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EXAMINING DISABILITY IN THE REGION OF WATERLOO:
PHYSICAL ACTIVITY PROGRAMMING AND CAREGIVING

By

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DISSERTATION

Submitted to the Department of Kinesiology and Physical Education

in partial fulfilment of the requirements for

Doctor of Philosophy in Kinesiology

Wilfrid Laurier University

Nicole Joan Reinders Luymes © 2020

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Abstract

Physical activity (PA) is a necessary component of wellbeing for individuals with and without disabilities. Disabled young people experience many barriers to PA, resulting in inactive lifestyles that compound health issues and hinder their full participation in schools and communities. The following dissertation includes a literature review regarding the effects of PA for young people with a variety of developmental disabilities, in addition to three research studies examining community-based PA programming, and one study exploring the lived experiences of caregivers, all within the Region of Waterloo.

The first study was a needs assessment to examine PA perceptions, practices, barriers, and facilitators for young people within the Region of Waterloo collected via survey data. The second study examined the lived experiences of mothers raising autistic children through one-on-one interviews. Finally, the third and fourth studies were pilot research about an inclusive PA program for disabled young people to determine whether the program affected their wellbeing. Study three examined the program as a whole, while study four examined the experiences of one particular child. The implementation guide has been provided at the end of this dissertation to provide more context regarding the specific activities within the program.

Together, these four studies provide a greater understanding of PA for disabled children, specifically the relationships between PA and caregivers' perceptions of PA for their disabled children, barriers and facilitators to inclusive PA in the Region of Waterloo, and how an inclusive PA program influences disabled young people. The implications of this research are practical, by not only identifying directions for future research, but also providing information to organizations regarding community-based programming.

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This PhD dissertation came to fruition with a great deal of support, for which I am immensely grateful. First, I would like to thank my supervisors – Pam and Paula – for eight years of teaching and guidance throughout three degrees. As I prepare to move on in my career, I will think fondly of our meetings, holiday parties, coffee chats, and conference travels. You have provided countless opportunities that have shaped me both academically and personally.

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Last, to all those who participated in my studies. It has been an honour to speak with caregivers who gave so much of themselves to advocate for their children, and likewise, to watch the children in Movin' and Groovin' grow and develop over time. These four studies could not have been conducted without the support of community members and university volunteers who dedicated their time to participate in this research. It is my hope to motivate change in the community that will stimulate far-reaching benefits for disabled children and their families, both now and in the future.

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A Note on Language

The language around disability has changed greatly over time in attempts to reduce stigma and improve the lives of those most affected (Crocker & Smith, 2019). Person-first language is largely accepted in the literature as a way to show respect for the person as a unique individual, rather than someone who is defined by his or her diagnosis. However, person first language is not without flaws, particularly from a disability rights perspective, which argues that individuals have indeed been shaped by their disabilities and are not ashamed of that fact. By using person-first language, a disabled person may be patronized and belittled as a “victim” of his or her condition, as a person whose life has been reduced by the mere diagnosis. Further, person-first language has been used as a reminder that a disabled person is indeed a person; however, this rule does not apply to other traits such as athlete, Canadian, and gender. Society needs no reminder the athlete is indeed a person and it would be awkward to use the phrase “an individual who is an athlete”. So why then, does society use this language around disability? In his series about person-first language in academic writing, Robert Collier (2012) says,

> *“No reasonable person would challenge the intent behind person-first language. Who, after all, would prefer to be known as a condition rather than as a person? But is this massive effort to change the language of disability and disease having any effect? Is it actually changing attitudes, reducing stigma or improving lives? Skeptics point to the nonexistent body of evidence. Advocates claim it starts with language and that results will follow.”* (p. 1977)

Non-disabled people have contributed to disability research and should be commended for their work, but they have historically been the ones to set the tone and language to describe disability, which is inherently problematic. Thus, from a disability-rights perspective, disability should be described first, as that is part of the individual’s identity. No longer do we use the terms “spastic" or “retarded" to describe Cerebral Palsy and Down syndrome, respectively, and in the same way, it is time to move away from describing someone as "diagnosed with Autism spectrum disorder". Autistic people have voiced their opinions to be referred to as just that: an *autistic person* (Cohen-Rottenberg, 2015; Sinclair, 1999), and it is necessary to respect this decision (Crocker & Smith, 2019). The author of this dissertation recognizes her position as a non-disabled person conducting research *with* disabled people and their caregivers. Communication between disabled and non-disabled people is essential in academic research, just as it has been said by the disability rights movement for years: “nothing about us without us” (Charlton, 1998, title). There will always be room for improvement and humility is necessary in disability research, and therefore, this dissertation utilizes disability-first language.

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List of Abbreviations

ASD: Autism Spectrum Disorder

TD: Typically Developing

PA: Physical Activity

MVPA: Moderate to Vigorous Physical Activity

M&G: Movin' and Groovin'

C: Child (e.g., C6 = child 6)

M: Mother (e.g., M6 = mother of child 16)

V: Volunteer (e.g., V6 = volunteer of child 6)

JV: Junior volunteer (e.g., JV1 and JV2 because there were two junior volunteers)

MABC-2: Movement Assessment Battery for Children, second edition

SRS-2: Social Responsiveness Scale, second edition

SOFIT: System for Observing Fitness Instruction Time

Literature Review

The purpose of this PhD dissertation is to understand the relationship between PA and other health considerations for disabled children and youth, primarily those with developmental disorders. PA is the primary focus of the four studies conducted, with the overall goal of examining the PA behaviours of disabled young people ages 4 to 18. The findings may be utilized in community-based agencies for program development and enhancement. As summarized by Boslaugh and Andresen, (2006), “[a]ny effort to develop interventions for people with disability must be based on knowledge of correlates of physical activity for that population” (p. 4). Therefore, it is necessary to understand both PA and disability before delving into the importance of PA for disabled young people. PA and disability are each discussed below.

Physical Activity and Sedentary Behaviour

PA is any form of purposeful movement that moves the body above resting metabolic rate (Speakman & Selman, 2003). It could take the form of sport, exercise, leisure, self-care, physical therapy, transportation, and play. People engage in PA for many reasons, ranging from enjoyment to rehabilitation. It has been found that risks for various preventable health conditions (e.g., heart disease) were reduced by maintaining an active lifestyle (World Health Organization, 2017). In a systematic review, Poitras and colleages (2016) reported PA of any level (i.e., light to vigorous) was associated with positive cognitive, physical, psychological, and social outcomes for young people aged 5 to 17. Conversely, sedentary has been defined as any wakeful activity below 1.5 METS (metabolic equivalent) while siting, lying, or reclining (Tremblay et al., 2017).

The Canadian Society of Exercise Physiology conducted four systematic reviews to develop research-based guidelines regarding active lifestyle behaviours for young people aged 5 to 17. These reviews examined: (1) health and PA, (2) health and sedentary behaviour, (3) health and sleep, and (4) combinations of all three. Based on this research, the Canadian Society of Exercise Physiology reported young people should achieve 60 minutes of moderate to vigorous PA (MVPA) each day, limit sitting for extended periods, and attain 9 to 11 hours of uninterrupted sleep each night (Tremblay, Carson, & Chaput, 2016). These 24-hour guidelines have become the national standard for PA in Canada.

PA and sedentary behaviour are closely linked to wellbeing for people of all ages; however, many Canadians do not lead active lifestyles. Physical inactivity was prevalent in 2012 and 2013, when only 9% of typically developing young people aged 5 to 17 reached 60 minutes of daily moderate to vigorous PA (Statistics Canada, 2015). Not only were Canadian young people inactive, but they were also sedentary an average of 8.5 hours each day (Statistics Canada, 2015). While PA positively influenced health, it did not mitigate the negative influences of sedentary behaviour (Katzmarzyk, Church, Craig, & Bouchard, 2004). Further, Yang, Helgason, Sigfusdottir, and Kristjansson (2012) found a dose-dependent relationship between electronic screen use (e.g., a common form sedentary behaviour) and mental wellbeing in Swedish young people aged 10 to 12 years (n=10,829). Indicators of poor mental health became more prevalent with increased screen usage. The most prevalent symptom was reduced appetite in boys (15.3%) and sleeping problems in girls (24.8%) (Yang et al., 2012).

Physical inactivity was not only related to mental health concerns, but also overweight and obesity, in that sedentary individuals were more at risk for weight gain (e.g., body mass index). Boyle, Jones, and Walters (2010) reported body mass index and PA were negatively correlated ($r=-0.14$, $p<.001$) for youth aged 11 to 15 years old (n=1,114). Nearly one third of Canadian youth were classified as overweight or obese according to body mass index measures (Statistics Canada, 2015). PA and sedentary behaviour were health concerns for typically developing individuals, but they were even more common for disabled individuals (Boslaugh & Anderson, 2006; Maïano, 2010). This was due in part to personal factors such as disability symptoms and restrictive interests, and environmental factors such as lack of inclusive programming (van der Ploeg, van der Beek, van der Woude, & van Mechelen, 2004). The effects of disabilities have been far reaching, both in Canada and around the world. For the purpose of this dissertation, inclusion has been defined as the participation of disabled people once access has been secured (Kuippis, 2018), specifically a program that has been created with diverse needs in mind, rather than a program that has been retrofitted to suit participants with various disabilities (Harman, 2016). For example, a program that offers supports to ensure a particular child "fits" would be considered integrative, while a program that changes to help all participants thrive would be considered inclusive (Harman, 2016).

Disabilities and the Determinants of Health

> *Disability is part of the human condition – almost everyone will be temporarily or permanently impaired at some point in life…. Disability is complex, and the interventions to overcome the disadvantages associated with disability are multiple and systemic – varying with the context.* (World Health Organization, 2011, p. 7)

Disability is multi-faceted, encompassing issues that affect body function (e.g., physiology), body structure (e.g. anatomy), performance of day-to-day activities, participation in society, environmental factors (e.g. physical barriers), and personal factors (the World Health Organization, 2007). Results from The Canadian Survey on Disability revealed that 13.7% of Canadians aged 15 and older reported some form of disability (Statistics Canada, 2015). The most common disabling issues were excessive pain, reduced flexibility, and restricted mobility. Learning and developmental disorders were the least prevalent (above "unknown" at 0.3%), reported in 2.3% and 0.6% of the population respectively. One in four people reported that their disability was severe and four out of five people with a disability relied on assistive devices

(Statistics Canada, 2015). Disability prevalence increased with age and affected 42.5% of individuals aged 75 and over. In addition, women were more highly represented than men in all age groups, except for the 15 to 24 age group, in which male disability was 0.2% more prevalent than female disability.

Children aged 14 and under were not included in the Canadian Survey on Disability. The most recent statistics for this age group were recorded in 2006, when over 200,000 (1.5%) children aged zero to 14 were reported to have a disability (Statistics Canada, 2008). Statistics regarding individuals aged four and under were difficult to collect, as many concerns were not identified until the children transitioned into daycare or school. While Statistics Canada presented few statistics about this age group, it was reported that 1.2% of children had a disability related to chronic health conditions such as Cerebral Palsy (CP) or Fetal Alcohol Syndrome (FAS) (Statistics Canada, 2008).

Of all school-aged youth 5 to 14 years-old, 3.2% reported a disability (Statistics Canada, 2008). Chronic, learning, and speech related disabilities were the most common among this age group, with boys more likely to be diagnosed than girls. Auditory, motor, and visual disabilities were the least reported (above “other”), with girls more highly represented than boys. For school-aged youth, learning disabilities increased more than all other types between 2001 and 2006. It was also reported that children diagnosed with one disability were more likely to have comorbid diagnoses. Three in four young people had two or more diagnoses and each additional diagnosis was associated with more severe health concerns (Statistics Canada, 2008).

Developmental and Neurodevelopmental Disorders

The statistics above represented a wide variety of disabilities, including developmental disorders, which manifest during growth. Many developmental disorders have been characterized by deficits in conceptual, social, and practical domains that arise during development (before the age of 18) and influence functionality and coping skills (Roebuck, Paquet, & Coultes-McLeod, 2008). Social, motor, and cognitive skill development delays were common in disabled young people and these skills were found to be interrelated (Houwen, Visser, van der Putten, & Vlaskamp, 2016).

Developmental disabilities affecting mental function have been termed neurodevelopmental disorders. According to the American Psychological Association (APA, 2013), neurodevelopmental disorders "typically manifest early in development, often before the child enters grade school, and are characterized by developmental deficits that produce impairments of personal, social, academic, or occupational functioning" (p. 31). Unlike other developmental disorders, the cause of neurodevelopmental disorders is unknown, but has been attributed to a combination of genetic and environmental factors (Roebuck et al., 2008). For instance, Attention-Deficit/Hyperactivity Disorder (ADHD) clusters in families and therefore it was believed to be genetic in nature. Conversely, there has been evidence that exposure to environmental toxins, such as lead, may also be related to ADHD development (Mayo Clinic, 2017). The neurodevelopmental disorders listed in the DSM-5 included intellectual disabilities, communication disorders, Autism Spectrum Disorder (ASD), ADHD, specific-learning disorder, motor disorders, and "other" neurodevelopmental disorders (APA, 2013). Because ASD was the most prevalent diagnosis of the participants in this dissertation, a detailed description of the disorder has been presented below.

Autism Spectrum Disorder

ASD has been characterized by reduced ability in social communication and interaction, as well as restricted and repetitive behaviours and interests (APA, 2013). ASD was first described by Dr. Leo Kanner in 1943 as the "inability to relate [oneself] in the ordinary way to people and situations from the beginning of life" (Kanner, 1934, p. 242). Although the cause of ASD has not been determined, it has been classified as a neurological condition with both genetic and environmental origins. It has been estimated that ASD affects 1% of the population, with males diagnosed four times more than females (APA, 2013).

As specified in the name, ASD has encompassed a wide spectrum of concerns. Therefore, the APA specified three levels of support required for both social functioning and behavioural functioning, which were level one (requiring support), level two (requiring substantial support), and level three (requiring very substantial support). ASD has been reliably diagnosed as early as two years; however, symptoms have typically been detected once children attend formal education. Two categories of specifiers have been defined to provide more detail in an ASD diagnosis: (1) accompanying intellectual impairment, and (2) accompanying language impairment. Individuals have been diagnosed with one, both, or neither of these specifiers (APA, 2013).

ASD has also been associated with other conditions (e.g., medical, genetic) and disorders (e.g. mental, behavioural) (APA, 2013). While ASD has not been characterized by physical concerns, it has been accompanied by delayed motor development and/or stereotyped or self-stimulating motor behaviours (APA, 2013). Rinehart et al. (2006) found that high functioning autistic children (n=10) and those with Asperger's disorder[1] (n=10) displayed abnormal arm postures as compared to a neurotypical control group (n=10) when completing a 10-metre

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[1] *Asperger's disorder was a sub-classification of ASD described in the DSM-IV-TR. Rinehart, et al. (2006) used the DSM-IV-TR for their research; however, the APA has since released the DSM-5 (2013) and removed Asperger's disorder from the ASD diagnosis.*

walking task. Specifically, autistic individuals exhibited more gait variability than children with Asperger's or neurotypical development, while children with Asperger's showed different head and trunk postures than autistic children or neurotypical development. Unfortunately, the motor tests were not sensitive enough to thoroughly test motor skills in autistic children; therefore, the authors urged that future studies utilize more sophisticated measures when testing a highly variable population such as autistic children (Rinehart et al., 2006).

Further to motor concerns, McCoy, Jakicic, and Gibbs (2016) showed that PA likelihood decreased as ASD severity increased ($p<.001$) for children aged 3 to 17 ($n=915$). Additionally, the study found autistic young people were significantly less active and more overweight ($p<.001$) than those without ASD ($n=41,879$). Autistic individuals were less likely to be involved in sports teams ($OR=0.26$, $p<.001$) or extracurricular clubs ($OR=0.47$, $p<.001$) and those with more severe ASD symptoms were less likely to be physically active ($OR=.40$, $p<.001$) (McCoy, Jakicic, & Gibbs, 2016).

Sleep disturbances have been associated with ASD as well. Autistic young people displayed lower sleepiness ratings than young people with other intellectual disabilities or neurodevelopmental disorders, which resulted in concerns such as bedtime restlessness and nighttime wakefulness (Cotton & Richdale, 2010). Rzepecka, McKenzie, McClure, and Murphy (2011) found young people with intellectual disorders and/or ASD ($n=167$) displayed positive relationships between sleep and anxiety ($r = 0.56$, $p < .001$) as well as challenging behaviour (e.g., inappropriate speech, stereotypic behaviour, $r = 0.61$, $p < 0.001$) after controlling for use of medications. Sleep has been considered a secondary concern in ASD, but pharmacological and non-pharmacological treatments have alleviated primary signs and symptoms associated with this neurodevelopmental disorder (Deliens, Leproult, Schmitz, Destrebecqx, & Peineux, 2015).

In sum, ASD has primarily affected behaviour and social relationships, as well as motor function, physical activity, and sleep.

Comorbid Conditions

Comorbid occurrence of neurodevelopmental disorders has been common, meaning that a child received more than one diagnosis based on DSM-5 criteria. For instance, in a community-based sample of 162 children aged four to eight, 18 of 44 autistic children were also diagnosed with ADHD (29%) (Rao & Landa, 2014). A review of 17 studies revealed that 45.1% of individuals with ADHD have also been diagnosed with learning disorders (DuPaul, Gormley, & Laracy, 2013). Further, Ontarian autistic children (n=25) had several secondary conditions, including communication/speech delays (68%), developmental delays (60%), learning disorders (32%), and behavioural disorders (20%) (King et al., 2000).

Individuals with comorbid diagnoses generally experienced more severe symptoms than those with a single neurodevelopmental disability (Statistics Canada, 2008). Children diagnosed with ADHD (Neto, Goulardins, Rigoli, Piek, & Oliveira, 2015) and ASD (Liu, 2012) experienced delayed motor development associated with their disorders. Further, children with psychological disorders (including ASD and ADHD) displayed reduced gross motor performance (e.g., balance and ball skills), as found in a systematic review of motor performance in disabled young people (Emck, Bosscher, Beek, & Doreleijers, 2009). While each child is unique, the literature has demonstrated many similarities in the difficulties faced by children with a variety of developmental disorders. Therefore, the remainder of the literature review will examine developmental disorders more broadly with respect to PA.

PA for Disabled People Across the Lifespan

Physical inactivity has been a health concern for neurotypical youth, but it has been more concerning among disabled young people (Boslaugh & Anderson, 2006; Maïano, 2010), in part due to the fact that disabled young people tend to be more sedentary than their typically-developing peers (Hinckson & Curtis, 2013). Regular PA is an important determinant of health for disabled young people, as reported by Gapin and colleagues (2011), who reviewed the literature and found PA reduced the symptoms associated with ADHD, both short term (i.e., immediately after PA) and long term (i.e. reduced symptoms even without recent PA). Further, Hinckson and colleagues (2013) demonstrated their PA and nutrition program increased motor abilities (e.g., further distance covered in six-minute walk test), improved diet (e.g. reduced confectionary consumed), and improved overall health (e.g. fewer sicknesses) for children with intellectual disability and ASD ($n=22$, $M_{age}=14$ years ± 4 years).

PA programming has also shown far reaching effects for disabled children. For instance, PA programs have been shown to increase social skills (Ibrahim & Nasser, 2010) and attention in school (Tan, Cohen, & Pooley, 2013) for autistic children. Individuals aged 11 to 92 ($M_{age}=49$ years ±16.4 years, $n=788$) with poor physical functioning were more likely to experience reduced mental health and social interactions, and vice versa (Blick, Saad, Goreczny, Roman, & Sorensen, 2015). Further, individuals diagnosed with intellectual disabilities who were more physically active were more likely to be engaged in their communities through routine tasks such as grocery shopping and attending social events (Blick et al., 2015). Intellectually disabled people who made community outings (supermarket $p=.021$; shopping mall $p=.048$; social drinks $p=0.29$; errands $p=.002$) were more active in day to day life (Blick, Saad, Goreczny, Roman, & Sorensen, 2015). Quality of life was found to be positively related to recreational activities (OR

= 3.22, 95% CI:1.22–8.49, p = .01) for autistic adults (n=108, M_{age}=25.5 years ± 6.4 years) (Billstedt, Gillberg, & Gillberg, 2011). Therefore, it may be argued that higher levels of PA have been associated with greater community involvement, including recreation, which subsequently influenced quality of life.

Given the importance of PA, there is a dearth of literature pertaining to PA for disabled individuals, particularly young people. For instance, Rimmer and colleagues (2010) reviewed the literature regarding PA interventions for individuals with physical and/or cognitive disabilities and found an overall need for stronger research that included valid and reliable outcome measures pertaining to specific types of PA. Similar reviews were conducted pertaining to other developmental disorders (Andriolo, Ramos, Atallah, & da Silva, 2010; Heller et al., 2011; Koldoff & Holtzclaw, 2015; Lang et al., 2010). One concern highlighted by Rimmer et al. (2010) was the importance of measuring PA dose, including frequency, intensity, time, and type (FITT) in PA research so that research findings may be applied in other contexts. For instance, if a research study claimed a dance program was beneficial for autistic young people, a professional would need to know several details before implementing the program, such as how often the individuals danced (e.g., once per week), the length of time they danced (e.g., 60 minutes), and the types of dance incorporated into the program (e.g., ballet, hip hop, jazz). Other factors would be important as well, including number of participants in the program, skill of the instructor, and the presence of instructional assistants.

PA programming has been shown to be beneficial for disabled children; however, several challenges have been experienced in efforts to facilitate them. For example, Fragala-Pinkham, O’Neil, and Haley (2010) evaluated a 14-week aquatic exercise program for developmentally disabled children (n=16). The objectives of this program were to: (1) improve children’s swimming skills, (2) encourage children to engage in PA, (3) achieve high parental satisfaction, and (4) develop a sustainable community-based PA program. Through interviews, swimming skill assessment, and questionnaires, it was found that the first three objectives were met; however, the program was not sustainable due to facility and instructor costs (Fragala-Pinkham et al., 2010). Clearly there has been a need for inclusive programming; however, there are barriers that first need to be surmounted before these programs can be implemented.

PA Barriers and Facilitators

Physical inactivity has been shown to reduce overall health for disabled young people. Unfortunately, few disabled young people engage in regular PA (Rimmer & Rowland, 2015; Roebuck, Paquet, & Coultes-Macleod, 2008). The International Classification of Functioning, Disability, and Health (ICF) model has been created by the World Health Organization (2001, 2007) to depict the barriers and facilitators associated with body functions/structures, activities of daily living, and community participation for disabled people. Based on the ICF, as well as the literature surrounding disability and PA, van der Ploeg and colleagues (2004) created the Physical Activity for people with a Disability (PAD) model, which includes personal and environmental barriers of and facilitators to PA, which has been utilized to examine PA and disability in the present dissertation.

Historically, PA was not a priority in the treatment of many autistic young people (Green et al., 2006), although physiotherapy has been common among disabled children (King et al., 2000). Physical inactivity has been found in relation to many health determinants, such as weight management, early development, and sleep quality. Unfortunately, several barriers to PA have been identified for young people with and without developmental disorders. The Canadian Fitness and Lifestyle Research Institute (2013) found the primary barriers to PA for typically developing young people aged 5 to 17 were limited time (e.g., of parent), other obligations (e.g. child's homework), personal characteristics (e.g. child's lack of interest), environmental characteristics (e.g. location of programs), and physical activity costs (e.g. sport registration fees).

Disabled young people experienced similar barriers to their typically developing peers; however, these barriers were magnified by factors associated with disability. For instance, the review of reviews by Martin Ginis et al (2016) highlighted that disabled children and adults have been more sedentary due to personal factors (e.g., intrapersonal and interpersonal), and environmental factors (e.g. institutional, community, and policy). Research pertaining to individuals of varying ages and disabilities was included in the development of the social ecological model (Martin Ginis et al., 2016). Therefore, articles regarding individuals of all ages with a variety of disabilities were included in the review.

Personal Factors

As depicted in the social ecological model, research regarding intrapersonal factors for PA encompassed psychological factors, body functions and structures, and employment status (Martin Ginis et al., 2016). van der Ploeg, van der Beek, van der Woude, and van Mechelen (2004) also listed health conditions, self-efficacy, intention, and attitude as personal determinants for PA. Additionally, Shields, Synnot, and Barr (2012) reported that lack of skill, personal preferences, and fear were personal barriers to PA, while desire to be active and non-competitive opportunities for skill practice were facilitators of PA. The personal factors identified by Martin Ginis, et al. (2016) have been organized into demographics, health conditions, and intrapersonal factors for the present review.

Demographics

As listed above, demographic factors such as gender and culture, have been shown to influence health for disabled individuals (Roebuck et al., 2008). These factors not only affected heath, but also PA. For example, Boslaugh and Anderson (2006) reported that age, race, ethnicity, sex, education, employment, and income were significantly correlated with PA ($p<.001$) for disabled adults ($n=8342$). Specifically, PA rates were positively associated with income and education, but negatively associated with age. Disabled adults were less likely to engage in PA if they were female and/or a visible minority (Boslaugh & Anderson, 2006). Conversely, a study comparing typically developed and disabled youth ($n=98$, aged 13-21) found no group-by-sex or group-by-age differences in the amount of time spent in PA, although disabled females reported significantly more variety in the types of PA in which they engaged and at increased frequency (Stanish et al., 2019). The authors noted these differences did not translate to increased PA for disabled girls, indicating that frequency and variety did not necessarily indicate more time spent in PA overall. This difference did not exist between typically developing and disabled males (Stanish et al., 2019).

Health Conditions

After controlling for demographic factors, young people with a comorbid diagnosis of learning disabilities and ADHD were more likely to be obese than those without learning disabilities and/or ADHD (Cook, Dongmei, & Heinrich, 2015). Further, PA was less likely for young people with learning disorders and/or ADHD than neurotypical young people. These relationships were further complicated when considering medication status (e.g., using medications or not). For instance, trends for physical activity increased for individuals with

ADHD and/or learning disabilities who were on medication, while obesity and sedentary behaviour decreased (Cook et al., 2015).

From Cook and colleagues' (2015) study, it appeared disabled young people were at risk for physical inactivity and obesity. This was particularly concerning because overweight or obese youth with disabilities experienced more adverse health effects (e.g., higher blood pressure) than overweight or obese typically developing youth (Messiah et al., 2015). Signs and symptoms associated with developmental disorders further influenced the risk for inactivity. For example, refer back to the findings of McCoy, Jakicic, and Gibbs (2016), who found an inverse relationship between PA likelihood and severity in autistic children and adolescents, who were also shown to be less active than their non-autistic peers. It has been suggested that many autistic individuals disliked social interactions and excessive sensory stimulation, making participation in typical physical education classes more difficult (Srinivasan, Pescatello, & Bhat, 2014).

Not only was PA influenced by primary concerns associated with developmental disorders, but also secondary health issues. As found by Boslaugh and Anderson (2006), PA was negatively associated with body mass index and general health issues in disabled adults ($n=8342$, $p<.001$). Unfortunately, young people diagnosed with intellectual disabilities (including ADHD and ASD) were more overweight or obese than neurotypical young people (95% CI:1.00, 2.02, $p=.052$) (Curtin, Anderson, Must, & Bandini, 2010; Slevin, Truesdale-Kennedy, Mcconkey, Livingstone, & Fleming, 2014). Obesity has been a significant secondary health condition for young people with learning disabilities, as highlighted in a systematic review by Maïano (2011). The evidence above demonstrated PA was closely tied to health indicators, including weight management, medication use, and disability severity.

Intrapersonal Factors

The review by Martin Ginis et al. (2016) listed intrapersonal psychological considerations as important for disabled individuals, which included negative affect and emotion, attitudes, beliefs, perceived benefits, and self-perceptions. Intrapersonal factors included social support, attitudes, and processes (Martin Ginis, et al., 2016). Personal PA motivators for individuals with intellectual disability have been divided into intrinsic and extrinsic influences (Hutzler & Korsenky, 2010). An intrinsic factor was one's personal reasoning for becoming active, such as enjoyment from PA (Hutzler & Korsenky, 2010). Individual skill level has been shown to be an intrinsic barrier for PA (Shields, Synnot, & Barr, 2012), but unfortunately children with psychological disorders (including ASD and ADHD) displayed lower self-perceived motor competence (Emck, Bosscher, Beek, & Doreleijers, 2009), which may have deterred PA for these children.

Extrinsic factors to PA were those influenced by others, such as recognition for becoming active by other people (Hutzler & Korsenky, 2010). Kwan, Cairney, Hay, and Faught (2013) studied PA in males aged 13 and 14 with developmental coordination disorder (n=19), a neurodevelopmental disorder primarily characterized by motor clumsiness (APA, 2013). Overall, young people with developmental coordination disorder (n=19) displayed significantly lower moderate to vigorous PA, attitudes towards PA, and perceived behavioural control towards PA than neurotypical young people (n=42) (Kwan et al., 2013). Further, the context of a PA program has been shown as a barrier to PA (Kodish, Kulinna, Martin, Pangrazi, & Darst, 2006). For instance, if a student does not like the instructor's teaching style, he or she may not have participated in the activities (Kodish et al., 2006). Clearly, intrinsic and extrinsic psychosocial factors have been relevant for examining PA behaviours for disabled young people.

Environmental Factors

According to the model by Martin Ginis and colleagues (2016), PA was affected by interpersonal, institutional, community, and policy factors for disabled individuals. Many PA considerations reported elsewhere cross these four levels of the social ecological model. To examine the facilitators and barriers in more detail, they have been organized into two categories for the present review: social influences and accessibility.

Social Influences

Social influences were categorized as interpersonal factors of PA for disabled adults (Martin Ginis, et al., 2016). According to King and colleagues (2003), two primary forms of social influence affected PA at the environmental level: relationships with the family and relationships with peers. PA for disabled children was highly influenced by their parents, whose involvement was integral for the PA behaviours of children (Jeong, Kim, & Lee, 2015). For parents of disabled children (n=68, children aged 5 to 13), it was found they positively perceived the importance of PA for their children, regardless of their children's physical abilities (Martin & Choi, 2009). Further, Martin (2006) discovered parental support was an important component of sport participation as perceived by young athletes (n=112, age 12 to 18) with physical disabilities.

Parental support of disabled children (n=240) was highly influenced by parents' behavioural beliefs (e.g. PA is important for child) and normative beliefs (e.g. important people believe parent should support child PA) about PA (Jeong et al., 2015). Parent and community created opportunities for PA were identified as facilitators for disabled young people (Shields et al., 2012). On the other hand, Frey, Buchanan, and Rosser Sandt (2005) reported social supports, including parents, teachers, and health care professionals, discouraged PA and encouraged sedentary behaviour in adults with intellectual disability (n=12). For example, one participant with intellectual disabilities remembered his physical educator told him not to “overdo it” (p. 248) by overexerting himself in his physical education class. In the case of physical education, several participants recalled experiences from the late 80’s and early 90’s when they were in school. It was possible their experiences reflected a lack of knowledge with respect to physical educators at the time (Frey et al., 2005).

Not only were parents and professionals important for PA among disabled children, but also non-disabled peers (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Peer modeling was shown to be a facilitator for PA (Hutzler & Korsensky, 2010), as demonstrated by Chu and Pan (2012), who found peer- and sibling-assisted swimming instruction resulted in greater skill acquisition and social participation than the control (e.g. coach-assisted) instruction for autistic children (n=31, aged 10 to 17). In addition, Ward and Ayvazo (2006), reported two eight-year-old autistic children had increased physical skills (e.g. ball catches) when they were engaged in class-wide peer tutoring as compared to regular involvement in the classroom.

Similarly, Shewen (2014) evaluated a community-based gymnastics program for disabled children with the objective of improving PA and social skills. Participants were randomly assigned to a peer-coached group (n=14) or a parent-coached group (n=13) to determine the effects of peer training. Both groups of children were evaluated before and after participating in the program using adaptive behaviour and physical performance scales. Data analysis revealed all participants experienced improvements in PA and social skills, where the peer group achieved significantly better scores than the parent group (Shewen, 2014).

Conversely, peer interactions have been equally damaging when typically developing young people demonstrated negative behaviours or attitudes towards their developmentally disabled peers (Shields et al., 2012). Specific social barriers of PA for young people with developmental disabilities included having few friends, being stared at by others, and being bullied, in addition to peers who were unsupportive and who viewed them as helpless (Shields et al., 2012). If neurotypical young people were ignorant to the needs of their peers with developmental disorders, they may not have had the knowledge or skills necessary for inclusion. Further, schools and community-based programs may not have had resources to facilitate inclusion between developmentally disabled and typically developing young people (Kodish et al., 2006). Unfortunately, the implications rooted in negative experiences with non-disabled peers and professionals persisted into adulthood for disabled adults and was found to be a barrier to PA (Rimmer et al., 2004).

Accessibility

Disabled young people experienced many barriers to accessibility; however, research primarily focused on disabled adults or the parents of disabled children. Issues associated with PA accessibility in Canada included institutional, community, and policy level facilitators and barriers (Martin Ginis et al., 2016). These issues were present in other countries as well, including Australia, where accessibility was influenced by facilities, transportation, availability of appropriate programs, costs, proximity, and skill of program leaders (Shield et al., 2012).

In the United States, Rimmer et al. (2004) explored external barriers to accessibility through focus groups with adults who had disabilities (n=42), as well as architects, recreation professionals, fitness specialists, park managers, and city planners. These focus groups revealed barriers were experienced both by disabled adults and those who supported PA for disabled adults. For example, the cost for inclusive programming was a barrier for disabled individuals; however, fitness and recreation professionals reported they had little control over costs regulated by facility owners and managers. It was also found gym and recreation facilities were not wheelchair accessible, did not have space to store specialized equipment, and charged the same membership fees for disabled and non-disabled clients, even though the facility was not fully accessible to disabled individuals. Clearly, there were many policy level barriers experienced by a range of professionals who would like to create inclusive environments for disabled individuals (Rimmer et al., 2004).

Barriers to accessibility also included issues with acquiring information pertaining to PA (Rimmer et al., 2004). Primarily, there has been little information indicating the accessibility of gyms and recreation facilities and therefore, disabled individuals had no way of knowing whether they would be accommodated. Fitness professionals did not feel adequately informed about how to improve accessibility, including where to buy equipment and how to adapt exercises. Many of the concerns highlighted by the participants could have been mitigated if government policies were created and procedures were implemented by governing bodies, such as the provincial government. One example of a government policy issue was the lack of transportation for disabled individuals to travel to a gym or recreation facility (Rimmer et al., 2004). While these concerns were highlighted by adults, disabled young people experienced these barriers through their parents, who often facilitated PA involvement for their children (Jeong et al., 2015). For instance, when transportation was unavailable for parents, it was likely unavailable for children.

Evidently, many internal and external factors must be considered regarding PA for disabled young people, specifically with respect to demographics, health concerns, psychological factors, social influences, and accessibility. Professionals should be mindful of these concerns when creating PA programming to reduce barriers for the families of disabled young people who wish to become involved.

Conclusion

The current literature review highlighted the importance of PA for disabled children. The literature review showed that many components of health are positively and negatively influenced by PA and sedentary behaviour for disabled young people. It is necessary to understand these relationships to develop suitable PA programming for disabled young people and subsequently improve their health. This dissertation summarizes four research studies addressing PA and health for disabled young people and their caregivers. Study one examined data collected from surveys to compare PA perceptions, behaviours, facilitators, and barriers of individuals with and without disabilities in the Region of Waterloo. To understand caregiving roles in more detail, study two utilized qualitative research methods to explore the lived experiences of mothers raising autistic children in the Region of Waterloo. This study provides context for the caregiving experience and understanding as to why PA has not been a top priority for families. Studies three and four described and evaluated a PA program for disabled young people called Movin' and Groovin'. The pilot studies explored the effects of the program through interviews with the instructor, volunteers, caregivers (study four only), and children (study four only), in addition to observational data and pre- and post- tests to measure motor and social skills (study four only). Overall, the purpose of this dissertation is to better understand the PA behaviours of disabled young people (study one), the role of their caregivers (study one and two), and how a community-based program influences these behaviours (study three and four).

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Evaluating the Needs of Families Raising Children with And Without Disabilities: Focus on Physical Activity

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Abstract

Background: More than 10% of children in Ontario have an additional need that may influence long-term lifestyle patterns, including physical activity (PA). It is necessary to understand how disabilities affect PA for young people; however, little is known about the influence on families. This study sought to assess the status of PA as well as the barriers to and facilitators of PA for families in southwestern Ontario raising disabled and non-disabled children.

Methods: Complete survey data were collected for 128 families for this study. Data were analyzed using a series of statistical tests such as Mann-Whitney U tests, chi square tests for independence, and descriptive analysis.

Findings: Compared to families raising typically-developing children, families raising disabled children reported reduced enjoyment from PA, were more likely to report programs as too expensive, were more likely to report their PA needs were not met in the region, and placed more importance on inclusive PA. Further, families raising disabled children were less likely to report benefits of PA, including physical fitness, sense of identity, and self-esteem, and were more likely to report negatives associated with PA, including lack of self-esteem, social anxiety, feeling inadequate, and concerns with body image. Despite these differences, there were no differences between amount of PA between the two groups. Open ended responses from the caregivers raising disabled children provided insight as to the need of families in accessing services and therapies throughout the region.

Conclusions: These results point to the importance of developing inclusive and affordable programming in the region to enhance PA enjoyment for all participants, particularly those with disabilities. Community, institutional, and policy level action are warranted to make these changes.

Introduction

More than one billion people worldwide have some form of disability (World Health Organization, 2018), which can affect anyone, regardless of age, gender, income, race, or ethnicity (Couser, 2005). One in nine children (11.1%) in Ontario is estimated to have “special needs” (Stapleton et al., 2015) stemming from a variety of concerns, such as genetic disorders (e.g., Down syndrome), neurodevelopmental disorders (e.g., Autism Spectrum Disorders), and environmental effects (e.g., early-life trauma). For the purpose of this paper, phrases such as special needs, genetic disorders, neurodevelopmental diagnoses, were all included under the umbrella term “disability”. The present study evaluated physical activity behaviours of young people in the Region of Waterloo, Ontario, Canada. According to the most recent statistics, there were more than 98,500 young people aged 5 to 19 years living in the Region of Waterloo in 2016 (Statistics Canada, 2018). If the statistic by Stapleton et al. (2015) holds true, there would be almost 11,000 (i.e., 11.1%) young people in the Region of Waterloo with at least one disability.

The International Classification of Functioning, Disability, and Health describes the relationship between a health condition (e.g., disability), environmental factors (e.g., inaccessibility), and personal factors (e.g., interests) and how these all influence a person’s activities and participation in day to day life (World Health Organization, 2007). There are many far-reaching effects stemming from these factors for disabled people of all ages. For example, Maïno’s review (2011) concluded young people with intellectual disabilities were more at risk for obesity than their typically-developing peers, and the risk continued to grow with age. Disability has also affected many others indirectly, namely caregivers, who often report feelings of burnout and distress when caring for a disabled child (Doig, McLennan, & Urichuk, 2009; Redquest et al., 2015). Additionally, while siblings of disabled children experience some positive effects such as personal growth and maturation, they have been more likely to experience negative outcomes such as anger and resentment (Williams et al., 2010). Co-morbid diagnoses, secondary conditions, barriers to healthcare, and many other elements affect the health and wellbeing of disabled people (World Health Organization, 2018), as well as their families.

There is a great deal of evidence regarding the relationships between physical activity, quality of life, and health for people of all ages and abilities. For example, Sarol and Çimen (2015) found autistic children experienced emotional and physical development after participating in an adapted recreational PA program for eight weeks. Unfortunately, disabled young people experience many barriers to PA, resulting in sedentary lifestyles that compound health issues (Messiah et al., 2015). Based on their review of 22 reviews, Martin Ginis and colleagues (2016) created a social ecological model to depict the barriers to physical activity for people with physical disabilities across the lifespan as they pertain to the healthcare and recreation sectors. The model included intrapersonal, interpersonal, institutional, community, and policy level concerns for disabled people. Children and youth were represented in 11 of these reviews, and all but one study (e.g., prosthetic users) included general and/or neurological disabilities.

PA barriers and facilitators have been well researched, but the question remains as to how these barriers and facilitators affect families, particularly in comparison with families raising children without disabilities. Ayvazoglu et al. (2015) studied PA patterns and beliefs in six families raising autistic children and found both parents and children did not get enough daily PA. Parents highlighted barriers to their own PA (e.g., not enough time) and their children's PA (e.g., lacks social skills), in addition to their personal concerns about their children participating in PA (e.g., fear of child getting hurt) (Ayvazoglu et al., 2015). It is necessary to understand the barriers to PA for disabled children and their families to make changes at the institutional, community, and policy levels. As Boslaugh and Andresen (2006) contended, "[a]ny effort to develop interventions for people with disability must be based on knowledge of correlates of physical activity for that population" (p. 4). Unfortunately, data about said correlates have not been included in much of the literature regarding PA for disabled young people (Askari et al., 2014). For instance, a review of 16 articles found autistic children were less active and had more narrow PA interests than children who were typical developing, but only five (31%) of the studies adequately described factors affecting PA (Askari et al., 2014).

The purpose of this research was to compare the PA patterns, beliefs, barriers, and facilitators of families raising disabled and non-disabled children. The research questions were threefold: (1) what is the status of PA for families raising disabled and non-disabled children; (2) are there differences in barriers and facilitators to PA for families raising disabled children as compared to those with typical development; and (3) what are the needs of families raising disabled children? This research was conducted in conjunction with several other studies regarding the experiences of families raising disabled children in the Region of Waterloo. Therefore, a secondary purpose of this study was to evaluate the state of the community with respect to PA and disability services to provide context for the research conducted.

Methods

A cross-sectional mixed methods design was utilized for this study. Young people aged 18 years and younger, as well as their parents and legal guardians (herein "caregivers") were the population of interest and will herein be referred to as families. NJL created the survey, collected and analyzed the data, and wrote the manuscript, while PCF and PJB supervised the research. One caregiver was asked to complete a survey on behalf of his or her family and provide specific responses for each child (e.g., PA levels of child one vs. child two). The survey addressed PA, factors related to PA participation (e.g., facilitators and barriers of PA), and demographic information about the family (Appendix 1). Survey questions were developed based on the interRAI Child and Youth Mental Health and Developmental Disability assessment (Stewart et al., 2015), the Physical Activity Questionnaire for Older Children and Adolescents (Kowalski, Crocker, & Donen, 2004), the Enjoyment of Physical Activities and the Beliefs about Physical Activities surveys (Stanish et al., 2015), as well as the Physical Activity for People with a Disability model (van der Ploeg et al., 2004). In addition, questions were created for the Centre for Physically Active Communities (CPAC) to better understand the logistical needs of families within the region (e.g., ideal time of day for programming). The survey was edited and approved by the CPAC research committee and ethical approval was obtained before participants were contacted and data collection began.

Participants were recruited via email or flyer from school principals within the Waterloo Region District School Board and the Waterloo Catholic District School Board, links posted on social media (e.g., Healthy Waterloo online magazine), hard copies distributed at after school programming (e.g., volleyball coach asked parents of children in the program), and word of mouth. Survey data were collected electronically via Qualtrics^{XM} and non-electronically with printed copies, the latter of which were manually entered into the Qualtrics^{XM} software by a member of the research team. Data collection began in December 2017 and continued through November 2019.

Analysis

Several forms of statistical analyses were performed, including Mann-Whitney U test (e.g., comparing ordinal and scalar variables) and the chi-square test of homogeneity (e.g., comparing categorical variables) (Laerd Statistics, 2015). A non-parametric test has been selected (e.g., instead of a t-test) due to the ordinal nature of the variables, the non-normal distribution of the data, and utilizing medians to better understand the differences between groups. In addition, descriptive analyses were used to profile the families raising disabled children, such as the types of diagnoses as well as local resources needed for their children (e.g., access to services, unmet needs within the region, etc.). All analyses were carried out using SPSS Statistics v. 25. Thematic analysis was utilized to analyze the qualitative data at the semantic level to provide a description of the concerns outlined by families (for a full description, see Braun & Clarke, 2006).

Results

Participants

Overall, 152 surveys were recorded in Qualtrics^{XM}, but 24 were excluded because they did not complete all questions necessary for analysis (e.g., whether there were any children with a disability). There were 128 families remaining, which accounted for 253 children, or two children per family on average. The sample of children was 46.2% female and averaged 10.1 years of age. More than 60% of families made over $100,000 per year and 85.2% identified as Caucasian. Caregivers reported their children spent at least 30 minutes in MVPA (moderate to vigorous PA) an average of 4.71 days per week.

Twenty-seven families had at least one child with a disability and were compared to 101 families who did not report any disabilities. In this way, families who had both typically-developing and disabled children were organized into the disability category. The disabilities listed by the 27 families included: adjustment disorders, anxiety disorders, attention-deficit/hyperactivity disorder, Autism spectrum disorders, Cerebral Palsy, developmental coordination disorder, fetal alcohol spectrum disorder, learning or communication disorder, GATAD2B-associated neurodevelopmental disorder, Lesch Nyhan disease, and sensory processing disorder. Five families indicated they had a child with a disability but did not specify the diagnoses. Of the remaining 22 families, 13 listed two or more diagnoses per child and/or between multiple children (e.g., one child with two diagnoses or two children, each with a different diagnosis).

Comparing families with and without disabled children

Mann-Whitney U tests were used to determine if differences existed between families raising disabled and non-disabled children (Table 1, Appendix 1). Distributions amongst the dependent variables were deemed similar by visual inspection (Laerd Statistics, 2015). There were no statistical differences between children's age or family income across the two groups. The importance of inclusive PA was significantly higher in families with disabled children (Mdn=inclusive PA is *definitely* important) than those without (Mdn=inclusive PA is *probably* important, U=1647.0, p<.001). Child PA enjoyment was significantly lower in disabled children (Mdn=*often* enjoy PA) than those without (Mdn=*always* enjoy PA, U=1333.0, p=.013).

Altogether, families reported more facilitators (7.5 items listed on average) to PA than barriers (1.5 items listed on average). There were some differences between the two groups regarding the barriers and facilitators of PA; specifically, the ratio of barriers and facilitators was smaller in families raising disabled children (1.5:5.67) than families raising children without disabilities (1:8). The PA facilitators were statistically significantly lower in disabled children (Mdn=5.67 motivators listed) than those without (Mdn=8 motivators listed, U=921.5, p=.010). While not statistically significant, it is worth noting families with disabled children listed more barriers when enrolling their children in PA (Mdn=1.5 challenges listed), than families without disabilities (Mdn=1 challenge listed, U=1647.5, p=.092).

Altogether, families reported beneficial experiences from PA (9.8 items listed on average) than negative experiences (1.8 items listed on average). There were some differences between the two groups regarding the benefits and negatives of PA; specifically, the ratio of benefits and negatives was smaller in families raising disabled children (2.3:8.0) than families raising children without disabilities (1:10.5). The positive PA experiences were statistically significantly lower in disabled children (Mdn=8.0 benefits listed) than those without (Mdn=10.5 motivators listed, U=1014.5, p=.041). While not statistically significant, it is worth noting families with disabled children listed more negative experiences associated with PA (Mdn=2.33 negatives listed), than families without disabilities (Mdn=1 negative listed, U=1633.0, p=.110).

Chi-square tests of homogeneity were used to determine if there were differences between families based on disability status (Tables 2-4, Appendix 1). Fisher exact tests were utilized for any tests where more than 20% of the expected values in each of these comparisons were below five. Families raising disabled children were more likely to report programs as too expensive (n=8, 29.6%) than families raising children without disabilities (n=12, 11.9%), a statistically significant difference of proportions ($X^2_{(1)}$ =5.091, p=.036). In addition, families raising disabled children were significantly more likely to report their PA needs were not being met in the region (n=4, 16.7%, $X^2_{(1)}$ =6.598, p=.027) than families without disabilities (n=3, 3.1%).

There were no other statistically significant differences among the listed variables based on disability status; however, non-significant group differences were worth noting due to the exploratory nature of this research (Table 2, Appendix 1). Thirty-seven percent (n=10 of 27) of families raising at least one child with a disability also reported a health diagnosis (e.g., asthma), as compared to 19.8% families (n=20) without a child with a disability ($X^2_{(1)}$ =3.527, p=.060). In addition, 18.5% families (n=5) raising at least one child with a disability also reported the health condition interfered with PA, while 6% (n=6) of families without a child with a disability reported the same concern ($X^2_{(1)}$ =4.211, p=.055). Lastly, there was no statistically significant difference between the proportion of disabled and non-disabled families who reported their PA needs were being met, despite the difference noted above. Twelve families without disabilities provided a neutral response as compared to zero families with disabilities, which may have accounted for these contradictory findings.

There were several differences in the reported beneficial PA experiences in families based on disability (Table 4, Appendix 1). Families raising disabled children were significantly *less likely* to: 1) report becoming physically fit (n=12, 44.4%, $X^2_{(1)}$ =6.246, p=.012) than families without disabilities (n=71, 70.3%); 2) report building a sense of identity (n=11, 40.7%, $X^2_{(1)}$ =6.373, p=.012) than families without disabilities (n=68, 67.3%); and 3) and report building self-esteem (n=13, 48.1%, $X^2_{(1)}$ =8.767, p=.003), than families without disabilities (n=78, 77.2%). While not significant, families raising disabled children were less likely to report accomplishments as a benefit of PA (n=16, 59.3%, $X^2_{(1)}$ =3.091, p=.079) than families without disabilities (n=77, 76.2%).

Similarly, there were differences in the negative PA experiences for families based on disability (Table 4, Appendix 1). Families raising disabled children were significantly *more likely* to: (1) report lack of self-esteem (n=12, 44.4%, $X^2_{(1)}$ =5.037, p=.031) than families without disabilities (n=23, 22.8%); (2) report social anxiety (n=11, 40.7%, $X^2_{(1)}$ =7.936, p=.005) than families without disabilities (n=16, 15.8%); (3) report concerns with body image (n=7, 25.9%,

$X^2_{(1)}$ =7.891, p=.011) than families without disabilities (n=7, 6.9%); and (4) report feeling inadequate (n=10, 37.0%, $X^2_{(1)}$ =6.672, p=.010) than families without disabilities (n=15, 14.9%). While not significant, families raising disabled children were more likely to report bullying as a negative outcome of PA (n=8, 29.6%, $X^2_{(1)}$ =4.363, p=.075) and to report lack of support from peers (n=4, 14.8%, $X^2_{(1)}$ =4.284, p=.061) than families without disabilities (n=13, 12.9% and n=4, 4%, respectively).

Examining the needs of families with disabled children

At least 48% of families raising disabled children were dealing with more than one diagnosis (e.g., comorbid), making their needs complex. Families raising disabled children listed the services they had accessed (Table 5, Appendix 1), as well as the barriers and facilitators to these services (Table 6, Appendix 1). Twenty (74.1%) of these families had accessed at least one service and 18 (66.7%) had accessed at least one therapy for their disabled children. Pearson's correlation revealed a strong association between the use of services and therapies (r=.893, p<.001), meaning families tended to rely on both resources equally.

There were six open-ended survey questions specifically directed to families raising disabled children to gain clarity regarding their experiences in the region. Eighteen caregivers provided responses, which have been listed in Table 7 (Appendix 1). Generally, families reported the need for increased funding availability and amount, as well as increased flexibility regarding where these funds were spent. This was summarized by a mother who said,

> *"More flexibility - right now we get different envelopes of funding and are restricted to what each can be spent on when we're really like more of one and less of another... Flexibility in time services are available. Doesn't help much when they're primarily available [Monday to Friday] 9[am]-5[pm]... More flexibility in times available."*

Lengthy wait times for therapeutic intervention was a concern for caregivers, as described by a mother of three (one with multiple disabilities) who said, *"Resources in this* *region are very limited and waiting lists are too long."* Caregivers also described a *"lack of respite"* in the region, which was listed in three of the four open ended questions by one caregiver (other adult female of two disabled children) in particular. Further, a mother of four (one with Down syndrome) said *"More respite care. Massive wait list and it takes years to get [respite care]."* Similarly, the father of two children (one with Autism) said *"More affordable [treatments/services]. More support for those who need it."*

Not only did caregivers express the need for increased support, they also felt it would be helpful to have assistance for attaining funding, finding information about raising disabled children, and coordinating between the many services and therapy providers needed to support their children. At the time of this survey, there were some resources in the region for care coordination, as described by the caregiver (other adult female of a child with multiple diagnoses),

> *"We found [children's therapy centre] very helpful in helping us find resources, also [doctor D], Pediatrician. Also the [program] thru Family and Children's Services."*

However, there were more comments regarding the lack of information and service coordination, as described by a mother of two (one with Autism), who said

> *"I would love to see a more stream-lined approach to therapies/treatments. I feel they (services) are so disconnected, it's hard to navigate sometimes."*

A mother of three (one with multiple diagnoses) said, *"I find it difficult to find resources in this region"*, while another mother (one child with multiple disabilities) specified needing

> *"ACCESS TO INFORMATION. Whether therapies and treatments are public or subsidized or private, they are often out there but they are hard to find."*

Regarding her search for extracurricular programming, a mother (one child with multiple diagnoses) said,

> *"[children's therapy centre] published a guide to activities for special needs kids, but every season when I contact many program organizers, they don't actually have any*

> *programs for special needs kids scheduled or the program is so small/offered only once that we are put on a waiting list. This happens every season and it's very frustrating!"*

In the same way, caregivers expressed the need for *"more trained professionals"* who were able to work with disabled children. One caregiver described travelling to multiple cities to find the services she needed for her child with multiple diagnoses, saying *"It would be nice if we didn't have to travel to [city B] or [city C] but that is where the specialists are and it's worth the effort."* The mother of two (one with ASD) said,

> *"More qualified persons working [with] children [with] disabilities. I feel like there is a shortage. You have no choice but to hire and have a person train on your child. Getting lessons w/o having the person question whether or not they can "handle" your child (ex: swim lessons)."*

A father (of two disabled children) expressed his need for more services and treatments, but also a sense of defeat based on his past experiences,

> *"My son was removed from the IBI program when new provincial rules came into effect, though he was nowhere near finished. Receives ABA, but only for a short time once every 2 yrs or so… [There are] Many [treatments or services I would like to see in the region] but honestly given the state of things they seem like pipe dreams. Far more funding for ASD children's therapies is needed."*

Other services described by caregivers included occupational therapy (OT), sensory friendly gyms, alternative therapy options (e.g., art therapy), inclusive exercise programming, and tutoring. From these open-ended responses, it was clear there was room for improvement regarding the services and treatments available for families raising disabled children in this particular region of southern Ontario.

Discussion

Families living in one region of southwestern Ontario were asked to complete a survey regarding their demographics, PA patterns, and needs for raising disabled children. There were no significant differences between families raising children with and without disabilities based on income, minority status, or children's ages. Further, the families raising disabled children were equally likely to report health concerns than those without disabilities, and both groups reported similar levels of these health concerns interfering with their children's PA levels. These similarities allowed for better understanding patterns of PA between the two groups of families. There were few differences between the barriers to and facilitators of PA between these two groups, which were also reported in the review by Shields et al., (2016). However, the authors also reported specific barriers and facilitators for disabled children, such as program availability and physical impairments (Shields et al., 2016). In this study, differences were found between the perceived benefits and negative experiences associated with PA, in that families raising disabled children were less likely to report the benefits and more likely to report negatives.

Children with neurodevelopmental disorders have reported low levels of self-esteem and a general sense of feeling different from their classmates at school (Brook & Boaz, 2005), which can act as intrapersonal barriers for PA. Body image has also been a barrier to PA for adolescent girls (Slater & Tiggemann, 2011); however, PA contributed to improved body image, in addition to confidence, self-esteem (Bedini & Anderson, 2005), and self-perception (Smith, 2015) for disabled girls. Guest and colleagues (2017) found improvements in physical self-perceptions in PA (e.g., self-efficacy), motor skills, and social skills improved for autistic girls aged 8 to 11 years who participated in a multi-sport camp. The benefits of PA may extend beyond childhood, as PA was also found to affect self-esteem and autonomy in disabled young adults (Orr et al., 2019). However, having a sense of identity as an "active person" (p. 730) has been shown as an important predictor in PA levels of people with acquired and congenital disabilities (Saebu & Sørensen, 2011), and thus identity is both a predictor and an outcome of PA. In the present study, caregivers of disabled children were more likely to report lack of self-esteem and concerns with body image, and less likely to report building a sense of identity or self-esteem as pertaining to physical activity. Therefore, it would be beneficial for educators to emphasize the importance of self-esteem, identity, and body image as a component of PA for disabled children.

Similarly, children diagnosed with intellectual disabilities have been reported to have lower levels of physical fitness, but those who engaged in regular PA showed improvements over time (Golubović, Maksimović, Golubović, & Glumbić, 2012). While the literature suggests physical fitness as one of the many outcomes from regular PA, the caregivers of children in the present study were less likely to report this as a benefit of PA if they had disabled children. Though not statistically significant, caregivers of disabled children reported cognitive development as a benefit of PA more often, suggesting there may be differences in the caregivers' goals of PA for their children based on disability status. For instance, the caregiver of a child with learning disabilities may be more interested in developing his/her cognition than physical fitness. Liao and colleagues (2019) found differences in the frequency of activity participation reported by caregivers as compared to that of their disabled children, in addition to differences in rational between prioritizing similar activities. More research would be needed to understand the perspectives of children in the region, as the present study only included a proxy report of the children's experiences with PA.

There were no differences between families regarding PA importance or frequency of PA engagement together as a family, which may indicate ceiling effects on select survey questions. Previous research utilizing accelerometers has shown disabled children to be less active than their typically-developing peers (e.g., Lobenius-Palmér et al., 2018); however, data from typically-developing participants were collected in a separate study and therefore were not conducted at the same time and location as those with disabilities (Lobenius-Palmér et al., 2018). The present study examined caregiver perceptions of PA from the same region and point in time.

Perceptions of whether their children were getting enough PA and the number of days spent in at least 30 minutes of MVPA did not differ between the two groups in this study. It is possible the caregivers of disabled children reported PA differently from caregivers of typically developing children (e.g., due to different opinions of what constitutes moderate to vigorous PA based on the abilities of their children). Alternatively, because all families, regardless of disability status, reported great emphasis on the importance of PA, it is possible the caregivers of disabled children took additional measures to ensure their children were participating in PA, despite it being a less positive experience for the disabled children as compared to the typically developing children. A third possibility is that the PA levels of the siblings compensated for that of the disabled children, and there were in fact differences in PA levels. However, when the families who did not specify which children were disabled were removed (n=3 families, n=7 children), there was no difference in PA between children with and without disabilities and therefore siblings were not compensating for one another. Future research could examine caregiver perception of PA importance in comparison to young people and similarly could examine caregiver perception of PA frequency in conjunction with measured PA.

Overall, caregivers were most likely to report “probably yes” (median) when asked if they felt their children were getting enough PA each day; however, the caregivers in this study reported their children achieved 30 minutes or more of MVPA on 4.71 days/week on average. These PA rates are low considering the guidelines for young people suggest spending at least 60 minutes in MVPA seven days of the week (Tremblay et al., 2016). There were no differences between the two groups in this study regarding sedentary activities (assessed as computer time or TV time), but caregivers reported their disabled children had slightly lower levels of enjoyment from PA. Whereas disabled children “often” (median) enjoyed PA, children without disabilities "always" (median) enjoyed PA. King, Petrenchik, Law, and Hurley (2009) examined differences in enjoyment between formal and informal activities amongst children with and without disabilities. The authors surmised

> *"lower average enjoyment of formal activities by disabled children may reflect a series of cascading processes underlying lack of psychological engagement in activity: lower activity choice and intrinsic motivation, lack of opportunities for meaningful experiences within the activity setting, and lack of physical and emotional support to encourage involvement." (p. 124).*

According to King et al. (2009), enjoyment is a significant concern for disabled young people. Specifically, disabled children reported less enjoyment from formal activities than typically-developing children (King et al. 2009). While formal and informal activities were not specifically explored in this study, it would be important to consider strategies for improving PA enjoyment in disabled children for a spectrum of different activities.

Just as the measures of PA did not differ, there were no differences between caregiver reports of PA engagement at school or extracurricular activities between the two groups. Nonetheless, families raising disabled children were more likely to report their PA needs going unmet in the region. Arim, Finlay, and Kohen (2012) contended that health conditions and sociodemographic factors affected organized PA participation for disabled children but did not affect unorganized PA to the same extent. In the present study, the only significant barrier for families with disabled children was the expense of programming. Taken together, these results could indicate decreased participation in organized activities due to the associated costs and lower levels of enjoyment. It is likely specialized PA programs have been more expensive due to the additional resources required, such as accessible space, trained instructors, one-on-one support, and specific equipment. Alternatively, there are additional costs associated with raising disabled children (Haaf, 2015), such as the special services and therapies listed by over 75% of participants in this study. Thus, it could be families do not have sufficient funds for PA programs after paying for needed services.

As mentioned in the literature review, accessing "special" services may contribute to feelings of otherness for families raising disabled children in their communities (Walsh-Allen, 2010). Interestingly, there was a significant difference between the importance of inclusive PA programming. Caregivers of disabled children said it was "definitely important" (median), while caregivers of children without disabilities said it was "probably important" (median). It would appear from these findings that inclusive PA was more of a concern for families whose children have historically been excluded from group activities than for those who have been included. Fortunately, the caregivers of children without disabilities were not opposed to inclusive PA in this region, they were simply less inclined to list this as a high priority. The openness for inclusion should improve the likelihood of community and institutional acceptance to changes within this region to enhance opportunities for families raising disabled children.

Strengths and Limitations

There were notable strengths and limitations to this research. One of the strengths of this study was the high number of participants from one particular region, where the experiences of families raising children with and without disabilities could be compared. There has been a great deal of literature listing the barriers and facilitators of PA, both within and outside of the context of disability, but few have compared the two within the same time and location. The reviewed literature suggests there are few differences in the barriers of PA between these two demographics, which has been explored by this study. An additional strength was the inclusion of a variety of variables into the analysis to examine PA in depth, as well as the similar demographics between the two groups, which reduced the potential for confounding variables.

The primary limitation of this research was the potential for response bias due to the narrow demographic of individuals studied (e.g., primarily Caucasian and affluent), as well as the low number of families recruited with disabled children (n=27). There may be notable differences between families when more diversity is taken into account, such as lower income and English as a second language. It could be that families who experience privilege are able to overcome many of the barriers of PA, regardless of whether their children have disabilities or not. Therefore, the effect of important sociodemographic factors could not be accounted for in this research. Arim, Findlay, and Kohen (2012) listed caregiver education, family income, and urban location as important sociodemographic factors when examining PA for disabled children. In the present study, caregiver education data were collected for only one caregiver in the survey and therefore it was not possible to explore education level for the family as a whole (e.g., majority of caregivers were married, but education of spouse was not requested). However, income and location within the region were both found to have no relationship with physical activity or disability status. In this way, two important sociodemographic factors were accounted for, thus reducing some bias that could have surfaced due to the limited sample diversity.

A second limitation is the lack of disability information provided by five families. These families indicated at least one of the children were diagnosed with a disability but did not specify which child. As a result, it was impossible to know which of the children within each family had a disability, except for one family with an only child. This lack of information prevented analysis at the child level to deepen understanding of the results at the family level. That said, many studies have already examined PA at the child level, and therefore analyzing the children in this study may have been redundant. As a result, this study considers disability as a family concern rather than an individual concern and contributed new understanding to the existing literature.

Families reported fewer differences from each other than children, perhaps due to the presence of typically-developing siblings within the families.

The last limitation to acknowledge is the caregiver report nature of this study. As noted by Shields et al., (2012), children tend to report personal, peer-related, and environmental barriers to PA, whereas caregivers emphasize social, policy, and program barriers. Therefore, some barriers may have been overlooked due to the lack of children's responses on this survey. In defense of this limitation, the qualitative study by Green et al. (2005) examined direct (e.g., report of disabled children) and indirect (e.g., report of mothers of disabled children) experiences of disability and found evidence of "courtesy stigma" (p. 198) for those with indirect disability experiences, meaning stigma was experienced by those associated with disabled individuals (e.g., mothers), not just the individuals themselves (e.g., disabled child). Therefore, it is likely the caregivers of disabled children were able to accurately report on the experiences of their children.

Conclusion

Despite these limitations, the strengths of the study were notable, and these findings contributed to understanding PA patterns in families raising children with and without disabilities. To summarize, families raising disabled children expressed desire for increased inclusive PA availability and reduced program costs. Disabled children were less likely to enjoy PA and reported fewer motivators; therefore, it is necessary to understand how to bolster enjoyment and motivation specifically for these families. Further, families raising disabled children reported fewer benefits to PA participation as compared to those without disabilities. Concerns with self-esteem, social anxiety, feelings of inadequacy, and body-image were more commonly reported as negative outcomes of PA for disabled children, who were also less likely to report benefits such as gaining physical fitness, a sense of identity, and self-esteem from PA. Despite the challenges listed, there was no difference in the PA levels reported by caregivers raising children with or without disabilities. Regarding disability services, families needed increased funding and increased flexibility in the ways they are allowed to spend said funds. Families also expressed the need for increased respite care, reduced waitlist times, increased information regarding service availability, and assistance with service coordination. From a social-ecological perspective (e.g., Martin Ginis et al., 2016), institutional, community, and policy level changes would be appropriate for addressing the needs uncovered in this research.

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Appendix 1: Evaluating the Needs of Families

Table 1

Mann-Whitney U Test results.

Dependent Variable	**U**	**p**	**r**	**Median: Disability**	**Median: No Disability**
Child age	1400.5	.829	.02	9 years, n=27	9 years, n=101
Family income	990.5	.330	-.09	$100,00 or more, n=27	$100,00 or more, n=101
Is PA important to your family?	1344.0	.894	-.01	Definitely yes, n=27	Definitely yes, n=101
Does your family do PA together?	1338.0	.920	-.01	Sometimes, n=27	Sometimes, n=100
Do your children enjoy PA?	1333.0	.013*	.22	Often, n=27	Always, n=100
Do your children get enough PA?	1094.0	.119	-.14	Probably yes, n=27	Probably yes, n=100
How many days do your children get MVPA per week?	1265.0	.562	.05	4.5 days, n=27	5 days, n=100
Do children do PA at school?	1196.5	.291	-.09	Often, n=27	Always, n=101
How much time do your children watch TV per day?	1366.0	.744	.03	1 hour/day, n=26	1 hour/day, n=101
How much time do your children spend on the computer per day?	1466.5	.540	.05	1 hour/day, n=27	1 hour/day, n=101
Total screen time/day	1443.5	.638	.04	2-3 hours/day, n=27	2-3 hours/day, n=101
Are your children enrolled in activities?	1171.0	.357	-.08	Yes, all year, n=26	Yes, all year, n=101
Are there any challenges (a.k.a., barriers) for your children to engage in PA?	1647.5	.092**	.15	1.5, n=27	1, n=101
Are there any motivators (a.k.a., facilitators) for your children to engage in PA?	921.5	.010*	-.23	5.67, n=27	8, n=101
Are there concerns (a.k.a. barriers) for enrolling your children in PA?	1563.5	.233	.11	1.67, n=27	1, n=101
Have your children experienced benefits (a.k.a. positives) in PA?	1014.5	.041*	-.18	8, n=27	10.5, n=101
Have your children experienced negatives in PA?	1633.0	.110	.14	2.3, n=27	1, n=101
Is inclusive PA important?	1647.0	<.001*	.34	Definitely, n=23	Probably, n=98

*p<.05 **p<.1

Table 2

Chi square test of homogeneity results: Demographics.

Dependent Variable	**Disability**	**No Disability**
At least one diagnosed health condition	10 (37.0%)***	20 (19.8%)***
Health conditions interfere with PA	5 (18.5%)**	6 (6%)**
Visible minority status	5 (18.5%)	14 (13.9%)
Family’s PA needs are met in the region	20 (83.3%)	83 (84.7%)
Family’s PA needs are not met in the region	4 (16.7%)*	3 (3.1%)*

*p=.05, **p=.055, ***p<.075

Table 3

Chi square test of homogeneity results: Facilitators and Barriers.

Dependent Variable	Disability (n=27)	No Disability (n=101)
Barriers		
Lack of interest in participating	10 (37.0%)	39 (38.6%)
No opportunities (e.g. no access to a pool)	1 (3.7%)	3 (3.0%)
Exercise equipment unavailable	2 (7.4%)	4 (4.0%)
Negative influence of friends	0 (0.0%)	3 (3.0%)
Negative influence of family	0 (0.0%)	1 (1.0%)
Does not have appropriate attire (e.g., running shoes)	0 (0.0%)	0 (0.0%)
Poor weather conditions	8 (29.6%)	25 (24.8%)
Unavailable/unaffordable programs	6 (22.2%)	14 (13.9%)
Parks and playgrounds unavailable/unsuitable	2 (7.4%)	3 (3.0%)
Lack of physical ability	0 (0.0%)	4 (4.0%)
Dislike of social situations	3 (11.1%)	15 (14.9%)
No programs available	0 (0.0%)	3 (3.0%)
Programs are too expensive	8 (29.6%)*	12 (11.9%)*
Programs are too competitive	4 (14.8%)	9 (8.9%)
Programs are too far away	1 (3.7%)	2 (2.0%)
Instructors are not trained for the needs of my child(ren)	0 (0.0%)	7 (6.9%)
He/she does not like the instructor	0 (0.0%)	2 (2.0%)
Program schedule or timing does not work with family schedule or timing	7 (25.9%)	21 (20.8%)
Facilitators		
Enjoyment from participation	26 (96.3%)	90 (89.1%)
Opportunities easily accessible (e.g. swimming pool)	15 (55.6%)	49 (48.5%)
Exercise equipment is available	4 (14.8%)	20 (19.8%)
Positive influence of friends	19 (70.4%)	68 (67.3%)
Positive influence of family	20 (74.1%)	71 (70.3%)
Has appropriate attire (e.g., running shoes)	12 (44.4%)	48 (47.5%)
Good weather conditions	16 (59.3%)	45 (44.6%)
Available programs	11 (40.7%)	52 (51.5%)
Parks and playgrounds available	15 (55.6%)	56 (55.4%)
Gets to practice physical skills	16 (59.3%)	47 (46.5%)
Likes social situations	16 (59.3%)	61 (60.4%)
Programs fit his/her interests	23 (85.2%)	72 (71.3%)
Gets to play with friends	23 (85.2%)	72 (71.3%)
He/she likes the instructor	15 (55.6%)	49 (48.5%)

*p=.05, **p=.055, ***p<.075

Table 4

Chi square test of homogeneity results: Positive and negative experiences in PA.

Dependent Variable	**Disability (n=27)**	**No Disability (n=101)**
Positive Experiences		
Made friends	19 (70.4%)	84 (83.2%)
Became physically fit	12 (44.4%)*	71 (70.3%)*
Increased physical activity	21 (77.8%)	88 (87.1%)
Enhanced creativity	10 (37.0%)	41 (40.6%)
Cognitive development	14 (51.9%)	48 (47.5%)
Enjoyment	22 (81.5%)	93 (92.1%)
Motor skill development	21 (77.8%)	83 (82.2%)
Opportunities to move around	19 (70.4%)	77 (76.2%)
Built a sense of identity	11 (40.7%)*	68 (67.3%)*
Developed self-esteem	13 (48.1%)*	78 (77.2%)*
Emotional development	13 (48.1%)	52 (51.5%)
Stress relief	12 (44.4%)	52 (51.5%)
Overcame challenges	12 (44.4%)	56 (55.4%)
Social skill development	16 (59.3%)	67 (66.7%)
Accomplishments	16 (59.3%)	77 (76.2%)
Learned new things	20 (74.1%)	86 (85.1%)
Other	0 (0%)	2 (2.0%)
Negative Experiences		
Has been bullied	8 (29.6%)***	13 (12.9%)***
Lack of self-esteem	12 (44.4%)*	23 (22.8%)*
Lack of enjoyment	12 (44.4%)	32 (31.7%)
Felt that there were no benefits	2 (7.4%)	8 (7.9%)
Felt sore afterwards	6 (22.2%)	14 (13.9%)
Felt sweaty afterwards	3 (11.1%)	11 (10.9%)
Felt bored during the program	8 (29.6%)	36 (35.6%)
Social anxiety	11 (40.7%)*	16 (15.8%)*
Concerns with body image	7 (25.9%)*	7 (6.9%)*
Self-conscious	7 (25.9%)	18 (17.8%)
Felt inadequate	10 (37.0%)*	15 (14.9%)*
Preference for sedentary activity (e.g., TV)	3 (11.1%)	13 (12.9%)
Too time consuming for child(ren)	4 (14.8%)	5 (5.0%)
Lack of support from coaches/instructors	4 (14.8%)	18 (17.8%)
Lack of support from peers	4 (14.8%)***	4 (4.0%)***
Other	0 (0%)	3 (3.0%)

*p=.05, **p=.055, ***p<.075

Table 5

Services Accessed in the Region by 27 Families with Disabled Children

Service	**n (%)**
Life skills training (e.g., increased independence)	6 (22.2%)
Self-care skills (e.g., dressing)	2 (7.4%)
Social skills (e.g., interpersonal skills)	17 (63.0%)
Family functioning (e.g., positive parenting, family cohesion)	3 (11.1%)
Cognitive skills (e.g., reading)	7 (26.0%)
Behaviour management	8 (30.0%)
Crisis intervention	0 (0.0%)
Family preservation (e.g., intensive in-home program)	0 (0.0%)
Family support (e.g., respite care)	3 (11.1%)
Sensory stimulation (e.g., music therapy) or sensory challenges	4 (14.8%)
Education on special topics (e.g., sexuality and safety)	2 (7.4%)
Medication management	5 (18.5%)
Spousal support (e.g., emotional)	0 (0.0%)
Extended family support (e.g., babysitting, emotional)	2 (7.4%)
Non-related community members (e.g., friends, neighbours)	2 (7.4%)
Support groups (e.g., mothers' group)	2 (7.4%)
Siblings (e.g., babysitting)	0 (0.0%)
Emotional regulation	5 (18.5%)
Communication	6 (22.2%)

Table 6

Facilitators and Barriers to Accessing Services and Treatments in the Region

Facilitators (n=15)	**n (%)**
Available funding	10 (66.7%)
Adequate funding	6 (40%)
Support from an allied healthcare provider	6 (40%)
Located within proximity of dwelling	9 (60%)
Access to transportation	4 (26.7%)
Resource coordination	4 (26.7%)
Barriers (n=13)	
Unavailable funding	9 (69.2%)
Inadequate funding	8 (61.5%)
No support from an allied healthcare provider	3 (23.1%)
Located outside proximity of dwelling	1 (7.7%)
Limited access to transportation	0 (0.0%)
Confusion about system/available resources	5 (38.5%)

Table 7

Responses (n=18) from Open-Ended Survey Questions to Families Raising Disabled children.

Question	Quote
If anything, what makes it easier for you to access services?	• "I don't access it much" (C43) • "Accessibility" (C83) • "Awareness of available services" (C88) • "More flexibility - right now we get different envelopes of funding and are restricted to what each can be spent on when we're really like more of one and less of another." (C91) • "credibility of service being provided - is it worth it?" (C117) • "I find it difficult to find resources in this region." (C133)
If anything, what makes it more difficult for you to access services?	• "WAIT LISTS" (C82) • "Flexibility in time services are available. Doesn't help much when they're primarily available M-F 9-5" (C91)
Are there any services or treatments that you are not able to access? If yes, are you seeking these services outside of the region?	• "OT was difficult to find treatment provider - ended up going to Pathways (also provide CBT for anxiety)" (C87) • "Cannot think of any" (C91) • "Specific forms of speech therapy, accessible only in [city A]." (C88) • "N/A" (C98) • "ABA been on waitlist for over 18 months" (C106) • "My son was removed from the IBI program when new provincial rules came into effect, though he was nowhere near finished. Receives ABA, but only for a short time once every 2 yrs or so." (C116) • "not really" (C117) • "all necessary services are available" (C118) • "Resources in this region are very limited and waiting lists are too long." (C133) • "We go to [children's hospital A] in [city B] to see [doctor A's] multi-disciplinary spasticity clinic, She is the Medical Director of Developmental Pediatric Rehabilitation and Autism Spectrum Disorders Services, she assesses and treats C.P. and has studied pediatrics, pediatric Neurology and developmental pediatrics. and [doctor B] who is an orthopedic surgeon there. We have also went to [children's hospital B] in [city C] for Strabismus eye surgery done by [doctor C]." (C134)
Are there any services or treatments you would like to see in the region?	• "tutoring services for kids who find it hard to concentrate in class." (C43) • "Sensory friendly family gyms geared towards children with special needs and their families" (C82)

	• “Would like group exercise for kids the same age (similar to [NL’s program]) but a zumba dance class for teen girls or a soccer group for younger kids so that they can get regular exercise with peers and develop friendships with kids the same age. There is a gym called Active Souls that has some classes but I have not looked in to the cost.” (C87) • “Therapies in the arts: music, art and dance, for example, are rare in our region, both individual and group (and of course they are not covered by insurance)” (C88) • “Unknown” (C91) • “N/A” (C98) • “OT” (C109) • “n/a” (C118) • “Coordination - it's difficult to manage the system” (C114) • “What I need or look for is available in the public space. In public school its not readily made available.” (C117) • “lack of respite” (C120) • “Yes, all of them” (C133) • “It would be nice if we didn't have to travel to [city B] or [city C] but that is where the specialists are and it's worth the effort.” (C134) • “More respite care. Massive wait list and it takes years to get. More camps that accept kids over the age of 13 that provides workers” (C135)
Are there any improvements needed to treatments and services offered in the region?	• “same as previous question” (C82) • “More funding for therapy’s, and different options for natural therapy’s” (C83) • “More OT services available to the school boards” (C98) • “More access to OT. Therapy based groups that work on independence (self care, riding the bus, manage money, relationships with friends and eventual partner)” (C87) • “ACCESS TO INFORMATION. Whether therapies and treatments are public or subsidized or private, they are often out there but they are hard to find.” (C88) • “More flexibility in times available.” (C91) • “Not have autism services coordinated through Erinooke kids. They are not helpful or informative.” (C106) • “Reduce wait times” (C109) • “More affordable. More support for those who need it” (C113) • “Accessibility. Promotion - hard to find/time consuming” (C114) • “Many but honestly given the state of things they seem like pipe dreams. Far more funding for ASD children's therapies is needed.” (C116)

	• “I would love to see a more stream lined approach to therapies/treatments. I feel they (services) are so disconnected, its hard to navigate sometimes” (C117) • “n/a” (C118) • “lack of respite” (C120) • “More trained professionals” (C133) • “See above” (C135)
Do you have anything else to add regarding treatments and services offered in the region?	• “[children’s therapy centre] published a guide to activities for special needs kids, but every season when I contact many program organizers, they don't actually have any programs for special needs kids scheduled or the program is so small/offered only once that we are put on a waiting list. This happens every season and it's very frustrating!” (C 174) • “N/A” (C196) • “More qualified persons working w/ children w/ disabilities. I feel like there is a shortage. You have no choice but to hire and have a person train on your child. Getting lessons w/o having the person question whether or not they can "handle" your child (ex: swim lessons)” (C117) • “n/a” (C118) • “lack of respite” (C120) • “We found [children’s therapy centre] very helpful in helping us find resources, also [doctor D], Pediatrician. Also the [program] thru Family and Children's Services” (C134)

Needs Assessment Survey

Please complete the following questions about yourself.

Q3 What is your birth month and year? (mm/yyyy) ______________________________

Q4 In terms of gender, how would you identify yourself? __________________________

Q5 How would you identify yourself in your family? (e.g., what is your relationship to the children you care for and/or parent)

○ Mother

○ Other adult female (e.g., step-mother, grandmother, aunt, etc.)

○ Father

○ Other adult male (e.g., step-father, grandfather, uncle, etc.)

Q6 What is your marital status?

○ Single

○ Married

○ Widowed

○ Common law

○ Other

Q7 Where do you live in the Region of Waterloo?

○ Kitchener

○ Waterloo

○ Cambridge

○ Township of Woolwich

○ Township of Wellesley

○ Township of Wilmot

○ Township of North Dumfries

○ Other

Q8 What is the highest level of education that you have completed?

○ Did not complete high school

○ High School or GED

○ Some college

○ Trade or apprenticeship

○ Bachelor's degree

○ Master's degree

○ Advanced graduate work or PhD

○ Other

Q9 What is your current employment status?

- ○ Full time
- ○ Part time
- ○ On temporary leave
- ○ Unemployed
- ○ Student
- ○ Other

Q10 What is your ethnicity?

- ○ Asian/Pacific Islander
- ○ Black/African American
- ○ Indigenous (First Nations, Métis, or Inuit)
- ○ Latino/Hispanic
- ○ Caucasian
- ○ Multi-racial/Multi-ethnic
- ○ Other ____

Q11 What is your family's annual income?

- ○ less than $25,000
- ○ $25,000-$40,000
- ○ $40,000-$55,000
- ○ $55,000-$70,000
- ○ $70,000-$85,000
- ○ $85,000-$100,000
- ○ $100,000 or more
- ○ Prefer not to say

Q12 What is your primary mode of transportation?

- ○ Walk
- ○ Bike
- ○ Bus or public transit
- ○ Personal vehicle
- ○ Other

Q13 Do you have access to a personal vehicle?

- ○ Yes
- ○ Sometimes
- ○ No

Please answer the following questions about your family.

Q15 Is physical activity important to you and your family?

○ Definitely yes

○ Usually yes

○ Neutral

○ Sometimes not

○ Definitely not

Q16 Does your family engage in physical activity together?

○ Always

○ Sometimes

○ Never

Q17 Please complete the chart below about your child(ren).

	Child 1	Child 2	Child 3	Child 4
Birth (mm/yyyy)				
Identified Gender				

Q18 How would you identify your child(ren)'s racial or ethnic background? Please select all that apply.

	Child 1	Child2	Child 3	Child 4
Asian/Pacific Islander				
Black/African American				
Indigenous (First Nations, Métis, or Inuit)				
Latino/Hispanic				
Caucasian				
Multi-racial/Multi-ethnic				
Other				

Q19 In which type of education is (are) your child(ren) enrolled?

	Child 1	Child 2	Child 3	Child 4
Public				
Catholic				
Private				
Other				

Q20 Do(es) your child(ren) have any health conditions (e.g., asthma, diabetes, etc.)?

○ No

○ Yes, please list ____

Q21 Do any of these conditions affect your child(ren)'s ability to participate in physical activity?

○ No

○ Yes, please specify which conditions ____

Q22 Does your child have any developmental disorders and/or disabilities?

○ Yes

○ No

Q23 Please indicate your child(ren)'s diagnoses. Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Adjustment disorders				
Angelman Syndrome				
Anxiety disorders				
Attention-Deficit/Hyperactivity Disorder				
Autism Spectrum Disorders				
Bardet-Beidl Syndrome				
Cri-du-chat Syndrome				
Cerebal Palsy				
Developmental Coordination Disorder				
Disruptive Behaviour Disorder				
Down Syndrome				
Fetal Alcohol Spectrum Disorders				
Fragile X Syndrome				
Hunter Syndrome				
Hurler Syndrome				
Klinefelter Syndrome				
Learning or communication disorder				
Mood disorders				
Muscular Dysrophy				
Prader-Willi Syndrome				
Reactive Attachement Disorder				
Schizophrenia or other psychotic disorder				
Spina Bifida				
Substance-related Disorders				
Seizure Disorders				
Rett Syndrome				
Turner Syndrome				
William's Syndrome				
Other, please list: __________________________ ____				

Q24 Has(ve) your child(ren) utilized any formal treatments (e.g., physiotherapy) or services (e.g., respite care) within the Region of Waterloo in the last 12 months?

	Not applicable	Satisfied	Somewhat satisfied	Neither	Somewhat dissatisfied	Dissatisfied
Psychiatrist						
Social worker						
Psychologist						
Behaviour therapist						
Recreation/ art/ music/ play therapist						
Child/youth counsellor						
Child protection						
Developmental services worker						
Healthcare aid/personal support worker						
Dietitian						
Physiotherapy						
Occupational Therapy						
Speech/language pathologist						
IBI/ABA						
Respite care						
Chiropractor						
Osteopathy						
Massage						
Naturopath						
Pediatrician						
General practitioner						
Other (please list)						

Q25 What is the focus of services utilized for your child(ren) with disabilities? Please check all that apply.

	Child 1	Child 2	Child 3	Child 4
Life skills training (e.g., increased independence)				
Self-care skills (e.g., dressing)				
Social skills (e.g., interpersonal skills)				
Family functioning (e.g., positive parenting, family cohesion)				
Cognitive skills (e.g., reading)				
Behaviour management				
Crisis intervention				
Family preservation (e.g., intensive in-home program)				
Family support (e.g., respite care)				
Sensory stimulation (e.g., music therapy) or sensory challenges				
Education on special topics (e.g., sexuality and safety)				
Medication management				
Spousal support (e.g., emotional)				
Extended family support (e.g., babysitting, emotional)				
Non-related community members (e.g., friends, neighbours)				
Support groups (e.g., mothers' group)				
Siblings (e.g., babysitting)				
Emotional regulation				
Communication				
Other (please list): ______________________________ ____				
None of the above				
Not applicable				

Q26 What, if anything, makes it easier for you to access the services you need in the Region of Waterloo? Check all that apply.

☐ Available funding

☐ Adequate funding

☐ Support from an allied healthcare provider (e.g., doctor, therapist)

☐ Located within proximity of your dwelling

☐ Access to transportation

☐ Resource coordination

☐ Other (please list) ____

☐ None of the above

☐ Not applicable

Q27 What, if anything, makes it difficult for you to access the services you need in the Region of Waterloo? Check all that apply.

- ☐ Unavailable funding
- ☐ Inadequate funding
- ☐ No support from an allied healthcare provider (e.g., doctor, therapist)
- ☐ Located outside proximity of your dwelling
- ☐ Limited access to transportation
- ☐ Confusion about system/available resources
- ☐ Other (please list) ____
- ☐ None of the above
- ☐ Not applicable

Q28 Are there any therapies or treatments in the Region of Waterloo that you are not able to access? If yes, what are these services and are you seeking these services outside of the Region of Waterloo?

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Q29 Are there any therapies or treatments that you would like to see in the Region of Waterloo?

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Q30 If any, what improvements would like to see regarding therapies or treatments offered in the Region of Waterloo?

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Q31 Do you have anything else to add regarding therapies or treatments offered in the Region of Waterloo?

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Please answer the following questions about your child(ren)'s current physical activity.

Q33 Overall, do(es) your child(ren) enjoy physical activity? (Reminder, physical activity includes active transportation, sport, play, etc.)

	Child 1	Child 2	Child 3	Child 4
Always				
Often				
Sometimes				
Rarely				
Never				
Not sure				

Q34 Overall, do you feel that your child(ren) is (are) getting enough physical activity each day?

	Child 1	Child 2	Child 3	Child 4
Definitely yes				
Probably yes				
Might or might not				
Probably not				
Definitely not				
Not sure				

Q35 In a typical school week, how many days did your child(ren) participate in physical activities or sports at these locations over a 7 day period? (e.g., answers will be 0 to 7)

	Child 1	Child 2	Child 3	Child 4
School grounds (during school)				
School grounds (outside of school hours)				
Fitness centre (e.g., YMCA, other gyms, etc.)				
Arenas or studios (e.g., hockey, dance, etc.)				
Public or private swimming facilities				
Park or playground				
Public outdoor recreation facilities (e.g., soccer field, baseball diamond, etc.)				
Neighborhood (e.g., sidewalks, backyards)				
Indoor gymnasiums (e.g., basketball, volleyball)				
Other, please specify				

Q36 Do(es) your child(ren) engage in physical activity at school?

	Child 1	Child 2	Child 3	Child 4
Always				
Often				
Sometimes				
Rarely				
Never				
Not sure				

Q37 In what types of physical activities do(es) your child(ren) participate in school?

	Child 1	Child 2	Child 3	Child 4
Before school activities				
After school activities				
Lunch hour activities				
During balanced school day breaks				
Physical Education				
Other				
Not sure				

Q38 On an average school day, how many hours do(es) your child(ren) watch TV?

	Child 1	Child 2	Child 3	Child 4
Does(do) not watch TV on an average school day				
Less than 1 hour per day				
1 hour per day				
2-3 hours per day				
4 or more hours per day				

Q39 On an average school day, how many hours do(es) your child(ren) play video or computer games or use a computer/tablet for something that is not schoolwork? (Include activities such as Ninetendo, DS, Play Station, Xbox, Facebook, Twitter, computer games, and the internet).

	Child 1	Child 2	Child 3	Child 4
Does(do) not play video or computer games or use a computer/tablet for something that is not schoolwork				
Less than 1 hour per day				
1 hour per day				
2-3 hours per day				
4 or more hours per day				

Q40 How many days during a typical week do(es) your child(ren) engage in at least 30 minutes of moderate to vigorous physical activity? Answers should range from 0 to 7. Examples of moderate intensity: walking briskly (3 miles per hour or faster, but not race-walking), swimming, bicycling slower than 10 miles per hour, dancing, active play. Examples of vigorous intensity: jogging, or running, bicycling 10 miles per hour or faster, jumping rope, playing a sport (e.g. soccer, hockey, basketball).

	Child 1	Child 2	Child 3	Child 4
Number of days				

Q41 Is (are) your child(ren) currently enrolled in any sports or structured activities?

	Child 1	Child 2	Child 3	Child 4
Yes, all year				
Yes, seasonally				
No				

Q42 What are the reason(s) you enrol you child(ren) in physical activity programs? Select all that apply.

	Child 1	Child 2	Child 3	Child 4
To develop general physical skills				
To develop sport specific skills				
To make friends				
To be with friends				
Respite for caregiver				
For child(ren)'s enjoyment				
To develop active lifestyle choices				
To keep your child(ren) busy				
Other				
Not applicable, not enrolled in physical activity				

Q43 In which ways is (are) your child(ren) physically active? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Transportation (e.g., biking to school)				
Physical education class at school				
Exercise games (e.g., Wii Sport)				
Physical activity programs (e.g., swimming)				
Sports or teams (e.g., soccer)				
Interactions with pets (e.g., dog walking)				
Active play with friends (e.g., play date)				
Active play with siblings				
Personal fitness (e.g., yoga, gym)				
Other				
No activity				

Q44 In what type of physical activity is (are) your child(ren) engaged? Please check all that apply.

	Child 1	Child 2	Child 3	Child 4
Walking or hiking				
Running or jogging				
Cycling				
Rowing				
Swimming or scuba diving				
Racquet sports (e.g. tennis)				
Leisure maintenance activities (e.g., housework, gardening)				
Exercise or dance class				
Team sports (e.g. soccer)				
Home work out (e.g. yoga, body weight training)				
Other				
None				

Q45 Is there anything that makes physical activity challenging for your child(ren)? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Lack of interest in participating				
No opportunities (e.g. no access to a pool)				
Exercise equipment unavailable				
Negative influence of friends				
Negative influence of family				
Does not have appropriate attire (e.g., running shoes)				
Poor weather conditions				
Unavailable/unaffordable programs				
Parks and playgrounds unavailable/unsuitable				
Lack of physical ability				
Dislike of social situations				
No programs available				
Programs are too expensive				
Programs are too competitive				
Programs are too far away				
Instructors are not trained for the needs of my child(ren)				
He/she does not like the instructor				
Program schedule or timing does not work with family schedule or timing				
Other				
Not applicable				

Q46 Are there factors that motivate your child(ren) to become physically active? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Enjoyment from participation				
Opportunities easily accessible (e.g. swimming pool)				
Exercise equipment is available				
Positive influence of friends				
Positive influence of family				
Has appropriate attire (e.g., running shoes)				
Good weather conditions				
Available programs				
Parks and playgrounds available				
Gets to practice physical skills				
Likes social situations				
Programs fit his/her interests				
Gets to play with friends				
He/she likes the instructor				
Other				
Not applicable				

Q47 If any, what are the negatives that your child(ren) have experienced with physical activity programs? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Has been bullied				
Lack of self-esteem				
Lack of enjoyment				
Felt that there were no benefits				
Felt sore afterwards				
Felt sweaty afterwards				
Felt bored during the program				
Social anxiety				
Concerns with body image				
Self-conscious				
Felt inadequate				
Preference for sedentary activities (e.g., TV)				
Too time consuming for child(ren)				
Lack of support from coaches/instructors				
Lack of support from peers				
Other				
None				

Q48 If any, what are the benefits your child(ren) has experienced with physical activity programs? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Made friends				
Became physically fit				
Increased in physical activity				
Enhanced creativity				
Cognitive development				
Enjoyment				
Motor skill development				
Opportunities to move around				
Built a sense of identity				
Developed self-esteem				
Emotional development				
Stress releif				
Overcame challenges				
Social skill development				
Accomplishments				
Learned new things				
Other				
None				

Q49 If any, what are your concerns with enrolling your child(ren) into a physical activity program? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Program expenses				
Safety concerns for your child(ren)				
Lack of supervision				
Bullying of your child(ren)				
Lack of enjoyment of your child(ren)				
Too time consuming for you				
Too time consuming for your child(ren)				
Feel that it is not a priority				
Other				
None				

Q50 Please list your typical program registration expenses and for which programs (e.g., $200 for 10 hours of dance instruction). Please list all activities separately. If not applicable, write N/A.

	Child 1	Child 2	Child 3	Child 4
Program 1 and cost				
Program 2 and cost				
Program 3 and cost				
Program 4 and cost				

Please answer the following questions about the ideal physical activity programming for your child(ren).

Q52 How far are you willing to travel for physical activity programs for your child(ren)?

	Child 1	Child 2	Child 3	Child 4
Less than 5km				
5-10km				
10-15km				
15km or more				

Q53 How long should a physical activity program last for your child(ren)?

	Child 1	Child 2	Child 3	Child 4
8 weeks or less				
8-12 weeks				
12-16 weeks				
Entire school year				

Q54 What is the ideal length of time for a physical activity session for your child(ren)?

	Child 1	Child 2	Child 3	Child 4
30 minutes or less				
30 minutes or more				
45 minutes or more				
60 minutes or more				

Q55 When would you prefer physical activity programs to begin for your child(ren)? Check all that apply.

	Child 1	Child 2	Child 3	Child 4
Fall				
Winter				
Spring				
Summer				

Q56 How many times per week should a physical activity program run for your child(ren)?

	Child 1	Child 2	Child 3	Child 4
2/week or less				
2/week or more				

Q57 During what times would you prefer the physical activity sessions to run for your child(ren)?

	Child 1	Child 2	Child 3	Child 4
Weekday before noon				
Weekday 12pm-4pm				
Weekday 4pm-6pm				
Weekday after 6pm				
Weekend before noon				
Weekend 12pm-4pm				
Weekend 4pm-6pm				
Weekend after 6pm				

Q58 Is inclusive physical activity programming (e.g., children of all abilities) beneficial for your child(ren)?

○ Definitely yes

○ Probably yes

○ Neutral

○ Probably not

○ Definitely not

Q59 If any, are there any other types of extracurricular programming that you are interested in enrolling your child(ren)? Check all that apply.

- ☐ Cooking classes
- ☐ Nutritional education
- ☐ Scientific education (e.g., biology, chemistry, physics, math)
- ☐ Humanities education (e.g., psychology, sociology, anthropology)
- ☐ Arts education (e.g., English, history, languages, communications)
- ☐ Computer science
- ☐ Creative arts (e.g., dance, drama, music, visual arts)
- ☐ Social group (e.g., fun activities and games with similar children)
- ☐ Mental health education (e.g., depression, anxiety, self-esteem)
- ☐ General health education
- ☐ Volunteer opportunities within the community
- ☐ Other (please specify) ____
- ☐ None

Q60 If at all, where do you look for physical activity programming for your child(ren)? Check all that apply.

- ☐ Internet
- ☐ Word of mouth from family and/or friends
- ☐ Community activity guides
- ☐ Prior experience with the program
- ☐ Healthcare professionals
- ☐ Other ____

Q61 Do you feel that your family's physical activity needs are met in the Region of Waterloo?

- ○ Definitely yes
- ○ Probably yes
- ○ Might or might not
- ○ Probably not
- ○ Definitely not

Q62 Are there physical activity opportunities/programming that are currently missing for your child(ren)?

- ○ No
- ○ Yes, please specify: ____

Q63 If you could change anything to better support your family (yourself, your children, etc.), what would it be and who needs to know about it?

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Thank-you for completing this survey! After the survey data has been collected, we would like to interview a smaller group of people to get more information about physical activity in the Region of Waterloo. If you would like to do an interview, leave your phone number or e-mail address at the bottom of this page and tear on the line. Your contact information will not be connected to the responses that you gave in this interview.

"It's Not a User-Friendly System": Mothers' realities of raising Children with Autism Spectrum Disorders

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Keywords: Autism Spectrum Disorders, child, mother, qualitative, phenomenology, resources

Abstract

Background: Mothers of autistic children experience the stressors of parenting, as well as the effects of caregiving for disabled individuals. One in 66 children is diagnosed with ASD in Canada, but there is no known cause of the disorder. While research has explored the many effects of ASD and potential therapies and treatments, less is known about the lived experiences of the primary caregivers who support autistic children. This study sought to explore the experiences of mothers raising their biological children diagnosed with ASD in southwestern Ontario.

Methods: Eleven mothers participated in one-on-one semi-structured interviews to discuss their children, their children's needs, and the effects of caregiving for families.

Results: Four themes emerged through thematic analysis: (1) *Figuring it out,* (2) *Do your own research,* (3) *We fall in a gap,* and (4) *What about the family?* The themes each have three subthemes further describing the mothers' experiences. Overall, many concerns existed for mothers raising autistic children that change over time (e.g., noticing the first symptoms, getting a diagnosis, searching for resources, and long-term coping).

Conclusions: Mothers who raise autistic children are in dire need of support as they care for their growing children and maintain their own wellbeing. Suggestions have been provided as to how this support may be most effectively provided to families.

Introduction

Caregivers are an integral component to the Canadian healthcare system, providing hours of unpaid informal support to persons with disabilities and additional needs. Included in this demographic are parents of children diagnosed with Autism Spectrum Disorders (ASD), a neurodevelopmental disorder affecting one in 66 children in Canada (Public Health Agency of Canada, 2018). Mothers of autistic children typically function as primary caregivers in families and report feelings of stress that negatively affect quality of life (Vasilopoulou & Nisbet, 2016). Specifically, a variety of domains were listed as relevant to quality of life, including parental factors (e.g., gender), disability related factors (e.g., ASD severity), and contextual factors (e.g., household income) (Vasilopoulou & Nisbet, 2016). While both parents experienced distress related to raising their autistic children, research has shown mothers have been affected more severely (Gray, 2002). As compared to mothers raising typically-developing children, mothers of autistic children reported increased stress, fatigue, time caring for children, and work intrusions, along with reduced leisure time and decreased positive affect (Smith et al., 2010). Further, O'Brien (2008) emphasized the direct and indirect effects of parenting autistic children, such as feelings of ambiguous loss after the diagnosis, which correlated to stress and depressive symptoms. Ho, Fergus, and Perry (2018) found similar findings in their qualitative study examining nine families raising autistic adolescents in Toronto. In general, Canadian families raising disabled children faced many obstacles, including education, income, support, and child care (Human Resources and Skills Development in Canada, 2006). Interestingly, health professionals were among the notable stressors:

> *"46.7% had doctors or health professionals who took a "wait and see" approach with the child's disability; 39.3% experienced long waiting periods to get the diagnosis; 29.5% had difficulty getting referrals or appointments; 25.7% could not obtain the diagnosis locally."* (p. 9)

Unfortunately, mothers have been vulnerable to aforementioned stressors, and a myriad of others, when raising their autistic children (Depape & Lindsay, 2015). This paper sought to understand the experiences of mothers' raising their autistic children in Southwestern Ontario, specifically over the course of their children's diagnosis and current access to resources.

Methods

Theoretical Orientation

To understand the families lived experiences, the theoretical orientation of interpretive phenomenology (Neubauer, Witkop, & Varpio, 2019) guided this research, in which "the researcher performs an active role in the interpretive process" (p. 91). To gain information about said experiences, information rich cases were integral to the research, as well as rigorous methods to ensure credibility. Recruitment and data collection procedures were approved by the university Research and Ethics Board before beginning the study.

Participants

The authors sought assistance from a local family resource centre which e-mailed a recruitment letter to clients who utilized ASD resources in the past. Eleven mothers agreed to participate, which was sufficient for saturation based on previous literature (e.g., Guest, Bunce, & Johnson, 2006) as well as recurring patterns found throughout analysis.

Data Collection

In order to provide context for the interview a priori, participants completed a short demographic questionnaire about themselves and their autistic children. Each mother participated in a one-on-one semi-structured interview (Appendix 2) at a time and location of her choice. The interviews were conducted by NJL (n=4), BKR (n=4) and LT (n=3), audio-recorded and transcribed verbatim, while PJB and PCF supervised the research and contributed to triangulation. Each transcript was e-mailed to the participant, where she could add, change, or remove any information (Lincoln & Guba, 1985) she felt necessary. Eleven member checks were emailed to participants, of which, one responded to provide more detail to her transcript. Additionally, in order to identify and reflect upon their personal experiences, the authors kept journals throughout data collection and analysis, including ideas about which questions should be asked based on previous knowledge, thoughts about the research, and expectations about the findings.

Credibility

Triangulation, the process of comparing several points of reference to ensure that a representative outcome is reached, is a key component in establishing credibility in qualitative research. Three forms of triangulation were utilized in this research: data, methods, and researcher (Lincoln & Guba, 1985; Patton, 2002). Further, the interviewers established rapport with the mothers when scheduling interview times, discussions before and after interviews, and conducting member checks via e-mail.

Analysis

The data analysis followed the steps outlined by Braun and Clarke (2006), through a phenomenological lens. Analysis of the data revealed recurring themes indicating saturation had been reached; therefore, no more participants were recruited.

Results

Eleven mothers of children who had been clinically diagnosed with ASD volunteered to participate in this study. The average ages of the mothers and children were 42.6 years and 11.6 years, respectively. Nine of the eleven mothers had more than one child and all mothers resided in Southwestern Ontario, Canada (Tables 1 and 2, Appendix 2). Interviews were conducted at participant homes or workplaces, local coffee shops, an office at the university, or on the phone. On average, the interviews were 67 minutes in length, ranging from 36 to 111 minutes of recorded time. Four themes emerged upon analysis of the transcripts (Table 3, Appendix 2), as well as how many mothers directly addressed each subtheme. Key quotes from each subtheme have been listed in Table 4 (Appendix 2).

Figuring It Out

All mothers commented on the challenges of raising children who demonstrated atypical developmental milestones or ASD-like behaviours, not only in determining their needs (Something's Up), but also in attaining a diagnosis (Jumping through Hoops) and navigating the healthcare system (Hurry up and Wait).

Something's Up

Eleven mothers described the years and months leading up to their children's ASD diagnosis. Some mothers felt a *"gut instinct"* or mother's intuition. Mothers highlighted the difficulty to diagnose *"high-functioning"* ASD in a young child during a 15-minute doctor's appointment, and one advised mothers to write down instances where something seemed *"off"* with the child to provide examples to a physician during routine check-ups.

One mother found it difficult to maintain composure when the physician was adamant her child did not have ASD. While some mothers had gut instincts, others did not notice any symptoms. Some mothers were unaware or in denial of any out of the ordinary behaviour, such as Cara who said *"... autism was the Rain Man, that wasn't my daughter."* Many believed their children were experiencing typical childhood development or that it was just a boy thing, or perhaps he/she was just shy.

The early years appeared to be a balancing act between searching for an explanation and allowing the children to grow and develop at their own pace. One mother felt the sooner she attained a diagnosis, the sooner her child could receive help, reducing the gap between him and his peers. On the other hand, another mother said she was hesitant to seek a diagnosis because she did not want to compare her child's development to other children. This seemed especially challenging for first time mothers to discern, because they did not have another child to compare.

Unfortunately, some mothers wished they were more persistent with physicians or acted on their intuitions sooner. Years later, it became clear for many that something was happening in those early years of life. Mothers wished physicians would have probed more into the social milestones of development (e.g., communication, eye contact, etc.) rather than solely motor and feeding. That said, mothers hoped early childhood educators could identify concerns that may have been missed, meaning symptoms may be detected within the first years of daycare or preschool.

Jumping Through Hoops

Another challenge faced early in development was the amount of time and resources required of the mothers. The diagnostic process had taken months to years for many of these families. Many mothers felt it was difficult but necessary to rule out other potential diagnoses, such as hearing issues, Attention-Deficit/Hyperactivity Disorder (ADHD), sensory processing, receptive language disorder, Obsessive-Compulsive Disorder (OCD), etc. It was not uncommon for mothers to be referred back and forth between different healthcare professionals during this time and they were expected to coordinate between many doctors and specialists. Some opted to pay for private specialists who could offer a shorter wait time if they could afford the additional expenses. Others had to leave town to reach specialists, like Brenda, who drove three hours to doctor appointments over the course of several months in order to avoid the waiting list.

In addition to challenges with healthcare specialists, some mothers experienced challenges with medicating their children. It was recommended for both Bailey and Cara to address their children's symptoms through medication, but this was a stressful decision for both. *"You never want to medicate a six-year old"*, said Bailey. Cara explained her daughter had to try more than one medication in order to find the best fit for her symptoms and side effects (e.g., anger, weight gain). There were also reports of long-term consequences from ASD-related medications. Brenda felt her son's suicide attempt was related to his medication use during childhood, as her healthcare professional mentioned mental health issues were a common side effect of his medication, but no one tracked these issues over time. Further, mothers sought additional *"psych assessments"* later in life, such as after their children entered the school system or moved into a different age group.

Hurry up and Wait

Not only did mothers wait for specialists, seven also reported waiting on services. At the time, many felt attaining the diagnosis was the hurdle, only to find out they would have to wait for therapies and services. It was a stressful time for many mothers, as they worried about their children waiting for services and missing important developmental milestones. They understood that the *"high-priority"* cases of ASD were first in line for these services (e.g., those who were lowest functioning), but that also meant the higher-functioning children waited months to years for important services. These wait times put them at risk for falling even further behind their peers. Even more frustrating, just as children outgrow clothing, they also outgrew the specialists or service age group. For instance, if a child was on the waitlist at age four and then attended school, he was removed from that waitlist and moved to the school wait list. Some mothers made choices between services because of the wait time, such as forgoing intensive behavioural intervention (IBI) because the applied behaviour analysis (ABA) wait list was shorter. Navigating the health care system was an uphill battle causing frustration for all the mothers.

Do Your Own Research

All mothers explained they were responsible for uncovering and seeking out resources for their children. Particularly, mothers spent a great deal of time reading about ASD and researching therapies that would best support their children's unique needs. Mothers also highlighted their need for help to find services and supports available for their families. The most significant support mothers felt would help in raising their children was a *"one-stop-shop"* for ASD information and resources.

Uncovering Your Child's Needs

A challenge described by nine mothers was determining the needs of their children. Several mothers had little to no understanding of ASD in general, such as how it is diagnosed, the levels of severity, or effective treatments. Some found reading about ASD in books and online was helpful, while others did not. Mothers reported it was difficult to identify their children's concerns due to the spectrum nature of ASD and the vagueness of published materials. For instance, reading was challenging for some mothers because what they found was not reflective of their children. As a result, mothers discovered various parenting techniques by *"trial and error"* until something seemed to resonate with their children. Lack of verbal skills made it particularly difficult when deciding if therapies and/or medications were necessary. Mothers had to judge their children's behaviours, facial expressions, and mood to determine if they were *"suffering"* (e.g., in pain or distress, but unable to communicate their needs verbally).

In this way, mothers became experts at reading their children's body language to try to understand their needs. When mothers discovered which routines worked, they tried to maintain a schedule as long as it seemed to be effective.

Once mothers began to understand these needs, they had to *"pick [their] battles"* based on the behaviours of their autistic children as compared to their own energy levels. For example, it required patience to coach a child to dress himself, but he was capable if given enough time. Unfortunately, mothers did not always have the time to allow their children to practice these skills. Some mothers (e.g., Wendy) allowed their children to act differently each day based on how they were feeling, because that is the nature of raising children. Other mothers (e.g., Hannah) were more regimented.

As mothers learned more about their children, they felt it was their responsibility to educate others. Not only did they have to describe their children to each ASD specialist during the diagnosis and treatment process, they also had to educate family members and school teachers. Mothers recalled it was difficult for some people to *"stomach"* the diagnosis, such as their husbands or parents. Some grandparents believed the children's behaviours were simply the result of *"bad parenting"*, which was an additional difficulty to manage. Mothers also described the necessity in helping others to understand how their children were different from other autistic children, let alone typically developing children.

"Roadmap of Resources"

When discussing the mothers' needs for raising their autistic children, it was common to hear about the confusing and impractical nature of ASD resources, including parent groups, social supports, system navigation, camps, activities, extra-curriculars, and playgrounds. All mothers spent a great deal of time researching what was available because there was no *"one-*

stop-shop" that covered the variety of resources they were seeking. Not only did the time-consuming nature of research cause mothers stress, they also worried about missing something or making mistakes that could be detrimental to their children's development. While many recognized it was difficult for physicians to suggest a course of action due to the variability of ASD (e.g., as compared to diabetes), mothers felt they had to become the expert of what resources were available. Mothers dedicated time and energy into researching, much of which led to dead ends (see *We Fall in a Gap*).

One mother said the system was disjointed, in that some organizations tried to keep clients to maintain or secure financial support, even if there were better options elsewhere. Some specific issues that arose during these discussions was the need for physical resources such as weighted vests and timers, which were primarily available online, reducing accessibility (e.g., could not physically try resources with children before buying, therefore no way to know what they would like/dislike). Finding summer camps was also a challenge, because many had limited spaces available and registration was often months in advance. Not only did parents have to secure a place for their children at camp, but some also had to secure a one-on-one support person for their children, which posed further challenges.

A mother's support group was discussed as helpful, if it focused on parenting techniques rather than *"complaining"* about the challenges of parenting autistic children. Mothers could suggest resources for other mothers and mentor families with a new ASD diagnosis about how to navigate the system, such as when camp registration happened and which resource centres were most helpful. Some mothers had personal or work connections that aided in their search for research, while others went to a service centre that highlighted local resources and/or were given a binder of options. That said, mothers who had these supports still struggled to find resources at times. Cara raised her child in a rural town and experienced amplified accessibility concerns as compared to families living within the city: *“I'm on my own and have been. And don't even know how to even access the help or even ask for it.*” Mothers were empathetic to parents raising autistic children who spoke English as a second language or who recently moved to a new city. Doing this research was time consuming for mothers, as lamented by Carolyn: *"... is this going to be my life?".*

Therapies and Alternatives

Eight mothers felt it was their responsibility to be versed in the treatment options for ASD and to discern which were appropriate for their children. For instance, mothers had to explicitly request a particular therapy (e.g., occupational therapy) from their physician or felt they were educating their physician on therapeutic options a result of their own research (e.g., Susanne). It was difficult for mothers to discern how much to *“push”* physicians for alternatives such as homeopathy and nutritionists. Some mothers (e.g., Debra) felt supported when the pediatrician provided suggestions as to which therapies to pursue over time, but this experience was less common. Alternatively, others were given a list of therapeutic options, but did not understand their purpose or know when they were needed (e.g., IBI vs. ABA).

Mothers felt certain therapies and alternatives were not intuitive, and they would not have known to research them in the first place. Cara learned about therapies and alternatives that would have benefitted her daughter, had she found them earlier in her daughter’s life. Wendy felt her experience with ASD therapies went more smoothly than others because of her background in the field of mental health. Some mothers were optimistic their needs would be met over time (e.g., Bailey, 6-year-old son), while others were not because their needs had not been met thus far (e.g., Brenda, 17-year-old son). Further, children may have benefited from a therapy at the time, but then regressed after the session was completed, and therefore the therapy research and application process began again.

In addition to therapies, mothers sought other forms of support. Susanne wanted regular care for her child, but not simply a babysitter who would watch her son, but someone with experience who could stimulate him and help him progress. A common stressor associated with researching therapies was the extensive paperwork required to apply for the service. Altogether, mothers expressed difficulties researching and attaining therapies and alternative treatments for their autistic children.

We Fall in a Gap

Many challenges associated with raising autistic children are rooted in the spectrum nature of the disorder. These differences created issues for *Funding*, *Programming*, and *Mental Health* resources because any inclusion criteria will exclude part of the population from accessing said resource. Mothers felt there were few resources for autistic people in the Region of Waterloo, and that they were excluded from many of these programs for a variety of reasons. One mother contended:

> *"If they don't help with these children when there 9, there is going to be a huge cost when they are 20 and they cannot succeed… They will cost the government a substantial amount of money, if they don't give money to help them succeed as a child; it's just the way it is."* – Debra

Funding: Too Little Too Late

All mothers felt their autistic children did not receive the financial support necessary to cover costs of therapies, programming, respite, and any other resource necessary for their development. For example, one mother said the government funds developmental disorders such as Cerebral Palsy because there are known medical expenses (e.g., physical therapy). However, this was not the case for autistic children, where many children with high functioning ASD are a lower funding priority. This was particularly difficult to swallow for mothers of high functioning children, who often fall behind their peers and experience social consequences.

Mothers reported applying for government support was tedious. Further, funding opportunities required parents to pay for the service first (e.g., pay for camp), and then apply for money afterwards. This process left families in financially unstable situations until the money was provided, and at times, deterred mothers from utilizing services altogether. Cara reflected on her financial situation, saying *"...Like food or assessment? I'd love the assessment, but I can't."* She had to choose between feeding her family or helping the development of one child over the other. Similarly, Bailey explained medication costs caused financial strain, while Vickie said *"... they're out of my reach"* when discussing summer camps.

Financial support varied amongst mothers in this study based on their income, ASD severity, and the funding representative with whom they worked. For instance, some mothers had a financial representative who helped find and secure funding for their children's expenses. On the other hand, some mothers did not have any representative, or they had a representative who was not well versed in the opportunities available. Mothers reported a variety of federal, provincial, and private funding opportunities for their autistic children and some services billed directly to these funds, which was most convenient for mothers.

Some mothers could afford out-of-pocket expenses to reduce service wait time. In other words, families who were wealthier could pay to receive support more quickly. Alternatively, many were unable to afford private services because the costs were astronomical (e.g., $150 CAD/hour according to one mother). One mother said she could advocate for lower costs of these services, but by the time any changes were made, her child would no longer benefit. In this way, mothers had to *"pick [their] battles"*, and sometimes it was easier to pay for additional supports.

A myriad of factors could affect funding provided to each family, including benefits packages from a parent's work. Some families had more coverage, but not all plans covered necessary services, such as Occupational Therapy. Further, some mothers were frustrated they did not qualify for funding based on their total family income, as they still felt they did not have the finances to support all the needs of their autistic children. Overall, funding caused a divide between families; those who could afford services and those who could not. Mothers felt this gap had far reaching effects for their children's development and wellbeing.

Programming

Within the theme of *We Fall in a Gap*, nine mothers discussed their experiences with programming for their autistic children. It was challenging to find programming that offered the right level of support for their children. For example, some children required minimal additional support within a *"regular"* program rather than the extensive support in some *"special needs"* programming. In addition to finding programs with the right amount of support, finding programs coinciding with the children's interests or maturity levels was also challenging. For instance, some programs were *"too kiddie"* for teens or were just for boys.

Many programs were inappropriate for autistic children due to their unique sensory needs. For instance, basketball in a gymnasium required participants to deal with excessive noise, which was challenging for many autistic children. Similarly, Bailey said there were few playgrounds that offered positive sensory experiences. Mothers expressed a need for individual activities that provided gainful experiences in a low-stress environment. Wendy reported her son enjoyed physical activities (e.g., biking) rather than group activities (e.g., soccer). Hannah described her son's difficulty with swimming due to the pressure of skilled performance to pass each level. Hannah experienced a gap in programming, because although there were several swimming programs, none suited her needs. Programs that emphasized enjoyment rather than skill (e.g., horseback riding) would be better suited for autistic children.

Mothers made suggestions to improve program accessibility and appropriateness for autistic children. First and foremost, programs were too expensive. Mothers understood many programs were more costly (e.g., need for specialized equipment), but they did not feel that should be their own expense. Additionally, mothers wanted *"gainful experiences"* for their children, such as employment, volunteer, or life-skill opportunities. Mothers felt their children needed experiences to develop self-worth and independence, such as learning how to handle money and cook for themselves. These experiences would help autistic children to thrive as independently as possible while growing into young adults. Similarly, there should be support in universities and colleges for students with ASD to navigate new schedules and environments.

Mental Health

In addition to the subthemes discussed above, seven mothers mentioned *Mental Health* as an area where supports were lacking. Mothers understood the negative aspects of the ASD diagnosis on the mental health of their children; specifically, they worried their children would limit themselves because of their diagnosis. For example, mothers were concerned their children would use ASD as a *"crutch"* during difficult situations, rather than overcoming challenges. While many mothers did not want to label their autistic children, it was certainly required for securing supports (e.g., funding, individualized education plan). Mothers felt that it was their responsibility to preserve their children's self-esteem due to any negative experiences arising in schools or the community.

Moreover, mothers were concerned about bullying because their children were often treated differently or segregated from typically-developing children. Mothers felt bullying affected the mental health of autistic children, especially if others made their children feel different, unintelligent, or disliked. Many sought programming and resources that allowed their children to be accepted as they were, rather than constantly trying to fit in. Further, mothers thought bullying led to social withdrawal, as social engagement often highlighted their differences from other children. In this way, the *"invisible"* aspect of ASD affected social engagement. Unfortunately, these concerns sometimes occupied the views of other family members, whereby mothers had to defend the needs of their children to their parents. For instance, mothers wanted their children to be accepted *"as he/she is"* and felt they had to repeatedly explain the behaviours of their children to relatives.

Depression and anxiety were two mental health concerns highlighted. While not all mothers discussed these issues, it was a significant talking point for those who experienced it and therefore mental health was deemed a necessary subtheme. Depression was experienced by some autistic children and negatively influenced their feelings of self-worth. Further, prolonged medication use was attributed to depressive symptoms in some children, which mothers associated with two attempted suicides (Brenda; Vickie) among the 11 children.

Unfortunately for Vickie, her son's depression was not only related to medication, but his experiences with bullying. Similarly, Wendy commented on her son's anxiety as it pertained to his ASD, saying he worried excessively. Not only did the children experience mental health issues, but also the parents. Mothers commented they often felt alone (e.g., *"I'm on an island"* – Cara), overwhelmed, and in need of emotional support. Many focused on the needs of their children in the interviews, but it was clear mothers struggled as well, as mentioned here and described more in the next theme (*What About the Family*).

What About the Family

While most of the interviews were spent discussing the children (e.g., the three themes previously discussed), mothers also talked about their own needs, as well as the needs of other family members. It was evident ASD did not only affect the children, but also their families.

Mother's Resources

All mothers discussed resources they personally needed to raise their autistic children. When asked what she needed in order to raise her son with ASD, Bailey simply stated *"help"*. She then went on to say her income was not enough to support two children, especially when one required therapies and medications. Among the other resources listed were parent support groups where mothers could discuss their experiences raising autistic children, but that were divided based on their children's ASD severity (e.g., a high functioning group and a low functioning group). For instance, Wendy discussed her discomfort in attending a mother's support group because her son's needs were minor as compared to other group members. She felt uncomfortable talking about her challenges (e.g., how to help her son in a regular classroom) with other mothers because their experiences were so much more severe (e.g., child was not allowed to attend school due to aggressive behaviours).

Similarly, some mothers showed no interest in support groups because they did not find them useful. Instead, these mothers felt that psychologists or counsellors specifically trained in ASD would be the most helpful resource. In this way, mothers could discuss their challenges and stressors, but they could also receive advice about how to raise their children. Some mothers gained advice from the mother's support groups, but this was less common. In support groups, mothers reported others *"complained"* about their issues, making it an undesirable environment.

In addition to formal resources (e.g., funding, support groups, psychologists, counsellors), mothers were also in need of informal support from friends and family. Many found it isolating raising autistic children because their social networks could not identify with their experiences. Often mothers lost friendships because their time was consumed raising their autistic children. Further, some friends did not understand ASD and felt their children were unsafe together. One mother talked about the fact that her autistic child did not play with others on the playground, which further isolated the families from each other. In this way, mothers became more distant from friends and experienced difficulty creating new relationships.

Mothers' parents (e.g., children's grandparents) were both described as supportive and unsupportive in the interviews. Some mothers relied heavily on grandparents as additional supports for raising their children, while others could not rely on them at all. One issue emerged from grandparents' lack of understanding about ASD. Mothers felt grandparents were judging their parenting abilities, specifically, that their children could act more *"normal"* if they had more discipline and routine. Not all grandparents viewed ASD in this way, but for those who did, mothers felt it was due to generational differences of thinking.

The third area of support listed was from employers, particularly regarding job flexibility. Missing work or going in late often occurred due to their children's needs on a particular day. Gaining employer understanding of their unique parenting situations, was helpful for mothers on days that were more difficult than others. Employer understanding decreased stress associated with parenting and perhaps, if more employers were understanding of ASD, more mothers would choose to work full time.

Respite isn't an Option

Seven mothers expressed a deep need for respite care in a variety of different forms. Their lives were consumed by raising their autistic children and respite was considered necessary for their personal well-being. Unfortunately, the respite options available often fell short of their needs. Seven mothers discussed specifically their challenges in finding and financing respite care. Some mothers felt the government support for respite was sufficient for their needs, while others did not. Cara for example (a single mother), did not have respite care, could not rely on her mother, and had limited resources for her family.

Not only would respite affect the mother, but also other people in her life, such as her spouse and children. For instance, having respite care would allow both parents to leave the home and be together. Respite would also allow autistic children to attend camp or participate in school trips, two circumstances where typical adult support would not be sufficient for autistic children. In these cases, respite supports would allow autistic children to gain similar experiences as their peers.

On a day to day basis, mothers wanted to find babysitters with specific skills and traits, such as those with previous ASD experience or who could be patient with their children. In this way, not only would the child be cared for, but he or she could also be challenged to grow and learn rather than simply being supervised. Vickie described difficulty finding a babysitter who could handle taking care of her son when he was younger. Clearly, mothers needed more supports to take time for themselves and allow their children to be more independent.

"The Whole Family Needs Help"

Ten mothers discussed the influence of ASD on family members, including siblings and spouses. Eight mothers had two or more children, and seven discussed how ASD affected the relationships between typically developing siblings and their siblings with ASD. Bailey described the relationships between her son with ASD and his younger brother, saying *"the only friend that he ever talks about really having is his brother."* Similarly, Cara discussed the way in which her stepchildren supported and cared for her autistic child, saying *"they're very close knit".*

Other mothers, however, noticed strained relationships between their children, to the point that the siblings would benefit from their own supports and resources. Vickie said her children interacted as any other teenage siblings but wondered whether a family support group would be beneficial. The dissimilarities among sibling relationships was influenced by differences in age and functionality, and age at the time of this research. Hannah said her other children were *"not really affected"* by her son with ASD, but her husband had difficulty accepting the diagnosis. Five mothers discussed their husbands when considering their family's experiences with ASD, including Carolyn, whose husband disliked Nelly's ASD diagnosis. Vickie described her husband spending time outside in the evenings opposed to inside with the family, saying "*I think it's just to escape. He likes to hide outside a lot."*

Due to the difficulty for family members to accept the diagnoses, three mothers highlighted the importance of couples or family therapy to gain acceptance and cope together. Wendy said her husband sought counselling after the diagnosis, which was beneficial for their relationship. Undeniably ASD permeated the lives of all family members (e.g., ASD affected the family systemically), not just mothers, as denoted by Susanne *"…with ASD it is the whole family that needs help. Not just the kid."* Counselling and support groups were suggested as helpful resources, especially if family members were having a particularly difficult time accepting the diagnosis.

Discussion

Mothers faced many challenges when raising their autistic children, from attaining an ASD diagnosis to determining whether their children had mental health concerns. Specifically, mothers felt they had to learn about their children's needs, the most effective therapies, and available resources on their own.

The political climate for mothers raising autistic children in Ontario has not been supportive of autistic children's needs, with the burden primarily falling on mothers. Dudley and Emery (2014) argued "Relying on family to shoulder the lifelong burden of care in the face of inadequate service and supports is not a sustainable model of care" (p. 25). Yet, this is how mothers have experienced raising their autistic children. In Ontario, funding for families raising autistic children has seen extreme structural changes (see *Ministry of Children, Community and Social Services, 2019* for more information). These changes have affected accessible funding amounts for families raising autistic children in attempts to shorten the waiting time for resources. For most families, this means their access to funds has been reduced, so they cannot afford paying for the services, therefore, reducing waitlists.

Mothers in this study discussed similar experiences to those in other Canadian cities (Ho et al., 2018; Ho, Yi, Griffiths, Chan, & Murray, 2014) and in other countries (Depape & Lindsay, 2015). However, governments that have systems in place to meet the needs of disabled children early in life could reduce their healthcare costs in the long run. Stapleton and colleagues (2015) conducted a cost-benefit analysis on Individualized Education Plans for disabled children and found a return of $0.47 for every dollar spent during schooling years. In this way, arguments about funding cuts due to unaffordability lose traction because governments could see a return on investment by supporting childhood development. While it is important not to reduce families raising autistic children to dollars and cents, cost-benefit analyses have been necessary for regulatory decisions within the Government of Canada (Treasury Board of Canada Secretariat, 2007).

It is imperative to address the needs of other family members such as mothers, spouses, and siblings, with respect to respite care, overall family functioning and family counselling. Although much research on therapeutic and medical interventions for autistic children exists, there has been less emphasis on interventions for the family effects of ASD. Vasilopoulou and Nisbet (2016) reviewed 12 qualitative articles assessing quality of life for mothers and fathers and described a need for interventions to increase quality of life, specifically physical and mental health. Similarly, Lock, Hendricks, Bradley, and Layton (2010) discussed supports like "family fun days" and support groups, although mothers in this study felt support groups did not address their overall needs. In the present study, mothers said support groups relieved feelings of isolation, but they would not necessarily help to solve other needs, such as waitlists, funding, and respite care.

Giarelli, Souders, Pinto-Martin, Bloch, and Levy (2005) conducted an intervention for parents of autistic children, offering three additional hours of personalized nursing time in addition to the typical one-hour consultation and treatment plan information sheet. There were no differences in perceived stress or personal impact of diagnosis between the intervention and control groups (Giarelli et al., 2005), suggesting a long-term approach may be more effective than acute interventions. The mothers in this study said they saw physicians for short periods of time and/or there was too much information to sort through after diagnosis. What mothers wanted was ongoing support to assist them in finding and securing resources at different stages of their children's lives.

Social media could be one form of ongoing support to connect healthcare providers with families. In Saudi Arabia, Hemdi and Daley (2017) utilized an instant messaging app to educate and support mothers raising autistic children, which significantly reduced stress and clinically reduced depression over time. While this form of intervention could reach more families (e.g., rural and remote), the authors suggested it be augmented with other services (Hemdi & Daley, 2017), such as respite. Mothers in the present study and in past research (e.g., Smith et al., 2010) have expressed great need for respite services when raising autistic children.

Respite time was shown to have a direct link to the marital quality in 101 mother-father dyads raising autistic children, both indirectly (e.g., reducing stress, increasing daily uplifts) and directly (Harper, Dyches, Harper, Roper, & South, 2013). Respite care in the form of day programs has been shown to improve mental and physical health and reduce caregiver burden in those caring for frail elderly people (Mason et al., 2007). The review by Whitmore (2016) found that respite was associated with higher stress in some circumstances, such as parents in need of formal care due to burnout from caring for their autistic children. Whitmore (2016) called for additional respite research, creativity in practical application (e.g., unique solution for each unique family), and support from policy makers for parents, support professionals, and researchers.

The findings from this research point to the importance of a “family ASD representative” who could help parents find the resources, therapies, and funding best suited for their autistic children. This representative could find supports for both autistic children, such as camp funding, as well as their caregivers, such as respite, in addition to helping families complete funding paperwork. Gray (2002) found that use of support services decreased as autistic children aged into teenagers and young adults, not because the need for supports declined, but because of the limited resources available for adults with ASD. Further, Hare, Pratt, Burton, Bromley, and Emerson (2004) reported parents of adults with ASD experienced distress and unmet needs. An ASD representative would be most helpful in connecting families with resources already in existence but could also determine which resources are missing and advocate to local and provincial organizations for more support.

There are limitations worth noting in the present study, including the limited feedback from mothers in the member check process (e.g., only one mother provided more data when the member check was provided). In theory, more data could have been collected from mothers though more rigorous member checks; however, understanding the needs of this population, the researchers accommodated the mothers' schedules and allowed them to participate for as much time as they wished. In addition, while the themes were saturated, the study only represents the experiences of 11 mothers, which limits transferability to mothers as a whole. Interestingly, these two limitations further support the findings of this research: mothers were fully consumed in their efforts to provide for their autistic children and have limited time to engage in self-care, let alone research. All participants were mothers, Caucasian, and had at least a high-school education, which further limits the transferability of these findings to other parents (e.g., fathers, non-binary caregivers, etc.), minority ethnic groups, or less educated families. That said, all families were raising autistic children and, combined with ethnicity and education, this study represents a homogeneous group.

Another notable consideration in this research pertained to data collection by the first three authors, which introduced potential for biased data due to differences in interview style. This limitation was mitigated in various ways. First, all interviewers underwent the same training regime at the same academic institution, and therefore had shared understanding and knowledge of qualitative research methods. All authors worked together to create a semi-structured interview guide, which was utilized during the interview, thus ensuring similar questions were asked to each participant. The PJB and PCF supervised this research and read all the transcripts to ensure there were no concerns in interview technique that required clarification from participants. Finally, the first author (NJL), who conducted the analysis for this paper, listened to the audio files of the interviews she did not conduct to further become immersed in the data. While it is impossible to completely bracket the worldview of each researcher while interviewing participants, these methods mitigated concerns that may have arose.

To conclude, the present study examined the lived experiences of 11 mothers raising their autistic children in the Region of Waterloo, which can be summarized as follows: it's not a user-friendly system. Whitmore (2016) contended mothers raising autistic children experienced "chronic stress comparable to combat soldiers" (p. 630). There are still many gaps in resources for families raising autistic children, including funding, programming, and mental health. It is also imperative to address other family members such as mothers, spouses, and siblings in respite care and family counselling in future studies. The political climate has not been supportive of mothers raising autistic children. As such, immediate aid in the form of finances, counselling, and resource management is warranted, potentially in the form of a family autism consultant. Future research is needed to examine the real-world effects of these supports for all family members, as well as how to educate families on the resources available.

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Appendix 2: "It's Not a User-Friendly System"

Table 1

Demographic Information of Mothers.

Pseudonym	Level of Education	Marital status	Employed
Carolyn	'Some university'	Married	No
Deb	High school	Married	Yes: Full time
Justine	College	Married	Yes: Full time
Natasha	College	Married	No
Vicky	High school	Common law	Yes: Full time
Bailey	College	Separated	Yes: Part time
Cara	College	Single	Yes: Full time
Wendy	University	Married	Yes: Full time
Hannah	College	Married	Yes: Full time
Brenda	University	Married	Yes: Full time
Susanne	Master's Degree	Married	Yes: Part time

Table 2

Demographic Information on Children.

Parent Pseudonym and (Child Pseudonym)	Sex of child	Age of child at time of study (years)	Age of child at diagnosis
Carolyn (Lisa)	Female	18	16
Justine (Nathan)	Male	10	9
Deb (Dane)	Male	9	5
Natasha (Emily)	Female	6	4
Vicky (Andrew)	Male	14	6
Bailey (Tyson)	Male	6	6
Cara (Zoe)	Female	16	8
Wendy (Jack)	Male	10	6
Hannah (Timmy)	Male	16	6
Brenda (Steve)	Male	17	3
Susanne (Michael)	Male	6	3

Table 3
Themes and subthemes from one-on-one semi-structured interviews with 11 mothers of children with Autism Spectrum Disorder and the number of mothers who directly discussed the subtheme in their interview.

Theme	Subthemes	N (out of 11)
Figuring it Out	Something's Up	11
	Jumping Through Hoops	11
	Hurry up and Wait	7
Do Your Own Research	Uncovering Your Child's Needs	9
	"Roadmap of Resources"	11
	Therapies and Alternatives	8
We Fall in a Gap	Funding: Too Little Too Late	11
	Programming	9
	Mental Health	7
What About the Family	Mother's Resources	11
	Respite isn't an Option	7
	"The Whole Family Needs Help"	10

Table 4

Key quotes from each of the sub-themes.

Subthemes	Key Quote
Something's Up	*"One way is trust your gut. Definitely, if you feel there's something different, if you are in the park and you notice, why is my kid doing that? If you're asking yourself questions um that aren't the typical, oh how do I relieve teething? Or is this gas or is this not gas? Like if you're asking why is my kid not doing this? … like trust that, you know. Don't mind exploring that with your partner or with friends or with the doctor. And don't always take the first answer, you're ok to get second answers." – Bailey*
Jumping Through Hoops	*"... So it took a good year to get diagnosed, it wasn't something that was sudden... Again what happens is that you are referred to a place and what happens is that they spend a specific amount of time with you and then eventually say sorry we can't help you and then they put you to the next person and then that person puts you to the next person. Like I said it's a vicious circle that literally goes nowhere... I mean other thing like I said one diagnosis is for a lot of these organizations too. You need to provide them with assessments with data. A lot people, if I wasn't able to get my psych assessment paper myself, I would've never been able to obtain any of the resources because they require specific information to get the resources and every place is different. So what one person can take as a pysch. ed., they might want the data the next place." – Justine*
Hurry up and Wait	*"... we're starting private OT therapy. They have it at the school but we're on our waiting list and we haven't received it as of yet, we have been on the waiting list since um, over a year now I think." – Natasha*
Uncovering Your Child's Needs	*"I do a lot of looking online. And just reading different blogs and different articles and seeing all the different stuff about different families with their kids that are on the spectrum. And I guess it's kind of comforting knowing that you're not the only one, which I know. And then there's so many stories that I'm like, 'I can relate to that, I can relate to that, I can relate to that.'" – Vickie*
"Roadmap of Resources"	*"... I find the system here very disjointed. It is hard to find information. And to know everything that is available out there, like you would have to be on half a dozen mailing lists to know everything that is going on. And a lot of it is overwhelming." - Brenda*
Therapies and Alternatives	*"… you're an expert of your child, but you're certainly not an expert of the system, right. So I think you end up going down some dead ends quite often. Um unless you know somebody or you can call somebody." – Wendy*
Funding: Too Little Too Late	*"… so that's the problem, Dr. Scmitt, we were seeing her up until, just the beginning of October, it was continuous every 2 weeks going to see. Which was okay because we can do that but it comes to a point, like some people don't have benefits and its 185 dollars an hour and its 50, 50 minutes appointment. So we were fortunate that we can, can do it um we*

	used up all of our benefits, the consultation, like the psychological assessment was over 3 thousand dollars just to get her assessed." – Carolyn
Programming	*"I contacted, I don't remember who they were, but they said, 'there really is no resources for him at this point because he is 16. But when he turns 18 you could retry and see if there is anything to help with his independent living.' Which he wouldn't need because he is high functioning. That is what they said. They said 'if he did mainstream school. And he is high functioning there is no services here for you.'" – Hannah*
Mental Health	*"... depression was big especially when he hit puberty. Another thing people don't realize, he was on Adderall before puberty. He was stabilized on it for so many years because he started on it when he was little. And we just originally started it to slow him down, to teach him coping skills and then take him off. But you forget and you get complacent... But it was the mix of the artificial and the natural chemicals that all of the negative side effects of that medication came up, to the point of suicidal ideations, suicidal attempts... It took an emerge. visit and an emerge. doctor – not an autism specialist, not a psychologist, not a social worker – but just a straight out emerge. visit saying 'you know that some of the side effects are this this and this'. And you forget because it was years ago that you read about them. So we stopped* [the medication] *immediately and it all subsided. All of the* [suicidal] *behaviours stopped." – Brenda*
Mother's Resources	*"I think it's good to have support groups. Um I haven't really joined any. I haven't really done that. Um, not something I wouldn't entertain, but where do you get the time for it? Right? It's good to have support groups but then you're taking time away time from other things that could be helping him. Because a support group isn't helping Dane, you know what I mean?… the flip side of it is [pause] you lose grasp with the rest of the world, like not every child is like this, you have to deal with reality, right?" – Deb*
Respite isn't an Option	*"... you're running on high speed non-stop. There's no break. There's no one that comes in and says "ok, I'm going to take over, you go and lay down" or "you go and do this." Like wherever I went, my children were with me. Didn't matter where I went. There was no mom time. Mom time was driving from my house to work. That was my time and that was it." - Cara*
"The Whole Family Needs Help"	*"Yes. I think every family, because that is another thing that is important. With ASD it is the whole family that needs help. Not just the kid. And I think it would be really helpful if every family went through some sort of workshop or therapy or whatever you want to call it. An introduction to this world. And it can't be everything in one shot because it is too much. Like at least the parents, they need time with everything." - Susanne*

Background Questionnaire: Primary Caregiver

Please complete all the questions by either filling in the blank spaces provided or checking the box with the most appropriate answer. The following questions are about you:

1. What is your date of birth (MM/YYYY)
   ____

2. Highest level of education
   - ☐ Elementary school
   - ☐ High school
   - ☐ College
   - ☐ University
   - ☐ Post-graduate degree
   - ☐ Other (please specify): ____

3. What is your marital status?
   - ☐ Single
   - ☐ Married
   - ☐ Divorced
   - ☐ Separated
   - ☐ Widowed
   - ☐ Other (please specify): ____

4. What is your occupation?
   - ☐ Full time (please list): ____
   - ☐ Part time (please list): ____
   - ☐ On leave (please specify): ____
   - ☐ Unemployed
   - ☐ Retired
   - ☐ Other (please specify): ____

5. Relationship to child with ASD
   - ☐ Parent
   - ☐ Grandparent
   - ☐ Legal guardian
   - ☐ Other:____

6. Do you have other children?
   ☐ Yes
   ☐ No
   If yes, please fill out table below

	Gender	Date of birth (MM/YYYY)	Health Concerns/Comments
Child 1	☐ Male ☐ Female		
Child 2	☐ Male ☐ Female		
Child 3	☐ Male ☐ Female		
Child 4	☐ Male ☐ Female		
Child 5	☐ Male ☐ Female		

The following questions are in relation to your child with ASD:

7. When was your child diagnosed with ASD? (MM/YYYY) __________________________

8. What signs and symptoms does your child currently display that are associated with ASD?
   ____
   ____

9. Does your child have any secondary health concerns?
   - ☐ Yes
   - ☐ No

   If yes, please list

   ____

   ____

10. Does your child with ASD receive treatment and/or therapies specific to his/her ASD?
    - ☐ Yes
    - ☐ No

    If yes, please list

____

____

____

Thank you for taking the time to complete this questionnaire!

Mothers of Autistic Children Interview Guide

1. Please tell me about yourself.
    1. Interests, health, career, education, family, children
2. Tell me about your child with ASD
    1. Personality, diagnosis, strengths, behaviours, education, etc.
    2. Your relationship with him or her
    3. Relationship with siblings (if any)
3. What do you think a family needs to raise a child?
    1. To raise a typical child? What about a child with ASD?
    2. Are there differences between the two?
    3. Income, funding, time, help, etc.
4. Did your family access any resources prior to your child's diagnosis of ASD?
    1. Health, education, psychological, physical, spiritual, respite, financial, recreational, social, etc.
    2. Why did you access these? Were they effective?
    3. If not, how come?
5. Do you currently access any resources for your child with ASD?
    1. Health, education, psychological, physical, spiritual, respite, financial, recreational, social, etc.
    2. Why do you access these? Are they effective?
    3. If not, how come?
6. Would you improve a resource that is already available so that it is ideally suited for <u>your child's needs</u>?
    1. Could be a program you are using, but does not quite fit your child
    2. What would be an ideal support service for your child that is not currently available to them?
    3. Do you think other children with ASD would benefit as well?
7. Are there any resources you would use for your child with ASD, but do not have access to?
    1. Health, education, psychological, physical, spiritual, respite, financial, etc.
    2. Why would you like these?
    3. What are the barriers preventing you from accessing these resources? (i.e. cost)
8. Would you improve a resource that is already available so that it is ideally suited for <u>your needs as a parent</u> of a child with ASD?
    1. Could be a program you are using, but does not quite fit your needs
    2. What would be an ideal support service for you that is not currently available to you?
    3. Do you think other parents of children with ASD would benefit as well?

9. Do you attend a support group?
    1. Why are you a part of it, how did you get involved?
    2. Do you access any other supports or resources?
    3. Are there any resources that you would use, but do not have access to?
10. Do you feel that having a child with ASD has affected your life?
    1. Income, funding, time, help, etc.
    2. Positive or negative factors
    3. Relationships: spouse/partner, other children, friends, etc.
    4. Public situations, society, perceptions of others, etc.
11. Do you have any concerns about the future as a mother of a child with ASD?
    1. Concerns for yourself?
    2. Concerns for you child?
        - i. Independence
        - ii. Support services and day programs
        - iii. Jobs/Careers
        - iv. Housing
        - v. Care for the child
        - vi. Other
12. Optional** Can you tell me about the photo that you brought with you today?
    1. Why did you take it?
    2. What does it mean?
13. Do you have any advice that would be helpful for other mothers of children with ASD?
    1. For a new mother, or for yourself when you were a new mother for this child
14. Do you have anything else to add about your experience as a parent of a child with ASD regarding resources for you or your child?

Thank you for participating in this interview!

Evaluating an Inclusive Physical Activity Program

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Keywords: disability, physical activity, program evaluation, children, social

Abstract

Background: Inclusive physical activity (PA) provides disabled children with opportunities to become active, learn fundamental movement skills, and socialize with others; however, there are many barriers that limit the availability of these programs. This study examined Movin' and Groovin' (M&G), an inclusive PA program for disabled children and their siblings from a realist evaluation perspective to understand the mechanisms, context, and outcomes of the program.

Methods: Data were collected about M&G via video observations using the System for Observing Fitness Instruction Time (SOFIT, McKenzie, et al., 2015) to assess lesson context, PA, and social interactions (SI). Additional data were collected via caregiver surveys as well as focus groups with the volunteers and interviews with the researcher and instructor.

Findings: Data analysis revealed children in the program spent an average of 58.1% (24.8 minutes) of observed time in moderate to vigorous PA (MVPA) and 81.8% (34.0 minutes) in SI. Key mechanisms were child choice, one-on-one volunteers, focus on fun, fostering friendships, and support from parents. M&G took place in a context that was accepting, prioritized learning, provided social support, valued family, and was non-competitive. Positive experiences, skill development, and healthy lifestyle knowledge were the primary outcomes for children in the program, as well as a sense of self-fulfillment for the volunteers. M&G was not without challenges, but the instructor and volunteers worked with parents to accommodate the children's needs wherever possible.

Conclusions: M&G is one example of an inclusive PA program for disabled children and their siblings that demonstrated positive outcomes. This evaluation could serve as a model for coaches and physical educators to include children of all abilities into their school and community-based programs.

Introduction

Disability affects more than one billion people worldwide (World Health Organization, 2018) with approximately 11% of young people in the Ontario education system having special needs (Stapleton et al., 2015). There is a myriad of far-reaching effects for disabled individuals, such as difficulties maintaining healthy weight (Maïano, 2011) and making friends (Solish, Perry, & Minnes, 2010), as well as for their caregivers, including stress and burnout (Doig, McLennan, & Urichuk, 2009). Sedentary behaviour is associated with compromised health-related quality of life in young people (Omorou et al., 2016) and is a well-documented concern for disabled children (Sit et al., 2017). Extracurricular physical activity (PA) programming may alleviate some disability-related concerns and improve quality of life for families raising disabled children (Arbour-Nicitopoulos et al., 2018). PA is defined as any "bodily movement produced by skeletal muscles that requires energy expenditure" (Casperson, Powell, & Christenson, 1985, p. 126) and is associated with increased physical and psychological well-being for children with and without disabilities (Bremer et al., 2016; Dahan-Oliel, Shikako-Thomas; Johnson, 2009; Poitras et al., 2016). Numerous studies have documented the positive outcomes of different types of PA for disabled young people, including yoga (e.g., Chou & Huang, 2017; Rosenblatt et al. 2011), dance (e.g., Reinders, Bryden, & Fletcher, 2015; Scharoun et al. 2015), and general exercise training (e.g., Pontifex et al., 2013; Sowa & Meulenbroek, 2012).

Participating in a wide variety of PA has been associated with the progression of fundamental movement skills (FMS) in typically developing children (Lubans et al., 2010), which are necessary for a range of activities of daily living (e.g., walking, squatting) and sports (e.g., throwing, kicking). FMS competency has been associated with healthy lifestyle factors including PA, cardio-respiratory function, and healthy body weight for children and youth

(Lubans et al. 2010; O'Brien et al., 2016), and can affect the trajectory of health over time (Jaakkola et al., 2016). The disparity between motor skill development between disabled children and those without has been shown to increase with age (Capio et al, 2018; Lloyd et al., 2011; Rintala & Loovis, 2013). Disabled young people may require more time for developing physical skills, which can negatively affect participation in recreational PA (Askari et al., 2014; Martin, 2006; Stodden et al., 2009). PA interventions focusing specifically on FMS have shown promise for disabled children as a method for increasing physical activity (Tindall et al., 2020) and motor skill proficiency (Bremer & Lloyd, 2016; Capio et al., 2018; Kirk & Rhodes, 2011). For example, Capio, Eguia, Abernethy, and Masters (2015) found the effects of FMS training on PA and sedentary behaviour were more pronounced in children with Cerebral Palsy than those without; specifically, these children were less active on weekends. Further, Casartelli, Molteni, and Ronconi (2016) suggested utilizing a motor approach in therapeutic intervention for children with Autism Spectrum Disorder (ASD) as a means to address delays in social development. Thus, the importance of PA interventions for disabled children are numerous.

Unfortunately, disabled young people experience many barriers to PA, resulting in sedentary lifestyles that compound health issues (Martin Ginis, Ma, Latimer-Cheung, & Rimmer, 2016; Messiah et al., 2015; Shields, Synnot, & Barr, 2012). A growing body of research has been conducted regarding the facilitators and barriers of PA for disabled individuals, but little work has focused on PA interventions (Martin Ginis et al., 2016), particularly for persons with intellectual disabilities (Rimmer, Chen, McCubbin, Drum, & Peterson, 2010). Leisure activities have been associated with increased quality of life for disabled children; however, adaptations are needed to enhance participant enjoyment and ensure positive PA experiences (Dahan-Oliel et al., 2012). Barriers not only exist for disabled persons, but also coaches, instructors, and community organizations (Rimmer et al., 2004). Orr et al. (2019) highlighted the need, not only for rigorous evaluation of inclusive programming, but also rich operationalization of the components. In the present study, an evidence-based PA program developed specifically to reduce some of the barriers associated with PA for children, families, and instructors was evaluated from a realist perspective. Realist evaluations aim to examine “what works in which circumstances and for whom” in a particular program (Pawson & Tilley, 1997, 2004, p. 2). Thus, this research utilized multiple methods to collect comprehensive data from program stakeholders with the purposes of (1) understanding the program mechanisms; (2) describing the program context; and (3) examining the program outcomes (Pawson & Tilley, 1997, 2004).

Program Description

Movin’ and Groovin’ (M&G) was developed by two PhD students (one of which is the first author) in the winter of 2015 to improve the accessibility to PA in the region. M&G is a community-based PA program for children aged 7 to 14 with developmental disorders, including attention-deficit/hyperactivity disorder (ADHD), ASD, and other developmental disabilities (DD), as well as their neurotypical siblings over a ten-week session. M&G implemented evidence-based practices to improve FMS through sport, fitness, dance, and yoga and incorporated peer modeling approach by including siblings (Chu & Pan, 2012). In addition, M&G fostered a non-competitive environment, which has been listed as important in PA for disabled children (Hutzler & Korsensky, 2010; Rimmer & Rowland, 2015). The ratio of adults to children was low and special care was taken to develop a sensory friendly learning environment, as emphasized by Connolly (2008).

M&G is typically run by one or two instructors with the assistance of one-on-one volunteers recruited from a local university to support each participant. Junior volunteers were young people over the age of 14 who identified as having a disability, who also expressed interest in helping with the program. Junior volunteers encouraged the participants, distributed yoga mats, cleaned up equipment, and participated in the program as a role model. In this way, the junior volunteers gained valuable experiences in their community, which has been associated with increased feelings of competence and autonomy (Orr et al., 2018; Orr et al., 2019).

A logic model was created to define the inputs, outputs, and short, medium, and long-term outcomes of the program (Table 1, Appendix 3). M&G has been described in full (Luymes & Redquest, forthcoming), but can be summarized as follows:

1. Circle time: everyone shares their name and their answer to the "question of the day"
2. Warm up: 3-5 minutes of gentle movement to prepare for the class
3. Exercise: 7-10 minutes dedicated to improving fitness (e.g., endurance)
4. Fundamental movement skills: 7-10 minutes dedicated to improving FMS (e.g., aiming)
5. Dance: 7-10 minutes dedicated to creative movement (e.g., ribbons)
6. Yoga & relaxation: 7-10 minutes dedicated to stretching, breathing, mindfulness, etc.
7. Circle time: reflect on what they learned in class, finish with the M&G cheer

Methods

There were several research methods employed for this pilot study at three points in time during one 10-week session of M&G:

1. Before: ethical clearance was attained; consent forms were signed by caregivers and volunteers regarding the video recordings
2. During: classes were video recorded; the researcher made field notes
3. After: volunteers and instructor completed background questionnaires; volunteers participated in one of four focus groups; the researcher and instructor participated in one-on-one semi-structured interviews; caregivers completed a survey

NJL created the data collection tools (background questionnaires, interview guides, focus group guides, parent surveys), collected and analyzed the data, and wrote the manuscript, while PCF and PJB supervised the research.

Participant Recruitment

Ethical approval was granted by the university Research Ethics Board for all components of this pilot study. All M&G participants (e.g., caregivers, children, volunteers, and instructor) agreed to participate in the pilot study, and therefore this research was able to incorporate the diversity of M&G perspectives.

Caregiver Survey

Caregivers were asked to complete a survey (see Appendix 3) pertaining to their personal demographic information, as well as that of their children and their experiences in M&G. The researcher originally proposed to conduct one-on-one interviews with the primary caregiver of each child to gain in depth information about their lived experiences; however, some caregivers expressed feelings of stress when considering the interview, as it would take too much time in their already busy schedules. After speaking with caregivers, the researcher designed a 10 to 15-minute survey which better suited the time constraints of the caregivers. Therefore, it was deemed appropriate to distribute a short survey to all caregivers (n=9), ensuring data collection from everyone in as little time as possible. The survey data was conducted via Qualtrics and analyzed using SPSS v. 24. Frequencies and descriptive statistics were run on caregiver surveys and then collated into tables found at the end of this chapter. Qualitative data have been presented in the tables as well and summarized in the results section.

Background Questionnaires

Volunteers (n=13) completed background questionnaires (see Appendix 3) regarding their demographic information, such as age and program of study, as well as contextual information, such as past experiences and level of confidence working with young people who have developmental disorders. Questionnaires were completed by volunteers before the focus group began. The mothers of the junior volunteers (n=2) completed a caregiver survey in lieu of a background questionnaire, as it provided details about the junior volunteers’ diagnoses and PA patterns.

Focus Groups

The university-aged volunteers attended one of three focus groups conducted at the university, while the junior volunteers (n=2) did the fourth focus group together at the facility where M&G took place. Junior volunteers participated in a focus group on their own due to the likelihood their experiences differed from the university volunteers. The purpose of the focus groups was to stimulate discussion regarding the strengths and weaknesses of M&G. Volunteers were asked whether they felt prepared for the program, how, if at all, they could better support disabled young people in the program, and how, if at all, the program could better support the volunteers (see Appendix 3). They were asked if their original expectations for the program were met, how they would improve the program, and whether they would become involved again in the future. All focus groups took place within one week of the last M&G class to ensure participants retained memories about the program. The researcher conducted the focus groups and was assisted by a graduate student, who took notes on a large white board in the interview room. The graduate student helped for three of the focus groups, but not for the focus group with the junior volunteers, as there were only two participants.

Interviews

The instructor and researcher each participated in one-on-one semi-structured interviews (see Appendix 3): the researcher conducted the instructor's interview, and a graduate student proficient in qualitative methods conducted the researcher's interview. In the interviews, the instructor and researcher commented on program strengths, weaknesses, and short-term outcomes, as well as young people participation, volunteer support, class structure, and positive or negative events that occurred. The instructor and researcher were also asked about caregiver interactions, the registration process, and any concerns that occurred during the ten-week program. NVivo software (QSR International, 2020) was utilized to analyze all qualitative data from the surveys, focus groups, and interviews.

Field Notes

Field notes provided contextual information for the pilot study, and therefore it was necessary for the researcher to record what occurred before, during, and after the focus groups and interviews. Field notes have been defined as "feelings, reactions … and reflections" of an experience (Patton, 2002, p. 303), which were all from the perspective of the researcher. These notes were added to the verbatim transcripts, including where and when the focus group took place, any interruptions that occurred, or any strong feelings that emerged.

Video Recordings

Video recordings of M&G were made to document attendance, activities, children's behaviours, and interactions between participants (e.g., children, volunteers, and instructor). These recordings allowed for the collection of richer data than accelerometers alone, by allowing the analysis of context, interactions, and individual responses to activities. Video recordings were selected as opposed to live assessors to reduce concerns with inter-rater reliability (e.g., multiple raters for live vs. one rater for recordings), as well as logistical concerns with raters as a potential distraction for the participants. A portable SONY video camera was set up on a small tripod in the corner of the gymnasium. It was impossible to capture the entire space in the video screen, so participants who left the gymnasium or who were outside of the recording screen could not be included in the analysis at those times. There were several instances when the video recording was temporarily stopped during the class due to participant interference (e.g., a child closed the camera, causing recording to stop), low battery, or limited storage on the device. Due to these interruptions, approximately 70 minutes of video data were lost across five classes.

Observations

The researcher attended nine out of ten classes (absent for class five) and watched all of the video recordings four to six times. The video recordings were analyzed using The System for Observing Fitness Instruction Time (SOFIT, McKenzie, 2015) to capture rich data about M&G beyond PA alone. The SOFIT was created to record several types of information from a group PA setting, including (1) student activity (e.g., PA level, from one [lying down] to five [vigorous]), (2) lesson context (e.g., the type of activity), and (3) teacher involvement (e.g., promoting PA). The SOFIT is a validated measure of PA for children based on the five levels of activity. A SOFIT assessor must make three 10-second observations per minute. McKenzie et al. (2015) recommended one child be observed for four minutes, then a different child for the next four minutes, and so on for the duration of the PA time. However, due to the variable nature of disabled children, one child was not representative of the whole group of M&G participants as is suggested in the SOFIT. Therefore, the authors deemed it necessary to examine each child for the entire hour, rather than four minutes at a time. To examine the effects of M&G over time, each child was observed three times over the ten-week session.

The SOFIT included teacher involvement; however, much of the instruction at M&G comes from the one-on-one volunteers, in addition to the instructor. Further, one of the goals of the M&G program was to improve socialization between children, which the authors also wanted to capture. Unfortunately, most of these interactions were impossible to differentiate through the video recordings. Therefore, the teacher involvement component was broadened to include all social interactions, verbal and non-verbal. For example, any time a child was talking to a volunteer or passing a ball to another child was coded as “yes” under “social interaction”. Further, if a child demonstrated he/she was listening, such as raising a hand to answer a question, this interaction was coded “yes” as well. To simplify, children were only coded as “no” in the social interaction section when they were visibly off task (e.g., doing something different from what was instructed) and alone (e.g., standing in the corner while the rest of the group played a game). The child could not be coded solely for being off task because he/she may still have interacted with the instructor or volunteer at the same time (e.g., volunteer redirecting a child to the task at hand).

Taken together, the SOFIT (see Appendix 3) was utilized to asses each child, with three observation time points over the first nine weeks of the session. Class ten was omitted from the analysis because it was much less structured than the other nine classes and primarily spent in free time and game play. In addition, the researcher did not evaluate one of the 11 participants (C7), who spent the majority of M&G in the hallway and was not recorded. C7 had the most needs of all the children in M&G and did not like the loud environment, even when wearing noise-cancelling headphones. C7 would rarely enter the room, even with coaxing from the family and volunteer, so the volunteer and one of the junior volunteers did M&G activities with C7 in the hallway for the majority of class time. On the occasion that C7 did enter the room, it appeared to be a positive, yet stressful experience. C7 enjoyed being silly with the group (e.g., when asked to share a favourite activity in circle time, C7 responded “eating”) and doing the cheer at the end of class, but C7 still made every effort to cover his ears and leave the room when possible. The volunteer and instructor felt every second of C7’s time spent with the group was an accomplishment, but it was still not enough time to evaluate with the SOFIT.

Thus, ten children were assessed with the SOFIT three times over the course of nine-weeks to evaluate their participation over time. The researcher selected who would be assessed in each class based on their attendance (e.g., if a child missed class two, the researcher ensured his evaluation was either in classes one, four, and seven, or classes three, six, and nine). After attendance, the researcher organized children into observation days to increase variability by including children of different genders and abilities into the same groups. In addition to the SOFIT, the researcher recorded her observations about the class, such as which activities seemed to stimulate the most interest from the participants (e.g., smiles, excitement, etc.) and when participants focused elsewhere (e.g. needed to leave the room). She also made note of any relationships that developed between young people, volunteers, and the instructor.

Analysis

Several forms of analysis were utilized for this study. Qualitative data from the interviews, focus groups, and open-ended survey questions were examined via thematic analysis (Braun & Clarke, 2006). Regarding the SOFIT, three categorical variables were recorded (i.e., PA level, lesson context, SI) three times per minute (i.e., ten seconds observation and ten seconds recording for a 20 second observation period) for each child during the time they were within the video screen (McKenzie et al., 2015). These variables were summed, divided by the total observations, and presented as percentages of observed time. For instance, if C6 was in the screen for 180 observations (60 minutes x 3 recordings/minute) and was observed in MVPA for 100 observations, her observed time in MVPA would have been 55.56% (100/180 x 100%). To describe changes over time, the observed percentages were averaged across children and/or across classes to discover patterns in PA, lesson context, and SI.

Results

Participants

There were 39 participants in this research: 11 children, 11 caregivers, 13 university student volunteers, two junior volunteers, the instructor, and the researcher. Participant demographic information were collected at the end of M&G via caregiver surveys and volunteer background questionnaires. Ages were calculated from each person's birth month/year to the time of the session.

Four focus groups were conducted with the volunteers; specifically, two with undergraduate student volunteers (n=5, 65 minutes; n=3, 42 minutes), one with graduate student volunteers (n=5, 48 minutes), and one with junior volunteers (n=2, 20 minutes). The instructor interview was 54 minutes in length and the researcher interview was 34 minutes. The participant demographics have been summarized below.

Instructor and Researcher

The instructor (BR) and the researcher (NL) created M&G in April 2015 and continued to coordinate the program until the present research study was conducted. Both individuals were trained to facilitate programs for disabled people, in addition to extensive experience working with disabled children. The instructor had completed undergraduate and Master's degrees and was in her final year of study in her PhD program – all in the area of kinesiology. Similarly, the researcher had an undergraduate degree in health science, Master's degree in kinesiology, and was in the third year of her PhD in kinesiology. The instructor and researcher both had years of experience in qualitative research – making their observations and reflections of M&G during the period of research exceptionally rich. Further, both were knowledgeable about FMS development in children and were able to comment on skill progression over time.

Children and Caregivers

Participant demographic information was collected at the end of M&G via a caregiver survey (Appendix 3) about their experiences in M&G (children in Table 2, caregivers in Table 3, Appendix 3). The young people in M&G ranged in age from 7 to 14 years and averaged 9.8 years. There were five females and six males. Ten of the participants had at least one diagnosed developmental disorder, and one did not (C8, the younger sister of C11). One individual was participating in M&G for the first time during the evaluation (C6), while the rest had at least one session of experience. Four participants were only children and the other seven had at least one sibling.

There were two pairs of siblings enrolled in M&G and therefore there were nine caregivers in total. The average age of caregivers was 45.1 years, ranging from 42 to 51 and their demographic information has been summarized in Table 3. Caregivers were asked to provide detailed information about their children's disability related concerns and physical activity behaviours. Data for C7 and C8 were not provided, as they were the higher functioning siblings of other individuals in the program and caregivers were only asked to complete the survey for their children in M&G most affected by disabilities (e.g., their "lower functioning" child).

Table 4 (Appendix 3) lists the signs and symptoms for nine of the children (e.g., all except for C7 and C8), as well as their current medication use, educational status, and extra-curricular involvement. Attention was the most frequently listed concern (88.9%), followed by fine motor, social, emotional, and learning skills (77.8%). Five children were currently taking medications to address some of these concerns, or another health condition (e.g., asthma). All but one child (C3) were enrolled full-time in formal education at the time of this research. C3 was previously enrolled in formal education but was moved to a special education program. Two were in regular classes with special accommodations, four were in regular class with extra support, and three were in special education classes. All of the children were involved in at least one extra-curricular program (including M&G), with 3.7 programs on average per week or month.

University Volunteers

The volunteers were all females enrolled in a university degree program at the undergraduate or graduate level, ranging from 19 to 25 years of age at the time of data collection (average = 21.7 years). V1 through V11 all had previous experience with M&G before the evaluation, while V12 and V13 were new in the evaluated term. All volunteers reported a four or five out of five regarding their confidence in their abilities to provide one-on-one support for a young person in M&G. Ten out of 13 had previous experiences working with disabled individuals; however, only two had specific training for these experiences. Volunteer information has been summarized in Table 5 (Appendix 3).

Junior Volunteers

An important – and unique – component of M&G are the junior volunteers (JV). Two high school aged young people (aged 17 and 14 years) participated as JV in M&G (JV in Table 6, their caregivers in Table 3, Appendix 3). JV1 was recruited to volunteer via a connection between his mother and the first author, while JV2 was previously a participant in M&G. Both were diagnosed with developmental disorders that affected their physical and cognitive functioning; however, they were able to follow instructions and assist the instructor and volunteers in several ways. For instance, JV1 spent the majority of his time with C7, as he was often in the hallway during M&G. In this way, V7 had another person to assist her with C7 and to ensure C7 was never alone with an adult. JV1 helped to bring equipment from the gym to the hall (e.g., ribbons, basketballs, etc.) for C7 to use. He would also encourage C7 to try new things, such as kicking a soccer ball.

JV2 spent most of her time in the classroom assisting in various ways, such as distributing equipment (e.g., giving out ribbons), cleaning up equipment (e.g., rolling up yoga mats), and encouraging participants (e.g., saying “good job C4!”). At times JV2 spent more time talking with C11 than helping with M&G related tasks, but the two of them participated in activities together while socializing and therefore this interaction was viewed as supportive.

Of note, the JV were not entirely independent as the university volunteers and required additional support from the instructor. Often the JV benefitted from instructions, such as “will you hand out soccer balls?” (e.g., equipment prompt), “please encourage C10 with the fitness circuit” (e.g., socializing prompt), and “what kind of stretch should we do next?” (e.g., leadership prompt). That said, the JV acted as role models for the children in M&G, while also gaining valuable personal experiences in a leadership position. M&G participants could engage with the JV as older and “cooler” friends, and see disabled individuals giving back to their community in a valuable way.

SOFIT Results

The SOFIT was utilized to observe the children’s PA and social interactions (SI), as well as M&G lesson context. Approximately eight hours of video data were recorded over nine classes, an average of 53.1 minutes per class. Due to children moving in and out of the recording screen, PA was observed for 42.6 minutes and SI was observed for 41.6 minutes per class on average. Children spent an average of 58.1% (24.8 minutes) of observed time in moderate to vigorous PA (MVPA, a SOFIT level four or five) and 81.8% (34.0 minutes) in SI. The proportion of class time spent in MVPA ranged from 17.67% to 42.33% (Figure 1, Appendix 3). Similarly, proportion of time spent in SI ranged from 61.7% to 95.6% (Figure 2, Appendix 3). When collapsing all data over time (e.g., average of all 10 children plotted across three time points) MVPA increased by 1.93% (Figure 3, Appendix 3) and SI increased by 1.80% (Figure 4, Appendix 3).

Most of the class time was spent in skill practice, fitness, and management, followed by game play, knowledge, and other (Figure 5, Appendix 3). For a list of M&G activities that fit within each contextual element, see Table 7. There were patterns in how class time was spent across the nine observed classes: management, skill practice, and game play time increased while knowledge and fitness time decreased over time. For example, the knowledge component decreased as the children required less time to review names or rules over time. Alternatively, game play and skill practice increased as the instructor tailored M&G to the children, who tended to enjoy these activities more than fitness. Similarly, management time increased as the children became more comfortable at M&G and as the volunteers became more relaxed, leading to increased time transitioning between activities. Variations in lesson context occurred between children in the same class if one child arrived late (e.g., context was not recorded until the child arrived) or if there was unequal division of time between fitness and skill practice (e.g., half the children with soccer balls, half on exercise circuit). By observing at least three children per class, these inconsistencies were minimized, and the context of each class was well represented.

Survey and Interview Results

Overall, eight caregivers reported their child(ren) enjoyed PA and one specified her child enjoyed PA “as long as she doesn’t realize she is exercising…”. Caregivers listed many factors that positively and negatively affected their children’s participation in PA (Tables 8 and 9, Appendix 3). Of all the barriers listed, personal factors such as the children’s ability and cognition were the most prevalent (55.6%), whereas social stigma was the least (0%). Caregivers listed many more facilitators than barriers to PA, which primarily were socialization (88.9%) and well-trained friendly instructors (77.8%). Caregiver survey responses have been listed in Tables 10 to 13 in Appendix 3.

Why Participate in M&G?

All stakeholders were involved in M&G voluntarily, and therefore the researcher sought to understand why they chose to participate. Overall, all participants felt the program was a worthwhile investment of their time and resources.

Caregivers

Caregivers learned about the program from an online local program guide (n=5) and word of mouth from one of the instructors (n=3) or another caregiver (n=1). They described their reasoning for enrolling their children in M&G, which can be found in Table 14 (Appendix 3). For the most part, caregivers wished to increase their children’s skill development, both physical and social, in a fun and inclusive environment. Caregivers listed affordability and convenient time (e.g., 6:30pm) as two facilitators for their participation in M&G, in addition to the one-on-one volunteer support that accommodated their children’s specific needs. Of note, one caregiver also listed the non-competitive nature of the program as important.

Volunteers

The university volunteers also learned about the program through word of mouth from the instructors (n=6), a supervisor (n=2), or a friend (n=1), or through classroom announcements made by the research supervisors or other instructors (n=4). They listed a variety of reasons for volunteering with the program including personal development (e.g., learning by doing), personal reward (e.g., seeing the children grow), education (e.g., disability awareness), and a change of pace from their day to day schoolwork.

The junior volunteers were recruited by their mothers, who learned about the opportunity from the instructors. Their mothers sought out gainful opportunities for these two young people to develop leadership skills and responsibility. Notably, the junior volunteers' reasoning for volunteering fit within the same categories as the university volunteers listed above. Specifically, JV1 said *"it keeps me busy"* and *"it's good for me to get out of my house"*, while his mother said M&G *"gives him confidence"* and *"keeps my son involved in the community"*. When asked about her favourite part of volunteering for M&G, JF2 said, *"meeting new friends"* and *"I get to help little kids that need it."* JV2's mother listed socialization and acceptance as important factors and said, *"I like the fact my daughter always wants to return."*

Outcomes of M&G

Participants (caregivers, volunteers, instructor, researcher) listed various outcomes they believed to be associated with M&G, which have been summarized into three categories: (1) positive experience; (2) skill development; and (3) lifestyle habits. These results all pertained to the perceived outcomes for the children and junior volunteers by their caregivers, one-on-one volunteers, the instructor, and researcher.

Positive Experience

It was evident from the qualitative data that child enjoyment was the top priority of M&G. All nine caregivers said they would suggest the program to a friend and eight out of the nine were returning families, which suggested child enjoyment was achieved for those involved in the program. The primary factor for program success was attributed to the high ratio of adults to children, as well as the enthusiasm and energy they devoted to the program. As one caregiver said, *"She loves the class and is jumping with joy when I tell her we are going. She likes the instructors"* (P4).

Caregivers reported their children were happy and excited to exercise at M&G, which some caregivers said contributed to a sense of calm and even improved sleep. The children felt special and accomplished in M&G and built a sense of team spirit with the group cheer. Some favourite activities, as reported by caregivers and volunteers, included dance (e.g., ribbons, M&G dance, etc.), yoga, and games (e.g., Mr. Wolf, Groov-opoly, etc.). Caregivers and volunteers recognized that exercise "disguised" as games was effective to enhance the children's participation in PA.

Regarding the JV, JV2's mother listed social and acceptance as outcomes of JV2's participation in the program, partially due to the support she receives. JV1's mother said, *"he enjoys the social interaction with the kids and being in a leadership role."* Both JV commented on specific children who enjoy their company each class, which contribute to their positive feelings about the program. For instance, JV1 knew *"C7 loves [him]"* because of C7's frequent hugs. When asked if she had any suggestions for the program, JV2 answered the question unexpectedly, saying she was going to suggest M&G to one of her friends at school (i.e., the friend should volunteer). It was evident from the focus group that the JV felt M&G was positive, both for themselves and for the children who participated.

Skill Development

According to the instructor, the top two goals of M&G were social and physical skill development. The volunteers listed these as outcomes for the children, as did the caregivers, but to a lesser extent than enjoyment. Participants listed the following social skills practiced in M&G, including learning to follow instructions, connecting with others, and functioning in a (somewhat chaotic) group environment. The goal of M&G was for children to feel accepted and therefore gain confidence to be themselves. The children developed relationships with the instructor, volunteers, and each other over the course of the program by learning each other's names week after week at circle time and playing games together.

The importance of skill practice was emphasized, particularly with sports equipment, and was listed as a preferred activity. A variety of FMS were practiced throughout M&G (e.g., running, skipping), but the instructor dedicated time each class to practicing sport specific skills with bean bags, tennis balls, soccer balls, and basketballs. However, it was important to maintain a low-pressure environment to keep children engaged, rather than playing a game of soccer for example. P8/11 said she appreciated M&G was "*non-competitive*" and P2 liked that it was "*different from other programs that only focus on team sports*". To summarize, P1 reflected on the positive outcomes for his child, saying *"Most positive has been the social skills development by taking turns, learning the rules, being on a side, fair play, and good sportsmanship. He also enjoys the activities and getting better at the skills"*.

For the JV, both caregivers listed social skills as important outcomes of their participation in PA in general, which were certainly practiced in their JV roles at M&G. JV2 recognized the potential for the children in M&G to gain skills as well, saying *"learned how to move their body even when they're at home"* while JV1 said *"They learn how to be kind to people… and they make new friends."* When asked if there were any outcomes for the children at school, JV2 suggested *"they might help their friends at school with it… In like, helping them with, if someone's disability, like me, they might help them."* In this way it appeared JV2 felt the children in M&G were helping her participate, just as much as she was helping them, thus engaging in a reciprocal relationship.

Lifestyle Habits

A third goal of M&G listed by the instructor was *"to provide [children] with some knowledge concerning heathy living."* This was practiced through circle time questions, such as asking the children to list a healthy food they ate or what type of PA they did that day. Children were encouraged to think about how much exercise they should do each day and to feel their heart beating after a running game. In addition to gaining knowledge about PA, children learned about different types of activities by doing them. For instance, P10 wrote a positive outcome of M&G was *"[i]mprovement in gross motor skills, has learned about crunches, lunges."* In this way, children had the opportunity to develop their physical repertoire of movement, which could affect their overall physical literacy. This learning was demonstrated on several occasions, as children and/or caregivers shared which M&G activities they were doing at home, such as an exercise circuit (e.g., C8) or yoga (e.g., C6). While this was an important goal of the program, it was emphasized less by caregivers and more by the volunteers and instructor.

When asked about why to participate in M&G, JV2 said *"I think it's great because, because we get to move our body to keep us, our blood pumping.",* to which JV1 concurred, saying *"I think it's a great program for little kids [yeah?]. Um, and like JV2said, it's great for,* *to keep our pump, to keep our blood pumping."* Similarly, JV1's mother said *it "gives my son experience to put towards his future interests [and] plans."* In this way, M&G contributed to the development of positive lifestyle habits, including PA and personal development.

Challenges of M&G

There were a variety of challenges associated with facilitating this program that affected all the participants differently. A common challenge was the difficulty balancing the program activities based on the varying needs of the children. In many cases, an activity one child enjoyed (e.g., freeze dance) was too loud and chaotic for a different child (e.g., C7). The volunteers noticed variability in the effort required to motivate the children or keep them "on task" with the rest of the group. Some of this variability was related to the child's interests (e.g., did not want to exercise) or his/her previous day (e.g., tired from school). The one-on-one support was necessary for accommodating these varying needs, as volunteers adjusted the activities for each child based on his/her skills, interests, and mood.

Overall, the children were very positive toward M&G. However, to illustrate a negative case, C11 started complaining about M&G in class five saying it was *"boring"* and *"a little annoying."* The instructor spoke to his mother and they both felt M&G was not stimulating according to his interests and level of functioning. It is also possible C11 was feeling this way due to his age (11-years) and previous years of experience in M&G. He reported disliking some of the activities because they were too *"kiddie"* for his liking. To accommodate his concern, the instructor would often ask him for input into the class, such as which warm up or game he wished to play. He was also asked to provide leadership in other ways, such as being "it" for a game or helping to clean up equipment with the junior volunteers. By the end of class ten, C11 no longer seemed to resent M&G, but said he would miss the instructor and volunteer when it was over, and said he was excited for camp in the summer. This case demonstrates the need for flexibility in M&G and to provide autonomy to the participants wherever possible.

Not only was it important to accommodate the children's needs, but also to develop personalized relationships between the children and volunteers over time. One challenge in developing these relationships was the commitment of the volunteers over the session, as they had other priorities to manage such as school, work, and personal health. If a one-on-one volunteer was absent, the instructor asked a substitute volunteer to step in (e.g., V12 and V13). These volunteers found it difficult to get to know a new child each class, rather than working with the same person from week to week. At some points many volunteers were absent (e.g., preparing for mid-terms) and there were not enough substitutes. In these cases, the one-on-one volunteers may have been asked to work with a child who required more assistance. For example, C9 could participate in M&G independently, therefore V9 was paired with C1 for class five. While it was important for C1 to have one-on-one support, the researcher noticed C9 still looked to V9 for encouragement throughout the class. V12 was able to provide social support to C9 throughout class five, justifying the necessity for substitute volunteers.

On the other hand, while having many volunteers was often needed, some children were absent many times (e.g., C3 was absent five times, C10 was absent four times). If all the other children had one-on-one support, the volunteer of the child who was absent was allowed to decide if they wanted to stay or go home early. In many cases, the volunteers chose to stay to assist the instructor, support one of the junior volunteers, or simply participate in M&G herself. However, it was disappointing for the volunteers to dedicate their time to the program when their one-on-one partner was absent. Caregivers rarely provided notice ahead of time, in which case the volunteer would stay at home. While this was difficult for the instructor to manage, the volunteers understood it was a regular occurrence at M&G and were flexible to last minute changes.

Caregivers listed few challenges from their own perspective, such as difficulty socializing with other caregivers (e.g., due to her own anxiety) and feeling unsafe in the dark parking lot when bringing their children to and from M&G. Unlike the concerns for children and volunteers, the instructor could take less action to address the needs of the caregivers, and it was often difficult to balance the needs of the children and their caregivers. For instance, M&G moved to a school gymnasium to reduce distractions (e.g., no toys in this space), but the school parking lot was darker than that of the early education facility where the program previously took place. Three actions were taken to reduce safety concerns: (1) volunteers waited by the door for families to come in, thus serving additional support when walking outside, and (2) volunteers tended to come and go from the space at the same time as the children and therefore there were more people outside together, and (3) the instructor and researcher did not leave the school until everyone had left to ensure no one was left behind on their own.

Interestingly, the JV listed their own challenges in M&G. For example, JV2 stated that, while she enjoys yoga, she said *"I don't like sitting on the ground very much because, because I, then um it's bad for my leg kind of."* JV2 utilizes custom braces for her ankles due to complications with Cerebral Palsy, which did affect her mobility in M&G. However, the instructor and other volunteers encouraged her to create standing variations of the exercises, or seated variations using a chair. C10 was immunocompromised and was instructed not to lay on the ground by her mother, and therefore, JV1 was able to provide support and motivation to C10 as they both performed exercises standing and seated in a chair. JV2 similarly experienced physical challenges in M&G, saying he did not like playing soccer because *"[he] can't really play."* Otherwise, JV2 said there were no additional challenges for him as a volunteer in M&G.

While there were several challenges to facilitating M&G, all the children, caregivers, and volunteers seemed to have a positive experience overall. M&G contributed to the children's MVPA one day each week and facilitated the development of social connections with their volunteers. The volunteers reported personal gain from their one-on-one position and caregivers were happy with the inclusive nature and affordability of the program. These results indicated the program was worthwhile to the participants involved and contributed to their sense of community.

Discussion

The findings from this study revealed positive outcomes for the participants of M&G based on the context and mechanisms of the program. The children gained social interactions and PA as they practiced FMS and developed friendships with each other, their one-on-one volunteers, and the instructor. Caregivers felt their children were safe and accepted in the program and enjoyed watching them grow over time. The junior volunteers developed a sense of autonomy and independence as they engaged in leadership roles, while the university volunteers enjoyed the personal reward that accompanied their supporting children in the program. M&G was not without challenges, such as balancing the children's needs and ensuring sufficient volunteer support, but several mechanisms were utilized to overcome these challenges and create a positive environment.

M&G utilized well researched mechanisms to foster success for the children involved, several of which have been specifically outlined by Hutzler and Korsensky (2010) and Luymes and Redquest (forthcoming). For example, M&G included siblings, a wide age group, and junior volunteers to foster peer modelling, which has been shown to improve participation for people with intellectual disabilities and be a positive experience for peers (Block & Zeman, 1996; Chu & Pan, 2012; Hutzler & Korsensky, 2010). In addition, there was adequate social support by individuals who were educated about PA (e.g., university volunteers) and adapted PA (e.g., instructor), as well as support from the caregivers, which all contributed to success for the children who participated (Connolly, 2008; Hutzler & Korsensky, 2010). Finally, M&G focused on collaborative activities rather than competition (Hutzler & Korsensky, 2010) by changing games that typically result in eliminating players (e.g., Simon Says) and simply practicing sports-related skills rather than playing a game with teams (e.g., soccer).

Organized PA has been related to elevated overall PA levels in TD children (Holfelder & Schott, 2014), contributing to the hypothesis that adapted PA programming would have similar effects for children with DDs. However, review studies regarding PA participation for disabled people have revealed less emphasis on PA for disabled children than other demographics, such as injury or age-related disorders (Martin Ginis et al., 2016; Rimmer et al., 2010). The present study demonstrated a community-based program could contribute to MVPA for developmentally disabled children and their siblings, while also practicing FMS in a supportive environment. FMS in adolescence has been a moderate predictor of all of PA for young adults (Jaakkola et al., 2016), demonstrating the importance of FMS development in childhood to promote for life-long PA.

The benefits of inclusive PA not only affect the children involved, as discussed above, but also the caregivers and volunteers. Caregivers' experienced a variety of difficulties raising disabled children (Redquest et al., 2015), namely, finding respite services (Doig, McLennan, & Urichuk, 2009). In the present study, two caregivers commented on the support they receive from M&G as it pertains to raising their children (Table 12, Appendix 3), demonstrating extracurricular PA programs can serve as short periods of respite for parents. It is possible for programs like M&G to implement the parent-to-parent peer support method described by Bray et al. (2017) to reduce distress and improve coping among caregivers as they raise disabled children.

Similarly, M&G offered benefits for the university volunteers, including skill development, knowledge about disability, and personal satisfaction from helping others. Li and Wu (2012) found increased exposure to individuals with intellectual disabilities was correlated to positive attitudes towards inclusion for the typically-developed volunteers at the 2010 Special Olympic Games. Similarly, the study by Collier and colleagues (2015) revealed increased comfort levels towards disabled individuals for volunteers in the program, particularly if their initial comfort levels were low. There is potential for this integration of volunteers to affect their perspectives about disability and perhaps even the people around them, thus affecting societal norms regarding able-ism over time. While there are many positive outcomes of volunteering, it is necessary to support volunteers with training and ongoing support as they provide support to others (King et al., 2009).

Not only did M&G provide positive experiences for the university volunteers, but also the junior volunteers. There are few meaningful volunteer opportunities for disabled young people according to the scoping review by Lindsay (2016), despite the fact that many of these youth would be capable of filling such positions. Volunteering may contribute to various positive outcomes for disabled youth, such as increased self-confidence, social inclusion, and contributing to the community; however, similar barriers exist for volunteer opportunities as PA participation (e.g., limited transportation, negative attitudes) (Lindsay, 2016).

M&G was unique in the region in which it took place, but similar research has been conducted elsewhere. In Australia for example, Willis and colleagues (2018) conducted a realist evaluation on a physical activity participation intervention for disabled children and youth, as well as their families. The evaluation revealed four contextual factors (safe, learning, social, and family) and five mechanisms (choice, fun, friends, specialized professionals, and time) that contributed to six outcomes (achievement, aspiration, friends, independence, enjoyment in PA, and body functioning and activity level) for children and their parents (Willis et al., 2018). The mechanism-context-outcomes (MCO) configuration that resulted from their evaluation is not dissimilar to that of M&G, although there are some differences. The MCO model for M&G would change the contextual element “safe” to “accepting”, as the latter term more broadly represents the M&G environment. The M&G MCO configuration would also include a fifth contextual factor of “non-competition”, which was an important factor in the success for the children and their caregivers. Regarding mechanisms and outcomes, the volunteers’ time and sense of personal gain (both for the university and junior volunteers) would be added to the model, respectively. Lastly, an additional outcome for the children and caregivers in M&G was the practice of transferrable skills such as FMS, turn taking, and speaking/performing in front of a group. Several of the outcomes for children were likely present for the junior volunteers as well, though they were not examined in detail in this study.

In the “Quality Parasport Participation Framework” by Evans and colleagues (2018), inclusion and peer-mentoring were listed in the core social concepts vital to Parasport. In addition to the social environment, emphasis was placed on the need for adapted sport experiences to be meaningful and take place in an accepting, accessible environment (Evans et al., 2018). Without consideration for these concepts, participants would be unlikely to gain quality experiences in sport and PA, potentially leading to increased sedentary activity over time. According to Sit et al. (2017), disabled children spend only 17 minutes of the school day in MVPA and spent of 70% of their time in sedentary behaviour. If the proportion of 58.1% of class time spent in MPVA (observed, on average) holds true for a full 60 minute program, a child at M&G would spend almost 35 minutes in MVPA, which could significantly contribute to the likelihood these children achieve 60 minutes of daily MVPA, as recommended by Tremblay et al (2016). It is this sedentary lifestyle that may contribute to lower levels of health-related quality of life in disabled young people (Omorou et al., 2006).

Strengths and Limitations

A strength of this research was the community-based setting in which it occurred. The majority of literature has taken place in clinical and school settings (Marcus et al., 2006**)**, and therefore, the findings from this study present more information regarding the implementation of PA in community settings, which may be more applicable to the lives of families raising disabled children. In addition, this study followed the recommendations described by Martin Ginis et al (2016) by (1) working collaboratively in the community; (2) developing strategies to increase PA participation; and (3) including all stakeholders, rather than just examining the disabled participants. The findings from this research contribute to the development of meaningful PA experiences for disabled people in a more wholistic way, rather than interventions seeking to "fix" the participants (Askari et al., 2014).

However, due to the community setting of this research, the video recordings were incomplete as participants moved in and out of the recording frame and as the camera stopped recording (e.g., shut off, low power, or lack of storage). Therefore, the SOFIT results may not be entirely representative of the lesson context, MVPA, and SI of the participants in M&G. To mitigate this concern, data were represented as a percentage of observed time, rather than a percentage of the 60-minute class. In this way, the results from this study represent the *minimum* MVPA and SI achieved by the children in M&G. If it was assumed the observed time was representative of the entire class time, the children would have gained almost 35 minutes of MVPA and 49 minutes of SI, which is more than that reported in the results section. While it is possible the observed MVPA and SI were representative of the entire class, it was impossible to be certain and therefore the authors presented more conservative results.

Another limitation of this research was the potential for bias on behalf of the first author due to her role in creating the program. This concern was addressed by having the other instructor (a co-creator of the program) plan and instruct the session independently of the researcher. Therefore, the researcher was not evaluating her own lesson planning and instruction. Second, the researcher practiced self-reflexivity (Tracy, 2010) through journaling and a one-on-one interview by a graduate student studying qualitative research. By engaging in these methods, the researcher was able to identify her biases and thoughts about the program, particularly during analysis (Ahern, 1999). In this way, the researcher did not allow her thoughts about the program to interfere with the data and her presentation of the data. That said, including the researcher's personal experience is not necessarily negative and may contribute to the richness of the evaluation due to her deep understanding of the program (Tracy, 2010).

The third limitation of this research pertains to the SOFIT tool. While the SOFIT has been validated as a sound measure for PA for typically developing young people, it is less dependable for disabled children (Taylor & Yun, 2006). As noticed in the present research, as well as Taylor and Yun (2006), the SOFIT was not sensitive to qualitative differences within each of the five PA categories. For instance, walking has been coded as "moderate", but there were large differences between participants in the amount of energy exerted while walking (e.g., slow vs. fast walk). For the purpose of this research, walking was coded as a four (moderate) to ensure correct utilization of the SOFIT; however, future research examining nuances between moderate to vigorous activities on the SOFIT amongst disabled children is warranted.

According to the review by Cervantes and Porretta (2010), PA should be assessed using two or more tools in order to accurately represent disabled children. Accelerometers were not utilized for this research due to logistical concerns for some of the participants (e.g., Hinckson & Curtis, 2013); however, future research on M&G should utilize multiple PA measurement tools. That said, this research was similar to that by Tindall and colleagues (2020), who found disabled young people (n=12) aged 11 to 15 spent approximately 75% of time in MVPA while participating in an adapted PA program according to accelerometry. It is difficult to compare across two different programs, but the accelerometry results by Tindall et al (2020) are promising regarding the PA potential in adapted and inclusive programming. In addition, the study by Capio, Sit, and Abernethy (2010) found strong correlation between SOFIT and accelerometers and a moderate correlation between SOFIT and heart rate in young people diagnosed with CP (n=31) aged 6 to 14 during structured physical activities. Taken together, there are certainly limitations with the SOFIT, but it does offer a glimpse into the PA of disabled children as they participated in M&G.

Implications and Conclusions

Future research should be conducted to determine short term and long-term outcomes of M&G. Specifically, the findings from this research suggest studying the effectiveness of discussing lifestyle habits with the children, such as whether they apply their new skills in other settings such as home and school. There were instances where the children talked about doing yoga and fitness at home, suggesting there may be positive outcomes in this regard. Further, research should be conducted into the social skills, motor skills, confidence, and quality of life of the participants in inclusive community-based PA programs, particularly over time and as compared to their typically developing peers. The authors have conducted a case study on a 6-year-old autistic girl (forthcoming) after participating in M&G for the first time and found positive outcomes regarding her social and motor skills. However, the evidence would be stronger if more children were involved in the research, and for longer periods of time.

Programs supporting disabled children have far reaching effects. For instance, the cost-benefit analysis conducted by Stapleton et al. (2015) demonstrated a positive return-on-investment of each dollar spent on individualized education plans for children with special needs. Similarly, provincial and federal funds would have far reaching effects if dedicated to supporting PA programs like M&G by covering gymnasium rental costs and the continued development of accessible spaces. Post-secondary institutions – particularly those with physical education departments – can contribute to their local communities by recruiting volunteer support for inclusive programs.

In conclusion, M&G is one example of an inclusive community-based PA program that fosters positive outcomes for all the participants involved, both directly and indirectly. For more information about the class structure, activities, and lessons, see Luymes and Redquest (forthcoming). M&G demonstrated how to minimize barriers associated with PA with little monetary input, so long as an accessible space is available at a low cost. M&G contributed to MVPA, positive social interactions, FMS practice, and general education about living a healthy life for the children who participated. These outcomes, in addition to the author's (NL) five years of personal experiences with the program, suggest M&G is a viable option, provided appropriate facilities are available and the potential for volunteer support.

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Appendix 3: Evaluating an Inclusive Physical Activity Program

Table 1

Logic model of Movin' and Groovin'. M&G – the program under evaluation – is an exercise program for disabled young people and their siblings.

Program Factor	Program Considerations
Inputs	- Instructors
	- Volunteers (one-on-one support as needed, university students)
	- Disabled young people (up to 11/class ages 7-14)
	- Caregivers (parents and guardians)
	- Funders (Centre for Physically Active Communities)
	- Facility (Waterloo Region District School Board – elementary school)
	- Equipment (yoga mats, bean bags, ribbons, sport equipment, etc.)
Activities	- Find appropriate space and book for programs
	- Purchase equipment
	- Recruit/train volunteers
	- Register participants
Outputs	- One-on-one volunteer support achieved (or more where needed)
	- 11 disabled young people registered to participate
	- Caregivers gain support from peers and build connections
	- Volunteers trained on how to support young people in M&G
	- Volunteers gain experiences that can be applied to other situations
Short Term Outcomes	- Reduce barriers to participation in accessible and inclusive activities
	- Young people learn to be present within socially stimulating situation
	- Young people enjoy participating in group activities
	- Volunteers trained on how to support young people in adapted PA
	- Caregivers get respite care
	- Young people enjoy program and gain social interactions
	- Young people practice fundamental movement skills
Medium Term Outcomes	- Young people learn body awareness
	- Young people feel confident (or cope) in socially stimulating situations
	- Able to cope with socially stimulating situation
	- Caregivers deepen relationships (with other children, spouse, etc.)
	- Young people feel accepted within program
	- Volunteers to gain confidence in working with needs of youth
	- Young people apply skills in other situations
	- Young people able to feel comfortable and thrive in social situation
Long Term Outcomes	- Young people participate with new friends in other activities
	- Reduce barriers to participation in community-based activities
	- Young people understand personal abilities
	- Young people feel successful
	- Volunteers feel successful in supporting young people to become active
	- Volunteers apply skills to other youth/programs
	- To increase the physical activity level of youth

Table 2

Demographic information for young people who participated in Movin' and Groovin'.

	Age Range (yrs.)	Sex	Primary Conditions	Other Conditions	Prev. M&G*	M&G Attend-ance+
C1	9-10	M	Down syndrome	-	Yes	8
C2	9-10	M	VACTERL association	Deaf, ADHD, ASD	Yes	9
C3	7-8	M	ADHD	-	Yes	5
C4	9-10	F	Cri du Chat	-	Yes	10
C5	13-14	F	Down syndrome	-	Yes	9
C6	7-8	F	ASD, ADHD	Anxiety, speech/language	No	10
C7	11-12	M	Chromosome deletion	ASD	Yes	8
C8	9-10	F	-	Disabled sibling	Yes	10
C9	7-8	M	ADHD	ASD, disabled sibling	Yes	8
C10	11-12	F	Brain tumour	-	Yes	6
C11	11-12	M	ASD	-	Yes	10

Note: C represents children participants; age provided in range to protect anonymity

*Registration in at least one previous session of M&G before the testing session
+Total number of classes attended during the M&G testing session (out of 10 classes)

Table 3

Demographic information for primary caregivers of young people listed in Table 2

	Age (yrs.)	Sex	Employment status	Marital status	Highest level of education	Number of children
C1	42	M	Full-time	Married	Undergraduate	1
C2	45	F	Full-time	Married	Undergraduate	1
C3	51	F	Temporary leave	Separated	Graduate	1
C4	48	F	Part-time	Married	Graduate	2
C5	46	F	Full-time	Married	Graduate	3
C6	45	F	Full-time	Married	College	1
C7/9	43	M	Stay at home parent	Married	Undergraduate	2
C8/11	43	F	Stay at home parent	Separated	Undergraduate	2
C10	43	F	Temporary leave	Married	Graduate	2

Note: P represents the corresponding caregiver to the child in Table 2.

Table 4

Signs and symptoms, medication use, and education status of nine disabled participants.

	C1	C2	C3	C4	C5	C6	C7	C10	C11	Sum	%
Locomotion concerns (e.g. walking/moving around)					X		X	X		3	33.3
Fine motor skill concerns (e.g. tying shoelaces, writing)	X	X		X	X	X	X	X		7	77.8
Gross motor skill concerns (e.g. running, jumping)			X	X	X		X	X		5	55.6
Hand eye coordination concerns (e.g. catching a ball)	X	X		X	X		X	X		6	66.7
Foot eye coordination concerns (e.g. kicking a ball)	X			X	X	X	X	X		6	66.7
Social concerns (e.g. trouble making friends)	X	X			X	X	X	X	X	7	77.8
Emotional concerns (e.g. difficulty regulating mood)	X	X	X			X	X	X	X	7	77.8
Learning concerns (e.g. difficulties in school)		X	X	X	X	X	X	X		7	77.8
Attention concerns (e.g. focusing on one thing)	X	X	X		X	X	X	X	X	8	88.9
Sleep concerns (e.g. falling or staying asleep)		X				X		X	X	4	44.4
Restricted interests (e.g. lining up toys)		X					X			2	22.2
Motivation concerns (e.g. not wanting to do activities)		X	X		X			X		4	44.4
Non-violent behaviours (e.g. hand flapping)		X							X	2	22.2
Violent behaviors (e.g. hitting others)							X			1	11.1
Self-harming behaviours (e.g. hitting head)						X	X			2	22.2
Other concerns		X[*]								1	11.1
Currently using medications	X	X	X		X			X		5	55.6
Currently enrolled in school	X	X		X	X	X	X	X	X	8	88.9
Education Status											
Regular with accommodations						X			X	2	22.2
Regular with extra support	X	X		X				X		4	44.4
Special education classes			X		X		X			3	33.3
# of extra-curricular programs	6	3	4	5	5	4	1	4	1	33	3.7

Note: C8 and C9 were higher functioning siblings and not represented in the survey.

[*] Other listed as “doesn’t hear/can’t follow conversation”

Table 5

Demographic information for university volunteers. All listed here are female.

	Age (yrs.)	Level of study	Confidence /5	Previous training	Previous Experience[+]	M&G Attendance
V1	22	4th yr. UG	4	No	Yes	9
V2[*]	-	4th yr. UG	-	-	-	5
V3	22	4th yr. UG	4	No	Yes	7
V4	19	2nd yr. UG	4	No	Yes	9
V5	20	2nd yr. UG	4	No	No	8
V6	20	2nd yr. UG	4	No	Yes	9
V7	25	2nd yr. M	4	Yes	Yes	8
V8	22	1st yr. M	5	No	Yes	9
V9	23	1st yr. M	4	No	Yes	10
V10	22	1st yr. M	5	Yes	Yes	9
V11	23	1st yr. M	5	No	Yes	8
V12	21	3rd yr. UG	4	Yes	Yes	5
V13	21	3rd yr. UG	4	No	No	3
I	27	4th yr. PhD	4	Yes	Yes	10
R	26	3rd yr. PhD	5	Yes	Yes	9

Note: V represents the corresponding one-on-one volunteer to the child in Table 2, with two volunteers who were not paired with a child. Instead, volunteers 12 and 13 were on call in case one of the other volunteers was unable to come to M&G. I: instructor, R: researcher, UG: undergrad, M: master's degree, PhD: PhD Candidate

[*] V2 did not complete the background questionnaire, even after several attempts to follow up
[+] Previous experience with developmental disabilities (excluding the session under evaluation)

Table 6

Demographic information for young people who participated in Movin' and Groovin'.

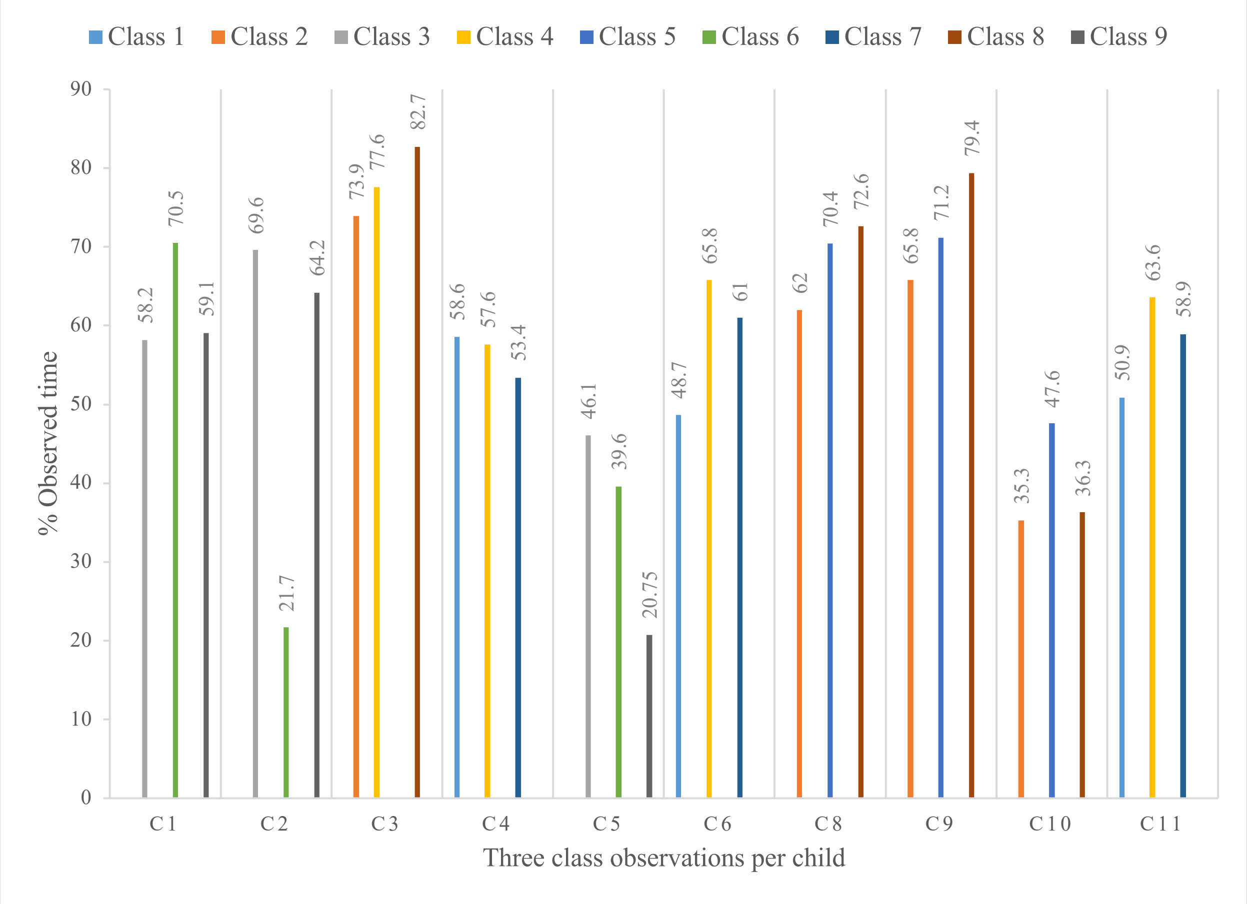
	Age (yrs.)	Sex	Primary Conditions	Other Conditions	Prev. M&G[*]	M&G Attendance[+]
JV1	17-18	M	Spinocerebellar ataxia	-	Yes	6[∀]
JV2	13-14	F	Cerebral Palsy	Epilepsy	Yes	8

Note: JV denotes junior volunteer.

[*] Registration in at least one previous session of M&G before the testing session
[+] Total number of classes attended during the M&G testing session (out of 10 classes)
[∀] Attended at least six, not visible in video data for four classes therefore unknown if present

Figure 1

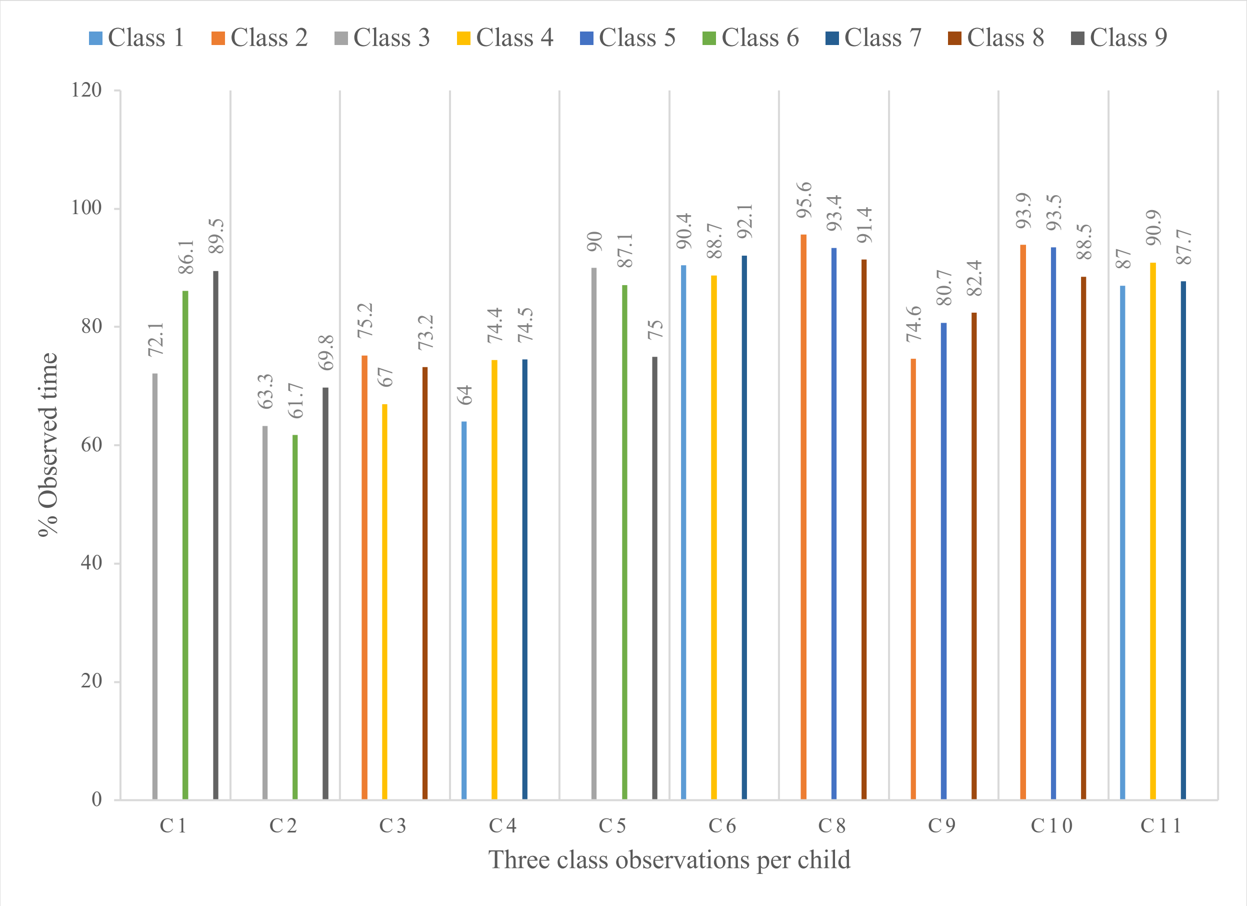
Observed MVPA for all children across three classes.



Note: Observed MVPA for all children across three classes. Observations presented as a percentage of the entire class. Children were each observed at three time points: time one (class 1, 2, or 3), time two (class 4, 5, or 6), and time three (class 7, 8, or 9).

Figure 2

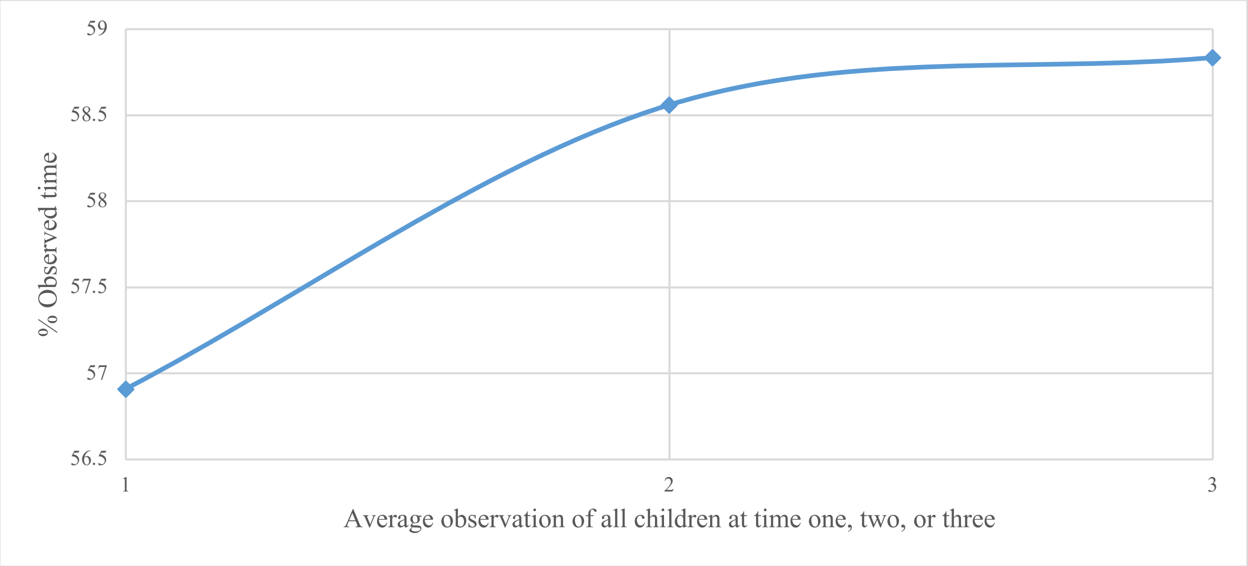
Observed SI for all children across three classes.



Note: Observations presented as a percentage of the entire class. Children were each observed at three time points: time one (class 1, 2, or 3), time two (class 4, 5, or 6), and time three (class 7, 8, or 9).

Figure 3

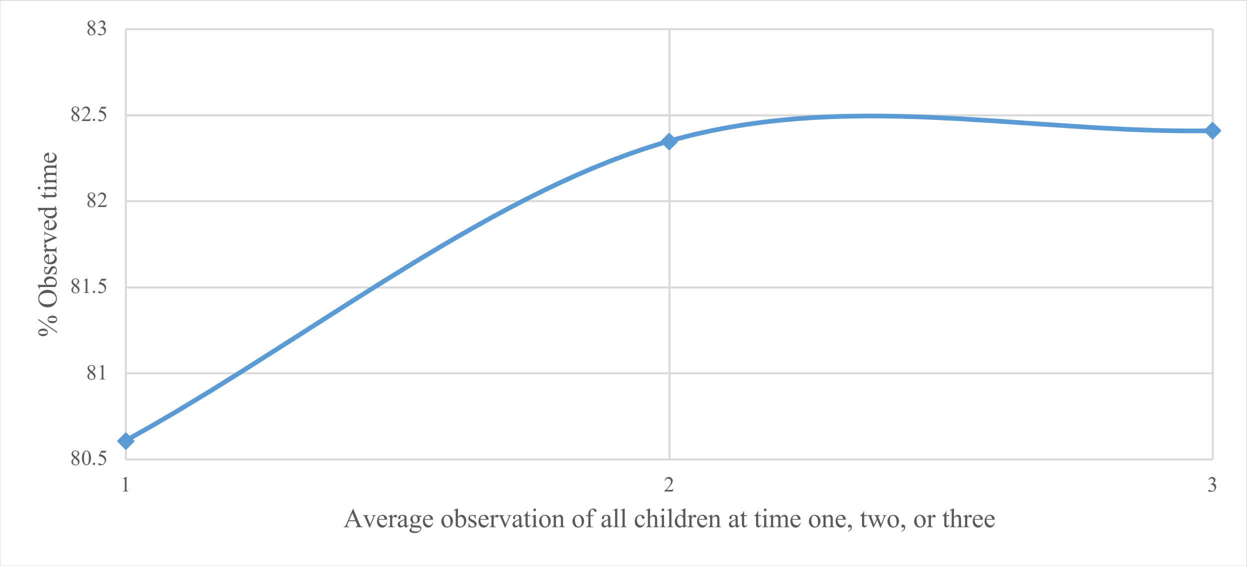
MVPA over time – collapsed.



Note: The percentage of time spent in MVPA was averaged for all ten children across the three observations times (one, two, or three). The increase in MVPA was nominal (1.93%) over the nine observed weeks.

Figure 4

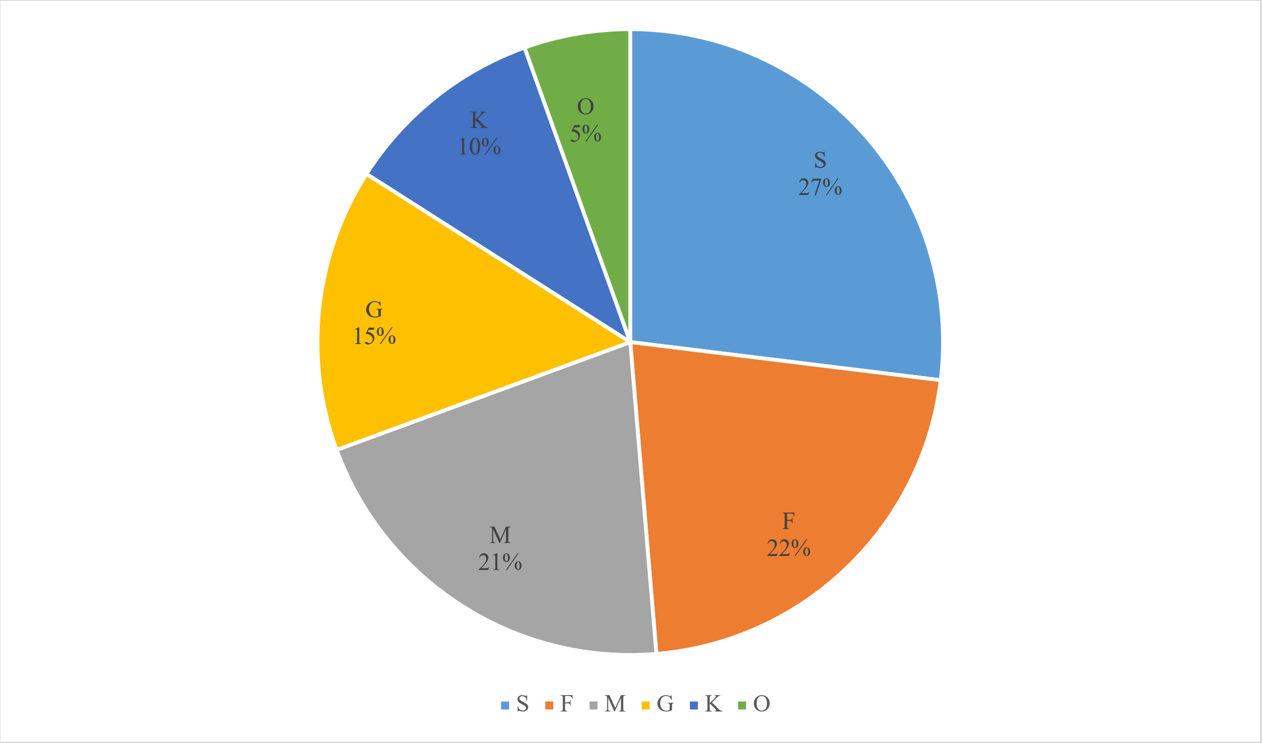
SI over time – collapsed.



Note: The percentage of time spent in SI was averaged for all ten children across the three observations times (one, two, or three). The increase in SI was nominal (1.80%) over the nine observed weeks.

Figure 5

Observed class time spent in each contextual element of the SOFIT.



Note: S: Skill practice, F: Fitness, M: Management, G: Game play, K: Knowledge, O: Other

Table 7

M&G activities and intensity according to the SOFIT.

Lesson Context	Activities	Duration* (avg. mins.)	Typical intensity**
Skill Practice	Fundamental Movement Skills - Dribbling (e.g., soccer ball and basketball) - Shooting (e.g., soccer ball and basketball) - Passing (e.g., soccer ball and basketball) - Catching (e.g., bean bag and tennis ball) - Throwing/aiming (e.g., bean bag and tennis ball) - Rolling/bowling (e.g., tennis ball) Creative Dance - Ribbons (e.g., freeze dance) - Choreography (e.g., M&G Dance)	16.17	4-5
Fitness	Warm-up - Dynamic stretching - Bungalow song (e.g., call and repeat song to get kids moving) Exercise - Fitness circuits (e.g., four stations: cardio, arms, legs, core) - Groov-opoly (e.g., exercise game board created by M&G instructor) - Deck of cards (e.g., hearts cards indicate burpees, spades indicate squats, etc.) Yoga & stretching - Sun salutation (e.g., up dog, down dog, etc.) - Static stretching (e.g., pigeon pose) - Deep breathing (e.g., laying, eyes closed)	13.04	1, 4-5
Management	Transitioning between activities - Choosing who will be it - Waiting for everyone to join the circle - Waiting for everyone to get equipment Water breaks M&G cheer at end of class	12.45	2-5
Game play	Games - What time is it Mr. Wolf? - Octopus - Red-Light Green-Light - Simon Says	8.78	3-5
Knowledge content	Explanation - Next activity (e.g., fitness circuit) - Game rules (e.g., Octopus) Education - Talking about healthy foods	6.29	2-4

	- Sharing PA behaviours (e.g., what kind of PA did you do today?)		
Other	Free time - Children waiting for everyone else to come at beginning of class, before circle time started - Time given during class to choose their own activity	3.29	3-4

Note: PA assessed out of 5 on the SOFIT (1=laying ,2=sitting, 3=standing, 4=moderate exertion 5=vigorous exertion)
** duration has been calculated based on the percentage of time children spent in each of the lesson contexts as defined by the SOFIT*
*** intensity has been generalized based on the purpose of the class, as well as the actual behaviours of the children in the observed videos; typically, a child would be expected to score within the range of numbers listed on the SOFIT recording form during the exercise context*

Table 8

Barriers and Negative factors affecting PA for children in M&G reported by the primary caregiver.

PA Factor	Sum	Percent
Barriers		
Lack of interest in participating	3	33.3
Lack of physical ability	5	55.6
Lack of cognitive ability	5	55.6
Dislike of social situations	2	22.2
No programs available	1	11.1
Programs are too expensive	1	11.1
Programs too competitive	3	33.3
Stigma	0	0
Programs too far away	0	0
Instructors are not trained	3	33.3
He/she does not like instructors	0	0
Other, please list: “physical activity limited to special programs with informed instructors” “When participating in integrated groups, his skills are not on par with his age counterparts. This makes it difficult to convince organizations to place him in younger groups as an equal.” “Programs don't usually fall in the mid-range to high function”		
Negative Effects		
“Nothing that has been noticed to be detrimental. When skiing with [ski club] at [ski hill] a number of years ago the extreme cold was an issue.” “SOB [shortness of breath]? occasional headaches” “Sore legs, knees, back”		

Table 9

Facilitators and Positive factors affecting PA for children in M&G reported by the primary caregiver.

PA Factor	Sum	Percent
Facilitators		
Enjoyment from participating	8	88.9
Gets to practice physical skills	6	66.7
Likes social situations	6	66.7
Programs fit his/her interests	6	66.7
Programs are affordable	3	33.3
Programs are close by	5	55.6
Gets to play with friends	4	44.4
Instructors are trained	7	77.8
He/she likes the instructors	7	77.8
Other	0	0
Positive Effects		
“Enjoyment, outlet for energy, stretching calms an drew relaxes him”		
“Good mood? better sleep Social intervention Over years improvement in gross motor/skills”		
“More socialization is positive. Haven't noticed more energy.”		
“Helps her calm down and get out some anxious energy.”		
“Most positive has been the social skills development by taking turns, learning the rules, being on a side, fair play, and good sportsmanship. He also enjoys the activities and getting better at the skills.”		
“not sure”		
“Yes, she sleeps better, has more energy and seems happier. She screams with excitement when she knows she is going to one of her gym programs.”		
“regulates energy and increases restful sleep”		
“yes he gets happy and calm after a physical activity.”		

Table 10

Likes and dislikes of M&G for children reported by the primary caregiver.

Likes	Dislikes
“[She] loves Movin and Groovin. For her it's a great fit as there are no set expectations or pressure to perform that she gets sometimes in other activities.”	“Choreographed dancing-too difficult to follow, put on music and have them free style dance is the best. Better cardio workout this way. Do 1-2 min sporadic sessions of this throughout class as with interval training. This will give kids better cardio workout but will allow them opportunity to catch their breath and last throughout class. Music can be quieter for those who have audio sensitivities.”
“Both [of my children] love it!”	“[My] eldest [son] thinks it’s too loud.”
“he loves all part of Movin and Groovin”	“Maybe the transition time, occasionally he has slightly negative interactions with other kids while waiting for program to start, but it's another opportunity to learn to socialize.”
“I think he enjoys most parts of the program, especially having one-on-one assistance. He likes the high level of energy and engagement of the instructors. He also likes the end routine of the group coming together in the middle and yelling ‘Movin' & Groovin'!!!’”	“Over whelming at times noise, skill”
“[She] loves to see the volunteers. She enjoys having people hear about thinks she likes (songs and dance moves).”	“She is sensitive to noise, so she sometimes dislikes it if other kids are loud.”
“Likes dancing, social aspects”	“The end LOL.”
“She loves the class and is jumping with joy when I tell her we are going. She likes the instructors.”	
“Social interaction with instructors”	
“The total team cheer helps bring the diverse group together. The one-on-one support is great as each child gets a buddy helper to focus on the skills of the week.”	

Table 11

Likes and dislikes of M&G for caregivers.

Likes	Dislikes
"Absolutely! [My daughter] is so happy going to Movin and Groovin and she's always made to feel special and like she's doing a great job! She gets that sense of accomplishment she doesn't always get in other activities."	"I wish it was longer, more classes...... we're both going to miss it when it's over!"
"All of it - great instructors and lots of fun for kids!"	"Not always suited for his ability"
"I like all part of it"	"Sometimes it's hard for me to chat with other parents while waiting because I'm not very energetic or social in the evening so I try to avoid other parents. At the end of each session, the feedback with the one-on-one is generally positive, although I anticipate negative feedback. Not reality, just my anxiety, so my issue, not the program's!"
"I like that she gets exercise."	"There is no real dislike (except for choreographed dance which is too difficult for [my daughter] - she just wishes she can dance and run around a bit). But here are some suggestions. To increases interest in physical activity and encourage participation until end of class, "trick" students into being more active." *
"Instructors are great, opportunity for him to improve physically, follow instructions with support available, non-competitive"	
"Length of program is good - I can get some work or reading done! I know that he's in good hands and having a positive experience."	
"Price is nominal. Being kept in the loop on the e-mail list is great. There are so many programs we try to get to and fill up our son's week that things get lost in the shuffle. The coaches Nicole and Bri have a good script going - by maintaining consistency from week to week on the program major items this helps the kids get stable quicker and into the games of the week."	
"Yoga, specific exercises, small group division within the whole group to do different skills"	

*this caregiver referred to this quote in Q28. "what makes M&G difficult for your child?" and in Q29. "suggestions to make M&G better for your children."

Table 12

Suggestions for the program reported by the primary caregivers.

Suggestions for Improvement	Suggest to other caregivers
“Doesn't really target mid to high functions kids. Some issues with other children hitting/ aggression should be red flagged immediately.”	“Absolutely! I think it's a great program. And the children in it seem to enjoy it as do the parents I've spoken with :)”
“I would love to say if it’s possible make the time a little bit longer.”	“Definitely - a great program”
“My son likes to know what's happening ahead of time, so maybe a short note to let parents know your intention with each class. He's much better with the unexpected now, but when he was younger, he would have benefitted from knowing ahead of time what might happen in each session.”	“Definitely have suggested it to friends! It's nice to have a very physically active program that is not focused just on sports. A lot of special needs kids want to exercise but they will never be able to participate in a regular sports program, like soccer or dance or hockey, so this is an amazing alternative.”
“The move from KidsAbility to the school wasn't a problem. However, for future sessions, KidsAbility is still a good location - if you move all the gym equipment and distractions out of the room and into an adjoining classroom. This is done in another program our son attends and it works well to focus the kids on the coaches and the program at hand instead of being tempted. Regardless of where the session is held, it is imperative in my opinion that distractions are minimized. This includes also corralling the children that like to wander outside the general group. Some kids wander the halls with their helper. It may be a thought to still have physical activities for those that may need to be separate for whatever reason from the main group, so they still get a physical component of the hour.”	“Sure. The price is good, the helpers are great and it’s at a good time in the evening.”
	“yes, I already did it and because is a great program”
	“Yes, I already have”
	“Yes, great staff and support”
	“yes, I haven't because classes have been at capacity”
	“Yes. Great group of people running it and working as volunteers. Very accommodating, exceptionally good price, locations in past always good (this lot a bit dark though), good core program.”

Table 13

General comments about M&G reported by the primary caregivers.

Overall thoughts about M&G	Anything else to add about experiences
“A very good and beneficial program”	“Can't wait for the camp in august!!”
“Excellent program, well organized, great instructors, lots of skills learned which are fun and engaging”	“just would love to say thanks for making our kids fell like others and have fun and giving parents a little free time.”
“Fantastic”	“My and [my child]’s personal goals are to have her move more than the usual speed she walks at (slow cadence). Music, fun physical games, free style dancing, tails tag game, skipping w ribbons are some ways to get her motivated enough to move her “bums”. She can’t do this for too long but if sprinkled between sessions of specific non-cardio skills (stretches, yoga, etc.) she would be able to repeat that higher aerobic short busy several times.”
“Good program. Some small changes to program structure but everyone’s heart and interest in the right place. Thanks for being so determined, motivating to improve and caring!”	“My son and I both feel very supported by the friendly and energetic instructors of M&G. You are all working really hard and care for the kids. It's only an hour a week but it really can make a big difference for parents who experience a lot of ongoing challenges with our kids.”
“Great program with wonderful volunteers and Leaders.”	“Teachers are wonderful and do a great job with each individual child.”
“I like the program. It has come a long way in the short time it has been around. My son enjoys the activities and seeing familiar friends over and over - which helps him with his social skills as much as the physical skills as well.”	“Was overall wonderful for the kids and I am so happy they had the opportunity to be part of it!”
“I think that it is a great affordable program.”	
“it’s a great opportunity for our kids to play the way they want and they can, there is no need to be perfect to do something, everyone can do anything they like and they see other kids with the same situation and they don’t feel lonely. I love it and my son love it. Thank you [to] all students who spent their time to help our kids. I appreciate your kindness and time.”	
“This program is unique and very much needed in our community!”	

Table 14

Caregivers reasoning for enrolling their children in M&G.

Why did you enroll your child(ren) in Movin’ and Groovin’?
“Cost was nominal, the intentions of the program were noble to provide physical activity skills, plus after 1st participation my son enjoyed the coaches, the activities and the games so to re-enroll was natural.”
“different from other programs that only focus on team sports, one-on-one assistance”
“for exercise and development of skills.”
“this program is match to my kid special needs, he loves the program and the students who take over the program, they are trained greatly and they put themselves into the program and they change their selves with the kid’s needs.”
“Thought it would be a great fit for her as she loves activity.”
“Thought it would be fun and good for him”
“To improve his physical condition, social, following instructions”
“to participate in a gym class for social and physical engagement”
“Wanted to continue w gross motor skills development, social intervention/participation”

Movin' and Groovin' Evaluation: Caregiver Survey

Thank you for participating in this survey! The questions are all about you and your child with developmental disabilities. Please answer the first set of questions about yourself.

1. Please specify your birth month and year (mm/yyyy) _________________

2. What is your gender? ________________

3. What is your current employment status?
   - ☐ Full-time
   - ☐ Part-time
   - ☐ Stay at home parent
   - ☐ Unemployed
   - ☐ Temporary leave
   - ☐ Other: ____________________________

4. What is your current marital status?
   - ☐ Single, never married
   - ☐ Married
   - ☐ Common law
   - ☐ Partner or significant other
   - ☐ Widowed
   - ☐ Separated
   - ☐ Divorced

5. What is the highest level of education you attained?
   a. High school
   b. Trade program
   c. College
   d. University – undergraduate
   e. University – graduate
   f. Other: ________________________________

Please complete the following chart about your family.

Child	**Birth month/year**	**Gender**	**Diagnosed Conditions** (if none, write "none", otherwise please specify the primary concern)
1			**Primary:** **Other:**
2			**Primary:** **Other:**
3			**Primary:** **Other:**
4			**Primary:** **Other:**

Please answer the following questions about your child with disabilities.

6. What are the signs & symptoms associated with your child's disability (check all that apply)?
   - ☐ None
   - ☐ Locomotion (e.g. walking or moving around)
   - ☐ Fine motor skills (e.g. tying shoelaces, writing)
   - ☐ Gross motor skills (e.g. running, jumping)
   - ☐ Hand eye coordination (e.g. catching a ball)
   - ☐ Foot eye coordination (e.g. kicking a ball)
   - ☐ Social (e.g. trouble making friends)
   - ☐ Emotional (e.g. difficulty regulating mood)
   - ☐ Learning (e.g. difficulties in school)
   - ☐ Attention (e.g. focusing on one thing at a time)
   - ☐ Sleep (e.g. falling asleep, staying asleep)
   - ☐ Restricted interests (e.g. lining up toys)
   - ☐ Motivation (e.g. not motivated to do activities)
   - ☐ Non-violent behaviours (e.g. hand flapping)
   - ☐ Violent behaviors (e.g. hitting others)
   - ☐ Self-harming behaviours (e.g. hitting head)
   - ☐ Other (please list): ____

7. Is your child currently taking any medications?
   - ☐ No
   - ☐ Yes, please list:

   ____

8. Is your child enrolled in formal education (e.g. school)?
   - ☐ Never enrolled
   - ☐ No, but previously enrolled
   - ☐ Yes, part-time
   - ☐ Yes, full-time

9. What is your child's education status?
   - ☐ Home-school
   - ☐ Regular class (no extra support)
   - ☐ Regular class with special accommodations
   - ☐ Regular class with extra support (e.g. 1:1 staff)
   - ☐ Special education class(es)
   - ☐ Special school/ program (e.g. vocational training)

10. Please list any extra-curricular programs (i.e., outside of school), physical activities, sports, clubs, etc. in which your child participates.

____

____

____

11. Does your child enjoy physical activity?

____

____

____

12. Does your child engage in at least 30 minutes of moderate (e.g. leisurely bike ride) to vigorous (e.g. playing a game of soccer) physical activity?

	Spring	Summer	Fall	Winter
Yes, list #/week				
No, list 0				

13. Does physical activity cause any positive effects for your child (e.g. more energy)?

____

____

____

14. Does physical activity cause any negative effects for your child (e.g. sore joints)?

____

____

____

15. Is there anything that makes physical activity challenging for you or your child? Check all that apply.

- ☐ Lack of interest in participating
- ☐ Lack of physical ability
- ☐ Lack of cognitive ability
- ☐ Dislike of social situations
- ☐ No programs available
- ☐ Programs are too expensive
- ☐ Programs too competitive
- ☐ Stigma
- ☐ Programs are too far away
- ☐ Instructors are not trained
- ☐ He/she does not like instructors
- ☐ Other: ___________________________

____

____

____

____

16. Is there anything that makes physical activity easy for you or your child (see above comments)? Check all that apply

- ☐ Enjoyment from participating
- ☐ Gets to practice physical skills
- ☐ Likes social situations
- ☐ Programs fit his/her interests
- ☐ Programs are affordable
- ☐ Programs are close by
- ☐ Gets to play with friends
- ☐ Instructors are trained
- ☐ He/she likes the instructors
- ☐ Other: ___________________________

____

____

____

____

Please answer the following questions about Movin' and Groovin'. The purpose of these questions is to improve the program, and therefore you are encouraged to provide positive and negative feedback. There are no consequences to providing honest feedback. Please comment on the physical activities, as well as any other component of the program, such as cost, location, time of day, etc. The goal is to make our program the best that it can be.

1. How did you hear about Movin' and Groovin'?

____

____

____

2. Why did you enroll your child(ren) in Movin' and Groovin'?

____

____

____

3. Does Movin' and Groovin' have any effect on your **child(ren)**? If you have more than one child in the program, please specify which child to which you are referring for each point.

	Positive	Negative
Short-term		
Long-term		

4. Does Movin' and Groovin' have any effect on **you**?

	Positive	Negative
Short-term		
Long-term		

5. Do you think **your child** likes any part of Movin' and Groovin'? If yes, please explain.

____

____

____

6. Do you think **your child** dislikes any part of Movin' and Groovin'? If yes, please explain.

____

____

____

7. Do **you** like any part of Movin' and Groovin'? If yes, please explain.

____

____

____

8. Do **you** dislike any part of Movin' and Groovin'? If yes, please explain.

____

____

____

9. Is there anything that makes it easy/difficult for you to enroll your child and/or for your child to participate in Movin' and Groovin'?

	Easy	Difficult
Parent (e.g., price, location)		
Child(ren) (e.g., activities, support)		

10. Do you have any suggestions that would make Movin' and Groovin' better for you or your child?

____

____

____

11. Would you suggest Movin' and Groovin' to a friend? Why or why not?

____

____

____

12. What are your overall thoughts about Movin' and Groovin'?

____
____
____

13. Do you have anything else to add about your experiences in Movin' and Groovin'?

____
____
____

Thank-you for completing this survey!

Movin' and Groovin' Evaluation: Volunteer/Instructor Background Questionnaire

Thank you for participating in this survey! The questions are all about you and your experiences with children who have developmental disabilities.

1. What your birth month and year (mm/yyyy): ______________

2. What is your gender: _________________

3. Are you currently enrolled at a college or university?
   ☐ No
   ☐ Yes
   Program____________________________
   Level of study _______________________
   Year of study ________________________

4. How confident are you in your abilities to support the participants in M&G, where one is not confident at all and five is extremely confident?

   1 2 3 4 5

5. Have you ever received training for working with children (aged 4 to 11) or youth (aged 12 to 18) with disabilities? Yes / No

6. ***Please complete the following chart about your experiences with children who have developmental disabilities.*** *if none, leave blank **please include previous M&G experiences

What was the experience?	What was your role?	How long were you involved?

7. From the listed experiences (if any), have you seen any positive or negative outcomes for the young people who participated?
   a. No
   b. Yes, positive
   c. Yes, negative
   d. Yes, positive and negative

Thank you for taking the time to complete this questionnaire!

Movin' and Groovin' Evaluation: Volunteer Focus Group

Thank you for participating in this focus group! My name is Nicole and I am a second-year PhD student at Wilfrid Laurier University studying Kinesiology. The questions in this focus group are all about you and your experiences in Movin' and Groovin'. As a reminder, you may pass on any of my questions and you can leave the focus group at any time.

Let's start by talking about you.

1. Please tell me about yourself
    - School and program
    - Prior experiences in physical activity
    - Prior experiences working with young people with disabilities

Now let's talk about Movin' and Groovin'.

2. Please tell me about your experience with Movin' and Groovin'?
    - How did you hear about it?
    - How long have you been involved?
    - Why did you become/stay involved?
    - Is there anything that you particularly like/dislike?

3. Please tell me about the children's experiences with Movin' and Groovin'?
    - What do you think they like/dislike?
    - What are they like throughout the class (e.g. beginning, middle, end)?

4. Does Movin' and Groovin' have any effect on the children who participate?
    - Positive, negative, neutral
    - Short term, long term
    - Abilities: physical, social, cognitive, emotional, academic

5. Is there anything that makes Movin' and Groovin' easy or difficult for you?
    - Facilitators (e.g. interest)
    - Barriers (e.g. transportation)

6. Did you feel prepared for Movin' and Groovin' before you started?
    - Did you get/need any training? If so, what?
    - Did you feel confident with your abilities before starting?
    - Is there anything that would have made you more confident?
    - Is there anything that would have helped you to better support the participants?

7. Would you recommend Movin' and Groovin' to a friend?
    - To volunteer or to register his/her child
    - Why or why not?

8. Is there any way that Movin' and Groovin' can be improved?
    - To better support you?
    - To better support the participants?

9. Do you have anything else to add about your physical activity experiences?

10. Do you have anything to ask me?

Thank-you for participating in this focus group!

Movin' and Groovin' Evaluation: Interview with Instructor

Thank you for participating in this interview! The questions in this interview are all about you and your experiences in Movin' and Groovin'. As a reminder, you may pass on any of my questions and you can leave the focus group at any time.

Let's start by talking about you.

1. Please tell me about yourself
    - Hobbies and interests
    - School and program
    - Prior experiences in physical activity
    - Prior experiences with young people with developmental disabilities

Now let's talk about your experiences with Movin' and Groovin'.

2. Please tell me about your experience with Movin' and Groovin'?
    - How did the program start?
    - Why did you become involved?
    - What is the goal/purpose of the program?
    - What do you like/dislike about the program?

3. Who is involved in the program?
    - Young people, volunteers, caregivers, instructors?
    - What are the dynamics between participants?
    - Is everyone equally involved? Why or why not?

4. Please tell me about a typical Movin' and Groovin' class.
    - How are the classes organized?
    - What activities are in a typical class?
    - How are the classes planned/prepared?
    - How do you decide what activities will be included?

Next, let's talk about the other people who are involved in Movin' and Groovin'.

5. Please tell me about the young people's experiences with Movin' and Groovin'?
    - What do you think they like/dislike? Why?
    - Are their needs accommodated? Why or why not?
    - What are they like throughout the class (e.g. beginning, middle, end)?

6. Does Movin' and Groovin' have any effect on the young people who participate?
    - Positive, negative, neutral, short term, long term
    - Abilities (physical, cognitive, emotional, academic)
    - Relationships (with volunteers and each other)

7. Does Movin' and Groovin' have any effect on the caregivers?
    - Positive, negatives, neutral, short term, long term
    - Respite care, meet other parents, inclusivity for their children, other

8. Does Movin' and Groovin' have any effect on the young people's siblings?
    - Those who are involved vs. those who are not?
    - Should siblings be involved? Why or why not?

9. Does Movin' and Groovin' have any effect on the volunteers?
    - Do they learn new skills or become more competent/comfortable?
    - Why or why not?

10. Does Movin' and Groovin' have any effect on you as an instructor?
    - Positives, negatives, neutral, short term, long term

11. Would you recommend Movin' and Groovin' to other people?
    - Caregivers who have children with developmental disabilities
    - Siblings of children with developmental disabilities
    - Potential volunteers
    - Why or why not?

Last, let's discuss the future of Movin' and Groovin'.

12. Is there any way that Movin' and Groovin' can be improved?
    - To better support you as an instructor?
    - To better support the volunteers?
    - To better support the young people?
    - To better support the caregivers?

13. Ideally, how would Movin' and Groovin' work?
    - Where would it take place?
    - Would instructors/volunteers be compensated? How much?
    - What equipment would be needed?
    - Are there other resources that would be important for the program?

14. Do you think Movin' and Groovin' is sustainable?
    - Why or why not?
    - Where do you see the program in the future (ideally, realistically)?

15. Do you have anything else to add about your experiences?

Thank-you for participating in this interview!

SOFIT Recording Form
Movin' and Groovin' Evaluation

Date: _________________ Child: ___________________ Observer: ________________

Time	Interval	Student Activity	Lesson Context	Social Interactions	Notes
0:00	1	1 2 3 4 5	M K F S G O	Y N	
	2	1 2 3 4 5	M K F S G O	Y N	
	3	1 2 3 4 5	M K F S G O	Y N	
	4	1 2 3 4 5	M K F S G O	Y N	
	5	1 2 3 4 5	M K F S G O	Y N	
	6	1 2 3 4 5	M K F S G O	Y N	
	7	1 2 3 4 5	M K F S G O	Y N	
	8	1 2 3 4 5	M K F S G O	Y N	
	9	1 2 3 4 5	M K F S G O	Y N	
	10	1 2 3 4 5	M K F S G O	Y N	
	11	1 2 3 4 5	M K F S G O	Y N	
3:59	12	1 2 3 4 5	M K F S G O	Y N	
4:00	13	1 2 3 4 5	M K F S G O	Y N	
	14	1 2 3 4 5	M K F S G O	Y N	
	15	1 2 3 4 5	M K F S G O	Y N	
	16	1 2 3 4 5	M K F S G O	Y N	
	17	1 2 3 4 5	M K F S G O	Y N	
	18	1 2 3 4 5	M K F S G O	Y N	
	19	1 2 3 4 5	M K F S G O	Y N	
	20	1 2 3 4 5	M K F S G O	Y N	
	21	1 2 3 4 5	M K F S G O	Y N	
	22	1 2 3 4 5	M K F S G O	Y N	
	23	1 2 3 4 5	M K F S G O	Y N	
7:59	24	1 2 3 4 5	M K F S G O	Y N	
8:00	25	1 2 3 4 5	M K F S G O	Y N	
	26	1 2 3 4 5	M K F S G O	Y N	
	27	1 2 3 4 5	M K F S G O	Y N	
	28	1 2 3 4 5	M K F S G O	Y N	
	29	1 2 3 4 5	M K F S G O	Y N	
	30	1 2 3 4 5	M K F S G O	Y N	
	31	1 2 3 4 5	M K F S G O	Y N	
	32	1 2 3 4 5	M K F S G O	Y N	
	33	1 2 3 4 5	M K F S G O	Y N	
	34	1 2 3 4 5	M K F S G O	Y N	
	35	1 2 3 4 5	M K F S G O	Y N	
11:59	36	1 2 3 4 5	M K F S G O	Y N	

*the SOFIT recording table continues four more pages in this format, but those pages have been left out of this appendix. The final page has been included (see next page).

Time	Interval	Student Activity	Lesson Context	Teacher Interactions	Notes
60:00	37	1 2 3 4 5	M K F S G O	Y N	
	38	1 2 3 4 5	M K F S G O	Y N	
	39	1 2 3 4 5	M K F S G O	Y N	
	40	1 2 3 4 5	M K F S G O	Y N	
	41	1 2 3 4 5	M K F S G O	Y N	
	42	1 2 3 4 5	M K F S G O	Y N	
	43	1 2 3 4 5	M K F S G O	Y N	
	44	1 2 3 4 5	M K F S G O	Y N	
	45	1 2 3 4 5	M K F S G O	Y N	
	46	1 2 3 4 5	M K F S G O	Y N	
	47	1 2 3 4 5	M K F S G O	Y N	
63:59	48	1 2 3 4 5	M K F S G O	Y N	

General notes:

“I Think She’s Found Her Groove”: Evaluating A Young Girl’s Involvement in an Inclusive Physical Activity Program

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Keywords: physical activity, Autism Spectrum Disorder, mixed methods, evaluation, motor, social, confidence

Abstract

Background: Physical activity (PA) has shown promise in addressing social, behavioural, and motor concerns in children with Autism Spectrum Disorder (ASD). The experience of a seven-year-old girl ("Sophie") diagnosed with ASD and other psychological disorders was examined as she participated in a 10-week PA program.

Methods: Sophie's motor and social skills were evaluated before and after the program via the Movement Assessment Battery for Children and the Social Responsiveness Scale. PA and social interactions were analyzed based on video recordings of Sophie as she participated in the program, one-on-one interviews with Sophie and her instructor, and focus groups with Sophie's parents and the program volunteers.

Findings: Sophie demonstrated some improvements in her motor and social skills after the PA program, in addition to gaining PA and social interactions. Sophie also gained self-confidence as she was supported by the instructor and volunteer, and acceptance as she was included in an environment with other children of varying ages and abilities.

Conclusions: Sophie's progress exemplifies the far-reaching effects of PA when offered in an accepting environment with adequate support.

Introduction

Autism Spectrum Disorder (ASD) affects an estimated 1% of the population, with males diagnosed four times more than females (APA, 2013). While ASD has not been characterized by physical concerns, it is accompanied by delayed motor development and/or stereotyped or self-stimulating motor behaviours (APA, 2013). Motor delays have been detected early in life (e.g., age one to three; Lloyd, MacDonald, & Lord, 2011) and into adolescence (e.g., age six to 14; Rinehart et al., 2006).

It has been hypothesized children with movement difficulties require more time to learn fundamental movement skills (FMS) than typically developing (TD) peers, resulting in a skill gap that widens with age (Wall, 2004). For instance, the gross motor skills of children aged nine to 12 years diagnosed with ASD (n=25) were significantly lower (p<.01) than age matched (n=25) and IQ matched peers (n=19; Staples & Reid, 2010). In fact, autistic children demonstrated similar motor skill development to typically developing children half their age (n=22; Staples & Reid, 2010), providing support to Wall's (2004) hypothesis.

In addition to the typical symptoms of ASD (e.g., repetitive and restrictive behaviours and interests; impaired social interactions), reduced FMS may be associated with barriers to participating in physical activity (PA) and therefore reduced moderate to vigorous PA (MVPA) in daily living. For instance, McCoy, Jakicic, and Gibbs (2016) showed a decrease in PA likelihood as ASD severity increased (p<.001) for children aged 3 to 17 (n=915). In addition, autistic young people were significantly less active (p<.001), more overweight (p<.001), less likely to be involved in team sports (OR=0.26, p<.001), and less likely to be involved in extracurricular clubs (OR=0.47, p<.001) than their TD peers (n=41,879) (McCoy et al., 2016).

Individuals with comorbid diagnoses generally experienced more severe symptoms than those with a single neurodevelopmental disability (Statistics Canada, 2008). Both autistic children (Liu, 2012) and children diagnosed with attention-deficit/hyperactivity disorder (ADHD) (Neto, Goulardins, Rigoli, Piek, & Oliveira, 2015) experienced delayed motor development associated with their disorders. Pan, Tsai, and Chu (2009) reported children aged six to ten with ASD had reduced gross motor, locomotor, and object manipulation skills than children with no diagnosis, and still less than those with ADHD. Further, children with psychological disorders (including ASD and ADHD) displayed reduced gross motor performance (e.g. balance and ball skills), as found in a systematic review of motor performance in disabled young people (Emck, Bosscher, Beek, & Doreleijers, 2009).

As Pan et al (2009) surmised, "… children learn and practice social skills as they play interactively with each other in these motor activities" (p. 1703), such as jumping and playing ball. The scoping review by Reinders, Branco, Wright, Fletcher, and Bryden (2019) found 40 research articles demonstrating relationships between social functioning and PA for autistic children, though relationship strength was lacking. To illustrate one of the stronger contributions, autistic children who participated in the motor skill intervention (n=11) by Ketcheson, Hauck, and Ulrich (2017) not only improved motor skills and gained MVPA, but also spent less time playing in isolation than the control group (n=9). PA programming has shown far reaching effects for autistic children with regard to social skills (Ibrahim & Nasser, 2010) and attention in school (Tan, Cohen, & Pooley, 2013). Due to the many benefits of FMS development, Lloyd, MacDonald, and Lord (2011) contended motor training should be considered early in therapeutic interventions. Based on these recommendations the objectives of this research were twofold:

1) to determine the social and motor effects from participating in an inclusive PA program for a young girl diagnosed with ASD, ADHD, speech/language disorder, and anxiety; and
2) to understand her experiences of this PA program through her perspective, as well as the perspectives of her parents and one-on-one volunteer.

Description of the Program

The PA program under investigation was created by two PhD students and operated out of an elementary school gymnasium. The goals of the program were to provide opportunities for PA, social interaction, and education in a welcoming environment. The PA component included exercise, dance, sports, yoga, and games in order to practice a wide variety of FMS. Socially, participants interacted with one another, the instructor, and their one-on-one volunteers. Emphasis was placed on education regarding physical, mental, and social wellbeing in each class during circle time questions and team building activities. The welcoming nature of the environment was established through the instructor's positive language in the classroom and one-on-one volunteers from the local university. For the purpose of this study, one 10-week session of the program was examined in a case-study design to explore if there were any outcomes associated with participation.

Description of the Case

Sophie (pseudonym) was seven years old and diagnosed with ASD, ADHD, speech/language disorder, and anxiety at the time of this study, and had not previously participated in M&G. According to her mother, Sophie struggled with the following: fine motor skills, (e.g. tying shoelaces, writing), foot eye coordination (e.g., kicking a ball), social skills (e.g. trouble making friends), emotional regulation (e.g. difficulty regulating mood), learning (e.g. difficulties in school), attention (e.g. focusing on one thing), and sleep (e.g. falling or staying asleep). Sophie was not taking any medication for most of this study but started an anti-anxiety medication in week nine of the PA program. Her parents said this medication did not affect her participation as they had not yet noticed its effects by week ten of the program. Sophie attended a regular school with additional classroom supports and was part of three other extracurricular programs while also in this PA program: swimming (45 minutes/week, four years of previous experience), horseback riding (60 minutes/week, three years of previous experience), and dance (60 minutes/week, one year of previous experience). Sophie was an only child and both her parents were involved in bringing her to the PA program from week to week.

Sophie participated in an unrelated study with the PA program instructor, where her parents learned about the PA program. Part of the study included motor and social testing, which occurred shortly before her participation in the PA program for the first time. Therefore, Sophie was an idea candidate for a case study to explore the potential effects of the PA program, which is how this study came to be. NJL created the data collection tools (background questionnaires, interview guides, focus group guides, parent surveys), collected and analyzed the data, and wrote the manuscript, while PCF and PJB supervised the research.

Methods

Data Collection

Several means of data collection were utilized to gain in depth information about Sophie’s experience in the PA program. Video data were collected for five of the ten PA sessions in order to evaluate PA and social interactions via the SOFIT (McKenzie, Sallis, & Nader, 1991) and to make observations about the class structure and learning environment. The SOFIT has been designed to record data from different participants over the course of the fitness instruction time, alternating between ten seconds of observation and ten seconds of recording time (e.g., three 10-second observations per minute). It has been validated with heart rate monitors in typically developing individuals (McKenzie et al., 1991); however, it has not been validated for disabled children. Therefore, the SOFIT was used to assess one child as she participated in five classes for the entirety of the video recording (e.g., assessed Sophie for 60 minutes, totaling 180 data recordings per class for classes one, three, five, seven, and nine) to capture in depth understanding of her participation in the program. Further, the SOFIT collects data about the instructor interactions throughout fitness instruction time, but this does not account for the one-on-one volunteer interaction with the child. Therefore, the instructor interaction section was broadened to include all “social interactions” (e.g., SI) and was coded “yes” if the child interacted with anyone else in the program (e.g., instructor, volunteer, or other children) and “no” when the child was isolated.

Lesson context was coded into one of six categories, which were: (1) management (M, e.g., moving into a circle, transitioning between activities); (2) knowledge (K, e.g., learning names, explaining how to play a game); (3) fitness (F, e.g., activities to increase heart rate or build strength); (4) skill practice (S, e.g., activities to develop skills such as throwing, dance, and yoga); (5) game play (G, e.g., time spent playing a facilitated activity); and (6) other (O, e.g., free play before class). PA was coded from one to five, with one as the lowest form of PA (e.g., lying down) and five as the highest (e.g., vigorous activity).

PA codes of four and five were amalgamated to represent Sophie’s moderate to vigorous PA (MVPA) in the program. Lesson context was coded regardless of whether Sophie was visible in the recording screen based on the rest of the children and the instructor’s directions (e.g., asking everyone to come to the circle), but PA and SI could not be coded in this way. PA was only coded when Sophie was visible within the ten second recording window. Similarly, SI was only coded when Sophie was visible, or if Lily (pseudonym, her volunteer) was visibly addressing her as she moved in and out of the recording screen. Therefore, all SOFIT data were aggregated as the percent of observed time, rather than the percent of class time because she was not visible for the entirety of recorded time.

To provide further context about Sophie, her mother completed a background questionnaire about her diagnosis, her developmental concerns, and her experiences in the PA program. In addition, the Social Responsiveness Scale – second edition (SRS-2) and the Movement Assessment Battery for Children – second edition (MABC-2) were utilized before and after the program to evaluate social and motor skills, respectively. The SRS-2 is a parent-report measure of social functioning based on recall over a six-month period (Bruni, 2014), while the MABC-2 is a series of researcher-conducted motor tests evaluating manual dexterity, balance, and aiming and catching (Schenkelberg, Rosenkranz, Milliken, & Dzewaltowski, 2015). Both of these tools have been validated for children of all abilities (Bruni, 2014; Schenkelberg et al., 2015). The PA program instructor conducted these assessments in order to reduce the potential for bias upon post testing (e.g., Sophie could have performed differently with NJL).

Lastly, qualitative data were collected via interviews with Sophie, her parents, and the instructor, as well as three focus groups with the volunteers. The interviews were audio recorded, transcribed verbatim, and supplemented with field notes. The instructor interview and volunteer focus groups included data about the PA program in general; however, any information that emerged about Sophie was extracted for the purpose of this study. The researcher (NJL) also collected qualitative data about Sophie's participation in the PA program via video observation, such her conversations with others, facial expressions (e.g., smiling), and responses (e.g., excitement) throughout each class. Ethical clearance from the affiliated university was granted for all methods described above.

Analysis

Statistical analysis of the SRS-2 and MABC-2 were not suitable for this study; instead, descriptive data provided an in-depth understanding of Sophie's social and motor skills, respectively. Content analysis (Bengtsson, 2016) was utilized to investigate the qualitative data and describe insights from Sophie, her parents, the volunteers, and the instructor. All quantitative and qualitative findings have been triangulated in the discussion section.

Credibility

To establish credibility, the researcher utilized rigorous methods and triangulation. Qualitative data collection (i.e., interviews, focus groups, video observations) and analysis followed the methods described by Patton (2002) and Braun and Clark (2006). In addition, three validated tools were used for quantitative data collection (i.e., MABC-2, SRS-2, & SOFIT). All methods were triangulated, along with the background questionnaire, to understand the Sophie's experience as she participated in the PA program. NJL created the data collection tools (background questionnaires, interview guides, focus group guides, parent surveys), collected and analyzed the data, and wrote the manuscript, while PCF and PJB supervised the research.

Results

Quantitative Data

Lesson context varied across the five classes and has been depicted in Figure 1 (Appendix 4). On average, the majority of time was spent in skill practice (25.54%), followed by management (20.32%), fitness (16.06%), knowledge (15.4%), game play (14.16%), and other (8.86%). On average, Sophie spent 62.94% of observed time in MVPA and 92.56% of observed time in SI and there were some positive changes in both MVPA (Figure 2, Appendix 4) and SI (Figure 3, Appendix 4) over time. Sophie also spent an average of 14.48% observed time in light PA, totaling 77.42% of time in light to vigorous PA on average.

The MABC-2 and SRS-2 results have been summarized in Tables 1 and 2 (Appendix 4). Sophie improved her component scores and percentile ranking for both manual dexterity and aim and catch on the MABC-2. Although she also improved her balance component score, the difference was not great enough to affect her percentile rank. Sophie's overall MABC-2 score increased from one to five, but she still fell within the significant motor difficulty category of development. Regarding social development, Sophie improved her social awareness, social cognition, restricted interests and repetitive behaviours, and social communication and interaction scores on the SRS-2. Despite her regression in social motivation and her static social communication score, her overall SRS-2 score improved as well, though still within the clinically severe category at post-test (Constantino & Gruber, 2012).

Qualitative Data

Sophie's experience in the PA program was discussed by Sophie, both her parents, and six of the 13 volunteers in the program. From these data, a pattern emerged, which can be summarized as follows: Sophie experienced personal growth that was attributed to the positive environment fostered by the PA program.

Set up for success

Sophie's mother and father discussed the environment as *"no pressure"* and *"accepting"*, which contributed to her success in the program. It was described as a place where *"she can just be a kid and have fun"*, but also where she had ample support. For example, Sophie *"[thrived] with one-on-one attention"* (e.g., Lily, her volunteer) and *"connected"* with the instructor over the course of the program. In her interview, Sophie said, *"I like everything"* and *"I'm glad you guys are just here"* when reflecting on the PA program. She listed her favourite games and activities but was also vocal about the program elements she did not like, such as dance.

Interestingly, when asked about playing with ribbons, Sophie seemed uninterested and instead talked about her sore arm. Her parents and volunteer all described Sophie's complaints of soreness (e.g., sore feet, knees, back) as a barrier to her PA, but they were unsure if the barrier was physical or psychological in nature. Lily speculated Sophie's dislike of dance was related to her fear of *"having the attention on her"*, which was something Lily herself disliked as a young girl. She empathized with Sophie and helped her find alternative options when anxiety interfered with the activity at hand. Further, Sophie's mother recognized the program balanced the interests of all the participants and said Sophie *"likes the mix"* of activities.

One unique factor about the PA program under investigation was the variety in participant age and ability, meaning Sophie interacted with kids who were older and whose bodies worked differently. The inclusive nature of the program was touted as positive for typically developing children, disabled children, and their families:

> *They win, she wins, we win. Like everybody wins. Their parents win… we've always promoted that with her too. Like encouraged her to be with all kinds of kids.* – Sophie's mother

Acceptance was said nine times throughout the interview with Sophie's mother and father, suggesting its importance for her participation in the PA program. When asked for his opinion on inclusion, Sophie's dad said, *"you can't separate these kids"*. Sophie's parents felt the inclusive nature was refreshing compared to the segregation they experienced in the school system or in other programs.

Not only did her parents appreciate the positive environment of the program, but also the program logistics (e.g., time of day, location, price), which supported their personal interest in the program. When asked if the program could be improved, Sophie's mother said *"I think it's perfect the way it is. I like how you guys play. Play, play, play, and then yoga at the end".* Sophie's parents enjoyed watching her participate and Sophie was comforted by their presence in the building during class. However, Lily explained the challenges associated with Sophie's reliance on her parents:

> *I noticed when her dad was there, she kept on going out into the lobby and wanting to be there more than she wanted to be in the classroom. So that's hard for me too… I want [Sophie] to be involved in the class and in the activity, so that makes it a little bit difficult.*

While Lily described this challenge, she also recognized it was important for Sophie's family to support each other in this way. Similarly, the other children in the PA program presented both positive and challenging interactions for Sophie and Lily. For instance, a different volunteer noticed a positive interaction between Sophie and another disabled girl:

> *"… during octopus she went up to [other girl] and she's like 'we have to catch them!' And I was like, she wouldn't have done that like during the beginning [of the program].*

But this volunteer also commented on the challenges between these two children:

> *I know [the other girl] really likes to just touch whatever she sees that she wants to touch. Like people's hair, [Sophie's] shoes. I know [Sophie] doesn't like it when she points at her shoes… so like telling her* [the other girl] *that you have to ask before you want to touch…"*

The volunteers and parents reported the benefits of inclusion in this PA program outweighed the challenges. The inclusive environment allowed Sophie to learn from other kids, but for other kids to learn from her as well. Another volunteer commented on teamwork between Sophie and a typically developing girl in the program.

> *"I think [she] was helping [Sophie] and they were both doing…What time is it Mr. Wolf. And like, that was huge because obviously [Sophie] is very shy and doesn't speak out a*

> *lot, but she trusted another kid to stand with her and them both do the game together, which I thought was really sweet."*

Not only did Sophie develop a trusting relationship with Lily and the instructor, but also some of the other children. Sophie's mother felt the program *"kind of counter balances all the other stuff that she's getting during the day. Like she comes here and it's nothing but acceptance and fun."* Taken together, the welcoming environment, fun activities, one-on-one support, and inclusive nature of the PA program set Sophie up for success. Despite some challenges, these components contributed to Sophie's growth during her involvement in the PA program.

More than just PA

As indicated from the quantitative findings, Sophie improved upon her motor and social skills and gained MVPA by participating in this program; however, analysis of the interviews revealed an additional positive outcome: confidence. Sophie reflected on the first class, saying she was nervous because *"I was really new"*, but she also said the instructor helped her feel more comfortable. When asked if she was still nervous about the program, Sophie said *"nope, not anymore"*. Sophie then listed several friends she had made over the ten-week session, including the instructor, the researcher, Lily, and two other children. Sophie's mother said *"she does say she has friends here. And she talks about the other kids."*

Sophie's mother also commented on her confidence: *"I think she's kind of found her groove like, here. I really do. I think that this is kind of giving her that confidence"*. Even Sophie said, *"because I'm good"* when explaining why she likes to be "it" during "What time is it Mr. Wolf?". She also said *"I'm good"* when talking about swimming lessons during the interview and suggested she teach the other children at camp the upcoming summer. These instances demonstrated Sophie's confidence in her own physical skills and leadership abilities. Lily also noticed this growth over the course of the ten-week session, particularly in Sophie's willingness to perform in front of her peers.

> *"I definitely noticed a positive impact towards the end because she, in the last class she actually did dance… like she did it on her own with everyone watching her. So, she's definitely grown in that sense, that she's getting more comfortable with the attention being on her, doing things on her own. So, I think that's really great, because then that translates into her school. So maybe she'll answer more questions in school, or like, just more positive things like that."*

Sophie's parents confirmed Lily's postulation, indicating Sophie's school teacher had observed a difference in her attitude toward learning.

> *"[Her teacher] said this morning that – since I've talked to him a few weeks ago – yeah, he's noticed a big improvement…. She's coming in happy now. Whereas before she would come in very withdrawn and sad. Um putting up the walls, like 'I can't do it, I can't do it'. And now she's back to being a bit more positive. 'I can't do it, but I'm going to try.'"*

Not only did Sophie's parents see a difference at school, but also in the community. For example, Sophie played with a girl she had never met at the dentist and was also less hesitant to play with neighbourhood kids at the park. Both parents attributed her changed behaviour to the PA program:

> *"Because she comes here and some of the kids come hug her right away right. And I think that's giving her the confidence to just like, 'hey, I can have relationships with other people.' And she's learning to be around, like I said, kids with all different abilities and not see that as being anything, other than these are other kids."* – Sophie's mother

In addition to teaching Sophie about understanding children who may be different than her, Sophie's mother said the PA program improved her comfort in playing with children her own age and older. Her parents felt this was an important life skill to develop, particularly as she grew and noticed differences of which she was not previously aware.

> *"I think as she's aging, I think she's seeing the differences a lot more. Because we find that, in her school that she goes to, she plays with kids that are younger than her. Like JK and SK, like kids that are two to three years younger. Because I think she has an easier time with them than she does with kids in her own grade, or in her own age range or*

> *older. And I think here, some of the kids are older than her, but they accept her. And I think that to her is like, gold."* – Sophie's mother

Sophie's parents reflected on Sophie's weekly activities, saying the PA program "*breaks up her week"* and supports her development, but is not regimented like her one-on-one therapy. Further, they said it was refreshing to participate in an inclusive program, rather than the more segregated environments of school and other activities, particularly one that allowed her to develop other skillsets.

> *Like positive reinforcement, positive attitudes. You know, she doesn't get that at school all the time… like she goes to therapy, and they focus on her anxieties and all that. She comes here and she doesn't talk about all that stuff for an hour."*

When asked if they would recommend the program to other parents, both said yes. Specifically, Sophie's father said, *"it's affordable, she really likes it, and she gets some physical activity in the middle of her week. And being accepted by a group of kids."* Both Sophie and her parents talked about practicing stretches and yoga poses learned in the PA program at home, suggesting it contributed to her learning about a healthy lifestyle. Furthermore, Sophie said *"I can't wait for* [PA program] *camp"* in her interview, demonstrating her enjoyment in the program and desire to continue participating. Overall, the PA program fostered a sense of self-assurance in Sophie which translated into her day to day life.

Discussion

This case study exemplified the physical, social, and personal growth of a young girl with ASD and comorbid psychological disorders through PA participation in a supportive environment. One of the objectives of this research was to determine if participating in the PA program was accompanied by any social and/or motor effects over time. Overall, Sophie showed improvement on all three motor skills measured by the MABC-2 and four out of six social skills measured by the SRS-2. Her improvements did not affect the clinical significance of her symptoms, as she still fell within the severe range for both the MABC-2 and SRS-2 at post-testing; however, no statistical tests were conducted due to the case-study nature of this research.

Whyatt and Craig (2012) suggested the cumulative nature of the MABC-2 scores could hide deficits and therefore it is important to examine the results in detail. The four-point improvement on her aim and catch score may be attributed to the amount of time to skill practice (29% of class time on average, see Figure 1), which included throwing and catching with bean bags, tennis balls, and basketballs. Both Sophie's aiming and catching scores improved on the MABC-2. These results were unsurprising based on findings by Bremer, Balough, and Lloyd (2011), who found improved object manipulation skills through their FMS program for four-year-old's with ASD (n=5).

It was surprising, however, that her manual dexterity increased by nine points, as fine motor skills were rarely practiced in this program. It is possible Sophie developed these skills in a different environment over the same course of time as the PA program or simply developed these skills with age. Upon closer examination, Sophie performed more poorly on the peg test but improved at threading and drawing, where her overall score increased. According to Sophie's parents, her teacher noticed improvement in her attitude toward learning at school, which could be one place where she practiced her fine motor skills.

Sophie also improved her balance by two points, but this did not translate into a change in her percentile rank. Specifically, Sophie's one leg standing balance decreased on the MABC-2. As with manual dexterity, this score was surprising because balance was practiced regularly through yoga, fitness, and games (e.g., freeze tag). From video data, however, Sophie was observed getting distracted during these activities and was not able to hold a yoga pose or stand on one foot (e.g., while stretching) for any length of time. Sophie may not have actually practiced the skill of static balance, even though these activities were facilitated in the program.

Conversely, Sophie's heel toe walking did not change, and there was marginal improvement in her single leg hopping. Dynamic balance was practiced through activities like line tag where kids walked heel to toe along the lines painted on the gym floor, and cross Canada where kids performed walking lunges in place of regular steps. Sophie tended to "cheat" these steps and run instead, which she said in her interview was one of her favourite activities. The children were never penalized for failing to perform a particular activity, but encouraged to try in their own way, and then praised when they showed effort. It could be this teaching strategy was not conducive to facilitating practice for certain skills. Research by Pan (2009) revealed noninteractive adult engagement (e.g., thorough encouragement, instructions, etc.) was significantly positively correlated to vigorous PA. While Sophie did not necessarily practice balance through the suggested activities, she could run whenever she wished and therefore gained MVPA throughout the program.

It may be useful to inspect the SRS-2 in the manner suggested by Whyatt and Craig (2012) regarding the MABC-2. According to the SRS-2, Sophie was also more likely to appear too tense in social situations and was more likely to cling to or depend on adults, which both also affected her social motivation score. Sophie's reliance on her parents throughout this PA program may have been her coping mechanism for over-stimulation in the new social situation. Perhaps Sophie had yet to clear this hurdle in her journey toward comfort in social relationships. Conversely, Sophie's mother reported Sophie seemed less interested in being alone on the SRS-2, which was also a component of social motivation. Clearly there was a great deal of complexity to Sophie's social development in this PA program.

Social interactions and social acceptance were crucial for Sophie's growth over the ten-week session. The play environment described by Sophie's mother could have contributed to the increases on her SRS-2 scores, in addition to the 42.46 minutes of direct social interactions recorded on average from the video analysis. As mentioned by Pan, Tsai, and Chu (2009), interactive play through physical activity fosters social development. In addition, McCoy, Jackicic, and Gibbs (2016) suggested a "need for targeted programs… to increase PA" (p. 2317) in children and adolescents with ASD due to the negative tends between ASD and participation in PA, clubs, and sports. The PA program under study is an example of such a targeted program, as Sophie spent about 34 minutes of observed time in PA on average per class, with 27.6 of those minutes in MVPA. Tyler, MacDonald, and Menear (2014) point to the importance of early PA to "bridge the gap" (p. 4) between TD children and those with ASD, not only regarding physical fitness, but also health disparities resulting from sedentary living.

Even after participating in the PA program, Sophie's physical skills and social skills were still delayed as compared to her peers. These delays were likely related to her diagnosis of ASD (Staples & Reid, 2010), and exasperated by her three comorbid diagnoses (Statistics Canada, 2008). Interestingly, treatment success in ADHD was also deemed to be affected by comorbid conditions, as found by Setyawan et al. (2015), who suggested treatment scope did not meet the complexity of these multiple disorders. Perhaps the treatment of children with psychological disorders has been too narrow and should be broadened to include PA and FMS training (Lloyd, MacDonald, & Lord, 2011).

Bo et al. (2019) examined FMS and social impairment before and after a PA program in boys with ASD (n=9) and found the greatest improvements amongst those with the most severe symptoms. The authors surmised "…poor motor performance in ASD could, in part, be due to lack of engagement of physical activities and optimal settings for those individuals with more social problems to learn and practice" (p. 419, Bo et al., 2019). Pan, Tsai, and Hsieh (2011) suggested the context, environment, and instructor are crucial for encouraging PA in autistic children (n=19). In this study, lesson context, social interactions, and individual perspectives were considered to shed light on the environmental factors in the PA program. For example, Sophie's social interactions were significantly correlated to MVPA, demonstrating the necessity for adequate social support in a PA environment.

Sophie's parents felt the accepting and inclusive nature of the program set up Sophie for success, not only in the program, but in other areas of life such as school. Specifically, the one-on-one support and fun activities fostered interpersonal skills and confidence and allowed Sophie to play and *"be a kid"*. Her volunteer saw growth in Sophie's comfort to work with other children and to perform in front of her peers, which was also observed in the video recordings. Interestingly, Sophie's social motivation score on the SRS-2 decreased; specifically, she was more likely to cling to/depend on adults. Taken together, these results provide support for the findings by Reinders et al. (2019) regarding the relationship between PA and social functioning.

This study demonstrates the importance of fostering a positive environment for children with psychological disorders such as ASD and ADHD, nonetheless there are limitations to consider, primarily the case study nature of this research. Despite some positive outcomes for Sophie, she is only one example and therefore this study cannot claim cause and effect outcomes of this PA program for other children. Further, the post-test occurred two days after class ten, but there was no measure of washout to determine if these results persisted over time. While five of the nine classes were observed, data were not recorded for all 60 minutes of each class due to issues with the video camera (e.g., shut off from a child bumping it) and Sophie leaving the recording frame (e.g., left the gym to see her parents). The PA and SI results represented her time within the recording frame, but some class time was not recorded.

In addition to the above limitations, only three motor skills were testing using the MABC-2, but Sophie practiced a variety of FMS in the PA program. Therefore, the MABC-2 did not assess all the possible physical outcomes of participating in this program. From these limitations, recommendations can be made for future research, which include testing more than one participant, conducting a washout period, incorporating more than one video camera in the space, and examining a greater variety of motor skills. From the parents' interview, it would have been interesting to include the perspective of Sophie's teacher to determine if the PA program affected her school behaviours.

Several recommendations can be made as a result of this research. First, healthcare professionals working with children with psychological disorders should inquire about the PA habits of the children they treat and recommend extracurricular PA involvement. Second, parents should not solely rely on therapeutic intervention to support the development of their children with psychological disorders, but also PA programs, particularly those which take place in social settings. In addition, physical educators and coaches should spend more time in skill practice to ensure all children have adequate time to develop FMS, regardless of diagnosis. Lastly, individuals who work with, raise, or educate, disabled children should use positive and accepting language to foster FMS and PA enjoyment, thus building positive lifestyle habits that carry into adolescence and adulthood.

In conclusion, this case study demonstrates the potential far-reaching effects of a weekly community-based PA program for a seven-year-old girl with ASD, ADHD, speech/language disorder, and anxiety. Sophie demonstrated some motor, social, and personal growth after attending the program for ten weeks, which translated into her home and school life. In addition, she made friends, learned about FMS, and gained additional MVPA. Future research should examine similar programs on a larger scale to determine if similar benefits could be acquired by other children with psychological disorders.

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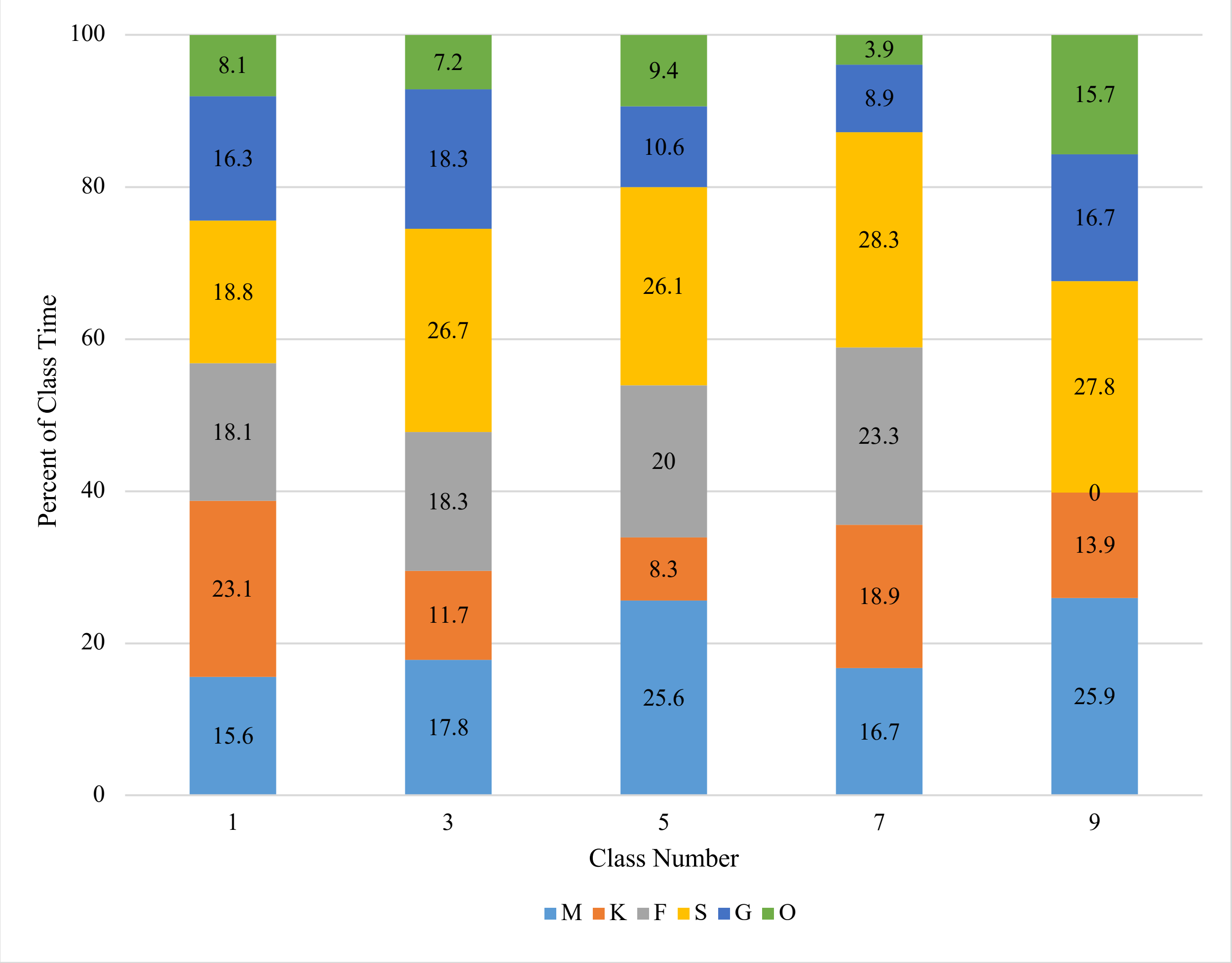
Appendix 4: "I Think She's Found her Groove"

Figure 1

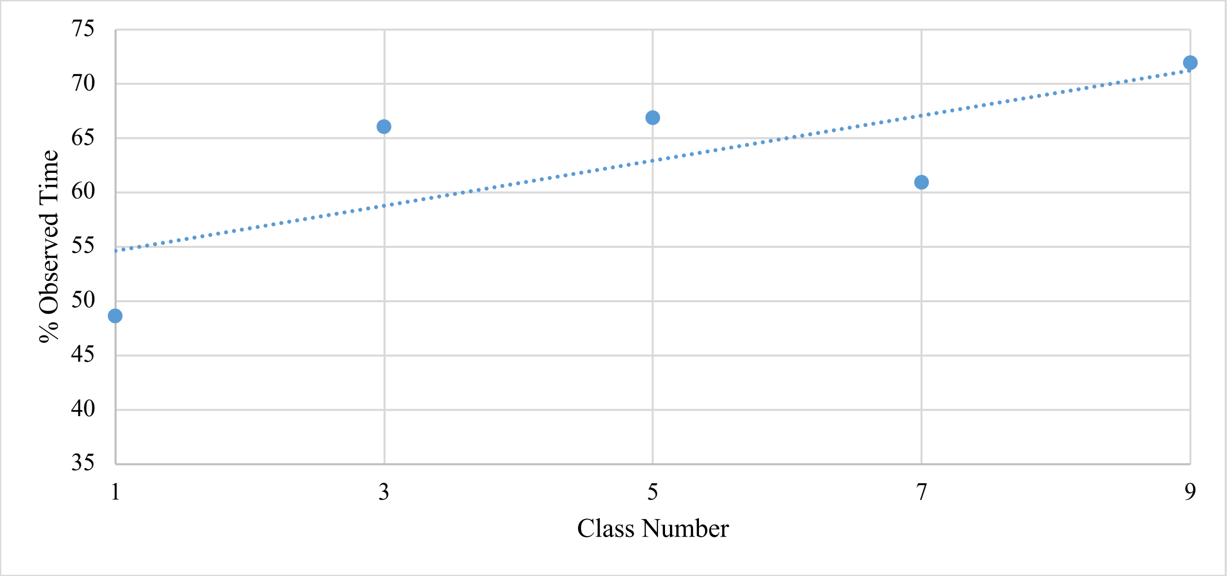
SOFIT lesson context data for Sophie over five classes.



Note: data were recorded as the percent of observed time spent in each of the six categories for the duration of the video recording. M: management (e.g., everyone moving into a circle between activities). K: knowledge (e.g., listening to instructions about a game). F: fitness (e.g., exercise circuit). S: skill practice (e.g., throwing/catching, dance, yoga). G: game play (e.g., What Time is it Mr. Wolf). O: other (e.g., free play before class began).

Figure 2

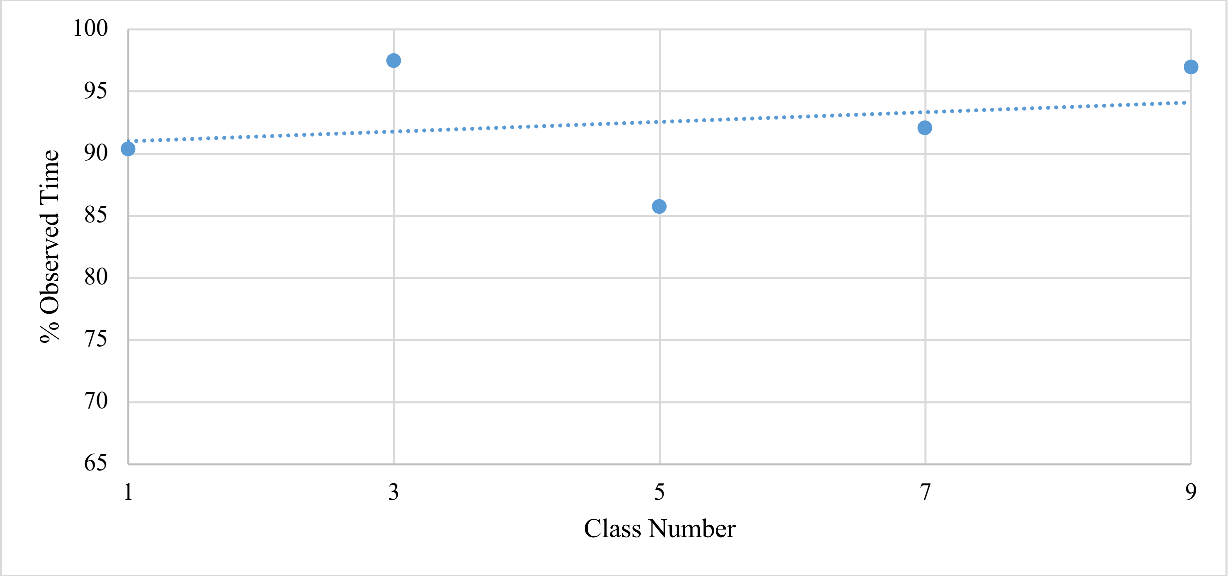
SOFIT moderate to vigorous physical activity for Sophie over five classes.



Note: PA data were coded as one (laying down) through five (vigorous movement) during observed video time. The amount of MVPA was determined as the percent of time spent at level four or five during the class. There appears to be an overall increase in PA with each class, with an average of 62.94% of class time spent in MVPA.

Figure 3

SOFIT social interactions for Sophie over five classes.



Note: SI data were coded as yes (any interaction with anyone in the class) or no (distracted or physically isolated from others) during observed video time. The amount of SI was determined as the percent of time spent interacting with others during the class. SI appears to increase over time, and Sophie spent 92.56% of classes interacting with others on average.

Table 1

Sophie's MABC-2 scores before and after M&G.

MABC-2		Pre-test	Post-test	Change
Manual dexterity	CS	10.5	19.5	+9
	SS	3	6	+3
	%	1	9	+8
Aim and catch	CS	11	15	+4
	SS	5	8	+3
	%	5	25	+20
Balance	CS	18.5	20.5	+2
	SS	6	6	0
	%	9	9	0
Total	CS	40	55	+15
	SS	3	5	+2
	%	1	5	+4

Note: Higher scores are indicative of less motor concern in the child. Light green highlight signifies improvement, while no highlight signifies no change. CS = Component Score. SS = Standardized Score. % = Percentile Rank. In children aged seven to ten, percentile rank scores below the 5th percentile signify significant motor difficulty, scores between six and 15 signify careful monitoring, and scores above the 15th percentile signify no significant motor difficulty.

Table 2

Sophie’s SRS-2 scores before and after M&G.

SRS-2		Pre-test	Post-test	Change
Social Awareness	RS	15	13	-2
	T	81	75	-6
Social Cognition	RS	25	22	-3
	T	88	82	-6
Social Communication	RS	38	38	0
	T	83	83	0
Social Motivation	RS	19	21	+2
	T	81	84	+3
Restricted and Repetitive Behaviour	RS	25	20	-5
	T	>90	82	-8
Social Communication	RS	97	93	-4
	T	87	82	-5
Total	RS	122	113	-10

Note: Lower scores are indicative of less social concern in the child. Light green highlight signifies improvement, while light red signifies regression. RS = Raw Score. T = T-Score. In school age children, T-scores of 76 or higher “…indicate deficiencies in reciprocal social behaviour that are clinically significant and lead to severe interference with everyday social interactions.” (p. 19, Constantino & Gruber, 2012).

Movin' and Groovin' Evaluation: Caregiver Interview Guide

Thank you for participating in this interview! My name is Nicole and I am a second-year PhD student at Wilfrid Laurier University studying Kinesiology. The questions in this interview are all about you, your child with developmental disabilities, and Movin' and Groovin'. As a reminder, you may choose not to answer any of my questions and you can end the interview at any time.

Let's start the interview with some information about you and your family.

1. Tell me about yourself.
    - Occupation
    - Hobbies
    - Interests

2. Tell me about your family.
    - Members and interests
    - Family relationships
    - What does a typical week look like?
    - What is your role as a parent/caregiver?

3. Tell me about your child with developmental disabilities.
    - Early life
        - i. Signs and symptoms
        - ii. Diagnosis process
        - iii. Associated comorbidities
    - Present life
        - i. Therapies, medications, other treatments
        - ii. Hobbies and interests
        - iii. Programs and extracurricular activities
        - iv. Abilities: physical, social, cognitive, emotional, academic
        - v. Behaviour

4. Please describe a typical day in the life of your child with developmental disabilities.
    - Morning, afternoon, evening
    - School, physical activities, therapies, etc.
    - Behavioural triggers

Next, let's talk about Movin' and Groovin'. I am interested to learn about the program from your perspective (positive and negative) and how it affects your child.

5. Please tell me about your experiences with Movin' and Groovin'?
    - How did you hear about it? How long have you been involved?
    - Why did you become/ stay involved?
    - If it was up to your child, would he/she be enrolled in the program?

6. Please tell me about your child's experiences with Movin' and Groovin?
    - What do you think he/she like/dislike?
    - What are he/she like before the class (e.g. excited, anxious)?
    - What are he/she like after the class (e.g. tired, misbehaved)?

7. Does your child share what happened in M&G with you after class?
    - Does your child do any M&G activities at home or show you the activities?
    - Have you done activities with him/her?
    - Does he/she talk about M&G instructors, peers, or volunteers?

8. Does Movin' and Groovin' have any effect on your child?
    - Positive, negative, neutral
    - Short term, long term, before class, after class
    - Abilities: physical, social, cognitive, emotional, academic

9. Is there anything that makes it easy or difficult for your child to participate in Movin' & Groovin'?
    - For you as a parent? (e.g. price, location)
    - For your child (e.g. inclusivity, interest, level of support)

10. Do you have any suggestions that would make Movin' and Groovin' better for you or your child?

11. Would you suggest Movin' and Groovin' to a friend?
    - Why or why not?

12. What would be the ideal physical activity program for your child with developmental disabilities?
    - If time and money were no object
    - Type of activity
    - Program: time, location, cost
    - Inclusive vs. segregated participation

13. Do you have anything else to add about your physical activity experiences?

14. Do you have anything to ask me?

Thank-you for participating in this interview!

Movin' and Groovin' Evaluation: Child Interview Guide

Thank you for talking to me! My name is Nicole and I am one of your teachers in Movin' and Groovin'. I would like to talk about you and what you think about Movin' and Groovin'. Let me know if you do not want to answer a question or if you want to stop our talk.

Let's talk about you first.

1. Tell me about yourself.
    - What do you do for fun?
    - Who do you spend time with?
    - What is school like?
    - What activities do you do before/after school?

2. Tell me about your family.
    - Who is in your family?
    - What do you do with your family?

Next, let's talk about Movin' and Groovin'.

3. What do you think about Movin' and Groovin'?
    - Do you like coming each week? Why or why not?
    - Do you like the instructors/ volunteers/ other kids?
    - What is your favourite activity/game? Why?
    - What activity/game do you dislike or wish you did not have to do? Why?
    - Can you show me something you learned?

4. How does Movin' and Groovin' make you feel?
    - How do you feel before you come?
    - How do you feel during the activities? Yoga, dance, relay races, etc.
    - How do you feel after you leave?

5. Would you tell your friends to come to Movin' and Groovin'?
    - Why or why not?

6. Do you have anything else to add about your physical activity experiences?

7. Do you have anything to ask me?

Thank-you for talking to me!

Grand Discussion

Drawing Conclusions

Four studies were conducted in the Region of Waterloo pertaining to the lives of disabled children and their families, taking into consideration the personal and environmental factors listed in the PAD (van der Ploeg et al., 2004). The research purposes, questions, and results have been briefly summarized below, followed by a general discussion of the findings as they pertain to each other and the published literature.

Study One: Evaluating the Needs of Families

Families raising children in the Region of Waterloo were surveyed to understand (1) what is the status of PA for families raising children with and without disabilities?; (2) are there differences in barriers and facilitators to PA for families based on disability status?; and (3) what are the needs of families raising disabled children? While the reported amount of weekly PA did not differ between the two groups, caregivers of disabled children reported more barriers, more negative experiences, fewer facilitators, and fewer benefits to PA for their children. The primary concerns for these caregivers were lengthy waitlists for services, difficulties attaining funding, lack of caregiver respite, and a general sense of needing more support. There were key differences regarding PA between families raising disabled children as compared to those with typically developing children (e.g., PA enjoyment, negative PA experiences, PA motivators, desire for inclusive PA, programs too expensive), suggesting the caregivers' concerns were far reaching in their children's lives.

Study Two: Mothers' Realities of raising Children with Autism Spectrum Disorders

To understand the experiences of caregivers in more depth, the lived experiences of mothers' raising autistic children were examined. Mothers described a variety of challenges associated with their autism journey, from noticing the first symptoms to attaining a diagnosis. Mothers felt it was their responsibility to research autism and find services offered in the region, but they felt isolated during this process. Areas of concern centered not only around their children's needs – which were not all met – but their own needs and the needs of their families as well. Similar to the caregivers in study one, navigating services, therapies, and funding were concerns for the mothers of autistic children. While PA was not explicitly explored in this research, it emerged as an issue from the analysis as mothers discussed PA amongst the resources they sought in the region. The subtheme "programming" within the theme "we fall in a gap" described mothers difficulties finding suitable community-based recreation (including PA) to suit the specific needs of their children.

Study Three: Evaluating an Inclusive Physical Activity Program

PA has been shown to be beneficial for autistic children and children with various other developmental disorders, in addition to their caregivers as a form of respite. Movin' and Groovin' (M&G) was created to reduce the barriers associated with PA and enhance the benefits for disabled children and their siblings. Study three utilized mixed methods to collect comprehensive data from M&G stakeholders to (1) understand the program mechanisms; (2) describe the program context; and (3) examine the program outcomes. It was discovered that M&G was successful due its focus on fun, relationships, volunteer support, and choice (e.g., mechanisms), in a context of acceptance, non-competition, and social support. M&G provided meaningful opportunities for MVPA and social interactions for each child.

Study Four: Evaluating A Young Girl's Involvement in a Physical Activity Program

The participants in M&G varied in ability, from profoundly disabled, to typically developing. The purpose of this study was to examine specific outcomes for a young girl who participated in the program for the first time, particularly (1) to determine the social and motor effects from M&G and (2) to understand her experiences through her perspective, as well as the perspectives of her parents and one-on-one volunteer. The quantitative results showed small improvements in her motor and social functioning, likely due to her time spent in MVPA and interactions with the children and volunteers. From a qualitative perspective, M&G was a positive experience and had far reaching effects on her well-being, particularly with respect to her sense of confidence at home, at school, in the PA program, and in her community.

Connecting the Dots

All four of the studies conducted included families living in the Region of Waterloo raising disabled children and, unsurprisingly, there were similar findings that appeared across the research. One of the most prominent themes was the concern among parents regarding accessibility to therapies, services, and programs within the region. Specifically, caregivers' were concerned with securing adequate funding to support their children, the need for and absence of respite care available, and the excessive amount of time spent on waitlists for services. Having assistance with program coordination, specifically amongst caregivers of autistic children was highlighted as a possible solution across the needs assessment paper (study one) and the mothers' resources paper (study two).

When examining PA programming as a specific type of resource for families, there were differing results between the studies. Caregivers of disabled children agreed that PA enjoyment was a necessary facilitator for getting active; however, the results differed between studies. While the needs assessment found PA enjoyment for disabled children was lower than that for typically developing children, most caregivers from the program evaluation (study three) said their children enjoyed PA. This difference could be attributed to the positive experiences' caregivers reported in M&G, while other caregivers may not have been happy with the programs in which their children were involved; however, research exploring other inclusive PA programs was not within the scope of this dissertation. The caregivers from the program evaluation were happy with the program and reported few concerns with how it was run, which potentially reduced the barriers associated with PA for the caregivers from study one.

One of the biggest concerns for disabled children identified in the needs assessment was lack of self-esteem; however, the case study (study four) demonstrated how a PA program could boost confidence in a young autistic girl with various comorbid conditions. Similarly, social skills services were deemed most important in the needs assessment, which were shown to improve in one child after participating in the ten-week PA program. The program evaluation demonstrated children who participated spent over 80% of their time on task with the rest of the group and/or interacting directly with another participant (child, volunteer, or instructor). Clearly this program offered opportunities for socializing with peers and with adults, therefore demonstrating its potential to boost social functioning for disabled children. It may be beneficial for caregivers in the Region of Waterloo (e.g., needs assessment study) to search for programs that offer these socializing opportunities in order to enhance the PA experiences of their children. Similarly, coordinators and instructors should take steps to foster socialization in their programs.

Another area where PA programming could improve the lives of disabled children falls in the realm of physical functioning. According to the needs assessment, caregivers were less likely to report physical fitness as a benefit of PA for their disabled children, but more likely to report practicing physical skills as important to PA as compared to caregivers of non-disabled children. The program evaluation found children spent over half of the observed class time in MVPA practicing FMS and Sophie showed some improvements in her FMS after ten-weeks in the program. While FMS are not a direct measure of physical fitness, they have been correlated with increased fitness for non-disabled people (e.g. Stodden, Langendorfer, & Roberton, 2009) and therefore warrant attention in future research. In addition, gross motor skill development has been associated with time spent in MVPA in disabled children (e.g., Bremer, Balough, & Lloyd, 2011; Capio et al., 2015), demonstrating physical development has been related to increased PA.

Interestingly, caregivers from the needs assessment were more likely to list cognitive development as a benefit of PA for their disabled children, while the caregivers in the program evaluation reported cognitive concerns as a barrier to PA. It could be that, once the barrier of lower cognition is overcome (e.g., through supporting children's needs), then cognitive development is an important outcome for disabled children. While cognition was not measured in the program evaluation or case study, the volunteers, instructor, and researcher (NL) discussed the potential for learning in M&G. For instance, children learned each other's names, game rules, the M&G dance, healthy lifestyle habits (e.g., what foods are more healthful), and much more. In addition, the confidence Sophie experienced affected her attitude toward learning in school and therefore had the potential to affect her cognition indirectly.

It is clear from these four studies, as well as the literature presented in each, that caregiving for disabled children is all-encompassing and PA has far reaching effects for children and their caregivers. It is necessary to examine personal and environmental factors when conducting research on the lived experiences of disabled people in community settings (van der Ploeg et al., 2004). While the focus of these studies has been more specific (e.g., caregiving and PA), this research revealed deeper rooted issues such as stigma and social inclusion. Caregiving stress and lack of inclusion in PA programming are direct results of systemic concerns in today's society. It is necessary to address these challenges for individuals, but even more important to change society's views of disability. Fortunately, disability rights have come a long way in the past decades and will continue to move forward over time.

Stigma and Inclusion

In the early 1900's, disabled individuals of all ages were segregated from the rest of society, often in the form of institutionalization (Polloway, Smith, Patton, & Smith, 1996). The medical model of disability was prominent, in which individuals were defined by their disabilities and viewed as issues that need to be "fixed" via intervention from healthcare professionals (Titchosky & Michalko, 2009). Fortunately, this paradigm has shifted towards empowerment and self-determination over the past century, and disabled individuals are now more integrated into society than ever (Polloway et al., 1996). There are many benefits to the current paradigm of disability, such as social inclusion and enhanced quality of life, but there are still many barriers hindering participation in the community.

Sigma has been a significant concern for nearly all minority populations (Link & Phelan, 2001), disabled people included. Not only does stigma affect disabled people, but also those who are associated with disabled people, such as family members and caregivers (Goffman, 1963). Green, Davis, Karshmer, Marsh, and Straight (2005) interviewed eight disabled adults and seven mothers of disabled children and found all participants experienced the seven components of stigma described by Link and Phelan (2001): labeling, stereotyping, separation, status loss, and discrimination. Of concern were the experiences of hostility and social shunning by others, which resulted in feelings of reduced self-worth, increased depression, and heightened social isolation (Green et al., 2005).

Walsh-Allen's (2010) findings point to the cyclical relationship between stigma and social exclusion. Interviews with young people with learning disabilities and their parents revealed the absence of adequate support in mainstream services and the subsequent need for special segregated services (Walsh-Allen, 2010). Unfortunately, accessing special services was also accompanied by the appearance of being different from the general population, which then contributed to segregation in their communities (Walsh-Allen, 2010).

It is necessary disabled young people and their families are not viewed as a burden on society, but valuable members who add richness to communities (Harrell & Bond, 2006; Titchosky & Michalko, 2009). When it comes to policy however, it may be enticing for policy makers to examine the monetary importance of inclusion, in addition to disability rights considerations (Pedlar & Hutcheson, 2000). Stapleton and colleagues' (2015) Ontario based cost-benefit analysis revealed inclusion as a more cost-effective method to support individuals with additional needs than institutionalization or segregation. Simply put, governments would spend less money on programming and intervention, while also gaining return on their investments. For instance, there were many costs to institutionalization in the 1900's (e.g., staff, facilities, health professionals), but very little return on said investments (e.g., people were forced to rely on institutions to survive). Alternatively, Stapleton et al. (2015) found integrated solutions (e.g., utilizing an educational assistant for children who need individualized education plans) paid off over the lifespan (e.g., individuals are more likely to contribute in society as an adult). This example is not suggesting disabled people are any more (or less) worthy of government spending, but rather exemplifies the far-reaching outcomes of investing in inclusive programming.

The Determinants of Health and Knowledge Translation

Disability rights is not only important when examining societal contributions such as paid or unpaid work; social inclusion has been considered integral for the well-being of disabled children. Social factors were included three times by Roebuck, Paquet, and Coultes-Macleod (2008) in their 12 determinants of health (i.e., social status, social supports, and social environment), clearly indicating its importance in the overall wellbeing of disabled children. Physical activity was included within the seventh determinant (i.e., personal health practices and coping skills), but discussion was limited due to the lack of research regarding the lifestyle patterns of disabled children. Roebuck and colleagues (2008) called for education and support for health behaviours of disabled children at a young age. Therefore, it is essential for knowledge translation to occur between academic and non-academic communities to ensure these findings are shared with caregivers, policy makers, service providers, and coaches in the Region of Waterloo. Communicating these findings with those who can implement change will directly influence the lives of disabled children and their families.

Concluding Remarks

This dissertation not only examined caregiving and PA, but also shed insight on disability in the Region of Waterloo as a whole. Unlike marginalizing demographics such as race or sex, disability is fluid. While someone is born Hispanic or female, many individuals experience a shift in their disability status at different points in their life. For instance, a child may break his leg and require a cast and crutches for several weeks, but then he heals and is able-bodied again. Similarly, an elderly woman may fall and fracture her hip, rendering her disabled for the remainder of her life. However, the experiences of the children in this dissertation have life-long disabilities and may encounter life-long stigma. While it is commendable to have empathy and compassion for the difficulties they face, it is essential to be aware of societal norms at play in their lives. It is necessary for non-disabled people to become self-aware of their privilege and take action to create a more inclusive community. This PhD dissertation came to fruition because of the researcher’s passion for children and families affected by disability. It has been an honour to speak with caregivers who gave so much of themselves to advocate for their children, and likewise, to watch the children in M&G grow and develop over time. These four studies could not have been conducted without the support of community members and university volunteers who dedicated their time to participate in this research. It is the researcher’s hope to motivate change in the community that will stimulate far-reaching benefits for disabled children and their families, both now and in the future.

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