Active Living and Seniors with Intellectual Disability - An Ecological Perspective

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Abstract

Active living is a "way of life in which physical, social, mental, emotional, and spiritual activities are valued and are integrated into daily living" (Active Living Coalition for Older Adults, 2008). As such, physical activity is a critical component of active living through which each citizen is encouraged to be active 30 minutes a day for health benefits. Seniors with intellectual disability (ID) are currently not included in this movement. The Ecological Model of Human Behavior (EMHB) stresses the importance of a supportive environment promoting healthy behavior. It is the theoretical framework of this thesis, which is composed of a series of three articles, and therefore structures the literature review and the two research studies conducted. The first study inquired about the physical activity barriers, needs, and preferences of seniors with ID. It was carried out among seniors with ID themselves and educators through a questionnaire and focus groups interviews. The second study investigated the organization of physical activity for seniors with ID. It was carried out among centers for people with ID, senior citizen centers, and centers for health and leisure, through an online survey. Overall, results showed a remarkable interest by seniors with ID who enjoyed sharing their different perspectives. A great number among them exercised while having optimistic outlooks on their health. Physical activity programs were not designed around seniors with ID. Although their needs increase as they age, seniors remained relatively ignored and did not benefit from any special support in health prevention. The results also suggested that educators and service providers required greater guidance to facilitate the implementation of physical activities. Active living through physical activity was not yet conceptualized as a vehicle to promote health among seniors with ID.

Résumé

La vie active est une « façon de vivre où les activités physiques, sociales, mentales, affectives et spirituelles sont valorisées et intégrées dans la vie quotidienne » (Coalition pour la Vie Active, 2008). Ainsi, l'activité physique est une composante critique de la vie active où chaque citoyen est encouragé à être actif minimalement 30 minutes par jour pour ressentir des bienfaits. Les personnes âgées avec une déficience intellectuelle (DI) ne sont présentement pas inclues dans ce mouvement. Le Modèle écologique du comportement humain souligne l'importance du soutien environnemental dans la promotion d'un comportement sain. Il est le cadre théorique de cette thèse, qui est composée d'une série de trois articles, et structure donc la revue de littérature et les deux études menées. La première s'intéressait aux barrières, besoins et préférences en activité physique des personnes âgées avec une DI. L'étude a été conduite parmi des personnes âgées avec une DI elles-mêmes et des éducateurs, à travers un questionnaire et des groupes de discussion. La deuxième étude examinait l'organisation des activités physiques pour les personnes âgées avec DI. L'étude a été conduite parmi des centres pour personnes avec une DI, des centres pour personnes âgées et des centres de santé et loisirs, à travers un sondage en ligne. Globalement, les résultats ont démontré un intérêt remarquable des personnes âgées avec une DI qui ont aimé partager leurs différentes perspectives. Un nombre important d'entre-elles faisait de l'exercice tout en ayant un point de vue optimiste sur leur santé. Les programmes d'activité physique n'étaient pas créés autour des personnes âgées avec une DI. Bien que leurs besoins augmentent avec l'âge, les personnes âgées restaient relativement ignorées et ne bénéficiaient pas de soutien spécial en matière de prévention de la santé. Les résultats ont aussi montré que les éducateurs et les fournisseurs de services nécessitaient d'un plus grand soutien pour faciliter la mise en place de programmes en activité physique. La vie active à travers l'activité physique n'était pas encore conceptualisée chez les personnes âgées avec une DI comme moyen de prévention de la santé.

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Chapter I: Introduction

Important progress in medicine, health care, nutrition, and education has helped individuals with intellectual disability (ID) age with the rest of the baby-boom generation in Western countries (Factor, 2005; World Health Organization [WHO], 2000). In fact, their life-span and aging process are comparable to people without disabilities, with the exception of people with Down syndrome who age prematurely (Adlin, 1993; Bigby, 2004; Boyd, 1997; Salvatori, Tremblay, Sandys, & Marcaccio, 1998). Given the increase in the number of seniors with ID, it is essential that policies and support services respect the Canadian action plan for individuals with disabilities in physical activity to encourage healthy behavior and ensure their social participation (Health and Social Services Ministry, 2001; National Advisory Committee on Physical Activity for Canadians with a Disability, 1988). This action plan, called the Blueprint for Action, challenges Canadians to facilitate and increase physical activity for citizens with disabilities through the development of health-related policies and programs (See Table 1). The plan is societal as it acknowledges that Canadian social structures, such as "the family, the schools, the workplace, and the health care system" (National Advisory Committee on Physical Activity for Canadians with a Disability, p. 16) play important roles in promotion of physical activity.

Seniors with Intellectual Disability

The estimated number of seniors with ID frequently includes people with developmental disabilities such as genetic syndromes (e.g., Fragile X, Prader-Willis, Down syndrome), problems of the central nervous system (e.g., epilepsy, cerebral palsy, and visual impairments), as well as individuals with autism or those with "milder" developmental disabilities (National Advisory Council on Aging [NACA], 2004). In 2001, approximately 44,700 Canadians between the ages of 45 and 64 and 11,080 Canadians between the ages of 65 and 74 had developmental disabilities (NACA). There are no national figures for the number of elderly Canadians with an ID. However, there were 48,100 people aged 55 and older in Quebec in 1997, constituting more than a quarter of all people with an ID in Quebec (Stat Flash, 1997). Nevertheless, these numbers of seniors with ID in the province may be an underestimation as they exclude seniors living in institutions, nursing homes, or on First Nation reserves (NACA).

Research initiatives have resulted from the growing number of seniors with ID. Over the past two decades, academics have focused mainly on the retirement of seniors with ID (Cordes & Howard, 2005; Heller, Miller, Hsieh, & Sterns, 2000; Heller & Sterns, 1996; Mahon & Goatcher, 1999), their health issues (Adlin, 1993; Carmeli, Merrick, Kessel, Masharawi, & Carmeli, 2003; Cooper, 1998; Fisher & Kettl, 2005; Janicki & Dalton, 2000; Janicki et al., 2002; McCarron, Gill, McCallion, & Begley, 2005; Moss, 1991; Thorpe, 2003; Tyler, Snyder, & Zyzanski, 2000; Van Buggenhout et al., 1999), their leisure (Boyd & Tedrick, 1992; Glausier, Whorton, & Knight, 1995; Hogg, 1994; Pedlar, Gilbert, & Gove, 1994; Rogers, Hawkins, & Eklund, 1998), and the delicate issue of their aging family caregivers (Engelhardt, Brubaker, & Lutzer, 1988; Hayden & Heller, 1997; Seltzer, Begun, Seltzer, & Krauss, 1991).

Additionally, numerous health reports assert that regular exercise is necessary for these individuals and they recommend more empirical studies about active living for seniors with ID. For instance, a first report advocated an "appropriate and ongoing education regarding healthy living practices in areas such as nutrition, exercise..."

(WHO, 2000, p. 19), another encouraged the development and evaluation of "health promotion programs encompassing health behavior education, nutrition, and physical activity" (Heller, Janicki, Hammel, & Factor, 2002, p.10). A third report advocated "increased practical, leisure, or life enhancing skills, improved or maintained dietary and general health status that prevents physical health factors from becoming an untoward hindrance on typical activity, a varied rhythm of life involving preferred activities" (Thorpe, Davidson, & Janicki, 2000, p.9). Finally, two other reports by Davidson, Heller, Janicki, and Hyer (2002; 2004) recommended the promotion of healthy aging and suggested the identification of "barriers and facilitators for persons with intellectual and developmental disabilities to participate in health-promoting activities, such as engaging in regular exercise" (2004, p.7). Although the fields of aging and ID are slowly expanding, the field of active living adapted to seniors with ID continues to lack empirical data.

Active Living and Physical Activity

Active living is defined as "a way of life in which physical, social, mental, emotional, and spiritual activities are valued and are integrated into daily living" (WHO, n.d.; as cited by the Active Living Coalition for Older Adults [ALCOA], 2008). Physical activity is a critical component of active living and is part of a number of other mental, social, and spiritual activities that contribute to overall well-being and enhance quality of life (ALCOA). Special examples of various active living activities include being part of a club (social), playing chess (mental), going to a play (emotional), and learning meditation (spiritual). The Canadian Declaration for Active Living and Older Adults (ALCOA, 1999) recognizes nine principles that help to attain a "collective vision of an active society where all older Canadians are leading active lifestyles, thereby contributing to their physical health and overall well-being" (See Table 2). It is important to acknowledge that active living is essential for daily life, and that physical activity should be encouraged beyond the traditional framework of "fitness" (i.e., being involved in a league or a work-out) in order to achieve health benefits and improve quality of life (ALCOA, 1999). As such, active living is a way of life in which everyone is encouraged to be active according to interests, environment, and schedules.

The benefits of being involved daily in physical activity are numerous. In fact, physical activity contributes to increased longevity (Markula, Grant, & Denison, 2001) and helps to protect against osteoporosis, hip fracture, obesity, falls, cancers, type II diabetes, high blood pressure, cholesterol, and sarcopenia (i.e., loss of muscle mass; DiPietro, 2001). Being physically active positively impacts physiological health (e.g., cardiovascular endurance, flexibility, muscular strength, and bone mass), and it has beneficial effects on psychological health (e.g., self-esteem, self-efficacy, and relaxation) because exercise increases well-being and reduces feelings of anxiety, stress, and depression (U.S. Department of Health and Human Services, 2006). A mere 30 minutes of moderate activity per day is recommended by the U.S. Surgeon General for all individuals to maintain or acquire psychological and physical health benefits (U.S. Department of Health and Human Services, 1996).

Empirical Studies

Despite some practical accounts of seniors with ID and physical activity (Frizzell, 1997; Hawkins, 1997; Rimmer, 1997), there are only seven empirical studies (Carmeli, Barchard, Masharawi, & Coleman, 2004; Carmeli, Kessel, Coleman, & Ayalon, 2002;

Carmeli et al., 2003; Carmeli, Zinger-Vaknin, Morad, & Merrick, 2005; Mactavish & Searle, 1992; Pogorski, Kessler, Cacia, Peterson, & Henderson, 2004; Steff & Reid, unpublished) about seniors with ID in the context of physical activity. Mactavish and Searle showed that physical activity helped the experimental group increase perceived competence, locus of control, and self-esteem, all of which remained unchanged for the control group. The intervention of Podgorski et al. (2004) lead to 92% of participants improving at least one fitness variable as a result of the exercise regime. The variables were mobility, gait, strength of the upper and lower body, and range of motion of the shoulder and hip. The third study (Steff & Reid) showed that seniors with ID improved on all four variables assessed (swimming skills, initiative taking, positive responses, and social interaction).

The last four studies, all conducted by Carmeli and his collaborators, indicated: 1) significant improvements in knee extension, flexion isokinetic, leg strength, and dynamic balance for the whole experimental group (Carmeli et al., 2002); 2) a positive relationship between well-being and physical activity in the exercise group (Carmeli et al., 2003); 3) improvement in walking speed, duration, and distance as well as a reduction of pain levels and an increase in the functional capacities for the experimental group (Carmeli et al., 2004); and 4) important functional changes in the experimental group relative to balance and muscle strength (Carmeli et al., 2005).

Theoretical Framework

A number of theories were considered for this dissertation. It included (a) traditional psychological theories such as Maslow's (1943) Hierarchy of Needs and the Theory of Selective Optimization with Compensation (Baltes & Baltes, 1990), (b)

sociological theories applied to aging with the Activity Theory (Fisher, 1995; Lemon, Bengtson, & Peterson, 1972) and the Continuity Theory (Atchley, 1972), and (c) theories supporting behavior change with the Decision Making Theory (Janis & Mann, 1977), the Health Belief Model (Becker, 1974), the Self-Determination Theory (Deci & Ryan, 1985), the Social Cognitive Theory (Bandura, 1986), and the Transtheoretical Model (Prochaska & DiClemente, 1983). However, traditional physical activity programs focusing exclusively on the individual person have shown limited success once the intervention ends because environmental and social factors have not been taken into account (Spence & Lee, 2003). In fact, healthy behaviors are multifaceted components of a broader system of behaviors which are influenced by society (DeBate, Plescia, Joyner, & Spann, 2004). People are influenced by internal factors (e.g., motivation, health, experience) as well as environmental factors (e.g., friends, access to facilities, workload).

The author decided to use the Ecological Model of Human Behavior (EMHB; McLeroy, Bibeau, Steckler, & Glanz, 1988) which stresses the importance of a dual focus on the individual as well as on the broader supportive environment that promotes healthy behavior. The model proposes five levels of environmental influences on behavior which will be used to guide and structure this doctoral dissertation. First, the *intrapersonal* level is related to the individual's psychological, biological, and developmental characteristics. For example, it is the initiative that one takes to exercise for weight loss. The second, *interpersonal* level is social support from friends, family, and co-workers. For instance, the social network mediates stress and influences overall well-being "including emotional support, information, access to new social contacts and social roles, and tangible aid and assistance" (McLeroy et al., p. 357). The third *institutional* level is defined as the organizational characteristics, rules, and development of structured services that facilitate access to local health facilities. For example, seniors in Quebec have access to programs like "Stand-up!" which prevent falls and fractures through group and home exercises (Quebec Health and Social Service Center Agency, 2008). Fourth, the *communal* level is the relationships and collaborations among organizations, institutions, and social networks that facilitate health behavior. For instance, "Stand-up!" service providers work together to promote the program and increase its quality. The last level of behavior influence is *public policy and laws* at local, regional, and national levels. Examples of the latter include better insurance rates for active individuals, laws protecting green space, and tax breaks for healthy behaviors.

The levels complement each other because "health depends on the dynamic interaction" of these multiple influences (Satariano & McAuley, 2003, p. 85). Therefore, interventions at various levels of the model can result in long-lasting changes and healthy habits, such as involvement in daily exercise programs (Marcus & Forsyth, 2003). The EMHB will provide a context in which to view seniors with ID and their relationship to physical activity. It will also facilitate further investigation about physical activity and ID. *Problem Statement*

Seniors with ID form a marginal group that lacks social power. Their voices are not heard by a society that claims to value self-determination, empowerment, inclusion, and healthy living. Potential health benefits are unlikely to materialize if their views are inadequately addressed.

The objective of this dissertation was to address the promotion of physical activities among seniors with ID from a health perspective. Most specifically, the research

question was: How do current physical activity programs address the barriers, needs, and preferences of seniors with lifelong ID in a North-American metropolitan context? *Barriers, Needs, and Preferences*

The predictors of regular physical activity (e.g., demographic, psychosocial, and environmental) have been fairly well documented among citizens of various ages and ethnic groups (Gauvin, 2003; Weiss, O'Loughlin, Platt, & Paradis, 2007). Improved physical activity planning, policy development, management strategies, and interventionprograms have been designed around these predictors to achieve health and recreational benefits. As such, the literature on barriers, needs, and preferences is as broad as the terms used (Brittain, Jones, & Rikli, 2002; Jones & Rose, 2005; McAvoy, 1979; O'Neill & Reid, 1991; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Shephard, 2002; Temple, 2007). Terms such as "perceived constraints," "facilitators," and "enjoyment" are employed depending on the study's theoretical model and aims. The present researcher used the terms "barriers," "needs," and "preferences" because they were fairly simple concepts that senior participants with ID could easily grasp.

Barriers. Barriers are the constraints that prevent individuals from being physically active. Barriers to physical activity for seniors in the general population as reported by Brittain, Jones, and Rikli (2002) include: (a) laziness / lack of self-discipline, (b) not enough time / too busy, (c) discomfort / pain, (d) weather, (e) lack of strength and stamina, and (f) lack of partner / social support (Brittain et al.). To our knowledge, no studies exist that identify barriers in physical activity among seniors with ID. However, in leisure, barriers for this group include having no one to teach the activity, having the decision be made by someone else, a lack of equipment, transportation issues, health, fear of getting hurt, loneliness, time, financial constraints, age, lack of informal support, and difficulty accessing the activities (Bigby, 1992; Glausier et al., 1995; Hawkins, 1991).

Others have conceptualized four types of general barriers to physical activity, independent of the individuals. They include: (a) physical / health, (b) psychological, (c) knowledge, and (d) administrative (O'Neill & Reid, 1991). Health barriers include physical injuries or illnesses. Psychological barriers are negative attitudes toward physical activity or toward one's own body (e.g., distorted image of oneself in a bathing-suit). Knowledge barriers include awareness of the benefits of physical activity and the misconception that physical abilities must decline as people age. Finally, administrative barriers are encountered in facilities, accessibility, transportation and cost.

Needs. Need is defined by Green and Kreuter (1991) as "whatever it requires for health or comfort". It includes personal, social, and environmental conditions, such as the need to feel included within one's family, to have friends to communicate with, and to access education. An early research study explains that seniors need physical activity for social reasons, self-fulfillment, feeling close to nature, and continual learning for selfsatisfaction (McAvoy, 1979). To our knowledge, no study has identified needs in physical activity among seniors with ID. Other studies in leisure report that this group needs activity supervision, transportation, funds, and skills (Bigby, 1992; Glausier et al., 1995; Sparrow & Mayne, 1990).

Preferences. Preference means enjoying one activity over another and choosing what is to be enjoyed. Studies point out that physical activity preferences vary depending on the senior's gender (Shephard, 2002) and physical functioning (Jones & Rose, 2005). For example, men enjoy more outside and competitive physical activities whereas women

prefer more relaxing physical activities. Seniors also enjoy activities that they can practice without physical limitations due to their age. Relative to other individuals with ID, they enjoy dancing, walking, bowling, weight training, aerobic classes, and exercise classes (Temple, 2007).

Overall, no studies directly ask seniors with ID about the barriers they experience in physical activity, what their needs are, which types of physical activities they most enjoy, why they choose them, how many hours per week they participate, and how they feel when they are physically active. It is unclear whether physical activity programs within broader day support services are appropriate, easily accessible, and in line with the needs and preferences of younger individuals with ID.

Other Definitions

Intellectual disability. According to the American Association of Mental Retardation (AAMR, 2002), an individual with an ID is "characterized by significant limitations both in intellectual functioning and in adaptive behavior as expressed in conceptual, social, and practical adaptive skills. The disability originates before age 18." (p. 13). The term "intellectual disability" is preferred to mental retardation, mental handicap, developmental disability, or learning disability because it is associated with less stigmatization and it is now used throughout North America (American Association on Intellectual and Developmental Disabilities, 2008).

Service provider. Service provider is commonly defined as a center which offers specific services to individuals. For this dissertation, there are specialized or community centers providing physical activity programs for seniors with ID in one of the three

following fields: intellectual disability (Gibson, Choi, & Cook, 1993), gerontology, and health and leisure.

Physical activity and exercise. Physical activity includes movements produced by skeletal muscles and results in an increase in energy expenditure (Public Health Agency of Canada, 2003). These movements can take place in a leisure or non-leisure context. Exercise is a noncompetitive "form of leisure-time physical activities that is planned, structured, and repetitive" to improve or maintain physical health (Public Health Agency of Canada, ¶ 3).

Age. There is no general defining age at which a person with an ID enters old age (WHO, 2000). For instance, the early aging process experienced by people with Down syndrome has been erroneously generalized to people with ID. Since researchers tend to include individuals with Down syndrome in their studies, they often resort to lowering the age limit of participation (Bigby, 2004). The WHO (2000) proposes using the sixth decade, meaning the chronological point of the 50s. Others have suggested common age-banding, starting from the 50s with 5 year intervals to facilitate comparisons between studies (Bigby & Balandin, 2004). For the purpose of this study, the defining age of the selected participants was 50 years old and above (WHO).

Organization and Methodology

This doctoral dissertation will be composed of three manuscript style stand-alone papers (chapters two to four). The first paper (chapter two) is a critical review of the scientific literature on seniors with ID and active living. It proposes the need to increase knowledge about this population so that appropriate physical activity services can be incorporated into their daily living. The EMHB is the conceptual framework guiding and delimiting the retrieval of articles.

The second paper (chapter three) examines the physical activity barriers, needs, and preferences among seniors with ID. This chapter explores intrapersonal and interpersonal factors of influence (McLeroy et al., 1998) of the EMHB using a questionnaire and focus group interviews. The questionnaire was an adaptation of the "Exercise Health Education Self-Assessment Packet for Adults with Developmental Disabilities: Baseline Interview Questionnaire" (Heller, Marks, & Ailey, 2006). Its completion was followed by focus group interviews with educators and seniors with ID.

The third paper (chapter four) investigates the organization of physical activity services for seniors with ID in Quebec. It corresponds to the institutional, communal, and public policy levels of the EMHB (McLeroy et al., 1998). Data were obtained with an adaptation of the "Survey on Physical Activity Services for Seniors with Intellectual Disability" (Bigby, Fyffe, Balandin, McCubbery, & Gordon, 2001). This survey was completed online by service providers in the fields of ID, aging, and health and leisure.

Finally, the last part (chapter five) summarizes and concludes this doctoral dissertation by answering the research question. Overall, this research endeavors to provide a voice for seniors with ID, and to address the scientific communities researching active living, physical activity, and seniors with ID.

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Table 1

Seven Ambitions of the Blueprint for Action

1. Facilitating the growth of self-empowered individuals through awareness, education, and support

2. Developing quality delivery systems and networks with clearly defined roles,

responsibilities, and communication links at all levels

3. Enhancing organizational planning and policy development by providing resources and

support mechanisms

4. Identifying, developing, and promoting effective programmes and services

5. Developing and promoting leadership by providing the programmes and support

necessary to meet needs

6. Developing public awareness through promotional strategies involving community

action and education

7. Identifying, promoting, and supporting research priorities and state-of-the-art

information

National Advisory Committee on Physical Activity for Canadians with a Disability (1988). Blueprint for action: Physical activity for Canadians with a disability. Ottawa: Fitness Canada (p.17)

Table 2

Canadian Declaration on Active Living and Older Adults Active Living Coalition for Older Adults (1999). Canadian Declaration for Active Living and Older Adults. GeoOrigin: National.

1. It is recognized that active living is essential for daily activity and a cornerstone of health and quality of life.

2. There is a need for more positive attitudes toward aging, with realistic images that depict older adults as respected, valued, and physically active members of society.

3. Older adults should be encouraged to participate in decision-making and leadership positions, in all phases of program or service development and delivery.

4. Through coordination and collaboration, consistent messages and programs pertaining to active living can have a significant impact on society and lead to long-term, positive change.

5. Issues, interests, and needs of older adults in their community must be identified; and accessible, affordable active living activities and programs must be designed to meet those needs.

6. While it is recognized that aging and learning are both life-long processes, it is appreciated that, for some, pre-retirement years may be a key time to re-focus on active living and well-being.

7. Canada is a society for all ages, therefore programs and services should be developed which accommodate older adults' choices to be with others.

8. There is a need to identify, support, and share research priorities that apply to active living and aging.

9. There is a need for education and promotion of the health benefits of active living as a way of life for older adults.
Author Contribution

The relative contributions of the two authors are as follows: As first author and primary researcher, I was responsible for 85% of the literature review. I was involved in the original concept, research design, article retrievals and analyses, and manuscript writing. As second author, Dr. Reid was responsible for the remaining 15%. He helped design the study, was consulted about the data analysis, and edited the manuscript.

Running head: SENIORS WITH INTELLECTUAL DISABILITY

Chapter II: Seniors with Intellectual Disability and Active Living: An Ecological

Analysis

Marion Steff and Greg Reid

Abstract

The number of individuals aging with a lifelong intellectual disability (ID) is rising. Seniors with ID currently represent a sizeable cohort, one which requires person-centered care and active living (AL) programs to address their physical, psychological, and social changes. The aim of this paper is to critically review the scientific literature on seniors with ID in the context of AL. The Ecological Model of Human Behavior (McLeroy, Bibeau, Stecker, & Glanz, 1988) is the conceptual framework used; it describes five broad factors that influence health behavior. These levels are (a) *intra*personal, (b) *inter*personal, (c) institutional, (d) communal, and (e) public policy. There is minimal research about AL and seniors with ID at all levels of the conceptual framework. Programs that suit the preferences and needs of seniors with ID are required to maintain and improve motor function. Caregivers and professionals need structure, training, and guidance from public policy makers in order to encourage an active lifestyle. Health, disability, and aging agencies as well as researchers should collaborate to facilitate the development of adapted physical activity programs. Seniors with Intellectual Disability and Active Living: An ecological analysis

Active living (AL) is defined as "a way of life in which physical, social, mental, emotional, and spiritual activities are valued and are integrated into daily living" (WHO, n.d.; as cited by the Active Living Coalition for Older Adults [ALCOA], 2008). Physical activity is a critical component of AL. In fact, being physically active not only positively impacts endurance, flexibility, and muscular strength but also has beneficial effects on physiological and psychological health. Physical activity is part of a number of mental, social, and spiritual activities that contribute to overall well-being and enhance quality of life (ALCOA). Examples of these other activities include being member of a club (social), playing chess (mental), going to a play (emotional), and meditation (spiritual). It is important to acknowledge that AL is essential for daily life, and that physical activity should be encouraged beyond the traditional framework of "fitness" (i.e., being involved in a league or a daily workout) in order to achieve health benefits and improve quality of life. As such, AL is a way of life where everyone is encouraged to be active according to their interests, environment, and schedules. Researchers have explored AL among the elderly population in considerable depth. However, they have yet to investigate AL among seniors with intellectual disability (ID). This negligence is surprising given the current societal focus on health promotion.

Present seniors with ID are the first sizeable cohort to live until later life in Western countries (Bigby, 2004). It includes people with ID above 50 years old (WHO, 2000). While there are no Canadian figures for the number of elderly with an ID, there are approximately 44,700 Canadian seniors with developmental disabilities between the ages of 45 and 64 and 11,080 Canadians between the ages of 65 and 74 (National Advisory Council on Aging, 2004). However, there were 48,100 seniors with ID aged 55 and older in Quebec in 1997, constituting more than a quarter of all people with an ID in the province (Stat Flash, 1997). This cohort surely has increased in size and it is necessary to address health-related activities to optimize their aging and prevent age-related functional impairments (Bigby). In general, people with ID tend to be less active and participate less frequently in regular physical activities (Rimmer, 2005). They often do not achieve the 30 minutes of moderate activity per day that is recommended for individuals of all ages to acquire psychological and physical health benefits (U.S. Department of Health and Human Services, 1996; Rimmer). Conditions encountered such as fatigue, weight gain, and pain are often substantially higher among people with ID. These are either "directly or indirectly associated with their disability, but in most cases are considered preventable" (Rimmer, p. 237). As such, seniors with ID must be recognized as a group with special needs to facilitate healthy aging.

The present study will critically review the scientific literature on seniors with ID and physical activity in order to better understand the state of current research, to guide service providers and to recommend needed research. Presently, health reports urge to have more studies about AL and seniors with ID. For instance, a first report advocated an "appropriate and ongoing education regarding healthy living practices in areas such as nutrition, exercise" (WHO, 2000, p. 19), another encouraged the development and evaluation of "health promotion programs encompassing health behavior education, nutrition, and physical activity" (Heller, Janicki, Hammel, & Factor, 2002, p.10). A third report advocated "increased practical, leisure, or life enhancing skills, improved or maintained dietary and general health status that prevents physical health factors from becoming an untoward hindrance on typical activity, a varied rhythm of life involving preferred activities" (Thorpe, Davidson, & Janicki, 2000, p. 9). Finally, two other reports by Davidson, Heller, Janicki, and Hyer (2002; 2004) recommended the promotion of healthy aging and suggested the identification of "barriers and facilitators for persons with intellectual and developmental disabilities to participate in health-promoting activities, such as engaging in regular exercise" (p. 7).

Collectively, the reports point to numerous factors to be addressed about the needs of seniors with ID and AL. A health-medical approach centered solely on the individual is insufficient given that people are influenced by internal factors (e.g., motivation, health, experience) as well as environmental factors (e.g., friends, access to facilities, workload). For instance, traditional physical activity programs focusing exclusively on the individual have shown limited success once the intervention ends because environmental and social factors have not been taken into account (Spence & Lee, 2003). Inactivity is a major public concern in Western countries and the "epidemic of inactivity has led theorists, researchers, and practitioners to seek innovative models and methods to understand and increase physical activity" (Spence & Lee, p. 20). In an effort to counteract inactivity among individuals with ID who are at heightened risk, a wide conceptual framework is needed to guide the present investigation. The Ecological Model of Human Behavior (EMHB; McLeroy et al., 1988) was selected because of its dual focus on the individual as well as on broader environmental influences, with a classification ranging from the person to the public policies.

McLeroy et al. (1988) explained health behavior is all the actions taken to maintain, attain, or regain good health, and to prevent illness. Health behavior reflects a person's health beliefs. McLeroy et al. outlined five levels that influence health behavior. First, the *intrapersonal* level refers to the individual's psychological, biological, and developmental characteristics. The psychological motivation or initiative that one takes to exercise for weight loss is an intrapersonal factor. The second, *interpersonal* level, is social support from friends, family, and co-workers. For instance, the social network mediates stress and influences overall well-being "including emotional support, information, access to new social contacts and social roles, and tangible aid and assistance" (McLeroy et al., p. 357). In the context of physical activity, interpersonal level would include friends running together to keep each other motivated. The third level, *institutional*, is defined as the organizational characteristics, rules, and development of structured services that facilitate access to local health facilities. For example, seniors in Quebec have access to programs like "Stand-up!" which attempt to prevent falls and fractures through group and home exercises (Quebec Health and Social Service Center Agency, 2008). The fourth level, *communal influences*, are the relationships and collaborations among organizations, institutions, and social networks that facilitate health behavior. For instance, "Stand-up!" service providers work together to promote the program and increase its quality. The fifth level of behavior influence is "public policy and laws" at local, regional, and national levels. Examples of the latter include better insurance rates for active individuals, laws protecting green space, and tax breaks for healthy behaviors.

The layers of this model complement each other as health depends on the dynamic interaction of these influences. Interventions at multiple levels can lead to long-lasting

health habits such as involvement in daily exercise programs. The EMHB provided a context in which to view seniors with ID and their relationship to physical activity.

The present study critically reviewed the scientific literature on seniors with ID, AL and health based on an ecological perspective. Specific questions include: 1) What is the current and relevant empirical work? 2) What are the critical implications at each level of influence that require future research? The ultimate aim is to understand seniors with ID in the context of physical activity and to encourage further empirical studies which may guide service providers.

Methodology

Computer searches of literature were conducted with the *berrypicking model* (Bates, 1989). In this active and adaptive process, one consults findings and continues searching until the data are saturated. Three strategies were adopted. In the first, five keywords (*senior, aging, intellectual disability, developmental disability,* and *mental retardation*) were entered into Academic Search Premier, SportDiscus, and ERIC databases. The database options (e.g., combine searches, find similar articles, and find citing articles) were maximized to find the most relevant articles. The second search strategy was footnote chasing, in which the reference lists of each relevant article was browsed to find additional articles (Bates). The last strategy was author searching, where authors' last names were derived from article references and entered into databases. All searches targeted English and French articles without restricting the date of publication. Articles related to health, leisure, and physical activity were retrieved and classified as belonging to one or more levels of the EMHB. For example, an article by Bigby (1992) was categorized as relating to intrapersonal, interpersonal, and communal levels because

the researcher interviewed seniors with ID, their caregivers, and service providers in the field of leisure. Additionally, the number of articles retrieved prompted the creation of subsections. For instance, articles that focused on the health of seniors with ID necessitated the creation of a "health" theme at the intrapersonal level. In sum, 39 journal articles, 10 books or book chapters, nine reports, and four Web sites were located. Fifty-four articles related to the five keywords were excluded because the content did not match with the health behavior focus of the EMHB. For instance, an article by Heller and Factor (1988) about "Permanency planning among black and white family caregivers of older adults with developmental disabilities" was excluded because it focused on securing long-term plans for their grown-up children, and is thus unrelated to the present literature review.

Results and Discussion

Intrapersonal Level

Twenty-seven documents were retrieved with respect to the intrapersonal level (See Table 1) and focused primarily on health and leisure.

Health. The health of seniors with ID is primarily influenced by three sources: lifelong disability, age-related losses, and the concurrent interaction of aging with a lifelong ID (Hawkins, 1991). According to the WHO (2000) and contrary to accepted wisdom, seniors with ID do not age faster than the general population. Their life-span and aging are comparable to people without disabilities. This is surprising to those who include ID with Down syndrome, a disability which causes people to age prematurely due to a chromosomal disorder (Adlin, 1993; Bigby, 2004; Boyd, 1997; Salvatori, Tremblay, Sandys, & Marcaccio, 1998) and show earlier onsets of Alzheimer's-type dementia (Bigby; Janicki & Dalton, 2000). As such, seniors with ID (other than Down syndrome) experience the same age-related conditions as the elderly population at large, such as reduced mobility, sensory loss, and falls. The slower functional, motor, and cognitive responses found regularly among aging individuals with ID can be explained in part by a poor lifestyle with little physical activities and an unbalanced diet (Robertson et al., 2000). A poor lifestyle can result in early onset of disease and symptoms linked to aging (Carmeli, Merrick, Kessel, Masharawi, & Carmeli, 2003), low level of fitness (Rimmer, 1997), as well as obesity and its related conditions (e.g., type II diabetes, hypertension, heart disease, stroke, arthritis, respiratory diseases, and cancer). In the literature, there are no research studies and programs relative to the promotion of healthy behaviors for seniors with ID. However, the World Health Organization (2000) does recommend educating individuals with ID to healthy behaviors to improve their quality of life. As such, while active living is widely encouraged among the population, it is not yet promoted among seniors with ID.

Empirical physical activity research studies. Seven studies have investigated physical activity interventions among seniors with ID and all demonstrated significant results in health. Carmeli, Barchard, Masharawi, and Coleman (2004) evaluated the efficacy of 15-week walking program on 26 seniors with Down syndrome who had an arterial occlusive disease. Using a treadmill and individually prescribed low-endurance walking at a comfortable speed three times per week, the experimental group (n = 14; mean age 65.5 years) significantly improved walking speed, duration, and distance. Pain levels were reduced and functional capacities increased. The control group (n = 12; mean age 62) who received no intervention showed no changes.

The second study investigated the effect of a treadmill walking program on muscle strength and balance for seniors with Down syndrome (Carmeli, Kessel, Coleman, & Ayalon, 2002). Twenty-six participants were assigned to either a control (n = 10) or experimental group (n = 16, mean age 63). Results indicated significant improvements in knee extension, flexion isokinetic leg strength, and dynamic balance for the whole experimental group. The control group, who received no intervention, showed no changes.

The third study evaluated the effect of a 10-month physical activity program on well-being and self-image in 62 seniors with ID living in residential care (Carmeli et al., 2003). An interview format with a self-perception profile questionnaire, as well as the Nottingham Health Profile to assess health and quality of life were use. Statistical analyzes showed a positive relationship between well-being and physical activity in the exercise group (n = 23; mean age 56.5 years).

Carmeli, Zinger-Vaknin, Morad, and Merrick (2005) determined the effect of physical training on balance, strength, and well-being of seniors with ID (N = 22, mean age 61.2 years). They used physical tests and an interview with a questionnaire. A control and an experimental group were respectively trained in a general exercise program (n = 12) or a balance and muscle strength exercise program (n = 10). Both groups were active three times a week for six months. Results showed significant improvements for all participants. Important functional changes were also seen in the experimental group relative to balance and muscle strength but not in the control group.

The fifth study investigated the effect of a 5-week physical activity program on perceptions of competence, locus of control, and self-esteem for seniors with ID

(Mactavish & Searle, 1992). Twenty-six participants with a mean age of 55.4 years were assigned to either a control or experimental group. The study was designed to promote responsibility and choice. Data were collected through interviews with the seniors before and after the intervention. Results indicated that physical activity helped the experimental group increase in perceived-competence, locus of control, and self-esteem, all of which remained unchanged for the control group.

A 12-week exercise program for 12 seniors with ID was conducted by Podgorski, Kessler, Cacia, Peterson, and Henderson (2004). Using two modified fitness tests, the authors assessed the mobility, gait, strength of the upper and lower body, and range of motion of the shoulder and hip. They found that 92% of participants improved at least one fitness variable as a result of the exercise regime. Following the intervention, the program continued under the supervision of the day habilitation staff; it remained popular among all participants, and they maintained their fitness gains a full year later.

The last study investigated physical activity in a swimming program for three seniors with ID. Steff and Reid (unpublished) explored four variables (swimming skills, initiative taking, positive responses, and social interaction) over a 9-week period using a case-study methodology. The data triangulation included interviews, participants' archival files, direct observations, daily journals, swimming skills assessments, and summary statements. The results showed that participants improved on all four variables. They had restricted range of motion, upper body kyphosis, and slower movement, which are well documented in the general aging population but not among seniors with ID. The positive motor learning, physical functioning, and psychological well-being outcomes found in the above seven empirical studies are encouraging. It is proven that seniors with ID benefit from exercise and should be active similarly to individuals without disabilities that have the desire to look after his/her health. However, not enough information remains once the programs are terminated and if the positive benefits subsisted.

Leisure insights from seniors with intellectual disability. Various researchers interviewed seniors with ID about leisure (Benz & McAllister, 1990; Bigby, 1992; Glausier, Whorton, & Knight, 1995; Hawkins, 1991; Rogers, Hawkins, & Eklund, 1998). They preferred activities such as going out to eat, visiting a friend, watching television, walking, and shopping (Benz & McAllister; Glausier et al.; Hawkins). Seniors with ID also participated in these activities more often than other activities. A third of the participants in the Benz and McAllister study expressed liking physical activities, with bowling as the first choice and basketball as the second. Their least favorite leisure activities were going to the movies, woodworking, leatherworking, reading, and doing senior center activities (Glausier et al.; Hawkins). Physical activities that individuals wanted to start include fishing, boating/canoeing, riding horses, riding bikes, golfing, volleyball, and camping (Hawkins).

Barriers that seniors reported as preventing their involvement in leisure activities include having no one to teach the activity, having the decision be made by someone else, a lack of equipment, transportation issues, health problems, fear of getting hurt, loneliness, lack of time, financial constraints, age, lack of informal support, and difficulty accessing the activities (Bigby, 1992; Glauser et al., 1995; Hawkins, 1991). Glausier et al. (1995) affirm that seniors with ID remain rather inactive, and this inactivity may be related to a lack of leisure opportunities, of awareness of activities, and of friends outside immediate surroundings, as well as the need for activity supervision, and skills (Bigby; Glausier et al.; Sparrow & Mayne, 1990). Hawkins (1991) also suggests that seniors with ID have difficulty expressing themselves, which can be mistaken for passivity. This may force caregivers to make decisions for them (Hawkins; Rogers et al., 1998). Overall, too little is known about how seniors with ID view physical activities aside from the fact that the majority would like to participate more frequently in structured and meaningful activities outside their residences (Benz & McAllister, 1990).

Implications and future research. The EMHB defines the intrapersonal level as the individual's influence on his/her own health. As mentioned, it is related to the individual's psychological, biological, and developmental characteristics. The review shows that seniors with ID are not yet targeted for health prevention even if empirical research studies proved they benefit physically and psychologically from physical activity interventions. Little health education leads to lifestyle-related risk factors (e.g., obesity, poor diet, and physical inactivity) which jeopardize life-span. These risk factors could be significantly reduced with appropriate health prevention awareness. Access to health care services by seniors with ID may be inadequate due to factors like communication difficulties or underestimating needs and practical issues (Felce et al., 2008).

Future research is needed to study the impact of physical fitness on seniors with ID to prevent premature health-related declines (Rimmer, 1997), to explore the benefits of physical activity on physiological and psychological health, and to understand the overall impact of AL on their quality of life. It is equally important to investigate (a) co-morbid issues that prevent participation or interest in physical activity (McCarron, Gill, McCallion, & Begley, 2005), (b) earlier health screening to avoid the development of pain or disease slowing functional motor and psychological responses (Van Buggenhout et al., 1999), (c) care needs to preserve good quality of life (Fisher & Kettl, 2005), and (d) general health among seniors with ID compared to seniors without ID to better understand the impact of active living on health (Janicki et al., 2002).

In addition, seniors were quite insightful to identify leisure barriers impeding them from accessing physical activity. They could identify issues they faced and name the needs they had to be more active. For that reason, more inclusive research is necessary with seniors with ID as research participants rather than mere subjects. In this way, they could respond directly or they could be represented by self-advocates (Jurkowski, 2008). *Interpersonal Level*

Eleven documents were retrieved that dealt with the interpersonal level (See Table 1) and described the organization of social networks and its personal insights.

Organization of social networks of seniors with intellectual disability. Social networks for aging individuals with ID are increasingly important due to their growing needs, the complexity of long-term care, and the aging or death of close family members (Family Caregiver Alliance, 2004). Seniors with ID tend to be surrounded by siblings, caregivers, and friends (Selzter, 1985). Unlike those without disabilities, they usually do not marry or have children and they are more likely to be socially isolated (Bigby, 1992; Krauss & Erickson, 1988). Generally, their social network are concerned with planning legal, residential, and financial arrangements as well as health care, community supports, vocational services, and leisure services (AAMR, 2005; Heller & Factor, n.d.).

Krauss and Erickson (1988) hypothesized that place of residence influences one's social network. Seniors with ID who live at home typically have a smaller network that is primarily composed of parents. Conversely, those living in community residences have

contact with family, friends, and professionals (Krauss & Erickson). Professionals might be more informed than aging parents about available resources and activities that promote AL.

The support of friends, family, and caregivers is important to the health and quality of life of seniors with ID. Research has shown that support is essential for the inclusion of seniors with ID in the community (Bigby, 2008). It can also counteract the adverse effects of declining abilities by helping them maintain active lifestyles, facilitating their participation in social activities, and encouraging their use of formal services (Seltzer, 1985).

Personal insights from members of the social network. No studies were found that focused exclusively on the perspective of members of the social network about physical activity and health. Researchers in four studies (Bigby, 1992; Bigby & Ozanne, 2004; Salvatori, Tremblay, & Tryssenaar, 2003; Thompson, 2002) interviewed caregivers and touched briefly on the topics of leisure and health. Caregivers noted that the lack of resources and funding limit social activities. They also expressed concern about the lack of leisure activities offered in their community (Bigby). Caregivers reported that there is often little follow-up to support other needs once residential planning is settled (Bigby).

A number of caregivers also stated that changes brought on by deinstitutionalization usually improved well-being, and these changes enhanced independence because seniors with ID made choices for the first time (Thompson, 2002). Caregivers were otherwise unsatisfied with the lack of physicians showing interest in this population, and with the communication between hospital staff and patients (Thompson). Health remains a major concern, especially for family members who are concerned about their own aging as well as the aging of their adult children. Parents had a propensity to overprotect their children to ensure that "their aging adult children will be able to continue the lifestyle that they, as close family members, had fought so hard to achieve for them" (Bigby, 1992; Salvatori et al., 2003, p. 6).

Implications and future research. The EMHB defines the interpersonal level as friends, family, and caregivers encouraging seniors with ID to be fully included in the community and lead an enriched social life that benefits overall quality of life. The review of the interpersonal level reveals that seniors with ID have different networks from other elderly adults, who are often surrounded by grown-up children. Their social networks are also different from that of younger adults with ID, who have young family members ensuring their access to meaningful services. Aging individuals with ID are more likely to be isolated as their needs increase and functional abilities decrease. Thorpe et al. (2000) asserts that healthy seniors engaged in meaningful activities will be less receptive to stress and have lower reactive behaviors.

Therefore, it is essential that seniors with ID be surrounded by people who advocate health promoting activities, as it might be difficult for seniors to initiate them alone. Active strategies need to be developed so that their social networks acknowledge the importance of being physically active. Physical activities can only be implemented when it is considered beneficial by both seniors with ID and their support networks, and when it is not seen as burdensome. Other research should explore the quality of life of people supporting seniors with ID when the latest are physically active and engaging in health-promoting activities.

Institutional Level

Twenty-two documents were retrieved with respect to the institutional level (See Table 1). Similar to the general population, seniors with ID want to remain involved in the community (Buys & Rushworth, 1997; Hawkins & Kultgen, 1991). As noted by the Quebec Health and Social Services Ministry (2001), social participation must be accompanied by services suited to the group in question. Rancourt (1989) identified four leisure needs of seniors with ID that impact service providers:

a) leisure, recreational, social and physical activities appropriate to the disability and age levels and for the promotion of physical and mental health maintenance;b) skill development and maintenance opportunities; c) peer socialization and friendship; and d) counselling and life planning (p. 51).

They are three main types of service models activities for seniors with ID: (a) ageintegrated intellectual disability service, (b) age-specialized service for seniors with ID, and (c) generic aging service (Seltzer, 1988).

Age-integrated intellectual disability service. This service delivery model focuses on the full age range of adults with ID. For instance, seniors with ID are included in day activity centers or supportive workshops with younger individuals (Bigby, 2005). Seltzer (1988) found that it is the most common day program in the United States. It provides challenges, stimulation, and opportunities for social interaction with people of all ages. However, activities are not always age-appropriate and may be "too difficult, too pressured, insufficiently sensitive to the clients' health needs, and not flexible enough" (Seltzer, p. 184). *Age-specialized service for seniors with intellectual disability*. This type of service is designed especially for seniors with ID (Seltzer, 1988). For instance, they are included in community access programs or day activity centers (Bigby, 2005). Services are individualized according to the person's age and abilities (Seltzer). Therefore, it offers flexibility and the potential for friendships with people of similar age and aptitude levels. Staff members also tend to have more expertise and knowledge about aging and ID (Bigby). However, it can lead to isolation, segregation, and stigmatization because of separation from friends of different ages or aptitude levels (Seltzer). Staff members are concerned about low levels of stimulation, expectation, and choice (Seltzer).

Generic aging service. This type of service is designed for all elderly people in the community, including seniors with ID. Examples of services include senior centers, companion programs, or adult day care (AAMR, 2005; Heller & Factor, n.d.). Their primary strength is that they offer age-appropriate activities (Seltzer, 1988) that staff members perceive as flexible, pleasant, and well-integrated in the community. Generic aging services facilitate inclusion, development of social relationships with older adults, and dissolution of attitudinal barriers in society (Krauss & Erickson, 1988). However, staff members tend to have inadequate knowledge concerning the needs of people with ID and they often dismiss the action (Krauss & Erickson). Given that some program activities are too advanced, seniors with ID can face prejudgment, social stigmas, and discrimination (Kenefick, 1985). Nevertheless, staff members support the integration of seniors with ID into the generic aging service model because their needs resemble those of elderly people in general (Janicki & Wisniewski, 1985).

Physical activities are developed through various local institutional initiatives. However, these initiatives for seniors with ID have not yet been subjected to empirical evaluation. Further investigation is needed to determine what physical activity interventions will seniors benefit most from; should seniors with ID participate in physical activities with other individuals with special needs or would they benefit more from being included among elderly people in senior citizen centers? Would they gain more from physical activity staff being specialized in ID or in aging? Similarly, would they gain more from accessing and practicing physical activities in centers for health and leisure serving all citizens in the community? A number of questions remain unanswered. Three out of the seven empirical studies about seniors with ID in physical activity settings focused on seniors in age-specialized services with participants in different locations. Steff and Reid (unpublished) and Mactavish and Searle (1992) used facilities in the community. Pogorski et al.'s (2004) intervention took place in a day habilitation center that exclusively served seniors with ID. The others four studies (Carmeli et al., 2002; 2003; 2004; 2005) did not specified their settings. Literature indicates (Hawkins, 1991) seniors with ID are usually included with younger individuals with ID. In the seven intervention studies, all participants were seniors with ID, they were not with younger individuals.

Participation in the three service delivery models. Several studies surveyed the organization of leisure services and observed the involvement of seniors with ID (Bigby & Balandin, 2005; Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004; Bigby, Fyffe, Balandin, McCubbery, & Gordon, 2001; Buys & Rushworth, 1997). Bigby and Balandin (2005) investigated whether 40 Australian generic aging care and community leisure

programs were accessible to seniors with ID. Twenty-six were accessed by at least one older adult with an ID; this constituted a rather small ratio. Seniors with ID were included in health-related activities, exercise, and various leisure programs like walking. Service providers had difficulty specifying the number of participants with a disability and the type of their disability because they did not have access to medical files and did not consider it important to distinguish participants. Forty-eight percent found it difficult to accommodate them in terms of transport, facilities and individualized support when they were made aware of the client's ID.

Bigby et al. (2004) surveyed Australian day-support programs for people with disabilities. They found that 19% of the clients were over 55, with the largest subgroup being individuals with ID. The programs were not designed for a particular age group. Service providers mentioned that they did not have enough elderly clients to adapt their activities and that activities were suited to interest but not age. They also reported little knowledge about aging and were often not optimistic about their clients' futures.

Buys and Rushworth (1997) surveyed 162 Australian community-based organizations. They found that only 36% provided services such as employment, education, and recreation to seniors with ID over a one-year period, and all of them were funded by ID agencies. Programs were specifically designed for facilities and staffing rather than for the particular needs of seniors with ID. Survey respondents wanted more services adapted to seniors with ID and adequate training for their staff.

Finally, Bigby et al. (2001) briefly described the involvement of seniors with ID in Australian AL programs that took place in the context of generic aging services or ID services. All of the programs emphasized choice, social networks, and participation. Maintenance of abilities, self-expression, and a healthy lifestyle were not necessarily encouraged (Bigby, 2005; Bigby et al.). Bigby argued that service providers were not concerned with promoting physical activity and AL because they did not view physical activity as a vehicle to promote healthy behaviors among individuals with ID.

Implications and future research. The EMHB defines the institutional level as the organizational characteristics, rules, and structured services that ease access to local health-related facilities. The review of the institutional level research shows that researchers in the field of leisure have described the organization of services for seniors with ID and observed their involvement. Conversely, researchers in the field of physical activity have not yet started to investigate seniors with ID. They fail to promote AL through physical activities and as a result, various lines of research must be explored. For instance, existing physical activity programs for seniors with ID should be evaluated to determine if they are age-integrated, age-specialized, or generic. Variables such as community structure, geographic location, transportation, funding, and staffing need to be investigated to comprehend which physical activity services are best suited to seniors with ID. Also, participants should receive regular physical and psychological evaluations to establish program benefits (Hawkins & Kultgen, 1991). Finally, service quality and client satisfaction should also be considered (Bigby et al., 2004; Buys & Rushworth, 1997) to ensure motor and psychological gains.

Communal Level

Fourteen documents were retrieved that dealt with the communal level (See Table 1) and focused primarily on barriers of service providers and their insights on physical activities.

Barriers. Over 20 years ago, Cantapano, Levy, and Levy (1985, as cited by Rancourt, 1989, p. 51) stated that day service programs for seniors with ID were in an "embryonic state" (Rancourt, 1989, p. 51). Kenefick (1985) identified barriers to innovation:

(1) competition among elder groups for services, (2) fiscal viability, (3) the regulatory squeeze, (4) structure of the bureaucracy, (5) planning myopia, (6) disengagement among service providers, and (7) the refusal by their contemporaries to accept aging and elderly developmentally disabled individuals (p. 356).

Little progress has been made since then to promote physical activity among seniors with ID. In Canada, there is no seamless coordination among agencies because there are no clear guidelines from service providers (Salvatori et al., 2003). Seniors with ID and their informal support groups use numerous agencies for funding, coordination, and delivery (Salvatori et al., 2003; Salvatori et al., 1998). Lavin and Doka (1999) add that the "older population with developmental disabilities has been forgotten and neglected, effectively lost in the crack or chasm between systems" (p. 9). Heller, Sterns, Sutton, and Factor (1996) state that recreational goals cannot be achieved if service providers doubt their value. Seniors with ID are most likely to reach these goals if educators or caregivers take personal initiatives to fund activities. These support individuals will ensure that seniors receive appropriate and meaningful activities due to the fact they are paying, unlike service providers who might encounter more administrative and financial barriers.

Insights of service providers on physical activity. Service providers recognize that the health of seniors with ID may be tenuous and that they need more breaks during the day (Bigby et al., 2004). Nevertheless, leisure programs for younger adults with ID are not always adapted for seniors (Bigby et al.) For instance, Bigby et al. found that 96% of service providers viewed self-expression and a sense of achievement as 'very important' outcomes of a day program. Physical fitness and functioning were rated the lowest with 61% identifying them as very important, 36% somewhat important, and 3% not important. When service providers are specifically asked how they can adapt leisure programs to seniors with ID, they recognize that they should take health needs and interests into consideration. Bigby et al. recommended a focus on individualized planning, choice, and flexibility. Service providers also reported that they should pay attention to the type of activities and their location, frequency, and intensity. According to Gibson, Choi, & Cook (1993), staff instruction about AL could be problematic because they have little knowledge about the commonalities among older clients with a lifelong ID. Physical activity programs are not viewed as meaningful ways to improve health because service providers have a lack of guidance and support.

Implications and future research. The growing number of seniors with ID creates a demand for service providers in the community (Gibson et al., 1993). In the EMHB, the 'community' is defined as a *power structure*: "Power structures in cities, counties, and states often play a critical role in defining community health problems and allocating resources- including funding, technical assistance, staffing, materials, and official and unofficial approvals- for their amelioration" (McLeroy et al., 1988, p. 364). Disadvantaged individuals such as seniors with ID may find it difficult to access sources of community power because they are initially considered "hard to reach" (McLeroy et al.).

In particular, seniors with ID do not participate actively in the identification and resolution of concrete problems. They are rarely included in community-based physical activity programs because no one has brought this issue to light. They also face the double hazard of age and disability, placing them at risk for social segregation and stigmatization (Herr, 1985; Rancourt, 1989). Several associations and offices in western countries (e.g., the Foundation for People with Learning Disabilities in 2002 and located in the United Kingdom; the Project 2015 in the US by Overeynder & Bishop, 2006) aim to include seniors with ID by addressing their economical, residential, and health needs. However, they often fail to resolve pragmatic problems (Bigby, 1992), especially relating to physical activity programs that are unfamiliar or lacking. Although seniors desire more involvement in physical activity programs, service providers pay more attention to agency and staff issues than to the individual requirements of seniors with ID (Ashman & Suttie, 1995).

Future research is needed to identify barriers to the creation of physical activity programs by service providers for seniors with ID. For instance, are these barriers related to knowledge, funding, staffing or other? Are barriers related to the lack of consciousness regarding the aging of individuals with ID? It is equally important to study the existing collaborative strategies set up by advocates for people with ID and physical activity service providers. Finally, more research is needed about how to coordinate agencies to promote health through physical activity for seniors with ID

Public Policy Level

Twelve documents were retrieved relative to the public policy level (See Table 1) and focused on public policies in Canada and in other Western countries. The sizeable cohort of seniors with ID presents ongoing challenges for policymakers. This is especially true of physical activity because literature on this topic is lacking or outdated. Hatzidimitriadou and Milne (2005) stated that service provision is fragmented with little choice of resources; policy objectives are not consistently applied, and are not always reached. They contended that "service planning is often incoherent, that many older people with ID and their caregivers receive poor quality non-specialist care and that staff are inadequately trained to manage the often multiple and complex need of this user group" (p. 341). While their concerns might be specific to the United Kingdom, they could also be relevant for other Western countries. Bigby (2004) asserts:

Policy not only signals desired ends but also, through the processes of implementation, the manner in which these will be achieved. Policy and its implementation therefore inform decisions and choices about the level and allocation of resources and types of programs developed (p. 241)

While this explanation is straightforward, it is unclear how seniors with ID fit into public policy development. They could fall into the category of care for aging populations or into the category of disability policy. Bigby suggests that since "potentially, either, neither or both sectors could take responsibility" (p. 242), this issue leaves room for debate and the question of responsibility remains ambiguous. Therefore, two pertinent questions are critical: Should all agencies for disability, health, and aging plan physical activity services for seniors with ID? Should they all be equally trained and knowledgeable about this group?

Canada. Over the last 25 years in Canada, there have been a number of reports about AL for people with disabilities. For instance, the Jasper Talks (1988) and the Blueprint for Action (National Advisory Committee on Physical Activity for Canadians with a Disability, 1988) influenced policies, physical activity, and disability even though they did not specifically address seniors with ID. Policies for seniors with ID are unclear in Quebec as Quebecois seniors with and without ID are included under the Health and Social Services Ministry (HSSM; 2006). However, there are no policies on the HSSM website for seniors with ID in the "HSSM and people with disabilities" or "HSSM and seniors" sections. Active living for that group is also absent. Janicki, Ackerman, and Jacobson (1985) note that seniors with ID are referred to in statistical reports but are not recognized as a distinctive group with special needs.

Other Western countries. For the past 20 years, the U.S. and Australia have tried to develop services for seniors with ID. In the U.S., laws are applied differently in each state (Forbat & Service, 2005). Nevertheless, the improvement in laws and services is evident in the 1987 Developmental Disabilities Assistance and Bill of Rights amendment (P.L. 100-142), the Older Americans Act; the Robert Wood Johnson Foundation Consumer Choice Initiative, the National Family Caregiver Support Program, and the creation of 24 state Aging and Disability Resources Center (Factor, 2005), all of which either target seniors with ID, their aging caregivers in the community, or both.

In Australia, public policy initiatives have addressed the retirement of seniors with ID (Bigby, 2004), and the Australian Federal government identified day support options

for seniors with ID (Bigby et al., 2001). Also, local initiatives have prompted day service programs, albeit without defined protocols (Bigby et al.).

Implications and future research. Doka and Lavin (2003) described the paradox of seniors with ID. They are forgotten and neglected precisely when they need the most services because of family losses, retirement, relocation, and declines in functional abilities. They are not considered in the implementation of policies and population-based health campaigns. Programs and services in the U.S. and the U.K. are often inspired by changes in younger people with ID (Bigby, 2004) rather than a real concern for seniors with ID. Developmental disability agencies are slow to react to the needs of seniors with ID, while aging services have not reacted at all (Janicki & Dalton, 2000). Public policies concerning aging do not include seniors with ID. For example, Canada's Physical Activity Guide to Healthy Active Living for Older Adults (Public Health Agency of Canada, 1998) promotes physical activity for older adults in general but does not address specific subgroups.

Researchers should explore the creation of policies where physical activity is fully addressed and adapted to all individuals in the society. It is important to investigate how population-based health campaigns could reach all seniors with ID. Other researchers should aim to facilitate collaboration among service providers and policy makers to endorse active living.

Conclusion

The overall purpose of this review was to gather together the scientific literature on seniors with ID and AL using the EHMB as a guide. The first question investigated the current and relevant empirical work on the topic. Seniors with ID, in the field of physical activity, are a group unknown and left neglected at all levels of the EMHB. Service providers and policy makers do not know or have not heard of seniors with ID because it is a disadvantaged group that requires support to advocate for its rights. There is a fundamental need for more empirical research on physical activity and AL for seniors with ID.

The second question wondered what were the critical implications at each EMHB level of influence that require future research. The review highlighted the necessity to create programs maintaining and improving motor functions of seniors with ID while suited to their preferences and needs (Hawkins, 1991). Caregivers and professionals require structure, training, and guidance from public policy makers in order to encourage an active lifestyle. Health, disability, and aging agencies have not yet collaborated to facilitate the development of adapted physical activity programs. Adequate guidance from researchers does not exist yet. Overall, this delay must be filled because appropriate physical activity programs for seniors with ID would enhance physical functioning, wellbeing, quality of life, and health while achieving full inclusion and social participation as recommended by the Quebec Health and Social Services Ministry (2001).

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Ecological Model of Human Behavior	Number of Resources	Resources
Intrapersonal	27	Adlin, 1993; Benz & McAllister, 1990; Bigby, 1992; 2004; Boyd, 1997; Carmeli, Barchard, Masharawi, & Coleman, 2004; Carmeli, Kessel, Coleman, & Ayalon, 2002; Carmeli, Merrick, Kessell, Masharawi & Carmeli, 2003; Carmeli, Zinger-Vaknin, Morad, & Merrick, 2005; Felce et al., 2008; Fisher & Kettl, 2005; Glausier, Whorton, Knight, 1995; Hawkins, 1991; Janicki & Dalton, 2000; Janicki et al., 2002; Jurkowski, 2008; Mactavish & Searle, 1992; McCarron, Gill, McCallion, & Begley, 2005; Podgorski, Kessler, Cacia, Peterson, & Henderson, 2004; Rimmer, 1997; Robertson et al., 2000; Rogers, Hawkins, & Eklund, 1998; Salvatori, Tremblay, Sandys & Marcacci 1998, Sparrow & Mayne, 1990; Steff & Reid, unpublished; Van Buggenhout et al., 199 WHO, 2000
Interpersonal	11	AAMR, 2005; Bigby, 1992; 2008 ; Bigby & Ozanne, 2004; Family Caregiver Alliance 2004; Heller & Factor, n.d. ; Krauss & Erickson, 1988; Salvatori et al., 2003; Selzter, 1985; Thompson, 2002; Thorpe et al., 2000
Institutional	22	AAMR, 2005; Bigby, 2005; Bigby & Balandin, 2005; Bigby et al, 2001; 2004; Buys & Rushworth, 1997; Carmeli et al., 2002, 2003, 2004, 2005; Hawkins, 1991; Hawkins & Kultgen, 1991; Health and Social Services Ministry, 2001; Heller & Factor, n.d.; Jani & Wisniewski, 1985; Kenefick, 1985; Krauss & Erickson, 1988; Mactavish & Searle, 1992; Pogorski et al., 2004; Rancourt; 1989; Seltzer, 1988; Steff & Reid, unpublished
Communal	14	Ashman & Suttie, 1995; Bigby, 1992; Bigby et al., 2004; Cantapano, Levy, & Levy, I985; Foundation for People with Learning Disabilities, 2002; Gibson et al., 1993; Heller, Sterns, Sutton, & Factor, 1996; Herr, 1985; Kenefick, 1985; Lavin & Doka, 19 Overeynder & Bishop, 2006; Rancourt, 1989; Salvarori et al., 1998; 2003
Public Policy and Laws	12	Bigby, 2004; Bigby et al., 2001; Doka & Lavin, 2003; Factor, 2005; Forbat & Service, 2005; Hatzidimitriadou & Milne, 2005; Health and Social Services Ministry, 2006; Janicki, Ackerman, & Jacobson, 1985; Janicki & Dalton, 2000; Jasper Talks, 1988; National Advisory Committee on Physical Activity for Canadians with a Disability, 1988; Public Health Agency of Canada, 1998

Bridging Manuscripts and Author Contribution

The objective of this doctoral dissertation was to address the promotion of physical activity among seniors with intellectual disability (ID) from a health perspective. The research question was: How do current physical activity programs address the barriers, needs, and preferences of seniors with lifelong intellectual disability in a North-American metropolitan context? The first paper (chapter two) systematically reviewed the scientific literature on seniors with ID relative to physical activity. The Ecological Model of Human Behavior (EMHB; McLeroy, Bibeau, Steckler, & Glanz, 1988) was the conceptual framework guiding and delimiting the retrieval of articles through its five levels of environmental influences (e.g., intrapersonal, interpersonal, institutional, communal, and public policy and laws). This second paper (chapter three) examined the physical activity barriers, needs, and preferences of seniors with ID based on the intrapersonal and interpersonal levels of influence of the EMHB (McLeroy et al., 1998). A questionnaire and focus group interviews were used to collect data from educators and seniors with ID. The relative contributions of the two authors are as follows: As first author and primary researcher, I was responsible for 85% of the manuscript and was involved in the original concept, research design, adaptation of the questionnaire, and its translation. I also carried out data collection (questionnaires and focus groups), data analyses, and manuscript writing. Dr. Reid was responsible for the remaining 15%. He helped design the study, was consulted about data analysis, and edited the manuscript.

Running head: PERCEIVED BARRIERS, NEEDS, AND PREFERENCES

Chapter III: Perceived Barriers, Needs, and Preferences in Physical Activity Among Seniors with Intellectual Disability

Marion Steff and Greg Reid

Abstract

The purpose of the study was to explore the barriers, needs, and preferences of seniors with intellectual disabilities (ID) with respect to physical activity. Forty-eight questionnaires designed to assess knowledge, skills, and attitudes toward physical activity were completed by seniors with ID. This was followed by four focus groups of seniors with ID (N = 15) and three focus groups of educators (N = 16). The results showed remarkable interest by the seniors to participate and they enjoyed sharing their perspectives. Seniors considered themselves active and understood the meaning of health. They knew about physical activity, had given it thought, and liked expressing their views on that matter. However, educators did not think that the frequency or intensity of senior's activity was sufficiently high enough to provide health benefits. Both seniors and educators reported important barriers and needs that prevented the organization of physical activities. The results also suggested that educators require greater guidance to facilitate the implementation of physical activity programs for senior with ID.

Perceived Barriers, Needs, and Preferences in Physical Activity Among Seniors with Intellectual Disability

The predictors of regular physical activity among citizens of various ages and ethnic groups have been well-documented in research about barriers, preferences, and needs to be physically active (e.g., Hall, 1998; Brittain, Jones, & Rikli, 2002; Deflandre, Antonini, & Lorant, 2004; Juarbe, Turok, & Pérez-Stable, 2002; McAvoy, 1979). As such, improved physical activity planning, policy development, management strategies, and intervention programs have been designed around these determinants to achieve health and recreational benefits for the general population (Bigby, 2004). However, disadvantaged individuals, such as seniors with intellectual disability (ID) who may face difficulties in expressing themselves or being heard, can overlook physical activity as an essential aspect of daily life (National Institute of Child Health and Human Development, 2005). Similarly to their younger counterparts, they may have little knowledge of the health benefits of physical activities; may be at risk for obesity; and may have low physical fitness, and capacity for exercise (Pitetti, Yarmer, & Fernhall, 2001). Seniors with ID may also lack motivation, have difficulties with accessibility and cost, and need to rely on support to be physically active, which collectively contributes to a sedentary lifestyles and minimal regular physical activity (U.S. Department of Health and Human Services, 1996).

These facts are alarming, considering that physical activity is widely recognized as having a significant and positive impact on health. The 1996 U.S. Surgeon General's report (Department of Health and Human Services, 1996) recommended that all citizens exercise for a minimum of 30 minutes per day for protection from osteoporosis, hip

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fracture, obesity, falls, cancers, type II diabetes, high blood pressure, and cholesterol. Also, being active also has well-known psychological benefits, such as reduced anxiety, stress, and depression (U.S. Department of Health and Human Services, 2006). While physical activity has gained importance in the minds of the general population, it may not be the case among seniors with ID.

Ecological theory research has shown that to sustain positive health benefits programs should not only focus on the individual, but also on his or her environment to maintain involvement and motivation during physical activity interventions (Spence & Lee, 2003). Physically active behaviors are influenced by a variety of factors such as the individual, family, resources, opportunities and barriers to exercise – these factors are all interrelated and multifaceted (DeBate, Plescia, Joyner, & Spann, 2004; Grzywacz & Marks, 2001). To frame this study, the Ecological Model of Human Behavior (EMHB; McLeroy, Bibeau, Steckler, & Glanz, 1988) was used, as it stresses the importance of a supportive environment that promotes healthy behavior with five levels of influence (intrapersonal, interpersonal, institutional, communal, and public policy). The two first levels pertain directly to the current study. The intrapersonal level is the influence of the individual's psychological, biological, and developmental characteristics. The interpersonal level is the role of family, friends, and other close individuals with regard to their overall influence on the individual's health and involvement in physical activity. The two levels are complementary as they influence people to lead an active and healthy lifestyle.

Although seniors with ID have been interviewed in various fields of study (e.g., leisure, health, retirement), there are no studies that directly inquire about their

preferences in physical activities, what they need to be active, and what barriers they encounter. The literature on barriers, needs, and preferences is as broad as the terms used (Brittain et al., 2002; Jones & Rose, 2005; McAvoy, 1979; O'Neill & Reid, 1991; Rimmer, Riley, Wang, Rauworth, Jurkowski, 2004; Shephard, 2002; Temple, 2007). For example, terms like "perceived constraints," "facilitators," and "enjoyment" could be employed depending on the study's theoretical model and aims. The present researchers used "barriers," "needs," and "preferences" because they are fairly simple concepts that participants with ID could easily grasp during data collection.

Barriers. Barriers to physical activities for seniors in the general population were reported by Brittain et al. (2002) and included: (a) laziness, lack of self-discipline, (b) not enough time, too busy, (c) discomfort, pain, (d) weather, (e) lack of strength and stamina, and (f) lack of partner, social support (Brittain et al.). Others have conceptualized four categories of barriers for seniors (a) physical and health, (b) psychological, (c) knowledge, and (d) administrative (O'Neill & Reid, 1991). There is no study, to our knowledge, that identified barriers to physical activities among seniors with ID. However barriers in leisure for seniors with ID have included having no one to teach the activity, having the decision be made by someone else, lack of equipment, transportation issues, health, fear of getting hurt, loneliness, time, financial constraints, age, lack of informal support, and difficulty accessing the activities (Bigby, 1992; Glauser, Whorton, & Knight, 1995; Hawkins, 1991).

Needs. An early research study explained that needs in physical activity for seniors without ID relate to self-fulfillment, closeness to nature, a continual learning for self-satisfaction, and interaction with others (McAvoy, 1979). Needs in physical activity

for seniors with ID have not been identified but in the leisure field, they are pragmatic: the need for activity supervision, transportation, funds, and skills (Bigby, 1992; Glausier et al., 1995; Sparrow & Mayne, 1990).

Preferences. Studies point out that physical activity preferences among seniors vary depending on their gender (Shephard, 2002) and physical functioning (Jones & Rose, 2005). For example, men enjoy outside and competitive physical activities whereas women like more relaxing physical activities. Seniors also enjoy activities that they can practice without physical limitation due to their age. Preferred physical activities for seniors with ID have not yet been identified, but younger individuals with ID enjoy dancing, walking, bowling, weight training, aerobic classes, and exercise classes (Temple, 2007).

The purpose of this study was to explore the barriers, needs, and preferences of seniors with ID with respect to their physical activities by listening to their voices. It corresponds to the intra and interpersonal levels of influence of the EMHB because input was sought from both seniors with ID themselves and educators. The results however will extend to all levels of the model. They will facilitate further understanding of factors necessary to consider for the promotion of active living among this group. It will also encourage the full inclusion and social participation of individuals with ID as recommended by the Health and Social Services Ministry (2001).

Method

Participants

Forty-eight seniors with ID and 16 educators agreed to participate. They were living in supervised apartments or residences (family-type, intermediate or community) and were recruited through four ID Readaptation Centers located on the island of Montreal. Prior to their involvement, the research was approved by the university review ethics board and by the Readaptation Centers' review boards.

Seniors with ID were included if (a) they were aged 50 and older at the time of data collection (WHO, 2000) and (b) they had "expressive and receptive communication skills necessary to understand simple directions and make understandable responses to question" (Hawkins, 1991, p. 14). The presence or absence of these skills was assessed by the Readaptation Centers' personnel.

Educators were selected and included if they: (a) had interacted with at least one senior with ID on a daily basis and (b) had more than two years of experience working with these seniors to ensure familiarity.

Instruments

Questionnaire. A questionnaire is an efficient tool for collecting large amounts of data and yielding valid and reliable information about the barriers, needs, and preferences of seniors with ID (Anderson, 1998; Neuman, 1997). An adaptation of the questionnaire "Exercise Health Education Self-Assessment Packet for Adults with Developmental Disabilities: Baseline Interview Questionnaire" (Heller, Marks, & Ailey, 2006) was used. It was designed to assess participant knowledge and attitudes toward physical activity.

Five subsections of the original thirteen subsections were used: (a) the overall health and activities, to explore perception about health and physical activity, (b) the Energy Fatigue Scale, to provide insights relative to activity energy and health, (c) the Pain Measures, to obtain information on body soreness and health of the participants, (d) the Exercise and Activity Inventory, to gain knowledge on their preferences in physical activity, and, (e) the Barriers to Exercise Scale, to portray barriers encountered by seniors with ID in physical activity. The subsections that did not directly relate to barriers, needs, and preferences were removed to shorten the questionnaire and to assist in maintaining the attention of participants. In the initial version of the questionnaire, the test-retest Pearson Product-Moment correlations for the subsections were significant, with the exception of the Exercise and Activity Inventory, where reliability was not applicable. Table 1 outlines Cronbach's alpha and the test-retest correlations for each scale of the initial questionnaire (Heller et al., 2006).

As noted, the questionnaire by Heller et al. (2006) was adapted. A subsection about physical activity needs was added because the initial instrument did not measure them. That subsection was based on the approach of Asadi-Lari, Packham, and Gray (2003) who stated that health needs can be defined under various perspectives (e.g., economic, philosophical, pragmatic, and societal). The perspective adopted was pragmatic with items covering personal and social conditions (Asadi-Lari et al., 2003) like "needed to be in better health" or " needed to have more friends to exercise." As in the original questionnaire, we used short words and sentences with single-cause, active verbs (e.g., "did you ever exercise a lot when you were younger?"). The present tense was employed when possible while abstract concepts, jargon, double negatives, figurative language, and colloquialisms were avoided (Perry, 2004). Readers may contact the principal investigator for copies of the modified questionnaire entitled "Questionnaire on Physical Activity of Seniors".

The adapted questionnaire was first evaluated by a professor and two PhD students in Educational Psychology at McGill University, as well as by the director of a

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center for people with ID. It was then pilot tested on three seniors with ID who were members of a private agency affiliated with the Quebec Health and Social Services Network Development Agencies.

Finally, the survey was translated into French to accommodate the francophone service providers in Quebec using the "back translation" methodology; one professional translator translated the instrument into French and another translator translated it back into English. This procedure ensures that both surveys correspond to one another and that results are comparable (American Psychological Association, 2001). Minor discrepancies were then discussed with the two researchers, both bilingual, who selected the terms best suited to the study.

Focus group. The focus group was a necessary complement to the questionnaire because it enabled the researchers to capture participants' experiences and perceptions in greater detail than a questionnaire (Perry, 2004). Using an "interview guide" approach, questions asked during the focus group interviews were based on the responses obtained from the questionnaire.

The focus group questions were first pilot tested with three seniors with ID who were members of a private agency affiliated with the Quebec Health and Social Services Network Development Agencies. Questions were posed in a conversational manner, using simple words. Each open-ended question was short, containing only one concept (Krueger & Casey, 2000). The following seven questions were the bases of the focus group questions:

1. What does it mean for you to be in a good health?

2. What do you do to stay in a good health?

3. Presently, what are you favorite physical activities?

4. What were your favorite physical activities when you were younger?

5. What are the barriers that prevent you from being physically active or that you encounter when you try to be physically active?

6. What would you need to be physically active?

7. Is your age preventing you from being physically active?

8. Is there anything you want to add?

The educators also participated in focus groups. The questions for the educators were pilot tested with three professionals from a private agency affiliated with the Quebec Health and Social Services Network Development Agencies. The questions were:

1. How do you perceive seniors with ID's health and physical activity?

2. Describe the physical activities that you observe among seniors with ID

3. What are the preferred physical activities of seniors with ID?

4. What are the barriers seniors with ID encounter when they are trying to get physically active or when they are physically active?

5. What do they need to be physically active?

6. Does their age play a role?

7. Is there anything you want to add?

Procedure

Communication with the Readaptation Centers was divided into five steps. First, the primary researcher contacted the research department of each center and introduced her study. Once approval from their review board was received, the researcher asked someone to facilitate communication, recruitment, and data collection within each center (O'Neill & Reid, 1991).

Second, the liaison person in each center selected a process to recruit potential participants. This step differed depending on the readaptation center. Half of centers preferred that the researcher directly contact the seniors and their educators according to a list of names provided. The other half preferred that she contact the services' directors, who would then identify eligible educators and seniors themselves. The final sample included 48 seniors with ID.

Third, educators introduced the seniors to the study and to the questionnaire in one of two ways. In the first option, the researcher met the seniors, introduced the study and its ethical principles (e.g., anonymity and withdrawal), and facilitated questionnaire completion with the help of educators. In the second option, the educators received a package by mail with the questionnaires and introductory letters explaining relevant details and rules about confidentiality. The educators explained the study and ethical principles to the seniors and distributed the package to potential participants. Educators who wrote the answers for seniors with writing or reading difficulties were instructed to include all answers, even those they deemed unrealistic and to avoid influencing seniors' responses. All 48 seniors agreed to participate; 34 questionnaires were completed with the researcher onsite and 18 were mailed to her.

Fourth, the primary researcher conducted focus group interviews with a reduced sample of seniors. She asked educators if seniors were willing to participate and whether their schedules permitted their involvement. Fifteen seniors with ID agreed to participate,

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and they were divided into three groups of four and one group of three. The audio from each session was recorded and sessions varied in length from 20 to 30 minutes.

Finally, the primary researcher randomly selected educators she met during the study to participate in a focus group. Using a *convenience sample* (Statistics Canada, 2006) of 16 educators willing to participate in the study, two groups of four and one group of eight participants were formed. Participants signed and dated the consent forms. The audio from each session was recorded, and sessions varied in length from 45 to 90 minutes as recommended by Geoffrion (1997).

Data Analysis

The questionnaire data were analyzed using descriptive statistics in Excel (Excel 5.0; Microsoft 2007) showing measures of central tendency (e.g., mean, median, and mode) and measures of distribution (e.g., distribution using percentage, and dispersion). The focus group interviews were transcribed verbatim. The data was then exported to Atlas-ti for Windows (Muhr, 1997). This text analysis program facilitated the coding of all qualitative data.

Coding procedures. Coding involved labeling all written narratives generated through focus groups and open-ended questionnaires for systematic analysis (Miles & Huberman, 1994; Patton, 1990). In this study, qualitative content analysis was first deductive with four main general dimensions (e.g., health, barriers, needs, and preferences) generated from the objectives of the study. Then the analysis was inductive with a hierarchical coding generated from the collected data. Researchers looked for expressions of an idea through single words, phrases, sentences, or paragraphs in the transcribed raw data. These *coding units* were then ordered as *first* and *second-order themes*.

For instance, "seniors with ID need someone to remind them to persevere to practice physical activity," was taken as a one coding unit, and then ordered as support (e.g., firstorder theme) and social (e.g., second-order theme) under the "need" general dimension.

Overall, the raw data themes of seniors in focus groups resulted in 335 coding units corresponding to 102 first-order themes, 13 second-order themes, and four general dimensions. The raw data themes of staff members in focus groups were coded in 367 text segments corresponding to 78 first-order themes, 16 second-order themes and 4 general dimensions.

Intercoder agreement. To measure intercoder agreement, the primary researcher coded all of the raw data themes and created two code books, respectively explaining the coding relative to the seniors focus groups and the educators focus groups. A research assistant independently coded 26.5% (89 text segments) of the first and second-order senior discussion and 22.9% (84 text segments) of the first and second-order staff discussions. Coding by the research assistant and primary researcher was compared to note disagreements and revise the code books accordingly.

At first, there was a low intercoder agreement rate of 76.2% for first-order themes in focus groups with seniors (Kennedy, 2005). The research assistant and the primary researcher discussed discrepancies, eliminated redundant or vague first-order themes, and added first order themes such as "health benefits" (which was later coded in the second order theme under education, in the general health dimension). The second coding comparison yielded an intercoder agreement rate of 98% for the first-order themes and 90.9% for the second-order themes. The coding comparison for focus groups with staff members yielded an intercoder agreement rate of 88.1% for the first-order themes and 92.3% for the second-order themes.

Trustworthiness

A method proposed by Lincoln and Guba (1985) was used to assess trustworthiness and to establish credibility, transferability, dependability, and confirmability. Five naturalistic techniques were employed. The techniques were: (a) triangulation, (b) member check, (c) peer debriefing, (d) saturation of the themes, and (e) thick description.

First, the findings were triangulated using qualitative and quantitative data (e.g., focus groups interviews and a descriptive questionnaire), and by having four Readaptation Centers, as well as two distinct groups of participants (i.e., seniors with an ID and educators). Thus, credibility and confirmability were improved because the findings emerged from several perspectives.

Second, a member check was conducted by one educator from each focus group (Lincoln & Guba, 1985). They read a transcript to verify the integrity and accuracy of collected data. These key informants also checked the transcripts of seniors' focus group instead of the seniors themselves. The reason why seniors did not check transcripts similarly to educators, was because of the cognitive limitations of individuals with ID (Perry, 2004) and their tendency towards acquiescence for the sake of being agreeable (Heal & Sigelman, 1995). This member-checking process provided another source of credibility.

Third, peer debriefing by experts in content methodology was conducted throughout data collection and analysis to continue strengthening credibility. The doctoral committee of the primary researcher, a doctoral student in statistics, a doctoral student in educational psychology, and a social worker were also consulted for their expertise. As noted by Harris, Pryor, and Adams (1997), coding agreement also became part of the peer debriefing process. The coding procedure was "consciously and collaboratively developed. . . ., rather than an objective assessment of the empirical truth of data classification" (Harris et al., p.11). Dependability of results was established with a transparent coding process, and through ongoing communication between coders. The second coder was a research assistant who was knowledgeable in physical activity and ID.

Fourth, the strategy of conducting multiple focus groups and accessing many individuals' perspective allowed for saturation of the themes, with no new topics emerging at the end of the data collection. Finally, a thick description of the themes with quotes from the questionnaire responses and focus groups' discussions is included in the results section to facilitate the transferability of results.

Results

General Profile of Participants

The mean age of the 48 seniors was 58.7, ranging from 51 to 70. Women represented 48% (23, mean age = 57.8) and men 52% (25, mean age = 59.1) of the sample. The mean age in the focus groups (15 seniors) was 57.5. Eight females (mean age = 58.5) and seven males (mean age = 56.4) participated. All seniors had a mild to moderate ID and four of them had co-morbid issues (hearing or visual impairment; physical disability). In the educator focus groups, 16 individuals (10 females and six males) shared their perspectives. The educators had either a Diploma of Collegial Studies focusing on special education, or a Bachelor's degree in psycho-education, psychology, special education and social adaptation or exceptional youth. The following are the combined results of the questionnaires and the focus groups. The data were originally viewed from the perspective of four categories: Health, barriers, needs, and physical activities. However, the results of the barriers and needs categories produced similar types of answers and insights, and are therefore presented together.

Health

General. Seniors rated their health as good or excellent in the questionnaire (see Table 2). These findings were generally corroborated the focus groups with seniors positively estimating their own health. However, educators challenged that optimistic outlook. They perceived the seniors' health to be rather poor and wondered about the consequences of taking medication throughout life. Educators were also surprised with the rapidly declining health experienced among people with Down syndrome. For instance, one described an active individual who developed asthma at 50 and then quit exercising abruptly because no physical activity adaptations were provided.

Seniors who reported themselves as healthy nevertheless noted tiredness or pain in legs they never experienced when younger. In the focus groups, they defined being healthy as achieving activities, moving, getting out of bed, and feeling happy. They highlighted health check-ups as important, especially blood pressure, heart functioning, and breast cancer for women. While concern about aging did not seem to be an issue based upon responses to the questionnaire, some seniors verbally expressed a fear of aging because of health decline. For instance, one said that he felt older because of arthritis and rheumatism; another felt weaker compared to his twenties. Others seniors simply noted their health changed with age but it was not a concern. Overall, based upon focus group input, it seemed that some individuals were worried about aging while others did not think about it.

Nutrition. Seniors highlighted the importance of having a balanced diet (see Table 2) to be healthy. In the focus groups, seniors particularly expressed the importance of eating fruits and vegetables daily, to chew slowly and to avoid sweets and fattening food.

Educators stated that they had an influence on seniors regarding their nutrition choices. Seniors modeled educators and if the latter were sensitive to healthy eating, seniors were more likely to eat a well-balanced diet and follow advices. Educators believed that healthy eating was also related to living arrangement. Seniors living in less autonomous settings did not often choose their diet but ate healthier. Independent seniors in apartments were more likely to gain weight because they selected their food and did their grocery shopping alone. Educators recognized that they tended to reward physical activities with unhealthy snacks, a routine they perceived as necessary to change.

Education. This category was raised solely by educators. They felt that seniors who were inactive were not aware of the health benefits of exercising when younger. Seniors had developed habits now difficult to modify. For instance, educators realized that seniors taking elevators rarely switched to stairs. When educators promoted the importance of leading a healthy lifestyle amongst their groups, most of seniors understood the importance of being active, but did not put it to practice.

Exercise. Seniors recognized the healthy value of exercising. They cited daily walking, riding stationary bikes, taking stairs, and shoveling snow. One stated she gained three pounds "but I will lose them tonight, because I am going to shovel snow," illustrating the direct association between being active and losing weight, although

exaggerating energy expenditure. Some participants explained they could not exercise as they had when they were younger. For instance, one woman felt physically stronger when being in her twenties, but her strength was now diminished. Another was not capable of running three laps like he used to, becoming breathless. Educators indicated that the implications of aging by seniors were not recognized in the Readaptation Centers, let alone the necessity for them to be physically active. They further explained that physical activities were promoted in terms of leisure as opposed to healthy lifestyle benefits. Also, they had never received guidelines from their supervisor to promote physical activity. Physical activities were implemented depending on the individual interest and initiative of educators.

Barriers and Needs

Health. Educators believed seniors had difficulty being active like anyone at that age, with no or little physical activity experience. Seniors also had health issues which impeded physical activity, such as painful varicose veins. Educators contended that seniors gained weight when they were inactive. They also believed that throughout their lives seniors had not been made aware of the positive health benefits of physical activity or did not comprehend them due to cognitive limitations. Interestingly, educators pointed out that it was not only seniors who needed more awareness about the importance of being active, but the supporters of the seniors as well. The individuals who assisted the seniors did not always value the importance of being physically active and therefore could not convey its benefits. Educators also mentioned they wanted to leave seniors in peace, because they were older and seemed to be fragile. They did not want to bother them.

For their part, seniors stated they were not accustomed to the effects of exercising on their body. One individual explained "when I exercise with my physical activity instructor, I become all numb. She tells me to arch my back like a cat. I still do it When she tells me that we are going to practice yoga, I find that hard. I become numb sometimes in those moves." Several seniors also declared they could not exercise like a younger person and needed to take their time during physical activities in order to be able to follow.

Organization. Seniors listed various external barriers that prevented them from being active in both focus groups and questionnaire. The barriers included: (a) being too far to travel to physical activities courses, (b) not having enough space, (c) not having enough time, (d) physical activities not being provided during winter, (e) finding activities too loud, (f) not having the equipment, (g) difficulties with accessibility, (h) hard-to-use equipment, and (i) hard-to-use fitness centers (see Table 3). Money was also an issue, as some seniors said they had a small budget and would benefit and feel more secure with extra: "not much, about five dollars, then I would have enough to be involved in activities." Others expressed that money was made to be spent and felt fine with their financial resources.

Educators also expressed nine organizational issues. The first dealt with accessibility and the necessity for the community, living residences, and centers to accommodate aging individuals with ID. For instance, the Metro (subway) system and sidewalks should be adapted to people with disabilities; living residences should provide more space; and centers should be closer to parks. Health and leisure centers are not always equipped to provide unisex changing rooms. Female educators stated they could not accompany male seniors into the male changing room and vice-versa. In some cases they decided not to provide physical activities to seniors to avoid this issue.

The second issue dealt with the location of day leisure centers. They were originally built for business purposes in remote industrial areas. Over the years, their purpose changed to leisure. This change of mission complicated the educators' task of organizing physical activities, because parks and physical activity services were far away and adapted transportation was required for any activities.

The third issue that educators raised was the disparity between the abilities and cognition of individuals with ID, making physical activities difficult to manage and adapt: "I find disparity in groups hard even if they (e.g., superiors) say it is stimulating. Having some individuals who are 30 years old, others who are 55, having individuals who are multi-handicapped in chairs, but who have sharp minds. . . . It's like. . . . how can I bring someone to the gym in a chair with the 9 others, I find it hard. Loud music is stimulating for some, bothersome for others. . . . I find it difficult to organize activities that will please everyone."

The fourth issue was the limited physical activity funds in Readaptation Centers. Educators explained they had been working with the same budget for 10 years. Consequently, social activities (e.g., bingo, crafts) were prioritized, due to low cost. Additionally, seniors had little money to pay for physical activities and often didn't realize they could be physically active without excessive spending. Money needed to be invested in physical activity as well as in programs led by specialists trained to work with seniors with ID and supported by educators. The fifth issue raised the question of security: "How much autonomy should be encouraged for a vulnerable person?" One educator said, "For instance, with F., she is capable of going dancing and she would love that, but she is an easy target for predators." In such a case, seniors needed support to attend physical activities, such as companions during the journey, to avoid possible dangers.

The sixth issue was the extra-work to organize physical activities, which was difficult to manage. For instance, after bowling, one educator explained "I am alone with seven to eight individuals, including four with motor difficulties. I push one wheelchair and the three other independent clients help the three who have difficulties. Then, I have to help them to get up and down the stairs and the sidewalks and cross the street. It limits the outings!" Additionally, while adapted transport was often required to go to a physical activity, it was also used by seniors to get back home. They had to return punctually so as not to disrupt the drivers' schedules, which were difficult to control.

The seventh issue was related to educators' abilities to organize physical activities. The relevant skills of those who provided physical activities were questioned by their superiors. Educators explained that it was discouraging to initiate activities that were not fully appreciated.

The eighth issue was the "over-adaptation" of physical activities, so much so that it did not provide health benefits any longer. For instance in bowling, a ramp facilitated throwing but the balls were often too heavy for the seniors to lift. Thus, the educators placed the balls on the ramp while the seniors only pushed the ball down the ramp. In the end, this was not a great deal of exercise. Educators stated that physical activity adaptations, as necessary as they may be, had to be used cautiously. However, seniors needed them because they were not always capable of understanding simple directives. Also, they needed definite and varied objectives to maintain their participation and motivation. For instance, educators would have their group eat lunch at the park in order to incorporate a walk into the daily activities.

Finally, the last organizational issue raised by educators related to living situations. Seniors in apartments were more sedentary due to a lack of guidance toward physical activity, as were seniors in host families who were provided with little autonomy. In residences, physical activity was facilitated more frequently, because educators knew the location of physical activity venues.

Social. Both educators and seniors themselves explained that they (e.g., seniors) could not be as active as they wanted due to a relatively small social network, the aging of close relatives, and an overall lack of friendship. In the questionnaires, seniors stated they needed friends or girl/boyfriend to start or continue exercising (see Table 3). The same complaint appeared in the focus groups. One lady wanted to receive calls inviting her to be active. "Alone" she explained, "it is not the same, you are shy and you are scared." Seniors also needed someone to show them how to use equipment. They found it difficult and discouraging when unaccompanied. One individual stated: "I would need someone to show me how it works, someone who stays at the residence and who can show me.... When we are alone, we do not have the courage or the will power." Educators believed that seniors had the same interaction needs as other seniors without ID, like the need for verbal exchanges and social activities. Yet the educators recognized that seniors needed more support and someone to remind them to persevere in physical

activity). I think that for them, it would be a need to have someone to support them." Educators also stated that a community that is open-minded and welcoming to individuals with ID is rare, but ultimately necessary. When negative incidents occurred out in the community, such as the locker room being left unclean, groups of people with ID were often blamed.

Psychological. While educators did not identify any psychological barriers or needs regarding seniors and physical activity, seniors explained that sometimes they experienced fear about being active based on previous incidents. For instance, one individual remembered the pain of a French lawn bowling ball falling on his foot, another indicated that falls from bicycling had created apprehension about continuing. Seniors also mentioned their fear of people acting aggressively toward them, their fear of being defrauded by contracts at sports centers, their discomfort with being in places full of only strangers, and their embarrassment at not fitting in.

Self-determination. While a number of seniors expressed their enjoyment of physical activity, some simply stated they had no interest or were not particularly skillful. Other seniors wanted to choose when to be physically active, because it was not always made optional. For instance, one lady explained that sometimes she wanted to stay home because of tiredness or poor weather, but her brother insisted she be involved in activities. Educators pointed out that seniors needed to be intrinsically motivated as well as extrinsically motivated. One stated: "Do they really need targeted physical activities these people? Sometimes we look for complicated activities. . . . but to walk, to simply move. . . .I think what is the most important is for them to be motivated." Motivation was also necessary for the staff: "It is not only a lack of money. We need to do our part too."

However, educators revealed that it was difficult to remain motivated because they needed, for example, to endlessly repeat to seniors the benefits of physical activity and this was tedious.

Some seniors also indicated they had few opportunities to be active when they were younger. For instance, one woman recounted living in a convent until she was 21 years old and then working for much of her adult life; the first opportunity she had to become physically active came at the age of retirement. Finally, very cold winters and very hot summers made seniors less eager to exercise.

Understanding and knowledge. Educators explained that physical activities practiced by seniors outside day centers often remained unknown due to issues that seniors had with expressing themselves and difficulty remembering. Educators also stated that they needed to frequently adapt activities, because seniors did not always understand simple directions. That necessity to adapt physical activity so seniors understood required extra-work which made it difficult for educators to organize it. Seniors themselves identified a need to know how to be physically active. They were simply unfamiliar with the certain activities.

Physical Activities

Through the questionnaires (see Table 4) and the focus groups, seniors listed a wide range of activities they enjoyed. These included bowling, ball games, badminton, dancing, jogging, line dancing, lawn bowling, shoveling snow, stationary biking, swimming, walking, and weight training. These activities were similar to the ones practiced during mid-life, with the exception of hockey which was not played anymore, because they believed it requires a lot of energy. They also rode stationary bikes instead

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of three wheeled bikes. When younger, they skipped rope, and played hopscotch and bolo ball at school. Overall, seniors expressed positive effects with being physically active, because they saw friends and they felt healthy and happy. From an organizational perspective, educators explained that seniors enjoyed physical activities adapted to their pace and ability. For instance, some seniors who were involved in a sports program at the university told educators they liked going there because they fit with the group, the instructors took the time to explain the activity, and it was adapted. A woman in her sixties with difficulty walking still played hockey by being seated in her chair and manipulating the stick and the puck from her seated position. They also gave the example of adapted bowling, which uses a ramp to facilitate throwing the ball. Seniors liked it because they could participate just like they used to when they were younger.

Discussion

This study explored the physical activity barriers, needs, and preferences of seniors with ID. The purpose was to facilitate further understanding of factors necessary for the promotion of their active living and to ensure full inclusion and social participation as recommended by the Health and Social Services Ministry (2001).

All seniors contacted had a remarkable interest in participating in the research, wanting to complete the survey and be included in focus group interviews. They were glad to share their perspectives, with responses suggesting they had given thought to the topic but never the opportunity to express their views. Overall, the physical activities preferences of seniors were similar to younger individuals with ID (Temple, 2007). Most of them walked (86%) while the others went bowling and danced.

Seniors with ID had a modest but naïve understanding of what is meant by being active and healthy. They understood the importance of exercising and were active, according to their own standards. However, they believed that if they exercised they will lose weight immediately. They also interpreted being healthy as continuing to work because they did not have to remain in bed. To some degree this is true, but the ability to go to work is a very restricted view of health. Aging was not a worry as most seniors did not grasp its meaning clearly. While some individuals expressed justified concerns (e.g., scared of getting older, pain never experienced before), becoming older did not bring pragmatic changes to their lives. As they age, their routine stayed identical; they did not retire and were not provided with age adaptations. For instance, seniors were included in dance sessions more appropriate for younger individuals due to loud music.

One of the most important findings was that an important number of seniors (36; 78%) believed they currently exercised. However, this was not supported by educators who believed that seniors were not physically active enough and that the activities they practiced often provided no health benefits. The finding of this study is not unusual. While most research has suggested people with ID have a tendency to lead sedentary lives (Hoge & Dattilo, 1995), Hawkins and Look (2006) revealed that a greater number of individuals with ID exercised than expected. They used qualitative methodology to assess levels of engagement and barriers to physical activity for 19 adults with ID, similar to the present study. They discovered that the physical activity levels among their participants were higher than previous figures for people with ID, but still lower than the general population. Future research should assess the physical activity levels of seniors with ID more comprehensively. They could be interviewed to understand what they

consider active as well as assessed quantitatively to analyze the intensity of their physical activities. The latter assessment would provide insight into actual health benefits. In the present study, educators generally believed adapted bowling did not have a health impact because the educators executed all the physical tasks (e.g., bend to grasp the ball, carry it, and place it). Most of the seniors simply pushed the ball which did not require a great deal of effort. Jobling (2001) explained that physical activities are often provided for fun and recreational benefits but do not convey the importance to exercise for additional health benefits.

The study revealed an optimistic outlook by seniors in their questionnaire responses with most of them being quite positive; thinking their health was good, very good, or excellent, and not preventing them from being active. Seniors did not experience many physical activities barriers other than the ones regularly reported in other leisure studies among seniors with ID (Bigby, 1992; Glauser et al., 1995; Hawkins, 1991). These include (a) being alone, (b) not having anyone to show how to exercise, (c) equipment being complicated, and (d) fitness centers being hard to use. However, additional barriers were identified in the focus group interviews which might not have been highlighted if only a questionnaire had been used. For example, seniors expressed some psychological fears due to past accidents (e.g., a fall from a bike) as well as apprehension of being taking advantage of, the awkwardness of not knowing anyone, and the embarrassment of not fitting in. While these barriers were deeply intrinsic and were dealt with by individuals differently, it is important to realize that people with ID, no matter their age or abilities, may have difficulty to express these types of issues. People with ID should be supported by an adapted physical activities specialist who, in addition to facilitating the

modification of physical activities for educators, could work individually with seniors to listen and remediate to their perception of barriers. This could ensure that seniors are well understood before and during their practice of physical activities and would more likely maintain their involvement in physical activities.

Educators knew the physical activities barriers, needs, and preferences of seniors even if they were not familiar about the extent of seniors' psychological barriers. Additionally, educators experienced a greater number of organizational barriers that were difficult to manage (e.g., heterogeneous groups, environment, competencies, etc.). They would benefit from clear policy guidelines describing their exact role and how to provide, adapt, and implement physical activity programs. This type of resource exists for younger people with developmental disabilities. It is called the "Exercise and Nutrition Health Education Curriculum for Adults with Developmental Disabilities" program (Heller et al., 2001) from which the questionnaire of this study was adapted. Individuals using this resource increased their participation in physical activity, while staff were provided with effective tools easy to implement (Heller et al.). Similar programs need to be designed to support educators of seniors with ID in Quebec.

Educators felt that the general population is not sufficiently open-minded and inclusive toward individuals with ID. Educators felt unwelcomed and discriminated against when bringing people with ID to sport centers. It is surprising to realize that these behaviors still persist in the twenty-first century. Sadly, positive changes will not come from the general population itself, but from individuals with disabilities and their support figures who must change mentalities by advocating for their own inclusion (Goodley, 2000). By going to sports centers, using the facilities, and being seen, people with disabilities can take an active role in their ultimate social participation.

Lastly, seniors with ID were capable of expressing themselves through a questionnaire with the support of an educator or the researcher, as well as during focus group interviews. As such, seniors with ID should be included more frequently in research studies. Although people may have a tendency to answer for them, it is clear that many people with ID are sufficiently capable to know what they experience, what they need, and what they like. Their voice should not be neglected as new research techniques such as photovoice, pictures, and interviews are available with regard to the expression of individuals with various types of ID and language skills(e.g., Jurkowski, 2008; Todd, 2007).

Two main practice recommendations emerged. First, interventions should not solely focus on the individual but also on support figures (e.g., educators) and the physical environment (e.g., accessibility) in order to be maintained. People with ID are often not self-directed in their pursuit of physical activity (Pitetti & Tan, 1992) and need to have educators directly involved in programs to sustain participation (Cluphf, O'Connor, & Vanin, 2001). Rimmer (1997) provided a list of steps to start a physical activity program with seniors with ID that could be used. The steps include: (a) obtaining physician approval before starting the program, (b) providing tips on how to increase physical activities (e.g., using the stairs instead of the elevator), (c) choosing the appropriate program, (d) exercising at least three days per week, and finally (e) maintaining motivation. Second, individuals with ID tend to sustain motivation and remain physically active when physical activity is diverse (Rimmer, 1994), barriers removed, and needs meet. It is no different for seniors who have to be provided with creative ways to exercise. For instance, Hawkins and Look (2006) suggested "locating health promotion materials which have already been developed/adapted for people with learning disabilities (e.g., ID) and preparing specific information leaflets, posters, scrap books, line drawings, local photographs, videos or audiotapes to aid with health promotion" (p. 223). Implementing physical activity requires advanced preparation with fun activities facilitating socialization and providing challenges to offer a sense of accomplishment (Hawkins & Look).

Limitations of the Study

The first limitation occurred because service providers tended to recruit young seniors with ID (e.g., between 50 and 60 years) because they thought it would be easier for the researcher. While the researcher specifically asked to cover a wide range of aging people, service providers still contacted "younger" individuals. Presumably the service providers did not want to bother the oldest seniors, assuming they needed quiet time or they would not be helpful. Therefore, most of the seniors in this study were between 50 and 60 years old.

Second, the original intent of the study was to obtain barriers and needs of seniors with ID in physical activity. A barrier is a constraint that prevents individuals from being physically active while a need is "whatever it requires for health or comfort" (Green & Kreuter, 1991). Seniors as well as educators did not distinguish particularly well between
the two concepts, or the questions were not clear enough, and therefore barriers and needs were combined.

Finally, the study was limited to individuals with mild to moderate ID to facilitate their answers of the questionnaire and participation in focus groups. Further research should examine barriers, needs, and preferences among seniors with severe and profound ID. In this case, greater use of informant ratings (Heller, Hsieh, & Rimmer, 2002) should be used as well as alternative investigation instruments (e.g., pictograms and pictures; Todd, 2007).

In conclusion, seniors considered themselves to be active and to understand the meaning of health. They had some knowledge of what is required to be physically active, had given it thought, and liked expressing their views on health and physical activity. However, educators did not think seniors were active enough nor that their physical activities provided health benefits. Overall, implementing physical activity among individuals with ID, no matter their age, requires important preparation so activities are adapted to their needs and preferences, with minimal barriers. They likely require continued support to overcome difficulties they may experience while being active. Viewing aging and physical activity within the context of current research on ID, this study provided insights for service providers looking to implement physical activity programs specially designed for seniors with ID. The physiological and psychological health of seniors with ID, as well as their support network, needs to be assessed. Health promotion should be emphasized so that seniors with ID who decide not to be active,

have been provided with the same information and opportunities as the general population and are free to decide (Frey, Buchanan, & Rosser-Sandt, 2005).

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Table 1.

Reliability of Scales from the Initial Questionnaire

Scale	Alpha Cronbach's	Test-retest correlation
	reliability $(n = 29)$	(<i>n</i> = 29)
Energy fatigue scale	.63	.44*
Pain measures	.86	.40*
Exercise and activity	NA	NA
inventory		
Barriers to exercise scale	.73	.55**

General note. The initial questionnaire is the "Exercise Health Education Self-

Assessment Packet for Adults with Developmental Disabilities: Baseline Interview

Questionnaire" (Heller, Marks, & Ailey, 2006).

Specific note. Overall inter-rater reliability = .95

* (*p* < .05)

****** (*p* < .01)

Table 2.Health Responses from Questionnaires

Questions	Percentage of seniors with
	intellectual disabilities
Overall health	
- Excellent or very good	- 29% (14)
- Good	- 46% (22)
What do you do to be healthy	
- Walking	- 58% (28)
- Remaining active	- 56% (26)
- Balanced diet	- 40% (19)
- Seeing physician, taking medication	- 17% (8)
Exercising as much as wanted	- 56% (27)
Energy fatigue scale	
- Not worn out	- 54% (26)
- Lots of energy	- 64.6% (31)
- Not tired*	- 35% (17)
- Energy to achieve activities	- 77% (37)
Pain measures. No soreness when :	
- Walking	- 73% (35)
- Climbing stairs	- 65% (31)
- Getting in and out of chairs	- 71% (34)
- Washing all parts of the body	- 96% (46)
- Putting on pants	- 92% (44)
- Putting on a shirt	- 94% (45)

*Other answers included 33% (16) it depends and 27% tired (13).

Questions on barriers	Answers	Questions on needs	Answers
Administration / organization		- A better health	- 52% (25)
- Too much money to exercise	- 50% (24)	- More energy	- 46% (22)
- Do not have anyone to exercise	- 52% (25)	- Less pain in the body	- 40% (19)
with		- Be younger	- 50% (24)
- Do not have anyone to show	- 54% (26)	- Like my body better	- 38% (18)
how to exercise		- Be better looking	- 33% (16)
Health		- Friends	- 52% (25)
- Too tired	- 25% (12)	- To know how	- 48% 23)
- Too old	- 29% (14)		
- Bad health	- 19% (9)		
Knowledge	~		
- Hard to find an exercise program	- 42% (20)		
- Exercise do not make healthier	- 17% (8)		
- Being sick after exercising	- 10% (5)		
 Not knowing how to exercise 	- 27% (13)		
 Not knowing where to exercise 	- 44% (21)		
- Equipment hard to use	- 56% (27)		
- Fitness centers hard to use	- 60% (29)		
Psychology			
- Do not feel like exercising	- 54% (26)		
- Exercising is too hard	- 31% (15)		
- Have not enough time	- 35% (15)		
- Exercise is boring	- 17% (8)		
- Too lazy to exercise	- 23% (11)		
- People would make fun of	- 29% (14)		
him/her			

General note. The phrases in bold are the barriers and needs identified by seniors with intellectual disabilities in the questionnaires. 120

Table 3.Barriers and Needs Responses from Questionnaires

Table 4. Physical Activities Responses from Questionnaires	
Questions	Answers
 Exercise and activity inventory Currently exercising Types of current practiced exercises Number of time exercising per week Number of time exercising per week Currently playing a sport Types of current practiced sports Types of sports wanted to start if not presently involved in sports Types of sports of sports Types of sports and the to start if not presently involved in sports Currently in Special Olympics Sport practiced in Special Olympics Changes over time Currently exercising a lot Wanting to start exercising if not exercising a lot Exercising when younger 	 78% (37) Walk (86%/ 32), bowling (27%/10), stretching (16%/6), dancing (13%/5) Five times and more (40%/15), three to four times per week (17%/6); one to two times a week (17%/6); vary (24%/9) 54% (26) are not Bowling, biking, darts, hockey, swimming, walking Bowling (8%/11), baseball (6%/3), hockey (6%/3), swimming (6%/3), not start a new sport (17%/8) 17% (8) Bowling (6%/3), not start a new sport (17%/8) 17% (8) Bowling (100%/8) 48% (23) think they do; 48% (23) think they do not 57% (13) would like to start tight away or in few weeks 58% (28)

Bridging Manuscripts and Author Contribution

The second paper (chapter three) examined the physical activity's barriers, needs, and preferences among seniors with intellectual disability, based on the intrapersonal and interpersonal levels of influence of the Ecological Model of Human Behavior (EMHB; McLeroy, Bibeau, Steckler, & Glanz, 1988). A questionnaire and focus group interviews were used to collect data among seniors with intellectual disability and educators.

This third paper (chapter four) investigated the organization of physical activity services for seniors with intellectual disability in Quebec. It corresponds to the institutional, communal, and public policy levels of the EMHB (McLeroy et al., 1998). A survey was completed online by service providers in the fields of intellectual disabilities, aging, and health and leisure, some of which offer physical activities to seniors with intellectual disability.

The relative contributions of the two authors are as follows: As first author and primary researcher, I was responsible for 85% of the manuscript. I was involved in the original conception, research design, adaptation of the survey, and its online development. I also carried out the data collection, data analyses, and manuscript writing. Dr. Reid was responsible for the remaining 15%. He helped design the study, gave advice about data analyses, and edited the manuscript. Running head: ORGANIZATION OF PHYSICAL ACTIVITY SERVICES

Chapter IV: Organization of Physical Activity Services for Seniors with Intellectual

Disability in Quebec

Marion Steff and Greg Reid

Abstract

The purpose of the study was to investigate the organization of physical activity services for seniors with intellectual disability (ID) in Quebec. Fifty-one centers in three related fields were surveyed: 15 (30%) centers for people with ID, 14 (27%) senior citizen centers, and 22 (43%) centers for health and leisure. The online instrument was a systematic adaptation of the Australian "Survey of Aged Care Day Programs and Community Leisure Services" (Bigby, Fyffe, Balandin, McCubbery, & Gordon, 2001). Results showed that programs were not designed around seniors with ID. Although their needs increase with age, seniors with ID remain relatively ignored and do not benefit from any special support or guidance in health prevention. Service providers have yet to conceptualize physical activity as a vehicle to promote health among seniors with ID.

Quebec

Important progress in medicine, health care, nutrition, and education has helped individuals with intellectual disability (ID) age with the rest of the baby-boom generation in Western countries (Factor, 2005; World Health Organization [WHO], 2000). Presently, seniors with ID are the first sizeable cohort to live until later life in developed countries (Bigby, 2004), and are said to enter old age when they are above 50 (WHO). A number of research initiatives have resulted from the rapid emergence of this subgroup.

Over the past two decades, academics have focused mainly on the retirement of seniors with ID (Cordes & Howard, 2005; Heller, Miller, Hsieh, & Sterns, 2000; Heller & Sterns, 1996; Mahon & Goatcher, 1999), their health issues (Adlin, 1993; Carmeli, Merrick, Kessel, Masharawi, & Carmeli, 2003; Cooper, 1998; Fisher & Kettl, 2005; Janicki & Dalton, 2000; Janicki et al., 2002; McCarron, Gill, McCallion, & Begley, 2005; Moss, 1991; Thorpe, 2003; Tyler, Snyder, & Zyzanski, 2000; Van Buggenhout et al., 1999), their leisure (Boyd & Tedrick, 1992; Glausier, Whorton, & Knight, 1995; Hogg, 1994; Pedlar, Gilbert, & Gove, 1994; Rogers, Hawkins, & Eklund, 1998), and the delicate issue of their aging family caregivers (Engelhardt, Brubaker, & Lutzer, 1988; Hayden & Heller, 1997; Seltzer, Begun, Seltzer, & Krauss, 1991). However, the organization of physical activities for seniors with ID is unknown, despite physical activity being linked to numerous health benefits in the general population. Physical activity contributes to increased longevity (Markula, Grant, & Denison, 2001) and helps protect against osteoporosis, hip fracture, obesity, falls, cancers, type II diabetes, high blood pressure, cholesterol, and sarcopenia (i.e., loss of muscle mass; DiPietro, 2001). It also has important psychological health benefits given that exercise increases well-being and reduces feelings of anxiety, stress, and depression (U.S. Department of Health and Human Services, 2006). A mere 30 minutes of moderate activity per day is recommended for individuals of all ages to acquire psychological and physical health benefits (U.S. Department of Health and Human Services, 1996).

Generally, individuals with ID tend to be overweight; they have low physical fitness, low levels of muscle strength, and little capacity for exercise (Pitetti, Yarmer, & Fernhall, 2001). They are also less likely to engage in regular and moderate physical activity than those without disabilities and are therefore more sedentary than their age counterparts (U.S. Department of Health and Human Services, 1996). Overall, many factors contribute to an inactive lifestyle in individuals with ID, such as a lack of motivation, issues of accessibility and cost, and reliance on support to be physically active.

Interventions to increase physical activity often result in small behavioral changes dissipating within few weeks (Spence & Lee, 2003) probably because the focus is solely on the individual instead of the individual and his/her environment. In fact, physically active behaviors are influenced by a variety of factors (individual, familial, resources, opportunities and barriers to exercise) that are all interrelated and multifaceted (DeBate, Plescia, Joyner, & Spann, 2004; Grzywacz & Marks, 2001). Ecological approaches to intervention are necessary to improve physical activity (Spence & Lee).

The Ecological Model of Human Behavior (McLeroy, Bibeau, Steckler, & Glanz, 1988) stresses the importance of a supportive environment that promotes healthy behavior. The model proposes five levels that influence behavior (intrapersonal, interpersonal, institutional, communal, and public policy), three of which pertain directly to the organization of services. "Institutional level" refers to organizational characteristics and rules adopted by institutions, centers, and health care structures to facilitate one's health behavior. An example is a program called "Stand-up!" for seniors in Ouebec to prevents falls and fractures through group and home exercises (Quebec Health and Social Service Center Agency, 2008). "Communal level" refers to the relationships and collaborations among these institutions, centers, and health care structures. For instance, "Stand-up!" service providers work together to promote the program and increase its quality. "Public policy" is the influence that political bodies at the local, provincial, and national levels have on health promotion. It includes for instance, tax breaks for healthy behaviors. These three complementary levels help structure health services and facilitate the organization of physical activities for all citizens.

To organize is defined as "to form as or into a whole consisting of interdependent or coordinated parts, especially for united action" (www.dictionnary.com). In the last decade, service providers have come to realize that physical activity services have health benefits, and an increasing number of centers have organized themselves to provide physical activity programs for seniors in the general population (Jones & Rose, 2005). As such, skillful instructors have been trained to specialize in fitness and aging given the different health issues found in elderly populations compared to young adults (e.g., diverse medical conditions, varied functional abilities; Jones & Rose). This has yet to be applied to seniors with ID, who are growing older while simultaneously coping with a lifelong ID (Hawkins, 1991). Despite the rapidly growing emergence of seniors with ID, it is unclear who is responsible for their health and well-being. Although centers exist to support ID, aging, and health, none of them have assumed leadership responsibility for this population's health (Bigby, 2004). Moreover, research has yet to investigate the organization of physical activity programs for seniors with ID. This is startling given that being physically active is crucial to a high quality of life. The current research is an exploratory investigation into the organization of physical activities for seniors with ID. It aims to identify what is being done in one urban community to promote health benefits among a segment of the population with various special needs.

Three types of centers may be related to physical activity service provision for seniors with ID. The first is *"centers for people with ID*." Their primary objective is to provide people with ID with services, such as nursing, dietetics, physiotherapy as well as placement and support in workshops, employment, residential programs, and volunteer group services. They attend to the full age range of people with ID and their access is typically free.

The second type is *"senior citizen centers."* They focus on the elderly and offer a wide range of services such as transportation, meals on wheels, legal assistance, residential programs, day activities services, and educational associations. The cost depends on whether they are private or not.

The last type is *"centers for health and leisure."* These public and private services are offered in city boroughs and city sport centers, such as sports venues and arenas. They provide health and recreational activities to all citizens through their facilities, staff, and equipment. Access typically involves a fee.

These three types of centers may play a major role in the lives of seniors with ID as they could assume health and other responsibilities in place of deceased or elderly parents. Hence, basic questions need to be investigated to understand whether centers supporting ID, aging, or health, organize physical activity programs for seniors with ID, if these programs are designed around seniors, or if they aimed more broadly at the general population. It is important to know also if seniors with ID are included and if staff members receive in-service training on issues specific to aging while coping with an ID.

Therefore, the purpose of this study was to examine the organization of physical activity services for seniors with ID in ID, aging, and health centers. Based on the literature, the current study investigated the following four hypotheses:

- Centers for people with ID, while being aware of the aging of people with ID, do not adapt physical activity to the age-related needs of seniors.
- Seniors with ID have little access to senior citizen centers or centers for health and leisure;
- Senior citizen centers and centers for health and leisure do not believe that seniors with ID should be one of their primary concerns;

 Physical activity is not perceived as being important to the overall health of seniors with ID by all centers.

Method

Participants

Three types of centers were contacted. The centers for people with ID, senior citizen centers, and centers for health and leisure were located on the island of Montreal to avoid comparisons between rural and urban services. Centers were identified in the "Répertoire des Services Communautaires du Grand Montréal" (*Repertory of Community Services*, Centre de référence du grand Montréal, 2006), which is a directory of community centers created by the city. The number of centers contacted and the response rate are described in the results section.

Instrument

The Australian "Survey of Aged Care Day Programs and Community Leisure Services" (Bigby, Fyffe, Balandin, McCubbery, & Gordon, 2001) is designed to collect data about the diversity of the day support programs provided by specialist disability services for seniors with developmental disabilities. It was selected for two reasons. First, while the reliability and validity of the survey were not determined, it was approved by the Australian State and Commonwealth Human Services Departments to assess the organization of service providers in welcoming and including seniors with ID in leisure services. Second, it initially investigated the field of leisure, which is similar to physical activity in terms of cost and staffing constraints and could thus be easily adapted for the current study.

The modifications made to the survey were straightforward. First, the title, "Survey of Aged Care Day Programs and Community Leisure Services" was changed to "Survey on Physical Activity Services for Seniors with Intellectual Disability". Modifications were made throughout the survey adding "centers for people with ID" and replacing the term *leisure* with *health* because the current focus was on the organization of physical activities from a health perspective. Second, the words "physical activity", "exercise" and "sport" were inserted where necessary. For instance, the tenth question originally asked "What programs and activities does this day care or leisure service provide?" This question was re-written as "What physical activities does this center provide?" Third, the initial survey was created for seniors with disabilities who are 55 years old and above. In keeping with recommendations made by the WHO (2000), the expression "aged 55 years and older" was modified to "aged 50 years and older." Finally, the original survey examined seniors with developmental disabilities, which includes, but is not limited to, individuals with autism spectrum disorders, genetic syndromes (e.g., Down, Fragile X, or Prader-Willis), individuals with ID, or those with problems of the central nervous system (e.g., cerebral palsy or epilepsy). Our modified survey examined physical activity primarily among seniors with an ID. Therefore, the expression "older people with a disability unrelated to aging" was replaced with "older people with an ID unrelated to aging". Readers may contact the principal investigator for copies of the modified survey.

The survey was administered online using Survey Monkey software (http://www.surveymonkey.com) and was completed by representatives of each target center. A Web survey was selected because of the low cost and rapidity of data collection (Denscombe, 2006). The adapted survey was first discussed and refined by two university professors, two social workers, and two doctoral students in the ID field. It was later pilot tested by four service providers who were randomly selected from the "Répertoire des Services Communautaires du Grand Montréal" directory (Centre de référence du grand Montréal, 2006).

The survey was translated into French to accommodate the francophone service providers in Quebec using the "back translation" methodology; one professional translator translated the instrument into French and another translator translated it back into English. This procedure ensures that both surveys correspond to one another and that results are comparable (American Psychological Association, 2001). Minor discrepancies were then discussed with the two researchers, both bilingual, who selected the terms best suited to the study. For example, the original survey used the term "Community-based leisure service." It was translated into the French "Centre de santé et de loisirs" and then translated back into the English "Center for health and leisure." The latter was selected because it was a better description of the Canadian environment.

Procedure

The study was conducted over a 6-week period. In the first week, the primary researcher contacted all target centers by phone. The person in charge of physical activity or recreation planning at the center listened to a description of the study and was then asked to complete the survey. Upon acceptance, a link with the survey URL was emailed to the participants who provided their email addresses.

The second and third weeks were spent responding to the representatives who called back, contacting others for a second time if they were not reached during the first week (e.g., busy, no answer, left a message but did not return the call), sending links to the survey, sending reminders to representatives who agreed to complete the survey but did not complete it, and thanking the participants who did.

The fourth and fifth weeks consisted of answering representatives who called back late, sending the survey link to representatives who agreed to participate, sending reminders to participants who partially completed the survey, and thanking the participants who completed it.

The last week was spent ensuring that all participants who completed the survey later on received a thank you note. Access to the online survey was then discontinued.

Survey Analysis

The quantitative data were analyzed using descriptive statistics (medians, ranges, and averages) and frequency distributions. The raw data from each survey was exported to a spreadsheet in Excel (Excel 5.0; Microsoft 2007) in order to be analyzed. Questions 24 to 32 were qualitative and open-ended. They were analyzed using content analyses. Atlas-ti software (Atlas-ti 5.12; 2007) was used to assist in data coding and to facilitate its handling.

Trustworthiness

Four standards outlined by Guba and Lincoln (1989) were followed to ensure trustworthiness for open-ended questions: (a) *credibility* which refers to how truthful findings are, (b) *confirmability* which refers to neutral results, (c) *transferability* which pertains to how applicable findings are in other settings, and (d) *dependability* which relates to consistent and reproducible results. The three following naturalistic techniques were used to reach these standards: (a) triangulation of data, (b) thick description, and (c) intercoding agreement.

First, credibility and confirmability were established through triangulation of data. Credibility and confirmability require a variety of sources to provide multiple views on the topic of interest. In this case, a wide range of centers were contacted and the survey was completed by representatives with different professional designations such as the sports and leisure animator, director of recreation, sports coordinator, and elderly project coordinator. Open-ended questions were analyzed with both descriptive statistics and qualitative coding to ensure greater credibility and confirmability.

Second, transferability was ensured with a thick description of results. This consists of writing in an extensive and organized manner to facilitate the appraisal of findings and their transfer to other settings. Therefore, significant results by representatives were included to depict their viewpoints accurately.

Finally, dependability was established through intercoding agreement, in which questions are coded independently by researchers to obtain reliable results (Harris, Pryor, & Adams, 1997). In this study, the research assistant and the primary researcher resolved minimal discrepancies through discussions, verifications, and transparent coding.

Results

Response Rate

All three types of centers identified in the "Répertoire des Services Communautaires du Grand Montréal" (Centre de référence du grand Montréal, 2006) were contacted. This represented 94 centers of which 51 completed the survey (see Table 1). The response rate was 54%, which was considered high. Forty-three centers did not complete the survey: 22 (51%) were not reached after two messages, 3 (7%) declined by mail or online, 6 (14%) began the survey but did not finish it and 12 (28%) centers agreed to participate but never did. Table 1 shows a detailed account of the number of centers contacted in categories and the specific percentage of responses. Overall, response rate was high in centers for people with ID, with 75% of centers completing the survey. The response rate was strong in senior citizen centers and centers for health and leisure with 50% and 48% of surveys completed, respectively.

General Information

The first five questions of the survey were introductory and were posed to all 51 centers. They requested descriptive information, such as the name and type of center in which the respondent worked, his or her name and responsibilities, the postal code as well as the aims of the center to ensure that the correct service providers were targeted. No further analyses were conducted.

Functioning of Centers

Functioning of centers (questions six to nine) referred to the number of days per week the center operates, its opening hours, the numbers of users, and their age

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range. The centers for people with ID and the centers for senior citizens were typically open during regular business hours, whereas centers for health and leisure were typically open seven days a week with longer operating hours. The average number of users per week varied from 560 in centers for people with ID, 240 in senior citizen centers, and 800 in centers for health and leisure. Nine centers for people with ID welcomed individuals of all ages whereas the remaining six centers only welcomed adults older than 18 or 21. The senior citizen centers had diverse entering ages that ranged from 50 to 65. Centers for health and leisure generally served individuals of all ages. Overall, the three types of centers represented the full range of functioning.

Physical Activities

Question 10 asked which physical activities were provided to all members of centers, without distinguishing age or abilities. The most often physical activities listed in centers for individuals with ID included bowling, swimming, walking, and dancing. Twenty-five other physical activities were mentioned in some of those centers and included fitness (e.g., aerobics, dance, relaxation, etc.), sports (e.g., curling, skiing, soccer, etc.), and assorted physical activities (e.g., bean bag toss, ball activities, racquet, etc.). Physical activities cited most often in senior citizen centers in the general population included aerobics, bowling, dancing, French lawn bowling, pilates, the Stand-up! program, adapted work out, bean bag, balance activities, taï-chi, and yoga. The physical activities cited most often in centers for health and leisure and offered regularly among all citizens in the community included aerobics, aquaform, badminton, basketball, dancing, cardio, fitness, judo, hockey, pilates, skating, soccer, swimming, taï-chi, volleyball, weights, and yoga.

Physical activities in senior citizen and ID centers were numerous even if their primary mandates are to focus on the promotion of leisure activities (e.g., spiritual, physical, social, and emotional) rather than on physical activities in order to encourage, facilitate, and promote daily participation. As expected, centers for health and leisure offered the widest variety of physical activities to its members, in accordance with their main mandate to promote active living.

Facilities and Equipment

Question 11 asked the type of facilities and equipment the centers provided (see Figure 1). Thirteen of 15 (87 %) centers for people with ID lacked facilities for indoor physical activities. Additionally, 11 (73%) did not own any equipment for physical activity. The rest were poorly equipped: One center mentioned a gym, a room, and a nearby park, while others owned equipment, such as hockey sticks, balls, training mats, weights, and a bicycle.

Senior citizen centers were also poorly equipped in terms of facilities; six of 14 (43%) centers only had one room for practicing physical activity while the others had nothing. However, 10 (71%) centers owned variety of equipment, such as bikes, selective weight stack machines, free weights, exercise balls, core boards, resistance tubing, dart boards and darts, French bowling bowls, mats, yoga elastics, bean bags, mini-golf, badminton racquets, and parallel bars.

All centers for health and leisure had an extensive variety of facilities, such as tennis and squash courts, swimming pools, dance studios, weight rooms, playing fields for basketball, volleyball, and hockey. There was also a wide range of equipment with specialized materials, such as bows and arrows, weights, mats, elastics, as well as balls, bats, rackets, cords, and nets for baseball and golfing.

Overall, centers for people with ID had few facilities and little equipment to organize physical activities, even if they attempted to provide physical activities with bowling, dancing, swimming, and walking. Interestingly, senior citizen centers were more organized to implement physical activities as they had purchased a variety of equipment in spite of lacking facilities. Centers for health and leisure were best able to offer physical activities to the general population with extensive equipment and significant investments in sport facilities.

Special Groups

Question 12 asked if centers aimed to provide physical activities for any particular groups of people in the community, such as individuals with Down syndrome, frail seniors or pregnant women. The following question (#13) asked if members of the center were 50 years of age and older.

All centers, without distinction, offered physical activity services to particular groups of people in the community. For instance, a center for people with ID developed a program for children with Down syndrome while another offered physical activity services to clients with pervasive developmental disorders. Similarly, senior citizen centers had various physical activity programs for frail seniors whereas centers for health and leisure had special physical activities for diverse groups which varied by origin or religion (e.g., Italian, Jewish), pregnant women, and individuals with physical disabilities. Although 49 centers (96%)

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reported supporting individuals aged 50 and up, none of the 51 surveyed centers offered organized, specialized, and segregated physical activity programs that were strictly for seniors with ID.

Access to Seniors with Intellectual Disability

This section dealt with six questions (14 to 19) related to the use of centers by seniors with ID. Question 14 asked if they currently offered physical activity services to one or more seniors with ID. Twenty-four did not, and were therefore redirected to question 27 to answer general questions. The 27 (53%) other centers that did offer services to seniors with ID were asked more specific questions. The 27 centers comprised 13 for people with ID (48%), nine for senior citizens (33%) and five for health and leisure (19%; see Table 2).

Question 15 asked what type of ID these seniors had and question 16 asked if these seniors also had associated conditions that did not relate to aging. Overall, the types of ID as well as comorbid health issues among seniors were clearly identified in centers for people with ID. Other centers (14 out of 27) either did not know the particular disability or confused ID with bipolar disorder, depression, and stroke. However, the seven centers remaining were often capable of specifying various types of comorbid health problems, such as visual and speech impairments, chronic illnesses, blindness, hearing disabilities, and difficulty walking. All five centers for health and leisure mentioned that they did not always know the comorbid issue. Intellectual disability and comorbid issues remained difficult to identify for nonspecialists and were often confounded with conditions that are more "expected" in society or more acquainted with depression or stroke, for instance. Questions 17 to 19 asked how many seniors with ID used the center, what their age range was, and how seniors with ID found out about the center. On average, there were 91 seniors with ID in centers for people with ID with an important standard deviation of 139, seven in senior citizen centers with a standard deviation of four, and 13 in centers for health and leisure with a standard deviation of nine. The age of seniors with ID ranged from 50 to 80 in centers for people with ID and both 50 to 75 in two other types of centers. Eight-five percent of centers (25) believed that seniors heard about these centers through family, friends, caregivers and/or professional support. Overall, the number of seniors with ID in centers for people with ID was larger than the number of seniors with ID accessing senior citizen centers and centers for health and leisure. Diverse supporters (e.g., family and educators) helped seniors with ID enroll in senior citizen centers and centers for health and leisure.

Physical Activities for Seniors with Intellectual Disability

Question 20 asked in which physical activities seniors with ID participated, question 21 inquired about the staff members' qualifications, and questions 22 and 23 focused on the number of days per week and hours per day these seniors participated in physical activities. The four questions were posed to all 27 centers offering services to seniors with ID (see Table 3).

Centers for people with ID had the most physical activities which seniors with ID participated: 22 versus 10 in senior citizen centers and four in health and leisure centers (see Table 3). Centers for people with ID listed physical activities such as ball activities (4, 31%), bowling (2, 15%), dancing (2, 15%), swimming (2, 15%), and

walking (2, 15%). The most reported physical activities in senior citizen centers included bowling (3, 33%) and working out (4, 44%). In centers for health and leisure, only dance, yoga, pilates, and free swim were listed as activities in which seniors with ID participated. Across centers, the most common physical activities for seniors with ID were bowling and dancing, which are also common among younger individuals with ID (Temple, 2007).

Six centers for people with ID (46% of the 13 respondents) indicated that the staff members in charge of physical activity were specialized educators. Four centers (31%) reported that their staff lack specific qualifications, and two centers (15%) reported having received *sensitivity training* by the Special Olympics. The staff in senior citizen centers had diverse qualifications and included volunteer training, bachelor's degrees, and certificates in leisure, special care counseling, and physiology. One staff member was a certified tai chi instructor. In the health and leisure centers, certifications included special care education, bachelor's degrees, life guard training, as well as dance, yoga, and pilates instruction. In one center for health and leisure, the pilates, dance, and yoga instructors were also trained by the Special Olympics. Overall, staff training was diverse and either related to special populations, the human body, or physical activity. Surprisingly, staff members in only two centers for ID were trained in physical activity.

Eight centers for people with ID (61% of the 13 respondents) offered physical activity to seniors on a weekly basis; one to three times a week for 15 minutes to four hours. Four centers (31%) only provided physical activity once or twice a month or seasonally (e.g., soccer during the summer), while another center (8%) provided

physical activity once or twice a year. Physical activity was offered more frequently in senior citizen centers as well as health and leisure centers, with 11 centers (79%) providing sessions one to five times a week for periods of one to four hours. Physical activity was not offered on a monthly or yearly basis. Despite efforts to provide a choice of physical activities, centers for people with ID offered less physical activities each week compared to other centers, with little equipment and facilities to facilitate their organization. In senior citizen centers and centers for health and leisure, seniors with ID can be more active.

Barriers in Physical Activities

Question 24 was the first open-ended question in a series of nine. It asked if seniors with ID had trouble participating in physical activity (e.g., difficulties of understanding, being included, socializing, having fun, and making progress). The 27 centers which offered services to seniors with ID responded to the question.

Eight centers for people with ID (62%) experienced difficulty in getting seniors with ID to participate in physical activities because of physical / health barriers (e.g., physical impairment), psychological barriers (e.g., apprehensive about the activity, lack of interest), communicational barriers (e.g., problems with understanding and communicating), or environmental barriers (e.g., issues with integration due to prejudice, activities that are ill-suited to clients, and inaccessible locations).

Less than half of the senior citizen centers (4, 44%) reported having problems with seniors with ID in physical activity. They identified communicational barriers (e.g., difficulties with general understanding) and environmental barriers (e.g., lack of supervision and advice; the staff being concerned about unforeseen issues such as locked bathrooms and late transportation during outings). Centers for health and leisure (3, 60%) identified similar communicational barriers with comprehension issues during fitness classes but not during dance sessions.

Interestingly, the centers which indicated that seniors with ID had no difficulty participating explained that individuals with a disability had to function within the environment to be accepted (e.g., they had to be autonomous); otherwise, they lacked the required resources to provide continued support. Only one senior citizen center reportedly adapted its activities to the needs of seniors with ID. *Support and Resources in Physical Activities*

Questions 25 and 26 asked if centers provided any support (e.g., guidance, monitoring, direction, etc.) or if they required additional resources (staff, transport, facilities, etc.) to assist seniors with ID with their participation in physical activity. The two questions were asked only to the 27 centers offering services to seniors with ID.

Eight centers for people with ID (62%) provided support which included guidance and monitoring from staff and volunteers to facilitate inclusion. Half of the senior citizen centers and health and leisure centers provided similar support to seniors with ID, while the other half did not distinguish seniors with ID from other members in their centers.

Twelve (55%) centers for people with ID and senior citizen centers did not think that they needed additional support or resources to assist seniors with ID in physical activity. The 10 others (45%) wanted more volunteers to support seniors during activities to increase participation. Half of the 10 also reported difficulty with transportation and that they would benefit from a better system and/or funding. All five of the health and leisure centers stated that their clients already received sufficient support and resources in physical activity. For instance, they had companions for those with special needs and free access to programs for these companions.

Overall, most of the centers provided special support to seniors with ID to facilitate their participation in physical activities. Centers that did not provide additional resources to support seniors with ID in physical activity did not want to make a distinction between their users and providing special assistance to seniors with ID was not part of their mission.

Policies, Procedures, Initiatives, Collaborations, and Written Plans

Questions 27 and 28 investigated whether centers developed any policies, procedures, and initiatives to support access and participation in physical activity for seniors with ID. Question 29 and 30 asked if centers had contact with other organizations to facilitate physical activity among seniors with ID and if centers had individual written plans addressing the needs of seniors with ID concerning physical activity. All 51 centers were asked to answer questions 27 to 30.

Overall, 40 centers (78% of total sample) did not have policies or procedures about access and participation in physical activity for seniors with ID (see Figure 2). They often stated that it was not their mandate, and that seniors with ID were not their primary clients. Centers that did have policies and procedures in place indicated that individuals must (a) be able to walk, (b) have a mild ID, (c) be autonomous and (d)
meet health requirements. As mentioned above, some centers provided companions for those with special needs, and offered free access to programs for these companions.

Additionally, 37 centers (73%) had not developed initiatives to support access and participation in physical activities for seniors with an ID (see Figure 2). For instance, one center for individuals with ID employed a low staff per person ratio and emphasized the importance of integration principles for both older and younger individuals with ID. A senior citizen center mentioned that their clients with ID were reluctant to participate in physical activities even if the staff tried to stimulate their interest with more explanations and attention.

Nine centers for people with ID (60%) and nine senior citizen centers (64%) collaborated with other organizations to increase access and participation of seniors with ID in physical activity (see Figure 2). For instance, they worked with health and leisure centers to use gyms and pools, as well as with the private sector to use bowling alleys. Ten health and leisure centers (45%) assisted with centers for people with ID to provide space for activities.

Finally, only 12 centers (24 % of total simple) had a written individualized plan addressing the needs of seniors with ID. The plan was generally not related to physical activity; it was more of a general intervention plan to support each individual.

In terms of policies, procedures, initiatives, and written plans, little had been done to support access and participation in physical activities for seniors with ID. Centers stated that it was not their first mandate and had other priorities. Relative to collaboration, more than half of all centers had organized themselves to work alongside other organizations to increase access and involvement of seniors with ID in physical activity. This is seen as an important and positive step in the promotion of physical activity for seniors with ID.

Discussion

The aim of this study was to investigate the organization of physical activity services for seniors with ID in ID, aging, and health and leisure centers in light of the Ecological Model of Human Behavior (McLeroy et al., 1988). The following discussion will be divided in accordance with the 11 subsections of the results section, and will address the four hypotheses.

Response Rate, General Information, and Functioning of Centers

The response rate of 54% was high with sufficient representation from centers (Dillman, 2000). Centers for people with ID responded most often (75%) perhaps because they were most acutely aware of the needs of seniors with ID. When talking on the phone with their representatives, they expressed a real concern for their aging clients as well as for health prevention through physical activities and were eager to respond to the survey. Over the telephone and through email responses, other centers stated that seniors with ID were an uncommon topic and were not their regular clients. Nevertheless, they were very receptive to answering the survey and to learning more about seniors with ID.

As expected, centers for people with ID and senior citizen centers were administratively open five days a week. Conversely, centers for health and leisure had a mandate to provide physical activities to the general population, and were open every day for longer periods of time to accommodate working individuals and families. It is noteworthy that for accepting individuals into senior citizen centers, the age ranged from 50 to 65. Therefore, aging individuals with ID can access services adapted to the needs of an older population.

Physical Activities, Facilities, and Equipment

Physical activities provided in centers for people with ID were similar to those reported in other research studies in ID (e.g., bowling, swimming, walking, and dancing; Temple, 2007). However, they lacked physical activity facilities and equipment compared to senior citizen centers or centers for health and leisure because presumably because centers for people with ID focus on primary services such as medical health, care, employment, and residency rather than on secondary services, such as the promotion of physical activity.

Physical activity was as diversified in senior citizen centers as in centers for people with ID. However, senior citizen centers were ahead of centers for people with ID in the development and implementation of physical activities with many equipment purchased but little facilities. The available equipment and programs suggest that senior citizen centers acknowledge the importance of being active and to promote it among their clients. It could be related to the fact that seniors without disabilities have the ability to express themselves and their participation desires. Their physical activities are well-adapted to aging individuals; they are low-impact such as in bowling, French lawn bowling, and taï-chi.

The three types of centers may represent a continuum with regard to investment in facilities and equipment. At the low end would be centers for people with ID with a will to incorporate regular physical activities but with few resources. At the middle are senior citizen centers which provide diverse physical activities and equipment but little facilities because they are expensive. At the high end would be centers for health and leisure with countless choices of physical activities, facilities, and equipment, as they are specialist and need to stay up to date to keep their clients. *Special Groups and Access to Seniors with Intellectual Disability in Centers*

All centers provided physical activity to special groups, such as individuals with Down syndrome, frail seniors, or pregnant women. However, seniors with ID were not singled out as a particular group with special needs. No programs were specially designed for them. Services providers did not consider it necessary to organize or adapt physical activities to seniors with ID for leisure or preventive health. In centers for people with ID, seniors with ID were not distinguished from younger individuals because centers wanted to treat them equally, without distinction of age or abilities. Previous research (Seltzer, 1988) indicates that seniors who are not separated from younger friends remain challenged and stimulated, even if activities are not always age-appropriate.

In reality, seniors with ID were a small group in both senior citizen centers and centers for health and leisure. There was an average of seven seniors with ID out of 240 users in senior citizen centers, and an average of 13 seniors with ID out of 800 users in health and leisure centers, both of which were rather low figures. Representatives of these centers claim that it would be unnecessary to organize a special program for seniors with ID because there is no real demand. The contrary could be argued. There is no real demand because no programs exist already. Seniors

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with ID and their support figures would not use a senior citizen center or a center for health and leisure because it could be difficult for seniors to be included without for instance staff being knowledgeable in physical activities and aging while having an ID.

Physical Activities for Seniors with Intellectual Disability

Seniors with ID participated in 22 different types of physical activities in centers for people with ID. They participated in 10 different types of physical activities in senior citizen centers and 4 in centers for health and leisure (see Table 3). Despite a lack of equipment and facilities for physical activity, centers for people with ID realized the importance of being physically active either for leisure and/or for health benefits and prevention. The practitioners have developed a mandate to encourage, facilitate, and promote the participation of their clients in the daily social life of their community. Their expertise has led them to implement different physical activities for aging individuals with ID even if they do not usually employ specialized physical activity instructors. Senior citizens centers try to include seniors with ID whenever possible whereas centers for health and leisure, despite a mandate to support access to all citizens, have few seniors with ID in their facilities. Although society endeavors to integrate people with ID (Health and Social Services Ministry, 2001) and provide them with physical activity, it seems difficult for health and leisure centers to start. They lack clear practical guidelines such as medical clearance for seniors to start an activity and instructions on the adaptation of physical activities for educators. The staff may also lack the training or knowledge about individuals with ID to facilitate their inclusion in physical activity.

Barriers, Support, and Resources in Physical Activities

The barriers preventing seniors with ID from participating in physical activity ranged from physical and health-related to psychological, communicational, and environmental in centers for people with ID. These centers reported the most barriers, possibly because their mandate necessitated them to accept all seniors, independent of their functioning and comprehension levels. Centers that work less with seniors with ID only encountered communicational and environmental barriers because they ensured that senior members could be integrated with other clients. In this way, seniors were much more autonomous and functional than the ones in centers for people with ID. Overall, their barriers were similar to those found in younger individuals with ID (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). However, it remains unknown whether these barriers intensify with aging or if barriers become more numerous with time.

Support and resources provided to seniors with ID to facilitate their participation in physical activity were similar to what is expected in the field of ID with monitoring, guidance, tips, and volunteers. Surprisingly, no centers expressed a need for better facilities or more equipment, including centers for people with ID which were poorly equipped. It could be related to the fact that physical activity has not yet been thought of as a vehicle to promote health. Centers for people with ID may want to spend money on matters they believe more important such as residential issues.

Policies, Procedures, Initiatives, Collaborations, and Written Plans

Few policies, procedures, initiatives, and written plans were put in place by centers to facilitate access and participation into physical activity by seniors with ID. This probably is a function of them being not yet recognized as a distinct group. While precise policies and plans reflect local priorities associated with the existing of improved social and service configurations (Bigby, 2004), none of the centers received clear guidelines for encouraging the inclusion of this group from higher authorities. Thus, they lack a plan of action and often claimed that it was not their mandate to care for one particular group of individuals. They tried to provide fair service to everyone, explaining that the creation of new policies would necessitate more funding and staff for a subgroup that remains relatively small.

However, centers have started to collaborate in terms of accessibility or locations of facilities, to facilitate participation of individuals with ID. Collaborations may be easier to implement than programs because renting a dance studio, for instance, does not require serving directly individuals in need of more support. Individuals with ID are still supported by centers for people with ID who remain in charge of the programming of activities. To provide more physical activities relative to health prevention, it is important to develop interaction based on each center's field of expertise where all centers contribute to serve seniors with ID. The collaboration should be more than just renting facilities. It is advisable to hire physical activities specialists with training in ID and aging to provide seniors with ID with individualized services.

Hypotheses

Four hypotheses were tested. The first hypothesis predicted that centers for people with ID, while being aware of the aging of people with ID, did not adapt physical activity to the age-related needs of seniors. Seventy-five percent of service providers from centers for people with ID completed the survey likely because they wanted to express their views on the topic and because they were aware of their clients aging. They elaborated on their answers and explained how their centers operated toward seniors with ID. They wanted to learn more and were eager to receive the results of the current study. Centers for people with ID had not developed special physical activity programs for seniors; seniors were simply integrated with younger individuals. Their support to seniors was evident as 62% of centers with ID provided volunteers and monitoring from staff to facilitate inclusion. However, they would do it for any individual with ID, independent of his or her age and abilities. Thus, the first hypothesis was confirmed.

The second hypothesis predicted that seniors with ID had little access to senior citizen centers or centers for health and leisure. Only 33% of senior citizen centers and 19% of centers for health and leisure dealt with seniors with ID. Physical activity services were offered to frail seniors and individuals with physical disabilities but not to seniors with ID. However, senior citizen and health centers may not identify these individuals because their knowledge on disabilities or comorbid health issues was rather poor. Seniors with ID constitute a group that remains to be acknowledged possibly by higher political realms in order to better guide centers, so seniors can lead healthy and included life while also maintaining control of what is of importance to them (Bigby, 2004). This hypothesis was therefore supported as seniors with ID were rarely involved with citizens without ID.

The third hypothesis predicted that senior citizen centers and centers for health and leisure did not believe seniors with ID should be one of their primary concerns. Most centers had not developed any policies, procedures or initiatives to facilitate the organization of physical activities for seniors with ID. Centers for health and leisure assisted seniors with ID as they would help anyone else; they did not believe that they should specifically adapt to this subgroup. However, senior citizen centers had started to collaborate with some centers for health and leisure to practice physical activity. This was done mainly to rent space. Physical activities were viewed in terms of accessibility to facilities with separate places (e.g., location of dance studios or gymnasiums) rather than in terms of social integration among other users (Bigby et al, 2001). Thus, the third hypothesis was partially confirmed.

The last hypothesis predicted that physical activity was not yet perceived as being fundamental to the overall health of seniors with ID by all centers. Because seniors with ID were not singled out as a group in need of specialized support, they may not have been encouraged to participate in physical activity. Service providers explained that individual characteristics (e.g., limited understanding, little motivation, lack of skills) made it difficult to get seniors with ID involved in physical activity. Although some studies stated that these characteristics hinder participation (Bigby et al., 2001; Glausier et al., 1995), research has clearly demonstrated that physical activity has important health prevention benefits and should be encouraged among all

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citizens, regardless of their age or abilities (U.S. Department of Health and Human Services, 1996). The last hypothesis was therefore partially confirmed.

Implications and Conclusion

Seniors with ID are not yet recognized as a group with unique needs and characteristics in physical activity. No physical activity programs have been adapted to their aging. Consistent with the literature on leisure services (Seltzer, 1988; Bigby, Balandin, Fyffe, McCubbery, & Gordon, 2004), seniors with ID are mainly involved in age-integrated disability services that include individuals with ID of all ages. They are rarely integrated in senior citizen centers or centers for health and leisure, and when they are, it is because they have a mild ID, are in good health, do not impede social integration, and meet the requirements for mobility and autonomy. Seniors with ID rarely access centers for health and leisure alone; they usually come with a group that rents space.

Despite the high response rate and interest in the topic, service providers have not adapted their physical activities to aging individuals with ID probably because they lack guidelines from the political realm to support and assist service providers from different specializations. Although seniors' needs increase as they age, this cohort remains relatively unknown; they do not benefit from any special support or guidance in health promotion because they have never been included in populationbased health promotion campaigns. Although the positive impact of physical activity on health is promoted in seniors in the general population, physical activity is not conceptualized as a means to improve health among seniors with ID. No special adaptations have been made to encourage an active lifestyle. Perhaps physical activity is not perceived as a viable strategy to maintain or enhance health because it only minimally functions as a leisure activity.

Overall, the aging of people with ID should be addressed outside centers for people with ID. In a time where the inclusion of people with ID is advocated, it is important to raise awareness of this growing group of seniors, to increase their participation in physical activity, and to ultimately prevent health problems in this cohort. It is necessary that service providers play a key role in the lives of seniors with ID and that they organize and deliver physical activities to encourage healthy living. Seniors with ID need to be guided and informed about the benefits of physical activity. Senior citizen centers and health centers should facilitate the implementation of services. They should also work with centers for people with ID to be receptive to the needs of this aging population.

Future research should investigate how to facilitate the implementation of physical activity programs in this segment, how public policy makers can support practitioners, and which action plans can ensure that the health of seniors with ID is not neglected. Additional studies must identify the physiological and psychological benefits of physical activity for seniors with ID. They should also determine whether the intensity of physical activities currently offered provides health-related benefits.

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Table 1

Response Rate

Centers	Contacted	Responses	Percentage	Percentage of
			response	final sample
People with ID	20	15	75%	30%
Senior citizen	28	14	50%	27%
Health and	46	22	48%	43%
leisure				
Total	94	51	/	100%

Table 2

Survey Completion

Centers	Number of Centers Completing	Number of Centers
	the Survey	Currently Offering
		Services to Senior(s) with
		ID
People with ID	15	13
Senior citizen	14	9
Health and leisure	22	5
Total	51	27

Table 3

Physical Activities Participation by Seniors with Intellectual Disability in Centers

Physical activities	Centers for people	Senior citizens	Centers for health
	with ID	centers	and leisure
Aquatics			
free swim			\checkmark
swimming	\checkmark		
Fitness			
aerobic	\checkmark		
balance exercises		\checkmark	
dance	\checkmark	\checkmark	\checkmark
nanbudo	\checkmark		
mild exercises	\checkmark	\checkmark	
pilates		\checkmark	\checkmark
stretching	\checkmark		
tai chi	\checkmark	\checkmark	
treadmill	\checkmark		
walking	\checkmark	\checkmark	
working out	\checkmark	\checkmark	
Yoga			\checkmark
Sports			
cycling	\checkmark		
skating	\checkmark		

soccer

Other physical

activities

bean bags✓✓bowling✓✓hockey ball✓✓horse riding✓✓outings✓✓French bowling✓✓
bowlingImage: Constraint of the second s
hockey ball✓horse riding✓outings✓French bowling✓
horse riding✓outings✓French bowling✓
outings French bowling ✓
French bowling \checkmark
C C
PIED programme 🗸
Special Olympics 🗸
special programs

 \checkmark

Figures Caption

Figure 1. Facilities and Equipment for the Practice of Physical Activity.

Figure 2. Policies, Procedures, Initiatives, and Collaboration Regarding Access and

Participation in Physical Activity for Seniors with an Intellectual Disability.





Chapter V: Summary and Conclusion

This doctoral dissertation was a series of three manuscripts intending to provide a voice for seniors with ID, and to address the scientific communities researching active living, physical activity, and seniors with ID. The objective was to address the promotion of physical activity among seniors with ID from a health perspective. More specifically, the research question was: How do current physical activity programs address the barriers, needs, and preferences of seniors with lifelong ID in a North American metropolitan environment?

The first study (chapter two) was a systematic review of the scientific literature on seniors with ID and active living. Based on the five levels of the Ecological Model of Human Behavior (McLeroy, Bibeau, Steckler, & Glanz, 1988) to guide and delimit the retrieval of articles, the search yielded few studies on active living and seniors with ID at all levels of the conceptual framework. This segment of the population has been overlooked in the field of physical activity. There were no research studies conducted to assess their barriers, needs, and preferences and empirical investigation into maintaining and improving their motor functions were minimal. Additionally, the results suggested that caregivers and professionals required structure, training, and guidance from public policy makers in order to encourage an active living lifestyle. It was recommended that centers for disability, aging, and health and leisure, all with their own expertise, collaborate to facilitate the development of adapted physical activity programs. Overall, there was a need to increase knowledge about this population so that appropriate physical activity services can be incorporated into their daily living.

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The second paper (chapter three) examined the physical activity barriers, needs, and preferences among seniors with ID. It corresponded to the intrapersonal and interpersonal levels of influence of the Ecological Model of Human Behavior in terms of participants contacted. Forty-eight questionnaires were completed by seniors with ID. The questionnaire was an adaptation of the "Exercise Health Education Self-Assessment Packet for Adults with Developmental Disabilities: Baseline Interview Questionnaire" (Heller, Marks, & Ailey, 2006). Its completion was followed by a random reduction of the sample in order to conduct four focus groups with 15 seniors with ID. Sixteen educators were also interviewed in three focus groups. Participants met to discuss physical activity barriers, needs, and preferences as well as health. The results showed a remarkable interest of seniors to participate in the study who enjoyed sharing their perspectives. A great number of seniors with ID did exercise while having optimistic outlooks on their health. Their physical activities preferences were similar to younger individuals with ID. Educators were more likely to report barriers and needs than seniors with ID. Educators required greater guidance to facilitate the implementation of physical activity programs. Future research should assess the physical activity levels of seniors with ID by interviewing them to check what they consider active, at what intensity they are exercising, and if their engagement provides actual health benefits.

The third paper (chapter four) investigated the organization of physical activity services for seniors with ID in Quebec. It corresponded to the institutional, communal, and public policy levels of influence of the Ecological Model of Human Behavior. Fifty-one centers in three related fields were surveyed: 15 (30%) centers for people with ID, 14 (27%) senior citizen centers, and 22 (43%) centers for health and leisure. The online

instrument used was a systematic adaptation of the Australian "Survey of Aged Care Day Programs and Community Leisure Services" (Bigby, Fyffe, Balandin, McCubbery, & Gordon, 2001). Results showed that programs were not designed for seniors with ID. Although their needs increase as they age, this segment of the population remained relatively neglected and did not benefit from any special support or guidance in health prevention. Service providers had yet to conceptualize physical activity as a vehicle to promote health among seniors with ID.

To answer the research question, little has been done to address the state of physical activity programs for seniors with ID, nor to recognize seniors with ID as a group with its own characteristics. The findings should facilitate the implementation of physical activity programs among seniors with ID by providing a better understanding of their barriers, needs, and preferences, as well as, exposing the reality of the physical activity services in the community. It is important to conceptualize seniors with ID as a distinct group entitled to receive adequate physical activity services, either while remaining with individuals of similar age and ability, younger individuals with ID, or seniors without disabilities.

This research had methodological implications, as well. The entering point into old age was a challenge to define because no general agreement exists among researchers. Reviewing 35 studies, Seltzer and Krauss (1987) found various starting points of old age, ranging from 40 to 75 years. This is related to the fact that the aging of people with ID is still a recent phenomenon and that individuals with Down syndrome have a tendency to age prematurely. In this dissertation, the cut-off point of 50 was adopted as recommended by the World Health Organization (2000). A number of issues arose when designing and conducting the first study relative to barriers, needs, and preferences of seniors with ID. Service providers tended to recruit young seniors with ID (e.g., between 50 and 60 years). They thought it would be easier for the researcher to conduct the study with younger participants, especially since it was related to physical activity. While the researcher specifically asked for a wide range of aging individuals, service providers continued to contact younger individuals. The researcher also felt service providers did not want to bother oldest seniors because they needed quiet time or because they would not be helpful.

Second, the original intent of the study was to obtain barriers and needs of seniors with ID in physical activity. A barrier is a constraint that prevents individuals from being physically active while a need is "whatever it requires for health or comfort" (Green & Kreuter, 1991). Seniors as well as educators did not particularly distinguish between the two concepts and they were therefore combined.

Finally, the study was limited to individuals with mild to moderate ID to facilitate their answers of the questionnaire and participation in focus groups. Further research should examine barriers, needs, and preferences among seniors with severe and profound ID. In this case, greater use of informant ratings (Heller, Hsieh, & Rimmer, 2002) should be used as well as alternative investigation instruments (e.g., pictograms and pictures; Todd, 2007).

In the second study (e.g., on the organization of physical activity services), the main issue was related to the topic itself. Centers for people with ID wanted to complete the survey, but were unsure how they could complete it correctly as they were not specialized in physical activity. Senior citizens' centers and centers for health and leisure, especially the latter, wondered why they were contacted and stating that it was not their mission to work with individuals with ID. While some centers still decided to answer the survey, some others declined because of that reason.

Overall, physical activity intervention programs designed around the aging of seniors with ID should be implemented and assessed to assist them in grappling with the changes they experience and to facilitate that period of life. The impact that physical activity has on physical health should be measured. A greater understanding of physical activity, in the light of self-determination and quality of life for seniors with ID, is also important to promote inclusion. Further research with seniors from outside the health network is necessary. Researchers must go beyond the Readaptation Centers to assess physical activity. In fact, a number of seniors with ID remain unidentified by specialist services (Bigby & Balandin, 2004), but their voices are equally important and they need to be provided with services if required. Finally, higher realms in the public policies sector should recognize the aging of individuals with ID, as no specific service provision has been made to guide service providers. Bigby (2008) posits that "it is no longer tenable to argue that a lack of policy is the result of a lack of knowledge about the particular needs of ageing people with ID." It is particularly true in the field of active living and physical activity, where it is well-known that being active benefits all citizens and that no one should be denied that right because of poor policy development.

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Appendix A: English letter of consent for seniors with intellectual disability

June 27, 2007

McGill University Faculty of Education Department of Educational Psychology and Counselling 3700 McTavish Street Montreal, Quebec H3A 1Y2

Dear _____

My name is Marion Steff and I am a graduate student at McGill University who specializes in seniors and physical activity.

I would like you to participate in research on physical activity and adults aged 50 and older. This study is to evaluate your needs, barriers, and preferences in physical activity. If you are interested, you can give me your opinions and share your experience with me.

To assist in your decision about participating, the following details are provided:

- If you participate, you will complete a questionnaire about your health, physical activity, and how you are feeling. If you need help for the completion of the questionnaire, you can ask a staff member working with you.
- Your questionnaire will remain anonymous. This means that I will not know your name and I will keep everything you write to myself.
- A few weeks later, you will participate in a focus group. A focus group is a discussion you will have with me and other participants to share your opinions and experiences about physical activity and health. This discussion should be a quite enjoyable experience! *
- The focus group interview will be audio-taped. However, I will keep all the tapes secret and will not share your name with anybody. *
- At the end, you will receive a small item from the McGill bookstore and a certificate of participation as a souvenir of this experience.

It is important to understand that your participation is voluntary. You can decide to withdraw from the study at any time, for any reason. This research will respect your right to privacy. Your name, and the name and location of this Readaptation center, will be protected in any presentation or publication.

Thank you for your cooperation and your help! If you have any questions or need more information, you can talk to me now or ask the staff working you later. If there is still something unclear or if you have worries with respect to this study, you may contact me at XXX-XXX-XXXX.

Sincerely,

Marion Steff, McGill Doctoral Student I, *(write your name)* ______ agree to participate in the study conducted by Marion Steff. I understand the purpose of the research. I am aware that my participation is voluntary and that I can stop participating at any time for any reason. I am aware that the confidentiality of my identity will be ensured.

I consent to be audio-taped:

Yes

No*

Signature

Date

* If a participant only takes part in the first section of the study (e.g., answering the questionnaire), these segments will be deleted.

Appendix B: French letter of consent for seniors with intellectual disability

27 Juin 2007

Université McGill Faculté d'Éducation Département de Psychoéducation et Counselling 3700 Rue McTavish Montréal, Québec H3A 1Y2

Cher(e) _____

Mon nom est Marion Steff. Je suis une étudiante au doctorat à l'Université McGill et m'intéresse aux personnes âgées et l'activité physique.

Je voudrais vous inviter à participer à une étude sur l'activité physique et les personnes âgées de plus de 50 ans. Cette étude a pour but de comprendre vos besoins, préférences, et barrières en activité physique. Si vous êtes intéressé, vous pourriez me donner votre opinion et partager vos expériences avec moi.

Voici d'autres détails pour aider dans votre prise de décision :

- Si vous participez, vous aurez à compléter un questionnaire sur comment vous vous sentez au sujet de votre santé et de votre activité physique. Si vous avez besoin d'aide pour compléter ce questionnaire, vous pouvez demander à un intervenant qui travaille avec vous.
- Votre questionnaire va rester anonyme. Cela signifie que je ne saurai pas votre nom.
- Quelques semaines plus tard, vous participerez à un groupe de discussion. Ce sera une discussion que vous aurez avec moi et d'autres participants pour partager vos opinions et expériences au sujet de l'activité physique et de la santé. Cette discussion devrait une expérience très agréable!*
- Le groupe de discussion sera enregistré par cassette audio et par caméra. Dans tous les cas, je garderai tout les cassettes secrètes et ne partagerai pas votre nom avec quiconque.*
- A la fin, vous recevrez un petit souvenir de l'Université McGill et un certificat de participation, en souvenir de votre expérience dans cette étude.

Il est important de comprendre que votre participation est volontaire. Vous pourrez vous retirer de cette étude à n'importe quel moment, pour n'importe quelle raison. De plus, cette recherche respecte le droit à votre anonymat. Votre nom, le nom et la location du centre de Réadaptation seront protégés et changés en cas de publication ou de présentation.

Merci beaucoup pour votre coopération et votre aide précieuse. Si vous avez des questions ou si vous avez besoin d'éclaircissements, n'hésitez pas à me le demander maintenant ou à en parler un intervenant plus tard. Si vous avez toujours des interrogations, vous pouvez aussi me contacter au XXX-XXX-XXXX.

Marion Steff, Étudiante en doctorat Je, *(inscrivez votre nom)* ______, suis d'accord de participer à l'étude de Marion Steff. Je comprends le but de cette recherche. Je sais que ma participation est purement volontaire et que je peux arrêter de participer à n'importe quelle moment pour n'importe quelle raison. Je comprends que mon anonymat est préservé.

Je suis d'accord pour être enregistré(e) : Non* Oui

Signature

Date

* Si un/une participant(e) prend part seulement à la première partie de l'étude (e.g., répondre au questionnaire), ces sections seront supprimées .
Appendix C: English letter of consent for educators

McGill University Faculty of Education Department of Educational Psychology and Counselling 3700 McTavish Street Montreal, Quebec H3A 1Y2

Dear _____

I am Marion Steff, a Ph.D. student of Dr. Greg Reid from the Department of Kinesiology and Physical Education at McGill University. The purpose of this communiqué is to seek your permission to participate in my study, with the results to be used in my doctoral dissertation. I am conducting a research on the barriers, needs and preferences in physical activity among older adults with intellectual disability. I believe your opinion will complement the points of view from the seniors themselves.

To assist you in your decision to be involved in my study, the following details are provided:

- If you accept to participate, you will come once to McGill University as part of a focus group interview. A focus group interview is simply a discussion with several participants to share your opinions and experiences relative to seniors with intellectual disability.
- The focus group interview will be audio-taped. However, I will keep all tapes confidential and no person's identity will be shared with anyone.

It is important to understand that your participation is voluntary. You can decide to withdraw from the study at any time, for any reason. This research will respect your right to privacy. Your name, and the name and location of this Readaptation center, will be protected in any presentation or publication of these data.

Thank you for your cooperation and your help! Should you have any questions or concerns, please do not hesitate to contact me, at XXX-XXX-XXXX. If you agree to participate, please sign the form below and return it to me during the focus group interview.

Sincerely,

Marion Steff, McGill Doctoral Student June 27, 2007

I, ______ agree to participate in the focus group interview conducted by Marion Steff. I understand the purpose of the research. I am aware that my participation is voluntary and that I can stop participating at any time for any reason. I am aware that the confidentiality of my identity will be ensured.

Signature

Date

Appendix D: French letter of consent for educators

Université McGill 2007 Faculté d'Éducation Département de Psychologie Éducationnelle et Counseling 3700 Rue McTavish Montréal, Québec H3A 1Y2

Cher(e) _____

Mon nom est Marion Steff. Je suis une étudiante au doctorat sous la supervision du Dr Greg Reid, au département de Kinésiologie et Éducation Physique de l'Université McGill. Le but de cette lettre est d'obtenir votre permission pour participer à mon étude. Les résultats seront utilisés pour ma dissertation.

L'étude que je suis en train de mener s'intéresse aux barrières, besoins et préférences en activités physiques chez les personnes âgées avec une déficience intellectuelle. Je pense que votre opinion et savoir-faire viendront complémenter l'opinion des personnes âgées elles-mêmes.

Voici d'autres détails pour vous aider dans votre prise de décision pour participer à mon étude.

- Si vous acceptez de participer, je viendrai une fois seulement pour mener le groupe de discussion. Cette rencontre se fera sur votre lieu de travail pour vous déranger le moins possible.
- Le groupe de discussion sera enregistré par cassette audio. Cependant, je garderai toutes les cassettes confidentielles et toutes les identités resteront protégées.

Il est important de comprendre que votre participation est volontaire. Vous pourrez vous retirer de cette étude à n'importe quel moment, pour n'importe quelle raison. De plus, cette recherche respecte le droit à votre anonymat. Votre nom, le nom et la location du centre de Réadaptation seront protégés et changés en cas de publication ou de présentation de ces données.

Merci beaucoup pour votre coopération et votre aide précieuse. Si vous avez des questions ou si vous avez besoin d'éclaircissements, n'hésitez pas à me contacter au XXX-XXX. Si vous êtes d'accord pour participer, s'il vous plaît, signez le formulaire sur la page suivante et redonnez-le moi.

Marion Steff, Étudiante en doctorat 27 Juin

Je, ______, suis d'accord de participer à ce groupe de discussion. Je comprends le but de cette recherche. Je sais que ma participation est purement volontaire et que je peux arrêter de participer à n'importe quel moment pour n'importe quelle raison. Je comprends que mon anonymat est préservé.

Signature

Date

Appendix E: Questionnaire on Physical Activity of Seniors

Questionnaire on Physical Activity of Seniors

Educational and Counseling Psychology McGill University

Partici	pant's initials:	Facilitator's initials:	Date:
Dear p Thank health it. Ther hesitat going ready	participant, you for taking the time and how you are fee te is no right or wrong o te to ask a staff workin to stay a secret share to start!	e to answer this questionnaire ling. It is also about physical o answers. If you need help to o g with you. He or she will help d with McGill University. Now f	e. This questionnaire is about your activity and your opinion about answer a question, don't o you! All your responses are that you know all that, you are
GH1.	How old are you?		
GH2.	In general, would you say 1 Excellent or very good 2 Good 3 Fair 4 Poor	y your health is:	
GH3.	What do you do to be he	althy (to keep your body feeling go	od and not sick)?
GH4.	Do you get as much exer <i>question)</i> 3 Enough exercise	cise as you want or not enough? <i>(P</i> 1 Not enough	Please circle only one answer per 2 Neither or both
Ener have b	gy Fatigue Scale. 1 been with you during on).	hese questions are about ho <u>the past month</u> (<i>Please circ</i>	ow you feel and how things the only one answer per

EF1.	Do you feel worn out or do you	not feel worn out?	l worn out?		
	3 Feel worn out	1 Not feel worn out	2 Neither	4 Both	

EF2.	Do you have a lot of energy or do you have little energy?				
	3 Have a lot of energy	1 Have little energy	2 Neither	4 Both	
EF3.	Do you feel tired or do you not feel tired?				
	3 Feel tired	1 Not feel tired	2 Neither	4 Both	
EF4.	Do you have enough energy to do things you want to do?	the things you want or do you not ha	ave enough energy	to do	
	3 Enough energy	1 Not enough Energy	2 Neither	4 Both	

Pain Measures

How much does it hurt when you: (Please circle only one answer per question)

PM1.	Walk inside		
	0 Doesn't hurt	1 Hurts a little	2 Hurts a lot
PM2.	Climb stairs		
	0 Doesn't hurt	1 Hurts a little	2 Hurts a lot
PM3.	Get in and out of chairs		
	0 Doesn't hurt	1 Hurts a little	2 Hurts a lot
PM4.	Wash all the parts of your body		
	0 Doesn't hurt	1 Hurts a little	2 Hurts a lot
PM5.	Put on pants		
	0 Doesn't hurt	1 Hurts a little	2 Hurts a lot
PM6.	Put on a shirt		
	0 Doesn't hurt	1 Hurts a little	2 Hurts a lot

Exercise and Activity Inventory

- EP1. Do you <u>presently</u> exercise? 1 Yes 0 No
- EP2. If you said yes to the previous question, can you tell us what type of exercises do you do <u>now</u>?(Gardening, walking, etc.). If you say no to the previous question, go directly to the question EP4.

How often per	week do you exercise (presently)? For example, a little like less than a day, some
like one or two	b days a week, three to four days a week, or a lot like five days and more a week?
Do you <u>presei</u>	ntly play any sports?
1 Yes	0 No
If you said yes	s to the previous question, can you tell us what type of sports do you play presently
(Tennis, joggi	ng, golfing, etc). If you say no to the previous question, go directly to the question
EP6 and try to	answer it.
If vou don't do	o any sports or would like to start one, which one(s) would it be?
Are you <u>prese</u>	ntly in Special Olympics?
Are you <u>prese</u> 1 Yes	e ntly in Special Olympics? 0 No
Are you <u>prese</u> 1 Yes If yes, can you	e ntly in Special Olympics? 0 No 1 tell us for which sport(s)?
Are you prese 1 Yes If yes, can you	e ntly in Special Olympics? 0 No 1 tell us for which sport(s)?

Changes over time

SC1. Would you say that you **presently** exercise a lot like three times or more a week?

1 Yes, I exercise a lot

If yes, since how long do you exercise a lot (several months, several years, etc.)

0 No, I do not exercise a lot

9 I don't know

- SC1a. If you said "No, I do not exercise a lot" or if you said "I don't know" to the previous question, please tell us if you would you like to start exercising a lot? (If you said "Yes, I exercise a lot" to the previous question, go directly to the question BE1).
 - 1 Yes, I would like to start right away
 - 2 I would like to start in a few months
 - 3 I would never like to start
 - 9 I don't know
- SC1b. Did you ever exercise a lot when you were younger?
 - 1 Yes 0 No

If yes, why did you stop exercising?

Barriers to Exercise Scale (*Please circle only one answer per question*)

Administration / Organization:

BE1.	Do you think that exercise costs too much money or that it doesn't cost too much money?				
	3 It does	1 It doesn't	2 Neither	4 Both	
BE2.	Do you think that you de exercise with?	on't have anyone to do exercise with	you or that you do have s	someone to	
	3 Don't have	1 Do have	2 Neither	4 Both	
BE3.	Do you think that you do someone to show you he	To you think that you don't have anyone to show you how to exercise or that you do have omeone to show you how to exercise?			
	3 Don't have	1 Do have	2 Neither	4 Both	
Healt	h:				
BE4.	Do you think that you get too tired to exercise or that you do not get too tired to exercise?				
	3 Too tired	1 Not too tired	2 Neither	4 Both	
BE5.	Do you think that you get too old to exercise or that you do not get too old to exercise?				
	3 Too old	1 Not too old	2 Neither	4 Both	

BE6.	Do you think that your health keeps you from exercising or does not keep you from exercising?					
	3 Keep from exercising	1 Not keep from exercising	2 Neither	4 Both		
Know	ledge:					
BE7.	Do you think that it's hard to find a	a way of getting to an exercise prog	ram or it is not hard	to get to		
	an exercise program?					
	3 Hard	1 Not hard	2 Neither	4 Both		
BE8.	Do you think that exercise will no	t make you healthier or that it will n	nake you healthier?			
	3 Not healthier	1 Healthier	2 Neither	4 Both		
BE9.	Do you think that exercise will ma	ke you sick or that it will not make	you sick?			
	3 Sick	1 Not sick	2 Neither	4 Both		
BE10.	Do you think that you don't know	how to exercise or you do know ho	w to exercise?			
	3 Don't know how	1 Know how	2 Neither	4 Both		
BE11.	Do you think that you don't know where to exercise or you do know where to exercise?					
	3 Don't know where	1 Know where	2 Neither	4 Both		
BE14.	Do you think that the equipment (like machines/weights) is hard for you to use or not hard for you					
	to use?					
	3 Hard	1 Not hard	2 Neither	4 Both		
BE15.	Do you think that you would have	a hard time using a fitness center (h	nealth club, YMCA	, park		
	district) or not have a hard time using a fitness center?					
	3 Have hard time	1 You can	2 Neither	4 Both		
Psych	nlogv•					
DE16	Do you think that you feel like eve	proising or you don't feel like everei	sing?			
DEIU.	3 Feel like	1 Don't feel like	2 Neither	1 Both		
	5 Teel like	i Don't ieer like	2 Neither	4 Dom		
BE17.	Do you think that exercising is too	hard or that it is not too hard?				
	3 Hard	1 Not hard	2 Neither	4 Both		

BE18. Do you think that you don't have enough time to exercise or that you do have enough time to exercise?

	3 Not enough	1 Enough	2 Neither	4 Both
BE19.	Do you think that exercise is boring	g or not boring?		
	3 Boring	1 Not boring	2 Neither	4 Both
BE20.	Do you think that you are too lazy to exercise or that you are not too lazy to exercise?			
	3 Too lazy	1 Not too lazy	2 Neither	4 Both
BE21.	Do you think that people might ma	ke fun of you or do you not worry t	hat people might n	nake fun
	of you when you exercise?			
	3 Worry	1 Not worry	2 Neither	4 Both

Needs. What would you need to start or continue exercising? (Please circle only one

answer per question).

N1.	I would need a better health to exercise					
	0 No	9 Don't know	1 Yes			
N2.	I would need more end	ergy to exercise				
	0 No	9 Don't know	1 Yes			
N3.	I would need less pain	in my body to exercise				
	0 No	9 Don't know	1 Yes			
N4.	I would need to be you	I would need to be younger to exercise				
	0 No	9 Don't know	1 Yes			
N5.	I would like to like my body better to exercise					
	No	9 Don't know	1 Yes			
N6.	I would like to be better looking to exercise					
	No	9 Don't know	1 Yes			
N7.	I would need friends to exercise with					
	0 No	9 Don't know	1 Yes			
N8.	I would need to know	I would need to know how to exercise				
	0 No	9 Don't know	1 Yes			

Thank you for taking the time to answer this questionnaire! We appreciate you telling McGill University how you feel about health and physical activity. Appendix F: Questionnaire on Physical Activity of Seniors (in French)

Questionnaire sur l'activité physique des aînés

	Psychologie Éducationnelle et Counseli Université McGill	ng	
Initiales du participant:	Initiales de l'animateur:	Date:	
Cher/Chère participant,			

Merci de prendre le temps de répondre à ce questionnaire. Ce questionnaire porte sur votre santé et sur comment vous vous sentez. Il concerne aussi l'activité physique et votre opinion à ce sujet. Il n'y a pas de bonnes ou de mauvaises réponses. Si vous avez besoin d'aide avec l'une des questions, n'hésitez surtout pas à demander au personnel travaillant avec vous. Ils sont là pour vous aider ! Toutes vos réponses resteront secrètes et ne seront partagées qu'avec l'Université McGill.

GH1. Quel âge avez-vous ? _____

GH2. Selon vous, votre santé est généralement:

- 1 Excellente ou très bonne
- 2 Bonne
- 3 Acceptable
- 4 Mauvaise
- GH3. Que faites-vous pour rester en bonne santé (pour que votre corps soit en bonne santé et non malade) ?

GH4. Est-ce que vous faîtes autant d'exercice que vous le voulez ou pas assez ? (SVP, encerclez une seule réponse par question)
3 Assez d'exercice 1 Pas assez 2 Aucune de ces réponses 4 Les 2 réponses

Échelle d'énergie et de fatigue. Ces questions portent sur comment vous vous

sentiez et de comment ça allait pour vous au cours de ce dernier mois (SVP,

encerclez une seule réponse par question).

EF1.Est-ce que vous vous sentiez épuisé ou pas épuisé?3 Épuisé1 Pas épuisé2 Aucune de ces réponses4 Les 2 réponses

EF2.	2. Est-ce que vous aviez beaucoup d'énergie ou peu d'énergie?				
	3 Beaucoup d'énergie	1 Peu d'énergie	2 Aucune de ces réponses	4 Les 2 réponses	
EF3.	EF3. Est-ce que vous vous sentiez fatigué ou pas fatigué?				
	3 Fatigué	1 Pas fatigué	2 Aucune de ces réponses	4 Les 2 réponses	
EF4.	Est-ce que vous aviez assez d'énergie pour faire les choses que vous vouliez faire ou pas assez				
	d'énergie pour faire les ch	noses que vous voi	iliez faire?		
	3 Assez d'énergie	1 Pas assez d'én	ergie 2 Aucune de ces réponses	4 Les 2 réponses	

Évaluation de la douleur

Est-ce que ça vous fait mal quand: (SVP, encerclez une seule réponse par question)

2 Fait très mal
2 Fait très mal
5
2 Fait très mal

Inventaire sur l'exercice et l'activité

EP1.Est-ce que vous faîtes présentementde l'exercice?1 Oui0 Non

	t (Jardinage, marche, etc.). Si vous avez répondu non à la dernière question, allez
	a la question EP4.
Combien de d'une fois p	e fois par semaine faîtes-vous de l'exercice (présentement) ? Par exemple, moin par semaine, une ou deux fois par semaine, entre trois et quatre fois par semaine o
Est-ce que v	ous pratiquez présentement un sport ?
l Oui	0 Non
Si vous ave faîtes <u>actue</u> allez directe	z répondu oui à la dernière question, pouvez-vous nous dire quel genre de sport v <u>llement</u> (Tennis, jogging, golf, etc.) ? Si vous avez répondu non à la dernière que ement à la question EP6.
Si vous ne f	aîtes pas de sport ou si vous voulez commencer à en faire, lequel ou lesquels est
que ça serai	t?
que ça serai	<pre>t? /ous faîtes partie <u>présentement</u> des Jeux Olympiques Spéciaux?</pre>
que ça serai	rous faîtes partie <u>présentement</u> des Jeux Olympiques Spéciaux? 0 Non

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Changements sur une période de temps

SC1. Selon vous, est-ce que vous faîtes **présentement** beaucoup d'exercice comme par exemple trois fois ou plus par semaine?

1 Oui, je fais beaucoup d'exercice.

Si oui, depuis quand faîtes-vous beaucoup d'exercice ? (depuis plusieurs mois, depuis plusieurs années, etc.)

0 Non, je ne fais pas beaucoup d'exercice 9 Je ne sais pas

SC1a. Si votre réponse à la dernière question était « Non, je ne pratique pas beaucoup d'exercice » ou « Je ne sais pas », veuillez nous dire si vous aimerez faire beaucoup d'exercice. (Si votre réponse à la dernière question était « Oui, je fais beaucoup d'exercice », allez directement à la question BE1).

1 Oui, j'aimerais commencer tout de suite

2 J'aimerais commencer d'ici quelques mois

3 Non, je ne voudrais jamais commencer

9 Je ne sais pas

SC1b. Quand vous étiez plus jeune, est-ce que vous faisiez beaucoup d'exercice?

- 0 Non
- 1. Oui Lesquels ?

Si oui, pourquoi aviez-vous arrêté de faire de l'exercice?

Barrières à l'exercice (SVP, encerclez une seule réponse par question)

Administration / Organisation:

BE1.	Selon vous, est-ce que l'exercice coûte trop cher ou ne coûte pas trop cher ?				
	3 Oui, trop cher	1 Non, pas trop cher	2 Aucune de ces réponses	4 Les 2 réponses	
BE2.	Selon vous, est-ce que vous ne connaissez personne avec qui faire de l'exercice ou est-ce que vous				
	connaissez quelqu'un avec qui faire de l'exercice?				

3 Je ne connais personne 1 Je connais quelqu'un 2 Aucune de ces réponses 4 Les 2 réponses

BE3. Selon vous, est-ce que vous ne connaissez personne qui pourrait vous montrer comment faire de l'exercice ou est-ce que vous connaissez quelqu'un qui pourrait vous montrer comment faire de l'exercice?

3 Je ne connais personne 1 Je connais quelqu'un 2 Aucune de ces réponses 4 Les 2 réponses

Santé:

BE4. Selon vous, est-ce que vous devenez trop fatigué pour faire de l'exercice ou est-ce que vous ne devenez pas trop fatigué pour faire de l'exercice?
3 Trop fatigué 1 Pas trop fatigué 2 Aucune de ces réponses 4 Les 2 réponses

BE5. Selon-vous, est-ce que vous devenez trop âgé pour faire de l'exercice ou est-ce que vous ne devenez pas trop âgé ?
3 Trop âgé 1 Pas trop âgé 2 Aucune de ces réponses 4 Les 2 réponses

BE6. Selon vous, est-ce que votre santé vous empêche de faire de l'exercice ou est-ce que votre santé ne vous empêche pas de faire de l'exercice ?
3 Oui, ça m'empêche 1 Non, ça ne m'empêche pas 2 Aucune de ces réponses 4 Les 2 réponses

Connaissances:

BE7.	Selon vous, est-ce qu'il est difficile d'avoir accès à un programme d'exercice ou est-ce qu'il n'est			
	pas difficile d'avoir accès à un programme d'exercice?			
	3 Difficile	1 Pas difficile	2 Aucune de ces réponses	4 Les 2 réponses

BE8. Selon vous, est-ce que votre santé s'améliorera en faisant de l'exercice ou est-ce que votre santé ne s'améliorera pas?
3 Ma santé ne s'améliorera pas
1 Ma santé s'améliorera

2 Aucune de ces réponses 4 Les 2 réponses

- BE9. Selon vous, est-ce que vous deviendrez malade à cause de l'exercice ou est-ce que vous ne deviendrez pas malade à cause de l'exercice?
 3 Malade 1 Pas malade 2 Aucune de ces réponses 4 Les 2 réponses
- BE10. Selon vous, est-ce que vous savez comment faire de l'exercice ou est-ce que vous ne savez pas comment faire de l'exercice?
 3 Je ne sais pas comment 1 Je sais comment 2 Aucune de ces réponses 4 Les 2 réponses

BE14. Selon vous, est-ce que l'équipement pour faire de l'exercice (tel que les machines, les poids) est difficile à utiliser ou n'est pas difficile à utiliser?
3 Difficile 1 Pas difficile 2 Aucune de ces réponses 4 Les 2 réponses

BE15. Selon vous, est-ce que vous auriez de la difficulté à utiliser un centre sportif (club de santé, YMCA, parc) ou est-ce que vous n'auriez pas de difficulté?
3 J'aurais de la difficulté
1 Je n'aurais pas de difficulté
2 Aucune de ces réponses
4 Les 2 réponses

Psychologie:

BE16.	Selon vous, est-ce que vo	us avez envie de faire	de l'exercice ou est-ce que	vous n'avez pas envie
	de faire de l'exercice?			
	3 J'ai envie	1 Je n'ai pas envie	2 Aucune de ces réponses	4 Les 2 réponses

BE17. Selon vous, est-ce qu'il est difficile de faire de l'exercice ou est-ce qu'il n'est pas difficile de faire de l'exercice?

3 Difficile 1 Pas difficile 2 Aucune de ces réponses 4 Les 2 réponses

- BE18. Selon vous, est-ce que vous n'avez pas assez de temps pour faire de l'exercice ou est-ce que vous avez assez de temps ?
 3 Pas assez 1 Assez 2 Aucune de ces réponses 4 Les 2 réponses
- BE19. Selon vous, est-ce que vous trouvez-vous que faire de l'exercice est ennuyant ou ce n'est pas ennuyant?
 2. Ennuyant de la construction de la

3 Ennuyant 1 Pas ennuyant 2 Aucune de ces réponses 4 Les 2 réponses

- BE20.Selon vous, êtes-vous trop paresseux pour faire de l'exercice ou vous n'êtes pas paresseux ?3 Trop paresseux1 Pas paresseux2 Aucune de ces réponses4 Les 2 réponses
- BE21. Est-ce que vous avez peur que l'on se moque de vous ou est-ce que vous n'avez pas peur que l'on se moque de vous quand vous faîtes de l'exercice?

Besoins. De quoi avez-vous besoin pour commencer ou pour continuer à faire de

l'exercice? (SVP, encerclez une seule réponse par question).

N1.	J'aurais besoin d'être en meilleur santé pour faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		
N2.	J'aurais besoin de plu	J'aurais besoin de plus d'énergie pour faire de l'exercice			
	0 Non	9 Je ne sais pas	1 Oui		
N3.	J'aurais besoin d'avoir moins de douleurs pour faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		
N4.	J'aurais besoin d'être plus jeune pour faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		
N5.	J'aurais besoin d'être plus à l'aise avec mon corps pour faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		
N6.	Je voudrais être plus beau ou plus belle pour faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		
N7.	J'aurais besoin d'amis avec qui faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		
N9.	J'aurais besoin de savoir comment faire de l'exercice				
	0 Non	9 Je ne sais pas	1 Oui		

C'est fini ! Les chercheurs de l'Université McGill vous remercie d'avoir pris le temps de répondre à ces questions !

4 Les 2 réponses

Appendix G: Physical activity survey on seniors with intellectual disability

Dear participant,

Thank you for taking the time to fill out this survey! Your feedback will give me invaluable information about the physical activity involvement of seniors with lifelong intellectual disability, on the island of Montreal. The results will be used for my doctoral dissertation.

As I mentioned on the phone, this research will respect your rights to privacy. Your name, and the name and location of the center, will be protected in any presentation or publication of these data.

Your participation is strictly voluntary. You may refuse to participate or discontinue participation at any time, for any reason. Should you have any questions or concerns about the survey or your rights, please do not hesitate to contact me, at 514-985-9673 or my supervisor, Dr Greg Reid, at the Department of Kinesiology and Physical Education at McGill University.

Throughout the questionnaire, I will be referring to "physical activity". By physical activity, I mean "all leisure and non-leisure body movement produced by the skeletal muscles and resulting in an increase in energy expenditure" (Public Health Agency of Canada, 2003, ¶ 2). It includes sports such as, for instance, swimming or dancing. It consists also of exercises such as walking, gardening, going up and down the stairs, etc. Therefore, physical activity can be individual or in group, in supervised or unsupervised settings (World Health Organization, 1997).

It will take you approximately 20 minutes to complete the survey. Please try to answer all the questions as best you can by simply circled the option that best represents your answer. For some questions, you can write a brief answer in the space provided below. Keep in mind that all answers will remain confidential and known only to the researcher.

If you are ready to participate and agree with the above, simply sign the form below.

Thank you for your time and assistance.

Sincerely,

Marion Steff, McGill Doctoral Student I, ______ agree to participate in the survey conducted by Marion Steff. I understand the purpose of the research. I am aware that my participation is voluntary and that I can stop participating at any time for any reason. I am aware that the confidentiality of my identity and the one of my center will be ensured.

Signature

Date

Physical activity survey on seniors with intellectual disability

1. Name of organization/association?

2. Which of the following best describes this organization/association? Senior citizens centre Centre for health/leisure Centre for people with intellectual disability Other (please specify)

3. Name of person completing questionnaire, responsibilities, and phone/fax/email:

4. Postal code of this centre (*Enter primary postal code if this centre is located at different places*):

5. What are the <u>aims and outcomes</u> of this centre? (please send by email a copy of relevant documentation if available to the researcher)

6. How many <u>days per week</u> does this centre usually operate?

7. What are <u>its opening hours</u>?

8. Approximately <u>how many users</u> use this centre in a typical week?

9. What is the <u>age range</u> of the users using this centre?

10. What <u>physical activity does</u> this centre provide?

11. What <u>facilities/equipment</u> does this centre provide for exercising?

12. Does this centre <u>aim to provide</u> physical activity for <u>any particular groups of</u> <u>people in the community</u>, such as the frail seniors or a specific ethnic group?

No If yes, please specify

13. Does your centre have users of 50 years of age and older?

Yes If no, go directly to the question 27.

14. Do any of these people aged 50 years and older <u>have an intellectual disability</u> <u>unrelated to aging</u> (*By intellectual disability unrelated to aging, we mean a disability acquired in childhood rather than a disability associated with aging*)?

Yes If no, go directly to the question 27

15. What type of intellectual disabilities unrelated to aging do these seniors have?

Autism spectrum disorder Down syndrome Fetal alcohol syndrome Fragile X Prader-Willi I don't know Other (please specify)

16. Do these seniors with an intellectual disability have <u>other associated conditions</u> <u>unrelated to aging?</u>

No Paraplegia Quadriplegia Cerebral palsy Blindness Vision impairment Hearing disability Speech impairment Deaf-blind Chronic illness (diabetes, hypertension, etc.) Brain injury acquired after birth from for instance, a car accident or diving I don't know Other (please specify)

17. Approximately <u>how many seniors with an intellectual disability unrelated to</u> <u>aging</u> use this centre?

18. What is the <u>age range of seniors with an intellectual disability</u> unrelated to aging who use this centre?

19. How did the seniors with an intellectual disability unrelated to ageing <u>find out</u> about this centre?

Family or friends Caregivers Professional guidance Advertisement Other (please specify)

20. In which <u>physical activity</u> do the seniors with an intellectual disability unrelated to aging participate?

21. What are the <u>qualifications of the staff members</u> working with these users, during physical activity?

22. <u>How many days per week</u> do these seniors with an intellectual disability unrelated to aging participate in the physical activity the centre offers? (For instance: Less than weekly, 1 day per week, 2 days per week, 3 days per week, 4 days per week, 5 days per week or more.) 23. <u>How many hours per day</u> do these seniors with an intellectual disability unrelated to aging participate in the physical activities the centre offers? (For instance: An average of: 1-2 hours per day, 3-4 hours per day, or 5-6 or more hours per day.)

24. Do these seniors with an intellectual disability unrelated to aging have <u>any</u> <u>problems</u> in participating in physical activity (difficulty understanding, being included, socializing, having fun, making progress, etc.)?

25. Does this centre provide <u>any supports (e.g., guidance, monitoring, direction, etc.)</u> to these seniors with an intellectual disability unrelated to aging in order to facilitate their participation in physical activity?

26. Does this centre require <u>additional supports or resources (staff, transport, facilities, etc)</u> to assist seniors with an intellectual disability unrelated to aging to participate in physical activity?

27. Has this centre developed <u>any policies and procedures regarding access and</u> <u>participation</u> in physical activity for seniors with an intellectual disability unrelated to aging?

28. Has this centre developed <u>any particular initiatives to support access and</u> <u>participation</u> in physical activity for seniors with an intellectual disability unrelated to aging?

29. Has this centre had <u>any contact with another organization regarding access and</u> <u>participation</u> in physical activity for seniors with an intellectual disability unrelated to aging?

30. Do the participants in this centre have <u>a written individual plan addressing their</u> <u>individual needs</u> concerning the physical activity they are involved in?

If <u>"no"</u>, can you explain if there are <u>specific reasons why this centre does not use a</u> <u>written individual plan?</u>

31. Finally, are there <u>any other issues</u> in your centre, concerning access and participation in physical activity for seniors with an intellectual disability unrelated to aging, that you would like to comment on?

To contact the researcher or to place documents at her disposal, please send an email to Marion Steff: <u>marion.steff@mcgill.ca</u>

You can also send documents at the following address:

Marion Steff McGill University Faculty of Education Department of Kinesiology and Physical Education 475 Pine Avenue West Montreal, Qc, H2W 1S4

THIS IS THE END OF THE QUESTIONNAIRE! THANK YOU FOR YOUR ASSISTANCE AND TIME!

Appendix H: Physical activity survey on seniors with intellectual disability (in French)

Cher participant

Merci de prendre le temps de remplir ce sondage! Vos réponses me donneront des informations considérables sur l'activité physique des personnes âgées avec une déficience intellectuelle acquise à la naissance et cela, sur l'île de Montréal. Les résultats seront utilisés pour ma thèse de doctorat.

Comme je vous l'ai mentionné au téléphone, cette recherche respecte votre droit à l'anonymat. Votre nom, le nom et la location du centre pour lequel vous travaillez seront protégés en cas de présentation ou de publication de ces données.

Votre participation est purement volontaire. Vous pouvez arrêter de participer à tout moment et pour n'importe quelle raison. Si vous avez des questions concernant vos droits ou si vous avez des inquiétudes, n'hésitez pas à me contacter au 514-985-9673. Vous pouvez aussi contacter mon directeur de thèse, Dr Greg Reid, au département de Kinésiologie et d'Éducation Physique à l'Université McGill.

À travers le questionnaire, j'utiliserai le terme « activité physique ». Par cela, j'entends « tout mouvement du corps, dans le cadre des loisirs ou non, produit par les muscles squelettiques et entraînant un accroissement de la dépense énergétique » (Agence de Sante Publique du Canada, 2003, ¶ 2). Cela inclut les sports tels que, par exemple, la natation ou la dance. Cela consiste aussi à des exercices comme se promener, faire son jardin, monter et descendre les escaliers, etc. Ainsi, l'activité physique peut être individuelle ou en groupe, supervisée ou non supervisée (Organisation Mondiale de la Santé, 1997).

Il vous faudra environ 20 minutes pour compléter ce questionnaire. Veuillez répondre à toutes les questions du mieux que possible en encerclant l'option qui correspond le mieux à votre réponse. À certains endroits, répondez brièvement dans l'espace prévu à cet effet. N'oubliez pas que vos réponses sont confidentielles et ne seront connues que par la chercheure.

Si vous êtes prêt à participer et êtes d'accord avec ce qui vient d'être mentionné, signez s'il vous plaît le formulaire de consentement ci-dessous. Vous pouvez commencer le sondage !

Merci beaucoup pour votre collaboration et votre temps,

Sincèrement,

Marion Steff, Étudiante au doctorat Je, _____, suis d'accord de participer à ce sondage. Je comprends le but de cette recherche. Je sais que ma participation est purement volontaire et que je peux arrêter de participer à n'importe quel moment pour n'importe quelle raison. Je comprends que mon anonymat et celui de centre est préservé.

Signature

Date

Sondage sur l'Activité Physique des Personnes Âgées ayant une Déficience Intellectuelle

1. Nom de l'organisation ou association?

2. Laquelle des affirmations suivantes décrit le mieux l'organisation ou association ?

Centre pour personnes âgées Centre de santé et de loisirs Centre pour personnes ayant une déficience intellectuelle Autre (Veuillez préciser)

3. Nom de la personne qui remplit le questionnaire, ses responsabilités, son numéro de téléphone et de télécopieur, et son adresse de courriel :

4. Code postal du centre (*Entrez le code postal du siège social si le centre a plusieurs établissements*) :

5. Quels sont <u>les objectifs</u> de ce centre ainsi que <u>les résultats</u> de ses activités ? *(Si possible, veuillez envoyer une copie des documents pertinents à la chercheure.)*

6. Pendant combien de jours par semaine le centre est-il ouvert ?

7. Quelles sont ses <u>heures d'ouverture</u> ?

8. En moyenne, <u>combien d'usagers</u> utilisent ses services par semaine ?

9. Quelle est la moyenne d'âge des usagers du centre ?

10. Quelles activités physiques le centre offre-t-il ?

11. En matière d'activités physiques, quelles <u>infrastructures et quel équipement</u> le centre possède-t-il?

12. Ce centre offre-t-il ses activités physiques à <u>des groupes particuliers</u> comme les personnes âgées fragiles ou des groupes ethniques ?

Non

Si la réponse est oui, veuillez préciser.

13. Votre centre pour personnes âgées, centre de santé et de loisirs, ou centre pour personnes ayant une déficience intellectuelle a-t-il des <u>usagers de 50 ans ou plus</u>?

Oui

Si la réponse est non, allez directement à la question 27.

14. Parmi vos usagers de 50 ans et plus, est-ce qu'il y en qui <u>ont une déficience</u> <u>intellectuelle</u> non associée au vieillissement (*La déficience intellectuelle non associée au vieillissement est celle qui survient pendant l'enfance et n'est pas le résultat du processus de vieillissement*) ?

Oui

Si la réponse est non, allez directement à la question 27.

15. Quelle <u>déficience intellectuelle</u> non associée au vieillissement ces personnes ontelles ?

Autisme Syndrome de Down Syndrome d'alcoolisme fœtal Syndrome du X fragile Syndrome de Prader -Willi Je ne sais pas Autre (Veuillez préciser)

16. Ces personnes âgées ayant une déficience intellectuelle ont-elles <u>d'autres</u> <u>problèmes non associés au vieillissement</u> ?

Non Paraplégie Quadriplégie Paralysie cérébrale Cécité Déficience visuelle Déficience auditive Trouble de la parole et du langage Surdi-cécité Maladies chroniques (diabète, hypertension, etc.) Lésions cérébrales subies après la naissance (par exemple, comme dans un accident de voiture ou de plongeon) Je ne sais pas Autre (Veuillez préciser)

17. À peu près <u>combien de personnes âgées ayant une déficience intellectuelle non</u> <u>associée au vieillissement</u> utilisent ce centre ?

18. Quelle est la <u>plage d'âge des personnes âgées avant une déficience intellectuelle</u> non associée au vieillissement qui utilisent ce centre?

19. Comment ces personnes âgées ayant une déficience intellectuelle non associée au vieillissement <u>ont-elles entendu</u> parler de ce centre ?

Famille ou amis Intervenant(e)s ou soignant(e)s Conseils par des professionnels Publicité Autre (Veuillez préciser)

20. À quelles <u>activités physiques</u> les personnes âgées ayant une déficience intellectuelle non associée au vieillissement participent-elles?

21. Quels sont <u>les qualifications</u> des membres du personnel en contact direct avec ces usagers, en activité physique?

22. C<u>ombien de jours par semaine</u> ces personnes âgées ayant une déficience intellectuelle non associée au vieillissement participent-elles aux activités physiques du centre? (*Par exemple: moins d'un jour par semaine, un jour par semaine, deux jours, trois, quatre, cinq jours ou plus.*) 23. C<u>ombien d'heures par jour</u> ces personnes âgées ayant une déficience intellectuelle non associée au vieillissement participent-elles aux activités physiques du centre ? (*Par exemple: une moyenne de 1 à 2 heures par jour, de 3 à 4, de 5 à 6, ou plus de 6 heures par jour.*)

24. Ces personnes âgées ayant une déficience intellectuelle non associée au vieillissement ont-elles <u>des problèmes</u> à participer aux activités physiques du centre (*Par exemple: des difficultés à comprendre, à se faire inclure, à socialiser, à s'amuser, à faire des progrès, etc.*)?

25. Ce centre offre-t-il de <u>l'aide (des conseils, de l'assistance, de la direction, etc.)</u> aux personnes âgées ayant une déficience intellectuelle non associée au vieillissement pour qu'elles puissent participer aux activités physiques?

26. Ce centre a-t-il besoin d'<u>aide ou de ressources supplémentaires (personnel, moyens de transport, équipement, etc.)</u> pour soutenir les personnes âgées ayant une déficience intellectuelle non associée au vieillissement à participer aux activités physiques?

27. Ce centre a-t-il défini des <u>politiques ou un protocole régissant l'accès et la</u> <u>participation</u> à l'activité physique des personnes âgées ayant une déficience intellectuelle non associée au vieillissement?

28. Ce centre a-t-il pris des <u>initiatives pour faciliter l'accès et la participation</u> à l'activité physique des personnes âgées ayant une déficience intellectuelle non associée au vieillissement?

29. Ce centre est-t-il en contact avec <u>d'autres organisations</u> quant à l'accès et la participation<u>à</u> l'activité physique par des personnes âgées ayant une déficience intellectuelle non associée au vieillissement?

30. Les participants aux activités de ce centre ont-ils <u>un plan individualisé écrit qui</u> <u>reflète leurs besoins spécifiques</u> quant aux activités physiques auxquels ils participent ?

En cas de réponse « négative », pouvez-vous expliquer les raisons pour lesquelles le centre n'a pas de plan individualisé écrit ?

31. Pour terminer, avez-vous <u>d'autres questions</u>, dont vous voudriez parler, concernant l'accès et la participation à l'activité physique des personnes âgées ayant une déficience intellectuelle non associée au vieillissement?

Pour contacter la chercheure ou mettre des documents à sa disposition, veuillez envoyer un courriel à Marion Steff : <u>marion.steff@mcgill.ca</u>

Vous pouvez aussi envoyer vos documents à:

Marion Steff Université McGill Faculté d'Éducation Département de Kinésiologie et d'Éducation Physique 475 Av. des Pins Ouest Montréal, Qc, H2W 1S4

C'EST LA FIN DU QUESTIONNAIRE! MERCI BEAUCOUP POUR VOTRE PARTICIPATION!

Appendix I: Ethics Forms

🐯 McGill

Faculty of Education – Ethics Review Board McGill University Faculty of Education 3700 McTavish; Room 230 Montreal H3A 1Y2 Tel: (514) 398-7039 Fax: (514) 398-1527 Ethics website: www.mcgill.ca/rgo/ethics/human

Faculty of Education – Review Ethics Board Certificate of Ethical Acceptability of Research Involving Humans

Full

REB File #: 707-0906

Project Title : Perceived barriers, needs and preferences in physical activity among seniors with intellectual disability

Applicant's Name: Marion Steff Department: ECP

Status: PhD student Supervisor's Name: Greg Reid

Granting Agency and Title (if applicable): n/a

Type of Review: Expedited ✓

This project was reviewed by: Starke-Meyerring/Stapley

Approved by 31.2006 10

Signature/Date Robert Bracewell, Ph.D. Chair, Education Ethics Review Board

\$31/07 **Approval Period**

All research involving human subjects requires review on an annual basis. An Annual Report/Request for Renewal form should be submitted at least one month before the above expiry date. If a project has been completed or terminated for any reason before the expiry date, a Final Report form must be submitted. Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received. This project was reviewed and approved in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Subjects and with the Tri-Council Policy Statement on the Ethical Conduct for Research Involving Human Subjects.

10/30/06

McGill

Faculty of Education – Ethics Review Board McGill University Faculty of Education 3700 McTavish; Room 230 Montreal H3A 1Y2 Tel: (514) 398-7039 Fax: (514) 398-1527 Ethics website: www.mcgill.ca/rgo/ethics/human

Faculty of Education – Review Ethics Board Certificate of Ethical Acceptability of Research Involving Humans

REB File #: 704-0906

Project Title : Utilization, organization and delivery of physical activity programs for seniors with intellectual disability

Applicant's Name: Marion Steff Department: KPE

Status: PhD student Supervisor's Name: Greg Reid

Granting Agency and Title (if applicable): n/a

Type of Review: Expedited ✓ Full

This project was reviewed by: Hoover/Derevensky

Approved by Oct. 20, 2006 hell

Signature/Date Robert Bracewell, Ph.D. Chair, Education Ethics Review Board

Approval Period: 10/20/06 to 00/20/07

All research involving human subjects requires review on an annual basis. An Annual Report/Request for Renewal form should be submitted at least one month before the above expiry date. If a project has been completed or terminated for any reason before the expiry date, a Final Report form must be submitted. Should any modification or other unanticipated development occur before the next required review, the REB must be informed and any modification can't be initiated until approval is received. This project was reviewed and approved in accordance with the requirements of the McGill University Policy on the Ethical Conduct of Research Involving Human Subjects and with the Tri-Council Policy Statement on the Ethical Conduct for Research Involving Human Subjects.

10/20/06



December 21st, 2006

Mrs. Marion Steff Educational and Counselling Psychology (Special Populations) McGill University 3700 McTavish Montreal, Quebec H3A 1Y2

Subject: Utilization, Organization and Delivery of Physical Activity Programs for Seniors with Intellectual Disability and Perceived Barriers, Needs and Preferences in Physical Activity among Seniors with Intellectual Disability

Dear Mrs. Steff,

We acknowledge receipt of your research proposals as mentioned above.

Your research proposals have been approved and we accept that you conduct your research at our two establishments, i.e. Centre de réadaptation Lisette-Dupras and West Montreal Readaptation Centre.

Please note that the respondent at Information, Technology and Research Department will be Renée Proulx, who can be reached at (514) 364-2282, Ext. 2395 or by e-mail at RProulx.CRLD@ssss.gouv.qc.ca.

Wishing you success in your research, we remain

Yours truly,

rancine Wathier for

Dr. Katherine Moxness Director of Professional Services

KM:fw

cc Dr. Nathalie Girouard, Clinical Consultant for Programmation, DSP Dr. Céline Mercier, Director, DTIR

8000, Notre-Dame, Lachine (Québec) H8R 1H2

tél. : (514) 363-3025 téléc. : (514) 363-5855



Montréal, le 18 mai 2007

Madame Marion Steff Educational and Counselling Psychology (Special Populations) McGill University 3700 McTavish Montreal, Quebec H3A 1Y6

Objet :

Évaluation de la convenance institutionnelle du projet « Perceived Barriers, Needs and Preferences in Physical Activity among Seniors with Intellectual Disability »

Madame Marion Steff,

Après analyse du projet en titre, il me fait plaisir de vous confirmer que votre projet a été approuvé pour ce qui est de la convenance institutionnelle au sein du Centre de réadaptation Gabrielle-Major.

Notre établissement reconnaît que votre projet respecte les règles éthiques et qu'il est acceptable du point de vue de la pertinence et de la qualité scientifique.

Mme Daphné Morin, agente de planification, de programmation et de recherche a été désignée comme «personne contact» afin de faciliter votre collecte de données. Vous pouvez la joindre au numéro suivant (514) 259-2245 #246 ou par courriel dmorin.crld@ssss.gouv.qc.ca.

En retour, nous apprécierions recevoir une copie des résultats de votre projet de recherche lorsque celui-ci sera complété.

Au plaisir d'accueillir votre projet.

atherne Moxuen

Katherine Moxness, PhD Directrice des Services professionnels Centres de réadaptation Gabrielle-Major, Lisette-Dupras et de l'Ouest de Montréal

cc. Céline Mercier, directrice de la recherche et de l'enseignement Lyse Beaudet, directrice des services aux usagers Daphné Morin, agente de planification, de programmation et de recherche

6455, rue Jean-Talon Est, 6e étage St-Léonard (Québec) H1S 3E8 • Téléphone (514) 259-2245 • Télécopieur : (514) 259-59-06