PHYSICAL FITNESS AND INTELLECTUAL DISABILITY: A GROUNDED RESEARCH

STUDY

by

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Abstract

This study set out to discover what social processes effect the physical fitness choices of

people with intellectual disabilities. Within a constructionist grounded theory framework,

I explored participants' experiences with physical fitness and exercise activities. I was

interested in how the participants learned about fitness and health related behaviors, who

participated in these activities, and what their experiences meant to them. I also wanted to

learn what barriers they met in participating in their chosen activities. Twenty-six

individuals with intellectual disabilities living in Victoria, British Columbia participated

in this research. The participants lived in a variety of community settings ranging from

independent to semi-independent, home share and group homes. They ranged in age from

20 to 67 years. The data revealed how fitness and exercise choices were interwoven with

the participants lived experience as a whole. The influence of personal relationships in

the fitness choices and activity levels of participants was a dominant theme. Personal

relationships played a key role in the micro or proximal social processes that effected

fitness choices of the participants. On the micro level the results produced three models

of social interaction that captured the main influences on participant choices of fitness

activities. A macro analysis accompanies the interpretation of data. This second tier of

analysis extends the research to take into account the larger socio-cultural forces at play.

Here I combine Foucault's notion of the governmentality of difficult populations with a

critical look at neoliberal social and political philosophy to paint the back drop into

which the micro relationships and social processes depicted in the three models are set.

Throughout I kept the words of study s uppermost in my mind. The findings are

discussed in relation to existing empirical literature on physical fitness and intellectual

disabilities. The findings suggest that success in engaging people with intellectual disabilities in fitness activities requires an understanding of their fitness histories and involvement of people in their close social networks. (Key words: physical fitness, developmental disability/ intellectual disability; mental retardation and physical well-being; developmental disability/intellectual disability/mental retardation.).

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CHAPTER 1

1.1 Introduction

My interest in the phenomena of physical fitness and intellectual disabilities springs from personal experience working within Community Living British Columbia – the Crown Agency responsible for supports and services for adults with intellectual disabilities in British Columbia. During my time working as a manager for CLBC, I became increasingly aware of escalating costs due to the ageing and consequent infirmity of the people we supported. Over this period health care workers and human service agencies reported increasing difficulty in supporting people with intellectual disabilities who were experiencing high levels of physical impairment and disease. I became sensitized through observation and anecdotal information from care givers, parents, and service providers that the people we jointly served were becoming more susceptible to hypo-kinetic diseases (Emerson & Hatton, 2007; Prasher & Jenicki, 2002; Rimmer& Yamaki, 2006; Stanish, Temple, & Frey, 2006; Temple, 2007). In essence, these diseases are the result of a sedentary life style which promotes obesity and, subsequently, a variety of ailments and medical conditions. I wondered why this might be the case and became curious about the causes and possible solutions to what seemed a puzzling and unhappy circumstance.

I was aware of the marginalized existence that many of the people we supported lived. I recognized that they often were at the lower end of the socio-economic ladder and I began to suspect that financial barriers might be at least partly responsible for the inability of people with intellectual disabilities to access fitness activities. I prided myself on maintaining a fair level of fitness and could not understand why anyone given the opportunity would not choose to be fit. In the face of overwhelming evidence of the relationship between fitness and health getting active

seemed the only rational choice.

I also wondered how had this situation developed; was it a recent phenomena or had people with intellectual disabilities always been at the bottom of the health status pyramid? I felt strongly that this situation once clarified could be reversed. Why shouldn't people with intellectual disabilities enjoy the same health and longevity as the rest of the population? I set out to learn what historical antecedents might have produced this condition. I understood the most recent history of the community living movement because I had lived through it in my professional life. However, the details of health behaviour of the people we supported were foreign to me. At the outset of this journey my main interest was in solving the practical problem of how to help people with intellectual disabilities access fitness opportunities.

In some respects the very fact that I have undertaken research on the physical fitness of people with intellectual disabilities attests to the changes in the status of people with intellectual disabilities. My research into the history of intellectual disability has revealed that there was not always an interest in improving the health status of this population. In fact, throughout most of human history, the interest in people with intellectual disabilities has been in controlling, restricting and policing them often in isolation from the rest of humankind. By way of an introduction I will now provide a brief overview or description of the passage of people with intellectual disabilities from a population concealed within the family to social pariah to subject of modern scientific study and academic interest. I have drawn on the work Davis (2006) who has discussed the transposition of the "norm" from a standardized measure in architecture and the physical sciences to a metric against which human perfectibility might be measured. It is in the shadow of the norm that people with intellectual disabilities are defined and assessed today.

1.2 Historical Context

 Berkson (2004) places the history of mental retardation[1] into the dim record of pre-history. For the purposes of this dissertation and the present discussion I do not venture that far back in time nor do I provide a cavalcade of historical detail; however, in order to set the context for this study, I will touch briefly on the historical milestones of the process of change that marks the social evolution of the category of intellectual disability as a social classification. Overall this history has been less than ideal.

 Stainton (2004) traced the emergence of intellectual disability as a pejorative social status back to the early renaissance when concepts of the "rational individual" (p.225) began to edge out religious belief in God as the fundamental reference point for political and social thought. Stainton further argues that the ascendance of rationality brought with it a changing discourse which began to identify people with intellectual disabilities as the opposite of rational individuals. This new discourse began to equate this difference with social and moral depravity

 The history of intellectual disability parallels the history of mental illness. Like mental illness, society's understanding and treatment of intellectual disability has changed in step with variations in political, economic and practices (Manion & Bersani, 1987). Radford (1994) states that the slow separation between mental illness and intellectual disability began to take shape in the middle ages as a result of diverging interests among medical professionals. Sutton (1991) argued that mental health was less a product of physiology or innate pathology but rather the result of social institutions whose mandate is to identify measure and manage deviant populations. Similarly, a read of the historical account of intellectual disability suggests that

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[1] The term "mental retardation" is derived from the Diagnostic and Statistical Manual of the American Psychiatric Association (DSM 4 TR). Although this term is in disuse in the Community Living Field it remains as a descriptor within Axis2 of the DSM (DSM 4 TR).

over the period of modernization (16th century to present) the status and social position of people that we now refer to as having an intellectual disability has been adjusted in line with prevailing, social, moral, religious, economic and political beliefs. Wright and Digby (1996) provided an historical overview of these changes. They charted the transformation of intellectual disability from its conception as a family or domestic problem through the medieval period where a growing number of individuals labelled as idiots were removed from mainstream society and housed in institutions.

Wright and Digby (1996) further reported that from the seventeenth century on into the nineteenth the process of institutionalization gradually accelerated as European societies were swept up in the great tide of industrialization and urbanization that accompanied the growth of capitalism. According to these authors the development of Georgian and Victorian institutions was driven in equal measure by the need to protect society from undesirables and a growing ethic of care for the unfortunate. Whatever the philanthropic or eugenic motivation, a broad spectrum of people labelled as social misfits and deviants found themselves housed in such places.

In the last half of the nineteenth century, changing educational policies and the experiences of doctors in the management of prisons, asylums and work-houses combined to draw attention to both children and adults with mental deficiencies. The belief that educational disability and social ineptitude were two manifestations of the same hereditary tendency led authorities and experts to take action to protect society. They concluded that feeble-mindedness constituted a permanent and fixed feature of an individual's life. Being labelled as feebleminded had a totalizing effect on the view of such individuals. Significantly, this conclusion was reinforced by findings of a number of socially orientated commentators. These experts

contended that feeble-minded children and adults held two things in common: they were deviants from the norm and, moreover, they were qualitatively different from the population at large.

Stearns (1978) work on the development of the Mental Deficiency Act (1913) in England, and O'Brien's later work (2011) charts a similar evolution in the United States. These authors (O'Brien, 2011 & Stearns, 1978) link legislation regulating "feeblemindedness" with fears about the spread of moral and mental depravity that entered public discourse during the years running up to the First World War. Similar concerns about feeble mindedness and social depravity were raised in Canada however the Royal Commission set up to study the problem produced no legislative results. Eugenicists on both sides of the Atlantic formed organizations that lobbied for government to control the spread of feeblemindedness. These organizations put forth the idea that feebleminded women had many more children than women with desirable characteristics and consequently if something was not done the European race was doomed to have its superiority diluted. The newly developed IQ test armed the eugenic movement with a ready method of separating the sub-normal from the normal population. Thus, a scientific and rational device could serve to surface defective individuals. The solution proposed for the control of sub-normal populations was "forced institutionalization and involuntary sterilization" (O'Brien, 2011).

This application of science to human engineering put pay to the organic notion that society could contend with a range of intelligence among its citizens. The introduction of standard tests broke down the continuum that had previously stretched from the lowest to the highest intelligence and created two categories of people: normal and abnormal, healthy and pathological. The pathological view of people with disabilities remains intact as a legacy of this

period of modernization. Here is where Davis's (2006) paper on the concept of the norm as applied to physical disability can add to our understanding.

In the twentieth century the classification of people as mentally retarded and the social attitude towards their proper deportment has gone through massive alterations. Davis (2006) described the transformation of disability as beginning with the rise of industrial capitalism in the late eighteen and early nineteenth century. It is in this epoch that that the concept of the norm came to be the penultimate social measure. Disabled people began to be held up against the norm of the male body. Henceforth, disabled bodies increasingly became objects of study for the biological and social sciences. For Davis the key to understanding the association between disability and ability requires an interrogation of the social meaning of normalcy. Although Davis focused on the disabled body, the same standards of measure and social process of categorization and social marginalization applies to people labelled as mentally retarded.

In his paper Davis proceeds stepwise through the historical use of the "norm" and how nineteenth century statisticians came to subvert the original meaning and apply it to the measurement of human capacities. The results are present today in the ubiquitous use of the bell curve as a standard measure of everything from height and weight to the estimation of human intelligence. It is this last application that is most relevant to the creation of mental retardation. The Diagnostic and Statistical Manual of the American Psychiatric Association (DSM 4 TR) is the textual authority and foundational assessment tool that establishes eligibility for state sponsored support services for people designated as having an intellectual disability in the province of British Columbia. A key component of the diagnosis remains the IQ test.

Use of this tool has been described as technocratic justification for the delineation of deviance (Radford, 1994). Subjecting individuals to such an assessment before they may qualify

for needed supports is seen as an anachronism that holds people with intellectual disability hostage to modernist obsessions with scientific measurement for the purposes of social control. It is an oppressive legacy of modernity in a postmodern world.

When it comes to the social safety net, this metric separates classes of people into two broad categories. Normal people get normal services and abnormal people get special services. Davis coined the term "political arithmetic" (p. 4) to denote his distaste for this metric of abelism, and he describes how this socially constructed measurement – the IQ test – establishes benchmarks of normalcy. For people with intellectual disabilities reaching these benchmarks remains elusive.

In the physical realm, disability is a retrograde deduction falling back from the dimensions of the average man; small but not trivial are the implications of the word "man". Excluded by implication are women. The original model was a particular type of man: a white Western European man. Again, this standard was forged in the caldron of industrial capitalism with its need for standardization in order to measure and compare worker productivity. The logic of production entered the discourse on other social problems. Over time the concept of the average man with his average capacities became the archetype against which other populations were judged (Davis, 2006). This metric of the average man was applied to other areas of social life including intelligence. Today intellectual disability remains, at least in part, defined as two standard deviations from the norm on a standard IQ test.

The growth of Disability Studies as an academic discipline combined with the agitation of the Disability Rights movement has had a significant effect on attitudes toward all kinds of disability. In recent decades the personal deficit theory of disability has been thoroughly discredited in favour of disability as a social construction. Today it is generally recognized

among many academics and disability activists, that disability is not simply a fact of physiology but rather stands at the juncture where biology meets culture. It is a socially and culturally constructed identity (Linton, 2006; Manion & Bersani, 1987; Murphy & Perez, 2008; Tremain, 2001; Siebers, Tobin, 2006; Verstraete, 2007; Wendell, 2006). This relatively new approach to understanding intellectual disability lays at the foundation of a social constructionist epistemology and informs the model and methodology of this study. Social constructionism, however, is not alone. The other dominant model permeating the literature on physical fitness and intellectual disability is the biological or medical model and is characterized by an epidemiological perspective and a population health discourse in the literature. The outfall of the medical model of intellectual disability has been that diagnosis and treatment dominate as preferred models for improving the lot of people with intellectual disabilities. Treatment is applied to individuals and in large measure social context is pushed aside. That said, theoretically significant is the changing and evolving nature of intellectual disability. This evidence sets in motion the possibility of intellectual disability as a socially constructed designation rather than an immutable "social fact" (Durkheim, ([1895] in S. Lukes, 1982, p.2).The literature review that forms Chapter 2 of this dissertation references both these academic discourses – social constructionist discourses and biological or medical discourses. At this point I will turn to an outline of the dissertation highlighting specific content of each chapter.

1.3 Dissertation Overview

As mentioned Chapter 2 is a literature review. The use of literature review is a contested area within grounded theory practice. Some practitioners (Glasser, 1998) argue that no literature review should be undertaken in advance of the research project. On the other hand others

(Charmaz, 2006) are more concerned with preserving researcher creativity. Charmaz suggested that coming to the research project as a blank slate is impossible even for novice researchers. As I have had a long career in the field of intellectual disability, I have acceded to Charmaz's view that a literature review in advance of the study need not taint the outcome. In Chapter 2, I discuss the major themes present in the literature on intellectual disability and physical fitness. These themes are divided into four major topics: health education, quality of life, physical fitness and, social inclusion. Naturally these classifications bleed into each other but they are delineated for convenience based on the basic characteristics of their approach to the fitness and well-being of people with intellectual disabilities. Under each of these four headings I reflect how each of these topics is relevant to the needs of people with intellectual disabilities. After completing the data collection and analysis process of the study, I completed a secondary literature review. This review centered on positions taken in the theoretical discourse that provide the larger social context in which my study is lodged. This part of the review positions my analysis in current socio-political discourse. I also discuss the impact that neoliberal social and economic policy has had on service delivery for people with intellectual disabilities.

Chapter 3 provides detail on grounded theory as a methodology, briefly traces the history of grounded theory form the work of Glasser and Strauss (1968/1997) to the postmodern iterations of Clarke (2005) and Charmaz's (2006) constructionism. I include an overview of the constructionist epistemology and ontology and compare these to the more empiricist traditional methodology. I provide a rationale for my decision to model my study on Charmaz's (2006) constructionist methodology. Having established the foundations of the study, I move on to provide details of the methods, data gathering and analysis procedures undertaken. This is the nuts and bolts section of the dissertation. This part of Chapter 3 is laid out as a mechanic might

lay out his tools in preparation for work. It includes a description of coding ,memoing and other aspects of data analysis. Illustration 1 (p. 57) provides a graphic illustration of the complete process. Included towards the back of this chapter are discussions of reliability and validity as they relate to constructionist epistemology. I have concluded the chapter with a discussion of ethical issues that arise when working with a vulnerable population.

In Chapter 4, I provide the results. I began with a series of tables that highlight the demographic features of the study participants. I present the results of the study divided into eight key themes. As is appropriate within a grounded theory methodology, these themes were derived directly from the data provided by participants. Under the banner of each theme I detail representative content from the twenty-six participants. These segments of conversation form a link from the data through the analysis and ultimately rationalize the three theoretical propositions or models I diagram in Chapter 5. This is the logic of grounded theory research.

Chapter 5 summarizes and consolidates the findings in Chapter 4. This chapter introduces three theoretical propositions or models that capture the actions and experiences of the study participants. All three models are derived from the data provided by participants in combination with my analysis. They represent the life experience as revealed by participants. The three models depicted are: the social support model, the later life engagement model and the discipline and resistance model. The first two models describe how study participants become engaged in fitness activities and explains the antecedent experience that pave the way for an active life and the role important others play in participants fitness choices. The third model is derived from the data as well but owes its strength to Foucauldian notions of power relations in everyday experience.

I look at each model in reference to the thesis question and ask if they are sufficient to fully respond to this question. Through this process I explore what it means to be an individual entering the research situation. This leads to a discussion of the meaning of self, autonomy and subjectivity. Also in this chapter I look at other psycho-social explanations for the participants fitness choices. I then diverge and present an overview of three theorizations that have the potential to place the fitness choices of study participants inside the larger socio-cultural context. The three options discussed include: the medical/biological model, the social model of disability and asocial constructionist model. I conclude that social constructionism is the preferred model for gaining insight into how the fitness choices of participants fit within the larger social context. I give reasons for my choice and resolve the research question.

In Chapter Six I provide a discussion of the eight themes. I add to the depth of this analysis and theorization with reference to the work of Michel Foucault. Here I discuss the concept of governmentality as it relates to people with intellectual disabilities as a difficult to manage population. As well I discuss the relationship between the fitness as a moral choice and the ethic of self management. I show how fitness can be seen as an element of self- management that may be understood more broadly through a Foucauldian analysis. I also sketch in how self management meshes with neoliberal social philosophy.

This analysis draws on current literature relevant to each of the themes. I make reference to the social relations of disability in the current social-political environment in British Columbia. I draw on Foucauldian theorists to support my theorization of the social processes that affect the fitness choices of study participants. This discussion includes remarks on abelism and intellectual disability. Finally, I resolve the thesis question.

In Chapter 7 I briefly summarize the major themes that emerged from the data and provide review of the theoretical propositions presented in Chapter 5. I then comment on the link between the data as recorded and larger theorizations. Next, I note the limitations of the study and finish with some recommendations that outline how the study findings might be utilized to promote greater fitness for people with intellectual disabilities.

1.3 Thesis Statement

The research question asks: What social processes affect physical fitness choices of people with intellectual disabilities? The qualitative methodology I chose for this project is grounded theory. Throughout the research process, I followed the general guidelines for a constructionist grounded theory modeled based on the work of Charmaz (2006). This places my research project epistemologically and practically in the middle ground between the traditional practice of Glaser's (1998) work and Clarke's (2005) more recent work which is pushing the margins of grounded theory. The approach I have taken in this study is in line with Charmaz's (2006) approach. As such, I argue that theoretical propositions that accrue from a study will not corral the fundamental truth of the phenomenon and social processes under study but rather act as an "interpretive portrayal" of participant experience (p. 10). In short, the theoretical propositions I have developed are a representation of reality, not a duplication of it. These representations occur on two levels. The first captures the interpersonal interchanges that affect the study participants' fitness choices. The second links this effect to the socio-political environment.

1.4 Research Importance

The issue of fitness and intellectual disability is relevant firstly to persons with intellectual disabilities. Individual levels of fitness have a remarkable impact on overall health,

self esteem, and related psychological states (Prasher & Janicki, 2002) as well as long term quality of life and health outcomes. Individuals who meet a minimal standard of fitness, whether they are labelled as intellectually disabled or part of the "typical" population, live longer and are likely to suffer fewer restrictions in their daily activities as they age (Rimmer, 1994). For persons with intellectual disabilities, their families, and care givers, improved fitness and health means more autonomy and less dependence enforced by support needs.   In this way fitness can contribute to a rights perspective for people with intellectual disabilities.

A recent Canadian report suggests that the population of persons with intellectual disabilities over the age of fifty-five will likely double in the next twenty-five years (Canadian Mortgage and Housing Corporation [CMHC], 2006). At present this growth in the aging population of persons with intellectual disabilities is exerting pressure on public service budgets and stress on families. For persons with intellectual disabilities, this is likely to make living independently more difficult (CMHC, 2006). This impact is beginning to be felt today and is predicted to continue and worsen. As the aging population grows, it is likely to put a strain on both disability support resources and those of its sister system, the health related support network. Although some might argue that more tax dollars could solve the problem, this is an unlikely scenario given current political reality of "roll-out neoliberal" (Graefe, 2005, p. 2) moulded governments navigating public policy through the current economic turbulence.

Interestingly, Beange, Lennox, and Parmenter (1999) have suggested that attending to the health needs of persons with intellectual disabilities would lead to an overall reduction in government expenditures. Increased fitness levels have been shown to lessen the effects of numerous diseases and impairments (Doan & Scherman, 1987; Rimmer, 1994; Rimmer, Temple& Frey, 2006; Temple, 2007) and in this way might figure as part of any long term cost

containment strategy. Potentially, increased physical fitness levels may also serve to relieve at least a small element of human suffering.

The gap in health and fitness status between persons with disabilities and those without has been recognized as both a social and a moral issue. Neglect of this issue has been seen as "politically, socially, and economically untenable" (Beange, 2002, p. 1). Exploring social processes that affect the physical fitness of persons with intellectual disabilities may well shed light on what can be done to move towards lessening that gap.

Chapter 2: Literature Review

This literature review has looked at some of the noteworthy literature available, but it has not exhausted the topic. A complete and thorough literature review is not required in grounded theory methodology (Glaser, 1998). Glaser (1998) eschews a review of the literature in advance of theoretical development. His concern was to ensure that the researcher was not presupposed toward conclusions already explored in the literature (McGhee, Marland & Atkinson, 2007). Other writers (e.g., Charmaz, 2006; McGhee, Marland & Atkinson, 2007; Mills, Bonner, & Francis, 2006) are less orthodox and make the point that a literature review can simply provide "another voice" (Mills et al., p. 4) to round out the researcher's perspective. As Charmaz (2006) notes, even the novice researcher does not come to the project as a "tabula rasa" (p. 165). Her concern is that the literature reviews not quash creativity. Creswell (2007) suggests that a literature review may serve to show gaps or bias in the literature and thus provide a reason for a grounded theory. Following this suggestion, what is offered here is a preliminary step in canvassing the field to surface major themes and to establish that the literature I have reviewed to date has not revealed any grounded theory dealing with physical fitness and intellectual disability.

Taylor (2008) has suggested that a successful literature review will summarize the key ideas that have been discussed in the scholarly literature. He further advised that a literature review should achieve certain goals. It should:

- Be organized around and related directly to your topic (or in the case of a research project, the thesis or research question you are developing).
- Synthesize results into a summary of what is and is not known.
- Identify areas of controversy in the literature (p. 1).

The following review aims to satisfy these requirements.

One parameter I set for this review is the start and end date of articles selected. I have arbitrarily set 1987 as my beginning date and 2009 as my end date, the year in which I submitted my research proposal. During the drafting of this dissertation I carried out a secondary review to ensure my understanding of the literature was current. Relevant works from the 2009-2012 periods are cited in the findings section of the dissertation. In order to survey the broadest amount of information, I did not limit myself to a particular age range nor have I restricted my search to a specific aetiology or diagnostic category. I wanted to get a view of intellectual disability and fitness across the lifespan and, as intellectual disability is defined differently over time and geography[2] (Horwitz et al., 2000); taking a non-exclusive approach I believe proved fruitful. I accessed the University of British Columbia data bases, including Academic Search Premier, Social Service Abstracts, Ebsco Databases, as well as standard internet Google searches. Key words used included: physical fitness and developmental disability/ intellectual disability; mental retardation; fitness and developmental disability/intellectual disability/mental retardation; and physical well-being and developmental disability/intellectual disability/mental retardation. In addition, I used the same databases to search for grounded theory and developmental disability/intellectual disability and mental retardation. As noted, I recently carried out a secondary literature review with parallel results. Relevant articles are integrated into the findings section below. As a result of my search I have concluded that current understanding of the fitness and health status of this population can be conceived of as resting on four pillars of research, policy, and practice. The four pillars include Health Education, quality of

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[2] Terms and definitions of what constitutes intellectual disability vary throughout the literature. For the purposes of this dissertation I have chosen the term intellectual disability because it is recognized by the International Association for the Scientific Study of Intellectual Disability (IASSID) as the preferred term. This organization with its international affiliations seems as good a standard as currently exists.

life, physical fitness, and social inclusion.

2.1 Health Education

Health Education is seen as a prophylactic measure aimed primarily at informing and educating the subject population. Students often experience Health Education as part of family life programs in school. The emphasis is on making informed choices that promote healthy outcomes. Nutritional counselling for young mothers might stand as a common example. Some writers have expressed concern about the scarcity of prevention efforts directed toward people with intellectual disabilities (Beange, & Lennox, 1999; Emerson & Hatton, 2007; Horwitz, Kerker, Owens, & Zigler, 2000; Prasher & Janicki, 2002). Nevertheless, the same approach has been taken with this population.

Health Education initiatives vary from jurisdiction to jurisdiction but often contain similar elements. An assessment is made of the principle issues faced by the target population, work plans are established, and programs implemented. Evaluation follows. These government funded services are often time limited initiatives sponsored by public health authorities at the federal and or provincial/state level.

Lin, Loh, Yen, Lee, Chow, & Wu, (2005) enumerate the main goals of health education. Although Lin et al's study reflected institutional practice; its main components are readily applied to community living practice[3] in British Columbia. Lin et al. (2006) explains in the following way:

Health education planning in institutions is designed to help people with intellectual

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[3] Community Living practice are widely accepted human service practices that generally adhere to the Community Living philosophy developed over the past several decades initially in contrast to institutionalization. The principles of this practice include: a dedication to serve people with intellectual disabilities in community rather than in isolation/institutional settings and a citizenship/human rights perspective.

disabilities adopt healthy practices such as regular exercise (e.g. physical health and weight control), a healthy diet (e.g. food nutrition and selection), and good personal health skills (e.g. personal hygiene, sexual health and relationships, refraining from tobacco and liquor) (p.209-210).

Further along the authors reiterate, "These also help reduce the risk of disease and enhance the capacity of people with intellectual disabilities to achieve a better overall standard of health" (p. 210).

Another group of researchers (Rurangirwa, Van Naarden Braun, Schendel &Yeargin-Allsopp, 2006) articulate a laundry list of health indicators that included: being overweight and level of physical activity as well as tobacco and drug use, up to date immunizations and access to health care. Although these researchers argue that people with intellectual disabilities did achieve some standards indicating a healthy lifestyle; nevertheless, they concluded that "health gaps may place young adults with a history of DD (Developmental Disability, *sic*) at risk for poor health and quality of life" (p.381).

Health education researchers place a great deal of confidence in the idea that if individuals receive appropriate information and practice a discipline combining sound nutrition and physical exercise, they can offset many of the restrictions imposed as they age. Disappointingly, there is also general agreement that the understanding and personal habits of persons with intellectual disabilities falls short of outcomes desired by program designers (Horwitz et al., 2000; Prasher & Janicki, 2002; Rimmer, 1994).

2.2 Quality of Life

Quality of life is another contributor to the literature on health, fitness, and the well-being of persons with intellectual disabilities. Quality of life is seen as a multifaceted concept with no

universally accepted definition, although the claim that both subjective and objective measures

ought to be used would likely go uncontested. Some authors (e.g., D'Eath & Walls,2010;

Hensel, Rose, Kroese & Smith,2002; Perry & Felce, 2003; Shalock, Alonso & Braddock, 2002)

suggest that quality of life is not a single condition but more rightly seen as a web of

interconnected threads constituted by personal attributes and attitudes, supported by social

relationships. Perry and Felce (2003) posit that key indicators denoting quality of life include

physical well-being, material well-being, social well-being, productive well-being, emotional

well-being, and civic well-being. Research tells us that these same items are rarely achieved by

of persons with intellectual disabilities (Hensel, Rose, Kroese, & Banks-Smith, 2002). For

example, participants in Hensel et al.'s study (2002) who had poor physical fitness also had a

poor sense of their own quality of life. Interestingly, participants reporting a good quality of life,

received" individually tailored support to become full participants in the life of the community"

(p. 96). Unfortunately, however, study participants had less experience with friends in the

community as did people without intellectual disabilities. This finding suggests that service

models that work towards full engagement in community are likely to promote a higher quality

of life for people with intellectual disabilities. Engagement in community with friends and

family was also a factor in the life satisfaction of participants in the present study. This will be

fully explored in the results section below.

Research with young people in Ireland reinforces the proposal that quality of life is an

experience common to all. D'Eth, Walls, Hodgins and Cronin's (2006) research stresses that

quality of life is not simply a matter of material security. They included the less tangible

subjective experiences of positive personal relationships and a sense of social belonging. These

domains of daily living are particularly poignant for persons with intellectual disabilities who

regularly report shortfalls in some of these key measures. People with intellectual disabilities often struggle to obtain paid employment which makes material well-being difficult to achieve. Additionally, social isolation which often demarks life with an intellectual disability keeps emotional and social well-being at a distance (Abbot & Mcconkey, 2006). Study participants reflected a sense of social isolation as part of living with an intellectual disability. They also reported how sports involvement could help to diminish social isolation.

A team of researchers from Ontario (Brown, Raphael& Renwick, 1997) investigated how people with intellectual disabilities experienced quality of life (QoL). In a report to the Ministry of Community and Social Services, Brown et al. site the complexities of measuring quality of life. Nonetheless, they have set out some elements of programming that ought to be included in quality of life studies. Key understandings they worked from contain some interesting assumptions. These they summarized in point form.

- Quality of life for people with developmental disabilities consists of the same aspects of life as for all other people.

- Quality of life is based on common aspects of life for all humans, but it also reflects, from person to person, varying degrees of importance placed on those aspects of life.

- Quality of life for all people reflects how satisfied they are with aspects of life that are important to them.

- People live in environments. Thus quality of life results from the interconnection between people and the environments in which they live (p. 7/8).

It is interesting to note that in this area of life satisfaction the needs of people with intellectual disabilities cannot be distinguished from their counterparts in the "typical "population.

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2.3 Physical Fitness

The third pillar was composed of the literature on physical fitness and intellectual disability. Like other aspects of the physical well-being of persons with intellectual disabilities, physical fitness is a multifaceted concept with numerous definitions. For example, Stanish, Temple & Frey (2006) separated out different aspects of a person's fitness in the definition informing their research. They suggest that "physical activity is defined as skeletal movement that increases energy expenditure" and exercise is a sub category of overall fitness activity which they suggest "is planned, structured, and undertaken for the purpose of improving or maintaining fitness" (p14). In the context of my research, I was guided by Rimmer's (1994) definition that includes any physical activity or exercise that people regularly engage in that increases an individual's ability "to perform daily activities with vigor…"(p.3).

Within this literature it is repeatedly reported that the fitness level of persons with intellectual disabilities is particularly poor (e.g.,Beange,Lennox & Parmenter,1999; Hensel,Rose,Kroese & Banks-Smith, 2002; Jobling & Cuskelly, 2006; Pitetti,2006; Rimmer, 1994; Rimmer&Yamaki,2006; Stanish, Temple & Frey,2006; Temple,2007). Although a handful of researchers contest such conclusions (e.g., Rurangirwa,Braun,Schendel & Yeargin-Allsopp, 2004; Stanish, Temple, & Frey, 2006), the vast majority of researchers argue that persons with intellectual disabilities are some of the most unfit citizens in western countries (e.g., Coyle, Kinney, Riley & Shank, 1991; D'Eath, Walls, Hodgins, & Cronin, 2006; Fernhall et al., 1996; Heller & Rimmer 1998-2003; Heller, Wang, & Valerio, 2004; Krahn & Drum, 2007; Repp & Karsh 1999; Rimmer, Rimmer, 1994). Summarizing what has become the consensus of opinion, Rimmer (1994) reflected that "Study after study has shown that their fitness levels are much lower than those of the general population" (p. 1).

Studies of the incidence of obesity among people with an intellectual disability also

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figure in the overall picture of physical fitness (e.g., Pietti, 2006; Rimmer, 1994 Rimmer & Yamaki, 2006) here again the picture is not positive. As Rimmer and Yamaki state (2006), "Several studies conducted in the United States have reported a higher prevalence of obesity among persons with ID compared to non-ID citizens" (p.22). Pitetti (2006) recorded similar findings with people with Down syndrome. The concern expressed about this high incidence of obesity includes how being obese may affect various aspects of the lives of people with intellectual disabilities. The interaction between obesity and quality of life may also be negative. Rimmer and Yamaki (2006) argued that in addition to some of the possible health risks, obesity may reduce an individual's ability to participate in community leisure activities and to be actively employed (Rimmer & Yamaki, 2006). In a related way, Stanish, Temple & Frey (2006) put forth the idea that one of the greatest barriers to the social integration of people with intellectual disabilities is in their relatively poor health. This, it is argued, "is directly related to participation in regular physical activities" (p.14). Other research (e.g., Temple, 2007) has shown that in general few adults with intellectual disabilities reach the recommended activity level and as a consequence demonstrate poor cardiovascular fitness, lack of muscle strength and low levels of flexibility. As a result of the general low level of physical activity of people with intellectual disabilities they are missing out on the physiological and emotional benefits that accrue from regular exercise.

Writers exploring the physiological benefits of exercise have taken as axiomatic that increased fitness will buffer the losses exacted by the ageing process. This judgment is evoked on behalf of disabled and non-disabled populations alike. Rimmer (1994) contended that the benefits of fitness will pay out the richest reward as persons with intellectual disabilities advance in years. Temple and Walkley (2007) summarize some of the potential physiological benefits of

a moderate level of fitness. They site that simple exercise such as "brisk walking… [h]as protective effects for several chronic diseases, including coronary heart disease, hypertension, non-insulin dependent diabetes mellitus, osteoporosis and colon cancer" (p.28). Given the benefits of moderate exercise, removing barriers to the fitness of people with intellectual disabilities should rank high as a health education strategy.

Some writers (e.g., Carter, 2002; Pitetti, 2006; Prasher & Janicki, 2002; Stanish, Temple & Frey 2006) have suggested that there has been very little attention paid to what attracts people with intellectual disabilities to fitness activities. The research of Stanish , Temple and Frey (2006) set out to fill this information gap and arrived at a multifaceted list of barriers that included psychological, cognitive and emotional barriers as well as social relational barriers such as lack of interest by support staff and "negative messages from support systems" (p. 18). These researchers concluded that there remained a lack of knowledge on the fitness behaviour of people with intellectual disabilities. Despite this lack of information a number of research projects (e.g., Abbott & Mcconkey, 2006; Chabias, Reid & Hoover; Fender, Marsden & Starr, 2007; Repp & Karsh, 1992; Rimmer, Heller, Wang & Valerio, 2004) have tried to design programs that synthesize the right alchemy of fitness regimes and social support that would engage persons with intellectual disabilities for sufficient time to remediate their long term health status. One mechanism proposed to achieve the overall fitness and well-being of the disability population is to include them in generic fitness activities (Carter, 2002). The goal of these programs has been to accommodate persons with intellectual disabilities so that they may participate with the general population.

2.4 Social Inclusion

Disability activists have put social inclusion at the top of their agenda. It is also the fourth pillar contained in the literature on physical fitness, well-being, and the health status of persons with intellectual disabilities. In the United Kingdom inclusion forms a major component of how the government believes services for people with intellectual disabilities should be designed (Abbott & Mcconkey, 2006). Inclusion as a platform for public policy is a laudable goal; however defining social inclusion is an elusive task. For persons with physical impairments, universal design is considered the preferred paradigm for promoting social and environmental inclusion (Mackelprang & Clute 2009). This arguably is rarely achieved. Similarly, for persons with intellectual disabilities, full citizenship remains a distant dream. Recent publications (e.g., Abbott & Mcconkey, 2006) suggest that exclusion from social life is an immutable daily experience for persons with intellectual disabilities. In their exposure of the relationship between social exclusion and minority group status, Shaw, Dorling and Smith (2006) suggested that there is no universally accepted definition of exclusion. Nonetheless they offer:

> "Social exclusion" refers not only to the economic hardship of relative economic poverty, but also incorporates the notion of the process of marginalization - how individuals come, through their lives, to be excluded and marginalized from various aspects of social and community life. (p. 207)

This process of systematic exclusion based on personal characteristics could well be argued to form one of the barriers to the participation of persons with disabilities in recreation and sport activities. Social exclusion and isolation remain common experience for persons with intellectual disabilities despite advances made through the community living movement. A global report on the status of individuals with intellectual disabilities and their families (Inclusion International,

2006) made the observation that: "The reality facing our members is that despite the increase in the number of human rights provisions, the lives of people with an intellectual disability around the world are characterized by exclusion" (p.vii).

Some writers (e.g., Abbott & Mcconkey, 2006; Block & Obrusnikova, 2007; Carter, 2002; Mahon, Mctavish, & Bockstael, 2000) have proposed paving the way to inclusion by improving access to generic recreational activities for persons with disabilities. The vision here suggests that integrated programs will change public perception and challenge stigmatizing attitudes, thus reducing social barriers to fitness programs for persons with intellectual disabilities (Arbour, Latimer, Ginis, & Jung, 2007; Mahon, Mctavish, & Bockstael, 2000, citing Wolfensberger, 1972). Best practices for the inclusion of people with intellectual disabilities have been identified. Among the recommended practices listed was the development of individualized fitness plans, coordination of planning between support agencies and financial assistance (Carter, 2002). The overriding philosophy advocated by this approach can be characterized briefly as a belief that proximity will lead to acceptance, if not understanding. Programs featuring this design might best fall under the rubric of "normalization"[4] and later Social Role Valorization as developed by Wolfensberger (Osborn, 1998). According to Renzaglia, Karvonen, Drasgow and Stoxen (2003) normalization requires that the disabled population" should participate equally in the normal routines of community life" (p. 140). Included in the routines of community life are recreational activities. These researchers push the concept of inclusion past the point of physical or logistical access. They included in their comments the idea that self-determination and self-advocacy ought to be a part of any social philosophy that aims to support notions of full inclusion. Renzaglia and her associates reflect

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[4] The "normalization" principle first explored in Scandinavia was further developed in the USA and Canada by Dr. W. Wolfensberger, PhD, psychologist and advocate for people with intellectual disabilities.

that self-advocacy puts people with intellectual disabilities in charge of their own lives which

may act as an antidote to a history of being controlled by other forces.

Other research has focused more on attacking the problem of social exclusion at a

younger age by integrating children with disabilities into sports activity with their non-disabled

peers (Grenier, 2006). The goal of children's programs has been to set a pattern of engagement

in fitness activities that will carry over to their adult years. In the recreation field, Carter (2002)

reflects that inclusive leisure programs are considered best practice.

One might expect that universal education assures that at least for part of their

development, some disabled children will have access to generic health promoting activities.

However, a recent study in England (Block & Obrusnikova, 2007) revealed that although

inclusion was featured as a philosophical platform by educators, it was still difficult to

operationalize in the classroom setting. Grenier (2006) stated that exposing "typical' children to

their disabled peers in physical education classes in and of itself did not promote true inclusion.

Rather, she argued that "effective inclusion was dependent on meaningful and reciprocal

relationships between all children and the social climate of the classroom" (p.250). For the

majority of children with intellectual disabilities, once the relatively benign atmosphere of the

school house is vacated for the adult world, opportunities diminish. These integrative approaches

reflect the dominance of normalization or Social Role Valorization (SRV) as the prevailing

theory behind human service practice in the decades after deinstitutionalization (Yates, Dyson, &

Hiles, 2008).

One contemporary critique of normalization as the driving theory behind community

living services has been launched from disability theorists who have made problematic the

notion of normalization as a desired state. Tremain's (2001) interpretation of how professional

discourses police troublesome populations through their "technologies of normalization" (p. 186) seems particularly suitable to an analysis of the power relations and subjective social processes that impact the identity, beliefs, and behaviour of persons with intellectual disabilities. Other authors have taken a Foucauldian approach to the analysis of social processes in the human service industry. For example, Gilbert (2002) explored how the discourses of professional management have constructed subjectivity in social care. Others (e.g., Tremain, 2001) described normalization as a practice that employs scientific discourse and its classifications to "structure the field of possible action" (p. 662) for individuals. Recently, Yates, Simon, and Hiles (2008) have faulted normalization and its North American iteration, Social Role Valorization (SRV), for their underlying assumptions of the "individual-society dualism" (p. 248). These authors argued persuasively that hidden beneath the surface of SRV is the unexplored assumption that persons with intellectual disabilities existed separate and apart from the social processes that constitute their subjectivity.

Bevir (2005) has used Foucault's concepts of govenmentality and regimes of knowledge and truth to explore how an "ethic of care for the self" (p. 43) imposes responsibilities on individuals to manage themselves in socially appropriate ways. This exploration may have significance for the expectations placed on persons with intellectual disabilities to respond favourably to professional assessments of their needs for greater fitness participation. Bevir's (2005) work seems most relevant to population health efforts aimed at ensuring persons with intellectual disabilities accept personal responsibility to improve their own fitness. This theme will be given greater consideration in later chapters.

An interesting and hopefully enlightening aspect of developing a grounded theory in the arena of physical fitness and intellectual disability has been my ability to compare how the data

gathered in the research process reflects or contradicts current theoretical perspectives. An explication of my discoveries is available in Chapter's 4 (p. 70) and Discussion of Chapter 6 (p. 160). In brief, I argue in the results, findings and discussion sections that these Foucauldian approaches have proven their utility in supporting at least in part, a new iteration of the relationship between the fitness of persons with intellectual disabilities and health and human services. Now that I have described the four pillars that support the literature on physical fitness and intellectual disability, I will proceed with a note on the social context in which this study is situated.

2.5 Social Context

Taking to heart Charmaz's (2006) argument that constructionist studies ought to extend their analysis by placing their findings in the larger social context I carried out an additional literature review. The purpose of this review was to establish the current socio-political landscape that backdrops my own study. Throughout this section, I present various critiques of neoliberalism with a view to understanding its impact on the lives of study participants. Throughout this analysis I carry with me a Foucauldian critique that troubles the waters of trust and benevolence that pervade the human service industry.

Across the western world neoliberal philosophy dominates the practices of government respecting among other things, public funding of the social safety net (Cook, 2012; Dowse, 2009). Exploring neoliberalism is significant for this study because much of the support that study participants received that allowed them to access fitness and sport activities has been facilitated by their involvement with support workers and residential staff. The bulk of funding for theses support services comes from the crown agency, Community Living British Columbia (CLBC). As an arm of government and a body that funds human services this agency is directly

affected by the prevailing social and economic beliefs and policies of government.

There is a wide sweep of literature written on neoliberalism. Writers have employed various descriptions of the meaning of neoliberalism. As well, economic, political and social policies that are aligned with the neoliberal project have not been implemented in the same manner across political jurisdictions. There are, however, commonalities across jurisdictions. For the purposes of this dissertation, I have relied upon the definition of neoliberalism provided by Harvey (2005). Harvey offers a definition of neoliberalism that captures the common understanding of the term as presently used.

> Neoliberalism is in the first instance a theory of political economic practices that purposes that human well- being can best be advanced by liberating individual entrepreneurial freedom and skills within an institutional framework characterized by strong private property rights, free markets and free trade (p. 2).

A corollary neoliberal belief to be mindful of in relation to this dissertation is that the state should not function in the provision of human services and that, ultimately, all human relations including those of care, should be marketized (Harvey, 2005). As the tentacles of neoliberal thought extend into all avenues of social being, it is difficult to extract any nugget of social interaction that remains untouched. This is the picture of hegemony. Harvey (2005) has argued that neoliberal hegemony has dislodged all previous social relations including ideas about the provision of welfare benefits. Neoliberalism has taken on the attributes of a moral crusade pushing aside the once dominant social values of providing for the common good. The vigour of this hegemony has allowed neoliberalism to "guide all human action" (p. 3) into a frame of market ethics. This idea of an all encompassing philosophy is significant for this study because it allows for a more thorough understanding of the undercurrent of neoliberal social philosophy

that flows beneath the surface of relationships between study participants and others, most specifically professional helpers. This undercurrent surfaces in the form of directives by caregivers that study participants should be more self-sustaining. Physical fitness forms part of the constellation of independence building projects that are part and parcel of most community access programs.

 It would be a momentous task to summarize such a wide sweep of literature as is available on neoliberalism. Unfortunately, it is beyond the scope of this dissertation to pursue such an undertaking. However, within the thin strata of literature I have surveyed, I am able to identify aspects of this literature that are relevant to the social context in which study participants made their fitness choices.

Broadly speaking, the literature I have reviewed may be classified under two headings. The first category contains those articles that focus on the origins and ideology of neoliberalism. Much, if not all, of these samples use the term neoliberal in the pejorative sense. Apprehension about the impact of neoliberal social policy was evident as early as the 1980s. Altheid (1987) was one early writer who decried the comodification of care in the non-profit sector of the United States. Turner (2007) and Mudge (2008) are examples of authors who have taken on the challenge of plotting the origins and definition of neoliberalism.

Social policy stands out as a second theme in the literature on neoliberalism. For example, Evens, Richmond and Shields (2005) wrote on the impact of neoliberalism on governance in the non-profit service sector. McGregor (2001) has discussed the impact of neoliberalism on health care and Amable (2011) explored neoliberalism as a moral philosophy. In a related way, Peters and Tang (2004) called for international advocacy in response to the de-funding of women's centers by neoliberal regimes in British Columbia. Dominelli (1999) is one

author who has taken the global picture into account when investigating the impact of globalization and neoliberal social policy on the practice of social work. Smith (2004) has described the impact of marketization on support services in South Africa.

In Canada Teghtsoonian (2009) has brought her analysis to bear on manifestations of neoliberalism in Canada and British Columbia while Little and Marks (2006), Pedlar and Hutchison (2000) have applied their critique of neoliberalism to service delivery for people with intellectual disabilities. These latter authors are most relevant to the understanding of macro influences on the lives of people with intellectual disabilities. As a vulnerable population the participants in this study are among those groups in society who most regularly rely on products of the social safety net and consequently are in the main, more susceptible to shifting social policy. Social policy on how best to provide for vulnerable populations has shifted significantly in the past few decades.

Historically social policy in Canada can be characterized as belonging to the "liberal family" (Mahon, 2008, p. 342). Within this family the marketplace and the family are the principle providers of services. The state takes a secondary role. According to Mahon (2008), the different political parties that have ruled Canada vary only in the emphasis they place on the role of the state visa vie the market forces in determining the span and variety of human services available. Despite their similarities, each regime has significant differences when it comes to service redesign. Mahon (2008) divided liberalism in Canada into three groups. Classical liberalism arose out of mercantilism where "social policy was limited to assisting the "deserving poor and reinforcing the work ethic" (p. 343). In social liberalism, the state is responsible for creating social conditions where the individual can thrive and achieve their full potential (p344).This type of liberalism has been associated with the Keynesian welfare state. Third in

Mahon's scheme is neoliberalism which itself is sub divided into "roll back" and "roll out" neoliberalism. Roll back neoliberalism has challenged Keynesian ideas of the state as protector of the" social good" (Pedlar & Hutchison, 2000, p.639) whereas in roll out neoliberalism the state takes an active role in creating "a disciplinary apparatus to contain the marginalized and dispossessed (Mahon, 2008, p. 334). It is the shift to neoliberal social philosophy that is having the greatest impact on the human service industry at present. I will now provide a brief overview of the origins and basic values of neoliberalism as a foundation for further discussion.

Neoliberalism as a force in western society has its origins in Europe in the years running up to the Second World War. Neoliberalism as an economic and political force emerged out of the blackness of the Second World War. The origins of classical liberalism can be traced to the end of mercantilism late in the eighteenth century. A key turning point in the ascendency of the "new" liberalism was the development of the Mount Pelerin Society in (MPS) Switzerland in 1947 (Turner, 2007). The driving force behind this meeting was F.A .Hayek, his mentor Ludwig von Mises, Alexander Rustow and Michael Polanyi. These academics were united in their distaste for social collectivism that had emerged in the period of the economic depression preceding the Second World War. They set up The Mount Pelerin group part of whose mission was to turn back all forms of collectivism which in their minds all led to totalitarianism. State control of social life would eventually become oppressive. Freedom had to be protected. They considered liberalism as the cardinal precept driving and sustaining Western civilization (Turner, 2007). From its genesis in the Swiss Alps, the message of neoliberalism with its core values of the pre-eminence of individual enterprise and a market economy spread to America. Academics and economists helped to spread the word.

Hayek became the most renowned of this group and continued to produce economic

theory on behalf of the neoliberal movement for several decades. His efforts did not go unnoticed. Hayek was awarded the Nobel Prize for Economics in 1978 (Shared with Gunnar Myrdal. Royal Swedish Academy of Sciences, 1978), the Order of the Companions of Honour on Margaret Thatcher's recommendation, and the Presidential Medal of Freedom by George W. Bush (University of Chicago www.uchicago.edu/). Hayek's brilliance as an economist and his influence on social policy cannot be overstated. The legacy of Mount Pelerin remains today. The matching of freedom and democracy with neoliberal policy was a constant theme across the literature reviewed. It is the movement towards domination of neoliberalism in the human service field that shows the greatest potential to effect the lives of people with intellectual disabilities.

The language and discourse of the neoliberal bespeaks of its ideology as not just an economic practice but as an movement aimed at eradicating all forms of collectivism and holding as fundamental "normative principles favouring free market solutions" (Mudge, 2008, p 706). Advanced as the only solution to maintaining freedom in the Western world (perhaps the world as a whole), neoliberalism has been defined in various ways. Mudge (2008) offers his own version that includes the notion of a moral campaign.

> ...neoliberalism is defined here as an ideological system that holds the "market" sacred, born within the "human' or social sciences and refined in a network of Anglo-American-centric knowledge producers, expressed in different ways within the institutions of the postwar nation-state and their political fields (p.706).

On face value this concern with eradicating collectivism would predict an eventual clash with all varieties of identity politics and more directly linked to this study, the work of self-advocate groups for people with intellectual disabilities. The advancement of all social justice

agendas requires people to work collectively for their mutual benefit. This seems the antithesis of individual enterprise.

The concept of rational self interest that accompanies neoliberalism is sustained by a kind of social Darwinism that suggests that the principle force behind human behaviour is dominance of the fittest over the less fit (Harvey, 2005). In the cosmology of neoliberalism, the fit survive through competition and the unfit look for handouts. The role of the state is to clear the way for enterprise and keep the free riders to a minimum. If this logic prevails it is incumbent upon neoliberal governments to reduce public spending or spend wisely on projects that promote eventual independence from the public purse. Physically fit individuals contribute to this plan by managing their own health care through appropriate regimes of exercise and healthy diet. This is the approach population health advice takes toward hard to reach and vulnerable populations. And, this in essence is the message many study participants received from people who support them. The down side of this approach is that if the individual fails to bring themselves up to fitness standards they have only themselves to blame for this result.

Neoliberalism was to manufacture the ideal marketized world by enlistment of the power and influence of knowledge producers and political elites in a strategy of defining and limiting the parameters of political debate. In this system the free market is synonymous with democracy and freedom in all spheres of life. Ironically, the reach of neoliberal principles into non-economic aspects of society was to be facilitated by government action. Roll back neoliberalism shrank the welfare state and roll-out neoliberalism served to de-regulate business while applying new regulations that restricted access to public funds provided to help vulnerable people. Time limited welfare payments brought in by the Liberal government in British Columbia stand as an example of the latter (Peters & Tang, 2004) while the overall thrust of roll back neoliberalism

can be found in the policies of the Reagan/Thatcher years (Graefe, 2005). Although Reagan and Thatcher came to power in counties with significantly different social policy landscapes, they shared many ideological positions. Both subscribed to the idea that spending on social services was one source of economic difficulty (Lister, 1991). In Britain, this was expressed as a dysfunctional dependence on the state to provide "health care, education and social security" (p.96). In the US, the new agenda set out to "reverse the course in social policy" (Glazer, 1984, p. 77) that had been established in the post war era. The variety of economic and social policy initiatives taken during the Reagan and Thatcher administrations could fill (and have) volumes and are clearly too numerous for this discussion. However, their overall thrust can be said to have had significant impact on social service budgets and administration that to a large extent can be observed in Canadian federal and provincial social policy (Mahon, 2008).

According to Little & Marks (2006) the British Columbian government under the Liberal Party regime have taken a leadership role in embracing neoliberal policies. Pedlar and Hutchison (2000) argue that neoliberal regimes place emphasis on deficit reduction over service to people and as a result care becomes comodified. This change may be described as a shift from a Keynesian model of a "comprehensive social service system" (p.639) to one where state sponsored services become "residual" (p. 639). These authors express the concern that "[t]he vulnerability of people with developmental disabilities is exacerbated when deficit reduction takes precedence over people's needs" (p. 646).

A third position is taken by Dowse (2009) who allows that globalization and neoliberalism may produce some benefits for people with intellectual disabilities. Specifically he suggests that modern global technology allows self-advocates groups to communicate across the globe. They can build networks and share strategies thus strengthening their political

effectiveness. However, Dowse expressed grave concerns that the injection of marketization into traditional non-market areas may produce greater obstacles for people with intellectual disabilities to truly achieve self-determination.

Mahon (2008) underlined the fact that Canadian social policy has been defined by Anglo-American neoliberalism. She advanced the idea that there are "varieties of liberalism" (p. 342) evident in historical and current political regimes. Despite the fractionalized way in which neoliberal reforms have been implemented they do share common principles and similar social effects. All versions pledge themselves to a free market economy and consequently produce the same social relations. Additionally, all strains of Canadian liberalism adhere to an ethic of individualism. The individual is constructed as a male breadwinner. The neoliberal mind shares this distinction with its Keynesian forebears.

The Keynesian inspired welfare support system that developed in Canada after WW2 also advanced the notion of the male as the head of a household (Mahon, 2011). This proportioning of citizenship after the model of the average man is reminiscent of Davis's (2006) discussion of the ascendency of the norm as a standard of human capacity. Admitting women into the enclave of preferred status has been a recent development. People with intellectual disabilities are still in line.

The welfare state in Canada has succumbed, in good measure, to the forces of neoliberalism as did countries spanning the breadth of Western Europe. Both roll-back and roll-out neoliberal policies are in evidence in various Canadian political jurisdictions (Mahon, 2008). These incursions are earmarked by increased privatization and contracting out of public services as well as the encouragement of public-private partnerships. Some authors (e.g., Dominelli, 1999) have suggested that these partnerships are a vehicle for transferring public funds into

private hands and might more accurately be characterized as a "dismantling" and "comodification" (Pedlar &Hutchison, 2000 p. 637) of services For most of these writers neoliberalism is perceived as a threat to concepts of the common good or collective well being of the population.

Over the past few decades, federal and provincial governments across Canada have made substantial withdrawals from the common good of their populations. During the decade of the 1990s, the federal government reduced transfer payments to the provinces. Both the Canadian Assistance Plan (CAP) and its more recent iteration the Canada Social Transfer (CST) and Canadian Health Transfer (CHT) have been greatly reduced (Pedlar & Hutchison, 2000). These reductions in available funds have been ushered in at a time when an aging population is beginning to place greater demands on health and human services. As a result of these cut backs provincial governments of all stripes have had to implement deficit reduction strategies. Whether they went willingly or not nonetheless they went. Deficit reduction has been facilitated by a discourse of governmentality wherein the responsibility for health care has been wrestled from the arms of the welfare state and given over to an ethic of individual responsibility in line with the neoliberal revelation. Here the "sociological imagination" (Mills, 1959, p. 5) has been reversed. Social issues are recast as personal problems.

In British Columbia, the neoliberal agenda which privileges individualism and the logic of corporate management in the public sector can be evidenced in policies of deficit reduction as well as the discourse of personal responsibility (Teghtsoonian, 2009). Teghtsoonian took a Foucauldian perspective in her discussion of techniques of governmentality in neoliberal regimes. In a similar vein, I have utilized Foucault's notions of governmentality and related concepts in my discussion of study results. As an example of discourse put to work to

camouflage governmental retreat from the social good, Teghtsoonian (2009) cites the British

Columbia government's ActNowBC campaign. This campaign is replete with tips advising

individuals and families how to take charge of their own health and longevity: eat right and

exercise. This emphasis on self-management is reflected in the comments made by study

participants, their families, and professional support persons. This ethic of self care is a hallmark

of wisdom and citizenship in a world populated by rational, freely choosing individuals pursuing

the best interests of themselves and their families.

The non-profit sector of the economy has traditionally been a bastion of Keynesian

welfareism. The walls of this bastion are starting to tumble. Evens, Richmond and Shields

(2005) commented on the impact that neoliberal reforms have had on the non-profit sector.

Although non-profits have not been exclusive providers of human services in British Columbia,

they have provided a large measure of these services particularly to persons with intellectual

disabilities. The funding for these programs originates with the provincial government (with

some help from fund raising efforts) who have chosen to deliver services through arms length

relationships with community agencies and organizations. These agencies often have their

origins in grassroots movements.

Over the period of the 1950s and 1960s, parents had become dissatisfied with the lack of

community alternatives available to children with intellectual disabilities and so created

community organizations to support a better life for their sons and daughters. Many non-profit

organizations had their naissance at this time (Canadian Association for Community Living,

2011). During the decades that the process of deinstitutionalization began to unfold these

enterprises expanded to provide care and support for those individuals entering the community.

Families and disability activists can be credited, at least in part, for the advance of non-profit

networks across the province. Today there is a mixed economy of for-profit and not-for-profit service agencies as well as individual entrepreneurs and family based micro-boards all contending for government contracts.

Evans and his associates (2005) echoed Altheid's (1987) early concerns that neoliberal restructuring has had a detrimental effect on the operational ethos of non-profits. These organizations have traditionally modeled themselves in accord with community needs and the aspirations of their clientele. In today's economic environment, non-profits have had to adopt a business model approach to service delivery, cultivate competitiveness and put aside advocacy missions. These grassroots organizations have been sidetracked by increased competitiveness and shoehorned into a paradigm of commercialized care. In short, the ideology of welfare pluralism (Pedlar & Hutchison) that marked the old regime of Keynesian social contract has been trumped by the principles of free market economics. This is powerful evidence of aptitude of proponents of neoliberalism to extend the principles and conditions of market place economics into what has traditionally been locations of non-commercial relationships. Read (2009) citing Harvey (2005) argued neoliberalism has become hegemonic to the point of common sense. In this regard neoliberalism has succeeded beyond the economic and political realm and supplanted all other notions of human relations.

As Read (2009) further argued, neoliberalism has extinguished all other ideologies and laid sole claim to all social space through its insistence of the rational pursuit of self interest as the immutable core of human nature. Neoliberalism has captured the theatre in which the script of possible actions is played out. This grim prospect surfaces the issue of human agency and the nature of subjectivity in the neoliberal world. In later chapters I discuss the significance of this analysis in understanding the vocabulary that study participants use to describe self and how this

relates to their fitness choices. For now, it is sufficient to summarize the dilemma facing anyone who would offer an alternative world view. Equating neoliberal practice with human nature has created a seemingly impregnable fortress against which any siege is not just impotent but senseless. This is the rational for the marketization of all spheres of human activity including care relationships. It is inside this frame that the relational activities and common sense beliefs of study participants takes place. What impact neoliberal thought will have on the ability of people with intellectual disabilities to access community services is yet uncharted ground. How people with intellectual disabilities will traverse this new terrain is uncertain. According to some writers (Little & Marks, 2006; Teghtsoonian, 2009) other marginalized populations have not fared well.

In this chapter I have reviewed a cross section of the literature on physical fitness and people with intellectual disabilities and followed that by a short review of the literature on neoliberalism and its impact on human service delivery. In coming chapters (primarily 4 & 5) I draw on the work of Foucauldian theoreticians as a way of linking the common sense beliefs and fitness choices of participants with current regimes of neoliberal truth. But first I will lay the groundwork for the research study through the following discussion of methodology.

Chapter 3: Methodology

The literature on physical fitness and intellectual disability has led me to conclude that the much of the research in this field takes a positivist approach in theorizing intellectual disability from a medical paradigm. As Davis (2006) so well articulated, this paradigm is evident in population health and national fitness projects which gauge the performance of persons with intellectual disabilities against the "political arithmetic" (p. 4) of statistical norms wherein consensus has it that they perform poorly. With few exceptions contextual and relational influences on fitness behaviour are poorly represented in the literature. The first person experience of people with intellectual disabilities is rarely reported. Nor do we find the social determinants of health as explored in the general population (Marmot & Wilkinson, 2006) systematically applied to persons with intellectual disabilities. Even where the physical health of persons with intellectual disabilities is thoroughly explored (e.g., Prasher & Janicki, 2002), there is little explanation within physiology that explores the social or relational reasons that inhibit or enhance an individual's attachment to fitness, recreation or sport activity.

Each of the four pillars briefly explored above contribute some ideas about the poor physical well-being of persons with intellectual disabilities, but none, individually or in combination, provides a complete explanation. Population health measures try to instil commitment to healthful lifestyle choices. Social inclusion measures try to approach the situation through program integration, and studies in physiology and kinesiology provide substantial knowledge on the biology and mechanics of fitness and health. However, an explanation of this phenomenon from the perspective of individuals with intellectual disabilities seems absent. A thorough literature search has failed to locate any significant repository of research that explores the social processes that affect the participation of persons with

intellectual disabilities in health promoting physical activities.

One objective of qualitative research is to gain understanding about a social issue or problem from the perspective of those affected (Creswell, 2007). This is the basic drive behind ethnographic and phenomenological studies across disciplines. Over the historical development of qualitative research, each of these traditions has proven its utility in explicating a range of social issues. Creswell (2007) offered a choice of five traditions in qualitative research, including narrative research, phenomenological research, ethnography, case study, and grounded theory research. Where there is the absence of a theory that fully explains a process or phenomena, grounded theory is recommended (Creswell). The fact that I wanted to move beyond description of the essence of individual experience has propelled my interest past phenomenology and into the realm of grounded theory. Therefore, the research project I have undertaken employed the grounded theory methods.

Grounded theory moves beyond description and advances toward formulating an explanation of the studied phenomena or social processes (Creswell, 2007); consequently, it has the promise to explicate social processes that are missing in the literature. Glaser and Strauss (1967) pioneered grounded theory. Three decades later, Glaser (1998) suggested that grounded theory remains effective in generating theory in the human and social sciences. Secondarily, Glasser (1998) recommends grounded theory because its methods help guide the novice researcher through the research process. My choice of grounded theory is further fortified in a later suggestion that grounded theory "empowers the researcher" (Creswell, 2007, p. 116) such that he/she can make a significant contribution to his/her area of study.

One of the key principles of grounded theory is that explanations of social phenomena are best theorized by analysis of data rather than setting out to test apriori hypotheses of

traditional qualitative analysis. In short, theory is derived from "first order" data (Creswell, 2007, p. 119) and, thus, provides the opportunity for responsibly representing the experience of people with intellectual disabilities. This is an important factor in the choice of methodology as it recognizes and respects the expertise of persons with intellectual disabilities in describing their own experiences (Knox, Mok, & Parmenter, 2000) and in this way provides an opportunity for a respectful research process. This choice reflected my belief that the best way to gain knowledge is to make enquiries of those who have lived the experience or process under investigation. The ontological position implied here is that there is in fact something to be learned that can be to some extent captured through grounded theory methods and, subsequently, interpreted through written word.

Grounded theory, as realized in the 1960s, has recently been critiqued for its modernist/positivist epistemology where truth claims favour the researcher (Bryant & Charmaz, 2007). When poststructuralists like Clarke (2005) suggest that "there are no innocent positions" (p. 14), she is in fact arguing that the choice of methodology is intimately connected to the researcher's epistemological and ontological perspectives. What is not implied with this position is that the results represent an objective truth that I have been able to uncover and isolate. As Haraway (1988) has argued social constructionist researchers reject the notion that "ideologies about objectivity" (p.,576) can fully account for how knowledge is produced. While being reflective about my own positionality will keep me sensitive to interpretive bias, reflexivity cannot erase my positionality. Relevant to this thought, Haraway (1988) states: I am arguing for politics and epistemologies of location, positioning and situating, where partiality and not universality is the condition of being heard to make rational knowledge claims" (p. 589). Relevant to the discussion of knowledge claims Swigonski (1993) talks about researcher

standpoint offering that; "from that social position (of the researcher, *sic)* certain features of reality come into prominence and other aspects of reality are obscured" (p.172). Robinson (2002 as cited by McGhee, Marland & Atkinson, 2007) has succinctly argued reflexivity suggests: "...an awareness in which the researcher as an individual with a particular social identity and background has an impact on the research process" (p.335). Put simply as a researcher I had to be reflective about my own beliefs and recognize the power differential between myself as a privileged knowledge producer visa vie the study participants who are absent that privilege (Rose, 1997). The conclusions of my research are presented keeping these caveats in mind.

Part of my personal paradigm is that despite reality being an elusive prey, it can in part be snared. That said, this research is informed by the theoretical position of Charmaz (2006) and others (e.g., Burr, 2003; Gergen, 1985; Mills, Bonner, & Francis, 2006; Puig, Kprp-Ljungberg & Echevarria-Doan, 2008; Rose, 1997; Swigonski, 1993) who have contested an objective and a historical existence separate from the interaction of the knower and the known. My position is in alignment with these writers who have contended that reality is socially constructed, formed, and re-formed through social interaction. In this respect, my preferred method moves away from the orthodox structure initiated by Glaser and Strauss (Charmaz, 2006) and towards the symbolic interactionism described by Annells (1996) and is integral to Clarke's (2005) work.

A key epistemological principle that guided my approach was that my positionality will affect the research process; therefore, this dissertation, produced as it has been through my interaction with participants, must be recognized as an interpreted construction of the social process as lived (Annells, 1996). This position stands in contrast to the positivist and post-positivist paradigm that rest on the assumption of an objective truth that is detached from the researcher (Annells, 1996). Postmodern iterations of grounded theory challenge the notion of the

objective researcher uncovering social facts. The work I presented here moves in that direction and, consequently, imagines a multiplicity of social positions from which reality may be experienced.

One challenge to orthodox grounded theory that remains within the enclave of the grounded theory family is constructionism. As Charmaz (2006) expressed, the constructivist approach assumes that theoretical propositions emerging from grounded theory methodology render an "interpretive portrayal" (p. 10) of the world not as a stable or enduring reproduction. Clearly, application of these constructionist principles move my work beyond the classical grounded theory as proposed by Glaser (1998) and into the constructivist camp, whose dominant proponent remains Charmaz (Mills et al., 1996). Accordingly, my approach to the methods of grounded theory has been aligned with the general understanding developed in recent works (Bryant & Charmaz, 2007). From this perspective grounded theory is a systematic and inductive methodology that lends itself to a deep analysis of social processes, uncovered through a flexible application of principles rather than a rigid and prescriptive set of rules. My position may be understood as standing at a midpoint between the traditional post positivism embodied in Glaser's (1998) orthodoxy and the pursuit of the postmodern margins expressed by Clarke (2005).

3.1 Methods

Qualitative research methods are the nuts and bolts, the mechanics of the research project. Methods are the techniques whereby data is gathered, analyzed, and interpreted. The grounded theory process begins with data gathering. However, unlike other qualitative methods, data gathering, analysis, and theorizing are not discrete practices but proceed simultaneously and are advanced from the outset of the project (Charmaz, 2006). Throughout my research project, I

adhered to this principle: collecting data and formulating analysis was a continuous loop of related activity. In grounded theory practice, data gathering typically involves face to face interviews with participants. The nature of the information gathered and the treatment of interview material vary between the traditionalists and those such as Charmaz (2006), Charmaz & Bryant (2007) and Clarke (2005) who take a more poststructulist approach to interview transcription. Glaser (1998) provides the template for the more traditionally orientated researchers and minimizes the need for transcribing the detail of participant reports. His model assumes that "relevant associations" (Glaser, 1998, p. 107) will emerge through the constant comparative analysis[5]. In the present project, I practiced the tenets of postmodern constructionist methodology as proposed by researchers such as Charmaz, Bryant and Clarke. Charmaz (2006) advises that grounded theory methods are systematic yet flexible guidelines which ultimately produce theoretical propositions "grounded" in the data (p. 2).

An important understanding of constructionist perspective is that researchers create their knowledge through interpretation of data (Annells, 1996). Throughout the research process of this study, I have been in agreement with the interpretist thrust evolving in grounded theory. I believe that while we can observe the empirical world, people are "meaning making" (Glaser, 1998, p. 32) animals who make meaning of their world through interaction with others. Therefore, as Charmaz (2006) suggests, researchers cannot directly comprehend an objective reality, but rather reality "arises from the interpretive process and its temporal, cultural, and structural contexts" (Mills et al., 2006, p. 6). Haraway (1988) furthers the discussion of multiple social positions in her explication of the "tempting dichotomy" (p.576) of objectivity versus

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[5] The constant comparative method: a method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, with data with category, category with category, and category with concept. Comparisons then constitute each stage of analytic development (Charmaz, 2006, p.187).

subjectivity in representations of reality. She further argues that researchers are not in control of the world and that "surprises and ironies" (p.594) are central to all knowledge production.

The interactive nature of reality and knowledge production requires a commitment to respecting the nuances of the lived experience in the data gathering and analysis process. As a result, the explanatory power of a constructivist grounded theory is enriched through the veracity of participant voice. To this end interviews are characterized as a "directed conversation" (Charmaz, 2006, p. 25) whose goal is a detailed understanding of how and why the process or phenomenon is experienced. Throughout the interviews I conducted in my data gathering, I employed this conversational approach using my set interview questions as focus points while probing for meaning and responding in the moment to participants' responses.

3.2 Interview Process

As mentioned above, I employed a conversational approach to interviewing participants. I began the study and each interview with a stock set of interview questions (See Appendix F, p. 232 for details). As I progressed through the interviews, the questions were improvised to suit the receptive and expressive language skills of specific participants. I re-wrote a couple of questions to better communicate in simpler language. For example, after the first four interviews I noticed that question #6 seemed to be a little confusing to participants. I reviewed some sample questions provided by Charmaz (2006, p. 31); as a result, I amended this question from the original to a more direct question which simply asked, "What does fitness mean to you?" Interviews conducted subsequent to this change seemed a little richer as a result, and answers provided an enumeration of both concrete and more intangible, emotionally based meanings. Hallberg (2006) reminds us that grounded theory ought to make sense of the meaning people ascribe to their experiences. Moreover, the meaning people apply to their experiences has been

seen as instrumental to charting changes in behaviour and improving their quality of life (Forte, 2009). Importantly, in line with the theoretical perspective of this paper, social constructionism also places great emphasis on meaning making (Doan-Eschevarria, Ljungberg-Koro & Puig, 2008). I also added question #11 asking, "Is there anything about exercise activities you don't like?" I was hoping this question would isolate any negative experiences regarding the interviewee's fitness activities. For the most part, this addition provided little in the way of significant data; nonetheless in deference to thoroughness I continued to ask it.

I used prescribed questions in my interview protocol as focal points for our conversations, occasionally returning to the script when an avenue I was pursuing came to a dead end or the participant simply ran out of comments on the topic. Each of the pre-set questions was followed by probes which prompted a fuller response from participants. This part of the data gathering process can be likened to Hallberg's (2006) notion of being sensitive to the voice of the actor. This "funnelling" approach allowed me to chase down ad hoc hunches that sprang from my observation of the participants' inflections and body language. Sometimes these forays provided more clarity and depth as to the participants' meaning and other times they did not.

Responses to the eleven questions varied from person to person as might be expected. Interestingly, many of the participants did not recite a full list of their activities. They would begin by citing a couple of their fitness activities and then trail off into tangential events or experiences. Later in our dialogue they would mention in passing some other sport or fitness activity they had been engaged in. This episodic style of personal revelations seems a common structure in conversations where strangers negotiate the content of their verbal interchange. I suspected this layering of information results from the conversationalists having to build rapport and trust in advance of more depth of exposure, or perhaps simply the tangential nature of

conversation jogs the memory a bit at a time. As I became aware of this pattern I ensured in future interviews that I gave participants the time to reflect and encouraged them to return to ideas and remembrances they had initially skipped over. Backtracking in this way seemed to encourage more fulsome disclosure and consequently richer data.

Surprisingly, the vast majority of my participants had been, or were at the time of the interview engaged in physical fitness activities. My count of individual activities listed by participants totals thirty. The list ran the gamut from the more commonly expected activities such as swimming, walking, or going to the gym to the less common, like yoga, bocce, and golf, and culminating with the more exotic activities like snowshoeing, rhythmic gymnastics, and Taoist Tai Chi. This revelation flew in the face of conventional wisdom as proclaimed in the literature I had reviewed which established that persons with intellectual disabilities are as a general rule inactive and unfit (e.g., Beange, Lennox & Parmenter,1999; Hensel,Rose,Kroese & Banks-Smith, 2002; Jobling & Cuskelly, 2006 Pitetti,2006 ;Rimmer,1994; Rimmer, Heller, Wang & Valerio,2004;Temple,2007). The distinct trend of the literature reviewed for this project agrees with the conclusion that as a sub- population people with intellectual disabilities are less active and fit than persons in the typical population. The explanation for the discrepancy between my data and the consensus of opinion in the literature remains unknown. It may be in the sampling method I used or it may be a matter of a specialized population on the west coast of British Columbia where the weather is mild and consequently the availability of outside exercise remains relatively static throughout the year. According to a study conducted for the B.C. Ministry of Health Planning, "British Columbia has the most physically active people of any province" (Coleman & Walker, 2004, p. 7). Whether this higher level of activity may be applied to study participants is unknown. A second consideration on this point is that the absence of

first person narrative (e.g., Cooper, 1998; Heath & Fentem, 1999; Rimmer, 1994; Rimmer, Braddock & Pitetti, 1996) in much of the literature may have forced an oversight on their actual fitness activity levels.

Within the present study there was no intent to make quantitative measures of participants' fitness levels so it is not possible to quantify the impact of their activities on physiological performance. Nevertheless, some research in this area supports the idea that subjective reports of physical activity are as good as any predictors of longevity (Mullee, Coleman, Briggs, Stevenson, & Turnbull, 2008). These investigators additionally conceded that self perceptions of activity levels may in fact reinforce fitness behaviour (2008).

3.3 Data Gathering

I used a digital recorder to accurately capture participant voice in the in-depth interviews. Due to grounded theory's reliance on the iterative process and reliance on the content of data to direct further interviews, it was not possible at the outset of this study to be precise about the numbers of interviews required. Some studies have been conducted with as few as seven participants (Beart, Hardy, & Buchan, 2004) and, of course, others with large populations. I planned to interview between fifteen and thirty participants, and I ended up interviewing twenty-six participants, as well as one coordinator of Special Olympics from the Victoria area. Grounded theory research with similar topics have been conducted with similar numbers of participants (e.g., Beart, Hardy, & Buchan, 2004; Knox et al., 2000; Ruddick & Oliver, 2005). I found the model described by Beart, Hardy, and Buchan (2004) instructive and supportive of the "directed conversation" (p. 92) style they advised. This model included an interview guide with a series of open-ended questions (Charmaz, 2006; Swain, Heyman, & Gillman, 1998). It was also in keeping with the constructionist aim at exploring the social processes under study in

conjunction with participants.

Again, reflecting on Charmaz (2006) as well as my lengthy social work practice, I

endeavoured to listen and observe with the intent to go beyond the surface of verbal responses,

allowing the interviewees to reflect on their thoughts, feelings, and actions. In this vein, the

interviewer plays a role in data gathering as well as establishing a relationship of respect wherein

the person does not simply acquiesce to the researcher's authority but engages in an exploration

of the processes they have experienced. Persons with intellectual disabilities have often

experienced marginalization, and while this research project was not designed as liberational, it

ought not to be exploitive. Exploitation can in part be ameliorated by remaining mindful of

potential power differentials and recognizing that participants are not passive wells of

information, and, perhaps more importantly, by treating people as experts on their own lives.

Despite good intentions, it has to be admitted that entering a community for the purpose of

gaining knowledge seems inherently exploitive. In raw terms it uses participants as resources for

knowledge production. I have attempted to redress this balance in some degree, by offering to

return to the community to provide an overview of my findings through interactive meetings. I

have also committed to deliver executive summaries of the research project to the agencies and

individuals who participated.

3.4 Data Analysis

In grounded theory, data analysis begins at the onset of data gathering and continues

throughout (Charmaz, 2006). The analysis takes place through a systematic but non-linear

process of coding, memoing, and theoretical sampling until abstract categories are stagnant and

core processes are identified. The end result is a substantive theoretical explanation that accounts

for the phenomenon, action, or social processes under study. As a novice researcher working in

the constructionist mode, I appreciated the systematic method of coding and memoing and constant comparison as outlined by Creswell (2007), while also keeping in mind Charmaz's (2006) partiality to flexibility over prescription. Mills, Bonner, and Francis (2006) take a constructionist approach, arguing that despite differences in nomenclature between grounded theorists, there remain some elements common to many studies. Included in their scheme was coding, theoretical sampling, memoing, developing a core category, and constant comparison. Charmaz (2006) has diagrammed the grounded theory process. Her design recognizes the non-linear approach which includes feedback loops at each major juncture of the research project. Looking at the model step by step, she has included initial coding, initial memoing, advanced memoing, theoretical sampling, sorting and integrating memos, and finally, preparing the draft for dissertation (p. 11). This dissertation has been guided by these processes[6]

Coding involves applying labels to data that make abstract analytical sense of what is being said. I found in this project that some of the categories created in the coding process describe concrete events in the participants' lives such as; being inspired by parents or making friends. The data analysis process I have followed in this study began with a system of open coding as described by Charmaz (2006). As I reviewed each interview transcript I performed line by line coding that involved writing descriptive words or phrases next to each line of the transcript. These margin notes were aimed at capturing in a word or two the essence of the participants' comments and my interpretation of their more abstract meaning. For example, where a person spoke of the influence that a parent or sibling had on their own fitness involvement, I would code the line initially as an *in vivo* code, using the person's own words. Glasser (1998) suggested that this line by line coding can act as a check on the tendency to

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[6] An illustration of this process derived from Charmaz (2006) can be found on page57.

superimpose researcher biases and Charmaz (2006) argues, line by line coding helps to ensure that the researcher "...remain open to the data and to see the nuances in it" (p.50). Having said this, it is relevant to note that data analysis from the constructionist perspective allows for interpretations of meaning (Hallberg, 2006). In this respect, my data analysis methods stand in contrast to the rationalist notion of identifying social facts as first proposed by Durkheim (1895) in Lukes,1982).

Charmaz (2006) has described open coding as the first step in the analytical process. Following her suggestion, I started the analytical process of this study in the same vein. Secondly, I created topic codes that captured perhaps more abstractly the meaning I perceived in the person's statements. For example, a person's comments that "my mother inspired me" (Person B) would be the *in vivo* code which, through the analysis process, became the topic code of "Family Solidarity", later abbreviated to "Family Members", followed by Family Influence which eventually was merged with other topic codes to form "Getting Social Support". My thought was that participants, like many of us in general, please our parents and siblings by engaging in similar behaviours. This open code of and then to Family Influence" due to my belief that "Family Influence" was a more comprehensive concept that allowed for the inclusion of both nuclear and extended family influence on the participant's fitness choices. Additionally, the "Family Influence" code could encompass familial experiences that might enhance or suppress the participant's interest in fitness activities.

Over time I re-assessed the transcript content held within the topic codes. In some cases this review prompted me to re-code data to a more comprehensive code or merge content with a more substantial umbrella or parent concept. The second step in my data analysis method was to use focused coding as a way of developing analytical understanding. Here, emerging themes

were identified (Carroll, Adkins, Foth, Parker, & Jamali, 2008) and allowed to develop as I filled the categories with data. I spent some time comparing the data collected within a code across participants and memoing my observations. From these deliberations, I eliminated some extraneous codes, re-coding the data under a more appropriate title or merging data from one code to be housed under a more inclusive category. This may be recognized as a system of focussed coding. The more substantial parent or master codes eventually coalesced into master categories or theoretical codes which in turn were rendered into components of the theoretical propositions or models which completed my data analysis. In the sections on Results the reader will find that I have made judicious use of direct quotes or *in vivo* codes as one way to keep in touch with the participants' meaning. In doing so, I remained mindful of Charmaz's (2006) caution that the novice researchers should avoid the overuse of participant quotes.

My final coding step involved arranging categories into parent codes, thus creating a series of overarching abstraction that more incisively describes what is happening in the data. These theoretical codes produced the components of the three theoretical proposition models I have developed (See Figures 1-3 pp. 126-137) which capture the vast majority of the data and lend an explanation to the proximal social processes that determine the fitness choices of the participants. These theoretical codes are managed as themes in the Results section below. A full and detailed account of the coding and data analysis process is presented diagrammatically in Illustration #1 (p. 57).

Memo writing is a springboard to theory development and seen as an essential and productive ingredient in the grounded theory process. Simply put, it is a critical intermediate step towards the eventual dissertation (Charmaz, 2006) and can help the researcher explore his own thinking or act as leverage for "unblocking" (Strauss & Corbin, 1997, p. 180) conceptual dead

ends. Throughout the data gathering and analysis phases of the project, I created memos that reflected my thoughts on the meaning of the data, what seemed to be making sense and what remained a mystery. This process has been shown to help round out the meaning of the categories created in the coding (Clarke, 2005).

For every participant I created a memo on the entirety of their transcript. The memos I wrote draw attention to specific phrases that describe behaviour and carry concrete and symbolic meaning for the participant. In addition, some of the content of the memos were like sign posts directing me to questions I might want to pursue with future interviews. Sometimes they led me to theoretical questions for deliberation as more data was gathered.

I share Charmaz's (2006) belief that a visual representation of a problem or puzzle can work to jog the imagination and promote creative insight. Therefore, as my memos increased, I took some time to diagram what I thought might help explicate "hunches" I was ruminating over. Most of my efforts were without significant results; however, adding diagrammatic representations of my thoughts eventually took the shape of the three theoretical proposition models that are presented in Chapter 5 of this dissertation (pp. 114-156) and act as the foundation for later theoretical discussions.

The cross participant analysis and memoing I undertook led directly to theoretical sampling that formed the latter part of my data collection for this study. Essentially, theoretical sampling is a way of returning to the empirical world to gather data that helps to "elaborate and refine" (Charmaz, 2006, p. 96) the categories that have emerged from initial analysis. This essential component can serve to identify variant empirical experiences and is aimed at uncovering dissimilarities in the data or pointing to areas where more investigation is required. Theoretical sampling resembles purposive sampling wherein individuals with unique

experiences may fill gaps in understanding phenomena or process involved (Clarke, 2005). Through this method "outliers" are incorporated into the analysis, or as Clarke (2005) would have it, differences are embraced rather than rejected. Theoretical sampling is a key element in the constant comparison method which is a hallmark of grounded theory methodology.

The constant comparative method can be seen as means to further ground the researcher in the lived experience (Mills et al., 2006). Through the constant comparative method, old and new data are reviewed in reference to each other. This back and forth process builds sensitivity to the similarities, differences, and nuances of people's' thoughts and their implications for theory building. When new interviews no longer produce new insight, then the category in question is said to be "saturated" (Charmaz, 2006, p. 113) meaning a core process has emerged and theorization can be finalized. Saturation is a problematic in constructionist theory because of the provisional and localized nature of knowledge. However in practical terms I thought it justified to assume a level of saturation when no new information was arising from further interviews. In this research, I used theoretical sampling to clarify the differences in participant experiences that I understood may have impacted their interest and engagement in fitness activities. Through this process I was able to clearly delineate the differences and similarities in participant experience that impacted their fitness choices. This step was a crucial link to the eventual development of my theoretical proposals/models and social context analysis. A sketch of the full process follows.

Illistration1: Data Collection and Analysis Process

Writing the first draft

Focused Coding/Theoretical Sampling/Theoretical Coding → Building Theoretical Components

Cross Participant/Cross Code Memos

Topic Coding → Begin to build Conceptual categories

Data Collection & Memo Writing

Data Review &Transcript Memos

Note: The illustration is presented in linear fashion. The actual study process was a series of overlapping and recurring exercises.

Initial/Open Coding → May involve *in vivo* quotes

Data Collection

Adapted from: Charmaz, 2006, p. 11

3.5 Software

As an aid to data analysis and management, I employed NVivo9, a qualitative software program developed by Lyn and Tom Richards (Richards, 2006). Recent papers (Hutchison, Johnson & Breckon, 2009) have added to the literature that articulates the utility of NVivo in the development of grounded theory research. In a similar vein, Carroll and her associates (2008) report using NVivo in a grounded theory study framed in the constructionist model. The only caveat to the use of software packages is that none can substitute for the immersion of the researcher in his/her data and the process of analysis and abstraction that denote full engagement in grounded theory development.

3.6 Data Storage

Hard copies of research notes and interviews were kept in a locked cabinet. Electronic files are password protected.

3.7 Validity and Reliability

The world of quantitative research is not without its controversies; however, issues of validity and reliability can be adjudicated by assessing sampling techniques and checking the robustness of statistical correlations. Validity and reliability remain important aspects of positivist research (Golafshani, 2003) However, in the qualitative world, measures of validity and reliability remain a problematic. Issues have arisen about the inference that qualitative measures of validity must mimic quantitative protocols (Creswell, 2007). Today, standard qualitative techniques include prolonged engagement in field research, triangulation, member checking, and more recently, clarification of researcher positionality (Creswell, 2007). In this study I have employed each of these checks. Generally speaking, there is a continuum of evaluative standards applied to qualitative work. When Glaser and Strauss (1967) published *The*

Discovery of Grounded Theory, their proposed methodology stood in contrast to the dominance of the positivist paradigm in social science (Charmaz, 2006). Over the decades, grounded theory methodologies have multiplied forming a continuum from the post positivist traditions of Glaser and Strauss to Clarke's (2005) push to "regenerate" (p. xxxvii) grounded theory into a postmodern interpretive and situated project.

Winter (2000) offered a concise definition of validity and reliability and successfully characterizes the key points in contention between the quantitative and qualitative schools. He does not attempt to reconcile the two positions but rather calls upon Foucault's work to support his position. Winter suggests that claims and counter claims reflect a person's "notion of truth" (Winter, 2000, p. 10) and, consequently, battles over whose truth is more valid are essentially meaningless. Validity is correlated to both method of research and the research purpose and cannot be assigned any universal value (Winter, 2000). Foucault's conception of a multiplicity of truths is summoned to complete the discussion, suggesting that "each different truth inevitably requires different means of validation" (Winter, 2000, p. 11). The validity of the research put forward in this study must stand the test appropriate to constructionist grounded theory methodology. Here the soil is perhaps less rocky, albeit not without its hazards.

As a constructionist project, the work I conducted has been less concerned with coming up with a foundational and immutable truth as with application of theoretical propositions to explain the studied feature of participants' lives (Annells, 1996; Clarke, 2005). In the constructionist model, a variety of writers have suggested that (e.g., Charmaz, 2006; Denzin & Lincoln, 2005, Lincoln & Guba, 1985; Morrow, 2005)) concepts of validity and reliability are replaced by trustworthiness, credibility, transferability, and confirmability. Aguinaldo (2004) pushes the discussion further by asserting that: "validity polices the social sciences and operates

as kinds of powers that are practiced through its capacity to "de/legitimize social knowledge" (p.128). Golafshani (2003) argues that the context specific nature of much qualitative research renders the concepts of validity and reliability redundant. Charmaz's (2006) argument is that the validity of a report can be substantiated by the agreement of participants that the researcher has represented their world accurately. Likewise, Creswell (2007) recommends member checking as one of the quality control devices in qualitative research. As this approach seems to put the voice of study participants in the foreground I chose to include member checking in my research process. Consequently, as I was interviewing study participants I asked them if I could check back with them to ensure I had their information correct. Nine individuals participated in this process. When I had transcribed the interviews I contacted them in person, by telephone and /or by e-mail and provided them with copies of their full interview transcripts. I also contacted three of the participants' family members and/or support workers to ascertain if they agreed with my fundamental conclusion about the importance and influence of social support through family, friends, and care givers. The response of the people I contacted was unanimous that short of the odd misspelling, I had captured their statements with accuracy. They also agreed that my belief in the importance of family and friends in their sports involvement was accurate. I additionally interviewed a coordinator for the Special Olympics program and found that her observations ran parallel to my conclusions about the pivotal role of social support networks in introducing and engaging persons with intellectual disabilities in fitness and sport activities. She also agreed that over time some of the participants in Special Olympics developed identities enmeshed with their fitness activities. Her explanation of the social processes that influenced the choices of Special Olympians helped fortify my belief that the theoretical components I was developing captured the proximal influences in the lives of the study participants. The involvement of this person can

be seen as a source of generalized triangulation.

I agree with the opinion that reflexivity is a positive postmodern innovation on the theme of validity in qualitative research (Aguinaldo, 2004; Beart, Hardy& Buchan, 2004; Gergen & Gregen, 2007; Morrow, 2005; Rose, 1997). Therefore, in keeping with the constructionist model, I offer next a description of my own positionality (Charmaz, 2006; Clarke, 2005; Creswell, 2007; Haraway, 1988). While my goal was that the theoretical models that have emerged from my study may be transferable to other populations, I nonetheless take the post-structualist position that knowledge is constructed through social interaction and truth is a communal property that remains, to some extent, localized and temporal in nature (Charmaz, 2006; Gergen, 1985; Hallberg, 2006). In short, the application of a substantive theory to other situations needs empirical support and are otherwise delimited (Hallberg, 2006). Moreover I entered the research environment predisposed to see fitness in a positive light. I took the position at the onset of this research project that exercise and fitness were "good" things to include in one's life. Although not given to moralizing I had to accept that for me fitness was a pleasure that others should share. Additionally, I could not erase the fact that as an educated professional I entered the research situation from a privileged position. This position of privilege created a power differential not likely to be overcome during the time frame of the study. I had to remain conscious of my beliefs and positionality and reflect on this influence as I engaged with participants and assessed their choices.

On the issue of validity, Glaser (1998) provides a list of four criteria for judging grounded theory that are supported by Charmaz (2006).These criteria are: fit, woakability, relevance and modifiability. Upon reflection I concluded that these four criteria looked like a commonsense and practical approach to evaluating my own work. Fit, workability, relevance

and modifiability as described by Glasser (1998) seem to provide a practical measurement tool that does not push evaluation backward towards positivism or abandon entirely the need for evaluation. I believe these criteria are relevant within the specific context of my research. In conjunction with the principles expressed above. I would see them fairly applied to the project I have completed. Summarized for brevity, these criteria are:

- Fit - Do the concepts developed adequately express the patterns in the data?

- Workability - Does the way the concepts are related into hypothesis account for the main concern being studied?

- Relevance - Is the research important?

- Modifiability - The study is neither right nor wrong. New data does not disprove the study; it offers a new analytic challenge (Glaser, 1998, p.?).

 This last bullet points to the notion that the history of the social and natural sciences demonstrates that all knowledge is provisional, in postmodern terms, encircled "culturally and historically" (Gregen & Gregen, 2007, p. 470).

3.8 Recruitment

The first hurdle to overcome in a recruitment strategy is in defining the population from which potential participants will be drawn. This study required me to recruit persons with intellectual disabilities. This term and other synonyms remain problematic. A major obstacle in assessing the literature on the health needs of people with intellectual disability and understanding the significance of their health disparities lies in the continuing elusiveness of a definition of intellectual disability that can transcend single investigations. The need to define the catchment criteria is an essential part of any population health initiative. However, what is meant by intellectual disability continues to be uncertain because the terms and definitions

applied to research subjects vary widely. This is evident from project to project as well as within

and between the geographic locations of particular investigators. While some reports specify the

profile of their subject population (Down Syndrome or Autism Spectrum disorder for example),

many do not. Intellectual disability seems a preferred term currently in vogue with Canadian

writers, although it is often used interchangeably with developmental disability, a term that is

commonly used in the United States. The term, mental retardation, even though considered

pejorative in many quarters, nonetheless continues to surface in both journal titles and the

articles within. British authors regularly use learning disabilities or the even less definitive,

learning difficulties, to distinguish their study subjects. In Australia, Sutherland, Couch, and

Iacono (2005) use the term developmental disability to include conditions such as cerebral palsy

and autism.

This difficulty in pinning down common understandings also complicates estimates of

the prevalence of intellectual disability (Horwitz, et al., 2000). Clearly the heterogeneity of the

population is troublesome and can make comparison of study findings difficult. Smith (2002) has

been critical of this search for certainty suggesting the quest for a single definition is an artifact

of reductionist typological thinking combined with a social need to manage a population

perceived as "a threat, an inconvenience, or a social drain" (p. 63).

In many jurisdictions the medical profession remains in charge of the designations of

intellectual disability and its synonyms. The Diagnostic and Statistical Manual of Mental

Disorders, fourth edition (DSM-IV), the American Psychiatric Association's publication, plays a

major role in designations of mental retardation. This instrument establishes levels of

intelligence quotient (IQ) as a key determinant of mental retardation (BehaveNet Clinical

Capsule). In their explication of the needs of people with mental retardation in the American

context, Horwitz, et al., (2000) note that the American Association for Mental Retardation (formerly the AAMR, but now the American Association on Intellectual Developmental Disabilities, AAIDD) is the most regularly referenced body. This umbrella organization offers the following, "Intellectual disability is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviors expressed in conceptual, social, and practical adaptive skills. This disability originates before the age of 18" (home page).

Horwitz and her associates (2000) provide an understandable summary of the difficulties when they state that "MR" (mental retardation, *Sic*.) is not defined in the same way across research studies or service agencies (p. 6). In some reports, the population is defined by aetiology and in others, adapted behaviours are also employed (Crawford, 2008). My recruitment strategy relied on my association with individuals and agencies engaged in the community living movement and human service industry in British Columbia (BC). Consequently, I have drawn participants from the population eligible to receive services funded by Community Living British Columbia (CLBC), which is the crown agency mandated to provide services to adults with intellectual disabilities in BC. Eligibility for CLBC services is defined by the Community Living Services Act (CLBC, 2007). This Act defines intellectual disability as a significantly impaired intellectual functioning that exists concurrently with impaired adaptive functioning, is manifest before the age of 18, and meets other prescribed criteria (CLBC, 2007). Recently this definition has been challenged. As a consequence CLBC has been charged with providing services to adults with Autism Spectrum Disorder and Fetal Alcohol Syndrome. These individuals do not have not until recently met the standard criteria but exhibit the adaptive behaviour criteria for Fetal Alcohol Syndrome and Autism. These parameters are the criterion that delineated my population.

I began recruitment by contacting a large community living agency in the Victoria area. I spoke to the Executive Director and set up a time for us to meet so that I might discuss getting their help in contacting possible participants. In advance of our meeting, I sent an e-mail attachment with copies of my Recruitment Flyer and Information Letter (See Appendices A and B, p. 218-220) and in this way introduced myself and my research study. After my meeting the Executive Director passed the Information Letter and Recruitment Flyer on to program supervisors who had responsibility for client programs. Through subsequent e-mail and telephone conversations with these individuals, I was able to secure an opportunity to address a group of individuals living in semi-independent housing. During a question and answer session I walked the group through the research documents explaining the purpose and meaning of each. After each question and answer period with these groups, I left a signup sheet for interested parties to review. Each sign-up sheet included a statement clarifying that signing the sheet gave permission for me to contact the individual but did not mean they were committing to participation. I checked back with the program coordinators a week later. I approached all service providers in like manner.

  After each meeting, I also left my contact information so that interested parties could contact me at their own discretion. A few of the participants took this opportunity and contacted me by phone or e-mail. I arranged with agency staff to pick up the signup sheet a week or so later. The individuals who provided their contact information formed my first cohort of participants. I contacted each of these people individually by telephone. On the phone I talked to them about the study and asked if they were still interested in participating. For the most part they agreed and an interview date was set. At the outset of our meetings, I again ran over the intent and purpose of the research and walked the individuals through the consent form. If they

remained in agreement, we then proceeded with the interview. Throughout the data gathering

process this pattern of contact with agencies, presentations to agency staff and clientele,

questions and answer sessions, and leaving of signup sheets for possible participants followed by

telephone contact, remained as the process of my recruitment activity.

My overall strategy can be characterized as purposive sampling, utilizing a combination

of convenience and snowball sampling. Inviting the participation of individuals who on their

own were capable of engaging in a dialogue would undoubtedly narrow the field of possible

participants to those who can communicate verbally. In order to broaden this population, I also

stressed that I could accommodate participation from individuals who wish to be interviewed

with the assistance of a close friend, caregiver, or family member to act as an aid or proxy.

Although proxies can prove problematic (Swain, Heyman, & Gillman, 1998), they are also

recognized as a legitimate way to involve individuals who might otherwise be excluded

(Sheppard-Jones, Prout, & Kleinert, 2005). Therefore I decided to accept data from any adults

with intellectual disabilities as defined by the Community Living Authority Act (2004) whether

provided through direct participation, with assistance or by proxy or were aided by a trusted

family member, service provider or friend. Recruitment was restricted to the greater Victoria

area.

3.9 Ethical Issues

Ethical practice is an essential requirement of all research. Because persons with

intellectual disabilities are considered a vulnerable population, ethical practice must remain the

uppermost consideration in proposed research. The overarching provision for protection of

vulnerable populations in reference to research endeavours is the 1964 Declaration of Helsinki.

This United Nations accord focuses on the capacity to give informed consent and demands that

research be carried out with care (Tee & Lathlean, 2004). This declaration was established primarily in response to abusive medical research carried out during the Second World War. Informed consent remains an established hallmark of ethical research practice (Gregory, 2003). Nevertheless, the Helsinki declaration has come under attack for its implied paternalism and its inability to "transform the social relations of research" (Zion, Gillam, & Loff, 2000, p. 615).

Running parallel to the Helsinki accord is the more rights-based United Nations standard rules on the Equalization of Opportunities for Persons with Disabilities (Boland, Daly, & Staines, 2008) approach that strongly supports the rights of persons with disabilities to participate in research particularly if it may have some benefit on their behalf. In balancing these two international imperatives, I contend that vulnerability should not preclude persons with intellectual disabilities from research participation (Tee & Lathlean, 2004).

In British Columbia the arbitrator of decision making capacity for persons with intellectual disabilities is the Adult Guardianship Act (RSBC 1996). One of the foundational principles of this legislation is that "until the contrary is demonstrated", people have the capacity to make their own decisions. I believe that this statement is a respectful guide for principled and non-paternalistic research practice.

Recent writers (Tee & Lathlean, 2004) have suggested that the researcher must provide consent procedures that are sensitive to the possibility of variability of the capacity for decision making to change over the course of the project. I have been guided by this suggestion, recognizing that participation and consent need to be revisited with participants throughout the life of the project. As part of the consent process, I ensured that plain language was used in my discussions with potential participants and in research materials (e.g., consent forms, project information letter (see Appendix C, p.223). In recruitment talks, I took time to invite and answer

questions from potential participants and explained the intent and purpose of the study. I attempted to ensure full understanding of the research documents by answering any questions and explaining the meaning of difficult passages in understandable terms. I asked each group if I had explained things clearly and got their consent before moving on.

I agree with the contention that support for a research project should consider what benefit might accrue to participants. Although I could not predict research outcomes at the outset of my project, I worked under the premise that greater knowledge of the social processes that promote physical well-being would provide an, as yet missing, understanding of how to engage persons with intellectual disabilities in health enhancing activity, thus advancing the ultimate goal of improving the long term health status of persons with intellectual disabilities. Potential negative impact of the research could not be completely predicted either; however, on balance, it seemed reasonable to suggest that risks were minimal, given the topic does not immediately present as one charged with emotional impact. That being said, I entered the data collection process with a list of local support and counselling agencies just in case a person found our discussion emotionally overwhelming. Some of the participants did respond emotionally to the interview however, none of the participants felt the need for further assistance.

A second issue on the ethical front is that of confidentiality. The research study conducted ensured the confidentiality of participants through the data storage systems articulated above as well as assigning each interviewee a participant letter and number so that identifying information would not surface. During the course of the research printed material were kept in a locked file cabinet and electronic files were password protected. As stated above, at the outset of each interview I walked the participant through the consent form giving them opportunity to ask questions before committing to the interview process.

The research I have conducted adhered to established standards of ethical practice by ensuring informed consent and confidentiality. As well my approach accepted participants as valued contributors to research and knowledge production and recognized that they are the experts in their own experience. Furthermore, I made sure individuals were aware that their participation was based on a transparent process where ongoing involvement was not assumed but was rather a continuously negotiated relationship. Overall, this research study presented the opportunity for a significant contribution to knowledge in the field which may translate into positive outcomes for the participant population, and the potential for harm was minimal. I was granted ethics approval in December of 2010 from the UBC Behavioural Research Ethics Board.
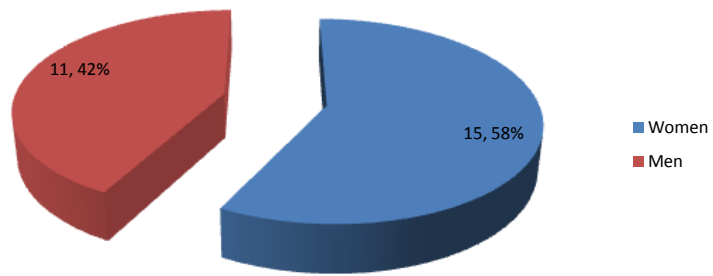
Chapter 4: Results

4.1 Demographics

There were twenty-six individuals interviewed for this study. Both women and men were interviewed. People interviewed ranged in age from nineteen to sixty-seven years of age and lived in a variety of settings. The following three tables depict the demographic profile of study participants. Table #1 shows the gender division of participants; Table # 2 shows the age range and Table # 3 shows the placement type. Raw numbers and percentage of total population are shown. No data on individual functional ability were gathered. Measuring functional ability is a contested area beyond the scope of this study.

Looking at the placement types, the demographics show that 7 individuals or 27% of the study population lived either independently or semi-independently whereas 15 individuals or 58% of the participants lived with a caregiver or in a group home. That the large majority of participants were able to express themselves and articulate their life experiences without aid may indicate that the functional level of participants was skewed to the higher end of ability. Nonetheless, as part of my recruitment strategy I made provision for individuals with difficulty in expressing themselves through an interview to be assisted by a proxy/aid. In this way I tried to ensure that to some degree, those with less expressive language ability could participate. Three people chose to have a proxy/aid help with the interview and two more chose to have a support worker present. No data on the socio-economic status of participants were gathered. There were 15 women and 11 men who participated in the study.

Table 4.1: Gender Division

11, 42%
15, 58%

- Women
- Men

N= 26

Table 4.2: Age Range

2, 8%
3, 11%
4, 15%
8, 31%
9, 35%

- 19-29
- 30-39
- 40-49
- 50-59
- 60+

N = 26

Table 4.3: Residential Type

- Ind. — 1, 4%
- Semi-ind — 6, 23%
- Caregiver — 7, 27%
- Group Home — 8, 31%
- Family — 4, 15%
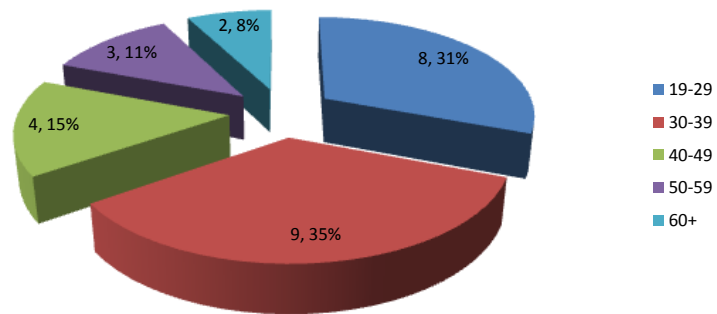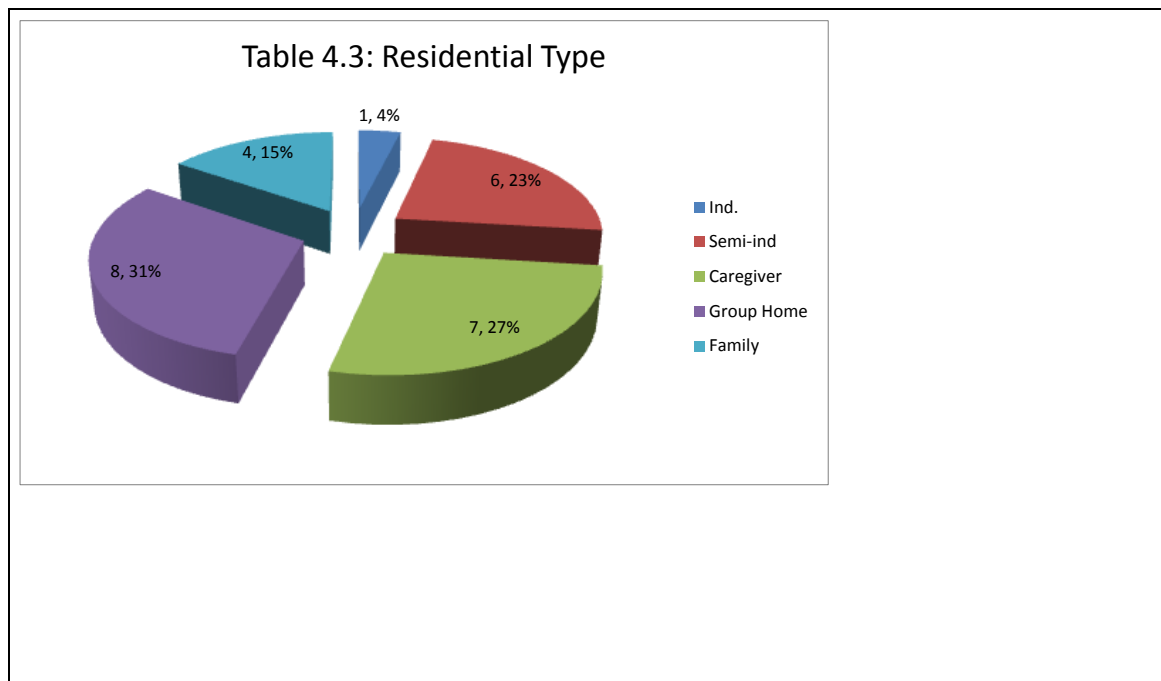
N= 26

4.2 Themes

In this section will I review the data that stimulated the major codes or categories created through the data analysis process. These focussed codes led to the development of themes. And in turn these themes evolved into the "wheels" of the theoretical propositions I have drawn out in Chapter 5. I have used this data analysis and thematic abstraction as a rationale for the design of the three theoretical models that outline the proximal social processes that affected the fitness choices of study participants. These theoretical propositions are subsequently used to initiate a discussion of the broader social context into which the actions of study participants may be placed. In the discussion section below I have cited relevant literature as a way of adding texture to my own observations and interpretations. I have summarized the data content within eight separate thematic headings. Each of these headings represents a theme that ran through the data.

The voice of study participants dominates this chapter. Direct quotes and paraphrases are used as jumping off points for discussion and analysis and serve as well as a touchstone to the concepts of fit, workability, relevance and modifiability as outlined above.

The responses provided by peoples in our conversations did, in many instances, provide detail and context to the individuals' experience as they express logistical, physiological, and emotional aspects of their fitness experience. Some peoples did not include an emotional tone in the descriptions of their fitness experiences. One or two of the people responded to questions by simply describing the logistical aspects of getting to a fitness venue or by giving a detailed account of the mechanics of registration and enrolment. Many of the study participants reported enhanced feelings of self-esteem as a result of participating in fitness activities. Self-esteem is the first of the eight themes I discuss.

4.3 Gaining Self-esteem

Self-esteem is a multifaceted psychological concept that is composed of a combination of self-perceptions (Kavas, 2009; Li, Harme, Chaumeton, Duncan & Duncan, 2002; Sonstroem, Harlow, Gemma & Osborne, 1991). The codes that I rolled into the focussed code of gaining self-esteem include topic codes such as acceptance, a sense of competence/ achievement, perfection, and self-worth. The reports of research participants regularly matched a person's increased self-worth with participation in exercise activities. Positive peer interactions in a new fitness activity contributed to some participants reassessing their competence in this sphere. For participants who gained a new social environment, negative memories of failure were replaced over time with a new assessment of capability in the physical realm. This new attitude helped to set in motion a cycle of engagement in a fitness activity, peer support, and re-engagement when new opportunities become available. In this way positive response to fitness opportunities can be

seen as resulting from a reinforcing cycle of affirmative social interactions and consequent positive self-evaluation.

One example that illustrates this point was provided by Person E. This person experienced an improvement in her sense of self when she moved into a new living arrangement, where her support staff took an interest in helping her connect with a fitness program. She related how in her school days, she had been teased and bullied, because she could not perform fitness activities up to the level of her peers or her teacher's expectation. Throughout most of her adult life she had avoided any fitness activity until she moved into her current semi-independent living situation. In the new situation she had become involved in therapeutic swimming. I asked her what she had experienced that had made a positive difference. She replied, "It just makes you feel accepted more, and that people accept for what, who you are, which is good". This feeling of acceptance bolstered her ability to get active on her own behalf and consequently she began to adapt her self-image as more competent and capable of participating in fitness activities. This change seemed to indicate that over time her self-esteem had been enhanced and self-perception altered. She had also acquired a sense of belonging through her involvement in her chosen activity. Her newly acquired sense of belonging seemed to fulfill a need on her part to be accepted by peers that was injured during her negative school experiences. This feeling of acceptance bound her emotionally to the friends she developed at the pool and to the activity itself. As a consequence both social and physiological rewards were open to her.

Further along in the interview I asked her about her perception of others in this new environment, and she explained that she felt that the stigma of "special needs" had been shelved in her new living situation. This comment is a strong indicator that Person E had lived with this stigma and endured the accompanying sense of self as an outsider that often accompanies

socially isolated individuals and groups. She expressed feelings of being excluded as a child which were diminished by her more recent experiences. The participant continued:

> Just the way people present themselves when you meet them they take you for what you are. Not because you have a special needs but they take you for what you are. And that's important they treat you like anybody else. And that's really good (Person E).

These comments suggested that through a combination of the acceptance the participant felt and the impact of her fitness activity on her self-perception she developed a renewed outlook on physical activity. An important note to consider in light of these comments is that the constellation we call self-esteem may grow and change in concert with our social environment. It is not a personal attribute brought about by individual psychology alone. This is a significant consideration in a constructionist model of social processes.

This idea of the importance of the way others responded to Person E was echoed by other participants as a reason for them feeling more comfortable with themselves and thus with trying a new activity. This woman's perception (E) of herself and her capabilities had a significant impact on her interest in her continuing with her swimming program. More broadly this perception of acceptance contributed to her sense of social inclusion.

This finding supports the argument that for this woman early experience of failure at physical fitness by participants likely coloured her adult expectations of personal competency in the physical arena.   Put in general terms, the successes and failures experienced in childhood form the personal histories we recount internally. These are often reflected in overt behaviour. A cross-participant comparison of the data included under the Sense of Competence code revealed

that a number of participants reflected how their engagement in exercise and fitness activities had favourably impacted their sense of self-efficacy.

Some individuals interviewed reported feeling stronger and more generally able to face day-to-day challenges as a result of exercise. I draw again from the transcript of Person E. She mentioned feeling stronger as a result of her new program. I might have assumed that it was only natural that a person might feel and in actuality, be stronger as the result of an exercise program. Getting stronger is a common goal of exercise programs. In a way I took getting stronger as a given but I had a greater interest in the more elusive mental health aspects of fitness. I asked her what feeling stronger meant to her. She first stated, "It gives you more confidence in yourself". When I probed to find out more, she finished her thought. "It just gives you more confidence in yourself, you can do it. So it's really good" (Person E). This growing sense of self- efficacy was perhaps best described by Person I who suggested his sports involvement had benefited his ability to perform at work. He stated: "And all that stuff and even it can help you for doing very heavy jobs too I mean like lifting things, lifting boxes, lifting furniture and stuff like".

This person went on to suggest more global results. He felt he could face the mental strains often associated with living with impairment. The participant said:

> Myself? I feel very proud I can do things if I want. I mean just because I'm visually impaired or have any other thing you know doesn't mean I can't do it I mean, I mean if I put my mind to it then I can do it because if you're letting your disability get in your way ... it just gets you nowhere ... (Person I).

These comments were about the spin- off affect exercise can have on the non-athletic aspects of a participant's life as well as the internalized feelings and thoughts that accompany success in one avenue.

The social aspect of sport involvement is also a strong feature of this person's interest. Moreover like the comments of Person E, Person I expressed the thought that his success and achievement in sports and fitness helped to alleviate the totalizing impact of "disability" as a global identifier. I would argue that these self-reported changes suggest that experiences such as increased strength, achievement, and confidence which were expressed as fitness outcomes by participants may be added to the overall enhancement of self-esteem they felt. Having achieved an enhanced sense of self these participants were able to translate that enhancement into other avenues of their daily lives. For Person E this was manifested in her enlarged social circle. For Person I this meant better work performance.

Also figuring in the concept of self-esteem as presented by s was the idea that sport participation offered them opportunities for a sense of achievement. A sense of achievement was expressed by many of the participants as they recounted both the tangible and intangible rewards of involvement in a sport or activity. Material evidence of achievement was signified by the winning of ribbons, medals, or trophies in organized activities, whereas the less tangible rewards were carried in the emotional content the remembrances evoked. Person I stated, "Oh ya, cause I was ah, I was really a great sport I was winning all those medals like the Okanagan, out in Cranbrook and Prince George and all those places". Person Q recounting a swimming experience said: "You can still remember that? I turned around and looked at myself and said; jeepers' creepers did I do that from all the way down there without stopping?" These remembrances were relayed to me with enthusiasm. They were memorable events in the lives of the participants and their retelling made people smile and relax. It seemed a privilege to witness this effect.

In this study, feelings of improved self-worth were regularly expressed by participants in association with positive reinforcement from peers or teammates. These expressions were exemplified in comments by Person W. I had been asking him about his first experiences in playing a team sport, and with great pride he happily described hitting a home run. I suggested that his teammates must have appreciated his effort. He agreed, stating they had cheered for him. I then asked him how that felt and he replied, "I feel a lot better". In describing the difference between his pre-sport days and his current level of involvement he added, "Yeah I do, I feel a lot better about myself". This positive notion of the self stood in contrast to his previous negative sense of self. He reflected on this dichotomy throughout our conversation. He and others in the study described their old selves as fat and/or lazy as compared to their new selves which were neither. A cross-participant review established that these or similar sentiments were reflected in the comments of 14 of the 26 participants. In my mind, these comments must be accepted as true and accurate in the minds of study participants having said that, they can also be moved into the realm of critical analysis. From this perspective, it was my perception that participants placed fatness and fitness on different ends of a moral continuum. They were mindful of where they fit on this scale in comparison to an imagined perhaps ideal, model.

Participants in this study regularly said that becoming fit "made me feel good" and "made me feel better about myself" when referring to their pre-fit selves, they reported feeling "lazy, sluggish" and so on. The data reflected that these recollections of positive feedback and concomitant improved self evaluation helped to solidify the persons' interest and engagement in other fitness opportunities.

Others remembered experiences can also contribute to an individual's predisposition to engage in physical activities later in life. On this note I now turn to a comparison of the early life

experiences of my study participants. The view here is to compare similarities and differences that may underlie the present fitness choices of the participants. Within the two themes of Remembering Childhood and Remembering School, I have captured a variety of comments which contribute to a discussion of the influence of early life experiences on the fitness choices of study participants. I considered remembering childhood experience to be the broader and more inclusive concept, while remembering school was specific to that venue. This section of the dissertation encapsulates the conversations I had with participants in response to question four and question seven on my interview guide. Question four asked: In what way did your parents, caregivers or friends encourage you to be fit and healthy? Question seven asked: When you were growing up, what did you learn about being fit? Perhaps unsurprisingly, family and peers figured prominently in the early fitness experiences of study participants.

4.4 Remembering Childhood

Question four in the interview guide asked participants to recall how family, caregivers and peers had encouraged them to be fit and healthy and question seven asked them to reflect more broadly on what they had learned when growing up. Responses varied across participant interviews but can be roughly characterized as forming four distinct groups. The first group, comprised of the most active of participants, often described the involvement of parents in their initiation into recreational activities. Parents as well as siblings were cited as models or inspiration for the persons' own activities. The second group of participants were also very active, and although their parents may not have been engaged in athletic pursuits, they encouraged participation and facilitated access to sport and fitness activities. A third group of participants received little health and fitness instruction as children or in younger years but had become more active since moving into new care arrangements or developing friendships with

others who were engaged in exercise or fitness programs. These new friends and caregivers often introduced participants to organized fitness activities offered by organizations such as Special Olympics or Operation Track Shoes. For some of the participants a move to a different social environment provided new supportive opportunities for being exposed to fitness programs. The fourth groupings of participants were the individuals who claimed distaste for exercise or only engaged in activities when cajoled by caregivers or support staff. For the most part, this group of participants had received little in the way of parental instruction other than perhaps generic reminders to eat right. The participants in this group had rather barren fitness histories and reported little or no familial encouragement.

 It could well be argued that serious physical impairment might be a determining factor in the activity level available to some study participants. However, when I compared the activity level of two participants with multiple impairments (Cerebral Palsy, intellectual disability, and mobility difficulties) I saw that one refused exercise and the other took advantage of every opportunity to get involved in recreational programs. The difference evident from their statements lay not in the impairment but rather in the family and caregiver energy and interest.

Interestingly, age also seemed less of a determinant than might be expected. The one participant who eschewed exercise or physical activity of any kind was the second youngest interviewed and was able-bodied. When asked if his parents had ever talked to him about health or fitness, he replied simply, "No, they just left me alone" (Person O).

Several of the study participants recollected their childhood experiences with sports or fitness activities initiated by family. These recollections were retold with positive emotions. The emotional ties of family created while involved in a sport or activity remained important to these individuals. The family environment often set the tone for future enjoyment of physical

activities. One participant who remained an avid swimmer related her early experiences of swimming at her grandmother's pool: "I've always been a big water baby. I love swimming. You could never get me out of the pool when I was a little kid" (Person C). Another participant remembered her parents taking her and her sister to the lake and encouraging them to get into the water and learn to swim. She recounted the support offered by her sister and mother, who encouraged her by saying they had confidence in her and repeating, "You can do it. I know you can do it, make me proud of you" (Person Q). For two of the most athletic individuals I interviewed, family or caregivers intervened directly to ensure they were exposed to exercise or sports activity. Person X recalled with humour and excitement how she was taught an exercise routine at home, with her mom and aunt acting as instructors.

Some participants grew up in foster care. For these individuals foster parents, particularly if they provided long time care, were instrumental in ensuring children had access to fitness opportunities. For example, finding that there were few sports activities that accommodated special needs children, Person Y's long term caregiver got together with other parents and formed a recreational soccer team. This coming together of parents of children who had special needs provided an environment where Person Y could learn both the physical and social skills necessary for him to participate in later years.   This seemed extraordinarily positive behaviour that went the extra mile to ensure that the participants had positive fitness experiences. At the time of the interview Person Y was preparing to travel to take part in the World Special Olympics. His pleasure and excitement were irrepressible.

On the health education front, virtually all the participants were able to recount being told as children to eat healthy foods. Many participants recited from memory that they had been told to eat lots of fruit and vegetables. Weight management showed up as a theme for both women

and men. Wanting to be thin or thinner was a preoccupation of some of the participants. In this respect I'd argue that the proper physical form for men and women in the study were gauged against cultural ideals of normative standards of masculinity and femininity that are put forth in popular culture. Simply put, male participants wanted to have flat stomachs and look good. Women wanted to become thinner. Person L was one example of a woman who expressed her interest in weight management through exercise. She remembered how she checked her weight every month. Later she acknowledged she actually talked to "everyone" about it and felt good that her caregiver and others were proud of her accomplishments on this front. She smiled broadly when remembering the positive comments others made and said it made her feel "good" and proud of herself.

I asked Person W what his sports involvement did for him and his immediate response was, "[it] keeps my weight down". He related how looking back on his life he was glad he wasn't his fat and lazy self. This association between excess weight and laziness seemed also to suggest the participant adhered to the idea that being thinner was a way of separating himself from a negative self-image. Later in the interview, Person W reflected how his mom and sister had remarked how he was "looking good". Looking good was associated with feeling good about himself and in that respect maintaining a healthy weight became attached to the emotional reward offered by the approval of family.

I asked participants to tell me what fit people looked like. For the most part their responses to this question reflected common social images of fitness as exemplified by thinness and muscularity. Person R was a 50 year old male who answered this question of what fit people looked like by stating simply, "They stay slim". Person N was a 48 year old woman who responded to this question by stating of fit people, "They are all skinny". Then perhaps more

poignantly she added, "I'd like to change myself to skinny". Person Y was a very active young man who responded to the same question initially by describing fit men. Here he said, "...muscular, like body builders...men have strong muscles". Later, when I asked if there was any difference between what fit men and fit women looked like, he suggested, "women can be strong too". So, in his mind women were not excluded from fitness. This attitude was echoed by Person X who was a 32 year old female Special Olympic athlete. She suggested that both men and woman could be fit and strong and that the sexes do sometimes "look almost the same". She later qualified this with the idea that men might have stronger muscles.

At the least active end of the fitness level continuum, some of the participants interviewed had very disappointing or even negative childhood experiences. The comments of participants' pointed to the possibility that just as positive childhood experiences can increase the likelihood that adults will engage in fitness activities, the lack of early experience may serve to dampen adult interest. When I reviewed the current and past activity levels of the participants, I witnessed these mechanisms at work in the data. In essence, the participants with positive childhood experiences in sport and recreation were more likely to have a fitness regime as part of their current health strategy.

When asked about their childhood sports experience, a number of the interviewees reported less than optimal exposure. The following comments were typical of people who had avoided or resisted exercise for the majority of their adult lives. Responding to my question about playing sports as a youngster, one person replied, "No not much, which is too bad I guess. I was never good in gym or anything" (Person G). Another interviewee exemplifies the participants with little fitness exposure and no current interest. His answers were expressed simply but emphatically.

Q: Yah, when you were a kid did you play any sports?

A: (Emphatic) No.

Q: No, did you play any sports at school?

A: No.

Q: No eh? And you don't play any sports now?

A: No (Person O).

Overall, the support and encouragement of parents and family members was a significant child hood recollection in the minds of many participants. Where a parent was not available, an active friend or interested caregiver could provide the encouragement necessary to increase the participants' activity level.

In this next section, I will describe the fitness and exercise experience of participants during their school years. Here I found a similar disparity between those who enjoyed sports and recreation and those whose experience was minimal or even undeniably negative.

4.5 Remembering School

There was a great deal of variation across participants in school sports and fitness experience. Some participants reported favourable memories of school. These participants were involved in a variety of sport activities. Person C recalled fond memories of her school dance classes. These positive memories predisposed her to happy anticipation of participating in similar activities as an adult. Person H was also a young woman who loved being active. She was very positive about her team involvement, yet it was clear from information provided by her mother that in grade 8 she was no longer involved in the actual game but relegated to helping the coach. As the gap between her sports ability and that of her peers grew, she lost the opportunity to play on the school team. She was included by the coach but not as fully participating player.

For persons with intellectual disabilities who cannot compete with classmates, this exclusion may mean loss of opportunities to be part of an organized sport or activity. As a consequence these individuals missed much of the social interaction and problem solving lessons that arguably accompany such group experience. These are missed lessons that could lay the foundation for social problem solving ability in adult life.

The comments supplied by participants provided a view of the negative side of school experience. The experiences recounted by some participants sketched a school life marked by failure and social isolation. The most horrific memory of school reported by the participants comes from Person E who was bullied because she could not perform in physical education as well as her peers. Sadly, in order to avoid ridicule, Person E reported hiding in the school bathroom until the other students had left the school. She concluded, "Yah, 'cuz in school I always got teased a lot and called names. It wasn't a very good experience, in school and so...". It takes little imagination to envision why she might avoid similar situations in adulthood.

Neutral or negative school memories were also reported by several other participants (e.g., F, G, L, O, and Z). This type of memory etched in childhood was not likely to inspire these individuals to seek out exercise opportunities as adults. In fact, Person E avoided physical exercise situations until in late middle age she moved into an apartment where professional staff supported her with information and approval. This acceptance opened her to the possibility of taking part in a health improving swimming program. As an offshoot, she has made some long-term friendships, broadening her social network and nurturing a more positive sense of self.

For Person F, physical activities associated with school were dominated by the pragmatic needs of rural life such as gathering and stacking fire wood. This person recalled little in the way of recreational fitness activity as a young person. However, like Person E, he recently moved to

a more supportive living environment and has become involved in two recreational activities, Tai Chi and carpet bowling.

When I reviewed the remarks of Person G, it was easy to see that this young man had also had a negative school experience. Although he did not provide a great deal of detail, I determined by listening to his tone of voice and reading between the lines that he was rather isolated and felt some rejection from peers. This rejection by peers was due to his inability to catch onto games at the speed of classmates. This brief excerpt captures the essence of his school experience:

Q: What was your school experience like in terms of activities? Can you remember?

A: Oh, very low.

Q: Yah.

A: I didn't do a lot.

Q: You weren't encouraged to do a lot?

A: No.

Later in our conversation, Person G revealed that his slowness in grasping the rules of team sports left him literally and figuratively on the sidelines. Similarly, Person Z recounted how physical education proved an isolating experience for her. I asked her what had happened in P.E. at school. She explained how she was asked not to take part and the embarrassment that caused her:

A: They wouldn't let me.

Q: Oh yah, what happened there?

A: I was in PE class and they found out I wasn't able to do it so they just, instead of trying to help me they decided no, just go read a book or something.

Q: Yah, and how did that make you feel?

A: Not really good but I didn't tell anybody.

The emotionally laden remembrances of these participants suggest that negative experiences in school and in childhood affects people well into middle age and, likely dampen their enthusiasm for exercise programs. Nonetheless, the experiences of some of the study participants demonstrated that this negative attitude and avoidance behaviour could be remediated. This was particularly true where individuals landed in a social environment that nurtured and supported personal growth. Through encouragement and support these long-term barriers were reversed. These participants expressed their enjoyment at the new activity and it is likely that they were beginning to feel the emotional and physiological benefits from engaging in new fitness activities. Participants in the study who came in contact with physically active peers or moved into a living situation where fitness was encouraged found themselves with new opportunities to evaluate their attitude towards fitness and exercise activities. They were able to evaluate their own lived experience against the new information provided by people in their new social context. This context included people they liked, respected or depended on. In many cases they fell under the influence of these new social conditions and relationships and consequently began to enjoy fitness activities.

Whatever their school experience, the comments of these participants provided the insight that peer interactions in childhood, and in this case specifically the school setting, left long lasting impressions. These memories and personal histories with exercise and fitness activities coloured the expectations of recreational activity among the people I interviewed. Having said that, it also appears from the statements of Persons E, F, L, and Z that although negative memories cannot be extinguished, attitudes towards exercise activity can be remediated. This change was facilitated by the individual moving to a living environment where people important to them endorsed physical activity.

4.6 Body Memory

In addition to these childhood memories recounted by participants I also observed a qualitatively different form of memory. This type of memory I noted in the tone of voice and body language behaviours of some of the participants. Some participants demonstrated a kind of physical excitement when recounting sports or exercise activities they had recently experienced or were anticipating in the near future. After some analysis, I eventually coded this behaviour as "Body Memory". I have termed this theme "Body Memory" because after interviewing a few participants I began to notice that as certain participants were recalling an exciting activity they seemed to become restless, excited and a little more animated. I thought that they were experiencing a pleasant and invigorating sensation when recalling the event or activity.

I began to think that their memories seemed to be lodged viscerally in their bodies and seemed to elicit a similar level of interest and excitement as you might expect from participation in the original activity. These recollections impacted the participants' emotional tone. As the participants were telling me about the events, they seemed more focused in their thoughts, and they often smiled and sometimes sat up more in their chairs. Their eyes shifted down as if looking towards a tableau of the remembered or anticipated event. I began to think they were having more than a cognitive experience in the retelling of their exercise, sport, or fitness anecdote. They seemed to be both cognitively and emotionally engaged in a more significant way than was apparent through the rest of their interview. Not every participant showed emotion in this way, but when I compared data across participants, it seemed those with a history of intense exercise or sport activities were the participants most imbued with this extra energy while telling their stories. I speculated that they had experienced more than the usual cognitive memory. They seemed to be experiencing energizing bodily sensations. This observation caused me to reflect on my own experience.

I remembered the verbal exchanges I had with other runners when I was training for a marathon. Some of the people in our running club who had been running for a longer time and had run previous marathons commented that they started to get excited when they were lacing on their runners in preparation for a training run. This anticipatory excitement they referred to as "runner's high" and considered it part of the endurance training experience. Anecdotally, my runner friends (two were physicians) speculated that some element of the endorphins released during or slightly after rigorous physical exercise may be present in the blood chemistry in anticipation of the activity.

Secondly, when I was a practicing martial artist, I observed a ritual of ironing my uniform before class. Often I began to feel excitement as I was ironing my uniform and putting my protective gear in my sport bag. I was not sure if this excitement was the body's response to the fight or flight syndrome that may have been thrown into gear as the body responds to perceived needs in preparation for a contact sport. This excitement I felt at the time of preparing for class registered as a positive sensation. It seemed to be a part of "psyching up" for class.

The bodily reactions I observed in study participants cannot be perceived from the text alone because the text does not include the body language evident in the context of the interview. Printed word lacks the nuances and texture of face to face interchange. I first noticed this phenomenon near the end of my conversation with Person C. She sat up and looked excited and commented that all the talking we had done about exercise made her anxious to go out and start running.

In the latter part of the data collection process, I interviewed two high achieving Special Olympians. In these interviews the body memory affect was more prominent when they recounted their experiences. Person X's face expanded into a full face smile when she was

recounting her sports activities. I brought this to her attention and pressed her to interpret the accompanying feelings. She replied, "I just get so excited my whole body just gets, starts to um kind of weird, a funny thing...it's just so hard to explain I know..". A little further in the conversation, she said, "Yes! (Laugh) Yes! I just want to come and be done it.... It's overwhelming. I just start to feel better. I get happy". I put a similar question to Person Y, asking him more directly if he experienced excitement when anticipating or recounting a sports activity. He put his feelings into words.

A: Yes I do.

Q: Uh huh and can you feel that excitement in your body?

A: Yah.

Q: Can you describe that for me?

A: It feels like I am, it feels like excitement. That I'm all happy and all ready to do it....motivated.

Q: Ah, so do you ever get those feelings when you talk to somebody about your sports?

A: Yes.

Q: Ah ok and can you feel that?

A: Yah.

Q: Can you tell me where?

A: In my body...like in my heart things like that.

Q: Uh huh and what kind of a feeling is that?

A: A happy feeling... excited feeling, like the adrenalin is pumping. ...things like that.

Significant in separating this excitement from manifestations of fight or flight syndrome are the participant's expression of happiness in recalling a past event or looking forward to a future one.

In an attempt to research this idea, I performed a few library search of the Sociological

and Social Work abstracts using the phrase "runner's high" as the key words, but there was not

much available. I eventually happened upon a paper on opioidergic[7] mechanisms as they occur

in athlete's brains (Boecker, Sprenge, Spilker, Henriksen, Koppenhoefer, Wagner, Valet,

Berthelot, & Tulle. 2008). I e-mailed the principal investigator in this study and discussed my

observations. Dr. Boecker kindly responded and replied that although his team had neither the

funding nor the time at this point to investigate this kind of anticipatory "runner's high", he

nonetheless added,

> ...but this doesn't rule out the possibility that raised mood states prior to exercise result

> From increased opioidergic neurotransmission.... (Personal communication, 11/3/29)

He suggested that the behaviour I had observed was an aspect of the experience of athletes he

was interested in pursuing in the future. For the present he would not rule out such anticipatory

effects (personal communication, 11/03/29). To this end then, I feel it is defensible to consider

adding this type of "Body Memory" as a potential supplement to the ranks of participant

memories that contribute to physical fitness or exercise choices.

4.7 Family Influence

The influence of family members was a major current running through the interview data

provided by participants. Parents and siblings in particular were cited by participants as

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[7] The cerebral neurochemical correlates of exercise-induced mood changes have been barley investigated so far Neurochemical changes are suspected as a possible cause of euphoric states following strenuous exercise. Recent researchers (Henning Boecker1,2, Till Sprenger3, Mary E. Spilker1, Gjermund Henriksen1, Marcus Koppenhoefer1, Klaus J. Wagner4, Michael Valet3, Achim Berthele3, and Thomas R, & Tolle3) tested the theory that release of endogenous opiods occurs in frontolimbic brain regions after sustained physical exercise and that there is its close correlation to perceived euphoria of runners. This may account for these euphoric states of athletes but more work needs to be conducted.

providing initiation into fitness or sport activities, encouragement to continue and facilitation of ongoing involvement. In some cases family members acted as models of fitness behaviour. Some participants said their family members inspired them.

Many of the participants had ongoing contact with their parents and siblings, and a few lived in the family home at the time of the interviews. Parental influence was evident in the answers of both younger and older participants. In response to the question of what she learned about being fit, Person B who was 25 years old stated, "My mom walks everyday for at least an hour....so my mom inspires me to walk". Persons C and D described how parents served as agents of fitness by prodding their children into action.

Person C remarked,

Um, my dad, the one who kind of nags me to get out and stuff and knowing that he goes out and keep telling me it's good for you healthy for you know it's better than staying inside on the computer he's telling me all the time just get out get out.

The reference to her father's nagging put me in mind once again of the importance of self-management plays in the ongoing communication between family members and study participants. For their part the parents are trying to encourage their children to establish and maintain regimes of fitness that are reputed to provide a better quality of life. The "soft' and supportive approach taken by participants' family members seems qualitatively different from the more strident admonishments of some of the professional support staff that figure in the study text. In my way of thinking the emotional ties of familial relationships render their approach more a matter of social support than verbal discipline which was balder in the comments of paid caregivers.

Adding to this mix Person D contributed, "My mom, she's a wellness person, she's writing a book on wellness... I guess having talking about it and I wanted her to stop so I thought I better do it (laughs). So I don't hear her anymore". Later in the same interview the individual added, "My mom is an avid swimmer she swims on a team. She's been swimming her whole life and so have I". In this vignette it is apparent that the mother has served as an inspiration and model for her daughter.

Person J was a very active young woman, despite having multiple impairments (Cerebral Palsy, hearing impaired). The data forming our conversation revealed a very intense involvement of parents. They instructed her about the importance of exercise and healthy eating. They helped her access programs in which she showed interest, and they actually went a step further by helping her perform her Yoga stretches. These parents were at the pinnacle of parental involvement as recorded in this study. The outcome for their daughter was that her Cerebral Palsy did not prevent her from accessing many fitness opportunities. She expressed great joy in her involvement with sports and exercise. These four participants are examples of young people who were all between the ages of 25 and 30. It is easy to understand how the family, particularly parents, might still figure as prominent influences in the early years of their independence.

Study participants provided ample evidence of this ongoing influence of family members. Through the regularity of their recreational pursuits this group of participants indicated their commitment to following family prescriptions and advice. They welcomed fitness and exercise activities as essential elements in living a good life. In doing so, they demonstrated a kind of solidarity with the value their families placed on fitness. The participants had accepted parental values of fitness as a "good thing" as compared to sedentary activities such as sitting at the computer which was seen as a "bad thing". Upon reflection it is easy to understand how people

who have experienced stigma and social exclusion such as reported by some study participants, would find great appeal in joining the ranks of the "morally correct" by attending to their own fitness. The appeal of social acceptance could provide the leverage needed to "inspire" individuals to get active. When participants expressed that their new regimes made them feel good about themselves and compared that self-evaluation with their previous "lazy" selves (e.g., Person W).

Virtually all of the participants in this study spoke at some length about the types of fitness activities they were exposed to within their family enclave. Some, like the young women just mentioned, gave examples of fond memories of participating in recreation with parents and siblings while the familial recollections of others were rather barren of health promoting experiences.

A number of participants provided some insight into the family influence where family members had provided little direct experience with fitness activities and even less healthy living instruction. This interchange with Person E illustrates:

Q: And what was their interest in fitness like?

A: Well my mom and dad curled. And they really enjoyed that.

Q: Uh huh, and did you go with them?

A: I went to watch a couple of games yah.

Q: But they never involved you in...?

A: No, no.

Q: Did they say anything about fitness or recreation?

A: No.

In this illustration, the memory as described lacked significant emotional content. In afterthought I interpreted this experience as neutral in terms of any impact on the daughter's future fitness interest. From this account, I concluded that the neutral position of the parents combined with the humiliation this participant suffered at the hands of peers served to dampen her interest in fitness activities.

Person F was an older gentleman whose young life, both at school and at home, was centered on the day-to-day necessities of providing for the basics of life. I asked him if his parents ever talked to him about fitness or involved him in sports. He said, "No, not really, I mean I worked on a farm for about 13 years." For this gentleman growing up was a serious business and although he recounted playing a bit of sports with his school chums it was clear from his delivery that planned fitness activities were not a high priority in his life or that of his family. For most of their adult lives, these two participants had minimal exposure to fitness activities. And each of them had only recently begun to explore physical activities. She attended a therapeutic swimming program and he had been introduced to carpet bowling and Tai Chi. They both had recently moved into a semi-independent living situation and the staff there had helped them with their new pursuits. From their accounts I determined that their families did influence their later fitness interest if only in the negative by not exposing them to specific opportunities. As members of an older generation it may have been as in the case with Person F that the practical needs of making a living and helping out around the house were priorities that could not be usurped by recreation. Families at different levels of social and economic strata set different recreational priorities for their children (White& McTeer, 2012). There may be less exposure to recreational sports in working class families. Clearly the working class environment highlighted by Person F did not allow for much free time activity.

Through this discussion I am not suggesting that there is a causal link between exposure to fitness activities in family of origin and subsequent practice in adulthood. There may be many factors at play. However, a review of the data across participants reveals a more substantial correlation than might be imagined by simple coincidence alone. Much early patterning takes place within the family with parents, surrogate parents, and siblings providing direction, support, and encouragement. Simply put the instruction and modeling of people in primary relationships to the participant's claims prominence as a major effecter of later fitness behaviour. Without this early family influence the participants in this study seemed to need to come across a personal influence that socialized them toward fitness activity.

To sum up family influence, those study participants who were most active at the time of their interviews disclosed a richer personal history with exercise and sport than those who were not as active.

4.8 Having Friends

When I asked the interviewees who had helped them in participating in exercise and fitness activities, friends came as a regular and immediate response. Next to family, friends were a dominant influence. The general aim of asking participants this question was to uncover the social relationships or support networks which helped participants in their fitness pursuits. People in the study who had experienced the pleasantness of peer interaction in the past may have anticipated similar feelings when contemplating involvement in a sport or recreational activity. The importance of friends and friend making as a catalyst for fitness participation was evident throughout the data collection process. Friends introduced participants to exercise and sport. Friends appeared in the form of teammates, and friends encouraged, supported, and cheered on study participants. The role of friendship in participants' activities varied but was

present in every conversation with active individuals. In the one case where the participant denied any physical activity, he nonetheless described spending free time with friends playing video games. His friends shared his interest in games and his distaste for physical activity.

Often friends provided a sense of welcome and enhanced the overall experience. Study participants cemented enduring bonds through common experiences with friends. As Person C told me, friends can inspire us to strive to do better or simply to carry on with the activity. The social process described in interviews involved meeting new people as well as re-kindling old friendships through participation at cyclical events. The following is an example from my talk with Person C:

Q: What about the swimming do you really like?

A: I keep meeting new friends at the pool and meeting old friends.

Another participant described going to an annual sports camp: "When I'm out I get to see friends I haven't seen in a long time and see I haven't seen before and see ones I know I may never see again and stuff (sad note) but at least it's really fun ..".(Person I).

The relationships developed by participants through their fitness activities often involved systems of mutual support. Here study participants had the opportunity to reciprocate the care and welcome they had received. As I reviewed this topic it occurred to me that most of the study participants relied to one degree or another on the help and assistance of others. They needed this help to find housing, navigate income security programs, access the community, or attend employment programs. It seemed clear that for individuals who were regularly dependent on others, the opportunity to provide support to others during sports or team activities might be rewarding in the extreme. Over the course of our time together, participants expressed much joy

and happiness in their experiences with group activities particularly where they felt they made a significant contribution.

Many study participants met people through their sports activity and later expanded their social networks through affiliation with teammates outside of the recreation setting. For some of the study participants, the experience of having a social network was novel and stood in contrast to their lives before sports. An older person who had spent some time describing her feelings of social rejection as a child talked about how her exploration of a swimming program had brought new people into her social sphere. She told me how she had made a couple of friends through the program and went out for lunch with them. I asked her how that felt and she replied, "Yah, it's nice to be part of a group because I never had close friends or friends when I was growing up" (Person E). The rewards of friendship are especially gratifying for persons with intellectual disabilities who like this woman, regularly report lives of social isolation.

The participant with the weakest reference to friend making was Person G. His support worker tried to be diplomatic in his evaluation of the participant's social skills.

Maybe less of a friendship where they spend time together ah, it didn't quite develop, You know it needed a bit more time or the personality ... I think it's been difficult at times for Person G to make friends out of a situation like that. He certainly, in my experience, enjoys being familiar with people to say hello and that...

Person G was a rather taciturn individual; nonetheless, he gave nominal agreement to the idea that friends played a part in the positive experience of fitness activities. His agreement on the importance of friends as one of life's pleasures only serves to amplify how he must have felt when rejected by his peers in his growing years. This exclusion from peer interaction and

acceptance likely had an effect on his interest in group activities as a young man. By contrast

Person I became enlivened when he recalled his athletic success during events with friends.

Person I summed up the importance of friends as an antidote to social isolation when he said,

> And I, I really enjoyed it a lot. Because I mean when you don't see friends a lot, you
>
> don't have their phone numbers; you don't have their addresses you know you could at
>
> least make up with them and they could have a chance at making up with you.

Person C described her experience of reciprocal and mutual social support that marks

successful peer interactions. Simply put, during meets she cheered on her teammates, and they

cheered her on. The ability to reciprocate is an important aspect of peer relationships and

promotes a sense of self-worth, because the person feels that he or she is a contributing member

of a team or peer group.

The Special Olympics movement offers opportunities for persons with intellectual

disabilities to take part in individual as well as team sports. This organization and its sister

organization Operation Track Shoes figured in the lives of a number of study participants. Most

of the research participants became engaged in sports activities after meeting friends or co-

workers who had some association with Special Olympics. They were often initiated into the

program through these friends and then subsequently remained engaged, partly in response to the

welcoming atmosphere created by the team members, their coaches, and volunteers. A

welcoming atmosphere cannot be overrated as an inducement to maintaining fitness activities.

The Special Olympics program aims to provide access to sport and recreation to people

with a wide variety of ability (Special Olympics Canada www.specialolympics.ca/). For a few of

the individuals I interviewed, "Special O" became a large part of their lives, offering them

opportunities to train and excel in team as well as individual events. Again, friendships figured

prominently, even in the thoughts of individuals who were well past the initiation phase of involvement in their chosen activity. One high achieving Special Olympian remarked, "I guess I just wanted to get into doing Special O... because it's and it makes you interact with other athletes and people and get to know them" (Person X).

In the latter part of the data collection process, I interviewed a young man who was at that time very active and successful in the Special Olympics program. Although his primary focus at the time of the interview was preparing to give a championship performance, he identified how important making friends had been to his sports involvement. I asked him to describe the benefit of doing sports with friends. His first response was simply that the effort to make friends was "worth it". After a probe for more details, he commented further that having friends around him was a good feeling and that the socialization that accompanied the practices and events was important because, "You have somebody to talk to and be good with", and more poignantly, "It's like you have company and you're not lonely" (Person Y). This ability for fitness participation to combat isolation and loneliness was a strong draw for this young man. He had a great deal of difficulty relating to peers and people in general and before his sport involvement his caregiver had to manage his behaviour in order for him not to be rejected by peers. His previous un-social behaviour threatened to get him ejected from activities.

For many of the study participants, being among friends on a team outing or while taking part in a sport, offered opportunities for reciprocal social support and nurtured a sense of belonging. This was particularly evident in those who were engaged in organized team sports. Similar feelings were expressed about team membership as were mentioned for the involvement of friends in general. I asked a number of study participants about their team involvement and how being part of a team affected their fitness choices. Person D provides a précis of the

comments, "I love the team aspect. I love swimming and I feel happy when I'm in the water ...We all support each other. It's so neat when we're in the pool practicing".

One parent who acted as aid for the interview with her son made a comment that captures the capacity of team involvement to create a sense of social inclusion. When describing a team outing where her son got to stay overnight with the group, she remarked that it was the "most inclusive experience of his life" (Person K).

Another participant expressed a sense of belonging when she was involved with a therapeutic swimming group.

> ...and you realize there is people like you, too, that have the same problems. You're not the only one who has it and ...We just sort of ask how we all are and stuff. When you do miss it people say: Where have you been? So it's kind of nice you been missed and that ... it feels really good like you're part of a group (Person E).

I would argue that such comments support the idea that involvement in sport reduced participants' social isolation and increased their community integration.

The literature review in Chapter 2 highlighted that social inclusion was an important aspect of the physical fitness of people with intellectual disabilities. This literature underscored how many people with intellectual disabilities live lives earmarked by social exclusion. They face systematic and global discrimination based on personal characteristic and the assumptions others make about their character and disability. In the light of this experience it is easy to understand how a friendly atmosphere could be conducive of regular attendance. Where a specific effort is made to create a welcoming atmosphere recreational team sports offer a sanctuary of mutualism where the person finds acceptance and support.

In summary, the participants surveyed overwhelmingly listed friends and family as instrumental in supporting their exercise activities. Friends and family provided both tangible and emotional support. Family offered material support in the form of rides to sport venues or helping the individual with enrolment and sometimes paying some of the registration fees associated with club or organization memberships. Additionally parents and siblings gave verbal encouragement for participants' ongoing engagement in fitness programs. Friends served mainly as inspiration or encouragement or simply laid the foundation for an inviting social environment which eased participants into new programs or events. Occasionally friends were also cited as providing rides to recreation centers.

The invitation to participate in fitness activities offered by friends and family are an example of how interpersonal relationships can foster a change in physical fitness practices. The feelings of worth and self esteem people get when welcomed into familial or friendship circle are very rewarding. Maintaining these rewards requires commitment in day to day practices. For those study participants' who lacked familial support for fitness activities paid helpers sometimes filled in. Caregivers and support persons were also influential in the lives of study participants. The support of these paid helpers formed another theme in the data analysis. I will now turn to a description of how professional support figured in the fitness choices of study participants.

4.9 Professional Support

For the majority of study participants, professional helpers also figured in their day-to-day lives. Under this heading I turned my attention toward a discussion of the role of caregivers, support workers, and sports coaches in initiating, maintaining, and engaging study participants in fitness and exercise activities. For persons with intellectual disabilities who live in group or

individual care homes, caregivers become influential in creating opportunities for fitness involvement and also are a source of advice for healthy living. Likewise service agency staff, particularly if they form an enduring relationship with their clients, can serve as an important force in initiating fitness regimes. The community access goals of agency staff often involve facilitating access to recreation centres in the community. The data suggests that those participants who were involved with professional support workers, who thought that their clients would benefit physically or mentally from exercise, were more likely to be regularly involved in fitness activities. It became clear through the interviews that support for fitness activities was not an ensured pattern of professional involvement. In some cases professionals provided active support for fitness activities and in other cases they did not.

Person E was a middle-aged woman with a lifelong aversion to physical exercise. This changed when a staff member from her semi-independent living program provided her with information on a swim program at the local recreation center. Given the participant's reluctance to be involved in fitness, I asked her how she became interested in her current activity. She explained that when she moved into her present placement she found the support staff really accepting. She continued:

Yah, when I came here we looked it up on the computer or something. So (not, *sic*) 'til I came here and ...had the support work of the staff, it's really good. I think when I moved here somebody got me into the, I think it was Community Living (Community Living Victoria *sic*) got me into it.

Other participants who had not taken part in any recreational exercise for lengthy periods of time also reported that their interest in exercise increased when they had moved into a new living situation where there was a caregiver who was interested in their physical health and provided

information, access, and encouragement. As a result of these new relationships, study participants found themselves becoming interested in fitness and taking up an exercise activity or sport. In this way I began to see that attitudes etched in youthful experience could be amended through contact with caregivers or other professional helpers with an interest in fitness themselves. My analysis of these cases brought forward the idea that the dampening effect of negative fitness histories could be reduced and interest in fitness re-kindled if someone in the new social environment was interested in and accepting of, the individual participant. I started to see that undeveloped fitness interest could be remediated through caring and encouragement.

In some cases, agency staff helped individuals sign up for programs or join fitness clubs such as the YW/YMCA where membership is affordable and various programs are available. Perhaps more importantly, support staff also worked out with their clients. Shared activity has the potential to create bonds that help to cement client's commitment to an exercise program.

For those study participants who grew up in care homes, their caregivers, if stable over a period of years, sometimes took on a role that went far beyond helping individuals' access exercise programs. In response to the question about how caregivers had encouraged him to be fit and healthy, Person I replied,

> They really teach you about what certain things are for your health... they explained
> about eating healthy foods and ah, fresh air and get enough rest drink enough liquids and
> ...explained about doing exercise what certain ones work and all that stuff. I got people
> around me to talk to that are good, I can trust to help.

Another study participant echoed these thoughts and gave more detail describing the depth of involvement and support some caregivers provided on behalf of the health and wellness of the people they supported.

People help me to do my stretches and they remind me that it's important to do them especially my arm, my left arm to stretch my muscles because it helps and it helps it to feel better... because he helps to hold my hand when we are doing the stretches. ---helps and he holds my arm and ---takes me for walks (Person J).

For the people I interviewed who had become engaged in team sports through more formal organizations such as Operation Track Shoes or Special Olympics, coaches served as another source of support. The role of coaches was of greater significance as people journeyed along the continuum of athleticism. Although the coaches cited by study participants volunteered their time, I have included them under the professional support umbrella because of their technical expertise and their positions within formal organizations. Most often people involved in organized sports reflected that their coaches were "always offering encouraging words" (Person V). Simple words of encouragement such as good work or congratulations were felt with enormous emotional impact by those I interviewed. The technical aspect of coaching did not go unnoticed with the more high achieving athletes in the study. These individuals reported that coaches made available one to one instructions on specific aspects of the chosen sport. Person V stated, "Well that was interesting. When first time I started I used to hit at all the bad pitches and then my coach got me (Laugh) one on one... He did a hitting clinic with me and then 'I got used to it'".

When I asked another athlete what coaches did for him, he answered: "Help, help you with the stroke improvement, things like that" (Person Y). In summary, coaches offer a combination of technical and social support that helps persons with intellectual disabilities remain interested and excited by their engagement in regimes of fitness and sport.

Family, friends and professionals all exerted their influence on the fitness behaviour of study participants. Conjointly they offered social support. The emotional rewards of acceptance, belonging and affiliation all provide psychological benefits. These benefits strengthened the willingness of study participants to go along with invitations to take part in fitness activities and bolstered resolve to keep active. When these inducements failed to engage people in being active there was likely to be some conflict between them and those in their social network that are trying to encourage a norm of self-management through fitness involvement. This tension was evident in some of the interviews I conducted with study participants. Drawing in a Foucauldian idea of power in relationships I coded these types of interactions as discipline and resistance.

4.10 Discipline and Resistance

During some of the study interviews, I noted when talking to people that in some cases they seemed to resent their involvement in fitness and exercise programs. They were resistant to the pressure to conform to socially approved health and fitness prescriptions. The resistance I noted was sometimes as subtle as tone of voice and at other times expressed as anger at being pressured into fitness activity. While these individuals had by in large acquiesced to the pressure to exercise more they nonetheless exhibited some residual antipathy to the need to adopt new health promoting activities. They may have understood that exercise was good for them but it still remained a bitter pill. This resistance came out in both direct defiance and at times was a little more subterranean.

The one outlier in the study was Person O. This young man took very little time to discuss his fitness experience. He was adamant that he and his parents were not in the least interested in fitness activities. He candidly told me that his parents and he were "not fit". I considered this assertion to fall into the category of demonstrating family solidarity. And as such

serves to re-emphasize the impact of family on fitness choices of study participants, albeit in the negative. In some respects this solidarity took the form of the entire family resisting in whole the social pressure exerted through popular culture and population health campaigns (Federal government's Participaction, BC's Act Now) to offset ill health through fitness activities. My analysis of the interchanges I had with participants who seemed to resent the push to fitness led me to consider the work Foucault (1978). As a consequence I created this theme and have included some of my observations below. Some examples indicating that a relationship of power and resistance were at work were subtle while others were more readily observed. Some of the relationships where I observed the interplay of power and resistance were between parent and child. Most were between professional helpers and study participants.

In my conversation with Person H, I had asked her how people at school had encouraged her to stick with an exercise program. She replied by saying the Physical Education teacher had simply told her "keep going, keep going". This encouragement, while aimed at managing the participant's behaviour seems more benign than coercive. It is in the following lines that I identified a sense of resistance to this "help".

Q: How do you feel about getting encouraged like that?

A: Ah sometimes...?

Q: Sometimes not so much? (Laugh)

A: Yah"

The participant was agreeing with my assessment that her "ah sometimes" remark indicated at other times she didn't much care for the "encouragement" offered by the coach. My thoughts on her resistance came from the tone of her voice and body language which signified a sense of exasperation. It was in this exasperation I perceived the emergence of resistance. Shortly

following this selection I tracked an interchange between the participant and her mother who was acting as a translator due to the participant's difficulty with expressive language. The mother explained for my benefit that she and her husband were going away for a short vacation leaving the participant's older sister in charge.

Mom: We are going away for spring break. And so her sister will look after her.

Person: We'll walk.

Mom: You'll go out for dinner but you'll walk to the restaurant.

Person H: Yah, not too far mom.

Mom: Why? Which restaurant are you going to?

Person: I don't know yet, maybe ABC or...

Mom: ABC well that would be quite a walk.

Person: Or MacDonald's.

My impressions of this conversation at the time and my subsequent analysis lead me to believe that this bargaining of exercise before fast food was a regular site of struggle between parent and child. The child was willing to acquiesce if not forced to walk too far. The mother concedes that walking to ABC might be overly ambitious. So the participant offers an alternative. It seems there was room to negotiate as long as the principle of exercise before treat remained intact. The parent wanted to impose exercise as a counter balance to her daughter's indulgence in less than healthy dietary options. Within this interchange I was able to determine that the relationship between mother and daughter held tension where the mother tried to mould her daughter's behaviour in such a way as to deter her from straying towards non-health promoting practices. The mother in this interchange had the best of intentions as she tried to influence her child to take the high road of healthy living. The mother believed, perhaps hoped, that exercise would

offset her daughter's indulgences. It seemed in this scenario the dyad has reached an impasse and perhaps for the sake of good relations they have agreed to the trade off of a walk before dinner; business before pleasure. To my ear there is a hint of sin and repentance in this dialogue. It is a common enough part of our internal dialogue that we tell ourselves if we exercise we are then at liberty to indulge in some edible sinful delight. In this vein I contemplated that secular morality based on the truth of health experts had replaced religious proscriptions as a disciplinary force. The secularized mission of health discourse had its own moral code; eat right and exercise.

The next selection is a description by another participant of her resistance to the direction of her parent and support worker to get more exercise. I began the interchange by asking the participant how she got to the activities she was newly undertaking. The participant comments speak for themselves.

Person U: They get me to walk back and walk home.

Q: Ok, do your, does your key worker talk to you about exercise?

A: Yes.

Q: What does she, is it a she or a he?

A: Get, walk home or take the bus home. Bus home or house, I do not like, I get mad.

Q: You don't like that and you get mad? How come?

A: My mom makes me walk home.

A: Your mom...? Why does she do that?

A: She want (me, sic) to get exercise.

Q: And what do you think of that?

A: I don't want to. Finished the days get a bus.

Q: Ok, what does she say?

A: Get, walk home. I do not like, I get mad (Person U).

It seems evident that this reflected a situation where the parent and support worker are applying their power to ensure the participant behaved in specific ways. I noticed in the first instance that the participant states "they" get her to walk back from the exercise venue. She might just have easily said simply that she walks back but clearly she sees the walk back as their idea and not her own. Also clear from the participant's words were her resistance and resentment at having to comply. Their combined purpose in forcing her to walk was twofold. First, they wanted her to get more exercise, assuming this will have health benefits, and secondly, they withheld total involvement with the purpose of making her more self sufficient. This behaviour can be recognized as an attempt to change the participant's behaviour such that it better reflected norms of healthy self management. Analysis of the content of this and other excerpts reported under the Discipline and Resistance heading reflected the intimate way in which human service practice and the relationships they engendered work to imbed macro health messages into micro /everyday experience.

The final excerpt is one taken from an interview with a young man (Person G). He had requested his support worker sit in on the interview. The passage describes how the support worker took the opportunity to remind the participant of the need for ongoing vigilance lest his less active, "lazy" self emerge and dominate his behaviour. The interchange was sparked by my asking if the participant's mother had ever encouraged fitness. The participant's short response was "yah sort of". The support worker (SW) found this answer inadequate.

SW: Would you say your mom has always encouraged you to be active?

Person G: Ah, yes yah.

SW: She did ...not to sit around all day but to get up and move around.

The support worker reminded the participant about his mother's injunctions against slothfulness.

He continued:

> SW: You know how some days you don't want to do anything, you'd rather sit…
>
> A: Uh-huh.
>
> SW: And watch TV all day and not leave the house. When you go do those things we do, those activities when you do those things do you feel better are you may be glad you did those things maybe that's...Does that make sense?
>
> A: I think so.
>
> SW: I know we've talked about that if you just sit and do nothing, nothing will happen. Your waist will get bigger and you won't know anyone. Or experience anything new...
>
> A: Yah.

Herein lays the fear factor. The support worker invoked social isolation and fatness as dangers that the participant must at all costs avoid. He identified the proclivity to sit around as a part (perhaps an elemental part) of the participant's personality that must be resisted lest it lead to dissolution and waste. This element of the participant's character must be resisted until the implantations of new patterns of activity are fixed enough to prevent any backsliding. The support worker aligned himself with the loved one, the mother and calls upon the fear of social isolation to convince the participant of his need to take charge and manage himself appropriately. The support worker was ready to help but the participant himself must not be passive on his own account. The vigilance of the support worker provided an early warning system that the participant should heed. Ultimately the participant must find the courage to adopt the truth of his flawed existence and imbed remedial activity into his daily thoughts and actions. Vigilance is the order of the day. Thankfully, the support worker was there for the long haul.

At this point in our conversation I moved on to ask the participant if there was anything about the exercise experience he did not like. He stumbled to express himself and then the support worker interjected.

SW: Does this also incorporate the work aspect of it?

Person G: Yah.

SW: Because there are times when you are working when you clearly don't want to be doing it because either your knee is sore or so ah, last summer we had a few times when you really didn't want to work.

A: Uh Huh.

SW: Because I think you'd rather sit around and not do anything. Is that right?

A: Yah, yah.

SW: If you take your time to think about it you usually come round to thinking its better to do something than to do nothing, right?

A: Yep.

SW: Do you think sometimes you just need to take some time just to think about it?

A: Yes. I guess so, yah (Person G).

The success of the support worker in getting the participant to change his fitness behaviour partially depended on the nature of trust in their relationship. Trusting expert knowledge is an earmark of the relationship between client and support worker. Recognition that the support worker is there to advise the client on how to improve their life seems like an essential ingredient to a harmonious and perhaps productive relationship.

The support worker in the above conversation was employed by an agency funded by Community Living BC (CLBC). Thus we can see the link between government initiatives and

daily human service practice. The aim of pressuring the participant into a routine of fitness is in part to increase his independence and ability to take charge of some aspects of his daily life. Building independence is a regular goal of human service workers. Through human service practices human rights and goals of self- management might remain imbricated. Both goals can be achieved in the same process.

Although it may well be argued that the social support offered by friends and family may serve the same purpose of greater self management as the admonitions of professionals, the methods they employ are significantly different. Joining with friends and family in fitness or sport activities gives immediate rewards of belonging and comradeship that bond people together. Doing something simply because it is good for you or you fear the outcome if you fail lacks the charm of human interaction and parallels the taking of medicine when you are sick. The good will of friends and family had demonstrated powerful positive effects on fitness behaviour of participants in this study. On the other hand, overt pressure met with heel dragging and avoidance.

Now that I have mapped out the contents of the focussed codes or themes created through my data analysis process, I will turn my attention to a discussion of the transformation of these categories into components or "wheels "of theoretical propositions I put forward as the proximal social processes that affect the physical fitness.

Chapter 5: Theoretical Propositions

5.1 Introduction

In the following section I move away from an exposure of the themes that arose in the data. I move forward by presenting three theoretical propositions that summarize the social processes that affected the fitness choices of study participants. These three propositions are presented in model form similar to those presented by Carroll, Adkins & Foth (2008) in their constructionist work on the socioeconomic influences on physical fitness activity levels. These figures depict the proximal or close to home social processes and how they functioned to encourage fitness involvement by study participants. As noted above an analysis of the larger or more distal social processes is tackled secondly. This analysis was based on the comments in the interview data.

What constitutes a theory remains a problematic with different schools of thought providing contending definitions. These contending definitions are bound up in long term ideological battles waged in the sociological literature (Charmaz, 2006; Gergen, 1985). According to positivist epistemology a theory needs to draw "relationships between abstract concepts that cover a wide range of empirical observations" (Charmaz, 2006, p. 125). Under the grounded theory banner there are also divisions. Charmaz (2006) takes the interpretist route. She suggests that her approach is for "theorizing" (p.128) rather than theory building. Sketching the difference between the objectivist wing of grounded theory and the interpretive wing, Charmaz argues that constructionism follows the interpretive strain. In many respects this branch depends on the interpretation of the researcher. For Charmaz (2006) demystifying theory is an important aspect of doing grounded theory as best as one can. In this paradigm theorizations must reflect what is found in the data. Consistent with this approach, I have developed three theoretical

propositions that reflect the actions described by study participants. The three diagramed models presented below represent these actions.

As recommended by Charmaz (2006), I carried out a comparison of data contained in the focussed codes I had previously constructed. This "code browse" (Richards, 2005, p. 95) allowed me to collapse less relevant codes and merge others with codes that better captured and accounted for the data and provided "analytical sense" (Charmaz, 2006, p. 57). This is the theoretical coding process as described by Charmaz. It is the process that produced the themes discussed above. In this way the three theoretical propositions or models represented in Chapter 5 have been folded into a more encompassing social constructionist theorization. Here the actions of study participants are situated in their socio-cultural context. This modeling combined with a second tier of analysis are ultimately applied as a response to the research question namely, "What social processes affect the engagement of persons with intellectual disability in physical fitness activities?"

Where the data was better understood by reassigning to a new topic, I did so. This process, accompanied with memoing, helped to solidify my thoughts and ultimately rendered a list of master or parent categories. This process of theoretical coding re-united the data that at one time had been separated into numerous topic codes for the purpose of initial analysis. This final coding process allowed for a coherent picture to emerge. As a result of this process, I was able to combine the focussed codes of gaining self-esteem, family, friends, and professional support into the theoretical conglomerate of Social Support. Secondly, I rolled together childhood and school experiences with body memory to form the simplified and broader Memories theoretical code. I recognized the theoretical strength of the Resistance and Discipline code and, consequently, left it as a standalone theoretical code. The results of this work delivered

conglomerates of related concepts to form the nucleus of the three theoretical propositions I have

presented.

5.2 The Social Support Model

In this next section I have taken my analysis of participant themes and converted them

into diagrams. These figures are a visual short hand that highlights the social process described

by study participants. Each of the three models pictured illustrates the social processes that some

portion of the participants described. Together they capture the entire picture as presented in the

data. There are of course a few problems with these figuress. They are simplistic because they

are generalized representations of reality. An interpretation built around my analysis. Secondly,

they are static. The flow of interaction between participants and their social environment are

multifaceted and complex and duel directional, difficult to nuance in such models. Within each

model I have inserted the self as process. This was included in each model because throughout

the interviews individuals described their ability to change their views of themselves as a result

of a process of social interaction

I start with the Social Support Model. This model covers most of what I heard from

participants. It shows the individual being introduced to an activity. The individual tries out the

new activity. The enjoyable experience "wheel" expresses the positive frame of mind that the

individual approaches the new experience with. This wheel implies that the pleasantness arises

from qualitative rewards such as parental approval and peer interaction as well as possible

physiological responses that may arise from sport participation. The reinforcement of social

support comes next. This is the core of the model.

As a new opportunity is presented the person reflects on their previous experience and

makes a judgment of how to react. The next wheel combines social support for choosing the new

activity with the individual's memories. These memories were referred to in the above sections

as the "fitness history "of the individual. Here the effects of childhood and school experience

come into play. Given a rich fitness history "body memory may also play a role.   Finally, in the

centre of the figure is the self-as-process. Through this device I hoped to accommodate the

signposts of changing identity that were apparent among high achieving athletes in the study.

Self as process is meant to suggest the constructionist vision of identity as a malleable ever

changing, socially constructed reference point. A key point to keep in mind is that the individual

in this process does not enter as a "tabula rasa "(Charmaz, 2006, p. 165) or blank slate. They

carry with them their personal fitness histories.

As is the case with many sociological terms, social support also has many and varied

definitions. Over the past several decades, a tremendous volume of literature has been written on

the nature and meaning of social support. Much of this literature has concerned its self with the

connection between social support and health. Richmond and Ross (2008) suggested that social

support is manifest at various levels. These levels start with the individual and their immediate

social network and radiate out into the community. These authors (2008) offered a definition that

includes supportive behaviour, concrete resources and emotional support. Taking their lead

within this study, I have defined social support as any tangible (material) or intangible assistance

that encouraged study participants to begin or maintain fitness, sport, or exercise programs. The

micro social processes that affected the fitness choices of people interviewed for this study began

with the individual being initiated or introduced to a recreational activity. Initiation in childhood

was usually instigated by family members whereas initiation in later life required the participant

to meet a new set of friends or be introduced to exercise or fitness through their relationship with

caregivers or support staff.

A number of the participants described their initiation phase as one of trying out an activity or two at the instigation of friends, and finally engaging with one or two activities that they most enjoyed. Once they had been introduced to an activity, the next step in the process involved receiving of social support for their involvement. This social support offered by friends, family, or professionals entailed positive feedback combined with tangible and intangible support. Participation in group fitness activities brought comradeship, acceptance, and recognition, all rewarding to one's positive self-esteem (Daniels, & Leaper, 2006; Openshaw, Thomas & Rollins, 1983; Walseth, 2006). Experiencing these rewards nurtured a positive attitude with which the participant assessed future fitness opportunities. The data pointed out that over a period of time study participants built up a reserve of memories that then contributed to the likelihood that in the future, fitness programs would be embraced. As they approached a choice of activity they reflected on the past experienced and judged the likely outcome of participation accordingly. Positive past experiences promoted engagement negative ones the reverse. These memories include school and early childhood experiences as well as "body memory".

During the phase of engagement the individual in question maintained his or her involvement in the activity and began to see the activity as a central part of regular life. Engagement thus earmarked was evident in the interview data provided by many study participants. Some of the people interviewed had been involved in an exercise or fitness program for years, even decades.

The Social Support Model shows how those with a history of social support, successful participation, and pleasant memories are likely to engage in new fitness activities as they become available. The data spoke loudly in this regard. This seems a simple and reflexive formula that I

could easily identify with. For participants who were very active over a long period of time and particularly those with high achievement in their preferred sports, this pattern of participation social support and success became a self-sustaining cycle of activity. Ultimately, a few study participants who were engaged in regular competitive sport developed a new view of themselves as athletes. They had through this process formed a "fit identity". I have incorporated the concept of self into the Social Support Model as a way of indicating how the self-concepts of participants were altered by their experiences and interaction with others. Self as process also sits at the center of the other two models.

Identity formation is a field unto itself and slippery ground to tread as part of a dissertation. There are as many definitions of identity as there are schools of thought. However, from a constructionist perspective the appropriate question is not so much what identity is, as what it is not. This is because in the constructionist paradigm identity is not a single core thing that a person possesses within themselves (Keddell, 2009; Roy-Chowdhury, 2010; Saari, 2005). Rather, identity is conceived as a fluid reference point that moves and evolves in response to internal and external influences and the social relationships we encounter in our daily lives (Gergen, 1985). This is as true for the participants in this study as it is for others. This "flexibility" allows for us to re-imagine or re-invent our identities throughout life. For some of the study participants, participation in sports or fitness activities opened the door to exploring new avenues of their selves that had heretofore been untapped. Through this exploration and the relationships they developed with others study participants were able to claim identities based more on their achievements and less on the ascribes status of intellectual disability. They began to see themselves in relation to their abilities rather than their disabilities. They found this rewarding. Employing the constructionist concept of identity as a fluid lifelong process allows

researchers and study participants alike an opportunity to escape the oppressive barriers of essentialism which "traps people into personalities that are limiting and sometimes pathological." (Burr, 2003, p.6). Elements of a process of identity fluidity can be recognized in specific comments of some study participants. In this next passage the change in identity reflects the influence of her family's opinions and also seems tied to physical changes athleticism brings. Person V responded to my question about what her family thought of her athletic endeavours. She answered,

Person V: They think I do very well. They think I'm a good athlete. They think I could improve in the future.

Q: Do you think you're a good athlete?

A: Yes.

Q: Yeah, and the proof is?

A: In the body.

Q: Ah, in the body?

A: Yeah.

Q: How so?

A: By my energy, my athletic ability.

This interview excerpt as short as it is also representative of the participant's perspective on her selfhood as an athlete. Clearly she had integrated the perceptions of her family. She also localized the rather abstract idea of athleticism in her very corporal, body. Interestingly, Siebers (2006) has argued that theorizing disability requires us to see that impact of "attitudes and institutions" (p.173) on our perceptions on what constitutes corporal reality. This theorist has also suggested that it is bio-power that determines how people perceive their body. The

participant has identified her family and her physical sensations as instrumental in her understanding of her identity as an athlete. The arm of bio-power seems remote from this description. It is only when we consider the social context with in which the participant and her family develop their ideas of the ideal body and its perfectibility through exercise that the relationship to social constructionism can emerge. Siebers (2006) provides a more refined way of expressing this thought. He says: "the materiality of the body cannot be dissociated from the historically contingent practices that bring it into being" (p. 187).

Other participants at the upper end of the sport participation scale also spoke of themselves in relation to other athletes and compared their present selves to the person they were before being active. Person W described how he currently associated himself with other athletes and defined himself as changed from his old self. This new identity is manifest in a more positive self-image. I asked him what being an athlete was like. He responded, "It feels good to be an athlete because I get to meet other athletes". He later remarked about how people around him also see him differently. His mother and boss have commented on his changed self.

Q: She sees a difference in you?

Person W: Yeah (Laugh)

Q: What does she say?

A: She says I've changed.

Q: Yah.

A: Even my boss at work says I've changed too.

Relevant to this comment, Charmaz (2006) has suggested that constructing a self-concept is a way of defining ourselves in contrast to others. It is a setting of boundaries. The new self described by these participants was sometimes held in opposition to their past identity as an unfit

person. I asked Person W what had changed from how he saw himself before his sports

involvement. Simply put, he answered: "I don't feel as lazy as I used to". Later in the

conversation he expanded on that thought.

Person W: Well in my younger years I was not too keen on doing sports.

Q: Uh huh.

A: Made me feel a bit lazy not going out there but now I don't feel lazy at all.

Q: Oh ok. Yeah, so you're not a lazy person?

A: No.

Q: Ok, but you are an athlete?

A: Yah.

A: And I have friends who are athletes and not lazy at all.

In defining the old self as lazy and the current self as an athlete, the participant was able to

distance himself from an unwanted identity, a disabled identity and establish firmly his

remediated identity. The participant was implying that he was one thing and later was another.

This simple dichotomy helped him communicate about the complex feeling and thoughts he had

about the changes in his physical ability and the social acceptance that had accompanied these

changes. Theoretically speaking, his shorthand analysis suggests that identity as he sees it can be

changed and altered through social processes. Thus, intuitively, he took the constructionist view

that identity need not be a constant and essential core of a person carried with them throughout

life. Identity in this case, was imagined as amenable to social influence and individual agency.

One indicator in the data that made the impression that participants were reframing their

self- image was that they began to develop an active interest in following proscriptions that

serious athletes must follow. This included curbing hedonistic impulses such as eating junk food

and drinking alcohol. This commitment to healthful habits helped some participants to see

themselves as able to change in order to improve themselves and fall in line with physical

regimes prescribed by coaches.

A: Well the coach said no more eating junk food.

Q: Is that right eh?

A: Yeah, when I first started at A&W in 2006, I used to eat their greasy food.

Q: Oh I bet.

A: And then the coach and I said I'm going to stop eating all this (Person W).

This is a description of a social process whereby coaches act to provide the kind of discipline

that the study participants could not impose on themselves. The outcome of this process is an

individual who has been "transformed and improved" (Tremain, 2006, p.622) and may stand as a

data embedded intimation of later theorizations. As Tremain has indicated; "the production of

seeming acts of choice ...on the everyday level of the subject makes possible hegemonic power

structures" (p.622). This type of explanation is congruent with Conrad's (1994) concept of

seeing wellness as a virtue as discussed above. Comparing their virtuous selves to the

slothfulness of their unfit selves added a moral quality to the quest to change or improve their

bodies through physical fitness. Avoiding junk food was one milestone along the path of virtue.

Participants reported a lot of approval from friends and family for transforming

themselves from being lazy to being active. I see this social approval as the key ingredient in

propelling study participants towards greater fitness and care of their own physical health. This

transformation mirrors the development of an ethic of self-management (Gilbert, 2005). This

ethic facilitates governmentality of the disabled body and additionally fulfills the kind of

sujectification that ensures disabled people have accepted the privileged status of able-bodied

norms. Verstraete (2007) has pointed out that autonomous individualism represents a link that locks together the goals of modern governmentality and neoliberal social philosophy. Sinister conspiracy is not implied by this observation. My aim is to point out how social, economic and political undercurrents can join with individual aspirations for a better life to produce a web of serendipitous outcomes. This serendipity highlights how theorizing patterns of everyday life in grounded theory ought to be connected to theorizations of the socio-cultural sphere that engulfs daily practice. This challenge will be taken up shortly.

While the majority of study participants joined activities for their social enjoyment, a minority of the participants wanted more from their sports involvement. A second aspect that separated athleticism from recreational sport among participants was the focus on performance over simple enjoyment. For example, Person X stated,

> Because usually I, ah...I just try and help myself to aim at goals I... As long as I could keep myself positive and when I try to give all my best and I, personal best then that's the most important to me. ... Ah always trying your best.

This participant echoed the thoughts of Person W in regard to eating right and maintaining a positive frame of mind. Person Y expressed a similar commitment to a fit lifestyle. He demonstrated his understanding of what it meant to be an athlete through his heart felt recitation of the Special Olympic Athlete's oath. He passionately asserted that his goal was to be "the best athlete I can be".

Scholars working in the narrative framework will recognize how the above cited participants took the opportunity within the interview to establish their new identities by highlighting key elements of the newly formed self image (Spector-Mersel, 2011). Hole (2004) has identified that stories people tell about themselves draw on currently available social

discourse to give substance to their own narratives. In this instance Person Y was drawing

directly from the cannon of the Special Olympic movement to lend meaning and understanding

to what he thought of himself.

There was a performance aspect to our conversations as there is in most conversations. I

reflected at the time on how important being an athlete was to the high achieving study

participants and how earnestly they stated their intentions to live up to the expectations that they

saw as part of their commitment to fitness and sport. They felt pride in themselves and their

achievements and wanted to have family, friends and others take pride in them as well.
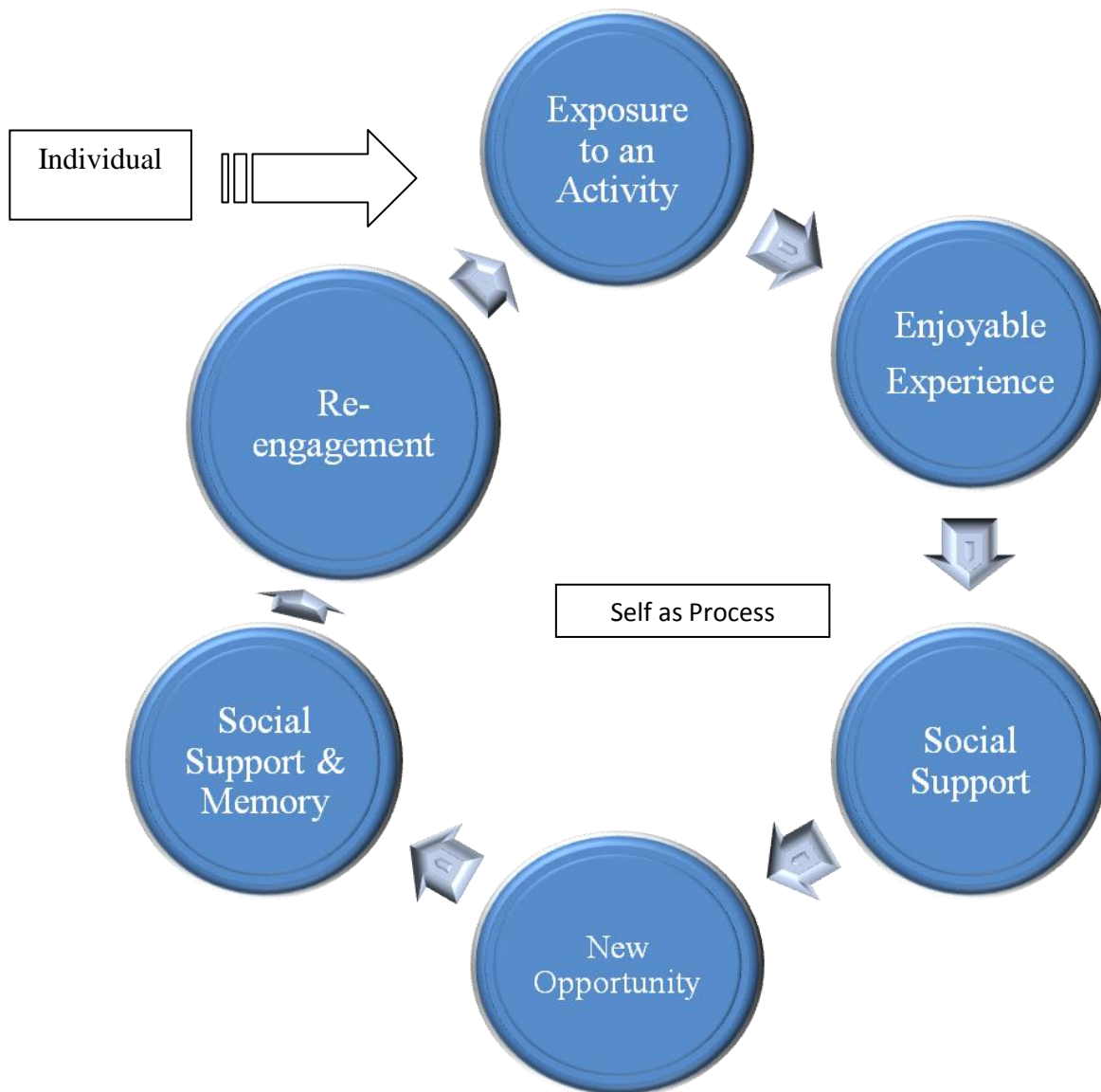
Figure 5.1 The Social Support Model

In summary, the Social Support Model suggests a pattern whereby:

- An individual is introduced to an activity.

- They find this activity to be enjoyable.

- They are rewarded through social support of friends, family or professionals.

- A new opportunity is appraised based on their previous experiences.

- Positive memories are combined with additional social support, and

- The individual becomes engaged or re-engaged in the new activity.

- For some individuals pattern will become recursive.

- Through this process some individuals will begin to see themselves as athletes

When proposing a theoretical model derived from the data in a grounded research study, it is also productive to look afield for alternate explanations. I have chosen two theoretical proposals that are derived from the sociology of sport. These two alternative proposals are relevant to explaining the attachment of individuals to sport activities. Leonard and Schmitt (1987), working within a Symbolic Interactionist framework, proposed the formation of identity as a staged process of commitment. For these authors, identity formation is relevant to a study of social processes such as those depicted by the Social Support Model I have advanced. In brief, these authors argued that identity formation as a result of sports activity occurs through a process whereby the actor imagines himself as occupying a position as an athlete and then must act in ways consistent with that view. Maintaining the new identity acts as a mechanism "that hold the actor in social positions and social relationships" (p. 252). This position is complimentary rather than contradictory to the position I have advanced.

The Social Support Model above is consistent with Leonard and Schmitt's (1987) position that identities which are acted out in public such as through sport involvement remain anchored to the social relationships that created them. However, my position also diverges from symbolic interactionism. Whereas symbolic interactionism implies a model of the self as an essential and enduring quality, I take the constructionist approach as laid out by Hole (2004) in which "self is no longer fixed and static" (p. 33). My position here is likewise consistent with other constructionist grounded theory research which suggests that people who experience a particular social context begin to adapt their beliefs and behaviours

in line with "the thing done" (p. 205) by others resident in that context (e.g.,Gergen,1985;

Roy-Chowdhury, 2010; Saari, 2005). It follows from this theorization that study participants

who were very engaged in an exercise program would come under the influence of others in

the program. It seems these participants had only two choices: they could reject the program

and its notions of correct behaviour or acquiesce and internalize the standards' of their peers

and family or coaches. The high achieving study participants had clearly chosen the latter.

Person Y for one identified so strongly with the Special Olympic creed that he could recite it

by rote

In respect to self as an athlete expressed by some of the high performing study persons, I

put forth the possibility that social support experienced within valued interpersonal

relationships is the flux which allowed participants to bind themselves (albeit temporarily) to

an altered self-concept. The concept of self can be imagined here as a creation of social

interactions. From this perspective study participants were able to integrate new behaviours

into their overall schemes of what constituted themselves. This contention is well aligned

with Foucault's notion that subjectivity plays out within such relationships (Roy-Chowdhury,

2010) as well as Leonard and Schmitt's (1987) description of sport identity as a process

"moored to ongoing interactions" (p.253). Roy-Chowdhury provided insight into how people

accommodate new information and new behaviours in order to form and re-form their

identities through the social interactions they experienced. Social constructionist theory holds

that the self is relational (2010) and in that respect supports the implications of Social

Support Model.

More recently, Koski (2008) has described a system of levels of sport involvement. He

theorized that these four roles are open to individuals when entering a social world:

strangers, tourists, regulars, and insiders. Koski posited that the postmodern world we inhabit offers more opportunity to define or re-define our identity in contrast to the restrictions of previous more traditional societies.   He argued that in recent years exercise or fitness activity has become one area of social activity where individuals have the opportunity to build or re-build their identities. The methodology, analysis and conclusions derived from the present study are in keeping with theorists who put forward a social constructionist position. The Social Support Model flaws intact, is representative of this position.

In terms of levels of engagement in physical fitness activity, the four roles Koski spoke of resonated with the variety of activity involvement described by participants in this study. The data gathered in this study reveals a similar gradation of involvement. There were participants who might be described as strangers to physical fitness, participants whose visitation into programs resembled the short lived experience of the tourist, and there were participants who regularly engaged in exercise. Finally, a small group of participants could be considered as "insiders" with a depth of knowledge and engagement far surpassing their fellow participants. However, missing from Koski's model is a detailed analysis of the social relationships that facilitate positive or negative sports ideation. The three theoretical propositions diagramed in this dissertation make a unique contribution to this literature.

The advantage of the Social Support Model over the two theorizations sketched above lies in its design which has emerged from the data provided by study participants. As a consequence, it has a direct relationship to the life experiences participant's described. This is the relevance and power of grounded theory. Additionally, through the data analysis process key antecedents of current behaviour have been incorporated into the components of the Social Support Model and its two sister models. Perhaps most importantly, the social

relationships that effected participant's current fitness choices have been given primary

consideration.

5.3 The Later Life Engagement Model

The second model applies to those study participants who came to fitness later in life.

Many of these individuals had negative or rather barren fitness histories. They either avoided or

simply never thought of seeking out fitness opportunities. The change that this model depicts is

that of gaining of a new social environment. For these participants, gaining a new social

environment led to a remediated view of fitness or sport involvement. This finding is consistent

with other research with people with Down's syndrome. This research suggested that social and

environmental factors play an influential role in fitness choices (Heller, Hsieh & Rimmer, 2003;

Krahn & Drum, 2007; Rimmer, Riley, Wang, Rauthworth & Jurkowski, 2004; Temple &

Walkley, 2007). Evidence for this process is available in study data and my subsequent analysis.

For example, in her interview, Person E traced a personal history that included rejection by peers

because of her inability to perform physical tasks. I asked her how it was that she became

involved in her chosen activity. She described how, after her move to her new semi-independent

living situation, the assigned support worker had sat down with her at the computer and helped

her become informed about what programs were available. The support worker encouraged her

to take advantage of the recreational opportunities. Her initial involvement was tentative, but she

soon found herself engaged and making friends at the program. She said that what had been

different was a sense of acceptance she found in her new living environment which was

previously absent. Due to her bad childhood experiences, she had avoided exercise in the past.

She gave credit for the turn around to an interested support worker, saying, "Yeah, so till I came

here and had the support work of the staff, it's really good".

Person F was an older gentleman who had moved into a new situation fairly recently. He had tried a Tai Chi class but found the setting uninviting. He related that his current program was much more suited to him. When asked why, he responded, "Well, I think, yeah, they make a point there that's one of the things um, they express is welcoming somebody. It's in the curriculum sort of you know." Later he described the feeling of making a connection with people as an important aspect of feeling comfortable at an exercise venue.

Another older participant also noted that becoming involved with a new work program had given her the opportunity to be more active. She related that her interest in fitness was the result of being able to go to an exercise program as a part of her new day program. She shared, "I didn't get fit until right now… I'm doing exercise at work" (Person L). She indicated further that staff in her new living situation had helped her become more active. I asked her what had helped her to get fit at this time. She explained that her caregivers had got her a gym pass. Since this change, people in the group home had said that they were proud of her because she had lost some unwanted weight. Parking my own misgivings and critical analysis about gender and ideal body image, I could see this acceptance and encouragement was clearly a novel and uplifting experience for the participant.

Another participant in the same work program had a similar experience. He told me that his "boss" had introduced him to yoga. It turned out later the "boss" was his program leader. Up to this recent juncture in his life, this middle aged man had very weak connection to fitness in part due to negative school experiences. Person Z informed me that she had hated exercise after being withdrawn from her school P.E. (Physical Education) programs because she could not keep up with her classmates. After a move of residences where she was encouraged by her caregiver to get active, she and her husband had begun walking together and were enjoying it

greatly. The new activity brought forth pleasant childhood experiences. It reminded her of when she was had walked with her mother. This memory carried within it a great deal of emotional impact.

The stories of these participants attest to the fact that individuals with a dim view of exercise who gain a new social environment may find that their attitudes and behaviours become remediated. Participants in the present study changed their fitness behaviour and their view of themselves when encouraged by new social circumstances. Such a finding resonates with the ideas put forward by previous researchers. For example, Heller, Kelly, and Rimmer (2003) asserted that pro-fitness expectations of care professionals can enhance the likelihood the people they care for will participate in exercise programs. Further, Castillo et al. (2010) described how new forces of socialization can turn around negative views of fitness. Again, these findings support the constructionist cause by implying the interactive nature of reality construction.

Figure 2 below offers a pictorial representation of the social process at work with the above cited fitness remediated participants. This representation begins with the un-engaged individual and all that is incumbent within their life experience. Their fitness history and relational selves come along. Through the new social environment they are introduced to a possible activity. As in the Social Support Model these individuals have some agency in deciding to accept or reject the offering. The level of agency might be questioned but given that some individuals in similar environments have avoided fitness involvement, some sense of agency must be admitted. The rest of the cycle depicted follows the Social Support Model and is realized through the same social/relational process.
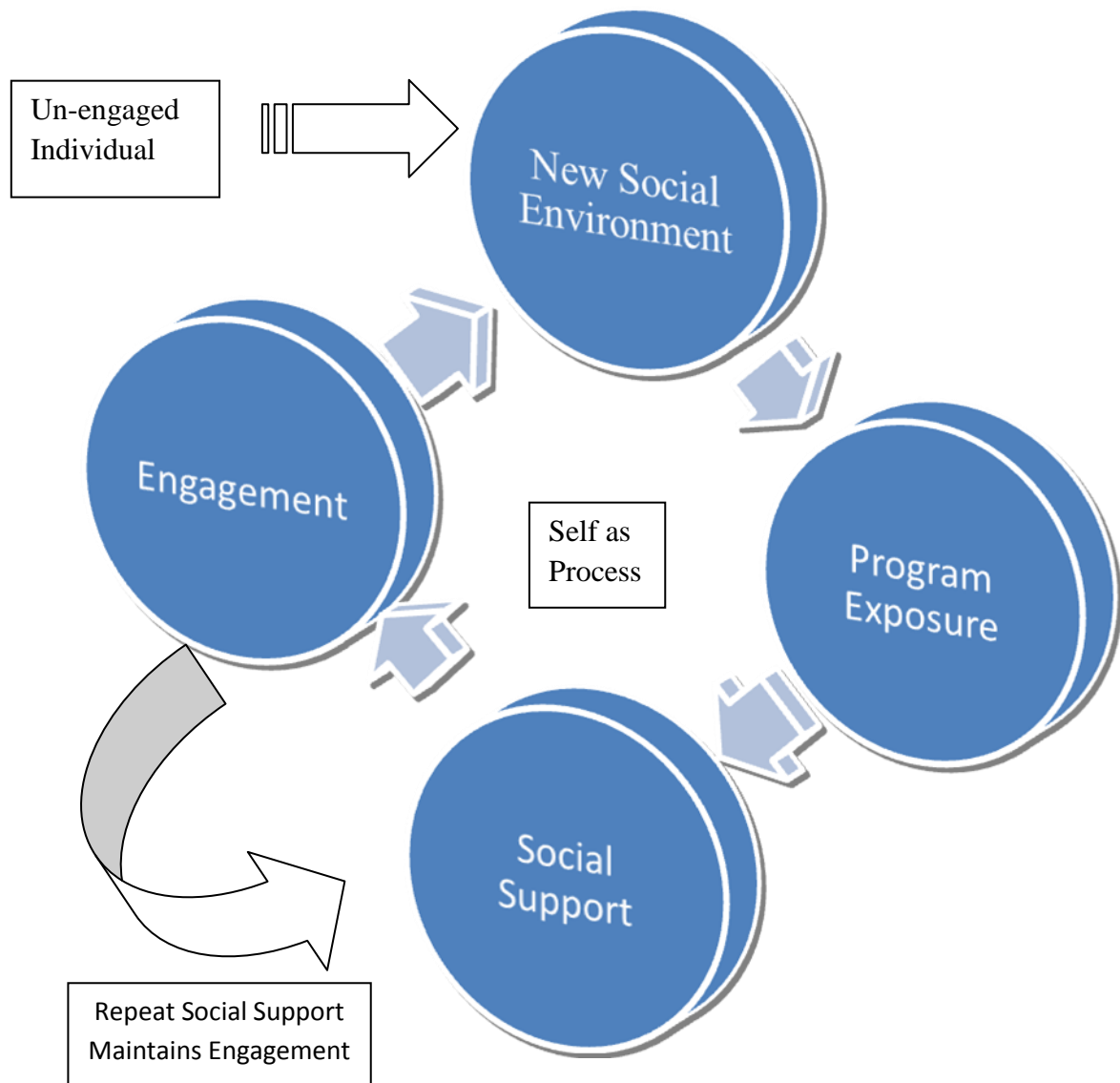
Figure 5. 2The Later Life Engagement Model

In summary this model suggests:

- Participants begin unengaged in fitness or exercise activities.

- Participants gain a new social environment.

- Participants receive social support for fitness activity.

- Participants become engaged in fitness or exercise activities.

- Repeat social support maintains the cycle

- Continuation in the social support cycle builds commitment and personal identification
  with the activity.

5.4 The Discipline and Resistance Model

The third model flows directly from the Discipline and Resistance discussion in the
Results section above (p.106). This process is at work with participants who showed
reluctance or resistance to the admonitions of people of influence in their social network who
exerted pressure on the participant to get involved in health sustaining exercises. I have
identified subtle and more direct examples of this pressure in the data. The construction of
this model derives from a Foucauldian perspective of power and resistance (Foucault, [1978],
1990). In this model, I have cast support workers, caregivers, and at times parents as agents
of "bio-power" and govenmentality (Tremain, 2006, p.185) in the lives of the people they
support. Through the use of their influence these collaterals have become disciplining forces.
The desired outcome of their efforts is the rendering of their subject into a "docile body"
(Tremain, 2006, p. 187) which may be moulded into a self-managing individual. This is not
an accident nor is it the conscious effort of family, friends or professionals to create a
governable subject. It is the application of health discourse in the lives of individuals.

The contribution of social support for study participants' involvement in exercise
activities can be understood as a strand in the "matrix of institutions, practices, power
relations and material interactions between people and things" (Tremain, 2006, p.187).
Friends and family share an interest in the health and well-being of the subject participants
and exercise what influence they can. That they do so with the best of intentions cannot be
doubted nor can it be suggested that giving in to this pressure will not provide physiological
and psychological benefits to the participants. The weight of evidence favours positive

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outcomes. Nonetheless the achievement of better health for these individuals also decreases

the risk of disease and illness that once established, put pressure on the health care system. In

Canada much of these costs are born by the state: federal and provincial. It is understandable

from this perspective how governmentality can find expression through the conduct of

individuals, their friends, and their family. Uncovering this relationship between the actions

of individuals and governmentality in the modern state invites a parallel and equally

plausible argument. The essence of this argument lays in how an individualized approach to

health care by study participants lends itself to a model of moral citizenship as inscribed in

the neoliberal canon.

Support agencies are mandated to assist people with intellectual disabilities achieve their

personal aspirations. Today much of this support is focused on gaining as much

independence as possible. The ultimate goal of this independence is to gain citizenship

status. Gilbert (2003) argued from a Foucauldian perspective and has highlighted that the

"dynamics of power" (p. 37) as imagined by Foucault allows for an analysis of how the

helping professions become engaged in the surveillances of troublesome populations. The

term governmentality may be used in this case to capture how health and human services in

their "every day practices" (p38) make the connection between state interests and the

aspirations of individuals and families. In the study data people with intellectual disabilities

that show reluctance to participate in technologies of self-management were admonished to

do better by their support workers. The directive, but not hostile tone taken by support

workers, caregivers and parents, was in accord with the notion that governmentality often

relies on subtlety more often than coercion (Greenwell, Cochrane & Gilbert, 2003).

The Discipline and Resistance Model illustrates the process in which professionals engage clients in improving their fitness and thus their independence from state sponsored care. As in the other models, I started with an individual who is not engaged in fitness or other self-managing behaviour. The first wheel represents any disciplinary power. In the context of this study I have identified, parents, caregivers and professionals all at some time can play this role. My own experience with human service practice parallels study participant comments that suggested that with adult clients this role most often falls to professionals usually, but not always, agency support staff. Relationships of trust are essential to the helping profession and also serve to give power of persuasion to agency staff. In the Discipline and Resistance circuit the disciplining power exposes the individual to an activity. If the person does not agree to participate then the disciplining force will adjust the message and try again. It is quite possible for this new approach to win compliance but if not more pressure is applied. Most study participants who were initially resistant to fitness activities eventually succumbed to pressure. If the client went along willingly then the process of social support or later life engagement may be applied. However, as discussed in the findings section, sometimes this acquiescence translated into agreement in word and not in deed. This problem can be revisited by reviewing the conversations I had with Persons H and U above. Heel dragging, pouting and other evasive measures were reflected in these interviews. Recalcitrant behaviours called forth repeated "pep talks" that reference unhappy outcomes. This technique is evidenced most clearly in the dialogue between Person G and his long term support worker. The hope of these repeat performances is to have the individual pick up the mantle of self-management gaining all the pleasure and pride that will accrue. The

possibility that the client may avoid the disciplinary power by dropping out of the

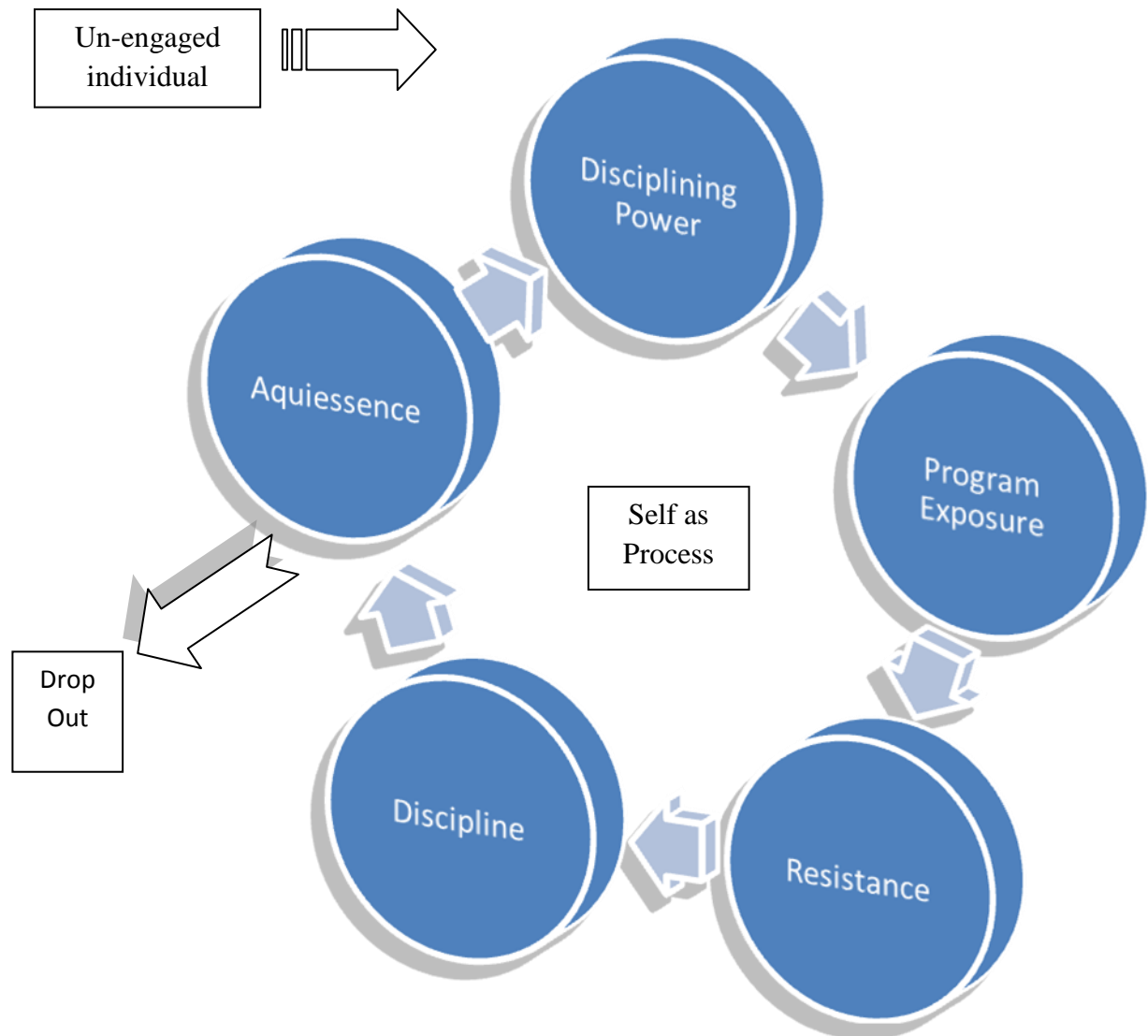relationship is also identified in the model.

Figure 5. 3 The Discipline and Resistance Model

In summary this model suggests:

- An un-engaged individual forms a relationship with a disciplinary influence.

- Power is exerted to have the individual participate in a program.

- Power meets with some resistance.

- Discipline is reapplied.

- The subject acquiesces.

- Cycle repeats.

- Subject may drop out.

The risk that the subject individual may drop out of the discipline and resistance cycle is consistent with literature that critiques fear-based population health campaigns. These fear-based projects envision the body as a potential "site of toxicity, contamination, and catastrophe" (Gagnon, Jacob, & Holmes p. 252) and, consequently, require a constant state of vigilance in order to deter backsliding. This approach requires a large output of disciplinary power. The peril involved in this model is that the individual may go through the motions without any genuine commitment to self-management. It is also possible that despite well intentioned support worker surveillance, the subject may backslide or choose to "drop out" of the cycle of struggle.

People have been shown to resent or ignore health advice that seems out of touch with the pleasures and practices of their everyday lives (Gjernes, 2010). People with intellectual disabilities as a generalized sub-population face many struggles in life and tacking on the requirement to adopt a fitness regime may be one too many things to attend to. Some of the study participants noted above reported having to go through a process of changing how they thought about themselves as a result of their fitness activities. Not everyone is successful at making that transition. This may be particularly true if their self-image is deeply fixed in certain behaviours that have provided them with a sense of stability. To become fit would require not only physical activity but discomforting identity activity as well.

Gjernes (2009) has investigated why some women resist health advice. In this work the author describes how women smokers resist health information. The women in this study resented being pictured as "uncivilized and irrational" (p. 477) by health officials. Although Gjernes concerns herself with smoking, there are some parallels in the methods of public health discourse concerning all health risk behaviours. Gjernes expressed the opinion that resistance to health advice can occur when the target population perceives themselves at a social distance from those proffering the advice. This social distance may act as a wedge that buttresses the target population against well meaning professionals. Anti-smoking campaigns have used stigma as a means of isolating deviant behaviour and assigning a moral value to following health advice (Gjernes, 2010). There was an element of the moral crusade in the approach disciplinary powers take towards the sedentary proclivities of study participants. Likewise, Bercovitz (2000) voiced criticism of broad based government health campaigns have insinuated that government's concern for individual and family health might serve more than the stated benevolent objectives.

In her critique of Canada's Active Living initiative, Bercovitz (2000) argued that establishing fitness as an essential part of life for hard to reach populations is one way that dominant social classes can impose their standards on others. She further suggested that in Canada the liability for public health has shifted from government to the individual and this shift marks the ascendance of neoliberal thinking into the health field. She also suggested that appealing to people's desire for "empowerment and emancipation" (p.33) disguises a more potent neoliberal agenda. Her assessment of this agenda is a familiar one. In brief, the political goal she identified is to move health out of the public realm and relocate it in the bailiwick of individual action. Her analysis neatly employs a Foucauldian perspective of bio-

power and the "panoptic gaze" (p.30) to uncover the mechanisms that facilitate the achievement of neoliberalism; namely, retreat from the collective good.

The impetus behind much of the health discourse about physical fitness and intellectual disability can be tarred with this brush. Laudable as health goals might be they also carry forward dominant ideals of self-management in an era of shrinking health budgets. Bercovitz (2000) has taken the idea further suggesting that shifting the responsibility for health care onto the individual is part of a larger scheme to privatize social services. The ultimate goal of this process is to siphon off tax dollars and divert them into capital accumulation. This critique must be considered when placing the theoretical propositions presented in these three models into larger social context.

Each of the three models presented described the proximal social processes that affected the fitness choices of some of the study participants. In combination, these three models transcribe the proximal social processes that affect the fitness choices of all the study participants. This graphic recording of the studied social process stands as significant mile post on the road to grounded theory development (Crooks, 2001). Moreover, as the above models and text combined presented theoretical concepts, delineate properties of each component, and explain the social process under investigation, they may be said to constitute a grounded theory (Hallberg, 2006). Accordingly, the models presented answer the research question, "What social processes affect physical fitness choices of persons with intellectual disabilities?" The data collection and analysis of my methodology as well as my epistemological and ontological perspective mark this as a constructionist work. As it stands the study represents a micro-analysis and theoretical model of the proximal social processes that affected the fitness choices

made by study participants; however, it remains for me to draw these propositions into the socio-cultural backdrop.

Some authors have taken a Foucauldian approach to the analysis of social processes in the human service industry. For example, Gilbert (2002) explored how the discourses of professional management have constructed subjectivity in social care. Bevir (2005) has used Foucault's concepts of govenmentality and regimes of knowledge and truth to explore how an "ethic of care for the self" (p. 43) imposes responsibilities on individuals to manage themselves in socially appropriate ways and Gilbert, Cochrane & Greenwell (2003) discuses how health and welfare services support governmentality of people with intellectual disabilities. Through such mechanisms as support agency practices, the state need not use coercion in order to obtain the desired results of health and human services (Gilbert 2005). Tremain's (2001) interpretation off how professional discourses police troublesome populations through their "technologies of normalization" (p. 186) seems particularly suitable. In the following discussion I have shed light on of the power relations and subjective social processes that impacted the view of self expressed by some study participants

In the findings of Resistance and Discipline above the descriptions of conflict experienced by some of the participants can be characterized as a struggle of support workers and parents to ensure participants managed their physical well being in accord with current "regimes of knowledge and truth" (Bevir). Bevir's (2005) work has dealt effectively with public health efforts aimed at ensuring persons with intellectual disabilities accept personal responsibility to improve their own fitness. His propositions help to delineate how "governmentality and an ethic of care for the self" (p.43) combine at the micro level. His analysis shows how overriding social forces intercede in the life choices of individual subjects.

This analysis has uncovered the relationship between governing of a difficult population and the expectations of self-care that participants felt obliged to accede to. In the study the forces of bio-power were realized by the admonishments of support workers who press participants to maintain healthful regimes.

Foucault ([1970], 1994) has argued that the formation of the human sciences brought with it "groups of phenomena" (p.356) which could be claimed as appropriate objects of a specific discipline. The right to enforce standards of health care on people with intellectual disabilities flows from the nature of power relations between the knowledgeable professional helpers and the ignorance (or innocence) of the person with intellectual disabilities. In reference to this study, it is my position that health and human service workers invoke this legacy when they prescribe health and fitness behaviour for the people interviewed. Study participants can be seen to have accepted the "moral code' of self care (Foucault, 1990, p.25) when they acquiesce to standards set by distant authorities. Through these mechanisms the bodies of persons with intellectual disabilities are disciplined so that they may be better governed, "reformed, and improved "(Tremain, 2006, p.187). Study participants described experiences that reflect these processes.

How people describe their experiences also contains clues that can uncover the social world they inhabit (Yates, Dyson & Hiles, 2008). Tremain (2001) described normalization as a practice that employs scientific discourse and its classifications to "structure the field of possible action" (p. 662) for individuals. Study participants' fitness behaviour was centered in just such a field. This field was rife with innumerable discourses. Foucault has argued that discourse is where power relations can be witnessed (Gilbert, 2003). This is because discourse directs our attention toward problems that require treatment. It is not possible to articulate every discourse

that may have impacted the fitness choices of study participants however citizenship has been cited as one discourse central to defining the spaces where people with intellectual disabilities may participate in society (Gilbert et al, 2005). The data suggested that the need to exercise, stay fit and manage personal health was one aspect of this discourse that impacted study participants choices. The salient point of this discussion is that the subjectivity of study participants was not derived solely though personal interactions. They were not immune to "... the incessant, disorderly buzzing of discourse" (Foucault, 1972, p. 229). In short, the actions of participants were subjected to the corralling power of health and human service discourse.

From a philosophical perspective the question arose as to what extent participants were able to choose their pattern of fitness behaviour and to what extent the field of possibilities (Tremain) was impacted by the larger matrix of health and fitness discourses. According to Foucault, a person's subjectivity is conditioned by social context (Bevir, 2005). Moreover, for Foucault power is ubiquitous therefore individuals cannot form their identities or sense of self extant of regimes of power that define the subject (Bevir). However, Bevir (2005) also argued that we need not reject human agency entirely. He suggested it is possible to separate subjectivity into two elements; autonomy and agency. In brief he put forward the position that there is evidence that different individuals react differently and choose different actions and beliefs albeit within the same social confines. He further suggested that although it holds that Foucault dismisses the possibility of a "founding subject" (p.48) what he really rejected was autonomy and not agency. Bevir divided Foucault's writings into two camps: those of the "excitable Foucault "(p48) who declares the subject to be dead, and the "composed Foucault" (p.48) who only rejects autonomy. Bevir imagined that the less strident Foucault allows space for the individual to evaluate meaning, make choices, and constitute themselves albeit within the

strictures of a regime of power (Bevir, 2005). Some study participants articulated a process

where they evaluated different patterns of action. They compared options and chose new

strategies that included fitness practices. As a result of this process, they came away with a new

sense of self. From these accounts I propose that for these participants, some agency was

possible. This agency did not imply that "disciplines of normality" (Wendell, 1996, p.88) had

been subverted. In effect, this discipline can be seen to triumph through the very pleasure study

participants expressed in the social approval for their new fit selves.

Having rounded out the three models offered with this brief discussion, I will now

respond to Charmaz's (2006) injunction to locate individual studies in their socio-cultural

context. To begin with, I have to ask if the three models presented provide that context. The

three models do a creditable job of outlining the relational processes that effected study

participants choices of fitness or exercise activities. In this respect, they may be said to capture

the proximal social relational processes that influenced how participants react to fitness

opportunities. The models simplified though they are, remain true to the data and are a close

representation of what participants said. This is a core responsibility of grounded theory

development. But next my task is to ground this representation through an investigation of the

backdrop from which the data and the theoretical proposition models emerged.

5.4 Theorizations

In this section I have provided an overview of three differing theorization s which could

be considered as offering epistemological and ontological grounding on which the results of this

study might rest. This is a limited exercise in contrasting and comparing my findings with the

purpose of illustrating how the third option, the social constructionist model best suits the data

results. This comparison of strengths and weaknesses of these theories offers a secondary ex

post facto rationalization for placing the study results within the parameters of the constructionist camp. Of course there are innumerable other theories that might be offered some of which I have referenced in the discussion of themes. The medical model was chosen because it clearly represents the positivist notion that theory ought to rely on "deterministic explanations" (Charmaz, 2006, p. 126). And the social model was reviewed because it represents the home ground of later sociological models that have highlighted the socio-political nature of disability as a culturally created subjectivity. Additionally, I have chosen to highlight the salient points of the medical and social model of disability because these two theoretical positions dominated much of the research I reviewed in the completion of this dissertation.

First, I will interrogate the biological/ medical model of disability that is at the root of population health initiatives. This approach was dominant in the majority of the articles presented in the Literature Review of Chapter 2. I then look at the social model with a view to seeing how it might be accommodated to explain the fitness choices of study participants. Finally, I return to the constructionist camp and discuss how the theory of the social construction of reality can be used to account for the fitness choices of participants. This model I conclude is the preferred model.

Although the knowledge produced by this study was confined in time and place its provisional nurture doesn't exempt it from reference to the larger social context in which the action of the study took place. This discussion provides the opportunity for me to link the action described by study participants to the overriding social realities in which this action takes place. My intention has been to knit the interpersonal interactions of participants into the warp and weave of the larger social matrixes that delineate the field of play.

5.5 The Medical Model

In this section I start with an overview and critique of the biological understanding of intellectual disability and how it has influenced thinking about fitness and well-being. I then discuss aspects of the medical paradigm that might be applied in response to the research question that framed this study.

The biological/medical model of disability has its naissance or at least its infancy in the "Western intellectual tradition" (Murphy & Perez, 2002, p. 62). The scientific method emerged during the eighteenth and nineteenth centuries as part of the socio-cultural movement of modernity. The scientific method became the shorthand for a new type of knowledge production. Instead of referencing universals laid down by the word of god or sovereign authorities, science would uncover truth through empirical observation. The empiricist (Pence, 2000) methods of called for a rigorous adherence to a specific pattern of objective observation and measurement. This process was fundamental to the explication of eternal truths that govern the natural world. Explorations of the human condition were later seen to fall within this same rubric.

Durkheim ([1895] in Lukes, 1982) argued that sociological theory must apply the scientific method to the habits of society and thereby uncover the incontrovertible "social facts" (p.2) that transcribe human behaviour. As a rationalist and positivist, Durkheim proposed that sociological knowledge stood outside the beliefs of the individual researcher and could best be uncovered through the scientific method that established the veracity of theory in the physical and natural sciences.

In our modern era the biological explanation of intellectual disability adheres to that same epistemology and ontology. In this way of thinking intellectual disability is a real thing that can be discovered, measured and ultimately treated. This theory underpins the public health

campaigns that have identified people with intellectual disabilities as sub-par performers in the fitness arena. Much of the academic research work done on the physical fitness of people with intellectual disability takes this positivist /post-positivist approach. Researchers in this vein put their trust in scientific method as a process that will make sense of the world through empirical observation and measurement (Creswell, 2007). These writers started their investigations on the premise that intellectual disability is a social fact established through formal assessment and diagnosis. This is contentious ground.

Intellectual disability according to Radford (1994) is one example of the medicalization of human conditions that are "insistent on the authority of measurement and classification" (p.9). The process of medicalization of disability turns over intellectual and in some ways, legal authority to doctors and other medical authorities. The "cognitive authority" (Wendell, p. 117) of medical and intellectual elites allows them to define the reference point from which the rest of society views disability. This influence is evident today. Government bodies look to these professionals to establish and legitimize eligibility criteria for public services. These criteria are implemented through social policy and consequently have a significant impact on the lives of people with disabilities. Community Living British Columbia (CLBC) relies on such standardized medical assessments performed by qualified psychologists (DSMIV TR) to include and exclude individuals from service[8]. Each one of the participants in this study had experienced these assessments.

Without the organizational system provided by biological science the classification of intellectual disability would collapse. The intricate web of services and supports dedicated to

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[8] A B.C. Supreme Court ruling in 2006 resulted in a broadening of criteria used to determine eligibility for CLBC services. As a result people with Fetal Alcohol Syndrome (FASD) and Autism Spectrum Disorders (ASD) can seek services. Diagnoses of these disorders likewise are carried out by professionally qualified practitioners (www.courts.gov.bc.ca/jdb-txt/sc/06/09/2006bcsc0900.htm(Fahlman v. Community Living B.C. & Others, 2006 BCSC 900).

supporting this population would likewise crumble. The human service industry deployed to aid and improve people with intellectual disabilities would evaporate as indeed would this and related research. Admittedly, this prediction assumes that the postmodernism perspective will not in the short term persuade government to release service eligibility from the grasp of medical professionals. Medical authority in this field serves practical purposes. It stands as a buttress against the anarchy that might prevail if subjective needs took the privileged spot as the main criteria for access to public funds. Additionally, holding medical experts responsible for defining who is eligible allows government bureaucracies a line of defence. Behind this line stands the objectively established unassailable science of intellectual disability.

Advocates of the social model of disability and post structural theorists such as social constructionists have brought severe criticism to bear on the medical model. Murphy and Perez (2002) argued that the objectivity of positivism is illusionary and positivist methodology tends to bleach subjective human experience out of research practice. In a similar fashion Smith (1999) decries the practices of "detachment of positivism" (p. 63) which allows sociological text to be cleansed of subjective positionality.

In pursuit of untarnished facts the medical or biological model of disability seems to commit to an a-historic view of reality that transcends any subjective influence. In this way, the medical model carries forward the epistemology of positivism in its mission to establish immutable "social facts" (Durkheim [1895], in Lukes, 1982). It can be argued that the medical model   as an approach to disability stands as an example of the legacy of modernism. Murphy and Perez (2002) have tied this up neatly by referencing the influence of the philosophy of Descartes on the epistemology and ontology of science. These authors (Murphy & Perez) argued that Cartesian philosophy has created the dualism of subjective verses objective reality.

Objective reality is where truth lays ready to be discovered. In order to find the truth, subjectivity must be marginalized. It is in this process that postmodern theorists discern the dehumanizing tendency of traditional positivist and medically orientated practice.

The offshoot of this epistemology and its accompanying ontology is that the social economic and political realities that encompass the lived experience of intellectual (and other) disabilities are discounted. This has been my critique of the literature on physical fitness and intellectual disability. The research reviewed for this dissertation is heavily weighted towards positivist methodology. Although passing awareness is made of social context, the trend in the literature assumes intellectual disability is an objective quality possessed by the individual (e.g., Block, 1991; Carter, 2002; Cooper, 1998; Heller & Rimmer, 1998-2003; Lahtinen, Rwtala & Malin, 2007; Pitetti, 2006). Remediation must then focus on modifying the beliefs and daily practices of that individual.

Woodhams and Corby (2003) highlighted that the medical model is a deficit model that starts off with the assumption that physical or mental disabilities occur because the individual lacks a required ability. Assigning the problem to the individual means that the remedy likewise lays with the individual. Tests need to be done to verify disability and remedial programs should be developed. Unfortunately the literature on physical fitness and intellectual disability demonstrates that this technocratic approach has by all accounts failed to improve the health status of people with intellectual disabilities. On the upside, this apparent failure lends itself to the possibility of different and fresh approaches. Significantly, some of the researchers surveyed for this dissertation noted that there is a paucity of lived experience represented in the literature (Carter, 2002; Pitetti, 2006; Prasher & Janicki, 2002; Rimmer & Yamaki, 2006: Stanish, Temple & Frey, 2006). This state of affairs lent substance to the position that the subjective opinions of

people with intellectual disabilities have been marginalized. It also provided some weight to the importance of qualitative research in this area.

In summary, the medical model presupposes that the poor physical fitness of people with intellectual disabilities is rooted in their disability. As nothing can be done about their genetic makeup it is their daily practices that need to be remedied. It falls to the individual and his family to overcome the disability through normalizing routines. Fitness and diet figure here.

Having now outlined the tenants and origin of the medical model the question arises: How can the medical model account for the fitness choices of study participants? To start with it is clear that the blade of medical diagnosis cuts both ways. Having an officially acknowledged diagnosis is the key to eligibility for services funded by the province of BC. You may have to wait but when your name comes up you will be eligible for a variety of support services. On the other hand the diagnosis of mental retardation is a stigma that cannot be shed. Stigma can become an indelible social identity (Goffman, [1963] in Davis, 2002).This stigma has had a totalizing effect on perceptions about people with intellectual disabilities. This perception misses the diversity of ability individual's posses and express in their every day interactions in the social environment.

All of the participants in this study had benefited materially from their eligibility for services. Many would not have been able to access community recreation options without the help of residential or community based staff. Some people might argue that this is a fair trade off.   However study participants also described life experiences marred by the stigma of being different. One of the major obstacles to physical and mental health experienced by study participants was the stigma and marginalization that accompanied being identified with an impairment that was socially devalued. It can be evidenced in the comments of participants who

recalled the humiliation they experienced by being different in the eyes of peers. Over many years study participants had to find ways to heal the scars of early humiliation.

Although their thoughts and feelings were often sensitively canvassed by support staff, ultimately professional judgement about the right fitness choices prevailed. The "exalted status" (Murphy & Perez, 2002, p. 64) afforded professionals dominates epidemiological studies that position the fitness of people with intellectual disabilities as a medical problem needing a fix. The solution regularly offered in the literature was to muster the right kind of support so that disabled individuals might perform up to "able bodied" standards. Inserted here is Davis's (2006) thesis on oppression of the norm. This is not to deny that fitness provides the kind of physiological and psychological benefits describe in the research literature. Instead the salient point is that medical science with its aura of pure knowledge established the rules of the game and the boundaries of the field of play where the fitness choices of study participants were made.

The designation of disability as an objective social fact has been contested for many years. There are many alternative views. Some of these views include a critique of the use of intellectual disability as an objective classification devoid of social, economic or political influence (Gilbert, 2003; Marks, 1999; Mawyer, 1995; Tremain, 2001). Put simply outside of socio-cultural context. Arising out of the disability rights movement in Britain in the 1960's, the social model of disability established the general principles of sociological theorizations that could contest the Medical Model.

5.7 The Social Model

To paraphrase Mills (1959) the proponents of the social model of disability applied the "sociological imagination" (p.5) to disability. They took the personal problem of disability and re-branded them as social issues. The reversing of the analysis of disability from the individual

to society promoted an understanding of disability as a product of social exclusion and the oppression of persons of difference. Early proponents of the social model of disability were primarily interested in physical impairment. Nonetheless the way the social model structured its critique of the exclusion of disabled people from the mainstream of society can be easily applied to the experience of people with intellectual disabilities.

One of the great strengths of the social model is its ability to coalesce groups behind a single cause. In this respect the model promoted a force for human rights based on identity politics. There are parallels between the ideological, political and social analysis of the disability rights movements with other emancipation agendas. The women's and gay rights' movements employ similar social action strategies as well as the sociological perspective that they are an oppressed minority (women in Canada are actually the majority). Shakespeare (2006) mapped out the essential components of social model thinking.

One key element he articulated was the separation between impairment and disability. In this way of thinking individuals are recognized as having impairments but it is the social response to these impairments that creates disablement. The personal tragedy implied by the medical model means that disability is the result of a personal deficit. It then behoves a caring society to offer prevention, cure and rehabilitation. The social model replaces this process with a call for civil rights as opposed to the largesse of institutional charity. The self-advocacy movement in BC reflects the social model's call for rights of citizenship and inclusion. The social model offers disabled people an opportunity to identify with others and join together for their collective betterment. This group identification process has had practical political outcomes. Identity of members shifts from a place of shame to a sense of strength in numbers that promoted social action and empowerment. Like feeling better after exercise that study

participants commented on, taking action with others can have a positive effect on self-esteem (Shakespeare, 2006). Whereas the individual model placed responsibility for change on the individual the Social Model places the "moral responsibility" (Shakespeare, 2006, p.199) on social institutions to change their policies and practices.

The community living movement has made great strides forward on behalf of its constituents and their families. However, the experience of study participants suggests that when it comes to fitness the emphasis remained on their individual actions rather than an interrogation of prohibitive social structures. This may be a legacy of the relationship between funding bodies, agency staff and individualized planning. Social agencies may ascribe to a social advocacy ideology but they must account for progress at the micro level.

The impact of the social model has been great. It has given rights groups a platform from which they may reach for more social justice collectively and gain empowerment individually. But, it also has its shortfalls. The strident claim of disability as an artefact of social oppression leaves little room for discussion of the very real problem of individual impairment. Other sociologically based theories have shown greater flexibility and are less ideologically dichotomous.

In the above cited paper, Shakespeare (2006) points out that the social model equates "disability with oppression" (p.201). This eliminates any theorization that grounds its conclusions on the voice of disabled people who say they are not oppressed. In this study most of the participants expressed a general state of calm if not outright joy at their living situations. None of them mentioned social oppression as a major factor in their health endeavours. The Discipline and Resistance Model demonstrated that some participants were pressured to participate in fitness but pressure tactics of caring helpers is far from the usual picture one might

conjure up of oppression. Admittedly, my own analysis and interpretation has painted the insidious nature of bio-power but this too seems more subtle and less corrosive than historical acts of violence against people with intellectual disabilities. In fact this evaluation mimics Foucault's (1978) notion that modern forms of govenmentality do not rely on traditional expressions of threat and violence characteristic of past forms of sovereignty. As Tremain argued (2006), this view of state power is what Foucault referred to as the "juridico-discursive" (p.186) idea of power as a possession of the state wielded to keep citizens in line. By contrast the disciplinary forces in the lives of study participants' were more subtle and the relationships between participants and caregivers more nuanced. Lemke (2000) has said that govenmentality allows for power to be exercised in such a way that empowerment can be achieved, albeit within a pre-cast field of play. A steadfast or rigid representation of disability as oppression would lose these insights.

The social model of disability has as its ultimate goal a barrier free world. But reality faced squarely suggests that individuals with degenerative diseases must be left out of that equation. No matter how ideal a world universal design could bring there remains people that will not be able to access all that their dreams might conjure. Here is where the fault line separates some of the people in this study and their fellows with degenerative mental impairments. Full citizenship in liberal society demands cognitive abilities that some types of impairment will preclude. All efforts should be made to assist people to reach their full potential. All possible sources of support should be provided but at the end of the day I find myself agreeing with Shakespeare (2006) who suggested that while moral responsibility for disablement rests with society, real people have real impairments that really hold them back.

Individuals find themselves confronted with intractable limitations. This need not be a

tragedy. In the broadest sense the experience of disability is likely to widen as the "baby boom"

generation ages. Despite sixty being the new forty, this aging population will also find

themselves encountering irreversible loss in physical and sometimes mental functioning. To this

end the restrictions of impairment may no longer be the purview of the disabled population

alone. How this will affect social attitudes toward disability remains to be seen. It may offer an

opportunity to re-frame the impairment/disability dichotomy.

One of the failings of the social model is its inability to consider the nuances and

complexity of interactions between individuals and their social environment (Shakespeare).

Liberation from social oppression cannot ensure the disappearance of impairment as a daily

experience for some people. A further short fall identified in the literature (Shakespeare, 2006) is

that the social model equates the struggles of people with disabilities with the same challenges

encountered by other minorities pursuing similar styles of identity politics (p.202). The problem

here is that removing social barriers may precede full citizenship for some minorities but it will

not eliminate the physical realities of impairment for some people with disabilities.

A major stumbling block to full acceptance of the social model in accounting for the

fitness choices of study participants is its lack of considerations specific to intellectual disability

and some of the social contingencies it presents. For example, Ryan and Thomas (1987) have

criticized the social model for its tendency to gloss over the needs of individuals in favour of

pursuing a political agenda. In the balance people with intellectual disabilities seem like an

afterthought. The social model does open up the possibility to discuss the interplay of macro and

micro social influences. It consequently fits with the social work principle of studying social

issues through a person-in-environment lens. As a result the social model produces a more

thoroughgoing theorization than the medical model offers. The social model can be applied to

the fitness choices of study participants in as much as it opened the door to an interrogation of macro social influences that the medical or individual model marginalizes. Application of the social model to this study can serve a theoretical link between the proximal social processes illustrated in the three models with the more distal social processes active in the socio-political environment. In short although imperfect in its applicability to the data produced by this study, the social model of disability has shed light on the path to follow.

A number of authors (e.g., Leiter, 2007; Schalock, Luckasson, Shogren et al, 2007; Siebers, 2006 & Wendell, 2006) have taken the position that intellectual disability, along with disability in general is a matter of social construction rather than physiology. I next review social constructionism as an appropriate theorization that accounts at a macro-level for the choices of fitness activity made by study participants.

5.8 The Social Constructionist Model

Social constructionism as an epistemological position arose in counterpoint to the positivist idea of an objective reality that correct methodology could uncover (Gergen, 1985). In advancing the constructionist case, Gergen (1985) argued that over time a number of social constructs such as: childhood, what constitutes self and the concept of romantic love have changed in meaning. This writer contended that it was not necessary for an object of study to transform in any way in order for research to demonstrate "historically contingent factors" (p. 267). The chronology of intellectual disability as a social designation shows the same features of historicy. This is the case in terms of the language used to define intellectual disability as well as what parts of the population various terms denote. As Schalock et al (2007) have argued, over the last two centuries the terms used to describe persons with intellectual disabilities have varied greatly.

Scepticism about the immutability of intellectual disability is inherent in an approach which sees social facts circumscribed by socio-cultural contingencies. Thus, the constructionist view troubles the secure world of objectivism. In a field such as physical fitness and intellectual disability this disbelief encourages researchers to ask if the literature is fully representative of the life experiences of people with intellectual disabilities. This is an important question to ask because as some authors have remarked (e.g., Carter, 2002; Pitetti, 2006; Prasher & Janicki, 2002; Rimmer & Yamaki, 2006; Stanish, Temple & Frey, 2006) there currently exists a scarcity of research that carries the voice of the subject population.

The constructionist model necessitates a focus on the social processes within which people come to understand and give meaning to their world. This is how the world is made.

Hole (2004) has identified that social constructionism has its origins in Symbolic Interactionist theory. Although constructionism has expanded the parameters of symbolic interactionism it remains in the constellation of theoretical positions that emphasize the relationship between individuals and the social environment they inhabit. Charmaz (2006) has established that constructionist theory also belongs to the interpretist sociological tradition.

The constructionist epistemology has imagined humans as active participants in creating and interpreting their lived world. This perspective is consistent with ontology of this study where firsthand experience is privileged. The literature review above demonstrated how little the thoughts and feelings of people with intellectual disabilities have been explored. The point is not to replace epidemiological or positivist based research but rather to offer a representation of the lived experience as described by people with intellectual disabilities in counterpoint.

The social constructionist frame invites researchers to place their findings within the larger social context while simultaneously respecting the voice of study participants. In this way

the constructionist ontology respects the capacities of study participants and the constructionist

epistemology troubles the certainty of intellectual disability as a social fact. Respecting the

capacity of people with intellectual disabilities has been suggested as a foundational belief of the

human rights perspective (Stainton, 2005). The emphasis of the constructionist methodology is

to represent the social processes that create meaning in the lives of study participants (Burr,

2003). It is just such subjective meaning that is in large measure absent in the fitness and

intellectual disability literature and thus the appeal of social constructionism as the preferred

theoretical model for this dissertation. This is a model that can unite endogenic and exogenic

principles. In short, this model imagines an individual with the capacity to reflect on their past

and present social environment and the agency to reposition themselves within a discourse where

they feel more credible even genuine. Constructionism can take into account the subjective inner

world of thoughts and beliefs that contribute to construction of the world in relationship with

others and at the same time place those interactive constructions inside the surrounding social

realities where social processes are the foundry for meaning and knowledge production (2003).

Consequently, the constructionist model is able to provide a more fulsome picture of how a

social problem is constructed and defined as well as describe the socio-cultural and temporal

nature of solutions.

Representing the social processes that affect people's behaviour is a major aspect of this

and other social constructionist research. To this end my analysis followed the words of study

participants' closely in a pattern that might be characterized as a co-creation. Here the individual

person interviewed has reflected on the interview questions and provided their perspective based

on their first hand experiences. Through this interactive process between the individual

participants and myself the data was formed. A second petition of constructionist epistemology

and ontology is to place findings in the "social, moral, political and economic institutions" in which they endure (Gergen, 1985, p.267-68). In summary, the social constructionist model best achieves the goal of responding to the thesis question: What social processes affect the fitness choices of people with intellectual disabilities? These social processes include micro relational processes of how fitness and disability are constructed by study participants in dialogue with their family, friends and care givers as well as the socio-cultural forces that define disability and construct its treatment in the larger social world. Finally, it is elemental to the constructionist model that the knowledge produced by this investigation remains localized to the study participants. This truth is provisional and situated.

Chapter 6: Discussion

A number of researchers have commented on the rarity of research studies on the fitness of people with intellectual disabilities that strongly carry the voice of people with intellectual disabilities (e.g. Carter, 2002; Pitetti, 2006; Prasher & Janicki, 2002; Stanish, Temple & Fry, 2006) or have connected those experiences to the social-relational context of the lived experience. The depth of first person data in this study is uncommon within the literature reviewed during the life of this research project. The themes explored in the findings section provide detailed and concrete examples of the lived experience as expressed by participants. Additionally, the three theoretical propositions modeled knit individual experiences into the fabric of participant's social networks and illustrate graphically the social processes involved. These features provide a unique adjunct to the current literature on physical fitness and intellectual disability. I have strengthened this contribution with a robust analysis of the socio-cultural context in which the action of the participants took place.

The *in-vivo* quotes presented in the findings opened up a window into the social processes that influenced the fitness choices of participants. From this data my interpretive insights have emerged. In this section I take a brief look at the eight themes developed from the data provided by participants and relate these themes to relevant literature as a way of adding texture to my own observations and interpretations. I start with self-esteem.

6.1 Gaining Self-esteem

Self-esteem is a complex psychological concept that is conceived as integrating a variety of self-perceptions. In this research, self-esteem encompassed concepts such as acceptance, a sense of competence/ achievement, self-perfection, and self-worth. Many of the participants in this study remarked on their improved sense of self- esteem as a result of their involvement in fitness pursuits. This coincides well with the variety of authors have argued that mental and

physical health is interconnected (e.g., Kavas, 2009; Musanti, 2012; Sonstroem & Morgan, 1989; Sonstroem, Harlow, Gemma & Osborne, 1991; Sowers, Rowe & Clay, 2009) have concluded that self-esteem can be altered through exercise. Our self-beliefs are significantly impacted by our interactions with others and how we perceive their evaluations of us (Crooks, 2001). Research has also shown that being accepted by our peers strongly affects how we see ourselves. Additionally, getting involved in a recreational fitness or sport activity has been seen as offering opportunities for positive peer interactions. (Kavas, 2009; Daniels & Leaper 2006).

Furthermore, positive peer interactions in a new fitness activity contributed to some participants reassessing their competence in this sphere. For participants who gained a new social environment, negative memories of failure were replaced over time with a new assessment of capability in the physical realm. This new attitude helped to set in motion a cycle of engagement in a fitness activity, peer support, and re-engagement when new opportunities become available. In this way positive response to fitness opportunities can be seen as resulting from a reinforcing cycle of affirmative social interactions and consequent positive self-evaluation.

Person E told a story of childhood rejection because she could not perform as well as her peers in school fitness activities. This negative experience in her youth coloured interest in fitness activities for much of her life. She felt incompetent in this sphere. However through the support of a staff person, she did become involved in a therapeutic swimming program. The welcoming atmosphere she encountered in this program convinced her to continue which in turn had a favorable impact on her self-perception. She developed a renewed outlook on physical activity. Research in this area has reported similar mechanisms for improvement in self-perception (Daniels & Leaper, 2006; Li, Harmer, Chaumeton, Duncan & Duncan, 2002;

Opdenacker, Delecluse & Boen, 2009). These theorists proposed that sport participation likely contributes to "global feelings of self esteem" (p. 779).

The welcoming and supportive semi-independent living environment that Person E had recently moved into contributed to her feeling more positive about herself and her abilities. Her negative view of fitness activities had been established by humiliation at the hands of other children. The respect and support she received in her new social environment was reversing this effect. This idea of the importance of the way others responded to Person E was echoed by other participants as a reason for them feeling more comfortable with themselves and thus with trying a new activity. Certainly it is well considered that people are all social animals (Lutz, Linder, & Greenwood, 2011), and the reception we get from others is central to our perceptions of ourselves and perhaps more broadly our sense of social inclusion. As Saari (2005) argued it is through our interactions with other people that we construct the world and place ourselves within it. Echevarria-Doan, Koro-Ljugberg and Puig (2008) have argued that our sense of who and what we are is effected by the social context of our experiences and the past. The finding of this dissertation supports the argument that early experience of failure at physical fitness by participants coloured their adult expectations of personal competency in the physical arena. I would argue that the successes and failures experienced in childhood form the personal histories we carry internally. These histories are often reflected in overt behaviour later in life.

Schneller & Vandsburger (2008) have enumerated self-efficacy as one aspect of self-esteem that helps maintain impetus to pursue fitness (2008). This idea was also reflected in participants' statements. A cross-participant comparison of the data included under the Sense of Competence code revealed that a number of participants reflected how their engagement in exercise and fitness activities had favourably impacted their sense of self-efficacy.

Maslow's motivational theory places self-esteem as a higher order need. In his hierarchy of needs structure, Maslow numbers among the attributes of self-esteem such things as strength, achievement, and confidence (Learning Theories Knowledgebase, 2011), all of which were expressed as fitness outcomes by participants in this study. It might be that in the case of study participants, once they had secured the necessities of life they were in a position to satisfy what Maslow has described as higher order needs. Fitness activities offered study participants one avenue to pursue these higher order needs.

Another aspect of the more comprehensive concept of self-esteem is a sense of self-worth. In this study, feelings of improved self-worth were regularly expressed by participants in association with positive reinforcement from peers or teammates. These, or similar sentiments, were reflected in the comments of 14 participants. In my mind these comments while they must be accepted as true and accurate in the minds of study participants can be held up for sociological analysis. Using this perspective I was moved to consider how participants placed fatness and fitness on different ends of a moral continuum. They were mindful of where they fit on this scale in comparison to an imagined perhaps ideal model.

Conrad (1994) offers an explication of the construction of health and wellness as a moral choice. Put simply, he argued that fitness has been designed in health discourse as the responsibility of citizens to choose well-being over disease by altering their lifestyles. He accorded the fear of loss of "vitality in modern society" (p.386) as a driving force in the social quest for human perfectibility. Disabled bodies, and in this case the disabled minds that operate them, are faulty because they deviate from the norm. Much of the research cited in this dissertation (e.g., Beange, Lennox & Parmenter,1999; Hensel,Rose,Kroese & Banks-Smith, 2002; Jobling & Cuskelly, 2006;Pitetti,2006; Rimmer, 1994; Rimmer&Yamaki,2006; Stanish,

Temple & Frey,2006; Temple,2007) has established that people with intellectual disabilities are one group that performs at a sub-par level. As optimum health is understood as a cardinal social value it falls naturally that every effort should be made to eradicate discrepancies. As a society we are duty bound to provide help. The moral tinge to this argument is remarkably reminiscent of the moral and genetic hygiene beliefs tied to the eugenic movement that rationalized the settling of the feeble minded in secure isolation outside the regular community of human activity. However, within the medical paradigm the problem of ill health is located in the individual's body (e.g., Rioux, 1994; Woodhams and Corby, 2003) and in parallel the solution lays in remediating the individual. Rather than social isolation, today's efforts are aimed at integrating the practices of the disability community into the social fabric of abelism.

The suggestion in participants' comments that exercise or fitness participation contributed to their positive self-esteem is supported by resent research (e.g., Biddle & Wang, 2003; Daniels & Leaper, 2006; Opdenacker, Delecluse & Boen, 2009; Ozsaker, Dorak &Vurgun, 2012). Furthermore, the positive effect of exercise on general mental health is well-established (Huang, Lee & Chang, 2007). Comments of participants in Conrad's (1994) study were very similar to comments recorded in my interviews. People regularly said that becoming fit "made me feel good" and "made me feel better about myself" (p.391). And when referring to their pre-fit selves they reported feeling "lazy, sluggish" (p.391) and so on. It would seem odd in the extreme if persons with intellectual disabilities participating in this study were immune to such effects. The data reflected that these recollections of positive feedback and concomitant improved self-evaluation helped to solidify the participants' interest and engagement in other fitness opportunities.

Being overweight was one issue that some of the participants seemed to struggle with. Weight management showed up as a theme for both women and men. Again the proper physical form for men and women were gauged against cultural ideals. Mahalik, Burns and Syzdek (2007) have suggested that normative standards of masculinity have an impact on men's attitudes towards health practices and behaviour; others (John & Ebbeck, 2008) have contributed research on gender differentiated body awareness and fitness involvement. And Dailey, Richards and Como (2010) have explored how significant others affect our thoughts and actions regarding weight management. Aubrey (2010) has described how the objectification of women's bodies affects their self-image and is embedded in health advice discourse. Gender differentials in health/ health risk activities are a vast field of knowledge. The debate on similarities and differences is far-reaching and far too diversified and extensive to review here. Perhaps it is sufficient for my present discussion to recognize that these differences are culturally prescribed and socially constructed leaving analysis of the academic discourse to another time.

The anxiety about losing weight and keeping it off expressed by study participants reflects current cultural concern with obesity and its health related liabilities. Large portions of the world's population face starvation on a daily basis. In stark contrast   North Americans and European populations are troubled by with has been dubbed an "obesity epidemic" (Gard, 2010). The public health and population health approach has linked carrying too much weight with tragic outcomes such as diabetes, congestive heart failure and other diseases (e.g., Ebbing, Pawlak & Ludwig,2002; Fabricatore & Wadden,2006; Klein,2004 ; Lobstein,& Millstone,2007) These concerns are well represented in the research on physical fitness and intellectual disability captured in the literature review of Chapter 2. Despite the World Health Organization's (WHO)

endorsement of the objective reality of a crisis of obesity, (Brandon and Prichard, 2011) some authors (e.g.Gard, 2011; Moffat, 2010&; Rich, 2011) continue to contest this notion.

Gard (2011) has identified the field of epidemiology as the academic discipline that first brought this issue into public discourse. The public and academic debate on the nature and extent of obesity can be recognized as the latest version of a dialogue on human health and the body that emerged as a preoccupation of medical and health practitioners at the turn of the twentieth century. Gard has characterized the debate as a dichotomy. The debate over the extent and consequence of being fat he has suggested can be represented (nuances aside *sic*) as two camps struggling for dominance in the academic and public discourse. One camp he represents as "alarmists" (p.37) and the other as "sceptics" (p.37). He describes the alarmist side as fronted by public health officials. The literature reviewed for this dissertation can be regarded as resident under the alarmist banner. On the sceptic side Gard lists: "feminists, queer theorists, and libertarians" (p.38) and himself. He argued that most of the academic work on this topic is a mixed bag of personal belief and contradictory social science.

The epidemiological position of the alarmist camp is prevalent in public health campaigns spearheaded by medical professionals (Moffat, 2010). This perspective looks to the individual and the family as the units of change. ActNowBC is an exemplar of such campaigns. This program can also be seen as well aligned with neoliberal individualism as it offers British Columbians advice on : "22 ways to feel good inside" and "24 ways to turn over a new leaf"(ActNowBC http://www.**actnowbc.ca**). Like neoliberal social philosophy, ActNowBC embraces a cult of "personal culpability" (Gard, p.39). The thrust of this approach is that individuals make poor or uneducated fitness and health choices and are therefore culpable in their poor health status and consequently responsible for taking appropriate remedial action. Eat

right and exercise. For their part the sceptics distrust the veracity of alarmist science and negate pronouncements of a looming health disaster. The sceptics argue that the medical professionals are on a mission of "re-engineering people's everyday lives" (p. 40). This position is suggestive of a Foucauldian analysis of governmentality and "technologies of normalization" (Tremain, 2006, p 186) through which the obese population can be separated from the population as a whole and subjected to special disciplinary attention. Through the mechanism of bio-power the bodies of fat people can be "transformed and improved" (p. 193).

Constructionist writers (e.g. Gard,2011; Moffat,2010; Rich,2011) have proposed that responsibility for obesity has to take into account that multinational fast food corporations make a great deal of profit from poor eating habits of North Americans and consequently focus needs to be jimmied away from the individual towards structural elements in the capitalist market place (Gard, 2011). Conversely, the Fraser Institute a neoliberal think tank centered in BC denies that fat people are victims of fast food capitalism. This organization puts the responsibility firmly back on the shoulders of individuals. They state"...overweight and obese people are a burden on society" (Gard, p. 42). The conclusion drawn by Gard is that the debate over the obesity crisis remains a problematic fuelled by a combination of "moral, ideological and theoretical motivations" (p.46). Moffat (2010) takes the position that the "truth" of growing obesity is not necessarily challenged by critiques of how the issue has been socially constructed. She suggests that biomedical and social constructionist paradigms tend to focus on different solutions. The biomedical model focuses primarily although not exclusively, on individual lifestyle changes whereas the social constructionists direct their critique at social, economic and environmental structures which contribute to the problem. Academic debate aside, it was clear from our conversations that the concern with being overweight had entered the vocabulary of study

participants. The preoccupation with weight management expressed by some study participants is a good indicator that they were not immune to this topic as part of current health and popular culture discourse. The next theme that emerged from the data was Childhood Experiences

6.2 Remembering Childhood

The lifelong impact of early childhood experiences is well established in the child development literature. For example, the impact of childhood trauma has been shown to impede the functions of adult mental health (Coates, 2010). Perhaps more directly relevant to this topic, others (e.g., Del Castillo, Navarro, Sanz et al., 2010) have identified early physical fitness activity to be a precedent often copied in adult life.

Body Mass Index is one standard measure of fitness used in the positivist oriented research (e.g. Rimmer & Yamaki, 2006). In reference to people with Down's syndrome, researchers (Moffat, 2010; Lobstein &Millstone, 2007; Rimmer & Yamaki, 2006) have identified that the support of friends and family can have an effect on their Body Mass Index (BMI). A social-cognitive perspective predicts that fitness behaviour may be shaped in part by past experience (Heller, Hsieh, & Rimmer, 2002). Although my approach has maintained a social constructionist perspective, I have concluded that in a similar way the childhood experience of study participants has had a significant impact on their adult fitness choices. Recent research by Castillo and his associates (2010) provided a short summary of the effect of childhood experiences on adult fitness choices. For example, Castillo et al. reported that "Significant relationships were found between the type of physical activity participation (in youth *sic*) and: being physically active at earlier life stages." (p. 1097).

Families of origin can play a significant role in introducing children to recreation and fitness activities. This was the experience of many of the study participants. For participants in

the present study who grew up in foster care the attitude and beliefs of care givers was significant. Having a caregiver that is interested in fitness or promotes fitness for the young people in their care can be very important. Some of the study participants reported their caregivers going to extraordinary lengths to ensure they had opportunities for fitness participation. These individual caregivers may be an exception to the rule established in the literature which suggests many care givers are not aware of the barriers to fitness that people with intellectual disabilities face (Heller, Hsieh & Rimmer, 2002).

6.3 Remembering School

School experience may be viewed as a kind of sub-section of overall childhood experiences. Sadly, some of the participants reported quite negative and isolating experiences due to their difficulties in keeping abreast of the fitness capacities of their peers. This isolation from peers can have long-term effects. Nakhaie & Arnold (2010) have suggested that sport participation forms a kind of bridge to social bonding that contributes to social capital. As a consequence of missing out on team sports participation individuals miss much of the social interaction and problem solving lessons that accompany such group experience (Greenleaf, Boyer & Petrie, 2009). These are missed lessons that could lay the foundation for social problem solving ability in adult life. Fortunately, some of the participants reported that they were able to re-evaluate the meaning of fitness once they met people who were supportive or encouraging. This capacity for older people with poor fitness histories to be re-socialized has been observed in other studies (e.g., Del Castillo, Navarro, Sanz et al., 2010). Re-socialization in this context may be seen as beneficial; yet, taking personal responsibility for your health and fitness may also take on more draconian nuances.

Lindsey (2010) advanced the opinion that modern beliefs about individual responsibility puts "a profound burden" (p. 482) on people to adhere to regimes of self management and maintain important social relationships. When in operation this two-pronged pressure may have contributed to the impact of changing social milieu on participants' behaviour. In particular, the pressure to achieve self-management of health through diet and exercise knits neatly with current public health initiatives which extol personal discipline (Lindsey, 2010). This social process by which public health discourse is carried to people with intellectual disability through the actions of caregivers and support workers can be equated to Foucault's notion of governmentality where the disciplining of errant populations takes place at arm's length from government. Over time support persons nurtured in their clients an ethic of self-care. Relationships of trust form the conduit to socially approved behaviour. Additionally, where self-management can be seen to have supplanted collective social responsibility for citizen's health, the neoliberal social project is in action. Shea and Beausoleil (2012) commented that health and fitness in our society has gone beyond what any one individual may desire for him/herself. This team of researchers have coined the term "healthism" (p.97) to reflect the public discourses that present self-care as a duty of citizenship. This nod to the morality of self-work was an undercurrent in the presentation of many of the research participants.

6.4 Body Memory

The concept of body memory arose out of my observations of some of the study participants. Certain of these individuals seemed to be getting more excited and animated during their remembrances of fitness activities in the recent past or in anticipation of future sports involvement. My personal experience and brief research on the topic of "runner's high" and associated states is documented above. It is such a new area of scientific research that there is

little more analysis to be added here. I have not found reference to this effect in any of the literature I reviewed for this dissertation.

6.5 Family Influence

Perhaps unsurprisingly family relationships influenced the fitness choices of all the participants. Where individuals lacked family long term caregivers fulfilled that role. For the most part family/caregivers acted benignly service what they felt were the participant's best interests. Nonetheless, a more in depth analysis of the meaning and purpose of these micro level interchanges can be instructive. This analysis provides the view that the family is not an entity insulated from greater social processes but in fact is a micro setting where macro forces are at work.

Using the Foucauldian perspective my analysis included that familial influence shared in this way suggests that these interactions between parent and child are not haphazard interchanges but rather directed at the goal of encouraging the child's independence. Gilbert (2003) has applied a Foucauldian analysis to illustrate the connection between everyday practices, the individual and the state. Applying the same kind of analysis to the familial interchanges in the data, I contend that the encouragement of family members stands as an example of where power is not always a coercive or oppressive. In this and other examples, this advice is given in the presumed best interests of the child. Nonetheless, it does not escape carrying a touch of the ethic of self care required of modern citizenship. Gilbert (2003) informs us that "[g] Governmentality also means: a focus on the particular forms of knowledge and practices drawn upon in health and welfare dynamics of the association between individuals, families, local communities and the state" (p. 38).

Often times the participants had accepted parental beliefs that fitness was a "good thing" as compared to sedentary activities such as sitting at the computer which was seen as a "bad thing". This dichotomizing of behaviour into good and bad practices is well explored by Conrad (1994). Conrad (1994) suggested that in the postmodern world the pursuit of health and wellness has replaced religious notions of moral turpitude. This suggestion is relevant to the study participants inasmuch as they too were subject to the flow of public health and fitness discourse, not to mention the plethora of fitness industry merchandising in popular culture. Upon reflection, it is easy to understand how people who have experienced stigma and social exclusion such as reported by some study participants, would find great appeal in joining the ranks of the morally correct by attending to their own fitness. The appeal of social acceptance could provide the leverage needed to "inspire" individuals to get active.

Gagnon, Jacob and Holmes (2010) as well as Clarke (2005) have recommended situational analysis as an adjunct to grounded theory research. These researchers explain that the mapping techniques of situational analysis involved may be used to uncover the links between current discourse and the social context in which agency is enacted. They contend that risks to health implied in public health campaigns act to force individuals to take up prescribed health practice norms. As a follower of Charmaz's model of constructionist grounded theory, I have not pursued the situational model preferring instead to situate my findings in the social processes that are the focus of the constructionist paradigm. As a result my theoretical propositions are designed to capture the relational aspects of participant's fitness choices. My social context analysis links the data to the macro social processes at play. Gagnon et al. (2010) have highlighted how risk and fear of illness and disease are conjured up in government sponsored discourse as a way to "manipulate people into becoming calculating, rational and self interested

subjects (p. 249).   Moffat (2010) has noted that an epidemic of obesity has proven an

opportunity for capitalist exploitation as well as "stigmatization of women, ethnic minorities and

those of low socioeconomic status" (p.2). Likewise, an air of knowledge and expertise held by

medical practitioners lends credibility and legitimacy to public policy discourses and thus fuels

the rush to uptake healthful norms in everyday life (Gagnon et al, 2010).

Much of the discourse of intellectual disability and physical fitness relies on the

expertise of medical practitioners to diagnose and human service practitioners to remediate the

unhealthy lifestyle of this at risk population. Expert opinion dominates the knowledge

production on this topic and has entered into the discursive environment in which commonsense

opinion is formed. Advice on the proper way to self-manage health through exercise is one type

of communication that comes under the influence of this discourse. Parents and other family

members cannot be seen as acting in a cultural vacuum, nor were the study participants. In this

regard, the impact of socio-cultural realities must be factored into the interchanges and

communication that forms their relationships.

6.6 Having Friends

Sharing fitness activities with friends was another theme that dominated the data and is

also deemed important in the fitness literature. Networks of social support are important as they

have a strong correlation with feelings of self-efficacy, which in turn aid the maintenance of

health related regimes (Schneller & Vandsburger, 2008;Stanish,Temple & frey,2006;Temple &

Walkley,2007). Similar findings on the importance of social connectedness to emotional well-

being have been reported by other researches (e.g., Lutz & Greenwood). People in the study

who had experienced the pleasantness of peer interaction in the past may have anticipated similar

feelings when contemplating involvement in a sport or recreational activity. Social

connectedness has been identified as one element in a sense of satisfaction with life in general (Lutz & Greenwood, 2011).   From a distant paradigm, evolutionary psychologists have speculated the early human survival depended on an innate desire for group affiliation (Stevens and Fiske, 1995).

Nakhaie and Arnold (2010) use the term social capital to describe human connections that are earmarked by, among other concepts, "norms of trust and reciprocity" (p.1037). The term "social capital" may be odious to some theorists because of its implied marketization of interpersonal relationships. That said social capital still ranks as a general predictor of overall health and well-being. The benefits of social capital include emotional support, which in turn has been linked with mental and physical health (Sowers, Rowe, & Clay, 2009). Other writers (e.g., Laursen & Hatrup, 2002; Vaquera & Kao, 2008; Vernberg, 1990) have investigated the nature of reciprocity in the production of valued relationships Verberg (1990) for one, has argued that forming positive relationships in youth are a good predictor of later life adjustment. Although the term "adjustment" might be troubled, Verberg's argument does underline the importance of social inclusion for people with intellectual disabilities. The data provided by study participants demonstrates how such early experiences affected later interest in health promoting fitness activities. Perhaps more directly relevant to this study, Sowers, Rowe and Clay (2009) predicted that positive inter-personal relationships in fitness activities reinforces adherence to health promoting behaviour. This being the case, friend making or its lack, had likely acted as a significant influence on the fitness involvement of study participants.

6.7 Professional Support

Professional (paid) staff played a major role in the fitness activities of study participants. There are some research projects in the literature which outline the impact professional human

service workers can have on the lives of people with intellectual disabilities. For example, Heller, Hsieh and Rimmer (2003) identified that the beliefs of caregivers can impact efforts to engage people with intellectual disabilities in exercise activities. Essentially, if professional support workers think that their clients will benefit physically or mentally from exercise, they are more likely to facilitate access. But not all support personnel are created equal. In the Heller, Hsieh and Rimmer (2003) study, only 50% of caregivers thought people with intellectual disabilities would benefit from a fitness program and less than 40% thought that there would be any positive outcome from fitness involvement. A great deal of current literature (e.g., Ciairano, Liubicich & Rabagiletti, 2010; Greenleaf, Boyer & Petrie, 2009; Huang, Lee & Chang, 2007) on the effects of exercise for people with intellectual disabilities stands in stark contrast to these beliefs. This discrepancy between common understanding of care providers and research findings highlights the need for better knowledge sharing between the academic and practice worlds.

The discourse of intellectual disability calls upon the expertise of medical and human service practitioners to diagnose and remediate the unhealthy life style of this wayward at risk population. However, parents, family member's friends and professional helpers cannot be seen as acting in a cultural vacuum, nor were the study participants. In this regard the impact of socio-cultural realities must be factored into the interchanges and communication that forms their relationship.

In the current study, the data clearly presented the influence of family, friends and professionals in supporting the participants to become engaged in fitness activities. Sometimes, however, the attempts of these three parties were met with resistance. This resistance is documented in the thematic findings above. When inducements failed to get participants

involved in desirable activities discussion of these activities became a site of conflict. This tension was evident in some of the interviews I conducted with study participants. Drawing on Foucauldian ideas of power in relationships, I coded these types of interactions as discipline and resistance.

6.8 Discipline and Resistance

"[M]micro-politics" (Gilbert, 2002, p. 38) of client- counsellor relationships can serve the processes of governmentality. The benefits of fitness have overwhelming support in the literature (e.g., Beange, Lennox & Parmenter, 1999; Bonhauser, Fernandez, Puschel, Yanez, Montero, Thompson & Coronado, 2005; Stanish, Temple & Frey, 2006; Temple, 2007). The effort of professionals to get people with intellectual disabilities to exercise shows an understanding of these benefits. However, a deeper analysis shows that the everyday practices of support agency personnel also serve a more distal purpose. That purpose has to do with the governmentality of disabled people (Tremain, 2001). The moral authority afforded professional knowledge gives social work practitioners credibility as advisers on proper health practice. The findings of the present study demonstrate how the ethic of self-care operated as a core technique of governmentality (Gilbert, 2002) that was promoted through therapeutic relationships.

Lindsay (2010) has described the self-management of the body as an expectation of governments in all the wealthy countries of the world. In this perspective, being healthy is a simple matter of putting well-established principles of health into daily practice. These practices are seen as the appropriate response of any rational individual. The unit of change targeted by public health initiatives remains the individual. The principles of good health are privileged as the best knowledge of experts drawn from sound scientific research. By implication, to ignore these principles is a rejection of rationality. Conversely, accepting and implementing well-

documented principles of health is a signal of responsible behaviour. As Lindsay argued, "self-surveillance" (p. 477) is the only appropriate response when a rational individual perceives risk in non-compliant behaviour. Social structural issues that may impact health practices are absent from this equation, and, the social determinants of health are also largely forgotten. This places responsibility for action on the shoulders of people with intellectual disabilities their families and others who care for them. Lemke (2000) described this shift from social issue to personal problem as a strategy of governmentality evident in neoliberal regimes. In this vein, people are supposed to make a personal risk assessment and assess the costs and benefits of specific patterns of behaviour. Given that the weight of research has established the importance of eating right and exercising; not following this prescription seems perverse. Put sharply, rational people make rational choices and as a consequence ill health can be attributed to poor decision making.

Unfortunately, the best advice of health experts has not been uniformly taken up. Some citizens do not conform thereby thwarting efforts to instil health discipline across society. Marginalized groups remain hard to reach and in some cases resist implementing such simple yet profound advice. People with intellectual disabilities are just such a population.

The physical fitness of persons with intellectual disabilities has been for sometime a topic of interest to academics (e.g., Fernhall et al, 1996; Horwitz, Kerker, Owens, & Zigler, 2000 Jobling & Cuskelly, 2006; Rimmer, 1994; Rimmer, Heller, Wang, & Valerio, 2004; Stanish, Temple, & Frey, 2006). Reports issued by the B.C. Ministry of Health Planning, such as the one prepared by Colman and Walker (2004), are a strong indicator of how important health and fitness are to government. Tremain (2006) identified bio-power or bio-politics as terms that best describes the growing concern governments have in controlling the health and well-being of particular populations. Bercovitz, (2000) has pointed out that Canadian health authorities have

recently added to their agendas the involvement of "sedentary and hard to reach" (p.19) populations in health improvement activities. Bercovitz (2000) further contended that the spiralling costs of public health care were the major factor driving new public policy initiatives. As a consequence, the poor fitness levels attributed to marginalized groups has come under closer scrutiny. This same author (Bercovitz) argued that targeting specific populations represents a state mechanism whereby government can promote individual reasonability and "self-surveillance" (p.30) and thus reduce health care costs. Accordingly, she argued that such initiatives stand as an illustration of Foucault's notion of the "self directed panoptic gaze" (p.30). Public health campaigns act as an arm of governance when they reinforce an ethic of self-care and remain mute on social equity issues that impact health behaviour. Public health discourse is the discourse of experts whose superior knowledge establishes norms of health practice that are to be implemented through individual actions in ever day life (Gagnon, Jacob & Holmes, 2010).

In British Columbia (BC), the concern of government to target the intellectual disability community for specialized service is manifest through the mandating of the crown agency Community Living British Columbia (CLBC) by the Community Living Authority Act (SBC, 2004). This Act directs CLBC to provide support and services to the intellectual disability population. CLBC in turn contracts with numerous support agencies to provide direct services to this population. This legislative mandate defines the parameters in which persons with intellectual disabilities, their families, caregivers, and support staff operate. From a Foucauldian perspective, these services rendered on behalf of government are the means by which the unruly body of persons with intellectual disabilities may be rendered "docile," transformed, and improved (Tremain, 2006). Within a Foucauldian framework, fitness activities can be seen to play a role in achieving the governmentality of people with intellectual disabilities.

Chapter 7: Summary

In this chapter I begin by reviewing the study and dissertation. I will then briefly summarize the major themes that emerged from the data and provide review of the theoretical propositions presented in Chapter 5. I next comment on the link between the data as recorded and larger theorizations. Finally, I note the limitations of the study and finish with some recommendations.

The principle reason for this study was to uncover what social processes affect the fitness choices of people with intellectual disabilities. The consensus of opinion in the field of intellectual disability and physical fitness is that people with intellectual disabilities are the least fit of our citizens (e.g., Fernhall et al., 1996; Horwitz, Kerker, Owens, & Zigler, 2000; Lotan,Yalon-Chamovitz & Weiss,2009; Lin,Lin,Lin,Chang,Wu & Wu,2010; Rimmer, 1994; Rimmer, Heller, Wang, & Valerio, 2004; Stanish, Temple, & Frey, 2006;Salaun & Berthouze-Aranda,2012). This appears to be the case across the much of the western world (Coyle, Kinney, Riley & Shank, 199; D'Eath, Walls, Hodgins, & Cronin, 2006; Fernhall et al., 1996; Krahn & Drum, 2007; Heller & Rimmer 1998-2003; Rimmer, Heller, Wang, & Valerio, 2004; Repp & Karsh 1999; Rimmer, 1994). Much of the research in this field takes a positivist epistemology in theorizing intellectual disability from the medical paradigm. Equally dominant is the epidemiological approach that is evident in population health and national fitness projects (Davis, 2006). These health discourses set the stage for the totalizing effect of the intellectual disability designation imposes on the lives of people with intellectual disabilities including those referenced in this dissertation. This effect means that all aspects of the individual's life are viewed from the perspective of disability.

The fitness of people with intellectual disabilities is measured against the standard of a "typical" able bodied/able minded individual. Much of the literature expresses an urgency to

have people with intellectual disabilities perform in the "normal" range of physical ability. Within this paradigm fitness is proposed to have a normalizing effect on one aspect of the life of the disabled person. The literature is replete with the awards and benefits that achieving fitness will bestow (Beange, Lennox & Parmenter, 1999; Bonhauser, Fernandez, Puschel, Yanez, Montero, Thompson & Coronado, 2005; Stanish, Temple & Frey, 2006; Temple, 2007). These benefits seem irrefutable. Consequently, a rational free choosing individual in possession of this knowledge ought to be propelled towards a life of self- management that includes regular exercise. Yet, the literature attests that for people with intellectual disabilities this very worthy goal has not been achieved. Why this remains the case is divined to rest, for the most part, within the failings of the individual.

With few exceptions (e.g. Stanish, Temple, & Frey, 2006), contextual and relational influences on fitness behaviour are poorly represented in the literature. Authors such as Carroll, Adkins, Forth, Parker & Jamali (2008) have argued that lack of qualitative research contributes to a vacuum of theory development that connects health related behaviour and the social context of individuals. This thought might partially explain why the fitness behaviour of people with intellectual disabilities has not been fully understood. Stanish, Temple & Fry (2006) suggested that the field lacked studies that can situate the fitness behaviour of people with intellectual disabilities within the relational and social context of their lived experience. In short, examples of studies that have visited the lived experience of people with intellectual disabilities are the exception. Through the qualitative methodology of a constructionist grounded theory this study gathered data from individuals with an intellectual disability and draws its conclusions from that data. The qualitative approach of grounded theory allowed for an exploration of the firsthand experiences of people with intellectual disabilities depicting the social context in which they live

and make their decisions about fitness activities. The findings reflect the firsthand experience of people with intellectual disabilities who were study participants. The comments of study participants in reference to the study questions opened up a window into their world from which interpretive insight might flow. It was my responsibility to preserve these thoughts and extend them through my own analysis. Through this process we conjointly completed the research project.

The data was gathered through face-to-face interviews with twenty-six persons with intellectual disabilities. Throughout these dialogues the participants responded to a set of eleven predetermined questions. The findings above illustrate how the questions often opened the door for participants to tell stories about their past and current lives. The content of individual responses often bled into the next response or made reference to a previous comment. In this way, the participants wove their fitness experiences through the detail of their lives with friends, family or caregivers. This demonstrated that the fitness of participants was not a discrete activity but rather took place within the context of their life experiences and relationships.

Study participants described how memories of childhood and school experiences contributed to their beliefs about themselves and impacted their beliefs about fitness. Some of the participants talked about how gaining a new place to live or making a new set of friends impacted their attitudes toward physical fitness and impelled them to become more active. During some of the interviews participants described conflict and struggle they experienced with parents or support persons who tried to cajole them into more healthful lifestyles. The conflict described lent itself to a Foucauldian analysis of discipline and resistance. What was most evident from the comments of participants was the pleasure they obtained from participating with loved ones in any type of activity. In this regard the data fails to uphold the ability/disability

dichotomy. The enjoyment and reward of the comradeship of friends and family must surely pass as a universal experience.

Data analysis yielded three major categories of action: social support, later life engagement, and discipline and resistance. These three categories were used as the focal point of theoretical models presented in Chapter 5. The models capture three patterns or social process that determined the nature and extent that participants engaged in fitness or exercise activities. The three theoretical propositions (Charmaz, 2006) describe the proximal relationships that impacted the fitness choices of study participants. As a consequence, the three models respond in part to the thesis question posed at the front of this dissertation. A further level of analysis was subsequently presented that contextualized the data embedded findings.

The Social Support Model was representative of the social process followed by most of the study participants. The essence of this theoretical proposition model is that positive early life experiences combined with social support from important others was the foundation for adult interest in physical fitness activities. One wheel in the social support cycle referred to memories the participants described in our conversations. For better or worse, these remembrances coloured participants' view of exercise and fitness, and of themselves. Those with positive childhood or school experiences with sport participation were most likely to be active as adults. Participants with negative or nonexistent fitness histories often were uninterested in exercise until they developed new relationships with friends or caregivers who encouraged an active lifestyle.

One aspect of memory at work in a few of the participants was what I have termed "body memory". I have likened body memory to "runner's high" an effect described by long distance runners. I applied the term body memory when I observed some of the participants exhibit an

enlivened physical attitude when recounting their sports involvement or anticipating future involvement. Investigating this concept is beyond the scope of this study and my expertise but nonetheless it remains an area of interest. The impact of body memory on the fitness choices of people with intellectual disabilities was not reported in any of the literature reviewed for this dissertation.

The Later Life Engagement Model captured the experience of some of the participants. These individuals had a negative view of exercise until they gained a new social environment where fitness was encouraged and rewarded. The Discipline and Resistance Model reflected a Foucauldian perspective, accounting for the social process described by participants who resisted pressure to adopt a more healthful lifestyle.

Combined, these three models account for the proximal social processes that engaged all of the participants in physical fitness activities. These are the day-to-day influences study participants felt and the everyday relationships they negotiated. Each of these models starts with the individual; this is not the atomized individual imagined in positivist/realist epistemology. Instead, it is a relational individual sometimes a child sometimes an adult who we glimpse through the data navigating themselves through the matrix of life experiences and the relationships engendered. This passage takes place within a larger matrix of socio-political and cultural influences. It is part of the constructionist grounded theory enterprise to insert the formulas of everyday life into the entirety of the human condition. This is a big task.

Neoliberalism is the dominant force in current social, political and economic philosophy and social service policy in the western world (Cook, 2012; Dowse, 2009; Harvey, 2005; McGregor, 2001). I have chosen to set the everyday lives as explored in the data inside this sphere. I have done so because of the demonstrated impact this force has had on human service

funding which directly affects the opportunities of people with intellectual disabilities in general and study participants in particular. The tenets of neoliberalism support an atomized, individualized notion of citizenship. This notion blends well with the medical model of disability that places emphasis on remediation of individual behaviours and ignores cultural practice.

Throughout the dissertation I have drawn heavily on the work of Michel Foucault. This work offers a sturdy platform from which to view daily practices as they march in lock step with dominant social discourses. From this perspective "technologies of normalization" (Tremain,2006) act as an aid to governmentality when dominant theories of human nature pass as common sense in daily practice This is bio-power realized.

How individuals form or reform their sense of self is a contested area of psychological study. The data gathered in this study points out that some of the participants changed their sense of self as a result of time spent in the cycle of social support captured in the Social Support Model. Others had their sense of what they were in relation to fitness altered by new social circumstances. All the participants were adults (age 19+ in British Columbia); consequently, the findings of the present study support the constructionist view of self as fluid (Hole, 2004; Moffatt & Miehls, 2008; Roy-Chowdhury, 2010; Saari, 2005) rather than static: not a destination but a journey. The data serve to support a constructionist notion of a malleable, contextualized and relational self. Recent constructionist research concurs with this position (e.g., Carroll, J., Adkins, B., Foth, M., Parker, E., & Jamali, S., 2008; Puig, Koro- Jungberg &Echevarria-Doan, 2008; Roy-Chodhury, 2010). The sense of self of study participants was amenable to change. However, individuals do respond uniquely to health advice. Change for some study participants meant an ongoing battle waged within themselves and between themselves and disciplinary forces in their social networks.

The first theme discussed was gaining self-esteem. Self-esteem is a multifaceted mental complex that captures a variety of internal thoughts and feelings about self. Self-esteem is responsive to the appraisal of others (Crooks, 2001; Leonard & Schmitt, 1987; Saari, 2008). Study participants who moved toward a fitter lifestyle were appraised favorably by friends, family and support staff. However these appraisals do not occur within a social vacuum. These important others are also subject to health discourses as well as discourses of fitness in popular culture. As argued by Hole (2004), these discourses are dominated by reference to able bodied/minded norms. Through this insight it is possible to see the chain of bio-power as it threads its way though discourse into the everyday expectations and common sense of beliefs of study participants and those who support them. This insight situates the proximal social processes depicted in the three theoretical propositions within the distal social processes of the socio-economic and political background. As insidious a process as this may seem it also has its benefits at the individual level. This is the fitness is good for you hypothesis.

Early life experiences also figured as a theme that had an influence on the adult fitness choices of study participants. The findings cited under the remembering school and childhood experiences headings underlined how indelibly these early experiences were etched in the minds of study participants. In general, happy fitness histories promoted adult interest and unhappy ones the reverse. In the case of positive early experiences study participants reported social support for trying their best and in some cases achieving success in fitness pursuits. Conversely, the fitness histories of some of the study participants described a losing battle to gain standards of normalcy set by the performance of their non-disabled peers.

Professional support figured prominently in the lives of study participants. Without this support and encouragement many of the participants would be hard pressed to access and attend

fitness programs. The professional helpers represented in the study summoned up discipline in aid of the fitness pursuits of the people they supported. This discipline was met with overt and covert resistance. Characterised as a conflict of wills the struggle to keep participants active can be readily understood from a Foucauldian perspective as fallout from unequal relationships where "technologies of normalization" (Tremain, 2006, p.187) are employed in the governing of problematic populations. This perspective gains ground in the search for macro connections to micro processes. Furthermore this connection puts the struggles of individual participants to achieve self-management in touch with the goals of neoliberal social policy.

As stressed at the front end of this dissertation, it is given as axiomatic that people with intellectual disabilities have very low fitness involvement compared to the non-disabled or "typical" population (Fernhall et al., 1996; Horwitz, Kerker, Owens, & Zigler, 2000; Rimmer, 1994; Rimmer, Heller, Wang, & Valerio, 2004; Stanish, Temple, & Frey, 2006). Researchers across much of the western world have come to similar conclusions (e.g., Coyle, Kinney, Riley & Shank, 1991D'Eath, Walls, Hodgins, & Cronin, 2006; Fernhall et al., 1996; Heller & Rimmer 1998-2003; Heller, Wang, & Valerio, 2004; Krahn & Drum, 2007; Repp & Karsh 1999; Rimmer, 1994). In contrast, my canvass of the study participants' produced a list of 30 separate fitness activities. These activities ranged from walking, bowling and swimming to Tai Chi, golf and dance. The list of activities enumerated by participants puts in question any notion that these participants were not interested in exercise and sport. The majority of study participants reported experiencing many of the social rewards associated with sports involvement. Some participants were more aware of the impact of their activities' on their bodies and sense of self. In this regard, the results of this study stand in contrast to the vast majority of research reviewed in advance of the study and during the drafting of this dissertation.

There is no valid proof in the positivist sense, which can settle why this is. It may be an artefact of the recruitment process. Selection of participants relied on the snowball and convenience sampling. These methods rely on going to where the people are which in this case often meant visiting day programs. As a consequence attendees who know each other may have influenced their friends to join the project. This would be the "birds of a feather" hypothesis. Agency staff also had input on who might sign up. It is possible that they picked individuals who they though best represented the group or simply were in their experience most able to respond verbally. Fortunately, this possibility was counterbalance by interviewing individuals with less verbal ability through aids or proxies.

Another interpretation of the discrepancy between my findings and that of most of the literature might lay in the comments of past researchers such as. Carroll, Adkins, Forth, Parker & Jamali,(2008) who remarked on how little qualitative research has been carried out on this topic or the conclusions of other researchers (e.g. Stanish, Temple & Frey, 2006) that the opinions of the subject population had been generally overlooked. If this is the case, then the findings of this dissertation provide a needed addition to current understanding. Moreover, the findings may provoke interest in further qualitative study.

Where important others presented healthful physical activities in an encouraging and supportive manner, the majority of study participants became engaged. The data also illustrates how pressure tactics employed to entice participants into fitness activities met with resistance. The struggle between participants, parents and professional support workers can be readily understood by referencing Foucault's ideas of discipline and resistance and the role of health and human service workers as agents of bio-power (Gilbert, 2003; Gilbert, Cochrane & Greenwell, 2005; Tremain, 2006).

A second point that contradicted current literature was that participants also reported a greater knowledge of the principles of a healthy lifestyle, such as eating well and exercising, than may have been predicted from the literature. In their explication of the goals of health education Lin and his associates (2005) enumerate the main goals of health education. In brief these authors maintain that the overall goal is to have people with intellectual disabilities understand the need for personal health skills that include exercise and a healthy diet. As was the case with physical exercise there is also general agreement that the personal habits of persons with intellectual disabilities falls short of wished for outcomes (Horwitz et al., 2000; Prasher & Janicki, 2002; Rimmer, 1994). It is an exceptional finding that virtually all of the participants in this study were able to cite some rudimentary truisms of health education such as the importance of eating right, staying fit and keeping active. Having this understanding does not verify that participants stuck by these rules. Many people across populations are unable or unwilling to implement prescribed health routines despite the moral authority of experts and professionals. Individual protests were described in the Discipline and Resistance section above. Also cited were research studies that argue that some sub-populations resist health advice that is delivered from authorities they rank as socially distant (e.g., Gjernes, 2009). This may demonstrate the advantage of friends and family as fitness advocates.

In terms of empiricism, the data provided by participants in this study express the significance of social support as a gratifying aspect of fitness and exercise activities. This information can contribute to the sound development of programs that aim to engage people with intellectual disabilities in fitness enhancing activities. As researchers such as Stanish, Temple & Frey (2006 have argued, an understanding of the current fitness practices of people with

intellectual disabilities can form a base for program development that will engage this hard to reach population

Methodologically speaking this research project showed how a qualitative approach can highlight the importance people within the personal network spheres as influences on fitness involvement. As cited above, Gjernes (2009) has put forth the position that epidemiological research tends to present findings that are isolated from the everyday experience of participants. The constructionist methodology brought forth the importance of interpersonal relationships in influencing fitness behaviour. This discovery can add depth to the epidemiological approach that has found difficulty in serving the needs of people with intellectual disabilities. As Kim and Canda (2006) have suggested, a more holistically orientated approach to health education is likely to succeed where the medical /public health approach alone has failed.

The study participants can be characterized as being engaged in a continuous interchange with their environment (Crooks, 2001). A primary condition of this interplay is the participants' ability to consider and construe meaning to their social world. The findings of this study suggest that participants did in fact reflect on messages about fitness and health. This introspection allowed study participants to evaluate their lives and lifestyles and set goals for improvement. People close to them inspired and facilitated this personal growth. It may be that further qualitative explorations that involve people with intellectual disabilities will nurture a more thorough picture of the social processes at work.

7.1 Limitations

This dissertation was modeled on constructionist grounded theory as modeled by Charmaz (2006). In her work on constructionist grounded theory, Charmaz remarks that researchers cannot directly comprehend an objective reality, but rather reality "arises from the

interpretive process and its temporal, cultural, and structural contexts" (p. 130). This comment establishes the methodological limitations of this study. The data gathering, data analysis and subsequent findings of this dissertation are presented in the "interpretive tradition" (p.130) which is a hallmark of the constructionist methodology. This dissertation does not purport to capture the" truth" of the situation for all people with intellectual disabilities. Instead it offers insight into how the participants came to engage in fitness activities, what people were influential in their choices, and what that engagement meant to them. The theoretical propositions modeled in this dissertation remain a co-creation of the participants' descriptions and my analysis and interpretation. Although some individuals with verbal or expressive challenges were interviewed my recruitment process depended on those individuals involved with social agencies and consequently some individuals eligible for recruitment would be overlooked. The findings are credible within the confines of the study but not replicable or generalizable to other populations. However, they do open a window into the lives of participants and thus insight into what processes occurred that engaged them physical fitness activities. These micro-processes are accompanied by an exploration of the cultural and socio-cultural practices in which the action of participants' lives was set.

7.2 Recommendations

The findings reveal that participants embraced fitness and exercise activities if the social climate they inhabited informed, invited, encouraged, and supported them. In this regard, the study participants seemed to lack distinction from the "non-disabled" population. As well, the people in this study all appeared to have internalized common health adages such as eating fruits and vegetables and keeping one's weight down. However, without a welcoming social environment, they were unlikely to be able to follow through on this knowledge. To enhance the

likelihood of success, a special effort should be made by people who support and work with persons with intellectual disabilities to enhance the social environment in which activities take place. This effort should harness the leadership of persons with intellectual disabilities and be enjoined by all parties involved in their support and care. The study points out that an organized approach to providing exercise opportunities by family, friends and professionals will yield results. Without a conscious effort to maintain fitness everyone is more likely to lose their capacity for independence in activities of daily living as they age (Ciairano, Liubich, & Rabaglietti, 2010).

Currently, some caregivers and support agencies have invested in the fitness of their clientele. This involvement should be encouraged and supported by funding agencies specifically, Community Living British Columbia (CLBC). CLBC regional managers could collaborate with self-advocates and willing partners to insert fitness outcomes in contract deliverables. These conditions could be applied to both individual care homes (Home Share) as well as larger contracted agencies. The focus here would be to integrate fitness into daily practice. Currently individuals who receive services funded by CLBC engage in the development of a Personal Service Plan (PSP). Individuals could insert health and fitness goals into such plans.

Volunteer run organizations led by families, parents, self-advocates, or caregivers could also take up this cause and include exercise and fitness enhancement in their social change agendas. Taking fitness as an essential part of their missions could benefit all parties. A long term approach suggests that improving the fitness of persons with intellectual disabilities would curb the spiralling care costs faced by government agencies such as CLBC (Colman & Walker, 2004).

Physical activity has been shown to provide physical and mental health benefits, including protection against major diseases that affect all British Columbians (Anderson-Hanly,Nimon & Weston, 2010; Fenton,1994;Penedo & Dahn,2005;Wood,1991) Research has also shown that positive fitness experiences in youth do impact fitness choices in adulthood (Dodge & Lambert, 2009; Greenleaf, Boyer, & Petrie, 2009). In this study, early childhood and school experiences had an impact the interest in fitness of the participants. Consequently, initiatives that put social support at the forefront could be launched by the education system to reach out and engage children with special needs in fitness programs that are friendly and inclusive. A note here can be taken from the practices of organizations like Special Olympics and Operation Track Shoes, who foster a welcoming social environment where individuals are encouraged and assisted to make friends, compete, and enjoy themselves to their full capacity. Furthermore, this study lends credibility to the idea that a key ingredient in providing successful fitness opportunities is to enlist the involvement of family, friends, and support persons.

A report commissioned by the BC Ministry for Health Planning (Colman & Walker, 2004) estimated that the lack of physical activity cost taxpayers in BC $211 million a year in medical expenditures (p. iii). If the Province was to allocate just a small percentage of that cost to getting school aged children physically active, the results have the potential to offset economic loss in preventable medical care, as well as millions of lost revenue to business due to productivity losses caused by premature death and disability (Coleman & Walker, 2004). Were this idea implemented, a specific budget could be allocated to enhance fitness opportunities for children and adults with intellectual disabilities with potential to bring about similar results.

Community Living British Columbia (CLBC) has established full citizenship as an overarching goal for persons with intellectual disabilities (www.communitylivingbc.ca/vision). However, the dream of full citizenship falls flat if persons with intellectual disabilities cannot retain the mental and physical capacity to fully enjoy this status. Through their influential relationship with self-advocates families and the contracted sector CLBC is well placed to champion the fitness and well-being of the individuals they were established to serve. Finally, by attaining a moderate level of physical fitness, persons with intellectual disabilities would be better positioned to realize their citizenship goals.

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Appendices

Appendix A: Recruitment Flyer

T H E   U N I V E R S I T Y   O F   B R I T I S H   C O L U M B I A

O k a n a g a n

YOU ARE INVITED!

I am a PhD student researcher from the University of British Columbia Okanagan in Kelowna. I am doing a research project called: **Physical Fitness and Intellectual Disability: A Grounded Research Study.**

I am interested in learning about what people with intellectual disabilities think about fitness activities. You do not have to be taking part in fitness activities to take part in the study. I want to hear from you.

I would like to talk to people who are at least 19 years old and who are eligible for services from Community Living British Columbia (CLBC).

Primary Investigator: Dr. Rachelle Hole

UBC Okanagan,

Kelowna, B.C. V1V 1V7

Tel: (250) 807-8741

Fax: (250) 807-8792

rachelle.hole@ubc.ca

I will have private 1- 2 hour interviews with **adults with developmental disabilities to hear about their experiences with fitness activities.**

If you would like more infromation or wish to participate , please call Peter Speers PhD Student Researcher at: 250-483-4304 or email speers@shaw.ca

Appendix B: Information Letter

Title of Study: Physical Fitness and Intellectual Disability: A Grounded Theory Study

Principal Investigator:	**Dr. Rachelle Hole**
	Assistant Professor
	UBC Okanagan School of Social Work, 3333 University Way, Kelowna, BC, V1V 1V7
	250-807-8741
	rachelle.hole@ubc.ca
Co-Investigators:	**Dr. Tim Stainton**
	Professor UBC Vancouver School of Social Work and Director of the Centre of Inclusion and Citizenship, UBC Vancouver School of Social Work.
	604-822-9674
	Dr. Lawrence Berg
	Centre for Social, Spatial & Economic Justice
	University of British Columbia,
	UBC Okanagan
Student Researcher:	**Peter D Speers,** PhD Student
	University of British Columbia-Okanagan
	Kelowna, B.C.
	250-483-4304

This research is being conducted by PhD Student Peter Speers, who is being supervised by researchers from the University of British Columbia Okanagan and Vancouver.

Invitation to Take Part

This research is being conducted by PhD student Peter Speers from the University of British Columbia Okanagan in Kelowna. Peter is being supervised by Dr. Rachelle Hole of the University of British Columbia-Okanagan (UBC-O). The goal of this research is to learn what people with intellectual disabilities think about fitness activities (exercise). It is hoped that this information will contribute to a better understanding of what is involved in the fitness choices of people with intellectual disabilities. You do not have to be involved in any fitness activity to take

part in the study. The researcher (Peter) thinks that your experiences will help him learn about what things affect fitness choices.

How will the project work?

We will be asking people about their experiences with fitness activities. The interviews with people with a intellectual disability will be confidential (private). The interviews will be digitally-recorded. They will take 1- 2 hours and will be conducted in a private and comfortable location. For example, the interview can be conducted in your home if you choose, or in a private place (e.g., office) in the community. Individuals who agree and want to have an interview with the researcher are called participants.

What if there are some things you want to say but want them to be private?

The researcher will make sure that only people on the interview team will be able to tell what you said. No one will be allowed to use your name when repeating what you said. Your name will not be on any tapes or reports. Your name will only be on your consent form. All of the information collected at the interviews will be kept in a locked office and locked filing cabinet at UBC-Okanagan.

What if you don't want to participate, or if you start and then decide you don't want to continue?

That is okay. If you change your mind, that's okay. We don't want anyone to do anything that they aren't happy to do. We want this project done in a good way from start to finish, so if you decide halfway through to stop, that's okay – no one will get into any trouble. Sometimes when people start talking about things that have happened, it can be hard. We hope this won't happen, but if it does, you can choose to not answer a question or to stop the interview.

What happens to the material after?

Answers to the interview questions will be digitally-recorded. Then the research student (Peter) will write a report. The report will be shared. He may also write articles to go into a journal or magazine, and may present the information at a conference (for example at the BC Association for Community Living Annual Conference). Your name will NOT be included in any reports or presentations.

What if I have any questions?

If you have any questions or concerns about anything to do with the project you can ask Rachelle Hole (250-807-8741) or PhD student researcher Peter Speers (250-483-4304 or speers@shaw.ca).

What's next?

This sheet is meant to tell you basic information about the project. After you have had a chance to think about it and ask any questions you want, you can let the researcher (Peter) know if you want to help out with (participate in) the project. If you do – great, if you don't – that's fine too.

If you want to take part we need you look over the **consent form.** This tells us that you understand the project and want to take part.

Right now Peter wants you to think things over. In about one week's time Peter will call you to see if you want to say **Yes or No.** If you say yes, you will need to sign the consent form and give it to the researcher. You can ask a trusted person (for example a family member or friend) to help you with the consent form. The researcher (Peter) will also go over the consent form with you to help you understand and answer any questions you have.

Appendix C: Consent Form

Title of Study: Physical Fitness and Intellectual Disability: A Grounded Theory Study

Principal Investigator:	**Dr. Rachelle Hole**
	Assistant Professor
	UBC Okanagan School of Social Work, 3333 University Way, Kelowna, BC, V1V 1V7
	250-807-8741
	rachelle.hole@ubc.ca
Co-Investigators:	**Dr. Tim Stainton**
	Professor UBC Vancouver School of Social Work and Director of the Centre of Inclusion and Citizenship, UBC Vancouver School of Social Work.
	604-822-9674
	Dr. Lawrence Berg
	Centre for Social, Spatial & Economic Justice
	University of British Columbia,
	UBC Okanagan
Student Researcher:	**Peter D Speers,** PhD Student
	University of British Columbia-Okanagan
	Kelowna, B.C.
	250-483-4304

This research is being conducted by PhD Student Peter Speers, who is being supervised by researchers from the University of British Columbia Okanagan and Vancouver.

Purpose of this research: The main purpose of this research is to find out what people with intellectual disabilities think about physical fitness activities.

Study procedures: (What you will be asked) The researcher (Peter Speers) will be asking people about their experiences with physical fitness activities. The interviews will be digitally-recorded. They will take about 1 - 2 hours and will take place in a private and comfortable location. For example, the interview can be in your home if you choose. Individuals who want to

have an interview with the researcher are called participants. If you decide to participate Peter will contact you to set up an interview time or you can call him at 250-483-4304. You can choose the time and place of the interview that best suits you. In the interview, Peter will ask you some questions about your experience with fitness activities (exercise). The interview will take about one to two hours. A second interview may be needed and you can decide if you want to participate then as well. Your overall participation in the project will take approximately two hours.

Confidentiality/Privacy: Your participation will be confidential (private) and your name or identity will not show in the study. No one will see your interview except the interviewer (Peter) and his supervisor. You may ask Peter any questions about the study before, during, or after the interview. When the study is complete, Peter will give you a copy of the results if you want one.

Possible Risks: There are no known risks in taking part in this study. It is possible that some participants may become psychologically upset during an interview. If this happens Peter will have a list of counsellors the participant may contact to talk about the experience. The study is rated as having minimum risks.

Benefits of Participation: This research project is of importance to people with intellectual disabilities, because understanding their experience with physical fitness activities will contribute to knowledge in this area. Being involved in this research will allow for your ideas to inform the findings of this research. Your participation will help the researcher understand what physical fitness means to people with intellectual disabilities. Better understanding of the fitness choices of people with intellectual disabilities may in time contribute to better health for people with intellectual disabilities.

Contact for concerns about the rights of research subjects: If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832 or if long distance, e-mail to RSIL@ors.ubc.ca.

Consent: Your participation in this study is completely voluntary and you may choose not to participate at any time without it being a problem. You are free to refuse to answer any question. If you decide not to participate after the start of the interview, any information you have provided will be destroyed and not appear in the final report. If you agree to take part in this study please sign this consent form below. A copy of this form will be given to you for you to keep.

Contact for information about the study: If you have any questions about this study please call Peter at 250-483-4304, or you may contact Peter's study supervisor Dr. Rachelle Hole at 250-807-8741.

Thank you for your help.

As the research continues, Peter might have more questions about your experiences with exercise activities. If Peter has any more questions, he would like to call you to arrange for a second interview to help him understand more about your experiences with exercise activities. If you agree to a second interview with Peter check the "YES" box. If you do not want a second interview check the "NO" box. If you check YES Peter can contact you again. It is okay to say NO.

YES ☐ a second interview would be OK.   **NO** ☐ I do not want a second interview.

Signing your name means that you are saying YES to taking part in this study. Your signature also means that you have a copy of this consent form.

_____   _____ _____
      Name of Person   **Signature**   **Date**

Peter D. Speers, PhD student, University of British Columbia-Okanagan

Appendix D: Assent Form

Title of Study: Physical Fitness and Intellectual Disability: A Grounded Theory Study

Principal Investigator:	**Dr. Rachelle Hole**
	Assistant Professor
	UBC Okanagan School of Social Work, 3333 University Way, Kelowna, BC, V1V 1V7
	250-807-8741
	rachelle.hole@ubc.ca
Co-Investigators:	**Dr. Tim Stainton**
	Professor UBC Vancouver School of Social Work and Director of the Centre of Inclusion and Citizenship, UBC Vancouver School of Social Work.
	604-822-9674
	Dr. Lawrence Berg
	Centre for Social, Spatial & Economic Justice
	University of British Columbia,
	UBC Okanagan
Student Researcher:	**Peter D Speers,** PhD Student
	University of British Columbia-Okanagan
	Kelowna, B.C.
	250-483-4304

This research is being conducted by PhD Student Peter Speers, who is being supervised by researchers from the University of British Columbia Okanagan and Vancouver.

Purpose of this research: The primary purpose of this research is to investigate what social processes affect the engagement of people with intellectual disability in physical fitness activities.

Study procedures: (What you will be asked) The researcher (Peter Speers) will be asking people about their experiences with physical fitness/exercise activities. The interviews will be digitally-recorded. They will take about 1 - 2 hours and will be conducted in a private and

comfortable location. For example, the interview can be in your home if you choose. Individuals who want to have an interview with the researcher are called participants. If you decide to participate, Peter will contact you to set up an interview time or you can call him at 250-438-4304. You can choose the time and place of the interview that best suits you. In the interview, Peter will ask you some questions about the your experience with fitness activities (exercise). The interview will take about one to two hours. A second interview may be needed and you can decide if you want to participate then as well. Your overall participation in the project will take approximately 2 hours.

Confidentiality/Privacy: Your participation will be confidential (private) and your name or identity will not show in the study. No one will see your interview except the interviewer and his supervisor. You may ask Peter any questions about the study before, during, or after the interview. When the study is complete, Peter will give you a copy of the results if you want one.

Possible Risks: There are no known risks in taking part in this study. It is possible that some participants may become psychologically upset during an interview. If this happens Peter will have a list of counsellors the participant may contact to talk about the experience. The study is rated as having minimum risks.

Benefits of Participation: This research project is of importance to people with intellectual disabilities, because understanding their experience with physical fitness activities will contribute to knowledge in this area. Being involved in this research will allow for your ideas to inform the findings of this research. Your participation will help the researcher understand what physical fitness means to people with intellectual disabilities. Better understanding of the fitness choices of people with intellectual disabilities may in time contribute to better health for people with intellectual disabilities.

Contact for concerns about the rights of research subjects: If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832 or if long distance, e-mail to RSIL@ors.ubc.ca.

Contact for information about the study: If you have any questions about this study please call Peter at 250-483-4304, or you may contact Peter's study supervisor Dr. Rachelle Hole at 250-807-8741. Thank you for your help.

Consent: Your participation in this study is completely voluntary, and you may choose not to participate at any time without it being a problem. You are free to refuse to answer any question. If you decide not to participate after the start of the interview, any information you have provided will be destroyed and will not appear in the final report. If you agree to take part in this study, please sign this consent form below. A copy of this form will be given to you for you to keep.

Title of Study: Physical Fitness and Intellectual Disability: A Grounded Theory Study

I, _____ have had the research project explained to me and I want to participate in this research but I want _____ to answer questions for me.

I understand that if I want to participate on my own at any time, the researcher (Peter) will tell me about my consent and ask me to sign a consent form, and then I can answer for myself.

I also understand that I may decide not to participate at any time and that this decision will end the participation of _____.

I also understand that if I decide not to participate, no one will be asked to answer questions for me.

I understand that signing my name below means that I agree to participate with this help and that I have been given a copy of this form for myself.

_____   _____
             Participant   **Date**

_____   _____
      Proxy Name (person helping)   **Date**

_____

Relationship to participant (e.g. friend, family member)

Peter D. Speers, PhD student, University of British Columbia-Okanagan

Appendix E: Sign-up Sheet

Title of Study: Physical Fitness and Intellectual Disability: A Grounded Theory Study

Principal Investigator:	**Dr. Rachelle Hole**

Assistant Professor
UBC Okanagan School of Social Work, 3333 University Way, Kelowna, BC, V1V 1V7

250-807-8741

rachelle.hole@ubc.ca

Co-Investigators: **Dr. Tim Stainton**
Professor UBC Vancouver School of Social Work and Director of the Centre of Inclusion and Citizenship, UBC Vancouver School of Social Work.

604-822-9674

Dr. Lawrence Berg
Centre for Social, Spatial & Economic Justice
University of British Columbia,

UBC Okanagan

Student Researcher: **Peter D Speers,** PhD Student
University of British Columbia-Okanagan
Kelowna, B.C.

250-483-4304

This research is being conducted by PhD Student Peter Speers, who is being supervised by researchers from the University of British Columbia Okanagan and Vancouver.

Invitation to Take Part

This research is being conducted by PhD Student Peter Speers from the University of British Columbia-Okanagan in Kelowna. Peter is being supervised by Dr. Rachelle Hole of the University of British Columbia-Okanagan (UBC-O). The goal of this research is to learn about what people with intellectual disabilities think about fitness activities (exercise). It is hoped that this information will contribute to a better understanding of what is involved in the fitness choices of people with intellectual disabilities. You do not have to be involved in any fitness

activity to take part in the study. The researcher (Peter) thinks that your experiences will help him learn about what things affect fitness choices.

How will the project work?

Peter will be asking people about their experiences with fitness activities. The interviews with people with a intellectual disability will be confidential (private). The interviews will be digitally-recorded. They will take 1- 2 hours and will be conducted in a private and comfortable location. For example, the interview can be conducted in your home if you choose, or in a private place (e.g., office) in the community. Individuals who agree and want to have an interview with the researcher (Peter) are called participants.

What if there are some things you want to say but want them to be private?

The researcher (Peter) will make sure that only people on the interview team will be able to tell what you said. No one will be allowed to use your name when repeating what you said. Your name will not be on any tapes or reports. Your name will only be on your consent form. All of the information collected at the interviews will be kept in a locked office and locked filing cabinet at UBC Okanagan.

What if you don't want to participate; or if you start and then decide you don't want to continue?

That is okay. If you change your mind, that's okay. Peter does not want anyone to do anything that they are not happy to do. Peter wants this project done in a good way from start to finish, so if you decide halfway through to stop, that's okay – no one will get into any trouble. Sometimes when people start talking about things that have happened, it can be hard. We hope this will not happen, but if it does, you can choose to not answer a question or to stop the interview.

What happens to the material after?

Answers to the interview questions will be digitally-recorded. Then the research student (Peter) will write a report. The report will be shared. He may also write articles to go into a journal or magazine, and may present the information at a conference (for example at the BC Association for Community Living Annual Conference). Your name will NOT be included in any reports or presentations.

What if I have any questions?

If you have any questions or concerns about anything to do with the project you can ask Rachelle Hole at (250-807-8741) or PhD student researcher Peter Speers (250-483-4304 or speers@shaw.ca).

Contact for concerns about the rights of research subjects: If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information

Line in the UBC Office of Research Services at 1-877-822-8598 or the UBC Okanagan Research Services Office at 250-807-8832 or if long distance, e-mail to RSIL@ors.ubc.ca.

What's next?

This sheet is meant to tell you basic information about the project. After you have had a chance to think about it and ask any questions you want, you can let the researcher (Peter) know if you want to help out with (participate in) the project. If you do – great, if you don't – that's fine too.

If you want to take part, Peter will ask you to sign a **consent form.** Peter will explain the consent form if you decide to take part in the study. Signing the consent form tells Peter that you understand the project and want to take part.

Right now Peter wants you to think things over. In about one week's time Peter will call you to see if you want to say **Yes or No.** If you say yes, you will need to sign the consent form that Peter will give to you. You can ask a trusted person (for example a family member or friend) to help you with the decision to take part. The researcher (Peter) will also go over the consent form with you to help you understand and answer any questions you have.

Please write your name and contact information below so that Peter can talk to you about whether you want to take part in the study. Putting your name down does not mean you have to participate. It only means you might be interested and it's OK for Peter to contact you about taking part in the study.

Name	Phone number	email

Appendix F: Interview Guide

Physical Fitness and Intellectual Disability: A Grounded Theory Study

Time of interview: _____

Date: _____

Place: _____

Interviewee: _____ Interview #: _____

The purpose of this study is to determine what social processes encourage people with intellectual disabilities to engage in physical fitness activities.

Questions:

1. What kinds of activities do you enjoy doing?

2. Tell me about your experience with exercise or fitness activities.

3. Who have you participated with in exercise activities?

4. In what ways did your parents, caregivers, or friends encourage you to be fit and healthy?

5. Who has helped you participate in exercise activities?

6. What does fitness mean to you?

7. When you were growing up what did you learn about being fit?

8. What do fit people look like?

9. Have you had any difficulty participating in exercise activities?

10. What kinds of things might help you participate in exercise activities?

11. Is there anything about exercise activities you do not like?

Appendix G: Community Referrals

<u>List of Victoria Area Support Agencies</u>

Vancouver Island Health Authority Crisis Line

Ph: 250-386-6323

Royal Jubilee Hospital

Ph: 250-370-8000

Community Living BC (CLBC)

Ph: 250-952-4203

Victoria Association for Community Living Victoria Self-Advocates

Ph: 250-477-7231

Appendix H: Ethics Board Approval

CERTIFICATE OF APPROVAL - MINIMAL RISK AMENDMENT

PRINCIPAL INVESTIGATOR: Rachelle D. Hole	DEPARTMENT: UBC/UBCO Health & Social Development/UBCO Social Work	UBC BREB NUMBER: H09-03249

INSTITUTION(S) WHERE RESEARCH WILL BE CARRIED OUT:	
Institution	**Site**
UBC	Okanagan

CO-INVESTIGATOR(S):
Peter Speers Tim Stainton Lawrence D. Berg

SPONSORING AGENCIES:
N/A

PROJECT TITLE:
Physical Fitness and Intellectual Disability: A Grounded Research Study

Expiry Date: Approval of an amendment does not change the expiry date on the current UBC BREB approval of this study. An application for renewal is required on or before October 18, 2011.

AMENDMENT(S):	AMENDMENT APPROVAL DATE: **January 10, 2011**	
Document Name	Version	Date
Assent Forms:		
Assent Form	3	December 20, 2010
Advertisements:		
Recruitment Flyer	3-10-12-20	December 20, 2010
Other Documents:		
Sign Up Sheet	2-10-12-20	December 20, 2010
Community Referrals	3-10-12-11	December 11, 2010

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

Approval is issued on behalf of the Behavioural Research Ethics Board Okanagan and signed electronically by: _____ Dr. Daniel Salhani, Chair