

Exploring Healthy Experiences of Youth with Physical Disabilities

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February, 2011

A thesis proposal submitted in partial fulfillment of the requirements for the  
degree of Master of Arts in Kinesiology and Physical Education

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### Abstract

This phenomenological study explored the lived health experiences of seven children with physical disabilities and associated secondary conditions. The children, between 9-13 years, attended the same elementary school. Semi-structured interviews were conducted with the children. Child experiences were sought through a scrapbook interviewing technique where photographs were utilized as prompts to enhance participant recall and reflection (Harvey et al., in press). Rich discussions were generated to capture the essence of the health for each child. The children were actively engaged in this visual approach to qualitative research methodology which assisted in the co-construction of their own health reality through a collaborative research process with the primary researcher (Harvey et al., in press; Knowles & Sweetman, 2004; Phoenix, 2010). Thematic analyses were conducted on the verbatim transcriptions of the interviews. Four themes emerged from the data: (a) my scrapbook, (b) what I do during my free time, (c) people around me, and (d) what helps me and what doesn't. The results demonstrated the effectiveness of the unique scrapbook interviewing technique to gain a child-driven understanding of the conception of health. The results also reflected the importance of family members, the leisure activities of the children, and the affordances and constraints that enabled or constrained the children to incorporate healthy behaviors. Data triangulation, member checks, audit trail, peer-review, and researcher reflexivity were used to establish trustworthiness of the children's stories. The children with physical disabilities told positive stories about health that may help to create child-friendly physical activity and health interventions at home, school, and community.

## Résumé

Cette étude phénoménologique a permis d'explorer des expériences de santé vécues par sept enfants ayant des déficiences physiques et les effets secondaires qui s'y rattachent. Les enfants, âgés entre 9 et 13 ans, fréquentaient la même école primaire. Des entrevues semi-structurées ont été menées auprès de ces derniers. Leurs expériences ont été recueillies dans un portfolio, dans lequel des photographies ont été utilisées afin d'inciter les participants au rappel et à la réflexion (Harvey et al., in press). De riches discussions ont été générées afin de faire ressortir l'essentiel de la santé. Ceux-ci ont été activement engagés dans cette approche visuelle de la méthodologie de recherche qualitative, ce qui a aidé à la co-construction de leur propre réalité concernant leur santé et ceci grâce à un processus de recherche en collaboration avec le chercheur principal (Harvey et al., in press; Knowles & Sweetman, 2004; Phoenix, 2010). Des analyses thématiques ont été réalisées sur les transcriptions textuelles des entretiens. Quatre thèmes ont émergé à partir des données : (a) mon portfolio, (b) ce que je fais durant mon temps libre, (c) mon entourage et (d) ce qui m'aide, ce qui me nuit. Les résultats ont démontré l'efficacité de la technique unique d'entrevue à travers le portfolio afin d'acquérir une compréhension de la conception de la santé auprès des enfants. Les résultats reflètent également l'importance des membres de la famille, des loisirs des enfants, des capacités et des contraintes qui ont permis ou empêché ceux-ci à intégrer des comportements sains. Traitement triangulaire des données, suivi des membres, vérification des pistes suivies, évaluation par un collègue et réflexivité des chercheurs ont servi à établir la crédibilité des dires des enfants. Les enfants ont fait part d'histoires positives sur la santé lesquelles peuvent aider à créer des liens parmi les jeunes à travers l'activité physique et des interventions au sujet de la santé, autant à la maison, à l'école que dans la communauté.

## Acknowledgements

I would first like to express gratitude towards my supervisor, Dr. William Harvey, for his feedback, guidance, and motivation to keep striving to constantly question almost everything I do and be the best I can be. I won't miss your constant inquiries: "WHY are you writing this? WHY are you using this method?" Thank you to my committee members: Dr. Greg Reid for sharing your extensive knowledge in the field of APA and Dr. Cathi Sabiston for your qualitative insight. I would also like to thank Dr. Mark Aulls for believing in my capabilities as a graduate student and for your class which has helped me become a better qualitative researcher.

A special thank you to my family, especially Steve, since regardless of your scientific background, you were able to provide me with suggestions. Also, thanks mamma for your constant understanding and support throughout the process of writing my thesis. I believe I am in this field mainly because you have instilled strong educational values in me throughout my life. Thanks to my group of girlfriends (you know who you are!). I am not sure how I would have completed this thesis without all your support and listening to my complaints! Thanks to the other graduate students in our department that were always willing to provide me with feedback, and especially Shawn for conducting my peer-review. Finally, a special thanks to Bob since without your advice and help throughout the process, my thesis would not have been possible. Your passion and dedication has influenced my pedagogical practices. A special thank you goes to the children and their families who participated in my project and were able to share their wonderful stories. The research was fully supported by the Social Sciences and Humanities Research Council of Canada (SSHRC) and Fonds de recherche sur la société et la culture (FQRSC).

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## Introduction

Health is a global issue which affects everyone from the lack of safe drinking water in some societies to the obesity epidemic in most societies. Poor health issues also surround individuals with disabilities (World Health Organization [WHO], 2011). Thus, understanding the need to live a healthy lifestyle is important for everyone, including children with disabilities. A phenomenology approach (van Manen, 1997) was used to explore the essence of the experiences of the children with physical disabilities about health.

This document is a manuscript-based Masters thesis that conforms to the standards of McGill University. There are two chapters in this Masters thesis. The first chapter is a review of the literature. This chapter begins with a history of individuals with disabilities and is followed by a more in depth review about persons with cerebral palsy (CP). It addresses the literature on health and physical activity (PA) in general. It was not designed to explore all of the intricacies of health for the general population but it does provide the relevant information necessary for understanding the health issues surrounding children with disabilities. The review of literature also provides information about qualitative approaches in general, and more specifically, the method employed in this study since the scrapbook interviewing approach is new (Harvey, Wilkinson, Pressé, Grizenko, & Joobar, in press). Chapter two is a manuscript that describes the current study, which explored the lived experiences for children with physical disabilities about health. First, the manuscript includes past research on the three health components for children with disabilities (e.g., social, physical, and mental well-being). Next, a description of the method carried out for the research project is explained. Third, a results section is provided with participant quotes to address the central research question. Finally, a discussion section is included which evaluates and interprets the implications of the four themes. The discussion



section also contains the strengths and weaknesses of the study, recommendations for future research, and a conclusion. Parents of the children with physical disabilities were also interviewed about the health experiences of their child. These interview data were not analyzed nor do they appear in this manuscript due to the novelty of the scrapbook interviewing technique for the children which became challenging in terms of time and interpretation of the data since it was the primary researcher's first formal study. However, the primary researcher was able to incorporate the parental discussions as support for the health of the children. These data will be analyzed at a later date to provide additional information about the health experiences of children with physical disabilities.

## Chapter 1

### Review of the Literature

The purpose of this phenomenological study was to explore the meaning of the ‘lived experiences’ of children with physical disabilities about their health. The phenomenon of interest was the experience that the children shared between living a healthy lifestyle and having a physical disability. This literature review will first present a history of individuals with disabilities and define the term disability. Second, an overview of the classification of disabilities and more specifically of cerebral palsy (CP) will be explored. Next, the social, physical, and mental factors surrounding a healthy lifestyle for children with disabilities will be reviewed. Fifth, the review will highlight the rationale for using a qualitative approach for this research project by describing the phenomenology approach, the research design, worldview, and interpretive framework. Lastly, the importance of including the voices of children in research will be covered as this plays an essential role in the methodology of the research study.

#### *History of Individuals with Disabilities*

Acquiring knowledge about the past may help one understand present and future trends (Sherrill, 2004a). The literature review begins with a history of individuals with disabilities by discussions about person-first language, historical chronological events, and the field of adapted physical activity (APA).

#### *Person First Language*

Person-first language accentuates that the individual comes first and the disability is secondary (Squair & Groeneveld, 2003). Terms such as “a woman with a physical disability”, “a child with autism”, or “a girl with an intellectual disability” assigns the importance to the person first and the disability second. Squair and Groeneveld (2003) claimed the medical community

played a large role in shaping societal understanding of people with disabilities by labeling people by their condition first. Terms such as “physically handicapped woman”, “autistic child”, and “mentally retarded girl” may have emphasized the disability first. The Active Living Alliance for Canadians with Disability coined the phrase “persons with a disability” and referred to using words with dignity to describe people with disabilities (Words with dignity, n.d.).

### *Historical Chronological Events*

Societal views towards individuals with disabilities were mainly negative in ancient civilizations and throughout much of history because they were inaccurately perceived and poorly treated (Jansma & French, 1994; Reid, 2003). The survival rate of children with severe disabilities was low due to the lack of medical and health service advances that may be found today (Jansma & French, 1994; Sherrill, 2004a). People who were claimed to be beggars, thieves, hunchbacks, and monsters, that we hear about in history, were most likely people with disabilities (Sherrill, 2004a). For example, people with mental illness may have been the most poorly treated because they were misunderstood (Sherrill, 2004a).

Jansma and French (1994) distinguished between five periods in relation to societal attitudes towards people with disabilities. The first period between the prehistoric era to 500 B.C. portrayed the causes and cures of people with disabilities through a spiritual-magical-medical lens (Jansma & French, 1994). Children with disabilities were usually abandoned or killed (Jansma & French, 1994; Reid, 2003; Sherrill, 2004a). The second period from 500 B.C. to 500 A.D. included Roman and Greek societies (Jansma & French, 1994). People also practiced infanticide during this period, but Greek physicians and philosophers provided more logical explanations for the causes of disabilities (Jansma & French, 1994). The Middle Ages constituted the third period between 500 A.D to 1500 A.D where the influence of religion gave

rise to controversy towards people with disabilities. Some children with disabilities were viewed as “children of God” while others were seen as possessed by the devil (Best, 2010). This period digressed from the previous era returning to cruelty and confusion (Jansma & French, 1994). The time between 1500 A.D and the early 1900s marks the fourth period. People with emotional disabilities were viewed as incompetent. However, this period also marked a turning point in the positive shift towards people with disabilities. Locke and Rousseau’s philosophy emphasized “the dignity of all individuals” (Jansma & French, 1994). For example, Dr. Louis Pinel at the end of the 1700s initiated the end of the cruelty displayed towards persons with mental illness (Harvey, Delamere, Prupas, & Wilkinson, 2010) and he provided positive treatment to these people with emotional disabilities (Jansma & French, 1994). The fifth period, from early 1900s to the present, is considered a landmark era because of the increased care, treatment, and educational services provided to people with disabilities (Jansma & French, 1994). This shift has also included the creation of US federal laws to provide opportunities for children with disabilities to be educated in the least restricted environment (Jansma & French, 1994).

### *History of Adapted Physical Activity*

Adapted physical activity is a cross disciplinary field, viewed as an umbrella term, which encompasses the academic field of study and service delivery for individuals with disabilities (Hutzler & Sherrill, 2007; Sherrill, 2004b). Its aim is to provide an enhanced active and healthy lifestyle for individuals with movement limitations and/or societal restrictions (Sherrill, 2004a; Sherrill, 2004b).

The term APA has undergone many name changes from its beginnings in the 1840s. Some authors suggested the origin of APA was in 1905 with the conception of the Association for the Advancement of Physical Education (Sherrill, 2004a). R. Tait McKenzie was a Canadian

physician, sculptor, and physical educator whose work was suggested as precursor in the field of APA (Reid, 2003). He wrote the book *Exercise in Education and Medicine* in 1909 and was among the first to describe the teaching of children who were deaf, blind, and have an intellectual disability (Reid, 2003).

However, the origins of APA were rooted in the medical gymnastics taught by physicians (Goodwin, 2003). In the 1800s began the growth of numerous systems of gymnastics in North America (Goodwin, 2003). For example, Swedish immigrants introduced medical and educational gymnastics in public schools in Boston by the late 1800s (Goodwin, 2003; Sherrill, 2004b). Proponents of this approach may have assumed that a disability was mainly biological in nature and not shaped by the social being (Goodwin, 2003). Swedish gymnastics focused on teacher directed health-related fitness which emphasized correct body posture and calisthenics (Sherrill, 2004b). Most likely, children without any visible disabilities attended public schools and participated in Swedish gymnastics exercises (Sherrill, 2004b). Children with physical, intellectual, and sensory disabilities may not have participated in Swedish gymnastics as they were mainly educated in residential schools (Sherrill, 2004b).

People with disabilities resided in institutions, special schools, and residential programs during the first half of the twentieth century (Reid, 2003). This segregation led to less contact between individuals with and without disabilities (Reid, 2003). Although children with disabilities were educated separately, this was an improvement over the previous practice of hiding and ignoring the children (Sherrill, 2004b). Many people in society continued prejudice and discrimination towards individuals with disabilities (Sherrill, 2004b). This era was dominated by “corrective therapy” where the problem was observed as residing within the individual (Sherrill, 2004b). The practice of corrective therapy ignored persons with intellectual

disabilities, deafness, and visual impairments as these disabilities could not be corrected. Society defined people with disabilities by their condition (e.g., what is wrong with these individuals) and how they could be corrected. This medical approach may have stigmatized people with disabilities and emphasized their disability. Reid (2003) claimed that it was also used in the education system to address posture and poor fitness in school-aged children (Reid, 2003).

The return of injured veterans after WWI and WWII played an important role on how people with disabilities were viewed in society (Goodwin, 2003; Reid, 2003). They added a powerful political voice to argue that their spinal cord injuries and amputations could not be “corrected” (Sherrill, 2004a). The war veterans were provided treatment, rehabilitation, physical access to employment, return to active duty, and other life activities (Best, 2010). People with physical disabilities had become visible to society (Sherrill, 2004b). Injured war veterans were viewed as being able to re-integrate into society. Sports in rehabilitation and wheelchair sports began (Sherrill, 2004a) and it coincided with the beginning of the growth of special classes in regular schools and other initiatives (Reid, 2003).

The term “mainstreaming” was introduced in the 1960s where correcting someone with a disability changed to providing services for that person (Reid, 2003). Children were placed into general classes and schools but there seemed to be confusion about how to provide special education in the regular education settings (Block & Obrusnikova, 2007). There was the assumption that through mainstreaming students with disabilities would be fully integrated socially, academically, and physically into schools, but this did not occur automatically. For example, children with disabilities remained in special schools, special classes, or group homes.

The United States (US) government enacted Public Law 94-142, the Education for All Handicapped Children Act in 1975 due to a growing dissatisfaction with special education

(Block & Obrusnikova, 2007). It was renamed Public Law 108-446, the Individuals with Disabilities Education Act (IDEA) in 1990 and has been reauthorized several times since 2004 (Apling & Jones, 2005). There was a shift away from the residential schools in the 1980s towards educating children in the least restrictive environment (LRE; Jansma & French, 1994). The LRE was where children with disabilities had greater opportunities to be placed in inclusive education settings if the child's needs were met (e.g., whenever possible) and provided the appropriate support (Block & Obrusnikova, 2007). The most restrictive environments were segregated such as residential institution, home-bound/hospital instruction, and segregated day school (Jansma & French, 1994). With the introduction of integrated environments, such as full-time special class in a regular school, part-time class in regular school, and regular class placement with support; the LRE of choice would be the inclusive setting in a regular class with no support. However, if the school environment could not provide the appropriate resources, then those resources, no matter the physical location, would be identified and provided for the child to meet her or his needs (Block & Obrusnikova, 2007; Jansma & French, 1994).

The term “inclusion” began to be used in the 1990s. Inclusion was defined as the philosophy of merging special and general education together where children are provided appropriate and individualized programs where needed (Block & Obrusnikova, 2007). The Canadian Charter of Rights and Freedoms (1982) and IDEA influenced inclusion in Canadian schools (Rousseau, Dionne, Vézina, & Drouin, 2009). Special Education in Canada parallels the US; however, in Canada education is a provincial responsibility with no federal legislation laws (Jansma & French, 1994). Québec in comparison to other provinces such as Ontario, Saskatchewan, Prince-Edward Island, and New-Brunswick, lagged behind in the adoption of inclusion (Rousseau, et al., 2009).

There still remains negative or inferior views of people with disabilities in society. Goodwin, Thurmeier, and Gustafson (2004) conducted a phenomenological study where 14 adolescents and younger adults with different types of physical disabilities were interviewed regarding their perceptions of how society views their participation in physical activity (PA). Three themes, defined as metaphors of disability, emerged from the data. The “don’t treat me differently” theme suggested members of the public stigmatized people with disabilities as dependent, pitiful, and socially rejected. The “managing emotions” theme suggested the participants were comfortable about their personal identities. However, they suggested the media did not portray an accurate representation of their lives. The “physical activity balances perceptions” theme suggested people with disabilities were viewed outside of their illness and demonstrated their abilities in a PA context. Fortunately, individuals with disabilities are being viewed more positively in society through the efforts of the Active Living Alliance for Canadians with a Disability, World Health Organization (WHO), and other like-minded organizations.

Understanding the past knowledge and history of APA may allow for better socially constructed teacher preparation programs, in-service pedagogy, and field research (Sherrill, 2004b). More importantly, it helps conceptualize assumptions and discover the need to further conduct evidence-based research with individuals with disabilities. A shift can be observed from a medical perspective where the focus was on the person’s disability to embodying self-determination to empower people with disabilities (e.g., Goodwin & Watkinson, 2000). Reid (2003) suggested that prior to conceptualizing the construct of self-determination as a path that persons with disabilities could take, it was assumed that an expert was “in charge” of the person with a disability. Thus, empowerment and self-determination are important constructs in APA



service delivery (Hutzler & Sherrill, 2007). Reid (2000; 2003) suggested that self-determination was an appropriate goal for persons with disabilities to pursue in relation to individual health and PA. He suggested individuals with disabilities need to feel in control of their lives, have the freedom to make personal choices about leisure activities, and be aware of their strengths and weaknesses (Reid, 2000).

### *Categorization of Disability*

This section of the literature review provides a definition of the term disability, an overview of the categorization of disabilities, and a thorough description of CP. A “disability” is an umbrella term which refers to the problems an individual may experience in functions (physiological and psychosocial), activity limitations, and participation restrictions (WHO, 2001). It is not a medical condition, but rather a concept of social construction with a dynamic interaction between the individual and the environment (Rosenbaum & Stewart, 2004). An “impairment” was defined as a significant loss or divergence in the body function or structure (WHO, 2001). It included an intellectual or cognitive dysfunction; however, it is not considered a disability.

The IDEA (2004) governs how states and public agencies offer services to youth with disabilities in the United States. According to IDEA, disabilities are grouped into 13 categories: autism, deaf/blind, deafness, hearing impaired, mental retardation, multiple disabilities, orthopedic impairment, serious emotional disturbance, specific learning disabilities, speech or language impairment, traumatic brain injury, visual impairment including blindness, and other health impairment (National Resource Center on ADHD, 2010). Sherrill (2004a) categorized disabilities in eight groups with an emphasis on sport. The first category, “infants and young children”, grouped together children from birth to eight years of age because the IDEA

legislation (1997) suggested children do not need to be assigned a disability prior to the age of nine. Thus, Sherrill identified children as having developmental delays prior to this age. The second category, “other health impairments” (OHI), was chronic or acute health problems that affected the child’s education. Some examples of OHI included obesity, diabetes, cardiovascular problems, hypertension, asthma, and cancer, which may also be referred to as secondary conditions. The third category combined children with learning disabilities, attention deficit hyperactivity disorder (ADHD), and developmental coordination disorder. The fourth category, “intellectual disabilities”, included people with Down syndrome and associated disabilities such as other chromosomal abnormalities, fragile X syndrome, Apert syndrome, and fetal alcohol syndrome. Individuals with an intellectual disability may demonstrate limitations in both intellectual functioning and adaptive functioning (e.g., social skills, dressing, communication skills).

The fifth category was called “serious emotional disturbance and autism spectrum disorder (ASD)”. The most common emotional disturbances included substance-related, psychotic, mood, anxiety, dementia, and eating disorders. ASD included autism, Asperger’s Syndrome (AS), and pervasive developmental disorder-not otherwise specified (PDD-NOS). The sixth category, “physical disabilities”, included three distinct groups of persons with disabilities: (a) orthopedic impairments; (b) CP, stroke, and traumatic brain injury; and, (c) “les autres” conditions and amputations. Orthopedic impairments focused on spinal paralysis and included spina bifida, spinal cord injuries, and poliomyelitis/postpolio syndrome. Sherrill rationalized grouping individuals with CP, stroke, and traumatic brain injury together as they had common needs.

Les autres conditions were “the others” that could not participate in the same sport

category as individuals with CP or spinal cord injuries. For example, people with muscular dystrophy, multiple sclerosis, and dwarfism may be placed in this category. The seventh category is “deaf and hard of hearing conditions”. Individuals who were deaf did not consider themselves as having a disability, and thus participated in their own sport events. The eighth and last category was “blindness and visual impairments”. It is important to note that this approach focused on a medical approach, and there are wide individual differences between and within each category (Squair & Groeneveld, 2003).

### *Cerebral Palsy*

All of the participants in the current research study had CP. Therefore, this disability will be discussed in greater depth. Cerebral palsy is “a chronic neurologic disorder of movement and posture caused by damage to the immature brain and accompanied by associated dysfunctions” (Sherrill, 2004a, p. 674). This disorder was named “cerebral” to denote the part of the brain affected and “palsy” to describe uncontrollable body movements or posture. The definition implies that it is nonprogressive, signifying that the brain will not deteriorate over time (Kriger, 2006). Individuals with CP acquire approximately 70-80 percent of brain damage in prenatal development and from unknown causes (Kriger, 2006). An individual with CP varies from mild, where the child is clumsy, to severe, where the child uses a motorized chair, uses assistive devices to communicate, and has almost no control over motor function (Sherrill, 2004a). Therefore knowing that a child has CP is not very informative for individuals working with that child and greater classification is required (Best & Bigge, 2010).

Various ways are used to classify CP such as topography, physiology, and a Gross Motor Function Classification System (GMFCS). The first method that CP is classified is by topography or the number of limbs involved (Pakula, Van Naarden Braun, & Yeargin-Allsopp,

2009; Sherrill, 2004a). The four types of CP include, (a) diplegia, (b) quadriplegia, (c) hemiplegia, and (d) triplegia. There are wide differences within each classification. For example, a child with diplegia may walk using no equipment, while another child also classified with diplegia, may use a walker or a wheelchair. Diplegia, also referred to as paraplegia, is where the lower limbs are affected more than the upper ones. Quadriplegia is where all four extremities are affected. Hemiplegia is where the entire right side or left side is affected. The last is triplegia where three extremities are affected, and it is usually both legs and an arm (Sherrill, 2004a).

Another classification method for persons with CP is through three physiological categories: spasticity, athetosis, and ataxia (Best & Bigge, 2010; Krigger, 2006). First, spastic CP affects 70-80 % of individuals with the disorder (Krigger, 2006). It is characterized through hypertonia where the muscles contract resulting in stiffness and scissor gait, which is a pigeon-toed walk, when muscles tighten abnormally around the hips. Next, the athetoid or dyskinetic type of CP affects 10-20% of people diagnosed with CP. It is characterized by involuntary, constant, and purposeless movements which is a problem to the head and upper limbs. When movement occurs, it overflows to other muscle groups leading to tremors, jerking, and shaking (Best & Bigge, 2010). The third type is ataxic CP which may be found in 5-10 % of children with CP (Krigger, 2006). It mainly affects balance and coordination. The three types of CP are often mixed and they are rarely found in their pure forms (Best & Bigge, 2010).

A third classification method is the GMFCS (Palisano et al., 1997). It is a five-level system for children with CP, between ages 0-12, that describes their self-initiated movement and focuses on sitting and walking (Palisano et al., 1997). The difference between the five levels are based on functional limitations and equipment used (e.g., manual wheelchair, power wheelchair, walker) rather than the quality of movement (Palisano et al., 1997). Within each level, four age

categories are provided, as motor function is dependent on age (Palisano et al., 1997). Children in level I perform gross motor skills independently, but have more difficulty with skills such as balance, coordination, and speed. Children in level II do not use equipment (or assistive devices), but have difficulty in performing gross motor skills on uneven terrain. Children require an assistive mobility device to walk for in level III. Children in level IV have limited independence, but may have self-mobility with a power wheelchair. Children in level V are severely limited in their self-mobility unless they operate an electrically powered wheelchair.

Individuals with CP have damage to the central nervous system (CNS) that affects both the brain and the spinal cord (Best & Bigge, 2010). Conditions associated with CP include sensory impairments, communication impairments, orthopedic deformities, nutrition and feeding needs, cognitive deficits, learning disabilities, and seizures (Best & Bigge, 2010). Sensory impairments include visual impairment which affects many daily living skills, mobility, reading, and writing. Children with CP can also have a hearing impairment. Communication impairments can include slurred, distorted or absent speech. In the latter, children who are unable to communicate via speech learn augmentative and alternative communication. This includes signs and gestures as well as manual communication board or simple switchboards to communicate yes and no (Sherrill, 2004a). It also includes a vast variety of computer technology to communicate that can be text or symbol based and accessed through eye control, head tracking, and different switches that can be attached to the wheelchair (Sherrill, 2004a). Furthermore, nonambulatory individuals and adults with spastic quadriplegia are at greater risk of osteopenia and osteoporosis (King, Levin, Schmidt, Oestreich, & Heubi, 2003). Some children with CP experience problems eating through the mouth and therefore receive nutritional supplements via gastrostomy or G-tube placed in the stomach. Furthermore, two thirds of individuals with CP

have an intellectual impairment (Kriger, 2006). Children with CP can vary tremendously in their intelligence from gifted to severe cognitive impairment. It should not be inferred that a child with a physical or speech disability necessarily has an intellectual disability (Best & Bigge, 2010). Lastly, a seizure is caused by damage to the CNS that may trigger abnormal electrical impulses (Best & Bigge, 2010). Epilepsy, which is the reoccurrence of seizure episodes, is more common in individuals with CP (Kulak & Sobaniec, 2003).

Thus, each child's educational needs are not met based solely on one impairment (Best, 2010; Best & Bigge, 2010). The children often require a team of different professionals to meet their educational needs. The term physical disability is often used, but it is important to note that there are associated secondary conditions (Best, 2010). For example, a child may be diagnosed with CP, but this may have an effect on his social interactions. Thus, there is no 'typical' individual with CP (Best & Bigge, 2010). Each child is unique and should have goals specific to her or his ability.

#### *The International Classification of Disability, Function and Health Model*

The WHO published the International Classification of Impairments, Disabilities, and Handicaps (ICIDH) in 1980 (WHO, 2001). The aim of ICIDH was primarily as a classification system (Rosenbaum & Stewart, 2004). It was suggested this model had flaws because it was unidirectional, paid insufficient attention to environment, and portrayed disability as negative (Rosenbaum & Stewart, 2004). In 2001, the WHO developed the International Classification of Disability, Function and Health (ICF) that adopted a holistic perspective of health to observe multiple factors that may affect the health of all individuals (WHO, 2001; see Appendix A). The ICF "provides criteria for classification, assessment, and intervention in health and disability" (Hutzler & Sherrill, 2007, p. 10).

The ICF considered the human function and disability of the individual (WHO, 2001). It illustrated an interactive and a three level relationship between a person's health condition, functional conditions, and contextual factors. Health condition was placed at the top of the model and it included disease and disorder. A disease is usually a biological condition while a disorder is often determined by signs and symptoms with no definitive diagnostic accuracy. The second level was functional conditions which was composed of three components: (a) body functions and structures, (b) activity, and (c) participation (WHO, 2001). Levels of functioning denote the positive interactions between the health condition and the contextual factors (WHO, 2001). Disability is the term used for issues that an individual may encounter with functioning (impairment, activity limitations, and participation restrictions; WHO, 2001). Body functions include the physiological as well as the psychological functions, while the structures include the anatomical parts of the body (WHO, 2001). For example, if an individual only has one leg, this does not signify that the individual is restricted in activities of daily living (ADL). A prosthetic leg may be an option to allow this individual to participate in certain activities. The loss of the leg is an impairment of the body structure and is not considered a disease or disorder (WHO, 2001). Another example of an impairment of body structure is the loss of vision due to an injury.

Activity referred to performing a task or an action during ADL and leisure (Hutzler & Sherrill, 2007; WHO, 2001). For example, shooting a basketball at a net. This task may be limited if the net is too high. Walking on an unlevelled terrain can be difficult for an individual who uses a walker. Participation is involvement in life situations (WHO, 2001). An example of participation would be playing for a basketball team. An individual may be restricted in the participation of certain activities. For example, an individual may want to ski, but cannot afford to rent the equipment.

The third level was contextual factors that included environmental and personal factors. Rosenbaum and Stewart (2004) suggested these factors were a significant addition to the ICF model from the previous ICIDH one because they may influence and modify all other components of the model. Environmental factors may be physical, social, cultural, or institutional in nature (Rosenbaum & Stewart, 2004). For example, environmental factors for children with CP can include the availability, quality, expertise, and focus of intervention programs (Rosenbaum & Stewart, 2004). Furthermore, family plays an important role in the lives of children with CP. Family members can help therapists to develop goals for children to achieve greater functional gains (Rosenbaum & Stewart, 2004). Personal factors include age, gender, education, lifestyle, and interests (Rosenbaum & Stewart, 2004). For example, the child is more likely going to participate in an activity that she or he enjoys. Thus, people working with children with CP should embrace the personal choices of the children and understand that every child is different (Rosenbaum & Stewart, 2004). The focus of the ICF model was about health by considering components of the model rather than a sole focus on the consequences of a disability (Rosenbaum & Stewart, 2004). The ICF model diverged from the medical model to promote functional activity that provided children with choices and preferences (Rosenbaum & Stewart, 2004). The interaction between functions, activities, and participation is related to health conditions and contextual factors which may be perceived as affordances or constraints to a healthy lifestyle (Hutzler, 2007).



### *Health and Children with Physical Disabilities*

Various definitions of “health” exist in the literature (Awofeso, 2005). The most common definition was created by the WHO (1948) which defined health as encompassing a complete state of social, physical, and mental well-being of all individuals. However, this definition has received three main criticisms (Larson, 1996). First, the word “complete” made it seem as though health was the ideal to achieve. Second, social well-being should not have been included in the definition as it constituted external factors. The term “psychosocial” was recommended to integrate mental and social components. Third, the definition was challenging to measure and operationalize across cultures. This type of criticism should be expected as Jadad and O’Grady (2008) suggested the term health might be difficult to define since, similar to beauty, it remains in the eyes of the beholder.

Health is a concern for all people. Mathers and Loncar (2006) predicted that, by 2030, the three global leading causes of death will be HIV/AIDS, depressive disorders, and heart disease. Most diseases can be preventable through lifestyle choices. The term “lifestyle” was defined as a modifiable set of behaviors, attitudes, and values people have in relation to their quality of life (WHO, 1999). For example, a modifiable lifestyle choice could be to incorporate a healthy eating habit or to participate in daily physical activity (DPA). Most chronic diseases leading to mortality, such as heart disease, cancer, lung disease, and diabetes, can be reduced through lifestyle behavior change (Glanz, Rimer, & Viswanath, 2008). Yet fast food consumption, poverty, and limited access to health care services have created major global challenges in health (Glanz et al., 2008). Although a healthy lifestyle may be encouraged, non-modifiable risk factors such as age, gender, ethnic background, and family history, also may affect an individual’s

lifestyle (Public Health Agency of Canada, 2010). For example, individuals are more prone to cardiovascular diseases as they grow older (Public Health Agency of Canada, 2009).

The health of typically developing children may be influenced by participation in DPA, reduction of sedentary activities, and adoption of good eating habits (Slawta, Bentley, Smith, Kelly, & Syman-Degler, 2008). However, there has been an increase in obesity and type 2 diabetes for children in North America (Katzmarzyk & Ardern, 2004; Slawta et al., 2008). For example, Shields (2006) compared direct measures of height and weight collected from Canada Health Survey (CHS) in 1978/79 to the Canadian Community Health Survey (CCHS) in 2004. In 1978/79, 15% of children between 2-to 17-years were considered overweight or obese. By 2004, the percentage had increased to 26% and, as such, children who are overweight or obese have almost doubled over the past two decades. Quality health promotion programs, in schools or in the community, may help prevent obesity, type 2 diabetes, and heart disease in youth (Slawta et al., 2008).

### *Social Well-Being*

Social well-being can be defined as the contexts that influence the health of people. In fact, the Public Agency of Canada (2010), emphasized that a healthy lifestyle includes a social network to create supportive environments. This literature review explored the family, school, and friends as social influences in the lives of children with disabilities. Of course, socialization does not only occur in a PA context. It can occur anywhere inside or outside of school.

*Family.* Parents and family members play an important role in family health. The family environment has been observed as vital to the development and well-being of children (Rosenbaum & Stewart, 2004). The role of the family is vital for children with physical disabilities, who also experience functional and cognitive limitations, because they place a high

dependency on their primary caregivers (Raina et al., 2005). The more severe the disability and related behaviors, the greater the effect on caregiver physical and psychological well-being (Raina et al., 2005). Family influence and support may be considered as important social determinants for all children to be able to reach their full potential (Kristén, Patriksson, & Fridlund, 2003). Parents and family members positively influenced their child with a disability through physical, emotional, and psychosocial assistance (Goodwin et al., 2004; Kristén et al., 2003; Taylor, Dodd, McBurney, & Graham, 2004). Some examples of negative influences include overprotection, lack of time, and lack of parental involvement such as driving the child to a friend's house (e.g., Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Seymour, Reid, & Bloom, 2009; Stevens et al., 1996).

Kristén and colleagues (2003) interviewed 20 parents of children and adolescents with physical disabilities between 9-15 years. This phenomenographical study explored parent perception of their influence on child participation in sport teams. The children and adolescents took part in orienteering, archery, or golf over a three-year period. Practices lasted one-to-two hours and were once per week. Three themes emerged. The first theme, "achieving good health", included the parent perceptions that the sporting activity was good for their child's health because the child felt good after the activity, spent time outside, and was learning a motor skill. The second theme, "being part of a group", suggested the children had a good time while meeting others and making new friends. The third theme, "learning a sporting activity", demonstrated the importance of participating in a PA from the perspective of the parents. Overall, the findings demonstrated that parents had a positive view of their child's participation in the sport program. Kristén et al. (2003) suggested future studies may explore differences between parent and child views about PA.

Taylor and colleagues (2004) interviewed 11 young individuals with CP, between 8-18 years ( $M = 12.7$ ,  $SD = 2.8$ ) and their parents after the completion of a home-based strength-training program. The program consisted of three exercises which were each repeated three times each exercise session. The program was performed three times per week and it lasted for six weeks. The encouragement and assistance of parents and family members helped their children to adhere to the exercise program. Environmental and personal factors influenced individual participation and adherence to the program. The environmental factors consisted of parents and family member support, availability of equipment, completion of an exercise logbook, and support from a physiotherapist. The authors suggested that family support was the most important environmental factor on program adherence. The personal factors included the participants' motivation, health factors such as fatigue, and effective time management. The most important personal factor included the individual choice to decide to participate in the strength-training program.

Goodwin and colleagues (2004) captured the metaphors of 14 participants with physical disabilities, between 14-24 years, through a phenomenological approach. They defined these metaphors as the perceptions of individuals with disabilities on societal views about persons with physical disabilities. The participants expressed that, beyond their immediate family and close friends, they received mostly negative messages. The participants expressed that their families and friends provided them with optimism, support, and encouragement.

Family members may also negatively affect youth participation in a PA context. For example, Rimmer and colleagues (2004) conducted a study where 42 participants were interviewed in focus groups across 10 different American cities. Barriers and facilitators that may have affected participation in DPA for people with disabilities were explored through four

different groups (e.g., people with disabilities, architects, fitness/recreation professionals, and city planners and park district managers). Ten themes emerged in this study: (1) “built and natural environment”; (2) “economic issues”; (3) “emotional and psychological barrier”; (4) “equipment”; (5) “use and interpretation of guidelines, codes, regulations, and laws”; (6) “information”; (7) “professional knowledge, education, and training issues”; (8) “perceptions and attitudes of persons who do not have a disability, including professionals”; (9) “policies and procedures both at the facility and community level”; and (10) “availability of resources”. The emotional and psychological barrier portrayed by people with disabilities suggested they had lack of support from family members and friends to access facilities and participate in recreation programs. Furthermore, fitness/recreation professionals stated family members of people with disabilities tended to be overprotective and therefore the individuals with disabilities did not participate much in DPA.

However, parents of children with disabilities were faced with the challenge of managing their child’s chronic condition while trying to cope with everyday life (Raina et al., 2005). One hundred and one adolescents, between 1-16 years and with different physical disabilities, completed the Health Behaviors in School-Aged Children with two additional questions (Stevens et al., 1996). The data was compared to a sample of 7,020 Canadian students. Children with physical disabilities expressed more positive views about school than children without disabilities. Yet, they expressed fewer aspirations for their future endeavors. Family relationships seemed to be strong or stronger for children with physical disabilities in comparison to the national sample. However, children with physical disabilities expressed parents as being overprotective.

*School.* The school environment may play an important role in the socialization process for children with and without disabilities (Block & Obrusnikova, 2007). Low retention rates of adolescents in Québec high schools led the Ministère de l'Éducation, du Loisir et du Sport (MELS) to reform the Québec Education Program (QEP) with a competency-based approach (QEP, 2001). The main goal of the educational reform was for 85% of students to graduate from high school prior to the age of 20, 60% to receive a CEGEP diploma, and 30% to obtain a bachelor degree (A new direction for success, 1997). Other growing societal challenges included the increase in the number of children with disabilities in schools and the number of illiterate adults (QEP, 2001).

The QEP embraced a constructivist framework which described the importance of placing the child at the centre of the educational process for the internalization of learning. Thus, the policy in Québec changed from providing education to all to success for all students (QEP, 2001). The reform aimed to achieve the success for all students through the learning knowledge at school, fostering of social development, and providing qualifications to the students with special needs (Ministère de l'Éducation du Québec [MEQ], 1999). The policy document on adapting schools for children with disabilities alluded to quantitative data that demonstrated an increased number of children with disabilities who were included in community schools (MEQ, 1999). However, the MEQ (1999) stated a main concern was a lack of data on the quality of services provided to students with special needs and the educational results obtained from these students. Thus, the question arose of whether school provided an effective socialization process for children with disabilities.

Twenty-four parents expressed their views on inclusion in a Québec context through a case study approach (Rousseau et al., 2009). Most parents suggested it was essential for them to

be initially involved in the school environment to help their child integrate effectively and acclimatize to the school. Most parents suggested a continual involvement in their school community throughout the education of their child. Teachers also play a role in the social inclusion of all children in the school. For example, teachers may adopt a positive attitude, model appropriate behavior, and encourage and reinforce positive social interactions (Block, 2007).

*Friends.* Children with disabilities may enhance their social development by having friends (Woolfolk, Winne, & Perry, 2003). Physical activity contexts can provide important means to promote positive peer relationships and enhance prosocial behaviors (e.g., sharing, helping others, cooperating on a team to achieve a goal). Seymour and colleagues (2009) interviewed eight children with a disability and eight children without a disability to explore what friendship in a physical and health education (PHE) context meant to all of the participants. Four themes emerged from the study. The first theme, “development of friendship”, explored the development of friendships in different contexts. Children with disabilities, in comparison to children without disabilities, talked mainly about school friends since they did not get the opportunity to see their friends outside of school. This constraint may have occurred because of different reasons such as parent involvement was required or their friend’s house was not adapted for persons with physical disabilities. The second theme, “best friend”, included the description, interaction, and affective outcomes of their best friend. Children with disabilities spoke mainly about sedentary activities they played with their best friend at home, while children without disabilities spoke about playing physical games and sports. The third theme, “preferred physical activities and outcomes of physical education”, suggested that children with disabilities participated less in organized activities outside of school compared to children without disabilities. The final theme, “dealing with disability”, demonstrated the ability awareness of all

children about disability. Children also spoke about adapting activities in PHE based on the needs of the children in the class.

Children with disabilities have also expressed negative emotions towards participation in PHE in relation to friends and peers. For instance, a study conducted by Blinde and McCallister (1998) demonstrated that children with disabilities expressed being embarrassed in PHE. One child stated that he did not feel good enough to participate in PHE and his friends perceived him in a similar manner. He was never chosen to be on a team. Parents also viewed sporting activities for their children as being part of a social group, by experiencing a feeling of togetherness, having a good time, and making new friends (Kristén et al., 2003).

### *Physical Well-Being*

Physical well-being can be defined as health-related factors associated with the physical body. For example, there are myriad of anatomical, physiological, genetic, and neurophysiological factors that help to determine sound physical functioning and associated human movement (Wall, Reid, & Harvey, 2007). Physical activity is one of the important ways to help improve the health of the human body (Biddle & Mutrie, 2008). Physical activity has also been described as movement of the body to expend energy (Biddle & Mutrie, 2008), DPA as an important component of this energy expenditure. For instance, youth can participate in DPA through a variety of ways (e.g., sports, recreation, play, active transport, PHE, dance, etc.).

Public health emphasis has become increasingly focused on the promotion of PA for a lifetime in North America (Pate et al., 2006; Welk, 2008). McKenzie (2007), for example, suggested targeting the educational system through “health-related physical education” (HRPE) to promote PA as a positive lifestyle behavior. However, education is a provincial/state responsibility in North America; therefore, making it challenging to impose federal educational



policies including those for students who require special education (Cooper, Cibulka, & Fusarelli, 2008; Smith, 1992). Still, researchers advocate the importance of promoting activity and health in schools to increase the likelihood for students to be active and healthy outside of school (Pate et al., 2006).

Health is of great importance for youth with physical disabilities who (a) tend to lead more sedentary lifestyles, (b) are at higher risk of acquiring secondary conditions in adulthood, (c) participate in fewer activities outside of school, (d) may increase functional ability with DPA (Causgrove Dunn & Goodwin, 2008; Steele et al., 1996; van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). Some examples of secondary conditions associated with disability in youth include chronic pain, fatigue, obesity, diabetes, osteoporosis, urinary tract infections, respiratory problems, cardiovascular disease, body image dissatisfaction, social isolation, diminished self-concept, depression, and decreased strength, endurance, fitness and flexibility (Causgrove Dunn & Goodwin, 2008; Fowler et al., 2007; Simeonsson, Sturtz, McMillen, & Huntington, 2002; van der Ploeg et al., 2004). Many of these conditions may be preventable health problems (e.g., medical, emotional, or social) that may be managed through DPA and may have a positive effect on individual quality of life (Causgrove Dunn & Goodwin, 2008; Liou et al., 2005). For example, DPA improved quality of life and prevented or delayed further disability (Liptak, 2008; van der Ploeg et al., 2004). Thus, a key strategy for health promotion initiatives for children with disabilities is PA (Kelly & Darrah, 2005; Public Health Agency of Canada, 2008).

Both PHE and PA may be considered as interrelated health interventions for school-aged children. The terms PHE and PA are often used interchangeably; however, a distinction between the terms has been made (Canadian Association for Health, Physical Education, Recreation and

Dance [CAHPERD], 2005). PHE is a program that is well-planned, structured and taught by qualified and enthusiastic professionals (Physical & Health Education Canada [PHE Canada], 2008). The focus of PHE is on youth, from kindergarten to grade 12, to develop skills, knowledge, and attitudes that are essential for an active and healthy lifestyle into adulthood (PHE Canada, 2008). PHE educates students in different activities to promote PA outside of the school environment. It is expected that a physically educated individual will lead a physically active lifestyle (PHE Canada, 2008). On the other hand, PA is a more general term. The focus in a PA context is more of a general participatory nature whereas student learning in PHE is governed by a predetermined provincial government curriculum. PHE has been expected to build qualities in youth that can be translated into lifelong participation in PA.

Thus, school can play an important role in developing the PA behaviors of children (Sit, McManus, McKenzie, & Lian, 2007). In Québec, the MELS (QEP, 2001) required PHE professionals to instruct children to: (a) perform movement skills in different PA settings, (b) interact with others in different PA settings, which is expected to lead to (c) adopt a healthy, active lifestyle. The first two competencies targeted in-school activities, while the third competency targeted both in- and out-of-school activities. A challenge for PHE teachers is to find ways to encourage youth to be physically active and healthy as part of their lifestyle. This educational outcome is certainly important for youth with physical disabilities who are more inactive and pursue greater amounts of sedentary leisure activities than youth without disabilities (Imms, Reilly, Carlin, & Dodd, 2008; Law et al., 2006).

Pate and colleagues (2006) also advocated for the important role of PHE teachers to empower youth by making links between in-school and after-school hours to increase opportunities to become physically active. For example, the WHO (2010) recommendation of 60

minutes of DPA may help children to achieve the QEP's third competency. However, these recommended DPA levels for all children may not be accomplished in PHE classes because instructional environments may not be designed for the sole purpose of DPA and 60 minutes of DPA exceeds most PHE weekly time allotments across Canada.

Sit and colleagues (2007) used the System for Observing Fitness Instruction Time (SOFIT) to assess PA levels, lesson context, and teacher behavior during PHE and recess in five Hong Kong schools for children with special needs. There were two schools for children with intellectual disability, one school for children with physical disability, one for children with hearing impairment, and one for children with visual impairment. Overall, children with disabilities were active for less than half the allotted time in PHE (41.9%). Children with physical disabilities were the least active in both PHE and recess in comparison to the other groups of disabilities.

Furthermore, PHE experiences for children with disabilities have not always been positive (Fitzgerald, 2005; Goodwin & Watkinson, 2000). For example, Fitzgerald (2005) interviewed five children with disabilities to gain their embodied experiences about PHE and school sport. The convenience sample included one child with a hearing impairment, three children with physical disabilities, and a fifth with a learning disability. The four themes that emerged from the study had a negative connotation. The first theme was "the status and value attributed to different activities" where the children suggested their PHE teachers did not afford as much importance to their activities as they did with their able-bodied peers. For instance, a boy explained that if you were the football team captain the whole school knew who you were. However, nobody knew the sport of boccia played by children with disabilities. The second theme, "embodying difference through the habitus" described the notion of difference. Children

with disabilities compared themselves to their peers and expressed that PHE portrayed the notion of “normality”. The third theme, “legitimate participation and attaining capital”, suggested that children with disabilities may be successful in PA, but were not recognized by peers. Children stated they often felt excluded from activities and peers would be calling them names. The fourth theme, “the physical education teacher as the nurturer of ability”, included child expressions of positive and negative views of their PHE teachers. On the one hand, some PHE teachers were perceived as considerate, thoughtful, attentive, fair, and filled with laughter. On the contrary, children perceived some PHE teachers as exclusionary and focused solely on children who were able-bodied.

Youth with disabilities are also more likely to engage in sedentary leisure activities and participate less in PA. For example, Steele and colleagues (1996) compared adolescents from a national survey to adolescents with different types of physical disabilities and determined that 39% of the participants with physical disabilities did not exercise in comparison to only 6% in the national survey. Zwier and colleagues (2010) used a multiple regression analyses to compare PA levels (measured by metabolic equivalents or METs) of 5- and 7-year-old children with CP and typically developing peers. Children with CP spent an average of 3.4 hours/week in PA ( $18.1 \pm 11.2$  METs x h/week) while typically developing children were active for an average of 5.8 hours/week ( $31.9 \pm 14.4$  METs x h/week). According to the WHO (2010), typically developing children should be active 60 minutes every day, this means 7 hours per week or 35 METs x h/week. Twenty five percent of the typically developing children met the hours per week of PA while only 7% of the children with CP did. However, limitations to this study include that the same MET was applied to all children not considering that a child with CP might be expending more energy, but allotted the same amount of MET as typically developing children (Zwier et al.,

2010). A second limitation is that active therapy was not included in the assessment of PA (Zwier et al., 2010). A third limitation was the lack of validity and reliability in the questionnaire (Zwier et al., 2010). Children in general participate in activity in short bursts and therefore this may not have been reported by parents.

Youth with disabilities participated in fewer activities outside of school when compared to children without disabilities. The sedentary lifestyle behaviors adopted by children with disabilities and the lack of PA may lead them to acquire secondary conditions (Rimmer et al., 2004). These conditions may be chronic pain, fatigue, and osteoporosis in children with CP (Fowler et al., 2007). Physical activity may help individuals with physical disabilities in daily living by improving their functional abilities. For instance, children with CP were faced with many challenges when participating in PA such as weakness, muscle spasticity, and deficient balance (Fowler et al., 2007). These challenges may lead to further lack of PA participation. These challenges may create a vicious circle because as their PA involvement is reduced due to the lack of PA, in turn, their functional abilities may also decrease. For instance, muscle strength training for children with CP has improved strength and therefore increasing functionality (Damiano & Abel, 1998). In a review conducted by Fowler and colleagues (2007), it was suggested that it is difficult to quantitatively measure muscle strength for children with CP. This measurement issue may occur because they are required to exert a maximum effort consistently, walk, and be able to follow directions, which is not always the case for all children with CP. Rosenbaum and Stewart (2004) suggested to look at the natural environment to assess the capacity of children with CP be it at home, school or community. Such an exercise for children with CP is aquatics. Kelly and Darrah (2005) reviewed three aquatic exercise studies and concluded that the aquatic environment helped children with CP improve flexibility, respiratory

function, muscle strength, gait, and gross motor function. In summary, there has been a lack of PA participation in different contexts for children with disabilities, including children with CP.

Physical activity for children with CP should be implemented at a young age to facilitate the early adoption of a healthy lifestyle. Children with CP and their families faced many barriers to PA participation such as lack of programs in community, safety concerns, exclusionary practices, inadequate equipment, inaccessibility to resources, perceptions of people without a disability, transportation issues, and financial challenges (Fowler et al., 2007; Rimmer et al., 2004). Physical activity can aid in the overall well-being and quality of life of individuals with CP. Thus, the understanding of what a healthy lifestyle represents for children with CP may help in the construction of intervention programs while considering their PA preferences.

### *Mental Well-Being*

Mental well-being was defined as a state where “every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community” (WHO, 2009, “Mental health: A state of well-being”, para. 1). Chronic pain, social isolation, and loss of functionality and independence associated with CP can affect the mental health of individuals with CP (Kriger, 2006). Furthermore, parents with psychological distress (e.g., depression, anxiety) tend to create an environment where the children with CP have similar problems (Wiley & Renk, 2007). Thus, assisting the mental health of parents of children with CP may prove to be an effective intervention for the whole family (Wiley & Renk, 2007). A study conducted by Janssen and colleagues (2010) determined that health-related quality of life (HRQoL) for children with CP decreased with a higher prevalence of internalizing mental health behaviors. HRQoL consisted of no physical complaints, motor functioning, autonomous functioning, cognitive functioning,

social functioning, positive moods, and no negative moods factors (Janssen et al., 2010).

Children with CP had a lower level of HRQoL in comparison to children without disabilities.

They suggested the greater the effects of the disability on child motor abilities, the lower the HRQoL.

According to a review on PA and school-age children, few quantitative studies linked PA and mental health (Strong et al., 2005). The three constructs explored included anxiety, depression, and physical self-concept. Participation in PA improved measures of anxiety and decreased symptoms of depression. The field of APA may view PA as an opportunity to develop identity and enhance perceptions of competence and self-worth (Taub & Greer, 2000).

Goodwin and Watkinson (2000) conducted a phenomenological study to explore the perspectives of children with physical disabilities in an inclusive PHE setting. The themes revealed positive and negative experiences represented by “good days” and “bad days”. The good days theme included sense of belonging, skillful participation, and sharing in the benefits. A “sense of belonging” property suggested the children enjoyed being part of an inclusive PHE class for various reasons. For example, peers without disabilities provided encouragement to the children with disabilities. The “shared the benefits” property suggested the children recognized the importance of the PHE program. The “skillfull participation” property demonstrated that children with disabilities enjoyed demonstrating their skills to others. The bad days theme included social isolation, questioned competence, and restricted participation. Children felt “social isolation” by rejection from peers, lack of communication with peers, and the perception of peers about their body. Children felt their “competence questioned” when they were not able to meet performance standards. “Restricted participation” was perceived due to lack of teacher support and physical barriers, such as the playground not being accessible to wheelchairs.

Youth with physical disabilities may have friends at school but relationships after school and in the evenings are limited (Stevens et al., 1996). Youth with various types of disabilities reported greater levels of psychosocial challenges than their peers without a disability (Hogan, McLellan, & Bauman, 2000). These issues included more interpersonal conflict, being less happy with life, lonelier, and feeling more isolated. Steele and colleagues (1996) incorporated the same sample as Stevens and colleagues (1996) and reported that youth with physical disabilities play games less with their friends than youth without disabilities.

### *Qualitative Perspective*

This section of the review of the literature explores different approaches in qualitative research and it includes discussions about research design, with special attention paid to phenomenology, children's voices in qualitative research, and interviewing. Qualitative research in the behavioral and health sciences has grown in the past decade (Creswell, 2007). Many different qualitative approaches have been used by researchers in various disciplines. Creswell (2007) described five approaches to qualitative research: narrative research, grounded theory, ethnography, case study, and phenomenology. These qualitative approaches differ in the primary objective of the study and are described from the perspective of Creswell (2007). Narrative research focuses on chronologically ordering the meaning of the experiences of a few individuals through the stories they tell. The grounded theory approach aims to discover a theory by generating data through participants' experience of a process. This approach often helps to explain practice or provide a framework for future research (Creswell, 2007). Ethnography focuses on researching the shared patterns of values, behaviors, beliefs, and language of a specific culture to understand in greater depth that culture. A case study is a more structured approach that explores an issue through one or multiple cases within a bounded system. The



researcher defines the boundaries, for example, looking at how children play in a playground versus a school setting. The phenomenology approach focuses on exploring a phenomena through the lived experiences of the participants (Creswell, 2007).

Flynn and colleagues (2006) suggested that “while quantitative studies may provide data on effectiveness of a program, qualitative studies are better suited to describe and therefore understand the key phenomenon that cannot be easily captured by quantitative studies” (p. 11). The researcher is considered as the research instrument (e.g., tool) to elicit data directly from the participants in the qualitative approach (Creswell, 2007). A qualitative researcher is interested in finding out more about the meaning of an experience through the voices of the study participants.

### *Research Design*

Creswell (2007) suggested that the research design in qualitative work begins with assumptions, followed by the research paradigm, and then the interpretive framework. All three stages influence how the research will be conducted. Research assumptions are often overlooked in the behavioral sciences (Strean, 1998). According to Creswell (2007), it is important to explicitly state the assumptions of a phenomenological study since this approach has a strong philosophical component. The assumptions for this study are organized according to Strean’s (1998) guidelines for three assumptions: paradigmatic, prescriptive, and causal. Examples of each assumption specific to this study are provided. Paradigmatic assumptions are basic organizing ideas that we take for granted and are the hardest to uncover (Strean, 1998). First, an assumption was made that children with physical disabilities were able to discuss what a healthy lifestyle represented for them. The researchers questioned whether children with physical disabilities were capable of sharing their experiences with a researcher in the scrapbook interviewing technique. Clearly, APA studies have demonstrated that youth with different

disabilities effectively utilized visual approaches in the qualitative method tradition (Fitzgerald, Jobling, & Kirk, 2003a; Goodwin & Watkinson, 2000; Harvey et al., in press).

Prescriptive assumptions are daily judgements of what we believe is the correct thing to do; they are value-based (Strean, 1998). For example, would the children follow instructions with the disposable camera provided and answer truthfully to the interviewer's questions? Fitzgerald, Jobling, and Kirk (2003b) conducted a student-led research study in two schools to explore the experiences of children with disabilities regarding PHE and sport. The researchers assumed that students would care about the research process. A second example falling under this assumption is the notion that the reverse integration program, where my study was conducted, was an ideal educational setting. However, there has been many debates and controversies in regards to the best school setting for individuals with disabilities (Causgrove Dunn & Goodwin, 2008).

Causal assumptions are the easiest to uncover and are based on an "if-then" process (Strean, 1998). An assumption that fell under this category is if the scrapbook interviewing technique would be used, it would produce richer, more in-depth data. Most research previously conducted for children with disabilities did not use visual techniques to aid recall and reflect information during interviews with children (e.g., Kristèn, Patriksson, & Fridlund, 2002). A second assumption is that parent interviews would help the researcher to learn about the children. Greene and Hill (2005) suggested the data collected from the parents should be viewed as complimentary to child experiences.

Furthermore, assumptions from a researcher positioning perspective may be considered. As a qualitative inquirer, active participation in the study environment was of great importance. I was able to obtain a deep and rich insider's perspective associated with the adoption of a healthy

lifestyle for youth with physical disabilities. I also obtained invaluable first-hand knowledge of the QEP PA levels of youth through my four pre-service PHE fieldwork experiences. In fact, I conducted my last student teacher experience at the research location. I further worked as a PHE and aquatic teacher at the site for three additional months and had an insider perspective of this specific community. Thus, my interest in the fields of APA and pedagogy enabled me to pursue a reflective practice where I was able to interact closely with the participants, gained their trust, and conducted my research project. However, as the primary researcher, I attempted to bracket my biases and assumptions so as not to influence the data (Creswell, 2007). For instance, a child might discuss an activity by not explaining how she or he was introduced to the activity. I might not think of posing a question on the topic because of my involvement in the environment as I may have believed that I already knew the answer.

A paradigm is a worldview and it is hypothesized as the underlying beliefs which influence the interpretations of the researcher in the research process (Creswell, 2007; Patton, 2002). A social constructivist worldview was used where the researcher was trying to understand the world of the participants by providing them with a voice (Creswell, 2007). I followed an inductive, bottom-up approach to develop patterns of meanings by referring back to the interview data, videotaped interviews, field notes, observations, and documents, rather than imposing an apriori theory that may be found in quantitative research (Creswell, 2007; Patton, 2002).

A pedagogic stance, or a research frame, reflected in van Manen's research tradition, was used during the research. According to van Manen (1997), phenomenology research is a caring act, where thoughtfulness and sensitivity to the lived experiences of the participants played a key role. Researchers are interested in finding out more about a topic they care about while remaining sensitive to the uniqueness of each individual.

### *Phenomenology*

Phenomenology is the research of studying the lived experience (van Manen, 1997). The lived experiences are understood through concepts and ideas expressed through language. Although words may not fully be able to attain the uniqueness of our inner thoughts, it may be the only method used to express the experience one lives (van Manen, 1997). The phenomenological approach aims at exploring the essence of the lived experiences of the participants instead of controlling the variables and context (Giorgi & Giorgi, 2008; van Manen, 1997). Essence makes something “the thing that it is” and without this essence it would not be the same thing (van Manen, 1997). The focus of phenomenology research is “to transform lived experience into a textual expression of its essence” (van Manen, 1997, p. 36). Meanings are derived from the individual descriptions of the participants (Moustakas, 1994).

The phenomenological method does not have a distinct procedure to follow but it does follow tradition and scholarship. It requires the researcher to be open to experience while remaining reflective, insightful, and sensitive to language (van Manen, 1997). van Manen’s (1997) methodological structure consists of six dynamic research activities. First, “turning to the nature of the lived experience” emphasizes that the phenomenological approach is a research concept in which the starting point is the lived experiences of the participants. Second, “investigating experience as we live it”, demonstrates awareness of our experiences and exploring the lived experiences of the participants while considering the context. Third, “reflecting on essential themes”, is a thoughtful process on the part of the researcher to describe what constitutes the nature of this particular lived experience. Fourth, “the art of writing and rewriting”, explains the challenges of interpreting speech through writing. Fifth, “maintaining a strong and oriented relation”, refers to the researcher being side-tracked. Phenomenology is

demanding and the researcher must remain grounded in the central research question. Finally, “balancing the research context by considering parts and whole”, refers to how easy it is to get lost in the writing, and question oneself about what the next step should be. Throughout the process, van Manen (1997) recommended to step back and to remember the bigger picture in order to observe how each part contributes to the whole. The themes which emerge should be viewed as systematic to the study of human experience.

It is important to consider what phenomenology cannot do and what it should not be described as. It is not based on the science of facts or to prove that one method is more effective than another; instead it is based on experience (van Manen, 1997). Also, through this approach, researchers do not make generalizations as the uniqueness of the human experience should remain intact to develop understanding (van Manen, 1997). Hence, phenomenology is interested in what is unique – what is different about this phenomena? Phenomenology asks questions about meaning.

### *Children's Voices in Qualitative Research*

This section in the research design is devoted to the importance of research *with* children and not *on* children. Children have been included as legitimate participants in qualitative research for the past two decades only (Tusdall, Davis, & Gallagher, 2009). For example, children may not have been asked to speak, the qualitative paradigm may not have been overt, or it may have been believed that children could not speak for themselves (Sanders, 1996).

There has been a growth in the qualitative research literature about youth experiences in PA, PHE, and sport contexts. O'Sullivan and MacPhail (2010) dedicated a text to research about the voices of youth in different PA contexts. The book topics covered different racial, ethnic, gender, and socio-economic groups, as well as different methodological approaches to research

with children. For example, Hickey and Fitzclareng (1999) explored the challenges of masculinity in a PHE class through a narrative approach to pedagogy. Holt and colleagues (2009) explored perceptions of neighborhood PA opportunities by interviewing Canadian inner-city children, school staff, and youth workers. Children were asked about positive and negative features of their neighborhood, PA opportunities and constraints, and their involvement in PA after school and on weekends. Qualitative research about typically developing children about PA experiences has influenced and informed current effective and equitable practices (O’Sullivan & MacPhail, 2010).

Historically, research with people with disabilities followed the medical model; thus, the children were viewed as research objects instead of participants (Fitzgerald, 2009; Greene & Hill, 2005). Children with disabilities were viewed as passive and dependent; thus, their voices were not heard (Priestley, 1998). van Manen (1997) emphasized that one should do research with individuals because one has an interest in the human sciences and not for the sake of doing research. This approach requires that the researcher has a phenomenological sensitivity to the lived experiences of the children, meaning an interest in finding out more about the children’s realities and lifeworld (van Manen, 1997).

Children’s perspectives should be valued and the researcher should be interested in finding out more about how children understand, interpret, negotiate, and feel about their daily lives (Greene & Hill, 2005). The pedagogical stance embodies the notion that the children are our teachers and thus we can listen and learn from them (van Manen, 2002a). This research was conducted to share the stories of children with physical disabilities.

How the research is conducted is important since the children should be actively engaged in the research process (Fitzgerald & Jobling, 2009). For example, Harvey et al. (2009)

interviewed six children with ADHD and six without ADHD regarding their PA experiences. They suggested that youth, ages 9-12 years, had difficulty expressing themselves through open-ended questions. Fitzgerald and Jobling (2009) suggested there is a need to undertake research to go beyond one-dimensional space. For example, focusing strictly on the school context instead of looking at how other environments influence the child should be avoided. In my study the children shared their perspective of what a healthy lifestyle represented for them in home, school, and community contexts. This multi-dimensional approach required the researcher to use a method to capture the lived experiences of the children. Hence, one of the reasons for using the scrapbook interviewing technique and encouraging the children to bring artifacts to the interviews (Harvey et al., in press).

Spencer-Cavaliere and Watkinson (2011) suggested there is a lack of qualitative research regarding PA and youth with disabilities. Fitzgerald (2009) stated there is a lack of children's voices in PA research. Children have a lot to offer and to share, and it is important to value their contribution to the research process (Fitzgerald, 2009). For example, an original research approach, conducted with eight children with severe learning difficulties, consisted of 13 tasks in nine one-hour sessions. Students went through a task-based approach to encourage their active involvement in the research process. In tasks one-to-eight, children chose symbols of PHE and free-time activities and were encouraged to discuss the activities verbally or through a communication device. In tasks nine and 10, students shared their favorite activities with classmates and were interviewed by the researchers. The final three tasks focused on further exploring why children do certain activities. This innovative pilot study allowed the researchers to gain a greater insight about PHE experiences, and then linked it to free-time activities that were determined to be mainly sedentary. Also, PA in general was minimal beyond the school

environment for these eight children with severe leaning difficulties. The research project allowed the students to provide their perspective on activities. Students played the central role in this research process. Having asked solely parents, teachers, or physiotherapist would not have yielded similar responses. “Childrens’ expression of need and experience may aid in the sensitive selection and modification to activities” (Goodwin, 2001, p. 16).

### *Interviewing*

Research with children is not an easy task to accomplish if done correctly (Greene & Hill, 2005). Researchers can easily pose questions a certain way to get desired responses from children. For example, what is healthy about PHE? This question assumes that the child believes that PHE is healthy and she or he must now answer why she or he believes that is the case. Instead a question such as, what do you do in school that is healthy?, is open-ended and does not persuade the child that a certain subject or activity in school is healthy. Children can also easily succumb to answering questions in a socially desirable way (Greene & Hill, 2005). This signifies that they will answer depending on what they believe the interviewer wants to hear. The interviewing process in this research study was about co-constructing a story about the meaning of healthy lifestyle for children with physical disabilities.

There is no cookbook on how to interview children (Westcott & Littleton, 2005); However, I claim to be aware of my pedagogic thoughtfulness or tact, and my reflexivity throughout the research process (van Manen, 2002). Pedagogic thoughtfulness or tact is a special kind of knowledge. Reading education literature only provides an external knowledge. It is the attention to details, the care one provides to the uniqueness of each child and situation, and the ability to distinguish what is appropriate that creates the pedagogical thoughtfulness or tact (van Manen, 2002). The researcher should be aware that no two children experience a situation the



same way. Reflexivity suggests that a researcher is self-aware of the cultural, political, social, linguistic, and ideological origins of one's own perspective (Sparkes, 2002). A reflexive researcher involves self-questioning and self-understanding of themselves, the participants, and the audience (Patton, 2002).

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February, 2011

To Whom It May Concern:

The purpose of this contribution letter is to confirm that the co-author (William Harvey) and the candidate (Cindy Pressé) are in agreement that the manuscript entitled *Exploring Healthy Experiences of Youth with Physical Disabilities* be placed in the candidates Masters thesis. The candidate's roles in this study included collecting and organizing the data, performing a qualitative analysis of the data, writing the manuscript under the guidance of the co-author and making modifications to the document in response to his comments.

I, the candidate, acknowledge the aforementioned roles and the co-author (William Harvey) contributions to the manuscript entitled *Exploring Healthy Experiences of Youth with Physical Disabilities*.

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Cindy Pressé

I, the co-author, agree that the candidate, Cindy Pressé, include the manuscript entitled *Exploring Healthy Experiences of Youth with Physical Disabilities* in her Masters thesis.

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William Harvey

Running head: LIFESTYLE OF YOUTH WITH PHYSICAL DISABILITIES

Exploring Healthy Experiences of Youth with Physical Disabilities

(February, 2011)

### Abstract

This phenomenological study explored lived health experiences of seven children with physical disabilities through a scrapbook interviewing technique where photographs were utilized as prompts to discuss these experiences (Harvey et al., in press). The children with physical disabilities, between 9-13 years, co-constructed their health experiences with the primary researcher (Phoenix, 2010). Four themes emerged from thematic analyses. The *my scrapbook* theme demonstrated the effectiveness of the interviewing technique to gain a child-driven understanding of health. The *people around me* theme reflected the importance of family members while the *what I do during my free time* theme demonstrated leisure activities of the participants. The *what helps me and what doesn't* theme identified affordances and constraints that enabled or constrained the children to incorporate healthy behaviors in their lifestyles. The children told positive stories about health that may help to create child-friendly physical activity and health interventions at home, school, and community.

(150 words)



## Exploring Healthy Experiences of Youth with Physical Disabilities

The World Health Organization (WHO) developed the International Classification of Disability, Function and Health (ICF) that adopted a holistic perspective of health to observe multiple factors that may affect the health of individuals (WHO, 2001). The WHO (1948) defined “health” as encompassing the social, physical, and mental well-being of all individuals. A “lifestyle” was defined as a modifiable set of behaviors, attitudes, and values people have in relation to their quality of life (WHO, 1999). For example, a modifiable lifestyle choice could be to incorporate a healthy eating habit or to participate in daily physical activity (DPA). Most chronic diseases leading to mortality, such as heart disease, cancer, lung disease, and diabetes, can be reduced through lifestyle behavior change (Glanz, Rimer, & Viswanath, 2008). Yet fast food consumption, poverty, and limited access to health care services have created major global challenges in health (Glanz et al., 2008).

Social well-being can be defined as the contexts that influence the health of people. For example, the support of parents and other family members was vital towards child development and well-being (Fitzgerald & Kirk, 2009; Rosenbaum & Stewart, 2004). Parents viewed sporting activities for their children as an important part of social well-being because they experienced a feeling of togetherness, had a good time, and made new friends (Kristén, Patriksson, & Fridlund, 2003). The encouragement and support of parents and family helped children with cerebral palsy (CP) to adhere to a home-based strength-training program (Taylor, Dodd, McBurney, & Graham, 2004). The school setting may also play an important role in the social well-being of children with disabilities. Eight children with a disability spoke about their friends in physical and health education (PHE) since they did not get the opportunity to meet these peers outside of regular school hours (Seymour, Reid, & Bloom, 2009). Further investigation needs to be conducted

about youth with CP and social activities with friends outside the home because children with CP were at a higher risk of peer rejection and social isolation (Kriger, 2006; Orlin et al., 2009).

Physical well-being can be defined as health-related factors associated with the physical body. For example, there are myriad of anatomical, physiological, genetic, and neurophysiological factors that help to determine sound physical functioning and associated human movement (Wall, Reid, & Harvey, 2007). Physical activity (PA) is one of the important ways to help improve the health of the human body (Biddle & Mutrie, 2008). PA has also been described as movement of the body to expend energy (Biddle & Mutrie, 2008), DPA is an important component of this energy expenditure. For instance, youth can participate in DPA through a variety of ways (e.g., sports, recreation, play, active transport, PHE, dance, etc.). However, 60% of the world population failed to meet required DPA levels to attain beneficial health outcomes (WHO, 2009). Furthermore, the percentage of Canadian youth who were overweight or obese had almost doubled over two decades (Shields, 2006). Obesity has also been a serious problem for people with physical disabilities as they had demonstrated a 1.2- to 3.9-fold increase in the prevalence of metabolic syndrome (Liou, Pi-Sunyer, & Laferrère, 2005).

The implications of pursuing an active lifestyle are important for youth with and without disabilities. However, youth with disabilities (a) tend to lead more sedentary lifestyles, (b) are at higher risk of acquiring secondary conditions in adulthood, (c) participate in fewer activities outside of school, (d) can increase their functional ability with DPA (Caugrove Dunn & Goodwin, 2008; Steele et al., 1996; Stevens et al., 1996; van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). Fowler and colleagues (2007) suggested that structured exercise programs may minimize secondary conditions and prevent the declines in functioning through the ageing process. Since involvement in community programs for children with CP

prevented the decline of function observed in adults with CP (Liptak, 2008), it is important for these programs to promote lifelong participation in PA and healthy behaviors.

Mental well-being was defined as a state where “every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to her or his community” (WHO, 2009, “Mental health: A state of well-being”, para. 1). The mental well-being of individuals with CP can be affected through the chronic pain, social isolation, and loss of functionality and independence associated with the disability (Kriger, 2006). Parents with mental health problems (e.g., depression) tended to create an environment where the children with CP have similar problems (Wiley & Renk, 2007). Thus, improving the mental health of parents of children with CP can prove to be an effective intervention for the whole family (Wiley & Renk, 2007).

Recent research on healthy lifestyles for children with CP has focused mainly on quantitative studies or proxy report from parents (e.g., Law et al., 2006; Orlin et al., 2009; Varni et al., 2005; Zwier et al., 2010). Few qualitative studies have investigated the experiences of children with disabilities in PHE and PA contexts (Fitzgerald, Jobling, & Kirk, 2003a; Goodwin & Watkinson, 2000; Spencer-Cavaliere & Watkinson, 2010). Previous research has not sought the perspectives of children because (a) parents or health professionals viewpoints were preferred (Coates & Vickerman, 2008; Irwin & Johnson, 2005), (b) it was difficult to obtain consent from parents and gain accessibility to children (Westcott & Littleton, 2005), and (c) children were viewed as unable to express themselves fully, were not seriously listened to by adults, or were considered unreliable sources of research information (Fitzgerald, 2009; Westcott & Littleton, 2005).

Physical education and PA researchers recognized children should be empowered to express themselves and play a key role in the research process (Fitzgerald, Jobling, & Kirk, 2003a; Fitzgerald, 2009). Researchers demonstrated that important child experiences have been captured through different types of qualitative methods (Goodwin, 2001). Fitzgerald, Jobling, and Kirk (2003b) used 13 “pictured” symbols, objects, gestures, words, and signs to explore PHE and free-time activities for eight children with severe learning difficulties. The researchers found PA during the after school hours was minimal. Favorite free-time activities were mainly sedentary. Goodwin and Watkinson (2000) explored the experiences of nine children with physical disabilities in inclusive PHE. The children were asked to draw what PHE meant to them to initiate and facilitate discussion. The themes revealed positive and negative experiences represented by “good days” and “bad days”. The good days theme included sense of belonging, skillful participation, and sharing in the benefits. The bad days theme included social isolation, questioned competence, and restricted participation. Lastly, Harvey, Wilkinson, Pressé, Grizenko, and Joobar (in press) compared concurrent and consecutive scrapbook interviewing techniques for children with attention-deficit hyperactivity disorder (ADHD). The children were interviewed either (a) while they created a PA scrapbook with the researcher (e.g., concurrent scrapbook interview) or (b) after creating the PA scrapbook (e.g., consecutive scrapbook interview). The concurrent technique yielded more data than the consecutive technique. This technique enabled children to recall and reflect about their PA experiences which provided richer and more in-depth responses.

Thus, qualitative research methods have provided an initial account of various experiences of youth with disabilities in the pursuit of a healthy active lifestyle. The purpose of this phenomenological study was to explore the meaning of a healthy lifestyle for children with

physical disabilities which guided the following central research question. How do children with physical disabilities experience a healthy lifestyle?

### Method

The voices of the participants guided the lead researcher to gain insight on the healthy lifestyle behaviors of children with physical disabilities. A phenomenology approach was used to explore the essence of the experiences of the children (van Manen, 1997) where meanings were derived from the interviews. This phenomenological research project was conceptualized as a caring act, where thoughtfulness and sensitivity to the lived experiences of the participants played a key role (van Manen, 1997). Pseudonyms were used throughout this document to maintain the confidentiality and anonymity of the participants and people related to their stories.

#### *Setting and Participants*

The study was conducted in a public school, with a reverse integration program, located in the urban area of Montréal. There were approximately 130 students, from 4-13 years, who had a combination of physical disabilities, speech and language disorders, and deafness. Thus, most children had a physical disability and associated secondary conditions. Children without disabilities were included in many of the classrooms as part of a reverse integration program where they attended the school for a period of one to two academic years. These students without disabilities provided a typical developmental benchmark for the teachers at the school. All students received 2.5 hours of PHE per week in the gymnasium and in the pool.

An emergent sampling technique (Patton, 2002) was used as flexibility was required as the research unfolded (Patton, 2002). All of the participants experienced a similar phenomenon (Patton, 2002): living a healthy lifestyle while having a physical disability. The study selection criteria included that participants: (a) communicated verbally or used an assistive communication

device, such as a DynaVox, to formulate their ideas, (b) attended the same school for children with physical disabilities, (c) were between the ages of 9-13 years, and (d) had a physical disability with or without an associated secondary condition(s).

The current study included seven children (five males and two females) with physical disabilities, between 9-13 years ( $M_{age} = 11y\ 5m$ ). The age range was chosen because children may be expected to provide reliable verbal responses at this age (Greene & Hill, 2005; Schneider & Pressley, 1997). Primary diagnosis for all participants was CP. However, most participants had a concomitant disability such as ADHD, and learning or emotional problems that affected their activities of daily living (ADL). Thus, the term physical disability in this study referred to a person with a primary diagnosis of CP and a secondary impairment or disability that affected their ability to function. Additional information for each participant is found in Table 2 (see Appendix C). Both parents were interviewed simultaneously following their child's interview.

### *Data Gathering*

An ethical approval certification was obtained from both the university and school board Research Ethics Board (REB) prior to gathering any data. Potential participants, who met the study selection criteria, received an initial letter from the PHE teacher at the school (see Appendix D). This teacher served as a third party to facilitate the research process and minimize any perceived coercion to participate in the study. The letter briefly explained the study and required the signature and contact information of the parents if they chose to be contacted by the lead researcher. If a positive response was received, the lead researcher conducted an initial meeting with each child and one of his or her parents. The study was described so the child and parents were informed about the study requirements if they chose to participate in the research.

The parent signed the consent form if the child and parent agreed to participate (see Appendix E).

Each child was provided with a disposable camera and a CD for data gathering purposes. They were asked to take pictures of what a healthy lifestyle represented for them over a two-week period. The lead researcher provided an example by explaining that she pursues a healthy lifestyle by going to swim practice three times a week, sleeping eight hours a night, and having fun with friends when she goes skiing. The lead researcher also explained that these activities were examples for her healthy lifestyle and the pictures would probably be different for them. She emphasized that each child should collaborate with his or her parents to take the pictures since the majority of photographs should have included the children and their personal healthy behavior experiences. The parents were contacted by telephone after week one and two to follow up and answer any questions or concerns the parents may have had. A second meeting took place approximately 2-3 weeks after the initial meeting so each child's pictures could be developed by the lead researcher.

The concurrent scrapbook interviewing technique was used with the children to explore their experiences about health during semi-structured interviews (Harvey et al., in press). This technique is based on collage, photo elicitation, and cognitive science talk-aloud methodologies where the participant photographs are utilized to generate rich discussion. The primary researcher was trained in the scrapbook interviewing technique by her co-researcher. The scrapbook and other necessary materials (e.g., glue, paper, stickers, glitter) were provided to each child. Interviews were conducted with each child while they created a healthy lifestyle scrapbook with the assistance of the primary researcher. Examples of questions asked to the children included: Please choose a picture. Tell me about this picture. What are you doing in the

picture? Why do you think this is part of a healthy lifestyle? Children were also encouraged to bring artifacts to the interview. Each child was interviewed for approximately 75-90 minutes.

An interview guide was created to record essential information, interviewer notes on the process, brief content notes, and any concluding comments (Creswell, 2007; see Appendix F). The interviews were videotaped using a Flip UltraHD video recorder. Field notes were also recorded in case the equipment did not work (Creswell, 2007). Each videotaped interview clarified the meaning of the transcription. For example, a transcription could seem to convey that a child was excited about an activity. A review of the video could indicate the child's non-verbal body language demonstrated sarcasm. For example, a child may roll his eyes while explaining that he enjoys participating in a certain activity. The audible interview data suggests that he enjoyed the activity, but his intention was sarcasm. Thus, the lead researcher reviewed the video and observed the whole context of the interview to determine any hidden meanings that each child was communicating.

The lead researcher remained aware (a) not to lead the interviewee in subtle persuasive responses through the help of the co-researcher and his critical feedback about the videotaped interviews, (b) of the potential power distribution between the interviewer and interviewee, and (c) not to push the participants to respond to questions about topics they showed extreme discomfort towards (Creswell, 2007; Patton, 2002). The interviews were conducted in a private classroom at the school which was considered as a safe and comfortable environment. This location was accessible for the participants who used wheelchairs and walkers.

### *Data Analysis*

The four following steps were implemented for data analysis (Côté, Salmela, & Russell, 1995). First, all child interviews were transcribed verbatim and read over several times to get an



overall idea and feel for each interview. This step encouraged the primary researcher to remain reflexive and become familiar with the language used in each interview. Second, a line-by-line free textual analysis was conducted by hand where key words, expressions or phrases were extracted from the transcription. This open-coding process led to the tagging or identification of meaning units. Third, similar meaning units were grouped together as properties. The researchers met on several occasions to discuss the content of emerging tags and properties to reduce their number and conceptualize their meaning. Fourth, the interviews were then uploaded in Nvivo8 qualitative software package for further thematic analysis. Steps two and three were repeated on several occasions. These iterations may be referred to as the constant comparative method where the data collected was compared to emerging properties and themes (Creswell, 2007). The properties were then grouped into higher order themes associated with the adoption of a healthy lifestyle for children with physical disabilities.

### *Trustworthiness*

The use of different strategies to document and assess the credibility of the findings is often referred to as trustworthiness (Creswell, 2007). Trustworthiness procedures were employed in this study through data triangulation, member checking, audit trail, peer-review, and researcher reflexivity. First, data triangulation uses multiple sources of information to strengthen the research study (Creswell, 2007). This project included three sources of information to explore the meaning of a healthy lifestyle for children with physical disabilities: (a) child stories being told through the scrapbook interviewing technique, (b) video reviews of each interview, and (c) parental input.

Second, member checks were performed to include the voices of the children in the research process (Harvey et al., in press). The children were provided with a brief summary

statement two weeks after the interview. Each member check was conducted in person. The primary researcher read the one-page summary to each child, and, in turn, the child provided feedback to the researcher to add or delete any information so the personal meaning of the interview was maintained. Finally, each parent interview confirmed the general content of their child's interview.

Third, an audit trail was conducted to keep track of statements mentioned by each individual when determining the meaning units (Lincoln & Guba, 1985; see Table 3, Appendix G). Fourth, a peer-review was used to demonstrate the credibility of the data (Creswell, 2007). The complete transcripts of two participants were randomly selected for a peer review by a graduate student who was trained in qualitative research methods and the scrapbook interviewing method. Five hundred and ninety one MU were peer-reviewed. The primary researcher and graduate student met and reached 96 % agreement (566 of 591 MU). This individual played a crucial role to ensure that the researcher remained honest and he questioned the methods, meanings, and interpretations of the data (Lincoln & Guba, 1985).

Lastly, researcher reflexivity was used to keep the primary researcher self-aware of her own perspective in relation to the experiences of the participants (Patton, 2002; Sparkes, 2002). The primary researcher's interests in the fields of adapted physical activity and pedagogy enabled her to pursue a reflective practice where she was able to interact closely with the participants and gain their trust. The rationale for using the five procedures was to provide transparency in the qualitative research process (Knowles & Sweetman, 2004) and bracket the primary researcher's preconceptions about the role of PHE on the health experiences of children (Harvey et al., in press). The primary researcher was also questioned in meetings by the co-researcher about her interpretation of the interview data. Hence, the primary researcher was held

accountable to tell the stories relayed by the children and not construct narratives based primarily on her prior experiences (Harvey et al., in press).

## Results

A total of 2773 meaning units (MU) emerged during the data analysis and 43 tags were formed (see Table 3, Appendix G). The tags were then grouped into 10 properties and four main themes emerged: (a) *my scrapbook*, (b) *what I do during my free time*, (c) *people around me*, and (d) *what helps me and what doesn't*. A total of 1860 MU formed the basis of the four themes, with 913 MU excluded from analysis because they were deemed incidental (van Manen, 1997). Tables 4, 5, 6, and 7, provide a detailed thematic audit trail for each theme (see Appendices H, I, J, and K). Examples of MU excluded from the data analysis included inaudible data, personal identification information, and hesitation or clarification statements.

### My Scrapbook

The *my scrapbook* theme referred to the process of assembling the scrapbook where the *materials* and *logistics* properties emerged.

*Materials*. The first property was called *materials* and it included statements about items the children used to create their scrapbook such as paper, stickers, glue, glitter, and scissors. The children provided reasons why they used specific material or performed a specific task when asked by the interviewer. Patricia suggested that she glued her picture on a yellow paper “because it’s the colour of the school bus”. Josh used glitter and stated, “I just think it’s pretty”. Myriam drew a strawberry in her scrapbook. She pointed to her picture and said “cause there’s red strawberries”. Children seemed to enjoy the process of making the scrapbook. Josh said, “... this is really fun making a scrapbook”. Paul wrote on a scrapbook page, “judo rocks”.

*Logistics.* The second property of the *my scrapbook* theme was named *logistics* because it referred to the organization of each individual scrapbook. Statements included the number and order of pictures utilized by each participant and questions about the process of constructing the scrapbook. First, they spoke about the number of pictures. “I took 11 pictures” (Myriam), “oh ya, four more to go” (Jeremy), “my next picture is ... that one [picks up a picture]” (Paul). Examples of questions about the process of constructing the scrapbook included, “am I going to get to keep this [scrapbook]?” (Paul). “Are we gonna finish all this today?” (Paul). “Should we put something else on the cover when we’re done?” (Josh). Can you draw this for me? (Josh). Ralph explained that he wanted to “talk about the next picture”. He also tried to figure out where to place the picture on the scrapbook page. “This one I’m not sure if we’ll have enough room. We’ll have enough room like that, but...”. Josh said, “I wanna cut a big paper, like... pass me a big paper, like yellow and I’ll show you what I want to do”.

### **What I Do During My Free Time**

The theme, *what I do during my free time*, included any type of activities the children suggested that they participated in during their free time. The *unstructured recreational activities* and *structured recreational activities* properties emerged since all children spoke about the organized and unorganized activities they performed.

*Unstructured Recreational Activities.* The first property of the *what I do during my free time* theme was called *unstructured recreational activities* because it included the unorganized activities that children were involved in during their free time. Statements included discussions about physical activities, play locations, sedentary activities, preferred activities, and daily routines of the children. Various self-reported physical activities included playing in the backyard, swimming, street hockey, soccer, biking, walking, ball games, hide-and-seek, swings,

and dancing. “I play games, play tag, play the ball game” (Myriam). “I... not like winter, but I like to go in the snow and build snow forts” (Jeremy). Some children mentioned playing outside all year long. For instance, Paul played hockey outside all winter with neighbors. Patricia went walking when there was snow outside on her street. However, the children mainly discussed activities that they could play outside in milder temperatures. Josh talked about biking outside, “like anywhere at a park, around the park, go biking to our neighbors or anywhere”.

The children also talked about sedentary activities which included playing with LEGO, arts and crafts, relaxing, and reading. Four of the seven children explained other favorite free-time activities were watching TV, playing videogames, and going on the computer. Ralph explained that he enjoyed playing videogames, “well I like to relax. I like to play my videogames. Like a lot of people, like a lot of kids”. Patricia said, “I like to go on Facebook”. Other reported unstructured activities included playing with pets and being outside. While pointing to a picture, Paul said, “that’s me, my dog and I”. Children also spoke about their daily routine such as what activities they do after school, chores they do around the house, and the time they go to sleep. Myriam said:

After my pool... my class on Tuesdays, I get home, after my homework, my mom tells me that I need to take a bath...and then after I can do whatever I want... and if I have time before supper or else the next day. It depends, eh... we usually have supper at 7 and I go to bed at 8:30.

Paul explained his routine after school, “show my mom my agenda, do, start some of my homework and then go play outside”.

*Structured Recreational Activities.* The second property of the *what I do during my free time* theme was called *structured recreational activities* because it included the organized

activities the children performed during their free time. Participant statements referred to any activity that was formally organized such as sport teams or other formal activities. The children described various activities, demonstrated sport-specific knowledge, discussed their preferred activities and how these activities were part of their daily routine. Sporting activities, reported by the children, included sledge hockey, sit-skiing, horseback riding, sailing, rugby, basketball, dancing, and soccer. All children described one particular annual sport event for youth with physical disabilities, “it’s... competition... for people with disabilities, and you can do swimming and running and bike” (Patricia). “It’s like the Olympics for kids with a handicap and you win medals, if you get first, second or third” (Paul). While Jeremy chose a picture he said, “let me see, this, this one it’s me playing sledge hockey, on a sled with my helmet, and I’m in an arena, and really cold”.

Some of the children also mentioned other structured activities such as sleep away camp, cubs, and art class. “That’s in the summer I go to camp alone by plane, for a month, for ... and I go horseback riding and dirt biking” (Paul). Ralph selected a picture and said, “I actually do cubs”. Josh explained community activities, “we did art outside, we’d do ... we bake some cookies with other kids”.

Children demonstrated sport-specific knowledge. They described techniques and equipment used during activities or demonstrated the physical movement during the interview. For example, Jeremy described a braking technique he used during downhill skiing, “I’m doing a ski move called the pizza or the V”. Myriam described her sit-ski experience where an instructor, tethered to her back, had assisted her to change directions.

Yes and he [points to picture] goes like ... a rope behind this kind of skis, all behind adapted seats, cause they’re adapted can’t ski with normal skis. There’s like

skis under the seat, and you can't tip and if it go this way [leans to the right] it goes that way [leans to the right] well you don't ...turn. And there's ropes that the person could attach to their arms if I don't have control, they still have it so I don't fly.

Children expressed individual preferences for activities based on weather, speed, sport training, intensity, and enjoyment. "Ya, depends if it's cold or hot... it's medium... it depends on the weather" (Myriam). "I like to go horseback riding cause I go fast" (Paul). "That you can train, get ready for Défi [sport event]" (Myriam). Paul mentioned he preferred rugby because of the intensity and elaborated by saying, "like how... it's played and how rough it's played. It's fun, I get to take out my anger. Like in Judo too, I take out my anger". "Because I like to... cause I like to do outdoor activities" (Jeremy). Children mentioned personal schedules in relation to their structured activities. For example, Ralph talked about his soccer practice, "every Sunday or Saturday, but it's only in the summer, yes and it's an indoor".

### **People Around Me**

The *people around me* theme encompassed the social network that surrounded the children. *Parental influence, family, school, and friends* were the four properties which emerged.

*Parental Influence.* The first property of the *people around me* theme was called *parental influence* because parents were primary caregivers and they played a key role in the lives of their children. Participant statements indicated parent assistance in activities of daily living (ADL) and parent involvement, decision-making, and teaching in the reported leisure activities. The children spoke about how their parents assisted them to brush their teeth, take a bath, get dressed, and transfer equipment. Myriam explained how her parents helped her in the morning, "because my dad or my mom come up and get me dressed and the other person can get drinks, juice, and

coffee ready and save up some time to get to school”. The involvement of the parents in the children’s leisure activities included actions such as driving them to an activity, participating in the activity with them, and watching them perform. For example, “my mom picks me up” (Patricia), “and sometimes my dad and I play like sword fight” (Myriam). Ralph spoke about performing a routine for his parents at the end of his dance class, “well we go to the dance class and umm ... we gotta perform at the end for the parents”.

The children also spoke about parent decision-making and teaching for leisure activities. Three participants suggested that parents decided what physical activities the children perform. Myriam talked about how often she goes curling, “depends what my dad and my mom want me to do or where they want me to go. Depends what they want”. The children also suggested that parents taught them about a healthy lifestyle and encouraged them to take steps towards good health practices. “Ummm.. my mom is always smiling at me when I do something good, like when I do something good, she’s always like ... Yeah Josh”. Ralph explained that his dad encouraged him to take the stairs even if there are only a few, “well, it’s good. I took the picture because my dad told me that it’s... that don’t take it if it’s too long [the stairs], but if it’s a couple of stairs take it...it’s healthy”.

*Family.* The second property of the *people around me* theme was called *family* because family members also played an important role in the lives of the children. However, the children did not speak about family members assisting them with ADL like they did with their parents. Participant statements reflected discussions about family-related leisure activities, personal involvement, events, and excursions. The children spoke about various unstructured leisure activities with family members such as walking, shopping, playing in the backyard, and going on the computer. Family members included siblings, cousins, aunts, and uncles. “That’s me and my



sisters, swinging” (Paul). “That’s where I’m playing hockey with my cousin” (Ralph). Josh spoke about playing on the computer with his aunt, “my mom’s sister, like she has a computer, she goes to ...to this program where you make your own videos and you put it on the disk and you bring it home and watch it”. Family members were personally involved in each child’s life by spending time with them. Myriam explained how she and her sister took turns cheering for each other during sport events, “and so when I saw my sister Erica at the Quebec race, she comes and sees me, cause we see each other. And cheering on for other people it’s really important”.

Five participants talked about events with the family that included holidays, family gatherings, and organized community events. “This is the four cousins and they came for, I don’t know for how long and ... and it was umm ... Christmas so that’s why we’re wearing those kind of colours, on Christmas” (Myriam). “We had an Easter egg hunt at my cousin’s house” (Patricia). “This one ... umm ... my mom and, my mom’s sisters came to the Starlight walk. Like we walked the whole area” (Josh). These children also discussed larger excursions with the family like going on vacation, to the cottage, camping, and family day trips. “Cause, cause... some weekends we like to go to up north sometimes. I mean in the summer time .. and being together as a family” (Jeremy).

*School.* The third property of the *people around me* theme was called school because it encompassed individual child perceptions of being healthy while at school. Participant statements reflected experiences in different school contexts as part of living a healthy lifestyle. The children spoke about academics, PHE, daily routine, recess, intramurals, and significant others. First, the children talked about academics such as doing homework and helping younger students to read. Patricia chose a picture and said, “I’m doing my homework”. Myriam explained that she read to the grade one class, “so I’m paired up with Steve and Ken, so then I read to them

and sometimes, if we have time, they read to me. And sometimes if they need help, I can help them”.

Next, six participants talked about what they learned and the activities they did during PHE class. For example, Ralph said, “it’s fun because you can use your parts like.. it’s like .. it’s good because like.. school you have to sit down all day and work, but at Phys. Ed. you can play and have fun and like that”. He also explained an assignment to be completed for PHE class “it’s good to... we had to do this journal.. this physical activity journal. You have to do at least one physical activity thing per day. And that was easy for me because I like to play the hockey a lot”.

Third, most of the children were aware of their daily routine at school such as time allocation for classes, the lunch time bike program, and their own everyday routine at school. Paul explained that he participated in the bike program during recess, “like when I’m in school, I have only... no ... two days to go outside cause I have bike program on Monday, Tuesday I help, Wednesday I have bike program, Thursday, and Friday”. Children also spoke about walking and taking the stairs as examples of daily behaviors in school. Josh explained that, at school, he was active by “sitting, walking up and down the halls, biking, walking up and down the ramp...”. Ralph mentioned, “yes and I usually take the stairs even at school”.

Next, five children spoke about how they ate snacks, played activities, and spent time outside during recess. Jeremy said, “ahh let me see... eating healthy snacks”. “At recess we play this game called slave tag” (Ralph). Fifth, the children discussed intramurals such as performing in a play, the Olympic week, and graduation. For example, Josh talked about preparing to perform for the school play. “So I’m doing the witch and Rebecca is doing the Dorothy ... and my, the rest of my class is doing the monkey. They’re being my helpers and that’s it”. Patricia talked about the Olympic parade at school. “And we had the opening ceremony, and we had

cabane à sucre [e.g., sugar shack], then we had ...we had closing ceremony”. Brandon programmed the DynaVox to explain the picture, “it is my graduation” and he exclaimed that it is important to “move on”. Lastly, the children spoke about significant others in school that included teachers, physiotherapists, and attendants (e.g., staff members who assisted children with ADL during school). “Natasha is, she’s like our gym teacher” (Myriam). “She [attendant] brings me to the bathroom, walks me, puts me in my wheelchair” (Myriam). Brandon used his DynaVox to explain that he enjoyed himself during a class excursion with “my teacher and Edward [attendant]”.

*Friends.* The fourth property of the *people around me* theme was called *friends* to indicate that the children valued social interactions with other children during leisure activities. It contained statements that reflected how children played with friends at home, in the community, and at school. Paul talked about playing with neighbors, “they come to ring at my doorbell at six something. They ask if I can go outside with them and we’ll have a big hockey game”. Children discussed playing with friends in the community and at school, “kids going on the Sports Adventure Club” (Jeremy), “my class friends” (Brandon). Sometimes, the children also spoke about playing alone. Ralph said, “I’m playing soccer in my backyard, alone”.

### **What Helps Me and What Doesn’t**

The theme, *what helps me and what doesn’t*, reflected either affordances or constraints to the pursuit of a healthy lifestyle that were encountered on a daily basis. The *affordances* and *constraints* properties emerged to form this theme.

*Affordances.* The first property of *what helps me and what doesn’t* theme was called *affordances* because it was related to child perceptions about different factors that enabled them to be healthy. Participant statements included information about physical activity, physiological

benefits, fun, the natural environment, awards, nutrition, hygiene, and choices as affordances to adopting healthy behaviors.

First, all children suggested that physical activity afforded them the opportunity to lead a healthy lifestyle. These physical activities included physiotherapy exercises, PHE activities, sports, and unstructured recreational activities. Myriam said, “to go swimming it’s good for you ... your body, you can move around”.

Next, children suggested that exercise afforded better physiological functioning such as increase in muscle mass, blood flow, heart rate, and burning more calories.

- |                    |   |
|--------------------|---|
| <i>Interviewer</i> | OK why did you choose that picture?   |
| <i>Participant</i> | Because when you like play, and all that, it keeps like if you ... if you lie down you won’t get umm, like it won’t lose calories or something like that. |
| <i>Interviewer</i> | If you lie down?  |
| <i>Participant</i> | Yes you won’t lose much, but when you run, you do. And it’s also good because your heart keeps on pumping and you get more blood and it’s good. (Ralph)   |

Third, children mentioned fun as an affordance to be active and healthy. Brandon typed on his DynaVox “me happy”. When asked why, he replied, “because I went out with my friends”. Ralph stated, “it’s fun to swing. It’s fun to be outside”. Next, six children suggested the physical sensations of the natural environment afforded the children to experience positive feelings about health. When they were asked the question, why did you choose this picture as part of a healthy lifestyle? They replied, “getting fresh air” (Brandon), “and the sun is good for you because you can tan” (Myriam), “ya, you go down the mountain, like the wind or the snow comes to your face” (Myriam).

Fifth, children spoke about receiving awards, medals, or certificates for school or sports. These rewards afforded the motivation for children to engage in active, positive, and healthy experiences. They suggested that receiving an award was for the enjoyment of it. “It’s just .. it’s

just because... it's just for the fun. The medals are just for the fun. And yes ...and trying your best is a medal too. Like I won two medals [shows two with fingers]" (Ralph). Three children brought a sport medal to the interview as they were encouraged to bring any object that reminded them of a healthy lifestyle. "OK that's when I got a medal and I stand on that first place podium" (Jeremy).

Sixth, all children suggested nutrition afforded an opportunity to engage in healthy behaviors. For example, they spoke about the consumption of foods and beverages, benefits of eating healthy, and knowledge of unhealthy eating habits. "I'm drinking milk cause I'm mostly thirsty and it helps your bones to get strong" (Josh). "Because you need to eat three times a day" (Myriam). "I just found out when food is in a can, when it's frozen in a can, they put high sodium in it" (Jeremy). Next, children suggested that daily hygiene routines were also an affordance to being healthy. For example, Patricia brought a hair brush to the interview and Jeremy mentioned, "ehh this is me before yesterday I had a bath".

Finally, children spoke about choice as an affordance to being healthy. Most children talked about the individual need for sleep and rest. Brandon typed in his DynaVox, "it is important to get sleep". They also spoke about the effects of daily choices in relation to their future health status.

Ya, it's really it's really important to exercise your body because when you grow up becoming a person, you won't be able to push on your leg, cause you won't be able to, you just collapse, you would just fall sometimes, you wouldn't, you wouldn't ehheh.. you wouldn't be able to get up, you wouldn't be able to do anything that normal people that can

do, you wouldn't be able to do anything else that you could do that ... to exercise, to help you exercise. (Josh)

“Cause when I grow up I want to live healthy and long, I wanna live a long life and yep...”  
(Paul).

Furthermore, children spoke about a choice to be active or sedentary.

It means that.. it's good that you rest and you you ... you... eat to get your fuel and to also play like 90 minutes at least for one day at least because a kid you need at least 90 minutes of physical activity. It's healthy. And to not sit down all day and play videogames and to .. to do physical activity and to educate your brain to go to school. (Ralph)

*Constraints.* The second property of *what helps me and what doesn't* theme was called *constraints* because it reflected daily challenges that the children encountered to being healthy. Participant statements included discussions about mobility issues, negative feelings, safety, and life circumstances as impediments to adopting healthy behaviors. Mobility issues referred to individual statements about the ability to physically move in their environment. Children spoke about equipment used for ADL such as wheelchairs, ankle-foot orthoses, and walkers. For example, Patricia needed “a chair” when she took a shower. The physical environment created challenges for the children such as using a railing to go up and down stairs, or a bar to get out of bed. Josh explained that an elevator would be installed in the family's new house, but in the meanwhile he explained how he moved on the stairs, “on my bum, like I go [moves back and forth] bum scooching down”. Children also suggested they were not able to participate in an activity because it was too difficult or they would get tired quickly. Jeremy explained how he

preferred sledge hockey rather than skating, “cause I don’t know how to skate, yet when I’m adult”.

Five children expressed negative feelings about ability levels, sport experiences, and daily challenges. Paul explained that he does not like riding his bike, “I’m embarrassed of my four wheeler and I’m 12 years old. I’m hoping I’m not going to have a four wheeler after my operation”. Myriam explained that she was unhappy at a sport activity and her parents immediately returned to pick her up. “No my dad came to pick me up cause I... I ... It isn’t really right for me”. Paul explained that peers in his karate class made unkind remarks: “they just make fun of the way how I walk”. Myriam talked about fighting with her sister over, “like the remote control, who gets it, what game you want to play on the Wii, plenty of stuff”.

The children discussed safety in some activities as another constraint. For example, Myriam talked about learning how to rotate from her front to her back in the water for safety reasons, “cause there’s like if ... if I sink, my private teacher taught me what to do. If... if whenever I sink I could get up and move over. And so it took a long time, but after I got it”. The life circumstances of significant others were also suggested as constraints to adopting healthy behaviors. For example, children suggested their parents were too busy, too tired, or divorced. Ralph said that during the weekends he helped his parents by playing with his younger siblings because ‘my dad wants to relax because he does a lot of work’. Josh explained, “but one night when I was so tired my dad carried me up [the stairs] because he’s strong, he kept saying to me: ‘Josh sometimes you need to walk up like, because it will break our backs someday’”. Paul discussed why he doesn’t play outside as much after his parents divorced, “I can’t, I don’t have really friends at my dad’s house ... so I can’t. I don’t play outside cause I don’t have friends to play with”.

## Discussion

The purpose of this phenomenological study was to explore the meaning of a healthy lifestyle for children with physical disabilities. The children shared their stories through the emergence of four themes: (a) *my scrapbook*, (b) *what I do during my free time*, (c) *people around me*, and (d) *what helps me and what doesn't*.

### My Scrapbook

Visual methods in qualitative research have grown in the past decade, but at a slower rate in physical activity (Phoenix, 2010). The use of photographs in qualitative research, called photo elicitation, may help children to articulate their thoughts and express their opinions (Banks, 2007). The scrapbook interviewing technique (Harvey et al., in press) enabled the children to recall their lived experiences and reflect on their personal views about health. For example, Jeremy selected a picture and stated that it was about his family going to watch his brother's hockey game (e.g., stimulated recall). He described the sporting environment and the unhealthy foods sold at the arena which provided more depth and details about the event (e.g., stimulated reflection). This technique provided flexibility for the interviewer to ask follow-up questions and gain deep and rich individual responses. Thus, the interviewer asked the children to recall and reflect on the people, locations, and activities displayed in the photographs. For instance, they were asked the following questions. Who is in the photograph with you? Who do you usually participate in this activity with? Why? Where did this activity take place? Why?

The children personalized their scrapbooks which suggested they were engaged in the research process. The scrapbook interviewing technique encouraged the co-construction of the health stories told by each child and the researcher. It also led to deeper insights about the lived health experiences of children with physical disabilities and provided a strong sense of



credibility for the findings. These findings support previous research that demonstrated children were capable of providing accurate and credible interview responses (Hogan, 2005) and they have valuable experiences to share throughout the research process (Fitzgerald, 2009). Thus, each child may be considered as knowledgeable about his or her own life and able to share his or her stories.

### **What I Do During My Free Time**

The photographs and personal stories of the children indicated that they participated in various unstructured recreational activities such as biking, playing street hockey, arts and crafts, and reading. However, four of the children preferred sedentary activities (e.g., watching TV or playing videogames) which could have been a major health concern if the activities constituted a majority of their daily time. Similarly, Imms, Reilly, Carlin, and Dodd (2008) found children with CP participated more frequently in videogames and arts and crafts than children without disabilities.

Since children with physical disabilities tend to participate in more informal activities and with less intensity than their peers without disabilities (Imms et al., 2008; Law et al., 2006; Orlin et al. 2009), then the health risks associated with sedentary behaviors become a major concern for the participants. In fact, these poor health behaviors have become a global public health issue for all children (Causgrove Dunn & Goodwin, 2008; Roux et al., 2008; van der Ploeg et al., 2004). It may be vital to establish a healthy lifestyle pattern during childhood to increase the likelihood that healthy behaviors may be adopted and continued into adulthood (WHO, 2003).

The discussion of structured recreational activities by six children with physical disabilities may not have been observed in the last few decades. For instance, DePauw (2009) suggested many opportunities in physical activity and sport were only recently created for

persons with disabilities in schools and community centers. One particular sport event, the Défi Sportif, was discussed by all of the children because it played an important part in their stories about health. This annual international sport event, for athletes of all ages and with different types of disabilities, was hosted in the large metropolitan city where the school was located. The children were introduced to Défi Sportif through school and they were prepared for the event months ahead of time. Participation in the event encouraged children to select a sport for competition. The children set personal goals, practiced their sport, and participated in a specific sport competition with children of similar abilities at this event. All children received a participation award and the top three children in each category received a medal. The participation of the children in this sporting event may have enabled society to view the children beyond their disability because they demonstrated their abilities in a physical activity context (Goodwin, Thurmeier, & Gustafson, 2004).

Some organizations in the community cater to persons with specific disabilities (e.g., Canadian Blind Sport Association), while others are designed for children with various disabilities (e.g., Special Olympics, Paralympic School Program). Some children with disabilities may prefer to participate in an inclusive program rather than a special program. However, it is important to identify a suitable program for each individual child based on their interests, parent interests, activities played by similar age peers without disabilities, and program availability in the community (Block, 2007). It is as important to identify whether the child will participate in an inclusive or special program. In North America, children with physical disabilities can participate in an array of leisure activities such as horseback riding, sailing, boccia, basketball, obstacle courses, skiing, curling, and skating. However, some of these leisure activities may be costly or transportation may be an issue (Block, 2007). Alternatives do exist. For example, if a

child with CP does not enjoy participating on a basketball team, he may enjoy shooting the ball at a net with a sibling in the driveway.

Children with disabilities should be encouraged to participate in available community activities. For example, all of the participants also spoke about swimming. In fact, five children had pictures where they were swimming in different contexts (e.g., backyard pool, school, le Défi Sportif). Past research has reported swimming as one of the most frequent activities for children with CP (Imms et al., 2008; Zwier et al., 2010). Thus, it is important to find structured physical activities for children with CP when they are young (Zwier et al., 2010).

### **People Around Me**

Parent support is critical in the lives of all children and it may include added dimensions when the child experiences functional limitations (Raina et al., 2005). In this study, for example, parents assisted their child in daily morning routines which may have included getting dressed, being fed, going to the washroom, and being driven to school. These findings are not surprising, given children with CP were highly dependent on their primary caregivers (Raina et al., 2005). Thus, understanding the health of the parents is important in relation to their child with a disability. Children in this study recognized that their parents assisted them in ADL and various leisure activities. For example, Myriam often rationalized throughout the interview that her leisure activities were dependent on the availability of her parents. The pictures of the children also depicted interactions with other family members during leisure activities. Myriam spoke about going sit-skiing with her family. She enjoyed the sport because her mom also had the opportunity to try sit-skiing. Additionally, Myriam played with her sister while she waited for the chairlift.

Rimmer and colleagues (2004) suggested that perceived constraints to participation included a lack of support and overprotection from family members. However, Fitzgerald and Kirk (2009) placed a positive emphasis on the role of the family since parent interests may have defined family leisure interests of the children with different types of disabilities. The findings of this study also shed some positive light on the experiences of each child and their family. The children were cognizant of the necessary daily assistance that each parent provided and they told positive stories about their family experience in health. Given the daily constraints related to each individual with a disability (e.g., time, physicality, finances, etc.), it would be understandable and reasonable that most of the unstructured and structured recreation activities of the children were dependent on the personal contexts of each parent. In fact, previous qualitative research has demonstrated the importance of family members to facilitate participation and create opportunities for youth with a physical disability to engage in physical activity (Goodwin, Thumeier, & Gustafson, 2004; Taylor et al., 2004).

Children spoke about their friends who appeared in the photographs from home, school, and community settings. The children seemed to value their friendships. For example, Patricia showed a picture of her birthday party and named all the people in the picture. One particular girl had attended the same school, as part of the reverse integration program, during the previous year. Patricia and this girl had kept in touch and remained friends even though they no longer attended the same school. Similar to the findings of Seymour and colleagues (2009), children with disabilities told stories about meaningful friendships.

School and structured recreational activities may help promote long-term social relationships (Block, 2007; Law et al., 2006). In this study, the children experienced many of the structured recreational activities through school. Some of the children and their families then

pursued these activities outside of school hours where the children may have the opportunity to meet new people and learn new skills. Parents and professionals working with children should foster such relationships because they may produce an enhanced quality of life. Developing social relationships through physical activity has been a goal shared by parents and their children (Kristèn, Patriksson, & Fridlund 2002; 2003; Spencer-Cavaliere & Watkinson, 2010). Thus, children with disabilities may enhance their social development through friendships (Woolfolk, Winne, & Perry, 2009). Physical activity contexts can provide important means to promote positive peer relationships and enhance pro-social behaviors (e.g., sharing, helping others, cooperating on a team to achieve a goal).

### **What Helps Me and What Doesn't**

The findings demonstrated the diverse meanings of health for the children. They recognized different factors afforded them to be healthy. For example, children knew that participation in physical activity may enable them to become healthy. These findings parallel past research where children with physical disabilities suggested that participation in exercise strengthened their bodies (Kristèn et al., 2002). The children also expressed knowledge about unhealthy behaviors as an affordance. For example, Myriam knew that if she did not eat three times a day, she would be weak, unable to carry things, and sink to the bottom of the pool. Thus, the knowledge of a constraint may be perceived as an affordance if the person is able to recognize the constraint and act upon the knowledge to adopt a healthy behavior.

Children were aware of the constraints they had to overcome on a daily basis. They discussed a few constraints which were specific to their disabilities such as the challenge of using different equipment for ADL. For example, Josh spoke about having difficulty when holding objects in his hands and he disliked when he practiced holding objects so his wrists

would remain flexible. Like other children, the participants also encountered daily constraints like not getting along with siblings or fighting over the remote control.

Research about youth with disabilities in the 1980s focused on the impairment of the child through a medical lens (Priestley, 1998). The WHO International Classification of Function, Health, and Disability (ICF) developed a model that considered the human function and disability of the individual (WHO, 2001). It encompassed an interactive relationship between the health condition (e.g., the disability) and contextual factors (e.g., personal and environmental). The ICF model diverged from the medical model to promote functional activity that provided children with choices and preferences (Rosenbaum & Stewart, 2004). People working with children with disabilities should focus on the needs, desires, and interests of the child. The functional goal is to increase affordances for children to become empowered and as independent as possible to achieve better individual health outcomes. For example, an adult working with a child with a disability may only provide physical assistance to a child when the child may be encouraged to be as independent as possible. The adult may provide verbal cues instead to help the child achieve her or his goal. Modifying rules to the game only when necessary and asking for the child's input. At the same time, constraints to leading a healthy lifestyle should be reduced or eliminated (Healthy People, 2020). For example, children should be encouraged to use a walker as a mode of mobility instead of using a wheelchair alone.

### **Strengths and Weaknesses**

This study adds to the literature on overall health and participation in physical activity for youth with disabilities (Causgrove Dunn & Goodwin, 2008; Rimmer et al., 2004). Three strengths of the study were the use of videotaped interviews, methodological consistency, and researcher reflexivity. First, the videotaping of interviews helped to observe nuanced language

(Harvey et al., in press). The researcher was able to refer to the videotaped interviews during transcriptions and data analyses to better understand the stories of the children and to question body language and associated verbal responses that did not seem to match.

Next, the methodological consistency of the scrapbook interviewing technique aided the children in providing credible responses. Children were provided with a short amount of time between the picture taking and the scrapbook interview technique which should have encouraged the children to recall events in the photographs. The stories were more credible because they were recent memories of the children (Harvey et al., in press). Lastly, Sparkes (2002) suggested the importance of researcher reflexivity on the research process and outcomes. The primary researcher engaged in prolonged engagement in the school through volunteer work, student teaching, and working at the school for a few months prior to the interviews. She had an insider perspective of the participants' educational community which lends much credibility to the study findings.

Limitations of the current study included generalizability of the findings and socially desirable responses. First, the study findings are not generalizable, nor would the total experience of the children be told (Creswell, 2007). Second, some children may have responded to the interviewer's questions in a socially desirable way, meaning they said what they thought the interviewer wanted to hear (Greene & Hill, 2005). Since the first author spent many hours with each child, she claimed the children were comfortable enough to disagree with her. Thus, the current study sheds light on future research and practice for children with physical and multiple disabilities.

## **Recommendations for Future Research**

Three recommendations for future research will be explored through the scrapbook interviewing technique, importance of aquatics programs, and links between school, home, and community. First, the scrapbook interviewing technique enabled children to reflect and elaborate on their responses beyond what was recalled in the photographs. The scrapbook interviewing technique may be worthwhile to use when conducting semi-structured interviews with all children. It was beneficial for the current participants who had learning difficulties or experienced difficulties when telling their stories about health.

Second, future research may focus on understanding the effects of aquatics programs for children with physical disabilities. Aquatics may be considered a beneficial type of PA that provides freedom of movement and socialization opportunities for children with CP. For example, several children with physical disabilities have reported on their proficiency and opportunity to excel in swimming (Goodwin & Watkinson, 2000). However, there is minimal evidence-based research on aquatics for children with CP (Kelly & Darrah, 2005). Finally, children with physical disabilities may be encouraged to pursue a healthy lifestyle through links between school, home, and community. For example, the children participated in community sport activities which were organized by the PHE teachers and physiotherapist at the school. Parents were encouraged to attend, observe, and obtain information about the sport activity. The information was relayed to the parents by a letter sent home from the PHE teachers. The children suggested that their parents took them to participate in the sport activities during the evenings or on the weekends. Finding alternative leisure activities is important such as going to the museum, going for a bike ride, or playing board games with friends. Behaviors and choices that may be learned at home may be reinforced at school and vice versa. If patterns of a healthy lifestyle are



instilled during childhood and adolescence, it may be more likely that the children will continue to be healthy in the future (Fowler et al., 2007; Zwi et al., 2010).

## **Conclusion**

Fitzgerald (2009) suggested that children need to be involved, engaged, and valued in the research process. In this study, the unique method of the scrapbook interviewing technique allowed the children to tell their stories. The method also enabled the researchers to explore child conceptions of health. Understanding the need to live an active and healthy lifestyle is important for all children, especially for children with disabilities because they are at a higher risk of acquiring secondary disabilities (Fowler et al., 2007; Rimmer, 1999). Thus, it is vital for children with disabilities to understand what constitutes good and healthy behaviors. This knowledge may impact their current and future choices about adopting and maintaining a healthy lifestyle. A reduction of the constraints to good health should be an overall goal for all persons with disabilities. The children described the enormous responsibilities their parents experienced when coping with the daily challenges of their disability while maintaining the requirements of everyday living (e.g., Raina et al., 2005). Thus, it is equally important for the parents to be aware of healthy lifestyles so they can maintain good levels of health for themselves and be solid caregivers for their children. Goodwin (2001) recommended to actively listen and to attend to the views of children to bring tactfulness and sensitivity to our pedagogical approach. However, health is a complex construct which occurs in many contexts. It is vital that health promotion, adoption, and maintenance are shared responsibilities between home, school, and community.

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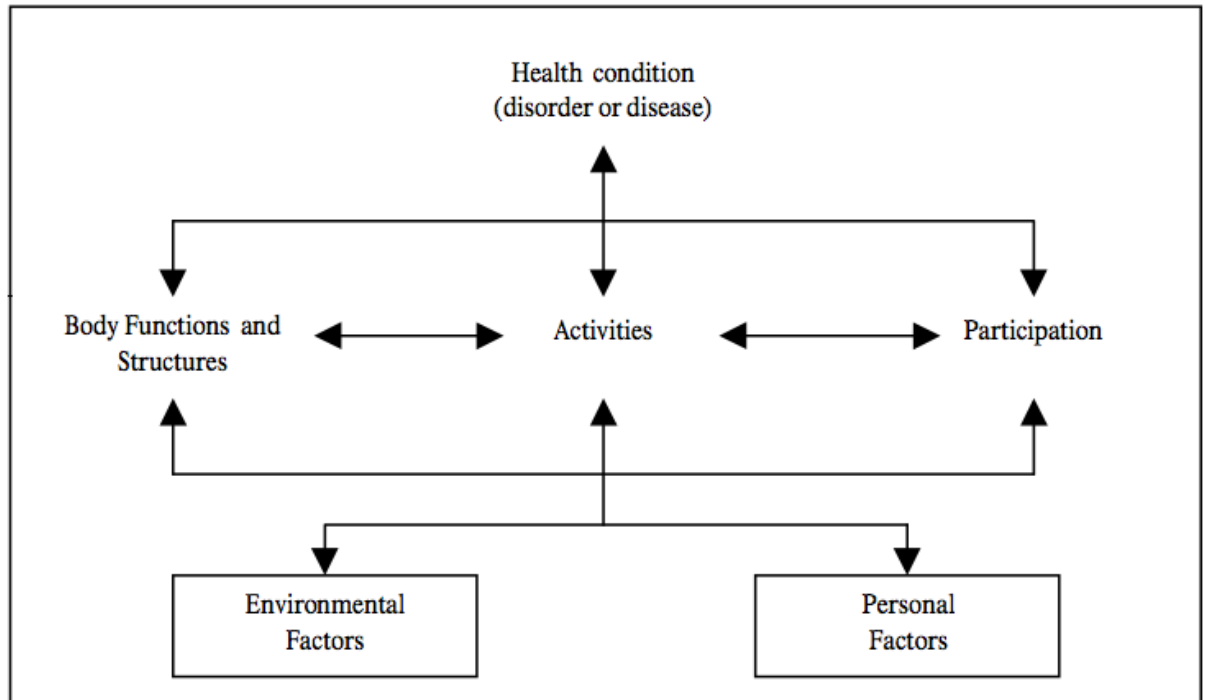
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## Appendix A

Figure 1. The Model of Functioning and Disability



*Figure 1.* The model of Functioning and Disability (ICF model)  
From the International Classification of Functioning, Disability and Health (WHO, 2001, p. 18).

## Appendix B

Table 1      *Research Design*

Research Design	Description
Research Assumptions	<p>What are the underlying assumptions in my research study?</p> <p>e.g., paradigmatic, prescriptive, and causal (Strean, 1998)</p>
Paradigms/Worldviews	<p>“A paradigm is a worldview—a way of thinking about and making sense of the complexities of the real world” (Patton, 2002, p. 69)</p> <p>e.g., postpositivism, constructivism, advocacy/participatory, and pragmatism</p>
Interpretive & Theoretical Frameworks	<p>Shapes the individuals studied, types of questions and problems examined, the approaches to data collection, data analysis, writing, and evaluation (Creswell, 2007)</p> <p>e.g., postmodernism, feminist research, critical theory, and disability theory</p>

*Note.* The three steps used in the table were adopted from Creswell (2007).

## Appendix C

Table 2 *Description of Participants*

Participant	Age in years	Disability and associated conditions	Girl/ Boy	Ambulatory	Equipment Used for ADL	Artifact
Patricia	11y 0m	CP	Girl	No	Manual wheelchair, walker, bike, AFO, sport wheelchair	Running medal, hair brush, HBR ribbon
Paul	12y 7m	CP, ADHD, learning problem	Boy	Yes	Bike with training wheels, AFO	Not provided
Myriam	11y 0m	CP, learning problem	Girl	No	Power wheelchair, gait trainer, bike	Not provided
Jeremy	13y 2m	CP, learning problem, vocal cord paralysis	Boy	Yes	Bike with training wheels, previously used a walker	Running medal, HBR ribbon, two good behavior at school awards
Josh	9y 3m	CP, learning problem	Boy	No	Manual wheelchair, walker, bike	Downhill skiing medal and certificate
Ralph	9y 6m	CP, emotional problem	Boy	Yes	None	Not provided
Brandon	13y 9m	CP, use of DynaVox for communication	Boy	No	Power wheelchair, manual wheelchair, gait trainer, prone stander, stroller, DynaVox	Not provided

*Note.* CP = cerebral palsy; AFO = ankle-foot orthoses.

## Appendix D

### Initial Letter to Potential Participants

Dear Parent or Legal tutor,

February 17<sup>th</sup>, 2010

My name is Cindy Pressé and I am a master student in adapted physical activity at the Department of Kinesiology and Physical Education at McGill University, currently under the supervision of Dr. William J. Harvey. During my Physical and Health Education degree, I completed my last field work experience at Mackay Centre School, followed by a three month work period at the school. In the last two years, I have been a substitute teacher in different classes, assisted in the pool, and volunteered for special events at Mackay Centre School. I have built a strong rapport with the children. Currently, we would like to invite you to participate in a physical activity research study that I will conduct at Mackay Centre School. This letter has been sent to you by Mackay's physical education teacher, Mr. Robert Simpson, on my behalf.

The curriculum in Québec, called the Québec Education Program, was reformed with a student-centered, competency-based approach. For physical education, one of the competencies that teachers are required to teach children is to adopt a healthy, active lifestyle. However, measuring this competency is quite challenging and remains an area to be researched. This research project will contribute to a better understanding of what living a healthy and active lifestyle entails for a child with a disability by asking each child and one of their parents about his/her experience. This may shed some light on the current physical education curriculum in Québec and assist people with disabilities to become healthy and active. Only recently has more attention been given to the importance of daily physical activity behaviors and people with disabilities.

There are three main parts to the project. First, I will provide each child and parent with a disposable camera to take pictures of what it means to the child to live a healthy, active lifestyle. Second, I will explore the feelings and attitudes that children with disabilities have about physical activity through an interactive interview by using the pictures taken by the child and his/her parent. Third, we will interview you, the parent, about your child's physical activity and health experiences. The main outcome of the research project is to understand the experience of what it means for a child with a disability to live a healthy and active lifestyle.

In order to participate in this study, your child has been identified by his/her classroom teacher as being able to express him/herself. Children selected for the study, will be English speaking so we can ensure that the information collected is consistent for all participants and we do not have to explain different terms that children, who speak different languages, use. If you are interested in participating in this study, we would appreciate if you could complete and sign the bottom of this form so I may contact you to set up an appointment to meet with you and your child in order to discuss the research project. Please return the bottom section of this form in the attached envelope, seal the

envelope, and provide it to Mr. Robert Simpson, by Friday February 26<sup>th</sup>, 2010. Thank you for your consideration of this research project.

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Cindy Pressé, B.Ed., P.E.  
MA Student in Adapted Physical Activity  
Department of Kinesiology and Physical Education  
McGill University

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William J. Harvey, Ph.D.  
Assistant Professor  
Department of Kinesiology and Physical Education,  
McGill University  
Associate Researcher and CHAMPS Lab Director,  
Douglas Mental Health University Institute

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If you agree that Ms. Cindy Pressé may contact you to set up an appointment, please complete the following information.

Child's name: \_\_\_\_\_ Parent's name: \_\_\_\_\_

Parent's signature: \_\_\_\_\_ Date: \_\_\_\_\_

Primary phone #: \_\_\_\_\_ Secondary phone #: \_\_\_\_\_

E-mail: \_\_\_\_\_

## Appendix E

### Consent Form

Dear Parent or Legal tutor,

My name is Cindy Pressé and I am a master student in adapted physical activity at the Department of Kinesiology and Physical Education of McGill University, currently under the supervision of Dr. William J. Harvey. This letter requests permission for both you and your child to participate in a research study. I believe that it will be an enjoyable experience for both of you. The purpose of this qualitative study is to explore the perception of youth about what it means for them to live a healthy lifestyle. Participation in this study will contribute to a better understanding of what living a healthy lifestyle entails for a child with a disability and it can shed some light on the current physical education curriculum in Québec. The agencies that are sponsoring this study include Social Sciences and Humanities Research Council of Canada (SSHRC) and Fonds de recherche sur la société et la culture (FQRSC).

I will ask you and your child to have an initial meeting with me, to receive information about the study and to provide both of you a disposable camera to take pictures of what a healthy lifestyle represents for your child. If you agree to participate, I will ask you to sign the attached consent form. Approximately one month later, a second meeting will take place, where a 30-60 minute interview will be conducted while your child and I create a scrapbook with the pictures that you and your child take. After your child's interview, you will be interviewed for 20-30 minutes. Interviews will be located at school in a secure location. All interviews will be videotaped so I may conduct a verbatim transcription of the interview for the purpose of a textual analysis. I will supply all materials and pay for all photo development. You and your child will be contacted after the second meeting to review whether my interpretation of the interview is accurate. An executive summary of the study will be provided to the parents/legal tutors.

There are no known physical or psychological risks associated with this study to any of the participants. Participants will not be paid for participating in this study. All required material will be provided by the researchers. Every effort will be made to ensure confidentiality of the information that is obtained in connection with this study. Transcriptions will be stored in a locked cabinet at Dr. Harvey's physical activity laboratory the Douglas Mental Health University Institute. The videotape, pictures, and scrapbook will only be viewed by the researchers and one graduate student for a data peer review. Names of the participants will not be used nor will they be associated with any presentation or publication that might emerge from this research. After the completion of the study, the scrapbooks will be returned to your child.

Involvement in this study is completely voluntary for both parents/legal tutors and children. Even if you sign the form on the following page, your child and you are both free to withdraw at any point or any time without question or consequence.

Please sign the following page of this form to indicate your consent for both of you to participate. If you have any questions or concerns about the research, please feel free to contact me or Dr. Harvey. If you have any questions or concerns about your rights or welfare as a participant in this study please contact the McGill Research Ethics Officer at 514-398-6831.

Sincerely,

Cindy Pressé, B.Ed.  
MA Student

William J. Harvey, Ph.D.  
Assistant Professor



## CONSENT TO PARTICIPATE IN RESEARCH

“Exploring the healthy experiences of youth with disabilities”

I have read the information provided for the study “Exploring healthy experiences of youth with disabilities” as described herein. I agree that the study has been explained in adequate detail to both my child and me. My questions have been answered to my satisfaction and I agree that my child and I will participate in this study. I have been given a copy of this form. I freely consent and voluntarily agree for my child and I to participate in the research study by Cindy Pressé and William J. Harvey. I understand that I am able to withdraw from the study at any time and for any reason. Doing so will not affect any school interventions or programs that are provided to me and my family.

I give permission for the photographs in the scrapbook to be used under the following public conditions (please check any or all of the following boxes that apply to you):

- ☐ Photographs in the scrapbook that do not reveal the identity of the people in the photographs may be used for academic presentations and publications.
- ☐ Any photographs in the scrapbook can be used for academic presentations and publications (images will be shown but names will not appear or be provided).
- ☐ Photographs in the scrapbook cannot be used at academic presentations and publications.

Please mark a check in the box that applies to you:

- ☐ Yes, I agree that my child and I will be videotaped during the interview (this video will only be seen by the research team – Cindy Pressé, William J. Harvey, and one research assistant).
- ☐ No, I disagree that my child and I will be videotaped during the interview. We prefer to be audiotaped.

\_\_\_\_\_  
Name of Child (please print)

\_\_\_\_\_  
Name of Parent/Legal tutor (please print)

\_\_\_\_\_  
Signature of Parent/Legal tutor

\_\_\_\_\_  
Date

\_\_\_\_\_  
Address

\_\_\_\_\_  
City

\_\_\_\_\_  
Postal Code

\_\_\_\_\_  
Name of person who explained study

\_\_\_\_\_  
Signature of the person who explained the study

\_\_\_\_\_  
Date

## Appendix F

### Interview Protocol

Exploring healthy experiences of youth with physical disabilities

**Time of Interview – Start:**

**End:**

**Date:**

**Place:**

**Interviewer:**

**Interviewee:**

**Diagram:**

**Description of project to participant:** Last time we met I gave you a camera and asked you to take pictures of what it means to live a healthy lifestyle for you. Today we are going to make a scrapbook together with the pictures you took. You can choose the paper, stamps, stickers you would like and if you need help, you can ask me (all the pictures will be laid out on the table). Remember we are here today, so you can share your experiences with me on what you think is a healthy lifestyle. If you do not understand a question, do not be afraid to ask me and I will explain it to you. Thank you for coming to do this scrapbook with me.

**Questions:**

Start with an initial ice-breaker for the child: What did you do today at school? Tell me a little bit about you. Choose letter stickers to write your name on your scrapbook.

1. Please choose a picture. Can you tell me about this picture?
  - Why do you like this picture?
  - What are you doing in this picture? Why?
  - Who is this in the picture with you? What are they doing? Why?
  - Where do you do these activities?
  - How do you feel when you play \_\_\_\_ (or whatever they are doing in the picture)? (sport or activity in picture)
  - Who helps you plan this activity?
  - How to you get to the activities you participate in? With who do you go with?

2. What do you do at school to be healthy?
  - Did you take any pictures at school?
  - What are you doing in this picture? Why?
  - Who is this in the picture with you? What are they doing? Why?
  - Where do you do these activities?
  - How do you feel when you play \_\_\_\_? (sport or activity in picture)
  - Who helps you plan this activity?
3. What do you like to do during your free time?
  - What do you do when you get home from school?
  - Do you have a picture to show this?
  - What are you doing in this picture? Why?
  - Who is this in the picture with you? What are they doing? Why?
  - Where do you do these activities?
4. What do you do during the weekend? Show me a picture of you during the weekend.
  - Describe how you play on the weekend. What do you mean by \_\_\_\_? (probe where I am asking for clarification).
  - How do you feel when you play this activity?
5. When you participate in physical activity or are being healthy, who is with you?
6. If a miracle happened tonight, and you had the power to create any kind of physical activity in the morning, one that was perfect for you, what would you create? (Holt & al., 2008)
  - What equipment would you need?
  - Who would participate with you?
7. What does it mean for you to adopt a healthy lifestyle?
8. What does living a healthy lifestyle mean to you?
9. How does your family adopt a healthy and active lifestyle?

- Tell me about an experience with you and your family were active? Healthy?
- What are things you *do* to live a healthy and active lifestyle?
- What are things you *can do* to live a healthy and active lifestyle?

**End:** Thank you for taking pictures and sharing your experience with me. The only person that knows about all the information you told me will be me. I might ask you to come back for a second interview. In a few days I will read to you a summary of what you told me and you will make sure it's right. Do you have anything you want to tell me? Do you have any questions?

## Appendix G

## Audit Trail

Table 3 *Themes and Properties with Frequencies as Expressed by Each Participant*

Themes and Properties	Participants							Total MU
	1	2	3	4	5	6	7	
<i>My Scrapbook</i>	56	33	103	63	171	112	5	543
Materials	27	24	59	33	76	33	4	256
Logistics	29	9	44	30	96	79	1	288
<i>What I Do During My Free Time</i>	47	113	68	70	59	92	2	451
Unstructured recreational activities	22	35	43	39	37	36	2	214
Structured recreational activities	25	78	25	31	22	56	0	237
<i>People Around Me</i>	64	57	100	61	51	73	14	420
Parental influence	12	5	25	7	18	8	0	75
Family	23	24	30	33	12	26	1	149
School	27	7	35	13	19	26	8	135
Friends	2	21	10	8	2	13	5	61
<i>What Helps Me and What Doesn't</i>	64	77	71	66	74	82	12	446
Affordances	59	48	54	56	58	72	12	359
Constraints	5	29	17	10	16	10	0	87
Total MU	231	280	342	260	355	359	33	1860

## Appendix H

## Individual Thematic Audit Trail for Theme One

Table 4 *Properties and Tags for the My Scrapbook Theme*

Properties and Tags	Participants							Total MU
	1	2	3	4	5	6	7	
<i>Materials</i>	27	24	59	33	76	33	4	256
Materials	25	21	57	32	57	31	0	223
Enjoyment	2	3	2	1	19	2	4	33
<i>Logistics</i>	29	9	44	30	96	79	1	288
Pictures	3	2	19	3	5	33	0	65
Questions	2	4	3	2	32	5	1	49
Choices	24	3	22	25	59	41	0	174
Total MU	56	33	103	63	171	112	5	543

## Appendix I

## Individual Thematic Audit Trail for Theme Two

Table 5 *Properties and Tags for the What I Do During My Free Time Theme*

Properties and Tags	Participants							Total MU
	1	2	3	4	5	6	7	
<i>Unstructured recreational activities</i>	22	35	43	39	37	36	2	214
Physical activities	7	8	3	2	11	8	1	40
Sedentary activities	7	5	17	9	11	4	1	54
Preferences	1	7	14	16	12	9	0	59
Environment	1	5	4	8	1	7	0	26
Routine	6	10	5	4	2	8	0	35
<i>Structured recreational activities</i>	25	78	25	31	22	56	0	237
Sports	10	42	9	13	6	13	0	93
Technique	6	10	6	4	5	12	0	43
Extracurricular activities	0	5	0	0	5	15	0	25
Preferences	7	10	5	10	4	8	0	44
Routine	2	11	5	4	2	8	0	32
Total MU	47	113	68	70	59	92	2	451

## Appendix J

## Individual Thematic Audit Trail for Theme Three

Table 6 *Properties and Tags for the People Around Me Theme*

Properties and Tags	Participants							Total MU
	1	2	3	4	5	6	7	
<i>Parental influence</i>	12	5	25	7	18	8	0	75
Involvement	9	4	21	6	13	6	0	59
Decisions	1	0	4	0	2	1	0	8
Teachings	2	1	0	1	3	1	0	8
<i>Family</i>	23	24	30	33	12	26	1	149
Leisure activities	3	8	6	12	5	26	0	60
Involvement	0	3	10	6	1	0	1	21
Events	20	0	6	3	6	0	0	35
Excursions	0	13	8	12	0	0	0	33
<i>School</i>	27	7	35	13	19	26	8	135
Academics	14	1	7	0	0	0	0	22
PHE	6	1	11	0	5	15	3	41
Routine	5	4	8	3	3	1	0	24
Recess	0	1	0	5	1	7	1	15
School related activities	2	0	2	1	7	1	2	15
Significant other	0	0	7	4	3	2	2	18
<i>Friends</i>	2	21	10	8	2	13	5	61
Home	2	9	7	6	0	10	0	34
School	0	5	2	2	0	2	4	15
Community	0	7	1	0	2	1	1	12
Total MU	64	57	100	61	51	73	14	420



## Appendix K

## Individual Thematic Audit Trail for Theme Four

Table 7 *Properties and Tags for the What Helps Me and What Doesn't Theme*

Properties and Tags	Participants							Total MU
	1	2	3	4	5	6	7	
<i>Affordances</i>	59	48	54	56	58	72	12	359
Active	6	5	4	1	7	7	2	32
Physiological	0	2	3	0	7	8	0	20
Fun	4	7	5	4	1	16	3	40
Environment	1	4	7	1	6	4	1	24
Awards	7	6	1	19	6	10	0	49
Nutrition	13	12	14	11	11	14	1	76
Hygiene	13	0	0	2	0	0	2	17
Healthy choices	15	12	20	18	20	13	3	101
<i>Constraints</i>	5	29	17	10	16	10	0	87
Mobility issues	4	7	5	3	5	1	0	25
Negative feelings	0	18	6	3	4	1	0	32
Safety	0	0	2	1	0	3	0	6
Circumstances	1	4	4	3	7	5	0	24
Total MU	64	77	71	66	74	82	12	446