of desire or need for close personal relationships.
2. Schools provide a safe and structured environment in which young people can pursue their interests alongside peers in a social academic environment, limiting the requirement for students with HFAC to socialize only during breaks in busy, unstructured environments.
3. Schools are funded to be proactive in providing supports for teaching skills and assisting in the development of relationships for students with HFAC.
4. Future research focus expands beyond the skills and conditions required for developing relationships in individuals with HFAC, to the challenges inherent in utilizing these skills.

### **6.7 Conclusion**

This chapter began with the identification of integral themes, each of which corresponded to a particular quadrant. The LR quadrant, initially left empty in the absence of any particular theme grounded within it, was addressed through a narrative analysis of each integral theme as it

## WELL-BEING IN ADULTS WITH HFAC

related to enactments inside of schools. While specific recommendations were made relating to each theme in the context of education, it makes sense to summarize the results of the narrative analysis by filling in the previously empty LR quadrant. This summary is represented in Figure 17.



*Figure 17. LR recommendations derived from narrative analysis of integral themes.*

## **Chapter 7: Conclusions**

### **7.1 Introduction: Research Questions Answered**

This chapter addresses the research questions that were proposed at the beginning of the study. It is organized using the integral methodological pluralism (IMP) quadrants from which each question emerged. A summary of the study results is presented, along with recommendations concerning how we—as individuals, as school communities, as a system—can improve education for learners with high functioning autism characteristics. The chapter concludes by revisiting the study problem and purpose statement, with a call for future action.

### **7.2 UR: The extent and nature of high functioning autism characteristics as identified and described by participants**

This section summarizes study results pertaining to the research question, “what is the nature and extent of high functioning autism characteristics as identified and described by study participants?”

As a group, the participants in this study exhibited autism characteristics that were clinically significant (based on the Autism Quotient). Characteristics from the autistic phenotype were described as permeating and influencing all areas of their lives.

Challenges relating to attention switching were identified as the most severe autism trait, followed by impairments to social skills. Both attention to detail and communication were identified as being equally disruptive. Imagination was presented as being the group’s least significant challenge.

### **7.3 UR: Well-Being in participants with high functioning autism characteristics**

This section summarizes study results relating to the research question “how was well-being experienced and described in people with high functioning autism characteristics?”.

Participants identified and described overall well-being as being lower in people with HFAC than that of individuals and groups from other studies. To date, this appears to be the first study that used the Psychological Well-Being Scales (PWBS) to measure well-being in people with characteristics of high functioning autism. By comparing the results of the PWBS with the deeper insight provided through the interviews and conversations, it appears that the PWBS was an effective instrument for measuring well-being in people with characteristics of high functioning autism.

It is important to remember that the PWBS was not developed with the intent of providing scores indicating strong or weak levels of well-being. The scales are intended to indicate areas in which individuals are currently experiencing satisfaction and areas that may require attention towards developing an improved sense of well-being.

A pattern emerged in this study where participants described self-acceptance and personal relationships as being the most significant challenges to well-being faced by people with high functioning autism characteristics. Challenges relating to skills in developing and maintaining relationships are consistently documented in autism research, so it was no great surprise that dissatisfaction with personal relationships emerged as problematic for participants. However, reports that difficulties pertaining to self-acceptance may be just as significant of a threat to the well-being of individuals with HFAC was a surprise. Self-acceptance is seldom explored in autism research.

## WELL-BEING IN ADULTS WITH HFAC

Study results describing autism characteristics that enhance well-being offered a similar surprise. It makes sense that autonomy was highly valued as an important asset to well-being, considering the typical profile of an individual with characteristics of high functioning autism. What was not expected was that participants indicated continuous growth and learning as a very important asset to their well-being. While younger students in the school system often demonstrate academic learning strengths, they also frequently exhibit a limited level of awareness and also experience challenges in seeing the big picture of any given subject. This can result in a mechanical learning process in which the transfer of knowledge and skills can be impaired.

Many participants described a dawning sense of awareness of both self and others in their young adult years—an awareness resulting in an ongoing quest for knowledge and understanding relating both to themselves and the world around them. This was described as contributing greatly to their sense of well-being. This passion for growth and learning was evident in the majority of participants and seemed to remain strong in participants, regardless of how old they were.

### **7.4 UR: The relationship between characteristics from the Autism Quotient Scale and the dimensions of the Psychological Well-Being Scale**

This section discusses study findings relating to the research question “how did participants describe the characteristics of high functioning autism as influencing well-being?”

Clear connections between the quantity and quality of high functioning autism characteristics (HFAC) and how each characteristic influenced particular dimensions of well-being, as assessed by the AQ and the PWBS, were identified. However, the quantity of data does

## WELL-BEING IN ADULTS WITH HFAC

not permit inferences beyond suggesting potential for further investigation. Strong relationships were suggested relating to the following:

- Poor attention shifting skills may be connected with lower levels of self-acceptance and more challenges relating to environmental mastery. Poor attention shifting ability may also be correlated with well-being in connection with creating a stronger sense of autonomy and personal growth.
- Higher AQ scores relating to attention to detail may be connected to poorer well-being regarding personal relationships, but to a stronger sense of life purpose.
- Weaknesses relating to social skills on the AQ may be connected to poor self-acceptance, but higher sense of life purpose on the PWBS.
- Less impaired communication skills on the AQ seemed to be connected to a higher sense of purpose on the PWBS.
- Less impaired imagination as identified by the AQ seems to have some relationship with a poorer sense of self-acceptance, but also to strengths relating to autonomy and purpose in life.

The data in this quadrant (the scales in the UR) did not suggest a connection between autism challenges relating to either communication or social skills and the level of satisfaction participants described with personal relationships.

No results suggested that the degree of autism characteristics exhibited had any connection to participants' overall sense of well-being. Individuals with higher AQ scores did not necessarily indicate that they had greater struggles with their overall sense of well-being than those who had lower AQ scores. This is similar to an observation made by the team who developed the AQ: after the cut-off AQ score of 26, which indicates a clinically significant

## WELL-BEING IN ADULTS WITH HFAC

quantity and quality of autism characteristics, individuals scoring higher did not appear to experience more or less difficulty with daily functioning than those scoring lower (Baron-Cohen, Wheelwright, Skinner, Martin, & Cubley, 2001).

Questions 7.1 to 7.3 used the UR methodologies, which provided objective measures of the phenomenon under study, without explanation of the phenomena. Question 7.4 sought the qualitative explanations for the phenomena.

### **7.5 UL and LL: Themes emerging as important to well-being in people with high functioning autism characteristics**

The research question addressed in this section is “what themes emerged as being important to well-being for people with characteristics of high functioning autism, and how do they compare with themes of well-being in people who do not have characteristics of autism?”

A total of 23 themes were identified using three different research methods. These themes were organized and then prioritized based on the number of methods in which they emerged and by the IMP quadrant(s) they represented.

A dozen primary themes were identified because they either were identified as important by each of the three research methods and/or they clearly connected with each of the IMP quadrants. These themes related to:

- Advocacy
- Autonomy
- Autism Assets
- Bullying and Abuse
- Diagnosis
- Continuous Growth and Learning

## WELL-BEING IN ADULTS WITH HFAC

- Balance and Environmental Mastery
- Mental Health
- Communication
- Awareness
- Self-Acceptance

From these primary themes, five themes were further extracted as being integral, because they were revealed as significant by each of the three research methods *and* could clearly be located in each of the four quadrants. integral themes were:

- Personal Growth and Learning
- Awareness
- Balance and Environmental Mastery
- Communication
- Relationships and Belonging

Each primary theme was subject to analysis, while integral themes were selected for narrative analysis. Narrative analysis examined how each theme is represented and handled in Alberta schools. Narrative analyses resulted in recommendations specific to Alberta's education system, representing the LR quadrant.

The qualitative and quantitative results indicate that the PWBS is as effective an instrument for identifying well-being dimensions in people with high functioning autism as it is for people without it. The six dimensions identified as foundations for well-being are personal relationships, life purpose, continuous growth, environmental mastery, autonomy and self-acceptance.

## WELL-BEING IN ADULTS WITH HFAC

While the same dimensions for well-being emerged as being equally important for people with and without HFAC, there were clear differences between how the two groups experienced each dimension. Relating to the PWBS dimensions, six the themes emerged, which are identified as significant determinants of well-being for people with HFAC included:

- Autism Assets
- Bullying and Abuse
- Diagnosis
- Self-Awareness
- Mental Health
- Communication

### **7.6 LR: Future directions for improving education in Alberta for learners with high functioning autism characteristics**

This section involves the research question, “what does this study suggest for future directions in improving how Alberta schools can better meet the needs of learners with high functioning autism?”

Through the narrative analysis, the themes identified as integral to well-being and high functioning autism were analyzed in the context of Alberta schools. For each theme, recommendations were made regarding how the system might enhance and facilitate learning to support the development of well-being in students with high functioning autism characteristics. The recommendations fell into three categories and were distinguished by (1) items that parents, professionals and school communities can take independent action towards implementing; (2) items that Alberta Education should attend to, and (3) recommendations for future research directions. Items for each category are identified below.

## WELL-BEING IN ADULTS WITH HFAC

### **Recommendations for parents, professionals and school communities.**

1. Recognize that positive relationships between teachers and students with HFAC will be critical for the student's growth and well-being, now and into the future.
2. Understand the importance of perspective and context in defining whether autism characteristics will be reflected as strengths or challenges.
3. Teach strategies to improve metacognition in students with HFAC.
4. Strive to understand that inflexible, self-centered patterns of behavior on the part of students with HFAC are likely the result of combined impairment in the student's awareness of self and others as well as difficulty in shifting attention. Focusing on developing awareness is likely to be more beneficial than emphasizing the elimination of undesirable behavior itself.
5. From a young age, teach children to distinguish between supporting details and important ideas to help them achieve balance and meet the demands of daily living.
6. Draw attention to the importance of life balance; teach strategies for promoting balance relating to awareness, attention and techniques for managing multiple obligations and expectations in their environments.
7. Recognize the likelihood that communication challenges in students with HFAC are more significant than they appear.
8. Recognize that the unsocial behavior of students with HFAC, who may appear fully capable of developing relationships, does not necessarily reflect a lack of desire or need for close personal relationships.

## WELL-BEING IN ADULTS WITH HFAC

9. Provide a safe and structured environment in which young people can pursue their interests alongside peers in a social academic environment, limiting the requirement for students with HFAC to socialize only during breaks in busy, unstructured environments.

### **System based recommendations:**

1. That information regarding teaching skills for working in groups, critical thinking, and combining and transferring existing knowledge and skills towards innovation and problem-solving be organized and systematically presented to teachers such that this knowledge can supplement existing curriculum instead of becoming new curriculum.
2. Speech Language Pathologist (SLP) support to be made available for students with HFAC as early as possible and should extend to include the duration of the student's school years if beneficial.
3. Schools are funded to be proactive in providing supports for teaching skills and assisting in the development of relationships for students with HFAC.

### **Recommendations for future research.**

1. Work is done towards identifying the foundational skills that are essential to a student's ability to work in groups, think critically, and to combine and transfer knowledge and skills towards innovation and problem-solving.
2. To explore how education focusing on improving self-awareness and awareness of others in young people with HFAC influences self-acceptance later in life.
3. To explore possible connections between an improved awareness of self and others and satisfaction in personal relationships for people with HFAC.

## WELL-BEING IN ADULTS WITH HFAC

4. Future research focus expands beyond the skills and conditions required for developing relationships in individuals with HFAC, to the challenges inherent in utilizing these skills.

### **7.7 Conclusion**

This study contributes knowledge and understanding relating to how well-being is perceived and experienced in adults with characteristics of high functioning autism. This understanding is accompanied by recommendations for improving education towards meeting the unique needs of this growing group of learners in Alberta schools.

Specifically, this study suggests that schools in Alberta are not focused on identifying or teaching the skills and attributes identified as most important to the well-being of HFAC learners. The contribution that schools do make to learning and development relating to the well-being needs of these learners is indirect and supplementary to current curriculum and practices. While schools in Alberta are meeting the needs of students with HFAC in terms of teaching academic skills and specific outcomes from programs of study, this study suggests that formal attention needs to be focused on ensuring that these learners have the opportunity to develop to their full potential.

Educational content that should be pertinent to learning, growth and development for these learners is notably absent on an official level. Strategies and practices to support the specific learning needs of HFAC learners tend to be sporadic and uncoordinated, dependent on the knowledge and advocacy of parents and/or individual professionals.

It is recommended that the school system formally recognize and respect learning that enhances the ability of these individuals to develop awareness of self and others, self-acceptance,

## WELL-BEING IN ADULTS WITH HFAC

the ability to manage and balance multiple demands, communication skills and strategies, and skills for developing relationships.

In today's world the population affected by the characteristics of high functioning autism has grown greatly in number, and our knowledge regarding the condition is expanding almost to match the pace of our increasing diagnoses. A clear assessment of autism characteristics as having both strengths and challenges, was expressed eloquently by Hans Asperger in 1944:

The good and bad in a person, their potential for success or failure, their aptitudes and deficits – they are mutually conditional, arising from the same source. Our therapeutic goal must be to teach the person how to bear their difficulties. Not to eliminate them for him, but to train the person to cope with special challenges with special strategies; to make the person aware not that they are ill, but that they are responsible for their lives. (Asperger, 1944)

Asperger was part of a clinical world that identified limited cases and occurrences of high functioning autism. The condition was initially recognized and interpreted only through the lens of a medical model that focused on physical conditions and mental illness, with an emphasis on therapeutic intervention.

While the condition still maintains a close connection with medical and health sciences, its prevalence should earn it more recognition in education. Education holds promise and potential, for both individuals and society, to identify and promote growing levels of awareness, knowledge, and acceptance. High functioning autism deserves the attention of Alberta Education and its efforts in helping individuals and groups recognize and achieve the ability connected with the disability.

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Appendix A



Conjoint Faculties Research Ethics Board  
Research Services Office  
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**CERTIFICATION OF INSTITUTIONAL ETHICS REVIEW**

This is to certify that the Conjoint Faculties Research Ethics Board at the University of Calgary has examined the following research proposal and found the proposed research involving human participants to be in accordance with University of Calgary Guidelines and the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* 2010 (TCPS 2). This form and accompanying letter constitute the Certification of Institutional Ethics Review.

Ethics ID: REB15-1950  
Principal Investigator: Veronika Elizabeth Bohac-Clarke  
Co-Investigator(s): There are no items to display  
Student Co-Investigator(s): Janice Beler  
Study Title: Perceptions of Well-Being by Youth with High Functioning Autism in Alberta  
Sponsor (if applicable):

**Effective:** November 26, 2015

**Expires:** November 26, 2016

**Restrictions:**

**This Certification is subject to the following conditions:**

1. Approval is granted only for the project and purposes described in the application.
2. Any modification to the authorized study must be submitted to the Chair, Conjoint Faculties Research Ethics Board for approval.
3. An annual report must be submitted within 30 days prior to the expiry date of this Certification, and should provide the expected completion date for the study.
4. A final report must be sent to the Board when the project is complete or terminated.

**Approved By:**

**Date:**

Appendix B



**Perceptions of Well-Being in High Functioning Autism  
Informed Consent**

Janice M. Beler  
Ed.D Candidate, Curriculum and Learning  
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**Supervisor:**

*Dr. Veronika Bohac Clark  
Educational Research, Werklund School of Education, University of Calgary*

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**Purpose of the Study**

To gather understanding of how young adults with high functioning autism characteristics perceive and experience well-being. This research is being conducted as part of the requirement of a PhD and has been approved by the University of Calgary Conjoint Faculties Research Ethics Board.

**What Will You Be Asked To Do?**

- To complete a questionnaire about your autistic characteristics. This questionnaire will take approximately 10 minutes to complete and will be sent and returned via email.
- To complete a rating scale regarding how you assess your personal state of well-being. This scale will take approximately 10 minutes to complete and will be sent and returned via email.
- To participate in email correspondence with the principal researcher over a four week period of time. The researcher will ask questions and describe scenarios

## WELL-BEING IN ADULTS WITH HFAC

regarding your own and other people's experiences with well-being. The email conversation is designed so that you can participate at your own time and convenience.

- To participate in an online forum group with up to two other participants to respond to anonymous stories about themes and experiences relating to well-being and autism.

Your participation in this study is completely voluntary and you may choose to stop participating at any time. You may refuse to participate altogether, or in any part of the study. You may decline to answer any and all questions, and may withdraw from the study at any time without penalty or loss. Your decision to withdraw from participation will not influence your relationship with the referring organization or the University of Calgary.

### **What Type of Personal Information Will Be Collected?**

Should you choose to participate in this study, your name, birth date and gender will be requested at the beginning of the study to contribute to a description of the group's general demographic information. You will also be asked to provide an email address for future correspondence and participation in the study.

### **Are there Risks or Benefits if I Participate?**

There are no foreseeable risks or harms to you in participating in this research process.

### **What Happens to the Information I Provide?**

Only the principle investigator will have access to the information you provide.

Your contributions to this research will be treated with confidence; all data you provide will be recorded under a pseudonym. No person other than the principle researcher will be able to identify your identity with the information and understanding you provide.

Participation is completely voluntary, anonymous and confidential. You are free to discontinue participation at any time during the study. No one except the researcher will be allowed to see or hear any of the answers to the questionnaire or the interview transcriptions. There are no names on the questionnaire. Only group information will be summarized for any presentation or publication of results. The questionnaires are kept in a locked cabinet only accessible by the researcher. The anonymous data will be destroyed upon the completion of this study.

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## WELL-BEING IN ADULTS WITH HFAC

### ***Signatures***

By completing and returning this form you indicate that 1) you understand to your satisfaction the information provided to you about your participation in this research project, and 2) you agree to participate in the research project.

In no way does this waive your legal rights nor release the investigators, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from this research project at any time. You should feel free to ask for clarification or new information throughout your participation.

Participant's Name: \_\_\_\_\_

Participant's Birth Date: \_\_\_\_\_

I consent to participate by completing the questionnaires for this study

I consent to participate in email conversations with the researcher for this study

I consent to participate in an online forum conversation in this study

Date: \_\_\_\_\_

### **Questions/Concerns**

If you have any further questions or want clarification regarding this research and/or your participation, please contact:

*Janice M. Beler*  
*Faculty of Graduate Studies, University of Calgary*  
*(403) 394-4779, [jbeler@ucalgary.ca](mailto:jbeler@ucalgary.ca)*

If you have any concerns about the way you've been treated as a participant, please contact the Research Ethics Analyst, Research Services Office, and University of Calgary at (403) 210-9863; email [cfreb@ucalgary.ca](mailto:cfreb@ucalgary.ca).

A copy of this consent form has been given to you to keep for your records and reference. The investigator has kept a copy of the consent form.

## WELL-BEING IN ADULTS WITH HFAC

This consent form, a copy of which has been given to you, is only part of the process of informed consent. If you want more details about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

The University of Calgary Conjoint Faculties Research Ethics Board has approved this research study.

Appendix C



**Information Sheet**

***Well-Being and High Functioning Autism Study***

Thank you for considering participating in this study of “Well-Being and High Functioning Autism”, which is being conducted to provide a better understanding of how individuals on the autism spectrum define and experience well-being. There is currently not much information available on this topic from the perspective of individuals with autism characteristics. It is anticipated that this information may be useful for future social, medical, educational and personal planning. This research is being conducted as part of the requirements for a PhD. The study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board.

**Who Can Participate**

- People 16 years or older who identify themselves as being on the autism spectrum.  
Participant’s do not need to have an official diagnosis, but must demonstrate a minimum level of autism characteristics as measured by the Autism Spectrum Quotient, which will be completed by participants at the beginning of the study.
- Residents of Canada
- People who have access to a computer with internet connection.

## WELL-BEING IN ADULTS WITH HFAC

- People who are interested in and comfortable with sharing their thoughts and experiences towards improving how we nurture and support future generations of young people with characteristics of high functioning autism.

### **Requirements for Participation**

- Participants will be asked to complete, via email, two questionnaires at the beginning of the study. One will focus on the degree and detail of the participant's autism characteristics. The other will summarize the participant's own measure of their personal well-being. Each questionnaire should take no longer than twenty minutes for participant's to complete.
- Participants should be willing to engage in individual email conversations about their perceptions and experiences with well-being and the autism spectrum over a period of two to four weeks. They should be prepared to respond to up to three short emails (generally two to three paragraphs) each week from the researcher. The researcher will ask questions to facilitate conversation about the participant's perceptions and experiences relating to well-being.
- Participants will have flexibility in choosing a convenient time to respond to emails and the forum and in the length of their personal responses.

### **To Participate in This Study**

If you are interested in participating in this study please contact the researcher directly through email, text or phone.

Janice Beler  
405 Meadowlark Drive West Mountain Meadows  
Lethbridge, Alberta  
T1J 4R9  
[jbeler@ucalgary.ca](mailto:jbeler@ucalgary.ca)  
(403)394-4779

Appendix D

## The Adult Autism Spectrum Quotient (AQ)

**How to fill out the questionnaire**

*Below are a list of statements. Please read each statement and rate how strongly you agree or disagree with it by highlighting your answer.*

**DO NOT MISS ANY STATEMENT OUT.**

*Examples*

E1. I am willing to take risks.	definitely agree	slightly agree	slightly disagree	definitely disagree
E2. I like playing board games.	definitely agree	slightly agree	slightly disagree	definitely disagree
E3. I find learning to play musical instruments easy.	definitely agree	slightly agree	slightly disagree	definitely disagree
E4. I am fascinated by other cultures.	definitely agree	slightly agree	slightly disagree	definitely disagree

WELL-BEING IN ADULTS WITH HFAC

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

## WELL-BEING IN ADULTS WITH HFAC

18. When I talk, it isn't always easy for others to get a word in edgeways.	definitely agree	slightly agree	slightly disagree	definitely disagree
19. I am fascinated by numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
20. When I'm reading a story, I find it difficult to work out the characters' intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
21. I don't particularly enjoy reading fiction.	definitely agree	slightly agree	slightly disagree	definitely disagree
22. I find it hard to make new friends.	definitely agree	slightly agree	slightly disagree	definitely disagree
23. I notice patterns in things all the time.	definitely agree	slightly agree	slightly disagree	definitely disagree
24. I would rather go to the theatre than a museum.	definitely agree	slightly agree	slightly disagree	definitely disagree
25. It does not upset me if my daily routine is disturbed.	definitely agree	slightly agree	slightly disagree	definitely disagree
26. I frequently find that I don't know how to keep a conversation going.	definitely agree	slightly agree	slightly disagree	definitely disagree
27. I find it easy to "read between the lines" when someone is talking to me.	definitely agree	slightly agree	slightly disagree	definitely disagree
28. I usually concentrate more on the whole picture, rather than the small details.	definitely agree	slightly agree	slightly disagree	definitely disagree
29. I am not very good at remembering phone numbers.	definitely agree	slightly agree	slightly disagree	definitely disagree
30. I don't usually notice small changes in a situation, or a person's appearance.	definitely agree	slightly agree	slightly disagree	definitely disagree
31. I know how to tell if someone listening to me is getting bored.	definitely agree	slightly agree	slightly disagree	definitely disagree
32. I find it easy to do more than one thing at once.	definitely agree	slightly agree	slightly disagree	definitely disagree
33. When I talk on the phone, I'm not sure when it's my turn to speak.	definitely agree	slightly agree	slightly disagree	definitely disagree
34. I enjoy doing things spontaneously.	definitely agree	slightly agree	slightly disagree	definitely disagree

## WELL-BEING IN ADULTS WITH HFAC

35. I am often the last to understand the point of a joke.	definitely agree	slightly agree	slightly disagree	definitely disagree
36. I find it easy to work out what someone is thinking or feeling just by looking at their face.	definitely agree	slightly agree	slightly disagree	definitely disagree
37. If there is an interruption, I can switch back to what I was doing very quickly.	definitely agree	slightly agree	slightly disagree	definitely disagree
38. I am good at social chit-chat.	definitely agree	slightly agree	slightly disagree	definitely disagree
39. People often tell me that I keep going on and on about the same thing.	definitely agree	slightly agree	slightly disagree	definitely disagree
40. When I was young, I used to enjoy playing games involving pretending with other children.	definitely agree	slightly agree	slightly disagree	definitely disagree
41. I like to collect information about categories of things (e.g. types of car, types of bird, types of train, types of plant, etc.).	definitely agree	slightly agree	slightly disagree	definitely disagree
42. I find it difficult to imagine what it would be like to be someone else.	definitely agree	slightly agree	slightly disagree	definitely disagree
43. I like to plan any activities I participate in carefully.	definitely agree	slightly agree	slightly disagree	definitely disagree
44. I enjoy social occasions.	definitely agree	slightly agree	slightly disagree	definitely disagree
45. I find it difficult to work out people's intentions.	definitely agree	slightly agree	slightly disagree	definitely disagree
46. New situations make me anxious.	definitely agree	slightly agree	slightly disagree	definitely disagree
47. I enjoy meeting new people.	definitely agree	slightly agree	slightly disagree	definitely disagree
48. I am a good diplomat.	definitely agree	slightly agree	slightly disagree	definitely disagree
49. I am not very good at remembering people's date of birth.	definitely agree	slightly agree	slightly disagree	definitely disagree
50. I find it very easy to play games with children that involve pretending.	definitely agree	slightly agree	slightly disagree	definitely disagree

**Developed by:  
The Autism Research Centre**

**University of Cambridge**

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Appendix E **Psychological Well-Being Scales (PWBS)**

## WELL-BEING IN ADULTS WITH HFAC

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
1. Most people see me as loving and affectionate.	1	2	3	4	5	6
2. Sometimes I change the way I act or think to be more like those around me.	1	2	3	4	5	6
3. In general, I feel I am in charge of the situation in which I live.	1	2	3	4	5	6
4. I am not interested in activities that will expand my horizons.	1	2	3	4	5	6
5. I feel good when I think of what I've done in the past and what I hope to do in the future.	1	2	3	4	5	6
6. When I look at the story of my life, I am pleased with how things have turned out.	1	2	3	4	5	6
7. Maintaining close relationships has been difficult and frustrating for me.	1	2	3	4	5	6
8. I am not afraid to voice my opinions, even when they are in opposition to the opinions of most people.	1	2	3	4	5	6
9. The demands of everyday life often get me down.	1	2	3	4	5	6
10. In general, I feel that I continue to learn more about myself as time goes by.	1	2	3	4	5	6
11. I live life one day at a time and don't really think about the future.	1	2	3	4	5	6
12. In general, I feel confident and positive about myself.	1	2	3	4	5	6
13. I often feel lonely because I have few close friends with whom to share my concerns.	1	2	3	4	5	6
14. My decisions are not usually influenced by what everyone else is doing.	1	2	3	4	5	6

## WELL-BEING IN ADULTS WITH HFAC

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
15. I do not fit very well with the people and the community around me.	1	2	3	4	5	6
16. I am the kind of person who likes to give new things a try.	1	2	3	4	5	6
17. I tend to focus on the present, because the future nearly always brings me problems.	1	2	3	4	5	6
18. I feel like many of the people I know have gotten more out of life than I have.	1	2	3	4	5	6
19. I enjoy personal and mutual conversations with family members or friends.	1	2	3	4	5	6
20. I tend to worry about what other people think of me.	1	2	3	4	5	6
21. I am quite good at managing the many responsibilities of my daily life.	1	2	3	4	5	6
22. I don't want to try new ways of doing things - my life is fine the way it is.	1	2	3	4	5	6
23. I have a sense of direction and purpose in life.	1	2	3	4	5	6
24. Given the opportunity, there are many things about myself that I would change.	1	2	3	4	5	6
25. It is important to me to be a good listener when close friends talk to me about their problems.	1	2	3	4	5	6
26. Being happy with myself is more important to me than having others approve of me.	1	2	3	4	5	6
27. I often feel overwhelmed by my responsibilities.	1	2	3	4	5	6
28. I think it is important to have new experiences that challenge how you think about yourself and the world.	1	2	3	4	5	6
29. My daily activities often seem trivial and unimportant to me.	1	2	3	4	5	6
30. I like most aspects of my personality.	1	2	3	4	5	6
31. I don't have many people who want to listen when I need to talk.	1	2	3	4	5	6

## WELL-BEING IN ADULTS WITH HFAC

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
32. I tend to be influenced by people with strong opinions.	1	2	3	4	5	6
33. If I were unhappy with my living situation, I would take effective steps to change it.	1	2	3	4	5	6
34. When I think about it, I haven't really improved much as a person over the years.	1	2	3	4	5	6
35. I don't have a good sense of what it is I'm trying to accomplish in life.	1	2	3	4	5	6
36. I made some mistakes in the past, but I feel that all in all everything has worked out for the best.	1	2	3	4	5	6
37. I feel like I get a lot out of my friendships.	1	2	3	4	5	6
38. People rarely talk to me into doing things I don't want to do.	1	2	3	4	5	6
39. I generally do a good job of taking care of my personal finances and affairs.	1	2	3	4	5	6
40. In my view, people of every age are able to continue growing and developing.	1	2	3	4	5	6
41. I used to set goals for myself, but that now seems like a waste of time.	1	2	3	4	5	6
42. In many ways, I feel disappointed about my achievements in life.	1	2	3	4	5	6
43. It seems to me that most other people have more friends than I do.	1	2	3	4	5	6
44. It is more important to me to "fit in" with others than to stand alone on my principles.	1	2	3	4	5	6
45. I find it stressful that I can't keep up with all of the things I have to do each day.	1	2	3	4	5	6
46. With time, I have gained a lot of insight about life that has made me a stronger, more capable person.	1	2	3	4	5	6
47. I enjoy making plans for the future and working to make them a reality.	1	2	3	4	5	6
48. For the most part, I am proud of who I am and the life I lead.	1	2	3	4	5	6

## WELL-BEING IN ADULTS WITH HFAC

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
49. People would describe me as a giving person, willing to share my time with others.	1	2	3	4	5	6
50. I have confidence in my opinions, even if they are contrary to the general consensus.	1	2	3	4	5	6
51. I am good at juggling my time so that I can fit everything in that needs to be done.	1	2	3	4	5	6
52. I have a sense that I have developed a lot as a person over time.	1	2	3	4	5	6
53. I am an active person in carrying out the plans I set for myself.	1	2	3	4	5	6
54. I envy many people for the lives they lead.	1	2	3	4	5	6
55. I have not experienced many warm and trusting relationships with others.	1	2	3	4	5	6
56. It's difficult for me to voice my own opinions on controversial matters.	1	2	3	4	5	6
57. My daily life is busy, but I derive a sense of satisfaction from keeping up with everything.	1	2	3	4	5	6
58. I do not enjoy being in new situations that require me to change my old familiar ways of doing things.	1	2	3	4	5	6
59. Some people wander aimlessly through life, but I am not one of them.	1	2	3	4	5	6
60. My attitude about myself is probably not as positive as most people feel about themselves.	1	2	3	4	5	6
61. I often feel as if I'm on the outside looking in when it comes to friendships.	1	2	3	4	5	6
62. I often change my mind about decisions if my friends or family disagree.	1	2	3	4	5	6
63. I get frustrated when trying to plan my daily activities because I never accomplish the things I set out to do.	1	2	3	4	5	6
64. For me, life has been a continuous process of learning, changing, and growth.	1	2	3	4	5	6

## WELL-BEING IN ADULTS WITH HFAC

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
65. I sometimes feel as if I've done all there is to do in life.	1	2	3	4	5	6
66. Many days I wake up feeling discouraged about how I have lived my life.	1	2	3	4	5	6
67. I know that I can trust my friends, and they know they can trust me.	1	2	3	4	5	6
68. I am not the kind of person who gives in to social pressures to think or act in certain ways.	1	2	3	4	5	6
69. My efforts to find the kinds of activities and relationships that I need have been quite successful.	1	2	3	4	5	6
70. I enjoy seeing how my views have changed and matured over the years.	1	2	3	4	5	6
71. My aims in life have been more a source of satisfaction than frustration to me.	1	2	3	4	5	6
72. The past had its ups and downs, but in general, I wouldn't want to change it.	1	2	3	4	5	6
73. I find it difficult to really open up when I talk with others.	1	2	3	4	5	6
74. I am concerned about how other people evaluate the choices I have made in my life.	1	2	3	4	5	6
75. I have difficulty arranging my life in a way that is satisfying to me.	1	2	3	4	5	6
76. I gave up trying to make big improvements or changes in my life a long time ago.	1	2	3	4	5	6
77. I find it satisfying to think about what I have accomplished in life.	1	2	3	4	5	6
78. When I compare myself to friends and acquaintances, it makes me feel good about who I am.	1	2	3	4	5	6
79. My friends and I sympathize with each other's problems.	1	2	3	4	5	6
80. I judge myself by what I think is important, not by the values of what others think is important.	1	2	3	4	5	6

## WELL-BEING IN ADULTS WITH HFAC

Circle the number that best describes your present agreement or disagreement with each statement.	Strongly Disagree	Disagree Somewhat	Disagree Slightly	Agree Slightly	Agree Somewhat	Strongly Agree
81. I have been able to build a home and a lifestyle for myself that is much to my liking.	1	2	3	4	5	6
82. There is truth to the saying that you can't teach an old dog new tricks.	1	2	3	4	5	6
83. In the final analysis, I'm not so sure that my life adds up to much.	1	2	3	4	5	6
84. Everyone has their weaknesses, but I seem to have more than my share.	1	2	3	4	5	6

## WELL-BEING IN ADULTS WITH HFAC

### Appendix F

#### Autism Quotient (AQ) Scores Raw Data and Averages

Column1	Column2	Column3	Column4	Column5	Column6	Column7	Column8
Participant	Attention Sw	Att. Detail	Social Sk.	Commun.	Imagination	Average	AQ Total
1	7	10	3	7	7	6.8	34
2	7	10	9	4	6	7.2	36
3	7	6	7	7	5	6.4	32
4	8	8	6	5	1	5.6	28
5	10	10	9	6	5	8	40
6	8	7	6	7	9	7.4	37
7	10	0	9	10	4	6.6	33
8	9	9	9	8	4	7.8	39
9	10	5	8	7	4	6.8	34
10	4	7	6	6	3	5.2	26
11	7	8	8	7	4	6.8	34
12	10	7	9	10	8	8.8	44
13	7	10	8	7	6	7.6	38
14	6	4	6	6	4	5.2	26
15	9	9	9	10	6	8.6	43
16	7	4	8	8	7	6.8	34
Average	7.875	7.125	7.5	7.1875	5.1875	6.975	34.875

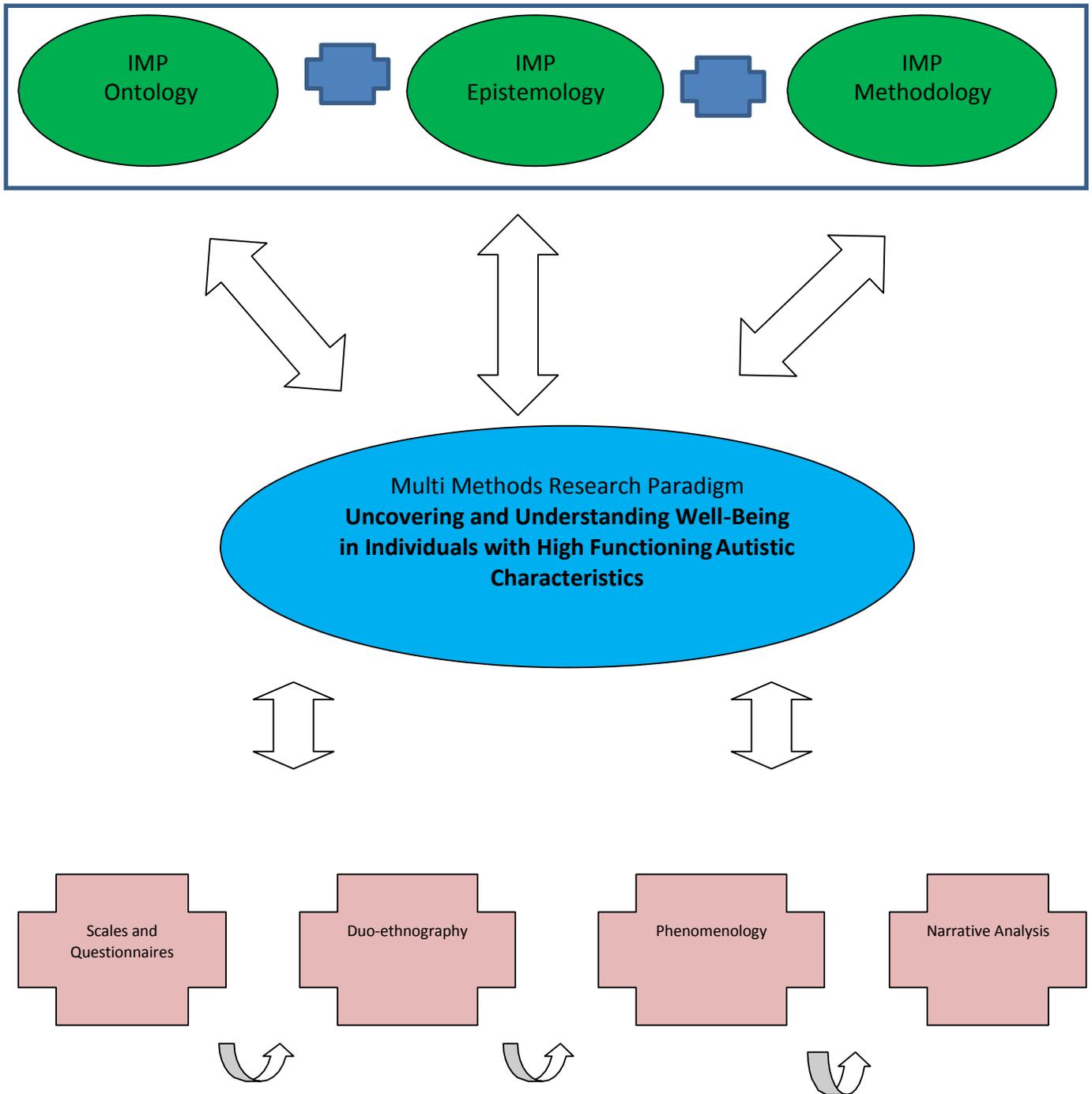
### Appendix G

WELL-BEING IN ADULTS WITH HFAC

**Psychological Well-Being Scales (PWBS) Raw Data and Averages**

Column1	Column2	Column3	Column4	Column5	Column6	Column7	Column8	Column9
Participant	Self-Acc	Relations	Autonomy	Env. Mast	Purpose	Pers Growth	Average	PSWB Total
1	42	40	57	46	43	81	51.5	309
2	31	34	71	33	60	49	46.33333	278
3	70	70	77	70	73	90	75	450
4	43	44	58	40	58	67	51.66667	310
5	28	25	42	34	37	29	32.5	195
6	52	28	61	41	45	64	48.5	291
7	14	16	48	18	23	21	23.33333	140
8	NA	NA	NA	NA	NA	NA		NA
9	25	46	34	34	37	50	37.66667	226
10	37	34	44	51	43	43	42	252
11	66	46	53	57	70	69	60.16667	361
12	18	38	59	15	37	44	35.16667	211
13	35	48	25	43	54	59	44	264
14	31	42	41	45	45	61	44.16667	265
15	42	35	56	45	50	51	46.5	279
16	19	21	71	21	28	57	36.16667	217
Average	36.86667	37.8	53.13333	39.53333	46.86667	55.66667	44.97778	269.8667

**Quadratic Cycle for Research Methods**



Phenomenological Questions for 1:1 Interviews

How do participants describe and make sense of broad autistic phenotype traits and how they influence well-being in both their own lives and the lives of other people on the spectrum?

Phenomenon in Question: well-being in autism

- 1) When we talk about well-being, I think it is important that we have a shared understanding of what we mean by the term. At this moment, I am thinking that well-being is all of the things that contribute to your happiness and satisfaction in life. This can mean in the past, present, and future. Do you agree with this definition? Would you like to change the definition at all? If so, how?
- 2) How do you think autism affects a person's sense of well-being? Please give me some examples.
- 3) Do you think that an individual's sense of well-being is different between individuals with autism and without autism characteristics? Tell me about it.
- 4) From your childhood, tell me about a time (or times) when you remember being happy.
- 5) Can you recall a situation from your childhood in which you were unhappy? Tell me about it.
- 6) When you were in elementary school, what kinds of things were most important to you?
- 7) Did the things that mattered most to you in elementary changed in junior or high school? If so, describe how it changed.
- 8) If you could go back in time to give your childhood self some advice about life, what would it be?
- 9) At this point in your life, what types of things matter the most to you and are important to your sense of well-being? Tell me about how this looks in your life.
- 10) What symptom(s) of autism do you consider as creating the most challenge in your life and to your sense of well-being? Tell me about an experience when this/these traits caused a problem. How did the situation emerge? What happened? How did you respond? What was the outcome? If you could, would you go back in time and change how you responded to the situation? Why?
- 11) Are their symptom(s) of autism that you consider to be personal assets in your life and to your sense of well-being? Tell me about an experience when this/these traits made your life better.
- 12) If you could eliminate the characteristics of autism that you exhibit, would you? Which characteristics would you want to discard? Which would you want to keep? Why?

