The Facilitators and Barriers of Physical Activity Engagement For Youth and Young Adults With Childhood Onset Physical Disabilities

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Graduate Program in Health and Rehabilitation Sciences
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Abstract

This thesis explored the motivators, experiences and challenges of youth and young adults (hereafter referred to as youth) with childhood-onset physical disabilities with respect to engaging in and sustaining physical activity. A focus group was conducted with youth \( n = 6 \) who were current or past clients of recreational programs offered through a pediatric rehabilitation centre. Youth also completed a Personalized Exercise Questionnaire. A separate focus group was conducted with centre clinicians \( n = 7 \). Data were analyzed through an interpretive description approach. A positive outlook towards physical activity was found among all participants. Youth recognized the physical, mental and social benefits of continued physical activity. Clinicians supported youth and families with a ‘can do’ approach to physical activity. Findings can help improve the development of inclusive physical activity programs for individuals with childhood-onset physical disabilities both before and after transition to adult health services.

Keywords: Physical Activity, Exercise, Physical Disability, Facilitators, Barriers, Inclusion, Childhood
Co-Authorship Statement

Matt Downs conducted the research for his master’s thesis under the supervision of Dr. Joy MacDermid, Dr. Janette McDougall and Dr. Denise Connelly who are co-authors of the manuscript in this thesis.
Acknowledgements

I would like to thank my advisor Dr. Joy MacDermid for all her support and encouragement over the course of my program. Her wealth of knowledge as well as her patience is something I truly appreciate. I would also like to thank Dr. Janette McDougall, a researcher at Thames Valley Children’s Centre (TVCC). Her willingness to assist me with research at TVCC has helped me tremendously. Her timely feedback during all stages of my project has been extremely helpful and essential for the success of my research project. I also want to thank Dr. Denise Connelly, a physical therapy professor at Western University. She has generously devoted her valuable time to assist with the analysis of my focus groups. The time, patience and insightful feedback that she has invested in my project have been greatly appreciated. I extend my appreciation to Liz Lusk, a TVCC physiotherapist who was an integral part of this study, recruiting passionate participants who were eager to participate in all aspects of this research project. I am very grateful to the youth and TVCC clinicians who participated in the study. The depth of their responses to the focus group discussion questions was invaluable to this thesis.
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Chapter 1: Literature Review

Importance of Physical Activity

Exercise is an activity that is planned, repetitive and purposeful which improves or maintains a component of physical fitness (World Health Organization [WHO], 2018). Physical activity is any movement which results in an increase of energy expenditure (Slaman, Roebroeck, Dallmijer, Twisk, Stam, & van den Berg-Emons, 2015). Exercise and other forms of physical activity contribute to physical fitness that provides a primary or secondary prevention protecting individuals against several chronic diseases. A lifestyle that incorporates physical activity, paired with minimal sedentary time is recommended for optimal health (Slaman et al., 2015). Participating in regular exercise during childhood and adolescence can have many health benefits that can carry forward into adulthood, including an increase in bone density, better body weight management and a reduction of blood pressure (Rimmer & Rowland, 2008). Sustained physical activity has been shown to decrease the likelihood of developing potentially serious conditions such as cardiovascular disease, hypertension and obesity (Schranz et al., 2014). Participating in physical activity during childhood can help build a strong foundation of the necessary fundamental motor and social skills for the years to come (Reedman, Boyd, & Sakzewski, 2017). Additionally, physical activity behaviour developed through childhood is likely to extend through to the adult years, which can limit the risk for morbidities later in life (Wright, Roberts, Bowman, & Crettenden, 2018).
Disability and Physical Activity

The word *disability* is commonly associated with functional limitations. According to the WHO’s International Classification of Functioning, Disability, and Health (ICF) (WHO, 2001), disability is an umbrella term for impairments, activity limitations and participation restrictions. ‘Impairments’ are defined as problems in body function or structure; ‘activity limitations’ are difficulties a person may have in carrying out daily activities; and ‘participation restrictions’ are problems an individual may experience in life situations (WHO, 2001).

Since many chronic health conditions can lead to disability, it is critical that individuals with these types of problems maintain their mobility as much as possible. Having impaired locomotion is usually associated with metabolic consequences (Durstine, Painter, Franklin, Morgan, Pitetti, & Roberts, 2000). These metabolic deviations often include higher oxygen consumption, higher heart rate, and an increase of perceived exertion at a leisurely walking pace (Durstine et al., 2000). Previous studies have shown that young adults with disabilities often have lower levels of physical activity, which contributes to an overall decrease in aerobic fitness compared to peers of the same age without disability (Buffart, Roebroeck, Rol, Stam, & van den Berg-Emons, 2008). Physical inactivity can lead to secondary conditions such as obesity, urinary tract infections as well as the development of comorbidities, such as type 2 diabetes, poor joint mobility, and cardiovascular disease (Newitt, Barnett, & Crowe, 2016). These potential health complications can be greatly reduced by participating in regular physical activity (Junker & Carlberg, 2011).
According to Healthy People 2010 (US Department of Health and Human Services, 2000) an increase in physical activity is strongly encouraged for all individuals. In addition, Healthy People 2010 specifically acknowledges the importance of physical activity for people with disabilities and includes specific goals and objectives that aim to increase their level of physical activity and fitness.

Physical activity guidelines may need to consider how the impairments and disabilities are likely to affect exercise capacity and responses. For example, a review article by Verschuren and colleagues (2016), summarizes five randomized control trial articles that have published exercise guidelines for individuals with cerebral palsy. The initial recommended frequency of training is once or twice weekly, assuming that the participants begin at a very deconditioned state. Recommended exercise intensity and time for this population fell within the American College of Sports Medicine (ACSM) guidelines, suggesting that individuals with cerebral palsy are able to seek the benefits of progressively intense aerobic exercise similar to the extent of their typically developing peers. The type of exercise recommended by the ACSM included running, step-ups, stair climbing, cycling, arm ergometry exercises, swimming and propelling a wheelchair. All of these activities can be easily adapted to fit the needs of individuals with physical disabilities (Verschuren, Peterson, Balemans, & Hurvitz, 2016).

Youth with Childhood-Onset Physical Disabilities and Physical Activity

Thanks to advancements in medical technology and care, a large majority of children diagnosed with chronic health conditions survive into adulthood (Strauss, Brooks, Rosenbloom, & Shavelle, 2008). Due to this, research on maintaining a healthy lifestyle throughout childhood and adolescence is taking precedence over research on disability
prevention strategies (Buffart, Westendorp, van den Berg-Emons, Stam, & Roebroeck, 2009). It is hoped that this will limit the development of secondary health conditions (Buffart et al., 2009). Developing physical activity habits for children and youth with physical disabilities is especially important as exercise can induce a wide variety of therapeutic benefits. Gross motor development, balance, coordination and cardiovascular endurance can potentially be improved (Shields & Synnot, 2016). Research shows that improving physical activity in the adolescent years can help minimize the deconditioning associated with sedentary behaviour in childhood (Koldoff, 2017).

Many individuals with childhood-onset physical disabilities still require ongoing health care as they transition into adulthood. Since physical activity behaviour in the adolescent stage strongly influences adult lifestyle, this period is an ideal time for interventions that promote physical activity. Therefore, it is important for youth to continue receiving rehabilitation services such as physical and recreational therapy aimed to improve/preserve physical functioning as they age (Lawrence, Hills, Kline, Weems, & Doty, 2016). For example, participation in a strength training program for adults with cerebral palsy could improve their ability to perform more physically demanding tasks, allowing them to preserve independence as they age (Rimmer, 2001). Studies that have focused on youth with cerebral palsy have found that strengthening programs result in improved function of gait speed and other gross motor abilities (Rimmer & Rowland, 2008).

Previous studies have clearly shown that there is a positive relationship between physical activity participation and an increase in physical and social health for children and adolescents without disabilities. Maher, Toohey, & Ferguson (2016) found that this
relationship also holds true for youth with physical disabilities. They examined the associations between physical activity participation, health-related quality of life and happiness in youth with cerebral palsy. Positive associations were found between physical activity, physical and social quality of life, and happiness. These results suggest that physical activity is beneficial for the overall well-being of youth with cerebral palsy.

**Factors Related to Physical Activity for People with Physical Disabilities**

According to the WHO’s ICF, a person’s functioning and disability are considered to arise from the interaction among health conditions and contextual factors, namely environmental factors (e.g. community attitudes, accessibility of the environment, peer relationships, service availability, etc.) and personal factors (e.g. age, gender, values, lifestyle, etc.) (WHO, 2001). A good deal of research has examined the factors related to physical activity for people with physical disabilities of all ages. Recent systematic and other review articles of both quantitative and qualitative studies (Li, Sit, Yu, Duan, Fan, McKenzie, & Wong, 2016; Martin Ginis, Ma, Latimer-Cheung, & Rimmer, 2016; Newitt, Barnett, & Crowe, 2016) have summarized this body of work. Table 1 collates and summarizes the findings of these review articles. Disability-related as well as numerous factors at the personal and environmental levels have been identified. This past research suggests that there are more contextual factors related to physical activity levels for individuals than there are disability-related factors.
**Table 1:** Factors Related to Physical Activity for People with Physical Disabilities Identified in Past Review Articles Using the ICF Framework

<table>
<thead>
<tr>
<th>Disability-Related Factors</th>
<th>Personal Factors</th>
<th>Environmental Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Balance and stability</td>
<td>Age</td>
<td>Climate</td>
</tr>
<tr>
<td>Movement and strength</td>
<td>Gender</td>
<td>Type of community (rural/urban)</td>
</tr>
<tr>
<td>Dexterity</td>
<td>Family income</td>
<td>Parent factors (ethnicity, education, marital status, health, physical activity preferences)</td>
</tr>
<tr>
<td>Muscular strength</td>
<td>Employment status</td>
<td>Family functioning</td>
</tr>
<tr>
<td>Weight/Body Mass Index</td>
<td>Number of siblings</td>
<td>Social support/connectedness (family, friends, peers, others)</td>
</tr>
<tr>
<td>Bladder and bowel control</td>
<td>Emotions and behaviour</td>
<td></td>
</tr>
<tr>
<td>Aerobic capacity</td>
<td>Attitudes/beliefs</td>
<td>Mentors/role models</td>
</tr>
<tr>
<td>Cognition</td>
<td>Self-perceptions</td>
<td>Societal attitudes</td>
</tr>
<tr>
<td>Fatigue</td>
<td>Perceived competence</td>
<td>Type of school (special)</td>
</tr>
<tr>
<td>Pain and stiffness</td>
<td>Physical activity preferences</td>
<td>Knowledge of health and other professionals</td>
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<tr>
<td>-------------------</td>
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<td>---------------------------------------------</td>
</tr>
<tr>
<td>Communicative abilities</td>
<td>Motivation</td>
<td>Support from health and other professionals</td>
</tr>
<tr>
<td>Injury</td>
<td>Fear of injury</td>
<td>Accessibility</td>
</tr>
<tr>
<td></td>
<td>Level of independence</td>
<td>Costs</td>
</tr>
<tr>
<td></td>
<td>Developing a routine</td>
<td>Products and technology</td>
</tr>
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<td>Goal setting</td>
<td></td>
<td>Transportation</td>
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<td></td>
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<td>Safety (equipment and environment)</td>
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<td></td>
<td>Rehabilitation services</td>
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<td></td>
<td></td>
<td>Government policies</td>
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</tbody>
</table>

Note: This table collates and summarizes data from review articles by Li et al. (2016), Martin Ginis et al. (2016), and Newitt et al. (2016)
Examples of Facilitators and Barriers to Physical Activity from Table 1

The factors presented in Table 1 can be considered facilitators or barriers to physical activity depending on individual circumstances. It is important to consider enhancing facilitators and removal of barriers through supports, services, programs, and policy changes as potential mechanisms for improving physical activity. Some of the more relevant factors from this table are discussed below.

Disability-Related Factors

Muscular Strength and Aerobic Capacity

Youth who have impairments in muscular strength and aerobic capacity may never or rarely participate in community exercise programs because they may be ashamed or embarrassed of their physical limitations when compared to typically developing peers (Martin Ginis et al., 2016). With this said, however, rehabilitation and other health care professionals can provide services to help mitigate these concerns. They can teach basic exercises and help implement behavioural change strategies, which can help facilitate future physical activity pursuits.

Personal Factors

Perceived Competence

Perceived competence can be a facilitator or barrier to physical activity. Discussed in the review article by Li et al., (2016), this factor could be considered a barrier to physical activity if youth are struggling to participate in an activity due to functional limitations and experience feelings of inadequacy related to abilities. On the other hand, one’s
perceived competence could be bolstered and considered to be a facilitator if the activity is being performed within an inclusive environment with others of similar skill levels.

**Age**

The age at which youth engages in physical activity is an important factor that could be considered a facilitator or barrier to ongoing physical activity engagement. Li et al. (2016) suggest that the physical activity level of youth with disabilities significantly declines with age. Furthermore, youth may be less inclined to participate in community activity programs after they are no longer eligible to participate in recreational services provided by many children’s rehabilitation centres.

As suggested by Martin Ginis et al., (2016) communities must focus on improving social attitudes and building stronger networks to provide more opportunities for individuals with disabilities to continue to participate in meaningful physical activity into adulthood. If inclusive programs continue to develop, age may no longer need to be considered a barrier to physical activity.

**Environmental Factors**

**Social Support**

Many youth could become motivated to exercise with positive support from family members, friends, teachers, health care professionals or other community members who readily adapt physical activity programs so that they provide an optimal level of challenge. Participating in such activities can provide an opportunity to interact and meet peers while improving physical function (Martin Ginis et al., 2016). However, this could also be considered a barrier to physical activity if other people are not supportive toward
persons with disabilities in exercise programs since engaging in exercise could cause fear, anxiety and embarrassment for individuals regarding how they may be perceived by others. If these negative feelings occur, maintaining a regular exercise routine may become jeopardized.

*Transportation*

Transportation is an important environmental factor that can facilitate physical activity or act as a hindrance. The cost or availability of specialized transportation can act as a barrier. Individuals may not have the necessary finances to afford bus or taxi fees to get to an exercise facility. Depending on the severity of their disability, individuals may need to rely on these modes of transportation. Even if cost is not an issue, travelling to and from an exercise facility may take longer than the time spent engaging in the activity itself, making it a major inconvenience (Newitt et al., 2016).

Ride sharing could act as a facilitator to physical activity. This could also motivate one to participate, if a group of people are travelling together which could be more practical and economical. Health promotion programs can educate individuals with disabilities to arrange their own transportation, use public transportation or to initiate carpools (Newitt et al., 2016).

*Cost*

Another barrier to physical activity that could potentially be removed is cost. In general, working-aged individuals with disabilities have higher unemployment rates compared to individuals without disabilities (Newitt et al., 2016). Furthermore, individuals with debilitating conditions that require expensive medications and/or adaptive equipment for
day-to-day function (Newitt et al., 2016) may use the majority of their financial resources to meet their day-to-day needs with little remaining to spend on leisure activity. If community centres offered highly structured activity programs that are tailored to specific disability-related needs that require little or no fee to participate in, costs may no longer be a barrier to physical activity.

**Family Physical Activity Preferences**

Family can have a significant effect on whether individuals with physical disabilities partake in physical activity. If fellow family members lead active lifestyles, it is more likely that the family member with the physical disability will be physically active as well (King, McDougall, DeWit, Petrenchik, Hurley, & Law, 2009). In such an environment, family members often seek out ways to include everyone in physical activity pursuits, even if it means adapting the activity to make it more accessible. On the other hand, if youth with physical disabilities have family members who lead sedentary lifestyles, or do not value the importance of exercise, family beliefs and values can be a barrier to physical activity participation (Li et al., 2016).

**Gaps in the Literature**

Although a good deal of quantitative and qualitative research has examined the barriers and facilitators to physical activity for individuals of all ages with physical disabilities, few qualitative studies have focused specifically on youth with childhood-onset physical disabilities (Buffart et al., 2009). Moreover, scant literature has explored the perspectives of rehabilitation clinicians regarding the barriers and facilitators to physical activity for youth with physical disabilities (Wright et al., 2018). Most studies have either just
focused on youth and/or their caregivers. Finally, few qualitative studies have focused on the perspectives of youth and others regarding the continuation of physical activity into adulthood (Morris, Imms, Kerr, & Adair, 2018). The studies discussed below are the few that have begun to address these gaps in the literature.

One qualitative study conducted by Buffart and colleagues (2009) examined the barriers and facilitators to physical activity specifically for young adults with childhood-onset disabilities, which included individuals with cerebral palsy, acquired brain injury, and rheumatoid arthritis. The mean age of the 16 participants was 22 years. The researchers utilized the Physical Activity for People with a Disability (PAD) model, which is closely related to the ICF framework. Personal barriers and facilitators were divided into physical and psychological factors, and environmental barriers and facilitators were divided into social factors and physical factors. The personal and environmental factors that were identified were highly reflective of those listed in the systematic and other types of reviews discussed earlier, with motivation, strength and energy level, perceived competence, informational and professional supports being identified as particularly important.

Wright and colleagues (2018) carried out one of the few studies that examined the barriers and facilitators to physical activity for youth with physical disabilities from the perspective of both youth and rehabilitation clinicians. The six clinicians (i.e., two physiotherapists, two occupational therapists, two recreational therapists) who participated in this study were all associated with a program that helped youth access physical activity opportunities in the community. They participated in semi-structured interviews. Twenty-eight youth participants completed surveys. They were between the
The identified barriers and facilitators were organized using the ICF framework. Wright et al. (2018) categorized both facilitators to physical activity and barriers of physical activity into “environmental” factors and “person-related” factors. These headings were then used to develop themes that were eventually ranked in order from the most discussed to the least discussed by the clinicians (Wright et al., 2018). The most significant facilitator to physical activity from the clinician’s perspective was “planning programs to promote success and inclusion”. Youth identified “the right people make physical activity fun” as their most significant facilitator to physical activity. “Practical limitations” and “time constraints and priorities” were the most significant barriers to physical activity identified by the clinician participants. Youth identified “bodily limitations” (physical limitations due to having a disability) and “self-restrictions” (psychological challenges) as their most significant barriers to physical activity (Wright et al., 2018).

Morris and colleagues (2018) conducted a qualitative study to identify themes related to “sustaining” physical activity rather than examining barriers and facilitators of engaging in physical activity. Semi-structured interviews with each of five youth, five parents and five physical activity ‘facilitators’ (e.g., fitness coaches) were completed; further, interviews were conducted with participants in small groups, or triads, comprised of a youth, a parent and a physical activity ‘facilitator’. The youth were between the ages of 13 and 16 years, and were diagnosed with cerebral palsy. They were involved in physical activity prior to agreeing to participate in the study (Morris et al., 2018).
facilitators included three fitness coaches, one personal trainer, and a physical activity coordinator. Themes related to sustaining participation were endorsed by all participants and included: “getting started”, which emphasized the importance of factors related to originally getting started in physical activity; “wanting to succeed”; having “a sense of belonging”; “a coach is important”; “endorsement to continue”; “endorsement to support”; and “being passionate”.

The purpose of this study was to expand on past research and further explore the experiences, motivators, and challenges of youth and young adults with childhood-onset physical disabilities to engage in and sustain physical activity from the perspectives of youth themselves and rehabilitation clinicians who provide physical activity programs.
References


*Disability and Rehabilitation, 0*(0), 1-9.
Chapter 2: Manuscript

Introduction

Physical activity is important for youth with childhood-onset disabilities to maintain mobility, health, well-being, social opportunities and for fun. Previous studies reported that young adults with disabilities have lower levels of physical activity, which contributes to an overall decrease in aerobic fitness compared to peers of the same age without disability (Buffart, Roebroeck, Rol, Stam, & van den Berg-Emons, 2008). Further, reduced levels of physical inactivity contribute to secondary health conditions such as obesity, urinary tract infections, type 2 diabetes, joint immobility, and cardiovascular disease (Newitt, Barnett, & Crowe, 2016). The risk for developing these comorbidities can be reduced by participating in regular physical activity (Junker & Carlberg, 2011).

Past research has clearly shown that there is a positive relationship between physical activity participation and an increase in physical, mental, and social well-being for children and adolescents without disabilities. Maher, Toohey, & Ferguson (2016) found that this relationship also holds true for youth with physical disabilities. They examined the associations between physical activity participation, health-related quality of life and happiness in youth with cerebral palsy. Positive associations were found between physical activity, physical and social domains of quality of life, and happiness (Maher et al., 2016). These results suggest that physical activity is beneficial for the overall well-being of youth with cerebral palsy.
Recent systematic and other review articles, using quantitative and qualitative methods, have examined the factors related to physical activity participation for people with physical disabilities of all ages (see Li, Sit, Yu, Duan, Fan, McKenzie, & Wong, S., 2016; Martin Ginis, Ma, Latimer-Cheung, & Rimmer, 2016; Newitt, Barnett, & Crowe, 2016). These review articles summarize the many factors related to physical activity participation utilizing the International Classification of Functioning, Disability and Health (ICF) Framework (WHO, 2001), or other currently favoured frameworks. Numerous factors at the personal and environmental levels, as well as disability-related factors, have been identified. Li et al. (2016) concluded that physical activity participation can be affected by the interaction(s) arising from the combinations of a person’s health condition, their functioning/disability, and personal and environmental factors.

Although many quantitative and qualitative research studies have examined the factors related to physical activity participation for individuals of all ages with physical disabilities, few studies have focused specifically on youth and young adults with childhood-onset physical disabilities (Buffart et al., 2009). One qualitative study conducted by Buffart and colleagues (2009) examined the barriers and facilitators to physical activity specifically for young adults with childhood-onset disabilities, which included individuals with cerebral palsy, acquired brain injury, and rheumatoid arthritis. The mean age of the 16 participants was 22 years. The researchers utilized the Physical Activity for People with a Disability (PAD) model. Personal barriers and facilitators were divided into physical and psychological factors; environmental barriers and facilitators into social and physical factors. The personal and environmental factors that were
identified were highly reflective of those listed in the review articles by Li et al. (2016), Martin Ginis et al. (2016), and Newitt et al. (2016), with motivation, energy level, perceived competence, informational and professional supports being identified as particularly important.

Wright and colleagues (2018) carried out one of the few studies that explored barriers and facilitators to physical activity for youth with physical disabilities from the perspectives of both the youth and rehabilitation clinicians. The six clinicians (i.e., two physiotherapists, two occupational therapists, two recreational therapists) who participated in this study were all associated with a program that helped youth access physical activity opportunities in the community. Each clinician participated in a single one-on-one, semi-structured interview. Twenty-eight youth participants completed self-report surveys. They were between the ages of 10 and 17 years, and were either current or past clients of the program. The majority had cerebral palsy (67.9%), while others had spina bifida (7.1%), muscular dystrophy (3.6%), and other diagnoses. The identified barriers and facilitators were organized using the ICF framework.

Wright et al. (2018) divided both facilitators to physical activity and barriers of physical activity into “environmental” factors and “person-related” factors. These headings were then used to develop themes that were eventually ranked in order from the most discussed to the least discussed by the clinicians (Wright, Roberts, Bowman, & Crettenden, 2018). The most significant facilitator to physical activity from the clinician’s perspective was “planning programs to promote success and inclusion”. Youth identified “the right people make physical activity fun” as their most significant facilitator to physical activity. “Practical limitations” and “time constraints and priorities”
were the most significant barriers to physical activity identified by the clinical participants. Youth identified “bodily limitations” and “self-restrictions” as their most significant barriers to physical activity (Wright et al., 2018).

Many youth with childhood-onset physical disabilities will require ongoing support for engagement in physical activity as they transition into adulthood. Since physical activity behaviour in youth strongly influences a physically active lifestyle in later life (Koldoff & Holtzclaw, 2015), it is important for youth to continue receiving rehabilitation services such as physical and recreational therapy aimed to improve/preserve physical activity participation as they age (Lawrence, Hills, Kline, Weems, & Doty, 2016). For example, participation in a strength training program for adults with cerebral palsy could improve their ability to perform more physically demanding tasks, allowing them to preserve independence as they age (Rimmer, 2001).

Studies that have focused on youth with cerebral palsy have found that strengthening programs result in improved function of gait speed and other gross motor abilities. (Rimmer & Rowland, 2008).

Morris and colleagues (2018) conducted a qualitative study with youth, their parents and physical activity ‘facilitators’ (e.g., fitness coaches) to identify themes related to “sustaining” physical activity rather than examining barriers and facilitators of engaging in physical activity. Semi-structured interviews with each of five youth, five parents and five physical activity ‘facilitators’ were completed; further, interviews were conducted with participants in small groups, or triads, comprised of a youth, a parent and a physical activity ‘facilitator’. The youth were between the ages of 13 and 16 years, and were diagnosed with cerebral palsy. They were involved in physical activity prior to
agreeing to participate in the study. Participants who were physical activity ‘facilitators’ included: three fitness coaches, one personal trainer, and a physical activity coordinator. Themes related to sustaining participation were endorsed by all participants and included: “getting started”, which emphasized the importance of factors related to beginning participation in physical activity; “wanting to succeed”; having “a sense of belonging”; “a coach is important”; “endorsement to continue”; “endorsement to support”; and “being passionate” (Morris, Imms, Kerr, & Adair, 2018).

Scant literature has explored the perspectives of rehabilitation clinicians regarding the motivators and challenges to physical activity participation for youth with physical disabilities (Wright et al., 2018). Furthermore, few qualitative studies have explored the perspectives of youth and others regarding the continuation of physical activity into adulthood (Morris et al., 2018). This is an important gap in our knowledge to understand from the youth themselves their perceptions of sustaining physical activity participation as they transition from youth to young adults. Therefore, the purpose of this study was to explore the experiences, motivators and challenges of youth and young adults with childhood-onset physical disabilities to engage in and sustain physical activity from the perspectives of youth themselves and rehabilitation clinicians that provide physical activity programs.

Methods

Research Design and Methodology

Single session focus groups were conducted separately with a group of participant youth with a childhood-onset disability and pediatric rehabilitation clinicians. The researchers
developed separate focus group scripts to probe the physical activity experiences of youth with a childhood-onset disability from the perspective of the youth and from pediatric rehabilitation clinicians prescribing and supervising physical activity in a pediatric-specific physical activity program.

Focus groups were employed to foster a deeper understanding of commonalities, shared perceptions and experiences, and differing experiences among participants. This method is consistent with interpretive description (Thorn, Kirkham, & O’Flynn-Magee, 2004), which was employed to explore the narratives from youth participants with a childhood-onset disability and pediatric rehabilitation clinicians. Using an interpretive approach to narratives, the researcher identified categories and themes from the discussions of participant focus groups. This approach considers it important to understand multiple viewpoints in a specific social situation. In addition, it allows researchers and participants to co-create knowledge collaboratively (Thorn et al., 2004).

**Statement of Self**

As a child with a disability, I have been involved with Thames Valley Children’s Centre (TVCC) from a young age. During my formative years, I received physical, occupational and speech therapy from many TVCC clinicians, all who were extremely optimistic about my future. Besides therapy, I have fond memories of participating in the many recreation services that TVCC provided to their clients. Some of these activities included fitness classes at the local YMCA, track and field, golf and soccer lessons. These experiences motivated me to stay active throughout my adolescent years allowing me to gain confidence in my abilities, and influenced my decision to pursue higher education in the health and rehabilitation field. Despite no longer being eligible to participate in these
services, I have stayed connected with Thames Valley Children’s Centre through volunteering. This has given me the opportunity to work and connect with youth who have diverse abilities and goals.

**Study Context and Participants**

TVCC provides a vast range of services for clients ranging in age from birth to 19 years. Using a family-centred approach, TVCC fosters the development of physical, communication, emotional, behavioural and life skills for children living with physical disabilities, developmental delays, communication disorders and autism spectrum disorders. The centre provides information, education and support to children, youth and their families to promote strong and supportive environments.

TVCC provides opportunities for clients to participate in numerous physical activity and recreational programs both within the centre and in the larger community. Examples include “Swim -Try it!” a recreational swimming program at TVCC and “Golf-Try it!”, a TVCC/community partnership program. TVCC also features an in-house Adapted Fitness Centre, complete with accessible cardiovascular and resistance training equipment. This centre also provides bosu balls, exercise mats and medicine balls, ideal for improving balance and tightness one may experience depending on their diagnosed health condition.

New clients receive a comprehensive fitness assessment which is done by a physiotherapist or a kinesiologist. An individualized exercise program is then created, based on the goals of the client. Once complete, clients work one on one with a volunteer to ensure a safe and effective exercise routine. Clients are encouraged to make use of this program on a weekly basis.
Participants were recruited by a physiotherapist at TVCC who acted as the Research Contact. Youth participants who met inclusion/exclusion criteria were invited in person or by phone to participate in a focus group. Youth were eligible for the study if they were between the ages of 10 and 25 years, diagnosed with a childhood-onset physical disability, were current or past clients of TVCC, and had participated in one or more of the recreational programs provided by TVCC. In addition, the youth needed to be able to cognitively understand and respond to the questions they would be asked as part of the study.

All rehabilitation clinicians employed by TVCC who had experience prescribing rehabilitation exercises for clients, as well as background knowledge of relevant community-based physical activity opportunities for TVCC clients, were eligible to participate in the study. TVCC clinicians were approached in person, by phone, or email by the Research Contact to ask if they were interested in participating in a focus group. All children and youth, and clinician study participants provided written consent/assent, as approved by the University of Western Ontario Research Ethics Board (Appendix A).

**Procedure**

Separate, semi-structured interview guides were created by the first author [MD], with iterative consultation with co-authors [JM, DC, JM], to guide the focus groups (See Appendix E and F). The aim of the interview questions were to understand the perceptions and experiences of participants about the motivators, experiences, and challenges that youth with childhood-onset disabilities face when participating in physical activity; and their perceptions and experiences in trying to maintain exercise outside of the TVCC fitness centre, and into adulthood.
Two focus groups took place at TVCC. One included six youth participants who were diagnosed with a childhood-onset physical disability and who were either current or past participants of recreation program(s) offered through TVCC (Table 2). The other focus group included seven rehabilitation clinicians who were employed by TVCC (Table 3). A 60 to 90 minute focus group session was carried out with each group of study participants by the first author [MD] using the respective semi-structured interview guide. Prior to conducting the focus groups, the first author [MD] completed training with an experienced interviewer.

A Personalized Exercise Questionnaire was distributed to youth participants prior to their focus group. This questionnaire was a modified version of a new tool to measure the facilitators, barriers and preferences to exercise in people with osteoporosis, which was created by Rodrigues, Adachi, Beattie, & MacDermid, (2017). The questionnaire included questions that reflected those discussed in the focus group. Each youth participant completed a questionnaire individually following the focus group.

**Data Analysis and Interpretation**

Focus group transcripts were read and re-read separately by two members of the research team [MD, DC] to become very familiar with the words of the study participants. Thematic analysis was used to explore: 1) motivations, experiences, and challenges related to engaging in physical activity; and 2) motivations for and benefits of continuing an active lifestyle into adulthood. Themes that are developed using an inductive approach are linked to the data, not necessarily relating to specific questions asked by the researcher. In contrast, a deductive or theoretical thematic analysis is often driven by the analytic interest of the researcher. Although this form of analysis provides less
description of the overall data, it does allow for a more detailed examination of some aspect of the data (Braun & Clarke, 2006).

Given the nature of the questions asked during the focus group, the data gathered in this study was analyzed using a deductive approach. The questions asked during the focus group sessions were aimed at investigating the study purpose. A focus group format allowed for a constructionist perspective where meaning and experiences are socially produced and reproduced (Braun & Clarke, 2006). The audio-recordings of each focus group were listened to and transcribed verbatim by the first author [MD]. Notes were taken during focus group sessions to assist in contextualizing participant responses during transcription. Transcripts were coded separately by the two authors [MD, DC], and then discussed for coding, categories and themes. Sample coding examples were discussed by all members of the research team.

Also, at the end of the focus group, each youth participant completed the Personalized Exercise Questionnaire. Participant responses were summarised as descriptive data to provide readers of the study with an understanding of how study participants may compare to their family members or peers.

Trustworthiness

Throughout this study, trustworthiness was maintained between the participants and the first author. Although the first author asked specific questions of each focus group, a semi-structured interview format allowed the participants to expand on their answers and discuss other thoughts that developed during this process. Credibility was enhanced within the focus group process through the first author’s use of techniques such as reframing, repeating, and expanding questions when required (Krefting 1991).
In addition, the first author [MD] maintained a reflective journal that addressed personal experiences of participating in various physical activity programs in treatment centres, schools and in the community. Moreover, the youth participants completed the Personalized Exercise Questionnaire after the focus group was completed. Several questions allowed the youth to express their thoughts privately in open ended responses, if they chose. Data collected from focus groups, questionnaire and reflection were used to stay true to the data and provided triangulation of the findings (Richardson, 2006).

Confidentiality

Identifiers (names) were removed from the focus group data during transcription. Only research team members had access to study data. Data was stored on Western University’s institutional network drive with firewalls. No identifying information was collected in the Personal Exercise Questionnaire. Consent forms, questionnaires and transcripts were stored in a locked, secured filing cabinet at Western University; and copies were kept at TVCC locked in a private office in order that all research team members were able to access data for analysis purposes.

Results

Youth Participants

Six youth participants were recruited and all completed the required focus group session and questionnaire. Most of the participants had cerebral palsy ($n=4$). Four of the youth were males. They ranged in age from 11 to 22 years, with the average age being 15 years. See Table 2 for further details.
Table 2: Descriptive characteristics of youth participants (n=6).

<table>
<thead>
<tr>
<th>Participant</th>
<th>Health Condition Diagnosis</th>
<th>Age (years)</th>
<th>Sex</th>
<th>Mobility aid</th>
<th>Level of Education</th>
<th>Involved in organized sport</th>
<th>Home exercise program</th>
<th>Attended AFC</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Brain Tumor Survivor</td>
<td>13</td>
<td>female</td>
<td>none</td>
<td>Gr 8</td>
<td>karate</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>2</td>
<td>Cerebral Palsy</td>
<td>22</td>
<td>male</td>
<td>none</td>
<td>College graduate</td>
<td>sledge hockey</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>3</td>
<td>Cerebral Palsy</td>
<td>13</td>
<td>male</td>
<td>4-wheel rollator walker</td>
<td>Gr 7</td>
<td>none</td>
<td>yes</td>
<td>yes</td>
</tr>
<tr>
<td>4</td>
<td>AK amputee from blood clot</td>
<td>11</td>
<td>male</td>
<td>manual WC</td>
<td>Gr 5</td>
<td>WC basketball, sledge hockey, archery, swimming</td>
<td>yes</td>
<td>no</td>
</tr>
<tr>
<td>5</td>
<td>Cerebral Palsy</td>
<td>18</td>
<td>male</td>
<td>4-wheel rollator walker</td>
<td>Gr 12</td>
<td>baseball</td>
<td>no</td>
<td>yes</td>
</tr>
<tr>
<td>6</td>
<td>Cerebral Palsy</td>
<td>11</td>
<td>female</td>
<td>none</td>
<td>Gr 5</td>
<td>none</td>
<td>no</td>
<td>yes</td>
</tr>
</tbody>
</table>

AFC = Adapted Fitness Centre

*Overarching theme from focus group discussion*

A fundamental belief expressed by the youth participants was how much they valued the importance of physical activity. The youth recognized the physical and mental health benefits from physical activity, as well as the social opportunities. Staying physically
active was an important goal for them. The following four themes emerged for the youth focus group: exercise is important; interest in physical activity; social opportunities in safe environments; and wanting to stay active. These themes will be discussed in depth below.

Exercise is important.

Good for your health. The youth recognized the role of exercise to maintain “body shape” [P1], “improve your mobility…not be restricted” [P2], “good for your health” [P4], “reduces my stress” [P2] and “makes me feel more healthy.” [P1]

I think it’s important to do physical activity because you can improve your mobility, right so not be restricted. If you’re moving the muscles and you do physical activity you got to train your body how to move it. Because if I sit for a long long time, I get stiff. It’s hard to move so you got to stretch, move it once in a while. Physical activity helps your mobility. [P2]

They talked about how physical activity is good for them within the context of their individual ‘bodies’, “If I participate for a long time I can actually get to my goal which is bringing down my weight so I actually don’t look fat. I actually like the shape of my body, that’s what I’m trying to say. It just makes me feel good about something.” [P1]. They commented that physical activity was a source of success for them and that they could optimize their abilities, “My most favorite thing in gym class is yoga, because I’m really really good at it.” [P1], “I’ve been able to move a lot smoother now.” [P2], and “I feel stronger. More stability.” [P3]
Interest in physical activity.

The youth participants shared an interest in being physically active which seemed to be an innate motivating factor. Participant 2 offered, “My classmates do physical activity and I just like, I just have an interest since I was a little baby. My father led soccer, so he got me into sports.” Another participant was supported by their mom, “my mom works here [TVCC] so … my mom told me about the gym at her work um I just felt like you know, I’m going to try this, see how it goes.” [P1] Parents and peers were the primary sources of support, “I feel like when the family is there and that like you can do swimming and track and field. They are my biggest fans. My dad’s just up in the stands yelling at the top of his lungs. My whole family’s like that.” [P4] One youth had a family gym in their home:

We have weights and all that in the basement. Treadmill, stepper, elliptical …. I go down stairs to do weights and that. I like to do it with my parents and my brother because they are there with me. So it feels like I’m not the only one who trains. My mom goes down every night. Like for half an hour. [P4]

One participant talked about the support they received at school, “And my friends are all really good with… they know I can’t really do something that well they give me, they help me a little bit with it.” [P4] Their interest in participating in physical activity was supported “because I have fun.” [P5] Participant 3 supported this by stating, “I like gym class. Um, it’s really good. We play games pretty much every gym class”. To be able to do activities like their friends was a motivator. Participant 6 described, “They motivate me because my friends can do like soccer and sometimes I have to do it in different ways. So I try and find different ways. So they motivate me to work harder and try to reach my goals.”
Social opportunities in safe environments.

Youth discussed the importance of physical activity for forming relationships with their peers who had similar challenges. Participant 1 talked about exercising with a fellow participant and how it provided motivation. These thoughts were supported by Participant 6.

I feel like I can actually have someone help me kind of do my best and also I can just look up to her because she’s been here longer, and look at me in the same way. And I feel like that’s just a really good relationship together. And knowing that we both have difficulty doing stuff and we’ve both had different things happen to us, just makes it a whole lot better. [P1]

Well I prefer a group because, well same like P1’s case. I think it’s like more fun. You get to be more social. You can like compete and stuff. And it you do something wrong, they can show you how to do it, instead of like always doing it wrong. And like ya, be more social. You can do like team goals. [P6]

Youth talked about preferring group exercise, whether at school or at the Adapted Fitness Centre, for a number of reasons, including “it feels safe” [P1], “That safe space and then to have that accessibility so you can get to…” [P7], and its’ “Good to talk to people.” [P5].

The group format for physical activity was preferred. Participant 2 described that physical activity was enjoyable in a group setting.

I prefer to exercise in a group because I like being social with people, and it’s more fun doing it. If you are doing it by yourself, you’re kind of… you… it’s not as fun, and you kind of get lazy at the gym. Not try as hard. If you have a buddy with you it can help motivate and compete and do more weights than the other person. I like the social activity.
Wanting to stay active.

Youth participants talked about how they currently participate in community programs and how they anticipated seeking out physical activity opportunities after leaving TVCC programs, “I’ve tried a few sports, basketball and wheelchair basketball. I play sledge hockey. I do archery. I swim, run.” [P4], “Play baseball.” [P5], and “I go to GoodLife almost every day.” [P2] Participant 1 spoke about karate, “I do karate, but it’s therapeutic so it’s not the actual hands on karate.” Participant 2 described that it has taken time for them to engage in community-based sports and exposure helped, “Then I graduated and I wanted to go provincial basketball actually. … now, I’m going to go down to Toronto and play some basketball.” A future goal in life for one participant was very sports oriented, “Ya. Paralympics one day.” [P4]

The youth spoke about being older, like seniors, when asked about how participating in physical activity would help them in the future. Their thoughts on the future though were grounded in their current physical capabilities and challenges.

I feel like you know, I can be stronger in the future. So I’ll be more active. So I won’t be like one of those old people who sit on the couch and not move. I’ll be one of those people actually walking around the whole retirement park or retirement places, but I wouldn’t even be retired. [P1]

I think it would benefit you in the future because, like you get more stronger and your muscles become better. In the future I am hoping to move my fingers. Because I can’t really move my fingers. [P6]

When asked about additional comments about participating in the future, the youth were very clear in their stories about the environmental day-to-day accessibility challenges they face.
I think it’s harder to get up a building if it has stairs. So more buildings should have elevators or ramps. Like even a ramp or something like that. Something that could help people in wheelchairs or people that can’t actually physically walk upstairs, get to the place they need to go. [P1]

I just have to say that, if you wanted to do physical activity in the community, the community has to make things more accessible, to get through the doors. [P2]

When I was… recently, If you’re in a wheelchair, everything is accessible if you need it and the door is about 30 pounds. And it was one of those that would automatically close as well. So it would be possible to get in but then the doors wouldn’t be wide enough to get a wheelchair in. And you could barely turn around. [P4]

And when I went to [college], I just graduated a month ago, there’s certain doors that don’t have automatic buttons, so I have to wait for someone to help me open the door and they’re walking down the hallway, and I have to wait for somebody, and that means I have to depend on somebody, which I don’t like doing a lot. [P2]

It was very clear that accessibility is still a common challenge in public buildings.

*Survey Questionnaire Data*

The theme of physical activity being ‘good for your health’ was an important reason for these youth to participate in exercise programs and was supported by survey data. Youth ranked the following physical components primarily as very important: muscle strength, better balance, more flexibility, more mobility, and feeling less tired. Two ideas that the youth did not talk about in the focus group but ranked as very important were falling less often and having less pain during the day with exercise. Preference for exercising at TVCC and as a group (i.e., with friends/family) with health care professional supervision (i.e., safe, encouraging place and receive feedback about their exercise/fitness programs)
were reported by the majority of youth participants in both the focus groups and the questionnaire. In their current exercise participation experience, youth participants reported in the survey that they did not feel limited by transportation, a place to exercise, confidence, mobility or lack of quality sleep. Finally, survey data supported the main themes from the focus group discussion, *exercise is important, interest in physical activity, social opportunities in safe environments and wanting to stay active*, and revealed that concerns about falling and pain could have been explored further with focus group questions.

**Clinician Participants**

Seven clinicians were recruited and all completed the required focus group session. Most were either recreation therapists or physiotherapists (see Table 3 for further details).

**Table 3**: Descriptive characteristics of clinician participants (*n*=7).

<table>
<thead>
<tr>
<th>Participant</th>
<th>Sex</th>
<th>Occupation</th>
<th>Program affiliation</th>
<th>Provides supervision to youth in Adapted Fitness Centre</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>female</td>
<td>physiotherapist</td>
<td>Early Childhood Service</td>
<td>yes</td>
</tr>
<tr>
<td>2</td>
<td>female</td>
<td>recreation therapist</td>
<td>Family and Community Service</td>
<td>yes</td>
</tr>
<tr>
<td>3</td>
<td>male</td>
<td>kinesiologist</td>
<td>all Services</td>
<td>yes</td>
</tr>
<tr>
<td>4</td>
<td>female</td>
<td>recreation therapist</td>
<td>Family and Community Service</td>
<td>no</td>
</tr>
<tr>
<td>5</td>
<td>female</td>
<td>recreation therapist</td>
<td>Family and Community Service</td>
<td>no</td>
</tr>
<tr>
<td>6</td>
<td>female</td>
<td>physiotherapist</td>
<td>Early Childhood Service</td>
<td>no</td>
</tr>
</tbody>
</table>
Overarching theme from focus group discussion

A fundamental belief expressed by the clinicians was their role to create a positive attitude of support for the youth and families in a ‘can do’ or ‘let’s make this happen’ approach. They exhibited an ‘openness’ and ‘outside the box’ thinking in discussing opportunities and participation for their youth clients. The following eight themes emerged from the focus group with clinicians: finding their right fit; development as individuals through physical activity; added therapeutic benefits with participation; making connections; increased community programs; parent advocates; families connecting; and transitioning to adult services. Each of these themes, along with a variety of sub-themes are discussed in further detail below.

Finding their right fit.

Opportunities for active participation. Clinicians talked about the importance of therapeutic programs to provide an opportunity for their youth clients to be able to physically participate in a wide variety of activities and sports, “because that’s what a lot of their peers are doing.” [P6] Programs at TVCC fill a gap for many youth clients. Participant 1 thinks,

For a lot of our youth they are looking for some way of participating when maybe mainstream sports aren’t a good fit, so I know as far as adaptive sports go, that may be one of their goals so that they can find a sport, or a recreation activity, leisure activity that they can participate in when mainstream isn’t working. [P1]
While addressing disability-related impairments, such as speech and other activities of daily living, programs at TVCC offered opportunities for exercise.

Ya. Things like adaptive life jackets. If you guys are going to allow participation in swimming. Or a sledge to try. They’re not sure if they want to do sledge, they can try it first. [P1]

Further, they spoke about activity or sport as a means for their youth clients to develop themselves, not only physically, but also as individuals.

When kids or youth they often identify with what they do is sort of who they are. And for a lot of our kids they haven’t really found that yet so they are looking for that. [P2]

*Development as individuals through physical activity.*

Clinicians talked about the importance of physical activity to address other aspects of a youth’s development including mental health, self-esteem, and “self-confidence.” [P3] Participant 2 talked about “for that social/emotional piece”. Participant 4 described physical activity as important “for the youth because then it spirals into that whole mental health realm as well, anxiety, depression, isolation.” The TVCC Adapted Fitness Centre provided a key place for youth to develop themselves before going out into the community, or in addition to organized sports in the community, where they built self-esteem and self-confidence. Participant 1 said, “And you hear from parents, I think especially in the fitness centre … about self-esteem, so for parents that’s a big goal to help with their self-esteem for participation.” Participant 2 supported this thought in the observation of the school environment:

Their social network and their social connections aren’t as established as maybe some of their siblings, or their typically developing peers. So families, I think
often feel that loss for their kids and they really want to find a spot so they can make those connections and gain that self-confidence.

Moreover, participating in physical activity built upon their experiences of success while having fun.

And I think just enjoyment. Like one of our little guys that’s in the fitness centre now, mom said “I’ve never seen him so happy like doing a physical activity”. Because he struggled to participate in anything. And [his mom] said, “ya, it’s the joy … peer relationships.” [P1]

Participant 6 remarked,

“I was going to say too maybe peers as vices as well as facilitators, depending on the child’s peer relationships and what kind of support they actually get from their peers and encouragement they get from their peers, they can be a vice or facilitator.”

Participant 7 added to this thought saying. “Peers are so big and [build] confidence to making those peer relationships because there’s connections and similarities. There’s things to connect and chat about.”

*Added therapeutic benefits with participation.*

Participant 3 discussed how being involved in a recreation program can benefit the youth in a variety of physical ways.

Joining something like the Adaptive Fitness Centre so the family might come in and say little [Jimmy] wants to improve just overall fitness and find out later on that we’ve improved his muscular strength or his balance or something like that. And it may not be something that they’ve picked up on, maybe it’s something that needed to be improved on right away, but after they come in and spend time, they may think “Oh, that was something we didn’t think of at first” and not focusing on [it], but we see the benefits of focusing on it now. [P3]
Youth often attend the program because they have a primary need or goal they want to address with exercise. But along with exercise, parents and clinicians notice youth gaining other skills and improvements even though it may not have been the primary goal for participating.

… I think that we see, you know, for example we saw it last night in bike clinic. So the [youth] are there to ride a bike, but now all of a sudden [parents are] commenting on … their child’s language, “oh my gosh he’s chatting so much tonight” because we facilitate language as part of the session. … they’re very motivated to engage [in] some speech goals … because they’re highly motivated to ride a bike and they want to be doing those things. We see that in the fitness centre too right. Like they’re there for fitness but we are always talking about secondary, even third goals around communication. [P2]

*Making connections.*

*Relationships with parents.* Clinicians discussed how parents were an integral part of providing recreational opportunities for their child with the help of the resources clinicians can offer to their clients and to their families. Clinicians talked about how families are aware of physical activity programs and how many families now expect various programs for their child and are prepared to commute further distances to get involved in these programs. Participant 4 noted from their experience that “there will be more of an expectation that there will be more opportunities. Where it used to be like, “Is there an opportunity?” Now it’s like, “Where is the opportunity?” Participant 5 added, “Families living in Huron Grey Bruce. A lot of those families are willing to drive farther for a program. Like they’re willing to drive an hour to sledge hockey.”
Increased community programs.

Adapted physical activities and sports are not only offered within TVCC, but are much more in the ‘mainstream’. Participant 2 noted that,

“the biggest change that I’ve seen is more in terms with the capacity of the community to offer more opportunities. Right, if we think back to 15 years ago, really we were doing a lot of stuff in house here. There weren’t the options in the community, and really now it’s made a big flip flop right, where we can have…like I think we have 5 pages filled with quality opportunities that engage people of all ages and all abilities. People are doing it in their own communities.”

P1 discussed some of the shortfalls of having youth participate in an inclusive activity in the community, as this may not be the ideal environment for every youth depending on their disability.

“I was thinking of integration vs. segregation and in the past everything was segregated and then we kind of went through a phase where everyone thought everything should be integrated, but I think we hear, over and over and over that families and youth still like some degree of segregation if you will. They don’t want to be the only one with a disability in the group, so they happen to participate more if there are similar peers. So I think that can be a facilitator or a barrier depending on the kid.”

As P4 pointed out, “Thinking really specifically, there’s an importance for some high school students to get their credits. So they want to be physically active about participating in their Phys. Ed. programs.” With this said however, there seemed to be a feeling among the clinicians that schools were not playing as large a role and as consistently as clinicians would hope in providing opportunity for their youth clients.

Participant 2 states,
“I think within the school it’s having people who have a willingness to think outside the box and look at solutions, because that doesn’t always happen. That’s why it’s so used upon school by school or teacher by teacher. You can have a great year in grade 8 in gym and then you can have not a great year in grade 7. So it still seems very silo in terms of what teachers are willing to do and not willing to do.” [P2]

Schools, and specifically classes, are likened to “little islands…The one grade 7 class room is an island. The other … is an island.” [P2]. Other clinicians spoke about barriers existing within schools……for example, P4 “And even when you have one school in particular. Yes we were able to provide a sport chair, but then you can’t get into the gym in a sports chair because of the bar between the doors. And a student can’t get in independently so there’s no way. Systematically now there’s a thing called lifting. You can’t lift over a certain weight. So EA’s aren’t always assisting with transfers and things so then you need a mechanical lift and there’s no mechanical lift in the gym so it’s physical barriers really that are baring someone from participating to their fullest.” [P4] and P5

The role that schools play in offering accessible physical activities is minor, sometimes even limiting. The physical layout of the school can act as a barrier towards active participation. School policy can also negatively affect the degree in which individuals with mobility impairments participate in activities:

“The other barrier that I hear a lot in schools is that the phys. ed. teachers are not phys. ed. specialists anymore, there’re generalists so they’re not even comfortable teaching physical activity to a typically developing peer, much less exploring adapting physical activity. I know that was one of the clinician’s big pushes. But that is certainly not having that phys. ed. specialist in the school does change things for a lot of kids.” [P5]

“They don’t. So their expertise is not in physical activity so not being able to teach and I think we see the impact of that on typically developing peers to their class. And they’re not taught how to throw properly or how to catch properly. So
those teachers who don’t have those good, basic, fundamental physical skills can’t teach them to a typically developing peer, have even a harder time teaching them with some adaptations for a change.” [P5]

Parent advocates.

The development of opportunities for participating in physical activities has arisen out of the increasing numbers of youth with disability and the parents advocating for opportunities within the community. Participant 2 thinks,

“More parents are better advocates for their kids and knowing that there are ways that their kid could be involved. I don’t know, I think I’m thinking maybe more about those kids in the autism program, but they’re more tied into their team and they have more of that rapport that they can get that support, where 12 years ago we were starting with a very small group of clients. 15 years ago, right, there wasn’t that happening.”

“When talking to a family I just often relate it back to how what opportunities am I looking for my kids. At the core of it, it’s the same. And to me it’s always just the matter of finding people who are willing to just boil it down to that simple nugget and then let everything else just trickle out from there. But sometimes it can be hard getting people to boil it down, right because everybody’s so busy or feel over stressed or overwhelmed or all that kind of stuff. But I think it’s the same with all kids.” [P2]

Families connecting.

Clinicians observed that their centre brought families of their youth clients together putting them in an environment where they talked with each other and shared information.

“The other thing that I see a lot more of is the connections between families that they’re learning about opportunities from each other as well because they’re all…
some of them may be in sledge hockey well there’s also wheelchair tennis, or you
know within they’re little peer network. There’s better relationships, better
connections there.” [P5]

“I think our biggest as TR [Therapeutic Recreation], our biggest resource that we
can provide families is relationships. So we know who the right person to talk to
in sledge hockey is. We know all of the groups and then who to connect to or who
families to talk rather than just saying go and explore. Here’s a list. So if the
family has a keen interest, then we can say you need to talk to… and then the
introduction.” [P5]

“And I think the kids too right, like they see “oh”. They never thought they would
really could do fitness or be interested and do that and through our discussions
and relations with them we’re talking about what’s coming up in track and field,
what’s coming up in school or what’s the school trip and then I think another
extension of that is those families who are sitting out in the lobby talking to each
other about high school transition and busing and all that kind of stuff. There’s all
kinds of benefits that are not just the activity that they’re doing.” [P2]

“That’s right. A lot of rural families, say oh, I wish it was out here. I can’t drive
into London every 3 nights.” [P1]

_Transitioning to adult services._

Clinicians talked about making an effort to encourage youth to be their own decision-
makers by presenting available options in the community. As youth grow older they need
to recognize the resources that would benefit them, and “they have to be really motivated
to carry on when all those supports fade away.” [P1] Clinicians know that youth will
outgrow pediatric rehabilitation services and will need to transition to community
services for adults.

P1: “Similarly with fitness centres so they graduate from our fitness centre and
then there’s limited accessible equipment if they need accessible equipment in the
community. Stoney Creek Y has some assessable equipment. Parkwood has a program, but again you don’t have things to provide support. So they’ve gone from here having one on one support to there without any support. And I think there’s a cost. There’s another gym that’s an accessible gym but really expensive. So that’s a barrier.”

“I think when they’re getting ready to transition into adult services, for example, I’ve witnessed this in the fitness centre, their intent is to continue on to participate in the community. However, I think then the realities of the limited venues there are in relation to what they just came from.” [P2]

“I find that there’s this, for me when I think about youth going into adult services, there’s all those things we are looking for in terms of leisure and rec in those adult living, in the senior population. They have all of those great facilities. They have all of that stuff but it’s too much of an age gap. So if there’s a way to bridge something in there, I think that would be great because there’s a lot of young retirees looking for things to do and facilities are popping up to cater to that population.” [P2]

“I think we’re lucky in our discipline in that we don’t really live inside of a box. We have that flexibility to be creative outside. I met a family in clinic last week from way up north by Collingwood who wanted to start a sledge hockey program. So we can support them in doing that even though that’s not the traditional TR role. I think we’re lucky in that way. TR’s here especially. So that long-term development.” [P5]

“I do think it’s important and I do think more people are more aware now like we’ve talked about over time. If there are more families saying, “Oh I would like to get an adult sized bicycle because so and so have been riding at school and it’s been great and want to carry that on”. So there’s more of that.” [P4]

“I think it does become harder for all those reasons that have been listed. The support, the availability of appropriate programs, the cost. It becomes tricky. I
think they have to be really motivated to carry on when all those supports fade away.” [P1]

Discussion

Summary of Results

This qualitative study highlighted the importance of exercise for the physical, mental and social well-being of youth with childhood-onset physical disabilities; and the multitude of strategies and activities that participants and clinicians enact to facilitate and sustain an active lifestyle. A positive outlook towards physical activity was found among all participants. Youth recognized the physical, mental and social benefits of continued physical activity. Clinicians supported youth and families with a ‘can do’ approach to physical activity. The findings across participants indicate the challenges that exist in the school and community environments and in sustaining physical activity when youth are no longer eligible to receive services from TVCC, and specifically when transitioning into adulthood.

Discussion

As with past studies, both personal and the environmental factors motivated and challenged youth participants in their quest to be, and to remain, physically active. Disability-related factors were also seen as being both challenging and motivating to youths’ physical activity. The influence of these factors on youths’ physical activity is reflected throughout the discussion below of the themes that emerged in this study.

Youth recognized how their disability could subject them to a sedentary lifestyle, but they stressed the importance of how continued physical activity involvement could help to prevent this from happening. “Exercise is important” was a primary theme that
emerged from the youth focus group. They were aware of the physical and mental health benefits from physical activity, as well as the social opportunities. Likewise, the clinician participants discussed the importance of physical activity programs to provide an opportunity for their youth clients to be able to physically participate in a wide variety of activities and sports. They were aware of the “added therapeutic benefits with participation”, which emerged as a theme in the clinician focus group. Clinicians spoke about how youth would come to an exercise program for physical activity but may also make gains in balance, strength, or language skills. “Development as individuals through physical activity” was another theme from the clinician focus group that emphasized youths’ notion of exercise as important. Clinicians saw how participation in various programs has a positive impact on youths’ self-esteem, self-confidence, and overall happiness.

Not only did youth see physical activity as important they actually had a genuine interest in it, as evidenced by another theme from the youth focus group; “interest in physical activity.” Youth talked about being interested in physical activity since childhood and that it was fun. Parents’ preferences for activity had a profound impact on youths’ motivation and enjoyment of various physical activities. One youth talked about becoming interested in a particular sport that their parent was involved with. This finding is supported by past research that indicates parental preferences for activity participation is related to youths’ preferences (King, McDougall, DeWit, Petrenchik, Hurley, & Law, 2009). Youth participants valued the support and encouragement they received from their parents. Parents also took a strong interest in their youths’ desire to be active, which was evidenced by the theme “parent advocates” that arose from the clinician focus group.
Encouraging youths’ interest in physical activity was also a significant goal of the clinicians, as they discussed supporting the youth and families in a ‘can do’ or ‘let’s make this happen’ approach.

Finding the right fit was also important to youth participants. Indeed, “social opportunities in safe environments” was a theme that emerged from the youth focus group. Youth talked about how they preferred to engage in group exercise, whether at school or at the TVCC Adapted Fitness Centre, for a variety of reasons, including being comfortable talking to peers in an accessible environment. Youth discussed how the Adaptive Fitness Centre was a “safe place”, which facilitated conversations in an enjoyable environment. This finding is supported by past research. For example, youth in the Wright et al. (2018) study identified “the right people make activity fun” as the most popular theme. Having fellow youth and instructors who were aware of their conditions encouraged them to be active within a “team” environment (Wright et al., 2018). A similar theme of “a sense of belonging” was discussed by Morris and colleagues (2018). The participants from that study viewed “doing the same thing as everyone else”, as an important motivator to activity engagement.

Clinicians noted that there has been an “increase in community programs” that are inclusive to a wide range of abilities. What used to be considered more “mainstream” programs are now accessible to participants with physical challenges. Morris et al. (2018) discussed the importance of “getting the right fit” in terms of the activity. Participants from that study suggested that the activity should be tailored to the participant so that it was an achievable challenge. In contrast, a parent in that study disapproved of her daughter’s decision to participate in a mixed-aged activity that was not inclusive to her
abilities (Morris et al., 2018). Despite the many benefits of both inclusive and segregated group participation, the clinicians in the present study discussed some of the shortfalls of having youth participate in inclusive activities, as this type of environment may not be the ideal for every youth depending on their disability. The clinicians discussed how some youth may not want to be the only one with a disability in the group. They felt participating with peers of similar ability may help to foster a richer physical activity experience. Some families and youth still like some degree of segregation.

From the clinicians’ perspective, many parents go to great efforts to “make connections” and find developmentally appropriate community programs for their children. Clinicians talked about how families were now more aware of physical activity programs and how their expectations have grown for various programs to be available for their children. Families were also prepared to commute further distances to have their children involved in these programs. Clinicians talked about how they worked with parents to ensure they were “finding the right fit” for their child’s individual activity preferences and needs. They suggested that a lot of youth are looking for an adaptive sport, or alternative recreational opportunity, or leisure activity when mainstream opportunities are not working. Clinicians commented that TVCC programs resulted in “families connecting” with each other to share experiences and advice when deciding what other programs might be good choices for their youth. Clinicians discussed how parents enjoyed networking with other families. Similarly, in the Wright et al. (2018) article, a significant facilitator identified by clinicians in was “parent/family motivation, support and commitment”.
Clinicians discussed a number of concerns surrounding schools being inaccessible and ill equipped to offer the needed resources to encourage physical activity. The physical layout was identified by clinicians as a barrier to physical activity for youth. A good deal of emphasis was placed on teachers not having the appropriate training to teach physical education even to youth without physical disabilities. They explained how youth with physical disabilities were often excluded because teachers did not make necessary adaptations. On the other hand, youth did not focus as much on physical accessibility within the school or on their teachers. Rather, they discussed how their peers at school encouraged them to participate in all activities, making the necessary modifications to facilitate enjoyment and success. Youth were very accepting of their disabilities and appreciated how their peers supported and included them in physical activities.

Being able to stay active was a significant motivator for youth. Indeed, “wanting to stay active” was a theme that emerged from the youth focus group. Youth saw physical activity as a source of success for them and that it could help them optimize their abilities and be good at things like yoga. They wanted to continue their success after leaving TVCC. They talked about trying out and being exposed to community-based sports, and how this gave them encouragement and future goals to reach for, even the Paralympics. Two similar themes, “wanting to succeed” and “being passionate” were identified in the Morris et al. (2018) study, as many of these participants had similar thoughts after they had become involved in physical activity (Morris et al., 2018).

The youth also spoke about being older and how sustaining a physical activity routine would benefit them as they aged. Their thoughts on the future however were grounded in their current physical capabilities and challenges. When asked about whether
they had any additional comments about participating in the future, the youth were very clear in their stories about the environmental day-to-day accessibility challenges they face in the community. Despite this, youth acknowledged the importance of seeking out physical activity programs after leaving TVCC. For this to occur, clinicians discussed how youth must be willing to take advantage of the multiple resources they have currently available to them and to have continued motivation to seek out additional resources when other supports are no longer available.

Clinicians talked about the importance of youth taking charge of their own needs and inquiring about adult adaptive recreational programs in the community. Although the clinicians were happy to provide resources when the time came for youth to be “transitioning to adult services”, clinicians attempted to instill a sense of responsibility, adding that youth need to try to explore these opportunities on their own by making connections with and discussing physical activity opportunities with fellow youth and their families. Clinicians also emphasized how parents were an integral part of providing recreation opportunities for their youth with the help of the resources that clinicians could currently offer to their clients and to their families. While clinicians recognized the importance of encouraging youth to be self-reliant in seeking out opportunities for physical activity in the future, their comments reflected the view that families have an important role in continuing to facilitate these opportunities as youth transition to adulthood.

Study Strengths

This study extended on the past studies described above by further exploring the motivators, experiences, and challenges related to physical activity specifically for youth
with childhood-onset physical disabilities using a wider age range of participants than that used in the Buffart et al. (2009) study. The Wright et al. (2018) study compared the survey findings of youth to semi-structured interviews conducted with clinicians. To allow for greater comparison across the types of respondents, this study conducted focus groups with both youth and clinician participants, facilitating discussion among individuals. Moreover, this study extended on the work by Morris et al. (2018) by including youth participants diagnosed with a range of childhood-onset physical disabilities, not just cerebral palsy. This study also extended on the Morris et al. (2018) study by examining both youth and rehabilitation clinicians’ perceptions of having community programs and an Adapted Fitness Program available to youth, how these clinicians can help to sustain physical activity when youth transition from pediatric services, the way in which the youth and clinicians’ view the impact of transitioning from pediatric to adult programs, and how sustaining physical activity will benefit youth in the future.

**Study Limitations**

This study has several limitations. While qualitative research is not intended to be generalizable, it is important to understand what group’s views the study represents. The views or experiences of youth who do not participate in formal exercise programs designed for youth were not represented. The clinicians and youth participants in this study were recruited solely from Thames Valley Children’s Centre (TVCC). This centre is considered a major rehabilitation site in Southwestern Ontario, providing many different resources for youth with a wide range of disabilities. However, there are 20 other children’s treatment centres across Ontario and the access, environmental issues,
policies and the various recreation programs could vary across different from which participants might also have been recruited. Therefore, the results from this study may not be generalizable to youth and clinicians from other treatment centres.

Youth who participated in this study were either current or past participants of one or more recreation programs offered through TVCC. These participants may have more favourable views of physical activity, not only compared to other TVCC clients, but to other youth with physical disabilities in general. Moreover, the youth participants had relatively mild physical disabilities. Their resultant barriers to physical activity may be minimal in comparison to youth with more severe disabilities. Youth with more debilitating conditions may have limitations that either prevent them from engaging in any form of physical activity or experience other disability-related health concerns that take precedence over any benefits physical activity would provide. Therefore, the study sample of youth may not be representative of the larger population of youth with a childhood-onset physical disability.

An additional limitation of this study involves the data collection procedure. While the youth participants did engage in a focus group prior to completing the Personalized Exercise Questionnaire, the focus group was the only data collection method used with the clinical participants. This makes it more difficult to be sure of data saturation. Although the questions asked during the youth focus group and the clinical focus group were organized in a logical way, some participants may have not been given the opportunity to fully express their thoughts for each question. This could have been due to time restraints of the sessions or apprehension amongst participants with respect to sharing information in a group setting. To rectify this, study researchers did offer
participants the opportunity to partake in individual interviews if preferred. However, no participants chose this option. The Personalized Exercise Questionnaire was also used to access whether additional perspectives were gained from an alternative method of collecting data. Finally, this study did not include the parents of the youth as study participants, as did the Morris et al. (2018) study. Parent perspectives would have provided additional insight into the benefits, experiences, and challenges of physical activity for youth with child-onset disabilities, thus enriching study findings.

**Study Implications**

This study has implications for practice, research and policy. Findings indicate that the Adapted Fitness Program and other community programs provided through TVCC offered youth with childhood-onset disabilities a “safe” and welcoming environment, where they could make friends with peers who share similar physical challenges. The Adapted Fitness Program provided a key place for youth to develop themselves and build self-confidence and self-reliance before going out into the adult community, or in addition to organized sports in the community. Clinicians encouraged youths’ interest in physical activity and provided parents with resources. The programs also offered opportunities to network with other parents. Youth and their families would benefit from the continuation of these programs and similar programs in communities where they do not exist.

The larger environment emerged as a significant challenge for youth when attempting to be physically active. In particular, the school environment could be more inclusive and physically accessible so that students with physical disabilities become more involved in day-to-day activities. This is especially true during physical education,
where meaningful activity opportunities should be continuously encouraged. It would be beneficial for researchers to investigate how school physical education and community recreation programs are delivered to learn how to best serve the needs and the goals of all participants, regardless of ability. Physical education teachers and staff who are hired to run community recreation programs should be required to take additional training sessions that prepare them to provide inclusive, enjoyable physical activities for participants with physical disabilities.
References


Chapter 3: Implications and Conclusion

Implications for Practice

Optimizing physical function while promoting independence and decision making for children and youth are key goals of TVCC and all other Ontario children’s rehabilitation centres. What has been learned from the youth responses as well as the feedback provided by the TVCC clinicians can help improve inclusive physical activity programs offered for youth with childhood-onset physical disabilities both before and after transitioning to adult health services.

A recent study by Gorter and colleagues (2017) engaged researchers and knowledge users in consensus planning to identify the most relevant elements to include guidelines to improve and develop physical activity programs for youth with cerebral palsy. The findings of this study support the most agreed upon elements and would be beneficial to children and youth with all types of childhood-onset physical disabilities. They include: 1) providing a variety of opportunities and experiences in the community to children and youth, including both integrated and segregated options; 2) providing appropriate and life-long education about the importance of physical activity; 3) expanding resources/adapted equipment to meet children and youths’ needs; 4) ensuring programs have enough staff; 5) ensuring program staff are adequately trained; 6) acknowledging the challenges families have; 7) obtaining the support of school boards to train and monitor follow-through of teacher education to ensure all students have equal opportunities for physical activity at school (Gorter, Galuppi, Gulko, Wright, & Godkin, 2017).
Findings of this study indicate that the Adapted Fitness Program and other community programs provided through TVCC offered youth with childhood-onset disabilities a “safe” and welcoming environment, where they could make friends with peers who share similar physical challenges. The Adapted Fitness Program provided a key place for youth to develop themselves and build self-confidence before going out into the adult community, or in addition to organized sports in the community. Youth would benefit from the continuation of these programs and similar programs in communities where they do not exist.

Clinicians in this study discussed some of the shortfalls of the school environment that surrounded active participation. Many of them felt that some teachers lacked the experience and/or the expertise to include every student in meaningful physical education experiences. They talked about how some teachers do not have a physical education background, making it difficult for them to teach even the basic, fundamental movement skills to typically developing students, let alone being comfortable adapting certain activities to meet the needs of students with physical disabilities.

Furthermore, the clinicians commented that aside from instructional shortcomings, some schools have physical barriers, such as the doors to the gymnasium being too narrow to accommodate a sport wheelchair, in which some youth would like to experiment with in physical education class. To provide valuable physical education experiences to students with physical disabilities, therapists could discuss adaptation and modification strategies for certain physical education activities with the physical education teacher. Recreation therapists could plan school visits to determine what strategies teachers could implement to promote equal learning opportunities to all
students, regardless of their physical ability. In some situations, students could become better self-advocates, taking it upon themselves to adapt certain activities to ensure richer physical education experiences.

Youth expressed their concerns about the physical accessibility of public buildings beyond school, which is something that needs to remain on the minds of health care professionals to advocate for on behalf of their clients. It would also be beneficial for adult physical activity programs in the larger community to have adaptive equipment and trained professionals available to facilitate and encourage youth to continue to exercise once they transition to adult services.

**Implications for Research**

The findings from this study indicate that youth are motivated to continue physical activity pursuits after being no longer eligible to participate in recreational activities offered through Thames Valley Children’s Centre. Although the clinicians in this study discussed some community programs that may be well suited to accommodate adults with disabilities, more research into the types of services these organizations provide and how they are provided may be warranted. For example, it may be reasonable to investigate the degree of knowledge and experience that staff at community programs have for working with individuals with disabilities to address their unique fitness goals while providing a safe and inclusive activity environment.

**Implications for Policy**

While Ontario children’s rehabilitation centres provide various recreation programs for children and youth with various physical disabilities, they have been reported to have
struggles with funding (Gorter et al., 2017). Moreover, programs in the community at large do not have the resources available to provide specialized services targeted for youth with disabilities. Increased collaboration among stakeholders such as children’s rehabilitation centres, municipalities, community agencies, school boards, teachers, parents, and youth collaborating together is important to the development of sustainable physical activity programs (Gorter et al., 2017). Advocating for government incentives and grants to support such programs and for establishing guidelines to ensure that staff receive adequate training and that facilities are accessible, safe, and inclusive are policy initiatives that stakeholders could work towards (Gorter et al., 2017).

The Ontario Health and Physical Education Curriculum (2018) provides insight into planning health and physical education programs for students with special needs (Ontario Ministry of Education, 2018). Depending on the needs of the student, they may require accommodations or modified expectations, or both. In any of these situations, teachers have the responsibility to ensure that the student is given the opportunity to participate as fully as possible in health and physical education activities. To ensure this, the Ontario Health and Physical Education Curriculum (2018) developed guidelines for meeting special needs in health and physical education. Some of the most pertinent strategies include focused instruction on what the student can do, rather on his or her disability, communicate with the student when choosing strategies that will help him or her succeed, ensure appropriate equipment is readily available, and be fair to all participants without drawing attention to specific accommodations or modifications (Ontario Ministry of Education, 2018). The Special Education in Ontario, Kindergarten to Grade 12 Policy and Resource Guide (Ontario Ministry of Education, 2017) includes
host of policy statements issued by the Ministry of Education. The “Daily Physical Activity in Elementary Schools, Grades 1-8” statement is particularly relevant to this research project (Ontario Ministry of Education, 2017). Issued in 2017, this document states that “School boards must ensure that all elementary school students, including students with special educational needs, have a minimum of twenty minutes of moderate to vigorous activity each school day during instructional time” (Ontario Ministry of Education, 2017, p. 1). To implement this, activities must be adapted to ensure all students can participate in them regardless of ability. The school principal is responsible for ensuring that these activities are performed in a safe manner (Ontario Ministry of Education, 2017). The hope and expectation is that the establishment of these very recent guidelines and policies will ensure that children and youth will be supported to participate as fully as possible in health and physical education activities. This type of support in childhood and adolescence will help to ensure they are prepared to continue a healthy and physically active lifestyle into adulthood.

**Conclusion**

This study provides insight into the experiences, motivators, and challenges of physical activity engagement for youth with childhood-onset physical disabilities. The study findings revealed how youth valued physical activity and how they were motivated to seek out physical activity programs in the community. The results also indicated the importance of the clinicians and how they played a crucial role in facilitating connections among youth, families and additional community resources, encouraging youth to become better self-advocates when attempting to pursue physical activity outside of TVCC and in the future. The findings across participants indicate the challenges that exist
in the school and community environments and in sustaining physical activity when youth are no longer eligible to receive services from TVCC, and specifically when transitioning into adulthood. More efforts are required to examine if these findings are generalizable to other Children’s rehabilitation centres across Ontario.
References


Appendix A: Western Ethics Approval

Date: 21 March 2018
To Dr. Joy MacDermid
Project ID: 110683
Study Title: The facilitators and barriers of physical activity engagement for youth and young adults with childhood onset physical disabilities.
Application Type: HSREB Initial Application
Review Type: Delegated
Full Board Reporting Date: April 3, 2018
Date Approval Issued: 21/Mar/2018
REB Approval Expiry Date: 21/Mar/2019

Dear Dr. Joy MacDermid

The Western University Health Science Research Ethics Board (HSREB) has reviewed and approved the above mentioned study as described in the WREM application form, as of the HSREB Initial Approval Date noted above. This research study is to be conducted by the investigator noted above. All other required institutional approvals must also be obtained prior to the conduct of the study.

Documents Approved:

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<th>Document Name</th>
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<td>Letter of Information – Clinicians – Revised Mar. 7</td>
<td>Written Consent/Assent</td>
<td>07/Mar/2018</td>
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<td>Letter of Information – Participants age 18 and over</td>
<td>Written Consent/Assent</td>
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<td>Letter of Information – Youth Participants – Revised</td>
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<td>07/Mar/2018</td>
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<td>Personalized Exercise Questionnaire - Revised Mar. 7</td>
<td>Paper Survey</td>
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<td>Updated Protocol</td>
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<td>Updated TVCC Questions – Clinicians - Revised Mar.7</td>
<td>Focus Group(s) Guide</td>
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<td>Updated TVCC Questions - Youth - Revised Mar. 7</td>
<td>Focus Group(s) Guide</td>
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No deviations from, or changes to, the protocol or WREM application should be initiated without prior written approval of an appropriate amendment from Western HSREB, except when necessary to eliminate immediate hazard(s) to study participants or when the change(s) involves only administrative or logistical aspects of the study.

REB members involved in the research project do not participate in the review, discussion or decision.

The Western University HSREB operates in compliance with, and is constituted in accordance with, the requirements of the TriCouncil Policy Statement: Ethical Conduct for Research Involving Humans (TCPS 2); the International Conference on Harmonisation Good Clinical Practice Consolidated Guideline (ICH GCP); Part C, Division 5 of the Food and Drug Regulations; Part 4 of the Natural Health Products Regulations; Part 3 of the Medical Devices Regulations and the provisions of the Ontario Personal Health Information Protection Act (PHIPA 2004) and its applicable regulations. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00009340.

Please do not hesitate to contact us if you have any questions.

Sincerely,
Karen Gopaul, Ethics Officer on behalf of Dr. Marcelo Kremschutsky, HSREB Vice-Chair

Note: This correspondence includes an electronic signature (validation and approval via an online system that is compliant with all regulations).
Appendix B: Thames Valley Children’s Centre Application for Approval of a Research Study

6 February 2018
Dr. Joy MacDermid

Re: The facilitators and barriers of physical engagement for youth and young adults with childhood onset disabilities

Dear Dr. MacDermid,

On February 5, 2018, Thames Valley Children’s Centre’s (TVCC) Research Advisory Committee (RAC) reviewed the above-named project. The study received ‘conditional approval.’ The Committee commented that this study fits well with the goals of TVCC to improve the functioning and participation of clients. The study objectives and overall research plan are clearly stated.

The study will receive full approval once TVCC Research Program has received a letter of approval for the study from Western University’s Health Sciences Research Ethics Board (HSREB). Once ethics approval has been received, you may contact Michelle Truppe to begin recruitment of study participants.

At the completion of your study, TVCC would appreciate it if you would: (1) present the research findings to staff members, (2) provide us with a copy of any final reports or articles that come out of the study, and information about any presentations that are made.

Please contact the Research Program upon the completion of the study to make arrangements for a presentation. The TVCC Research Officer will help you set a date, and will book a room and any audio-visual equipment you will need.

If you have any questions, please do not hesitate to contact me.

The Committee extends their best wishes for a successful project once the HSREB approval letter has been provided to the TVCC Research Program.

Yours sincerely,

Cc: Karen Lowry, Director, QM
    Michelle Truppe, Director, ECS/FCS
Appendix C: Letter of Information

Letter of Information – Youth Participants

Please note that the pronouns “you” and your” refer to your child, who is being invited as a participant in this study.

We are inviting you to participate in a research study that will attempt to identify the benefits of physical activity and exercise for youth and young adults with childhood onset physical disabilities. A physical disability is a limitation on a person’s physical functioning that can affect other areas of daily living.

Participation in this study is voluntary. Participants have the right to withdraw from the study during any stage or choose not to answer questions on the questionnaire without consequence.

Instructions

Please read this letter of information that explains the scope of the study. A research assistant will contact you by telephone or email to discuss your possible participation in the study and to answer any questions you may have.

What is the study about?

This research study will examine the facilitators and barriers to physical activity and exercise for youth and young adults with childhood onset physical disabilities. This study is also interested in determining if participants enrolled in an exercise program at a children’s treatment centre are motivated to continue with an active lifestyle after they are no longer eligible to participate in such community programs. Lastly, this project will examine the ways in which ongoing physical activity benefits youth and young adults with childhood onset physical disabilities in the short and long term.
The study researchers are Joy MacDermid (Principal Investigator), Professor, Western University, and Dr. Janette McDougall, Researcher, Thames Valley Children’s Centre. Matt Downs, a graduate student from the Health and Rehabilitation Sciences department at Western University is the Research Assistant for this project.

**Who will participate in this study?**

We are giving this letter to you as a potential research participant. We are looking for up to fourteen clients to participate in an individual interview or to be part of a focus group.

**What will happen during this study?**

If you decide to take part in this study, you will be a part of a focus group, or an individual interview, depending on your comfort level. The research assistant will administer a questionnaire. The questionnaires will be presented in a semi-structured interview format which will contain open-end questions. There are no right or wrong answers to open-end questions. These types of questions are used to encourage discussion. Participants will be given the opportunity to expand on thoughts that may not have been directly addressed during the data collection process.

The focus group/interview(s) will be audio recorded. The audio recordings will then be listened to and transcribed by the research assistant. The transcripts will be read by the research assistant, the thesis advisor and the thesis advisory committee member. Participant responses from the focus group/interview(s) will be compared and categorized by the research team to identify themes related to the research objectives.

The study will take approximately 12 months to complete. The length of time allocated for each stage is as follows:

- Participant Recruitment – 3 months
- Data Collection – 3 months
- Data Analysis – 3 months
Dissemination – 3 months

**Will anyone know my results?**

The researchers of this study will ensure that any information provided by you during this study will stay private, however full confidentiality cannot be guaranteed within the focus group environment. Identifiers (names) will be removed from all documents once collected. All audio-recordings will be free of identifying information. When results are reported, findings will be presented in a way that it will not be possible to identity anyone’s responses to the questions. All electronic data will be stored at Western University on their secure network. It will be stored in an area on the drive that only study investigators will have access to and will be password protected. Western’s Research Ethics Board (REB) may access records of this project. After a five-year period, all data will be destroyed. Paper data will be destroyed, and electronic data will be deleted from the Western University’s institutional network drive.

**What are the risks and benefits of this study?**

There are no foreseeable risks associated with study participation. Participation in this study is voluntary. You may refuse to participate, choose not to answer the questions, or withdraw from the study at any time, without affecting the services you receive from TVCC.

What we learn from the responses of the youth and TVCC’s clinicians may help foster the improvement/development of fitness programs and transition services for youth and young adults with physical disabilities.

**Will the study cost anything?**

Participation in the study will not cost anything.

If you have any questions about your rights as a research study participant, you may contact:
Office of Research Ethics

Questions?

If you have any questions about the study, please contact Joy MacDermid, the Study Principal Investigator.
Letter of Information – Clinical Participants

We are inviting you to participate in a research study that will attempt to identify the benefits of physical activity and exercise for youth and young adults with childhood onset physical disabilities. A physical disability is a limitation on a person’s physical functioning that can affect other areas of daily living.

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The study researchers are Joy MacDermid (Principal Investigator), Professor, Western University, and Dr. Janette McDougall, Researcher, Thames Valley Children’s Centre. Matt Downs, a graduate student from the Health and Rehabilitation Sciences department at Western University is the Research Assistant for this project.
Who will participate in this study?

We are giving this letter to you as a potential research participant. We are looking for up to seven therapists/service providers that are employed by Thames Valley Children’s Centre to participate in this study.

What will happen during this study?

If you decide to take part in this study, you will be a part of the focus group. The questions addressed in the focus group will be used to encourage discussion. There are no right or wrong answers to open-end questions. These types of questions are used to encourage discussion. Participants will be given the opportunity to expand on thoughts that may not have been directly addressed during the data collection process.

The focus group will be audio recorded. The audio recordings will then be listened to and transcribed by the research assistant. The transcripts will be read by the research assistant, the thesis advisor and the thesis advisory committee member. Participant responses from the focus group will be compared and categorized by the research team to identify themes related to the research objectives.

The study will take approximately 12 months to complete. The length of time allocated for each stage is as follows:

- Participant Recruitment – 3 months
- Data Collection – 3 months
- Data Analysis – 3 months
- Dissemination – 3 months
Will anyone know my results?

The researchers of this study will ensure that any information provided by you during this study will stay private, however full confidentiality cannot be guaranteed within the focus group environment. Identifiers (names) will be removed from all documents once collected. All audio-recordings will be free of identifying information. When results are reported, findings will be presented in a way that it will not be possible to identity anyone’s responses to the questions. All electronic data will be stored at Western University on their secure network. It will be stored in an area on the drive that only study investigators will have access to and will be password protected. Western’s Research Ethics Board (REB) may access records of this project. After a five-year period, all data will be destroyed. Paper data will be destroyed, and electronic data will be deleted from the Western University’s institutional network drive.

What are the risks and benefits of this study?

There are no foreseeable risks associated with study participation. Participation in this study is voluntary. You may refuse to participate, choose not to answer the questions, or withdraw from the study at any time. Participation in this study will not affect employment status at TVCC.

What we learn from the responses of the youth and TVCC’s clinicians may help foster the improvement/development of fitness programs and transition services for youth and young adults with physical disabilities.

Will the study cost anything?

Participation in the study will not cost anything.

If you have any questions about your rights as a research study participant, you may contact:
Office of Research Ethics

Questions?

If you have any questions about the study, please contact Joy MacDermid, the Study Principal Investigator.
Appendix D: Consent and Assent Forms

Consent Form

Study: The facilitators and barriers of physical activity engagement for youth and young adults with childhood onset physical disabilities

Investigators: Dr. Joy MacDermid, Dr. Janette McDougall

Instructions: Please print your name and sign and date this form. Return this form to the study interviewer.

I have read the Letter of Information, have had the nature of the study explained to me and I agree to participate. All questions have been answered to my satisfaction.

_________________________________  ______________________
Name of Participant: ________________

Signature of Participant: _______________ Date: ______________

Person Obtaining Consent

My signature means that I have explained the study to the participant named above. I have answered all questions

Print Name of Researcher: ______________

Signature of Participant: ______________

Date (DD-MM/YYYY): ________________
Youth Assent Form

Project Title
The Facilitators and Barriers of Physical Activity Engagement for Youth and Young Adults with Childhood Onset Physical Disabilities

Principal Investigator
Dr. Joy MacDermid, School of Physical Therapy
Western University

Why are you here?
We want to tell you about a study that looks at what makes exercise fun and enjoyable. We want to see how exercise may help you in the long run.

Why are we doing this study?
We want to see what you like about exercise and what you don’t like about it.

What will happen to you?
If you want to be in the study, we will ask you some questions about what makes exercise fun and what makes exercise not so fun. We can talk about your thoughts with other kids or individually.

Will the study help you?
This study will not help you directly, but in the future, it might help kids who do not like to exercise and be active.

Do you have to be in the study?
You do not have to be in the study. If you start the study, no one will get mad at you if you decide to quit at any time.

What if you have any questions?
You can ask questions at any time, now or later. You can talk to your parents, your family, Dr. MacDermid or Matt Downs.
I want to participate in this study.

Print Name of Child: ______________________

Date: ______________________

Age of Child: ______________________

Name of Person Obtaining Assent: ______________________

Signature of Person Obtaining Assent: ______________________
Appendix E: Youth Focus Group Questions

Focus Group Questions – Youth Participants

Background Questions – To be asked of each youth

1. Can you each tell me your age in years?

2. What is the condition for which you have received services at TVCC?

Warm-up questions – To be asked of the group

3. Do you think it is important to be physically active? Explain your thinking.

4. Do you enjoy participating in physical activity/exercise? Why or why not?

5. How do you usually feel after exercising?

6. Do you enjoy physical education at school? Why/why not?

7. Do you prefer to exercise on your own or in a group? Why is this the case?

Questions for Objective 1 – To examine the facilitators and barriers youth and young adults with lifelong physical disabilities face when attempting/engaging in physical activity.

8. What are some factors that motivate you to exercise/engage in physical activity?

9. What are some factors that discourage you from participating in exercise/physical activity?

Questions for Objective 2 – Are participants of an exercise program based at a children’s treatment centre motivated to continue with an active lifestyle after they are no longer eligible to participate in such community programs?

10. What benefits have you seen since you have started working out at TVCC?
11. Do you participate in any sports and/or recreational activities outside of TVCC? If so, what are they?

12. Do you engage in an exercise routine outside of TVCC? If so, what might this consist of?

**Questions for Objective 3** – How do youth with childhood onset physical disabilities think they will benefit from ongoing physical activity in the short and long term?

13. What do you think the benefits are of continuing to be physically active after leaving TVCC?

14. How do you think continued physical activity could benefit you in the future?
Appendix F: Clinician Focus Group Questions

**Focus Group Questions – Clinical Participants**

1. What are the major goals that clients wish to achieve in therapy/rehabilitation?

2. Where do you think engaging in physical activity/exercise ranks in terms of importance as a goal of therapy/rehabilitation for clients?

3. As a clinician, have you seen major deviations in how clients wish to engage in physical activity/exercise over the years?

**Questions for Objective 1** – To examine the facilitators and barriers youth and young adults (age 12-25) with lifelong physical disabilities face when attempting/engaging in physical activity.

4. What factors in the home, school, or community environments do you see as facilitators of physical activity/exercise for TVCC clients with physical disabilities? Anything else?

5. What factors in the home, school, or community environments do you see as barriers to physical activity/exercise for TVCC clients with physical disabilities? Anything else?

6. What kinds of resources do you as a clinician offer clients and their families regarding physical activity participation in the community? Do you feel there are any other ways that clinicians could facilitate clients’ physical activity participation in the community?

**Questions for Objective 2** – Are participants of an exercise program based at a children’s treatment centre motivated to continue with an active lifestyle after they are no longer eligible to participate in such community programs?

7. What benefits have you seen for clients who participate in exercise programs at TVCC?
8. Where do you think engaging in physical activity/exercise ranks in terms of importance as a goal for clients after they are discharged from TVCC?

9. What if any resources do clinicians at TVCC offer clients and their families after they leave TVCC that would encourage their continued participation in physical activity/exercise?

**Questions for Objective 3** – How do youth with childhood onset physical disabilities think they will benefit from ongoing physical activity benefit in the short and long term?

10. What benefits do you see for clients who continue to be physically active after leaving TVCC?

11. What are some concerns that you may have regarding the continued involvement of physical activity for past clients of TVCC?
Appendix G: Personalized Exercise Questionnaire

This questionnaire is being completed as part of the study called “The Facilitators and Barriers of Physical Activity Engagement for Youth and Young Adults with Childhood Onset Physical Disabilities.”

By completing this questionnaire, you will help us to better understand your exercise preferences, needs, and goals. Your answers will also help us to identify some of the factors that help you or keep you from exercising as much as you would like. What we learn from your answers could be useful for development of future inclusive physical activity programs.

Please complete all questions to the best of your ability. All answers will be kept strictly confidential and never will they be associated with your name.

What is your age? _________

Sex:  Male   Female

Section 1: My Exercise Goals

1. How important are the following goals to you in an exercise program?

<table>
<thead>
<tr>
<th>Not Important</th>
<th>Somewhat Important</th>
<th>Very Important</th>
<th>Not Applicable</th>
</tr>
</thead>
</table>

   a) Increase muscle strength

   b) Have less pain during the day

   c) Have better balance

   d) Be more flexible
e) Be more mobile throughout the day  □  □  □  □  □
f) Feel less tired while active  □  □  □  □  □
g) Fall less often  □  □  □  □  □

2. What is your MOST important exercise goal?

__________________________________________________________________
__________________________________________________________________

Section 2: My Access to Exercise

a) I have a place to exercise other than at TVCC:

□  Yes

□  No

If YES, where do you exercise? Check all that apply.

□  At home

□  At school

□  At a fitness facility (e.g., Goodlife Fitness, YMCA, etc.)

□  Outdoors (e.g., parks, trails, sidewalks, etc.)

□  Other: _________________________
b) I have transportation to and from an exercise site:

□ Yes

□ No

If YES, what type of transportation? Check all that apply.

□ Walking

□ Biking

□ Motor Vehicle

□ Public Transportation

□ Other:_______________________

If traveling by motor vehicle, who might take you? Check all that apply.

□ Myself

□ Family member

□ Friend

□ Other:_______________________

□ Not applicable

Section 3: My Exercise Preferences

a) Where do you prefer to exercise?

□ At home
□ At a fitness facility (e.g., GoodLife Fitness, YMCA, etc.)

□ At a rehabilitation centre (e.g., TVCC)

□ Outdoors (e.g., parks, trails, sidewalks, etc.)

□ Other: ________________________

b) What is the best time for you to exercise? Check all that apply.

□ Morning (between 6:00 am to 12:00 pm)

□ Afternoon (between 12:00 pm to 6:00 pm)

□ Evening (between 6:00 pm to 11:00 pm)

c) What is your preferred exercise class size? Check all that apply.

□ I prefer to exercise alone

□ With a partner/trainer

□ Small group (less than 10 people)

□ Large group (10 or more people)

□ Does not matter

d) How would you like to learn proper exercise technique? Check all that apply.

□ Taught by a health care professional (e.g., physiotherapist)

□ Taught by a personal trainer

□ Learn on my own from an exercise video

□ Learn on my own from a website with pictures
Learn on my own using an app

Learn on my own using a print handout

Have a friend teach me

Have another person with a physical disability teach me

None of the above

e) What level of exercise are you most comfortable doing? Check all that apply.

Easy to perform, slower pace

Somewhat challenging, moderate pace

Challenging to perform, faster pace (i.e., “I like a challenge”)

f) List up to 3 things that help you exercise more often:

1. ________________________________________________________________

2. ________________________________________________________________

3. ________________________________________________________________

Section 4: My Support Network

a) I prefer someone to supervise / assist me with an exercise:

Yes

No
If YES, with whom:

☐ Health care professional (e.g., TVCC staff)

☐ Personal trainer

☐ Other: ____________________

b) I have friends / family with a good attitude toward exercise that encourage me to be active:

☐ Yes

☐ No

c) I have a safe place to exercise:

(e.g., proper space to exercise, dry and clean floors, good lighting, etc.)

☐ Yes

☐ No

d) I have an encouraging place to exercise:

(e.g., pleasant people that motivate me)

☐ Yes

☐ No
Section 5: My Barriers to Exercise

a) Do you have things that stop you from exercising?

☐ Yes

☐ No

If YES, how often does it stop you from exercising?

☐ Always

☐ Very often

☐ Sometimes

☐ Rarely

b) I do not exercise as often as I like because (check all that apply):

☐ I do not like exercise

☐ I do not want to injure myself

☐ I feel pain when I exercise

☐ I feel bored when exercising

☐ Other:__________________
c) I do not exercise as often as I like because I have difficulty (check all that apply):

- [ ] Understanding the exercise
- [ ] Performing the exercise
- [ ] Other: ____________________

d) I do not exercise as often as I like because I do not have (check all that apply):

- [ ] A place to exercise
- [ ] Confidence
- [ ] Finances
- [ ] Mobility
- [ ] Proper quality of sleep
- [ ] Transportation
- [ ] Other commitments
- [ ] Motivation
- [ ] Other: ____________________
e) List any other things you can think of that stop you from exercising more often:

1. ________________________________________________________________

2. ________________________________________________________________

3. ________________________________________________________________

f) If you had fewer barriers would you spend more time exercising?

☐ Yes

☐ No

☐ Not sure

g) What mobility aids do you normally use? Check all that apply.

☐ Cane

☐ Walker

☐ Crutches

☐ Wheelchair

☐ None

☐ Other: ___________________
Section 6: My Feedback and Tracking

a) I would like to receive feedback about my exercise/fitness progress:

☐ Yes

☐ No

If you answered YES, please complete questions b, c, and d below. If No, skip to question e.

b) What type of feedback would you like to receive? Check all that apply.

☐ Regarding my exercise progress and future improvements

☐ Regarding proper exercise techniques

☐ Other: _________________

c) Who would you like to receive feedback from? Check all that apply.

☐ Health care professional (e.g., TVCC staff)

☐ Personal trainer

☐ Other: _________________
d) How often would you like to receive feedback about your exercise progress?

☐ Daily

☐ Weekly

☐ Monthly

☐ Yearly

e) I would like to track my exercise progress:

☐ Yes

☐ No

If YES, using (check all that apply):

☐ Cell phone

☐ Log book

☐ Wearable technology (Fit Bit, pedometer, watch, etc.)

Thank You for Completing this Survey!
Appendix H: Curriculum Vitae

Name: Matt Downs

Post-secondary Education: Bachelor of Physical Education
Brock University
St. Catharines, Ontario, Canada

Related Work: Research Assistant
Western University
2016-2018