# Physical activity participation among adolescent boys with autism spectrum disorder

by

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## Abstract

The purpose of this dissertation was to examine the physical activity (PA) participation of adolescents with autism spectrum disorder (ASD) as they are reported to be less active than their age-related peers. Driven by Norbert Elias' Figurational Sociology, this study explored the lives and perspectives of a group of adolescent boys with ASD, and examined how their PA participation was mediated by wider social, cultural, institutional norms, values, and beliefs (socio-cultural processes). The objective was to understand how the identified socio-cultural processes interacted with bio-physical and psycho-behavioural processes to enhance, shape, and curtail their participation. A critical qualitative study using a multi-method design was used where 10 adolescent boys with ASD participated in two face-to-face interviews, and each created a digital story. Findings of this study make three substantive contributions to the literature on PA participation. First, data generated with participants added novel, rich, and in-depth descriptions of PA participation, and preliminary insights into the daily lives of adolescents with ASD. Second, in examining the daily lives of participants, findings highlight that PA was not merely a behaviour determined at the level of the individual. The analysis illuminated how PA was shaped by wider social values, norms and assumptions about ASD, and by practices, and interactions within particular PA spaces. These socio-cultural processes in turn influenced the (conscious and

unconscious) choices and preferences made by participants in their particular social contexts, and shaped their habitus toward PA (dis)engagement. Finally, socio-cultural processes do not exist, or function in isolation. Rather, the study demonstrated how the interaction of bio-physical, psycho-behavioural, and socio-cultural processes interact to enhance, shape and curtail PA participation in numerous ways. These findings illuminate the complexity of PA participation, add nuance to the understanding of (in)activity, and highlight the need to consider these interdependent relationships when studying, conceptualizing and developing PA programs, opportunities, and interventions.

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# Table of Contents

# List of Tables

# List of Figures

# List of Appendices

# Chapter 1

# 1 My Interest in Studying Physical Activity

## 1.1 Introduction to the Study

My interest in studying physical activity (PA) among children and adolescents (henceforth adolescents) commenced ten years ago when I was training to be a health and physical education (HPE) teacher. Throughout my practice teaching placements, I noticed that some students seemed to be more inclined to participate in HPE class, while other students seemed to be disengaged, and did not actively participate. Despite attempting to use several teaching strategies that were supposed to enhance engagement and participation with students who seemed 'disinterested', I really struggled to engage these particular students in my classes. These challenges that I experienced however ignited an interest in research where I turned to the scientific literature to seek out methods and strategies to enhance the engagement of these students in my classes. While examining the literature, I learned that adolescent boys in Ontario public schools were increasingly dropping out of HPE as soon as they were allowed to do so by the institution. In some secondary schools in Ontario, rates of attrition between the 9$^{th}$ and 10$^{th}$ grade of HPE class eclipsed 90% (Atkinson, 2014; Jachyra, 2013). Despite these high rates of attrition, there was little research that examined what might be driving these boys toward inactivity at school. This lack of research in turn served as the impetus of my master's research (See Jachyra & Gibson, 2016; Jachyra, 2016; Jachyra, 2014) which ethnographically (See Jachyra, Atkinson, & Washiya, 2015; Jachyra, Atkinson & Gibson, 2014), examined how behavioural, social and cultural processes (such as masculinity) shaped the enjoyment, experience, and predilection of HPE participation among adolescent boys.

While conducting my master's research which involved observing four senior HPE classes between grades 6 and 8, I noticed that there were two groups of students across six HPE classes who rarely participated. Curious to learn more, I asked the teacher of the classes why these particular students were predominantly inactive in HPE. Much to my surprise, the teacher responded saying "it's because of their autism, they're just not interested in gym class. It's just not for them". Although I did not know what to make of the teachers' response, it prompted me to look into PA participation among adolescents with autism spectrum disorder (ASD). While sifting through the related literature, I was surprised to learn that adolescents with ASD were reported to be predominantly inactive both in school and community based contexts (Bandini, et

al 2013; Pan & Frey, 2006), but there was little research that examined why they were highly inactive. Concomitantly, there was almost no research that was conducted in Canada, and this lack of research examining PA participation among adolescents with ASD served as the impetus for this doctoral dissertation.

This dissertation is a study of PA participation among ten adolescent boys with ASD. The study generated rich descriptions, novel theoretical insights, and new substantive knowledge regarding physical (in) activity among adolescent boys with ASD. As will be illustrated throughout the dissertation, adolescent boys with ASD were not naturally lazy, or simply drawn to sedentary activities. Rather, the dissertation highlights that PA participation was shaped by the interrelations of the everyday lives of adolescent boys with ASD, situated within their broader temporal, political, social, and spatial contexts which they interact. This analysis of PA participation among adolescents with ASD is an original contribution which heretofore has not been described in the literature.

In this introductory chapter, I outline the research problem, and the aims of the research that were addressed by this study. Next, I introduce the critical social science approach which undergirded this study, and how this approach guided the selection of Norbert Elias' Figurational Sociology as the conceptual framework. After introducing these conceptual elements, I also include a few notes regarding how I conceptualized ASD, and the use of language in the dissertation. I conclude this chapter by outlining how the dissertation is organized, and provide a brief outline of the chapters which follow.

## 1.2 The Research Problem

Research consistently suggests that PA participation for adolescents with ASD can contribute to a number of positive physical, mental, and social benefits (Sowa & Meulenbroek, 2012). In this vein, it has been suggested that PA participation can enhance strength and improve fitness (Ketcheson, Hauck, & Ulrich, 2018), and facilitate participation in the community (Gregor et al., 2018). Improvements in psychological well-being (Lang et al., 2010), and decreases in self-injurious behaviour (Sowa & Meulenbroek, 2012) have also been noted in exercise intervention studies. Despite these reported benefits, research suggests that adolescents with ASD often do not meet PA guidelines that recommend 60 minutes of daily PA (Bandini et al., 2013). Compared to their age related peers, adolescents with ASD are reported to be less physically

active, and tend to participate in fewer PA activities (McCoy, Jakicic & Gibbs, 2016). Their inactivity however can potentially be problematic as they are positioned to miss out on some of the aforementioned benefits. Despite increasing research examining physical (in)activity among adolescents with ASD (Healy et al., 2018), and calls for research to enhance their participation (McCoy, Jakicic & Gibbs, 2016), it remains unclear why they are predominantly inactive.

To date, much of the PA research has examined bio-physical (e.g. gross-motor skills, sensory sensitivities) [MacDonald, Esposito, & Ulrich, 2011], and/or psycho-behavioural dimensions (e.g. motivation) [Eversole et al., 2016] and how they influence PA participation. However, qualitative investigations of PA participation have been a significantly neglected area of inquiry. In this vein, little is known about the perceptions, meanings, attitudes and beliefs of PA participation in the daily lives of adolescents with ASD. Directly engaging and conducting qualitative research with adolescents however has the potential to generate new and rich insights that might not be elicited using other robust methods, or by engaging only with proxy stakeholders such as caregivers, teachers/coaches, and service providers.

Complicating the lack of qualitative research with adolescents, is a significant dearth of research that has examined how PA participation is shaped beyond the level of individual impairments and/or cognitive processes. With the majority of research examining how bio-physical and psycho-behavioural processes shape participation, little is known about how wider social, cultural, and political (hereafter socio-cultural processes) shape PA. Recognizing that PA participation does not take place outside of wider socio-cultural processes in which adolescents are immersed, there is a need for research to examine how broader social relations influence participation. This knowledge gap is problematic as there also is very little research that has considered how socio-cultural processes interweave with bio-physical and psycho-behavioural processes to shape PA with adolescents, and particularly adolescents with ASD. Given that socio-cultural processes do not exist independently from the lived bio-physical, affective, cognitive, and existential dimensions of the body, there is a need for such an integrated investigation.

To examine physical (in)activity among adolescents with ASD, this study was conducted with a group of boys with ASD. I decided to conduct this research with boys only to build on my

master's research which studied how masculinity shaped PA participation. Building on this interest of my research program, this doctoral project extends my previous work to consider these questions in relation to adolescents with ASD, and the multiple and intersecting forces which shape their PA participation.

## 1.3 Research Aims

Given the knowledge gaps described above, a critical qualitative study was designed to:

> 1) Explore the attitudes, beliefs, conceptualizations, and experiences of PA participation among adolescent boys with ASD, and to contribute detailed descriptions of their lives;
>
> 2) Draw on their subjective experiences to interpret how social, cultural, institutional, and political processes (socio-cultural processes) mediate PA participation; and
>
> 3) Analyze how socio-cultural processes interact with bio-physical and psycho-behavioural processes to enhance, shape, and curtail PA participation.

Although the three research aims are presented separately, each are interdependent, and build on each other to contribute to the study of PA participation among adolescent boys with ASD. For example by exploring participants' perceptions, data generated was used to interpret how socio-cultural processes mediate PA participation. Identified socio-cultural processes were in turn analyzed to examine how these processes interacted with bio-physical and psycho-behavioural processes. Given the explicit focus on examining social relations, and the interdependencies across these processes, a critical social science approach was used to guide the aims of the study. This critical approach is described below.

## 1.4 A Critical Approach to Examining Physical (In)activity

The study is undergirded by a critical social science approach (Eakin, Robertson, Poland, Coburn & Edwards, 1996). Critical approaches acknowledge dialectical relationships between the individual, situated within their economic, political and social contexts (Eakin et al., 1996). As such, critical approaches posit that "practice and societal contexts determine what people think and do and that they even shape what people imagine is possible" (Townsend, Cockburn, Letts, Thibeault & Trenthan, 2007, p. 155). Critical approaches examine power relations, interrogate

the tacit and explicit assumptions and ideologies that undergird daily practices by examining how the micro-level of the individual interacts with broader and macro-level political, economic, and social context (Eakin et al., 1996) to shape daily lives. Critical approaches therefore are explicitly concerned with identifying and addressing mechanisms of social exclusion (Eakin et al., 1996), can be used as a tool to stimulate social change by obscuring the politics, vested interests and issues of power in the scientific process (Duchan & Leahy, 2008), and offer alternative approaches of inquiry and knowledge production (Gibson & Teachman, 2012). As a result of this explicit focus on stimulating social change, identifying social conditions and complex operations of power which shape the lives of human beings, critical approaches inherently also have an ethical focus. The ethical dimensions of using a critical social science approach in this study are discussed in Chapter 7.

A critical social science approach was employed in this study as it dovetailed with my interest in examining how social relations (socio-cultural processes) at the macro-level, interacted with forces at the micro-level (bio-physical and psycho-behavioural processes). A critical approach was also used to interrogate what might be some of the multiple (and potential unintended) effects of PA participation among adolescent boys with ASD. With the literature often positioning PA as a potential panacea to attenuate ASD symptoms, or an elixir to improve health/well-being given the reported benefits of PA (see Sowa & Meulenbroek, 2012), a critical approach was used to problematize the putative goodness of physical activity.

To foreground this analysis, I drew on Norbert Elias' Figurational Sociology. Elias' conceptual framework falls within the broad range of a critical social science approaches such that Figurational Sociology offers conceptual tools to draw attention to the interdependent and recursive relationships between the individual, and their larger social and political context. Drawing on Elias' concepts of figuration, hinge, and habitus, Elias' conceptual tools were used to move beyond merely describing participants' experiences in PA as has been done in much of the qualitative research to date (see Healy et al., 2013; Lamb, 2014; Arnell et al., 2018). In conjunction with a critical lens and Elias' conceptual tools, the analysis was oriented at examining how individual (biological impairments, behaviours, perceptions, experiences) and micro-level interpersonal processes, interact with, and are contoured by broader macro-level (social, institutional, community, and public policy) processes. Examining these interrelations

therefore are tools to analyze the forces which enhance, shape, and curtail PA participation among adolescent boys with ASD.

## 1.5 Conceptualizing Autism Spectrum Disorder

Across the academic landscape, ASD is a highly contested construct. In its most reductive conceptualizations, ASD is positioned either from bio-medical or a neurodiversity perspective. From a bio-medical perspective, ASD is conceptualized as a constellation of conditions that co-occur with other disorders and disabilities (e.g., intellectual disability, attention hyperactivity deficit disorder) (Anagnostou et al., 2014). With significant heterogeneity in presentations, ASD as a medical condition contributes to impairments in: social communication and social interaction, along with restricted, and repetitive patterns of behaviour, interests or activities (American Psychiatric Association, 2013). Symptoms often are identified by clinicians during early development, and are described as contributing to challenges impairments in social, occupational and other areas of functioning, (American Psychiatric Association, 2013). As a result of these impairments, medical treatments and interventions are aimed at alleviating the identified impairments in an effort to "facilitate the acquisition of skills, remove barriers to learning and improve functional skills and quality of life" (Anagnostou et al., 2014, p. 515).

In contrast to a bio-medical perspective, a neurodiversity approach argues that ASD represents one form of human and brain variation. Challenging pathological conceptualizations of ASD, a neurodiversity perspective argues that differences observed in the brain are natural forms of neurological and human diversity where the brain is 'wired differently' (Lai et al., 2018), but is not considered pathological in nature. Recognizing these differences, a neurodiversity perspective argues that ASD is a way of being, thinking, acting, and feeling that is accompanied by various strengths, differences, challenges, and identity formation and therefore should be embraced. Rather than preventing and intervening through therapy, a neurodiversity paradigm seeks to problematize negative conceptions of ASD as pathology, and to challenge social, political, and cultural barriers which limit participation in daily life (den Houting, 2018).

Although I have outlined the two predominant reductive conceptualizations of ASD in opposition, conceptualizing ASD from either as a bio-medical disorder or a form of neurological variation does not acknowledge the interconnected biological, social, and cultural complexities.

Rather than pitting these two approaches in diametric opposition, I suggest there is a need to move beyond reductive understandings of ASD and to understand the interdependencies of both approaches. To take into the account the biological, psychological, and social complexity of ASD described across these two approaches, in this dissertation, I propose that ASD cannot be simply reduced to a disorder (bio-medical approach) or a human variant (neurodiversity approach). Rather, I argue that ASD is a neurological condition with biological underpinnings that are situated in, and buttressed by scientific, social, cultural, political, institutional, historical, trajectories, practices, processes over time. Together, these biological, psychological, social and cultural interrelationships shape how ASD is conceptualized, shape what we imagine is possible, and produce social conditions which shape the everyday lives of individuals with ASD. In this vein, I propose that the biological social, and cultural foundations of ASD are fundamentally interconnected, and should be conceived as interdependent from the outset. Conceptualizing ASD in this way not only moves closer toward a more holistic understanding of ASD which heretofore has been missing from the literature, but also seeks to eliminate individual and social barriers in an effort to enhance one's participation and well-being in daily life.

## 1.6 Language and Terminology

Similar to the discordance regarding conceptualizations of ASD, language used to describe ASD is also highly contested. In reviewing the literature, there is substantial disagreement regarding how to describe individuals with ASD where both identity first, and person first language is often used. Despite the often interchangeable use of the terms 'autistic individual' and 'individual with autism' in the literature, there are important social, political, and ontological differences between these conceptualizations. For example, the usage of identity first language (autistic individual) posits ASD is not the result of a biological impairment as promulgated by the medical model of disability. Informed by the social model of disability, the use of identity first language proposes that disability generally, and in this case ASD specifically, is the result of particular social and political conditions such as exclusion, prejudice and discrimination (Goodley, 2011).

In stark contrast, person-first language 'individual with autism' draws on an impairment based conceptualization of the body in which impairment is the result of "real bodily variations" (Thomas, 2004, p. 25). Rather than conceptualizing disability to be the result of oppression or affliction (Hughes & Patterson, 1997) as proposed by an identity-first approach, person-first

language does not take into account the social conditions which produce disability (Tremain, 2005; Teachman, 2016). Drawing on the medical model of disability, disability and impairment are conceptualized to be natural, and a result of bodily deficits (Thomas, 2004). As such, in this formulation, ASD is conceptualized as a disorder as a result of impairments in social/communication skills, and behaviours.

The lack of consensus regarding the use of terminology across the literature is highlighted by Kenny et al (2016). Among a sample of autistic people, parents and professionals in the United Kingdom, identity first language 'autistic individual' was most highly endorsed among autistic adults parents, and family members, and was least endorsed by professionals working in the field (Kenny et al., 2015). On the other hand, person-first language (individual with autism) was most endorsed by health-care professionals. Although I recognize that this one study is located in the context of the United Kingdom and preferences likely differ across geographical regions, this study highlights the discordance regarding language. Given the discussion above, I recognize that there is no consensual way on how to optimally describe individuals with ASD. Recognizing this complexity, in this dissertation, I utilize person-first language (adolescents with ASD) as this was the preferred terminology selected by study participants. My rationale is to utilize language that respects how study participants in this particular study self-identified. Importantly however, I do not approach disability and impairment as dualistic concepts. Consistent with my bio-psycho-social conceptualizations of ASD described above, I concur with Thomas (2004) and recognize that disability and impairment are recursively interconnected, where biological underpinnings of ASD are situated within and interact with broader socio-cultural processes. Despite the usage of person-first language in this dissertation, I recognize that adolescents with ASD are not a homogenous group.

## 1.7 Organization of the Dissertation

To conclude this introductory chapter, I outline the organization of the dissertation and provide a brief overview of each chapter. The dissertation is partitioned into seven chapters, and uses a hybrid paper-based monograph-dissertation format. For example, Chapter 4 which describes the study methods is written in a monograph style, while Chapters Chapter 5 and 6 have been prepared as two manuscripts with the aim to be published in academic peer-reviewed journals. For each of these latter two manuscript chapters, an abstract is included, along with an

explanation of the target journal, and the status of the paper in the peer-review process. Given the use of a hybrid-paper format, there is some (inevitable) repetition in content across the dissertation (such as introductory components of the manuscripts). To facilitate flow in the dissertation, a brief explanatory preface precedes each of the paper-based chapters.

Following this introductory chapter, **Chapter 2** explores, and synthesizes various literatures on PA participation among adolescents with ASD. To further contextualize the study, the review provides a brief overview of ASD, highlights the common co-occurring physical and mental health challenges that have been described, and discusses the identified benefits of PA participation. In reviewing the literature on PA participation, I discuss how PA is predominantly conceptualized, and flesh out the substantive and theoretical knowledge gaps which served as the impetus for this study. I then highlight how these knowledge gaps resonated with the critical social science approach, and particularly Norbert Elias' Figurational Sociology which served as the conceptual framework for the study.

After outlining how my research serves as a point of departure to address these knowledge gaps, I briefly review literature about the daily lives of adolescents with ASD, and highlight the little research that has explored PA participation with adolescents with ASD directly. In doing so, I highlight the value in directly conducting research with adolescents with ASD to (co)produce new insights about PA participation. In closing this section, I highlight avenues for future methodological developments.

In **Chapter 3**, I set out the conceptual framework that oriented the study of PA participation among adolescent boys with ASD. Informed by Norbert Elias' Figurational Sociology, I describe Elias' Figurational approach, his sensitizing concepts, and outline how they informed my study of PA participation. Throughout the dissertation, I draw on the concept of the hinge as a lens to examine how socio-cultural, bio-physical and psycho-behavioural processes interact to enhance, shape, and curtail PA participation. Together, these conceptual tools and Elias' Figurational Sociology more broadly served as a lens to interpret the daily lives of adolescent boys with ASD, and as a tool to examine how various bodily, and non-bodily processes interact together to shape PA.

**In Chapter 4**, I describe the study methodology, and methods that were employed in this study. Drawing on a critical qualitative methodology, this chapter explains how data was co-constructed with the ten adolescent boys, along with details explaining how the data were analyzed. Throughout the chapter, I highlight how the combination of digital storytelling and two semi-structured interviews conducted with each participant produced a rich and diverse data set to address the research aims. To do so, I draw on a case example with a participant to demonstrate the use of the methods, and argue that the use of these methods together generated novel and innovative that would have not been generated if these methods were used in isolation.

The findings of the study are presented in Chapter 5 and 6. **In Chapter 5**, the findings describe the attitudes, beliefs, conceptualizations, and experiences of PA among 10 adolescent boys with ASD. In providing detailed descriptions of their PA participation and insights into their lives, I interpret their accounts to examine how broader socio-cultural processes shape their PA participation. In doing so, this chapter addresses the first two aims of this study, and argues that PA participation was shaped beyond individual level mediators which have commonly been reported in the literature.

In **Chapter 6**, I build on, and extend the findings presented in Chapter 5 to address the third aim of the study which served as the primary findings of my analysis. Drawing on Elias' concept of the hinge, I analyze how PA participation was shaped by the interweaving of bio-physical, psycho-behavioural and socio-cultural processes. In doing so, I argue that PA participation is not reducible to any one of these processes in isolation as has been predominantly conceptualized in the literature. Rather, the interaction of these processes and interactions within particular 'figurations' shaped each participant's habitus, and their predilections toward PA participation. I close this chapter by suggesting that the findings of the study highlight the need for a more nuanced understanding of PA participation which takes into account socio-cultural processes of PA participation.

To conclude the dissertation, **Chapter 7** summarizes the novel and original theoretical, and substantive contributions of this dissertation. In doing so, I discuss the key findings of the study, and highlight contributions for advancing theory and qualitative methods. After outlining these contributions, I highlight opportunities for future research, and suggest potential implications of

the research for children's rehabilitation and the promotion of PA participation for adolescents with ASD.

This dissertation is an amalgamation of my independent doctoral work which was completed with the supervision, and guidance of my advisory committee. As such, throughout the dissertation, I predominantly use the singular first person 'I'. The only exception is in Chapter 5 where the manuscript that has been submitted for review, and where I shift from the singular first person, to using the plural 'we' in order to acknowledge the contributions of my advisors.

# Chapter 2

# 2 Background and Literature Review

## 2.1 Introduction

In this chapter, I contextualize the dissertation by providing an overview of the literature regarding PA participation among adolescents with ASD. The review of literature examines the current knowledge base, and also outlines how PA participation is predominantly conceptualized. In reviewing the literature, I also identify substantive, theoretical, and methodological knowledge gaps. Substantively, the review of literature highlights a paucity of research that has examined how broader socio-cultural processes shape PA participation among adolescents with ASD. With much of the research examining how bio-physical (e.g., gross-motor skills) and psycho-behavioural (e.g., motivation) processes shape participation, little is known how wider social, cultural, and political processes enhance, shape and curtail PA participation. I suggest that there is a need for more critical research to examine how broader social relations influence participation, and to interrogate what might be some of the multiple (and often unintended) effects of PA participation for adolescents with ASD.

From a theoretical standpoint, the review of literature highlights a paucity of research that has considered how bio-physical, psycho-behavioural, and socio-cultural processes interact to shape PA participation. Although there is emerging work conducted in each domain (bio-physical, psycho-behavioural, and socio-cultural), much of this work has been conducted in isolation without considering how these processes interweave and interact together. Recognizing this theoretical knowledge gap, I draw on Norbert Elias' concept of the hinge (See Chapter 3) to consider how these interdependent (bio-physical, psycho-behavioural, and socio-cultural) processes enhance, shape, and curtail PA participation.

Third and finally, much of the research exploring the PA participation of adolescents with ASD has been conducted with proxy adults such as caregivers, teachers, or coaches. Despite their important contributions, there is limited research that has generated an in-depth examination of the daily lives, views, and perspectives of PA participation from adolescents with ASD. With research suggesting that the views of children and adolescents can differ from the perspectives of adults (Grover, 2004; Gladstone et al., 2006; Teachman & Gibson, 2012), there is a need for more research to be conducted with adolescents directly. Conducting research with adolescents

with ASD has the potential to generate a more nuanced understanding of PA participation which heretofore is missing from the literature.

Taking the substantive, theoretical, and methodological knowledge gaps together, I begin this review of literature by providing a brief overview of ASD. Drawing on biomedical conceptualizations of ASD, I highlight the core symptoms which have been used to diagnose and characterize ASD, along with the common co-occurring physical and mental health conditions that have been described in the literature. Following this introduction of ASD, I examine the reported benefits of PA for adolescents in general, and discuss the additional benefits of PA participation for adolescents with ASD to situate the dissertation. After discussing these reported benefits, I present research to suggest that adolescents with ASD are predominantly inactive, and given their reported lower levels of PA participation, I explore the various processes that curtail their participation that have been identified in the research. Although I present each of the bio-physical, psycho-behavioural and socio-cultural processes of PA participation in separate sections, I do so deliberately to highlight how much of this research has been conducted in isolation. By presenting how inactivity is predominantly conceptualized and researched in the literature, I then draw on Norbert Elias' concept of the hinge to argue that these processes are fundamentally interconnected to enhance, shape, and curtail PA participation among adolescents with ASD.

As will become apparent below, the extant literature has outlined the many benefits of PA participation and positioned PA in an overwhelming positive light. While PA has been championed to improve health and well-being, and attenuate ASD symptoms, there is a dearth of research that has problematized the putative goodness of PA as a health intervention. As such, there is a noticeable lack of literature that has interrogated the taken for granted ways of conceptualizing PA as an elixir to health, well-being and development. There is a need then to interrogate what might be some of the multiple (and often unintended) effects, or debilitating aspects of PA participation for adolescents with ASD, alongside the potential benefits. Doing so requires a conceptual framing, such as my critical social science approach that can accommodate this interrogation.

After reviewing the literature regarding PA participation and highlighting the substantive and theoretical knowledge gaps, the second part of the chapter provides brief insights into the daily

lives of adolescents with ASD. In reviewing this literature, I highlight the paucity of PA research that has been conducted with adolescents with ASD, and suggest further work in this area. I conclude the chapter by summarizing knowledge gaps, and reiterating the problems this research sought to address.

## 2.2 *Biomedical Descriptions of Autism Spectrum Disorder*

### 2.2.1 *What is Autism Spectrum Disorder*

In the biomedical sciences, ASD is conceptualized as a neurodevelopmental disorder which impacts development across the lifespan (Howlin & Magiati, 2017). With onset in utero, (Zwaigenbaum et al., 2005), research suggests that ASD has strong genetic aetiologies (Tick et al., 2016), and is influenced by the interplay of genetic and environmental factors (Mandy & Lai, 2016). In Canada, ASD is the most commonly identified developmental disorder (Government of Canada, 2018), where 1 in 66 Canadian children have been diagnosed with ASD. There is a preponderance of diagnoses among boys, where boys are approximately four times more likely to be diagnosed with ASD than girls (Government of Canada, 2018).

From a diagnostic standpoint, ASD is characterized by impairments in social interactions and social-communication, along with displaying repetitive and stereotyped behaviours, interactions, or activities (American Psychiatric Association, 2013). Although ASD is used as an umbrella term to capture these impairments, the number and severity of ASD symptoms are highly variable, and can be different for each individual. Given this high variability, there are varying impacts on language, behaviour, health, cognitive abilities, social, communication skills (among others), and trajectories over time (Szatmari et al., 2015). In addition to these ‘core impairments’, a number of co-occurring developmental challenges and characteristics experienced by individuals with ASD have also been noted. As such, research suggests that common co-occurring developmental conditions can include (but are not limited to): intellectual disability, and cognitive deficits, genetic anomalies (Richards et al., 2015), attention-deficit/hyperactivity disorder, learning disorders (Lundstrom et al., 2015), tic disorders, aggression, short attention span, tantruming, and impulsivity (Patel & Cutis, 2007). Similar to the heterogeneous nature of ASD symptoms, there also are varying impacts on physical and mental health experienced by individuals with ASD, and these varying health impacts are described below.

### 2.2.2 *Co-occurring Physical and Mental Health Conditions*

Research suggests that individuals with ASD have a higher probability of experiencing developmental, physical, and psychiatric health conditions (Davignon et al., 2018, Kohane et al., 2012, Muskens et al., 2017, Soke et al., 2018, Weiss et al., 2018) compared to the general population. In relation to physical health, adolescents with ASD experience a higher prevalence of co-occurring physical conditions such as epilepsy (Bolton et al., 2011), immunological conditions (such as atopy), and gastrointestinal (constipation) conditions compared to their peers (Muskens et al., 2017). Often commencing in childhood and persisting throughout the life course (Matson, 2016), Levy (2018) highlights that children with ASD can also experience higher rates of eating difficulties, and sleep problems when compared to children with other developmental delays and age related peers.

In addition to physical health challenges, mental health challenges have also been widely described in the literature. Anxiety disorders appear to be the one of the most common psychiatric disorders among adolescents with ASD. In this vein, van Steensel et al's (2011) meta-analysis on the prevalence of anxiety disorders highlights that 39.6% of participants (mean ages between 4.2 and 16.3 years) included in the study sample had at least one diagnosed co-morbid anxiety disorder. In addition to the high prevalence of anxiety disorders, attention hyperactive disorder, self-injurious behaviour, phobias, irritability, suicidal risk, mood disorders (such as depression), obsessive compulsive disorder, eating disorders, and psychotic disorders (Howes et al., 2018; Lai et al., 2014) have been described as possible co-occurring conditions.

In light of the high preponderance of developmental, medical, and psychiatric health conditions described above, Hirvikoski's (2016) Swedish cohort study found that individuals with ASD were at increased risks for specific-cause mortality. As the largest study of mortality and ASD to date, Hirvikoski et al (2016) note that individuals with ASD were at increased risks for diseases of the nervous, circulatory, respiratory and digestive systems, along with mental, and behavioural disorders. The increased risks for specific-cause mortality were tied to a 2.5 fold increased risk for all-cause mortality, and individuals in Hirvikoski's study on average died 16 years earlier compared to the generation population (Hirvikoski et al., 2016). Problematically, individuals with ASD with an accompanying intellectual or learning disability who were included in the study sample died on average 30 years earlier compared to the general population (Hirvikoski et

al., 2016). The high degree of co-occurring developmental, physical, and psychiatric conditions and co-morbidities highlight the need for preventative and primary care efforts to address health challenges experienced by individuals with ASD, and to reduce premature mortality. Given that individuals with ASD appear to be less active than their age-related peers throughout the lifespan, PA has been (uncritically) championed as a 'modifiable' risk factor that can enhance the health and well-being of adolescents with ASD (Healy et al., 2018). It is to this discussion that I now turn.

## 2.3 Physical Activity

### 2.3.1 *Benefits of PA participation*

Physical activity can be conceptualized as any bodily movement that expends energy (Caspersen, Powell, & Christenson 1985). PA can include various forms of movement such as arts-based, play, active transport, physical fitness and exercise (Jachyra & Gibson, 2016), and can be both structured (sports, organized programs) and unstructured (going for a walk, free play) in nature (Campos et al., 2019). Across the PA literature, research suggests that participation for adolescents is consistently associated with a range of positive physical, social and mental health outcomes (Poitras et al, 2016). In a review, Tremblay et al., (2016) note that adolescents who achieve a minimum of 60 minutes of moderate to vigorous PA each day are more likely to experience improvements in motor competence (Barnett et al., 2016); metabolic health (such as blood pressure, blood glucose, insulin, triglycerides) (Saunders et al., 2016; Kuzik et al., 2017), bone health (bone mineral density and content) (Poitras et al., 2016); brain and mental health (cognitive functioning, self-esteem, anxiety, depression (Biddle & Assare, 2011; Lubans et al 2016; Korczak, 2017); and health related 'quality of life'(measures of physical, mental, social and emotional health ) quality of life (Sampasa-Kanyiga et al., 2017; Tsiros et al, 2017). In addition, research suggests that higher levels of PA participation have been associated with academic achievement (math, reading, and writing scores on standardized tests) (Faught et al., 2017; Faught et al., 2017; Haapala et al., 2017). Adolescents with higher levels of PA are said to be more likely to develop positive peer relationships, learn new skills and movement patterns, and develop increased predilections for PA participation during adulthood (Utay & Utay, 2005).

The small amount of PA research conducted with adolescents with ASD suggests that participation in PA has some potential additional benefits. For example, PA participation can

contribute to the facilitation of schedules/routines, experiences of fun (Potvin, 2013), along with providing opportunities to participate in recreational activities (Potvin, 2013). Furthermore, PA participation has also been associated with enhancing overall fitness and aerobic capacity, improving motor control, reductions in stress and anxiety, and enhancing psychological well-being (Lochbaum & Crews, 2003). Improvements in attention, cognitive flexibility, executive functioning, socio-emotional behavior, and communication skills have also been identified (Redquest, 2018).

In addition to these psycho-behavioural benefits, participation in PA also has been reported to have a positive impact on ASD symptoms. In exercise intervention research, decreases in self-injurious and (Sowa & Meuleunbroek, 2012) maladaptive behaviour (Elliot et al, 1994), along with reductions in repetitive/stereotyped behaviour (such as rocking and hand flapping) have been reported (Healy et al., 2018). Research has demonstrated that symptomatic benefits were most pronounced immediately following a bout of activity (Lang et al., 2010) such as jogging (Rosenthal-Malek & Mitchell, 1997), horseback riding (Gabriels et al., 2015), and martial arts (Bahrami et al. 2016). There is no consensus in the literature regarding the frequency, type, duration, and intensity of activity that might have the greatest impact on ASD symptoms (Schmitz Olin et al., 2017). Despite these reported benefits in the literature, it is unclear why adolescents with ASD are predominantly inactive.

### 2.3.2 *Physical Inactivity among Adolescents with ASD*

Research suggests that children and adolescents with ASD are predominantly inactive (Healy, Haegele, Grenier and Garcia, 2017; Pan and Frey, 2006), and tend to become even less active during adolescence (MacDonald, Esposito, & Ulrich, 2011). Compared to their age related peers, adolescents with ASD often participate in fewer activities (Potvin et al., 2013), are less likely to be involved in a sport club (McCoy et al. 2016), and spend less time participating in PA (Bandini et al., 2013). In a study of adolescents in the United States, McCoy et al (2016) found that adolescents with ASD were 60% less likely to participate in PA, and 74% less likely to participate in an organized sport (McCoy et al., 2016) compared to their age related peers. Given their lower levels of PA participation (Healy et al., 2017; Pan et al., 2016), children and adolescents seldom meet recommended guidelines of 60 minutes of moderate, to vigorous PA daily (Bandini et al. 2013). Their inactivity however may be problematic as they are positioned

to potentially miss out on the social and emotional pleasures that have been associated with PA (Phoenix & Orr, 2014), or the physical and mental health benefits. Recognizing their lower levels of PA participation, there are increasing calls for research to understand why adolescents with ASD are predominantly inactive.

Despite increasing calls to enhance PA participation among adolescents with ASD (Healy et al., 2018; McCoy et al., 2016), Campos et al (2019) note that physical (in)activity is incredibly complex and influenced by individual, environmental, and systemic processes. In this vein, a range of bio-physical (e.g, gross-motor skills), psycho-behavioural (e.g., motivation) and socio-cultural (e.g., limited availability of PA programs) processes have been identified in the literature to shape participation, and each are explored in detail below.

I present each of the bio-physical, psycho-behavioural and socio-cultural processes as separate categories, to highlight how inactivity is predominantly conceptualized in the literature. Despite presenting these processes in isolation, I recognize they are fundamentally interconnected. Indeed a primary purpose of my doctoral work was to investigate these interconnections. However, there is little previous work that has considered how bio-physical, psycho-behavioural and socio-cultural processes interact to support or constrain PA among adolescents with ASD. Recognizing this substantive and theoretical gap, I drew on Norbert Elias' concept of the hinge in the research to examine how biological, psychological and social forces interweave to enhance, shape and curtail PA participation among adolescents with ASD.

## 2.4 Bio-physical, Psycho-behavioural and Socio-cultural processes which shape PA

### 2.4.1 *Bio-physical Processes: Motor and Sensory Challenges*

Across the literature, bio-physical processes such as impairments in motor skills have been reported as significant barriers to PA participation (Must et al., 2015). While motor disturbances are not considered 'core' ASD symptoms, research increasingly suggests that motor impairments are relatively common among adolescents with ASD. For example, in their study examining the prevalence of motor impairment among a cohort of 154 adolescents with ASD, Ming et al (2007) highlighted that 51% of adolescents with ASD in their sample exhibited hypotonia (low muscle tone), and 34% of participants also exhibited motor apraxia (difficulty executing motor

movements). Toe walking (19%), gross-motor delay (9%), and reduced ankle mobility were also identified (Ming et al., 2007). As a result of higher rates of motor impairment among adolescents with ASD, Ozonoff et al (2008) proposes that adolescents with ASD may experience challenges with motor development. Challenges with motor impairments among adolescents with ASD in turn contribute to greater deficits in catching and balancing skills (Ament et al., 2015) when compared to age related peers, and children with attention deficit hyperactivity disorder (ADHD). While motoric impairments alone do not determine PA participation, they can contribute to delays in acquiring fundamental movement skills such as catching, running, throwing, and jumping (Redquest, 2018). These delays are reported to negatively impact PA participation as these fundamental movement skills undergird many physical activities (Lloyd et al., 2013).

Whereas challenges with gross-motor skills have been identified to curtail PA, research also suggests that sensory sensitivities can adversely impact participation (Ghaziuddin, 2002). In the context of PA, sensory features such as hyper (heightened sensitivities or aversive reactions to stimuli) or hypo (such as reduced or absent reactions to stimuli) reactivity to noise, lights, temperature, smell, and touch often present in PA environments have been reported to make participation difficult (Srinivasan et al., 2014). Stanish et al (2015) note that sensory sensitivities can make PA feel like an overwhelming experience for some adolescents with ASD. Importantly, whereas gross-motor and sensory issues have been described to shape PA experiences and choices, there is a growing body of literature suggesting that psycho-behavioural processes also shape PA.

### 2.4.2 *Psycho-Behavioural Processes*

In psycho-behavioural approaches to PA participation, research suggests that adolescents with ASD are less likely to be active if they lack motivation (Stanish et al. 2015), or have low perceived motor skill competence (Loprinzi et al. 2015). By extension, adolescents with ASD are less likely to be active if they possess a low enjoyment of PA (Eversole et al. 2016), or have a disinterest in PA (Obrunsnikova & Cavalier, 2011). Arnell and colleagues (2018) propose that sustainable PA participation for adolescents with ASD is contingent on meeting each of the following five conditions: competence and confidence, motivation, adjustment to external demands, predictability and freedom of choice. Although Arnell's model goes some way in

identifying the psycho-behavioural processes which shape participation, simply conceptualizing PA to be shaped by these intrinsic factors presents a reductive understanding of PA. For example, the concepts of motivation or freedom of choice are presented as intrinsic factors that psychologically 'reside' within an individual. However, conceptualizing psycho-behavioural processes in this way does not take into account how one's motivation, or intentional choices are produced. In this vein, (in) activity is not merely an individual, intrinsic 'choice' based on volition or motivation alone as widely promulgated in psycho-behavioural understandings of PA participation. Given this critique of psycho-behavioural approaches generally, and Arnell's and colleagues model specifically, this dissertation draws attention to, and problematizes how, PA 'choices' are predominantly conceptualized, and calls on more critical research to interrogate how individual preferences and behaviours (to be physically active) are shaped by broader social, political, and cultural structures and processes. As argued throughout the dissertation, conceptualizing PA in these processual terms moves beyond a static and reductive understanding of PA, and opens up conditions of possibility to consider how PA participation is shaped beyond the level of the individual.

### 2.4.3 *Parental and Family Processes*

Parents have been identified as important stakeholders in shaping PA participation for their children (Fuemmeler, Anderson, & Masse, 2011). From enrolling their children in programs, to transporting children to PA activities, parents play a key role in providing and promoting PA opportunities for their children (Sallis, Proschaska & Taylor, 2000). While parents play a vital role in shaping PA participation, the additional demands often associated with raising a child with ASD (Nicholas et al, 2016) can influence PA participation. For example, parents of children with ASD describe time constraints (Gregor et al., 2018). Furthermore, the need for supervision of their children while participating in PA, a fear of child injury, challenges with attention, hyperactivity, and learning problems (Must et al., 2015) and increased parental stress from behavioural challenges (LaVesser et al., 2011) all have been described in the literature as dissuading parents from enrolling their children in PA activities.

Notably, with much of the PA research among adolescents with ASD focusing on the bio-physical and psycho-behavioural mediators of PA participation, there has been much less research that has considered the influence of socio-cultural processes. The identified gaps in the

PA literature highlight the need then to explore how PA is shaped by wider socio-cultural processes. These processes are discussed below.

### 2.4.4 *Socio-Cultural Processes*

Across the literature, research suggests that there are few PA opportunities in the community for adolescents with ASD (Obrusnikova & Cavalier, 2011). The paucity of PA programs is amplified during adolescence when there are even fewer programs and opportunities available (Healy et al., 2018). Limited availability of PA opportunities can be problematic. Sallis et al's (2000) review of correlates of physical activity of adolescents without ASD highlights that limited availability of physical and community programs can dissuade participation. Although the reasons for the lack availability of programs for adolescents with ASD is likely manifold, Must et al (2015) note that teachers and coaches may not possess the requisite knowledge, training and skills on how to adapt PA for adolescents with ASD. Furthermore, a lack of time for PA has also been identified where in one study, parents devoted significant amounts of time and financial resources to support therapeutic goals (Gregor et al., 2018)

Despite limited training and knowledge among coaches and community service providers, a nascent body of critical research argues that inactivity among adolescents with ASD is shaped by 'deficit-based' approaches that are pervasive in PA settings. In sport and PA contexts, Townsend (2018) notes that activities and coaching practices are predominantly underpinned by implicit bio-medical logics which position inactivity of adolescents with ASD as the result of individual impairments. As such Townsend (2018) argues that impairment-based adaptions reproduce normative assumptions of human development where bodies are expected to move in particular ways. While these impairment/deficit based practices are likely well intentioned, Townsend et al (2017) note that these practices nevertheless can create a "false ideology of inclusion" (Townsend et al., 2017, p. 1) that perpetuates exclusion as coaches may overly focus on teaching skills to improve/normalize individual impairments. As such, Townsend argues that rather than focusing on adapting PA activities to meet impairment needs, broader circumstances such as social, cultural, and individual barriers must be addressed first in order to facilitate participation (Townsend, 2018).

Although the socio-cultural processes described above serves as a valuable point of departure in understanding the social issues that shape PA participation, much of this research has also been

conducted without taking into account how socio-cultural processes interweave with bio-physical and psycho-behavioural processes. Given that socio-cultural processes do not exist independently from the lived physical, affective, cognitive, and existential dimensions of the body, there is a need for research to consider how these interconnections shape participation. As argued throughout the dissertation and drawing on Elias' concept of the hinge, conceptualizing PA participation in this way offers a new opportunity to examine how physical (in)activity is shaped by the simultaneous interweaving of bio-physical, psycho-behavioural, and social processes. This work is especially pertinent given the lack of research that has been conducted among adolescents with ASD, and it is to this discussion that I now turn.

## 2.5 Lives of Adolescents with ASD

I now provide a brief review of the empirical research that has described the everyday lives and recreation participation of adolescents with ASD. I review this literature to further contextualize the dissertation, and to highlight the paucity of research that has been conducted with adolescents with ASD generally, and the lack of research examining their perspectives, experiences, and habits of PA participation specifically.

With regards to activities of daily living, adolescents with ASD are described as having small social networks that they interact with. As such, adolescents with ASD are said to predominantly interact with close family members (Solish et al., 2010) where they tend to engage in more social activities with older adults and their parents than with friends and age-related peers. Adolescents with ASD are described to have fewer friends than children with psychiatric diagnoses (Bastiaansen, Koot, Ferdinand & Verhulst, 2004), age related peers (Koning & Magill-Evans, 2001), and children with intellectual disabilities (Solish et al., 2010). Fewer friendships described among children with ASD can also persist into adolescence where Orsmond et al (2004) note that half of their study participants reported having no relationships with peers.

Research suggests that adolescents with ASD engage in fewer social and recreational activities than their age related peers (Solish et al., 2010). In a cross-sectional study drawing on a national sample in the United States, Lee and colleagues (2008) highlight that children aged 3-17 years were less likely to participate in community services, religious services, and organized activities compared to age related peers, and to children with ADHD. Additionally, children with ASD have been found to participate in fewer recreational and social activities compared to their age

related peers, peers with intellectual disabilities, and have been described as disengaged from school activities (Solish et al., 2010). In this vein, adolescents with ASD are also less likely to participate on school sports teams and other school-based activities (Potvin, 2013).

Whereas the brief review of literature above provides preliminary insights into the lives of adolescents with ASD, there is a dearth of research that has included the perspectives and experiences of adolescents with ASD. To date, research has included the proxy perspectives of siblings, teachers, caregivers and health-care providers, but there remains a paucity of research conducted directly with adolescents with ASD regarding their daily lives, practices, and habits. Not only is there little research conducted with adolescents, there is even less research that has examined their PA participation from their perspective. However directly engaging with adolescents with ASD has the potential to generate rich insights regarding physical (in)activity as adolescents' perspectives likely differ from the perspectives of adults and caregivers (Grover, 2004; Gladstone et al., 2006; Teachman & Gibson, 2012). To this end there is a need to engage adolescents with ASD in research that investigates their lives, preferences, and choices. Drawing on the new sociology of childhood where adolescents are conceptualized as experts of their own lives and experiences (Brady, Lowe, & Lauritzen, 2015; James, Jenks, & Prout, 1998; Matthews, 2007), it is imperative to directly engage them in research as it has the potential to (co)produce new insights about PA participation (Jachyra, Atkinson & Bandiera, 2015).

## 2.6 Summary of Chapter and Conclusion

In this chapter, I provided a brief review of the extant literature related to biomedical conceptualizations of ASD, processes involved in shaping PA participation, and some preliminary insights into the lives of adolescents with ASD. In the first part of the chapter, I discussed research promoting the benefits of PA participation generally, and reported benefits of PA participation for children with ASD specifically. To examine why adolescents with ASD are predominantly inactive, I then discussed the multi-level bio-physical, psycho-behavioural and socio-cultural processes that have been identified in the literature in shaping PA participation. With much of the research to date focusing on the bio-physical and psycho-behavioural processes which position inactivity to be an issue situated at the level of the individual, the review identified a substantive lack of research looking at socio-cultural processes and their influence on PA. Given this lack of research, I suggest that there is a need for more critical

research to examine how social relations intersect with bio-physical and psycho-behavioural processes to shape PA participation. The critical qualitative methodology, and critical social science approach which undergirds this research situates PA participation as not merely a behaviour determined at the level of the individual. Rather, PA participation is situated within broader social relationships and processes.

In reviewing the various bio-physical, psycho-behavioural and socio-cultural processes which shape PA participation, the review of literature also identified a theoretical knowledge gap. As such, there has been little work that has theorized how these processes are interconnected and shape PA participation among adolescents with ASD. With a lack of research in this area, I draw on Norbert Elias' Figurational Sociology, and his concept of the hinge throughout the dissertation to propose that socio-cultural processes do not exist independently from the lived physical, affective, cognitive, and existential dimensions of the body. In the chapters that follow, I argue and demonstrate how PA participation is shaped by the simultaneous interweaving of bio-physical, psycho-behavioural, and social processes. Approaching PA in this way serves as a point of departure to conceptualizing PA participation in a more holistic manner which heretofore has not been described in the literature.

In the second part of this chapter, I reviewed the limited research investigating the lives and experiences of adolescents with ASD. Despite these few studies conducted predominantly from the perspectives of adults such as caregivers and teachers as proxies, there remains an overall paucity of research describing the lives, practices, experiences, and understandings of the world from the perspectives of adolescents with ASD. Furthermore, there is incredibly limited research that has examined adolescents' perspectives of PA participation. Given these knowledge gaps, there is a need then to directly engage adolescents with ASD in research in an effort to generate a more in-depth and nuanced understanding of physical (in)activity. In the chapters that follow, I describe my research and how it attended to the knowledge gaps and issues identified above, and I explore how socio-cultural processes enhanced, shaped and curtailed PA participation for a group of adolescent boys with ASD.

# Chapter 3

# 3 Conceptual Framework

## 3.1 Norbert Elias and Figurational Sociology

Norbert Elias (1897-1990) is widely respected as one of the greatest sociologists of the 20th century (Depealteau & Landini, 2013). Although Elias' work was not recognized *en masse* until the English version (re)print of his 1939 magnum opus *The Civilizing Process* in 1978, Elias is recognized with establishing Figurational Sociology. Figurational (or processed based) sociology involves conceptualizing research questions processually. Moving beyond static concepts (such as structure and agency) and conceptual distinctions that are isolated from one another (individual and society), Elias sought to altogether dissolve 'falsely' dichotomized understandings of human beings as problems. As such, he argued that any unit of investigation (such as human beings) cannot be analyzed in isolation. Nor should a unit of investigation be conceptualized stagnantly, or statically, where one does not acknowledge the evolving nature of temporality, and the role of time. Rather one must situate human beings within a long-term perspective to examine how interdependent social, historical, psychological, biological, and institutional processes shape human beings (including their affective, physical, existential, and cognitive dimensions). For Elias, the goal of sociology therefore resides in understanding individuals and society in relational pluralities and processes, where the researcher examines the fluid interrelationships and interdependencies of a particular unit of investigation. In this vein, Elias argued for the need to examine how people are recursively oriented, and deeply bonded with one another by understanding how macro and micro forces of life interact together. To think otherwise without understanding interrelationships, Elias argued, would hinder our understanding of human beings, and human relationships. Figurational sociology therefore is wholly relational and radically processual in nature (Dunning & Hughes, 2013). As described below, this approach fundamentally influenced Elias' research interests, and in particular influenced his corpus of research which was oriented at understanding who, and what humans beings are, and how they came to be.

Elias argued that human beings are at the centre of interrelationships with individuals, groups, and broader social processes. Starting with the premise that people are recursively oriented, and deeply bonded with one another, Elias drew on this Figurational approach to examine how intricate webs of individual and group interdependencies/relationships shape power, behaviour,

emotions, social order, understandings of death, and knowledge over time (Williams, 2017). This approach in turn influenced his work on: the historical development of individual identities and habitus emanating from self-discipline or becoming 'civilized'; the role of state formations in the development of individuals both socially and psychologically; sport, art, and leisure studies; an examination how social scientific knowledge is (re)produced; how communities are formulated; the dynamics which shape national identity-formation; the changing nature of violence in society over time; understandings of ageing and dying; and the evolution of manners (Williams, 2017). Whereas Elias' work has not received the same degree of exposure and uptake compared to other contemporary sociologists such as Michel Foucault, or Pierre Bourdieu, Elias' Figurational approach has been taken up across numerous disciplines such as: sociology, psychology, education, political science, global and globalization studies, history, the sociology of sport, and physical cultural studies.

In this chapter, I introduce key aspects of Elias' Figurational Sociology and its relevance for examining how social and behavioural dimensions shape PA participation among adolescent boys with autism spectrum disorder. In what follows, I begin by outlining Elias' Figurational approach, and define key concepts as they relate to this study: figuration, hinge and habitus. I outline how each concept aligns with the study aims, and highlight how the concepts and overarching Figurational approach grounded the research.

## 3.2 Elias' Figurational Approach

Although Elias opposed laying down fixed sets of doctrines which risked dogmatizing Figurational Sociology, he outlined five overarching concepts which characterize Figurational approaches. Elias' concepts challenged structuralist and functionalist understandings of social life, and were developed to move beyond some of the 'false' dichotomies and dualisms which pervaded sociology during Elias' time such as: the macro and micro, structure and agency, determinism and freedom, nature and nurture, the synchronic and diachronic, and the individual and society. Although I present each of these five overarching concepts separately, it is important to note that they are fundamentally interrelated, and are conceptual tools developed to facilitate the analysis of social life, human beings, and societies (Goudsblom, 1977).

### *1) Conceptualizing Research Problems and Questions in Processual Terms*

The first sensitising concept is that Figurationalists always conceptualize research problems/questions in processual terms. Elias argued a need to understand human societies and human beings in a processual manner. A processual understanding of bodies, lived experiences, and human beings, for example, recognizes that humans are circumscribed and linked by similar processes such as being born, maturing, and dying. Understanding human beings and conceptualizing research problems in this way also involves moving beyond the tendency to reduce processes to static states, which Elias called 'process-reduction' (Elias, 2018). For example, human history, is often divided into time periods such as The Middle Ages, the Renaissance and the Enlightenment with emerging human, societal and technological developments specific to each period. Characterizing human history in this way however reduces society to timeless states and static conditions, and therefore assumes subjects, objects, and processes have distinct finite starting and end points. Rather than focusing on starting and end points, thinking processually however requires us to recognize that human societies consist of long-term processes of development, rather than isolated and compartmentalized periods of time (Atkinson, 2018). To this end, a Figurational approach investigates continuous social interrelationships and processes, instead of approaching and conceptualizing history emanating from sequences of static events. As outlined by Elias, approaching human beings and objects *in medias res* (residing in the middle of things) opens up new conditions of possibility in thinking and seeing human beings and the world:

> Our languages are constructed in such a way that we can often only express constant movement or constant change in ways which imply that it has the character of an isolated object at rest, then, almost as an afterthought, adding a verb which expresses the fact that the thing with this character is now changing. …We say, the wind is blowing', as if the wind were separate from its blowing, as if a wind could exist which did not blow…. The reduction of processes to static conditions, we shall call 'process' reduction' for short (Elias, 1978b, p. 112).

In the context of this study, a processual approach guided me to move beyond dichotomized conceptualizations of ASD as either a biological disorder, or a social construction. Rather, a processual understanding considers how particular biological, social, cultural, political,

historical, scientific interrelationships, and processes together have come to shape how ASD has been conceptualized, diagnosed, and addressed over time. A processual approach is employed to consider together how these biological and socio-cultural interrelationships are fundamentally interconnected from the outset, and interact together to bring ASD to life, shape how ASD is conceptualized, and generate conditions of possibility which shape the everyday lives of individuals with ASD.

2) *A Focus on Relations, Rather than States*

The emphasis on process is related to the second concept of Figurational Sociology where there is a focus on relations rather than states. For example, when thinking about the concept of power, a relational understanding highlights that power is not an entity (whether perceived or real) that groups, persons or institutions possess to a lesser or greater degree. A relational understanding of power moves beyond static conceptualizations of power which assume that power is exerted from the structures of society (Williams, 2017). Elias argues that power relations are omni-present, and exist in ever-changing balances or ratios between human beings. Given that power is relational and not static, Gibson (2015) argues that power is situated within a triad of what Elias calls 'basic controls' such that power is enacted "*over nature*, including natural functioning of organisms as enabled by advances in technology and sciences; over *interpersonal relationships*, through social institutions and institutional processes, and *over ourselves as individuals*, through learning processes of self-restraint in relations to drives and desire" (p. 56, emphasis in original). Power therefore is relational, omni-present, and shapes the lives of human beings in multiple ways.

*3) Interdependencies of Human Beings*

A relational understanding of human societies and human beings contribute to the third concept, the interdependency of all human beings. At its core, Figurational Sociology examines how people are intimately connected through a multiplicity of interdependent and dynamic bonds (Elias, 1970; Murphy et al, 2000). In this vein, Figurational approaches argue that all humans are located within social relations, or what Elias called figurations (defined below) that they form with others. It is here that Elias argued that individuals do not possess an 'autonomous identity' with which they interact with one another to relate to an entity often referred to as society.

Rather, humans are social to the core and as a result, exist in and through relations with other human beings. Consistent with his focus on process, Elias argued that the interdependent nature of human action within a figuration is not deterministically fixed. As such, interdependencies can be both enabling and constraining, and may not be overt or obvious, especially in a globalized world with billions of people. Whether at a global, or local level, all individuals evolve in and are significantly shaped by these interdependencies with each other (Elias, 1939). These relations therefore contribute to the construction of the 'habitus', or what Elias often called 'second nature'.

*4) Interdependencies are not Static or Fixed*

The fourth concept highlights that these recursive and mutually co-constituting processes, relationships, and interdependencies are not static, deterministic, or fixed. Nor are they (pre)determined in any way. Acknowledging temporality and challenging structural-functional and methodological-individualist understandings of the social world, Elias argued that all figurations, social relationships and social structures are always in flux, such that interdependencies are constantly and endlessly evolving. The processual and fluxing nature of figurations therefore have effects on the social relationships therein. Some of these changes in social relationships and social structures are rapid, ephemeral and superficial, while other changes are slower but more enduring. Conceptualizing human beings and human societies in this way requires us to recognize that human societies consist of long-term processes of development and change. These changes however are largely unplanned and unforeseen (Jarvie and Maguire, 1994; Dunning, 1999)

*5) Human and Societal Trajectories are Largely Unforeseen and Unplanned*

For Elias, changes in interrelationships whether at the level of the individual (what Elias called psychogenesis), or society (sociogenesis) do not simply occur randomly. Rather, as posited by the fifth concept, interrelationships follow trajectories that are largely unforeseen and unplanned. While human beings engage in intentional action within societies, the outcome of these intentional actions when combined with other humans are unplanned. These (largely unplanned) trajectories in turn shape the development of human beings which take place within figurations. Drawing on these actions, the task for researchers resides in analyzing and explaining how

intentional individual actions interweave with unintended patterns of social life which occur over both short and long periods of time (Jarvie and Maguire, 1994; Dunning, 1999).

### 3.2.1 Figuration: Rethinking Structure and Agency

The concept of figuration is central to the Figurational approach, and was created by Elias as an alternative to prevailing dualistic concepts (such as structure and agency) and deterministic approaches which assumed social structures merely impose themselves onto human beings. To this end, Elias argued that assuming individuals exist independently from social structures was grossly misleading. Tellingly, he argued that social structures, society, and institutions do not exist independently from the people who constitute them. As a result, he suggested that human beings and societies should never be conceptualized as self-contained, isolated, self-determining, and 'closed' (*homo clausus)* from other people, society and structures. In an effort to move beyond thinking about human beings in static and compartmentalized ways (Mennell & Goudsblom, 1998), Elias argued that the body and the self, along with the subject and object are not separate entities. Rather, human beings should be understood in relational pluralities such that all human beings are bonded in, and through dynamic, open, and malleable (*homines aperti*) webs of interdependence. Interdependencies may not be overt or obvious, but they are always omni-present.

A banal example of the interdependent nature of everyday life is the act of driving a car. At the surface, each driver is exercising their agency and merely driving on their own accord without the influence of others. However, each driver is also dependent on the others to follow the rules of the road and not crash into another driver. Another example of interdependency is a baby's birth and development. Their interdependencies are biological, in as much as they are social. For instance, the baby's development depends on interdependent biological and social processes (Elias, 1978a). Biological growth cannot occur without a figuration/set of contingencies that includes at least one adult to provide the necessities of life. Social development occurs different with different biological realities such as the absence or presence of disease. Absence or presence of disease has both social and biological vectors that interact across time and space. The interdependencies of the baby and the adult are irreducible such that they both are bonded in a relationship from the very beginning. These interdependencies not only characterize human life

from birth, to death, but the explicit focus on interdependence undergirds the concept of figuration as discussed below.

Elias developed the concept of figuration to underscore how human beings *contribute to*, and are *shaped by* webs of complex, interdependent, social relationships. The combination of individual and group interdependencies coagulate to form *figurations* which are complex and entangled webs/networks of relations (Atkinson, 2012). For Elias, the concept of figuration is "a simple conceptual tool to loosen this social constraint to speak and think as if the individual and the society were antagonistic as well as different" (Elias, 1978, p, 130). The concept of figuration therefore highlights that society and human life are embedded within a loose structure, and situated with a system of relations involving mutually oriented and interdependent people. In this vein, human beings are not "isolated individual 'actors' who variously 'interact' with other individuals, groups, organisations or social institutions" (Dunning and Hughes, 2013, p. 52). Nor is a society merely a 'thing', an isolated 'entity', or an external structure imposing itself onto individual human beings. Rather, the lynchpin of the concept of figuration is such that it "invokes the individual, agency, society, social change, power, and structure simultaneously, but purposely without being reducible to any of these components" (Dunning & Hughes, 2013, p. 52). In this conceptualization, human beings possess some degree of autonomy and certain freedoms as agents, however, these freedoms are generated, and can only be expressed within the broader structure of social relations which afford certain conditions of possibility. Elias eloquently states:

> The network of interdependencies among human beings is what binds them together. Such interdependencies are the nexus of what is here called the figuration, a structure of mutually oriented and dependent people. Since people are more or less dependent on each other, first by nature, and then by social learning, through education, socialisation, and socially generated reciprocal needs, they exist, one might venture to say, only as pluralities, only in figurations (Elias, 1978a, p. 214).

Importantly, a figuration exists anywhere where there is a social connection, and an interdependency of any sort (Atkinson, 2012). As such, the concept of figuration is amenable to groups of individuals of various sizes (two people or five thousand), along with varying degrees of interdependence. The inter-and socially connected nature of human life runs the life course as

human beings are born into sets of interrelationships (figurations), develop within them, to an extent shape their dynamics, structure, and help create them, and then die within the interdependent ties they share with others (Jarvie and Maguire, 1994; Dunning, 1999). Even if a member of a figuration dies, the figuration lives on and is subject to change as long as there is one interdependency of any sort. Figurations for example can include the military, a state, a city, a family, economy, political context, a school, students in a classroom, a workplace, a community (Atkinson, 2012), or a group playing poker (Landini, 2013).

In the context of this study, adolescent boys with ASD are a part of, and interact with, several figurations. For example, boys with ASD are a part of the autism figuration as their symptoms group them together with a clinical diagnosis of ASD. Their diagnostic label in turn shapes their lives and trajectories as their diagnosis provides access to interact with other figurations such as accessing healthcare (therapy), school-based services (educational support), and social expectations of what an adolescent boy with ASD can or cannot do. In addition to this autism figuration, boys are also a part of their family figurations, along with HPE and PA figurations. Although each of these figurations have unique structure, logics, practices, and dynamic tension balances (power), they are fundamentally linked and interconnected as boys interact with these figurations daily, often superseding their conscious control.

To explain the concept of figuration, Elias often used dance, a chess game, or a soccer match (Elias & Dunning, 1986) as analogies to help conceptualize how states, cities, and or families are figurations. I draw on the soccer match analogy. A soccer match does not exist unless there are two teams participating, and the participation of each team enables the presence of the match. Notably, when engaged in the match, the teams are concurrently and concomitantly in cooperation with each other (needing each other to win the match), but also in conflict with one another as opponents. As both teams seek to win the match, they can only do so within the broader structure they participate in (the rules of the game). The use of a soccer match as an analogy enables Elias to jettison the duality between the individual/society and agency/structure as both teams have the autonomy to engage within the game, but only within the confines which make the match possible (Elias & Dunning, 1986). When engaged in the objective to score in order to win the game, the teams are constantly moving, and adjusting their movements in space to reflect the movements of teammates and their opponents. These continual adjustments made by both teams highlight that figurations are subject to constant change. Just as the soccer players

(small figurations) are always moving at some points more quickly and at other points more slowly, this constant process of movement highlights that all figurations (including societies) have a structure, yet are constantly in flux, dynamic, and processual in nature (Elias & Dunning, 1986). The constant changes highlighted in the soccer match are representative of changes in human life, whether large or small, all figurations are constantly evolving, and are shaped by tensile and dynamic power relations between individual people and social groups.

For Elias, figurations are organized as a result of dynamic, processual and fluctuating operations of power. Power is the binding factor between interdependent people and within figurations, and is universally present. It is present in all human relationships, is relational, and contributes to social order. To this end, one is not simply powerful or powerless. Nor is power simply a substance that is merely up for grabs between dominant and less dominant individuals. Power therefore is not a static entity, but rather power is expressed in ratios (or power balances) where power ratios are at a minimum bipolar, and often multipolar. The bipolar and multipolar nature of power emanates from the interdependence between social groups and individual people. Given that power ratios are not equal, power can be both simultaneously enabling and constraining (Elias & Scotson, 1994) with multiple effects. Elias remarks:

> From the day of its birth, a baby has power over its parents, not just the parents over the baby. At least the baby has power over them as long as they attach…value to it. If not, it loses its power… Equally, bi-polar is the balance between a slave and his [sic] master. The master has power over his slave, but the slave also has power over his master, in proportion to his function for the master-his master's dependence on him. In relationships between parents and infants, masters and slaves, power chances are distributed very unevenly. But whether the…differentials are large or small, balances of power are always present wherever there is a functional interdependence between people… Power is not an amulet possessed by one person and not by another; it is a structural characteristic of a relationship of all human relationships (Elias 1978b, p. 74-75).

As illustrated above, the processual network of power balances within figurations are beyond the control of a single individual or any group in particular (Elias & Schröter, 1991a; Jarvie & Maguire, 1994). Given that power is fully relational within figurations, the intentional actions of one individual, and intentional interactions emanating from many individuals can generate

multiple effects (Elias & Schröter, 1991a). Changes in figurations are perhaps best described in Elias' magnum opus *The Civilizing Process* (1939), where he illustrates how standards regarding violence, sexual behaviour, and table manners change over time. He suggests that, although the individual 'I' identity is never more powerful than the collective autonomy of the 'we' identity (Evans & Crust, 2015), the intended actions of a few individuals may generate unforeseen or unintended outcomes for the many situated within the figuration. As noted by Elias, "underlying all intended interactions of human beings is their unintended interdependence" (Elias, 2001b, p. 143) which in turn generates and establishes a (social) order that of which is significantly stronger than the individuals who constitute it. As I introduced above, power balances and relationships are not static, and they can change over time. Social order and relationships therefore are not fixed or predetermined as actions in the past have the potential to influence the present just as much as contemporary actions.

In the context of this study, the concept of figuration was a valuable point of departure to examine PA participation among adolescent boys with ASD for several reasons. First, I drew on the concept of figuration to examine how participants were bonded and socially connected with each other through their participation in both ASD and PA figurations. By examining their interdependencies and their relationship with others (including their peers in PA contexts), the concept of figuration enabled me to explore how participants in this study were positioned as 'the established' or 'the outsiders, and to understand how this impacted their PA participation. Secondly, the concept of figuration and Elias' other concepts were employed to emphasize the processual nature of participants' relationships, and to explore how power relations with others in their figurations enhanced, shaped, and curtailed their daily lives, and PA. By taking a Figurational and temporal understanding of PA, I explore how interdependent power relationships both enabled and constrained their participation over time. Thirdly, I drew on the concept of figuration to query how family figurations both within and beyond the PA context shaped their everyday lives and PA participation. Figuration guided the analysis of how familial values, norms, traditions, cultural rites shaped their participation throughout their lives.

### 3.2.2 Hinge: Bridging the Nature and Nurture Divide

Informed by his training in medicine, philosophy and psychology, Elias sought to combine his interests in the biological body and society into a singular, yet concatenated understanding of

human beings (Atkinson, 2012). Lamenting academic disciplines which dissected the body into individualized units of study (such as history and sociology, or psychology and biology), Elias' sought to transcend (artificial) disciplinary boundaries to generate a '*menschenwissenschaft*' (Reicher, Hayt, Garcia & Dolan, 2018); that is, a bio-psycho-social study of 'human science'. His efforts to generate a bio-psycho-social study of human science was also motivated by the dismissal of biological understandings of bodies within sociology during his time. Atkinson (2018) notes that these trends persist wherein sociologists "frequently struggle with the place of biology, human instincts, drives, or geneotypic and phenotypic natures in social theory on embodiment" (p. 292). Elias' efforts to generate a bio-psycho-social study of human beings also emanated from his critique of how nature and nurture were (and still are) frequently dichotomized such that "nature is usually understood to mean something which will remain unaltered, something beyond change. One unique aspect of humanity is that human beings are in certain ways changeable by nature" (Elias 1978b, p. 107). In this vein, Elias drew on biological and social approaches in an effort to connect "human nature with society" (Elias, 1987b, p. 348). By infusing biology into sociology, Elias argued that such an approach generated a more 'reality congruent' knowledge about social reality (Elias, 2009) compared to other approaches. Elias argued:

> Every investigation that considers only the consciousness of men (*sic*), their reason, or ideas, while disregarding the structure of drives, the direction and form of human affects and passions, can be from the outset of only limited value… A real understanding, even of the changes of ideas and forms of cognitions, can be gained only if one takes into account the changes of human interdependencies in conjunction with the structure of conduct and, in fact, the whole fabric of men's personality at a given stage of social development (Elias, 1994, p. 486).

Not only was his bio-psycho-social study of human science bold, innovative (Atkinson, 2018), and sought to move beyond dichotomies such as the corporeal body and society, Elias' approach sought to bridge the pervasive nature (biology) and nurture (learning and socialization) divide through his concept of *the hinge*. The concept of the hinge proposes that social and biological aspects of human beings are situated within a recursive, interconnected, and interdependent relationship. Instead of approaching social, physical and psychological (existential, cognitive, affective) dimensions of human beings as separate entities, the hinge proposes that natural

(biological) and social processes are fundamentally and deeply entangled from the outset. As a result of this entanglement, Elias argued that social processes and biological evolution are intimately connected structural processes where learned and unlearned traits come together:

> That there are different degrees of [bodily plasticity] is of the greatest importance especially for understanding the civilizing process. Here one sees most clearly the interplay of automatic and intentional self-steering. Automatic are the more animalistic drives and affects such as hate, jealousy, or whatever it may be. Intentional is the self-regulation of drives and affects, which we call learned 'self-control'. Human beings have by nature- more than any other creature- the ability to restrain or to modify their drive impulses according to the situation in question. The civilizing process is based on this ability (Elias, 2018, p. 285).

By connecting human nature (biology) with society, Elias' sought to highlight how social processes (society) and learned individual dispositions (human-self) blend with (unlearned) biological aspects (nature) to shape human conduct and humanly existence in everyday life. In this context, learned processes refer to social practices, learned behaviours, dispositions. On the other hand, unlearned processes include the anatomical make up of bodies, and the autonomic physiological functioning of the human body such as breathing. An example regarding the interaction of the learned and unlearned is highlighted through breathing. Human beings do not learn how to increase their respiration rate when they engage in physical activity (Gibson, 2015). While we can learn to control their breathing, increased inspiration and subsequent increases in respiratory volume during physical activity are modulated by unlearned, physiological, bodily processes. The inextricable relationship between the learned and unlearned aspects of the body is highlighted by Serres (1986) who eloquently outlines the presence, yet absence, of conscious bodily processes:

> (T)here is background noise from our biological processes: we are submerged to our neck, to our eyes, to our hair, in a furiously raging ocean. We are the voice of this hurricane, this thermal howl, and we do not even know it. It exists but it goes unperceived. The attempt to understand this blindness, this deafness, or, as is often said, this unconsciousness thus seems of value to me. We have eyes in order not to see

> ourselves, ears in order not to hear ourselves. The observer observes nothing, or almost nothing.

Another example highlighting the interaction of the learned and unlearned (hinge) is verbal communication. To generate verbal speech, biological/anatomical structures and physiological functions must be present, interact, and operate concomitantly. As a result of the functioning of these biological structures and processes, speech is generated. In the same vein however, verbal speech is only useful and meaningful if a child is able to learn how to use anatomical structures, learns a shared language, and learns how to integrate into social conventions governing verbal communication. It is only through learning that speech becomes of value given when speech is integrated into broader social values system(s) where verbal speech is privileged to a higher degree than others forms of (non-verbal) communication (see Teachman, 2016). It is only through the interaction of the learned and unlearned (hinge) that verbal communication is possible. The inextricable relationship of the hinge is echoed by anthropologist Clifford Gertz who comments, "our capacity to speak is surely innate, our capacity to speak English is surely cultural" (1973, p.50). The purpose in highlighting the breathing and speech examples is not to argue whether the learned or unlearned is more important than the other. Rather, these examples highlight that learned and unlearned aspects of life always are fundamentally linked. This recursive relationship regarding biological maturation and social development through learning is further explained by Elias as he remarks:

> But this overall process, which is entirely automatic and self-steering, includes levels and layers which are less automatic—layers of self-control grounded not in a pre-determined biological mechanism, but in the absorption of knowledge through learning. We have a tongue, lips, mouth muscles and vocal cords, but at best the most rudimentary innate patterns of their coordination. Only animalic sounds of groaning come out of human beings if they do not learn from other human beings to coordinate all these muscles, tongue, palate, vocal chord muscles and so on, so that they utter an articulated language which is comprehensible to other human beings. This is a learned form of self-control…Thus, within this framework of the broad unlearned self-control of the human process, there is wide scope for learned and extremely flexible self-control, which is shaped and facilitated by interaction with other human beings, and which is designed by

> nature for this social integration—because, without it, the organs, tongue, vocal chords, or whatever would remain unused (Elias, 2018, p. 283).

While nature and nurture cannot exist in separation and are always fundamentally linked, the degrees of linkages widely vary. As such, some of linkages of the hinge are tightly closed, while others are more widely open. For example, physiological functions such as breathing and digestion are largely autonomic and unlearned process. These bodily processes reflect the more tightly closed linkage of the hinge primarily relying on biology given that breathing and digestion can be regulated by human beings only to a small degree. On the other hand, Elias argues that drives, emotions, and sexuality are biological in nature but, through learning, these processes can be tamed through self-regulation. As a mix of both intentional and unintentional social processes, this self-regulation in turn reflects the more widely open linkages of the hinge where these learned aspects are more powerful than the unlearned bases of drives, emotions and sexuality. Notably, although biological makeup in human beings provides the conditions of possibility for learning and social development, Elias argues that learned behaviours 'trump' biological process. The unparalleled ability to learn emanating from the social aspects of human life is one of the hallmarks which characterizes and differentiates human beings from other species. For Elias, human practices, interactions, and behaviour are the concomitant result of learning and not merely as a result of biological impulses. In this vein, Elias argues that the learned features of human life are positioned in this way in order to enable survival:

> (S)tarting from the postulate that humans not only can but *must* learn in order to become fully human I have clarified the problem of the hinge. The biological propensity of humans for learning provides the answer. Without the changeability as well as the factual changes of what can and what has to be learned, without changes in knowledge including language changes, social development would not be possible. The *biological* dominance gained by learned forms of conduct links irreversible evolution to reversible development. Learned knowledge can be forgotten. The large human potential for forms of orientation and communication acquired through learning which is part of human nature also constitutes the hinge between nature and society, nature and culture, and in consequence between natural and social science (Elias, 1987b, p. 351).

Although the concept of the hinge is somewhat buried in Elias' corpus of scholarship, the hinge is at the core of his examination of state formation/the civilizing process (Elias, 1978a), manners (Elias, 2000), emotions (1987a), the development of the habitus (Elias 1991, 1996), and death (Elias, 1985). Perhaps the most poignant illustrations of the concept of the hinge were revealed in Elias' work on state formation/the civilizing process (Elias, 1978a), emotions (1987a), and death (1985). In his magnum opus *The Civilizing Process*, Elias cleverly illustrates how self-restraint emerges as an unlearned biological drive, but also is contoured socially throughout history and time that are constantly evolving. As democratic environments increasingly were pacified, centralised through monarchies, and became increasingly interdependent between the 1400s-1800s, Elias highlights how forms of social organization shape individual habituses. It is here that he argues that the inherent biological processes for self-regulation interact with learned mechanisms of self-control which emerge at different points in history.

One of the most explicit statements on the hinge is located within Elias' 1987a essay, *On Human Beings and their Emotions: A Process-Sociological Analysis.* The thesis of Elias' theoretical argument is such that unlearned aspects of human knowledge and 'biological hardware' provides the conditions of possibility for learning and social development. Learning however can only occur in the presence of social organization. Given that learned knowledge is only possible as a result of unlearned human traits, characteristics, and biological hardware, Elias notes then that humans must combine biological hardware with learning in order to survive (1987a). These themes are reinforced by Elias' recently released lecture on 'rediscovering' the body (2018) where he further explicates the recursive relationship between the social, physical, and psychological aspects of human beings.

Finally, in *The Loneliness of the Dying* (1985), Elias highlights how biological and social aspects of ageing, death, and the social rituals of death interact together. While human beings die more hygienically than ever before as a result of institutionalized routines such as palliative care treatment, hospices, and predictable death rituals, Elias argues that participating in institutionalized routines "provide a social framework for the situation of dying" (p. 24). This death framework not only shapes death to be devoid of any feeling and meaning, but also is reflective of one's social and cultural location. Thus as Elias argues, death in developed and highly individualistic societies reflect social isolation throughout the life course where "one dies alone matches the accentuation in this period that one lives alone" (Elias, 1985, p.48). In as much

as natural death is an unlearned, biological process, death is equally contoured socially and reflective of broader social conditions.

In the context of this study, I drew on the concept of the hinge to examine how individual dispositions, biology, and social processes meet and blend to shape PA participation among adolescent boys with ASD. With much of the research on PA among individuals with ASD focusing on individual biological (e.g gross-motor impairments) and psychological forces (e,g motivation), the hinge provided a conceptual point of departure to examine how PA participation is further contoured by broader biological social and cultural norms, values, beliefs, and assumptions. By exploring the learned and unlearned experiences and perceptions of PA, the hinge was used to interrogate how participation was enhanced, shaped, and curtailed by present and past relations, attitudes, perceptions, and PA experiences.

### 3.2.3 Habitus

Throughout his corpus of research, Elias was interested in understanding how learned and unlearned aspects of the body and society shaped the individual and society. In particular, he was interested in understanding how biological, social, and psychological elements of life interweave to shape human beings, both in daily life, and throughout the life course. The impetus to understand human beings across a variety of dimensions not only was congruent with his bio-psycho-social approach described above, but also emanated from his rejection of dichotomizing the body and society into separate entities. Elias remarked:

> "the structures of the body and human psyche, the structures of human society, and the structures of human history are indissolubly complementary and can only be studied in conjunction with one another. They do not exist and move in reality with the degree of isolation assumed by current body research. They form, with other structures, the subject matter of a single human science" (Elias, 1991, p. 36).

To highlight and study the interconnections of the bio-psycho-social, Elias drew on the concept of the habitus. Jettisoning the subject-object dichotomy, the habitus, or Elias' more frequent use of the term 'second nature', are schemes of perception and a mode of orientation that guide thought, perception, tastes, preference, performances, action, and (inter)action within the social world (Atkinson, 2012). For Elias, the habitus is social in as much as it is biological such that

dispositions are created through interdependent processes of sociogenesis and psychogenesis. Sociogenesis entails the internalization of social norms and cultural practices through participation and experiences in the social world. Psychogenesis includes psychological dispositions and personality structures of each individual. The combination sociogenesis, psychogenesis, biological processes, and experiences in the social world through socialization generate dispositions which guide and shape behaviours, habits, and ways of understanding the world. In tandem with the concepts of figuration and the hinge, the concept of habitus highlights how the psychological and the social are interconnected and become internalized. Elias (1991) explained:

> The make-up, the social habitus of individuals, forms as it were, the soil from which grow the personal characteristics through which an individual differs from other members of his society. In this way something grows out of the common language which the individual shares with other and which is certainly a component of his social habitus-a more or less individual style, what might be called an unmistakable individual handwriting that grows of the social script (p. 63).

Elias argued that development of one's habitus commences at birth, and these dispositions become incredibly deeply habituated such that "memory of the learning process has been forgotten or repressed" (Mennell, 2013, p. 6). Given that dispositions are deeply seated, the habitus often is beneath the level of conscious awareness and control (Jarvie & Maguire, 1994). As a result, schemes of perceptions emanating from the habitus become self-steering apparatuses (Elias, 1994) such that these ways of knowing and making sense of the world when immersed in daily practices appear to be natural and are taken for granted. Although the habitus is a heuristic, a mode of perception and orientation in which social actors make sense of their (inter) actions within the social world, the habitus is not fixed, linear, or irreversible. Nor is one's habitus circumscribed. In this vein, the habitus is durable, but not eternal, such that one's habitus evolves throughout the life course, and is specific to one's position(s), participation and interaction(s) within figurations. Thus while one's past experiences may contour perceptions and influence behaviour, the habitus is constructed within an individual's position within a figurations such that power balances and norms situated within the figuration concomitantly and concurrently influence the habitus (Jarvie & Maguire, 1994).

While the habitus operates at the level of the individual as described above, Elias demonstrated how larger figurations such as social class or interactions within particular groups also shape the development of one's habitus. In his study of *The Civilizing Process,* Elias poignantly highlights how the tastes, interests, and modes of perception of the social elite from the upper classes differed from individuals from lower social strata. From differing forms of entertainment such as interests and understandings of art, through clothing, comportment and deportment as markers of social distinction, Elias highlights how one's social position distinctly has an indelible impact in shaping one's habitus. As Mennell (1992) remarks, the habitus is composed of a particular "level of personality characteristics which individuals share in common with fellow members of their social groups (Mennell, 1992, p. 30).

Not only does social position (such as social class) influence one's habitus, Elias also identified how 'external' sociogenetic processes and 'internal' psychogenetic processes (Van Krieken, 2014) are interdependent, interconnected, and fundamentally shape the habitus. As such, Elias traces how personality structures and social changes are fundamentally linked, and interdependent. Tracing how social standards evolved since the Middle Ages in European societies in *the Civilizing Process*, Elias highlights how changes within society, contributed to broader changes at the level of the individual. For example, court circles (particularly courts of absolute monarchs) initially developed stricter control of impulses and emotions as part of the process of civilization (Jarvie & Maguire, 1994). As society increasingly became pacified with decreasing violence among individuals, the stricter control of impulses once limited to court circles permeated down the social scale. The changes in the control of impulses and expectations of exercising 'autonomic self-restraint' were internalized by the majority of members of urban industrialized societies over time (Jarvie & Maguire, 1994).

In this study, Elias' concept of habitus served as a valuable conceptual tool to examine PA participation among adolescent boys with ASD in my research. In conjunction with the concept of the hinge, I drew on the concept of habitus to unpack how human and PA experiences are mediated through socialization processes (sociogenesis) to shape an individual agent (psychogenesis). In this vein, the concept of habitus served as a conceptual foray to examine how individual dispositions interconnected with biological underpinnings, and broader macro and micro level practices to shape personality structures which enhanced, shaped and curtailed PA. By attending to the macro (state formation, norms, values, assumptions) and micro (habitus and

conscience formation) features of their lives, I drew on the concept of habitus to interrogate how short and long term socialization processes, conscious and unconscious acting, individual actions/interpretations, social constraints, along with planned and unplanned social developments interweave to shape PA among adolescent boys with ASD. The concept of the habitus, was an important conceptual tool to bridge the purported 'macro/micro gap' in sociological theory (Mennell, 2018) offering a "historical social psychology" (Elias, 2012b, p. 449) that is at once was psychogenetic and sociogenetic (Mennell, 2018).

### 3.2.4 Human Emotions, Pleasure and Leisure

Throughout his corpus of research, Elias argued that emotions, and one's expression of emotions are key constituting elements which define and differentiate human beings from other species. Situated within the concept of the hinge, Elias argues that emotions have both learned and unlearned components. In this vein, emotions bind human beings together first by nature as all human beings are born with emotions, and secondly through social learning as human beings learn to interrelate emotionally (Elias & Dunning, 1986; Jarvie & Maguire, 1994; Maguire, 2005). Whereas emotions are a central component of the human experience in all aspects of life and eloquently outlined in his essay *On Human Beings and their Emotions: A Process-Sociological Analysis* (Elias, 1987b), emotions also are fundamentally interrelated and a central component of sport, PA and leisure activities. In their examination of fox hunting, early forms of modern soccer, and cricket, Elias and Dunning (1986) in their book the *Quest for Excitement* argue that sport and leisure activities have taken up new meanings and social functions in modern societies. As societies increasingly became pacified over time, Elias and Dunning (1986) argued that societies have had become relatively unexciting places. As part of this process of civilization, changes in these levels of excitement coupled with an increased emphasis separating life from work have contributed to a greater emphasis on moving beyond "the routinization that a civilizing process engenders" (Elias & Dunning, 1986, p. 16).

Leisure activities in the 'spare-time spectrum' such as sport therefore serve a key social function as sport has inherited a new role to counter life from being too dull or boring. Theorized to be a site which elicits "pleasurable and de-routinizing emotional arousal" (Dunning, 1999, p. 3), sport can be a form of pleasurable excitement and provides an outlet to experience emotions that are generally repressed and avoided in everyday life such as anger, fear, anxiety, pleasure, and

sadness (Elias & Dunning, 1986). For example, Mierzwinski and colleagues (2014) highlight how women who participated in mixed martial arts (MMA) emphasized that highly civilized and disciplined routines of daily life are temporarily jettisoned. For these particular women, Mierzwinski et al (2014) highlight that the mental physical, emotional and psychological aspects of MMA which are absent from other features of daily life, elicited mimetic pleasure, joy, and fear. The intersection of emotion and sport are also highlighted by Atkinson's (2013) study of parkour, and Throsby's (2013) work on marathon swimming as they outline how sport can provide a quest for excitement by offering a "controlled decontrolling of emotions" where sport has the potential to enable participants to temporarily escape reality, and venture into the imaginary. It is here that sport elicits emotional arousal and provides a temporary opportunity to experience a quest for excitement where social habits and self-restraint are loosened. Whereas some sports and activities generate pleasure, other activities such as greyhound racing (Atkinson & Young, 2005), and American Football (Maguire, 1993) have been shown to generate apprehension, hatred, intimidation, uncertainty, feelings of victory, and the threat of defeat. By generating tensions and embodied emotions that would likely otherwise not be created or avoided in everyday life, participating in sport and leisure activities therefore can be key components in the formations on one's identity (Maguire, 1991) as individuals navigate the social world.

In the context of this study, examining the role of emotions, leisure practices, and Figurational concept of the spare-time spectrum (Jarvie & Maguire, 1994) served as a point of departure in examining participants' expressed thoughts, motivations, embodied emotions, and pleasure taking part in PA. With much of the research on pleasure examines risk, thrill and extreme sport (Pringle, 2009), exploring the role of pleasure and the spare-time spectrum provided an opportunity to explore this generally unexplored landscape by analyzing the role, pleasures, and meaning of PA in the lives of adolescent boys with ASD. Adopting this approach elicited the opportunity to examine the interconnections between emotions, PA, and boys with ASD which heretofore have not been described in the literature. The negative emotions that can be associated with PA are discussed in Chapter 5 and 6.

### 3.2.5 Alignment with Study Aims

Elias' conceptual framework aligns with the study aims in the following ways. First, the study aims to contribute new knowledge regarding the subjective experiences, understandings, and meanings of PA participation among adolescents with ASD. The data generated with participants highlights the activities, relationships, routines, activities and conditions which contribute to their PA participation, and their everyday lives. The data were analyzed to examine how figurations and social relations interact to shape PA practices. The second aim of this study was to examine how PA is influenced beyond the level of individual physical impairments (gross-motor deficits, sensory factors). Drawing on the concept of figuration, hinge and habitus, this work examined how biological aspects of ASD and PA participation intersect with and are contoured socially. Rather than assuming that participation in PA was putatively biological *or* social, the concepts of the hinge and habitus provide theoretical tools to examine how the biological and sociological aspects of PA participation are interconnected and fundamentally linked. Drawing on a Figurational perspective was a point of departure to think about and analyze the data processually where significance was placed on understanding how changing configurations of power in participants' relationships shaped PA participation. Adopting this approach allowed me to theorize how PA was shaped over time, and to consider how PA was mediated by broader socialization processes.

### 3.2.6 Conclusion

In this chapter, I have outlined Elias' conceptual tools of figuration, habitus and hinge, and have explained how these tools afford analyses of PA participation among a group of adolescent boys with ASD. In doing so, I outlined how Elias' Figurational Sociology guided my investigation of PA participation as shaped by broader socio-cultural processes beyond the level of individual impairments. In conjunction with a critical lens and Elias' conceptual tools of figuration and habitus, the analysis was oriented at examining how individual (behaviours, perceptions, experiences) and micro-level interpersonal factors, interact with, and are contoured by broader macro-level (social, institutional, community, and public policy) forces.

Building on Elias' concepts of figuration and habitus, I drew on Elias' concept of the hinge to examine how the identified socio-cultural processes interacted with bio-physical and psycho-behavioural processes to shape PA. Not only did the concept of the hinge serve as a valuable

resource to guide my analysis, but it was also a unique application of this concept in research with adolescents with ASD. In the next chapter, I describe the study methodology, and methods that were employed in this study.

# Chapter 4

# 4 Study Methodology and Methods

Across the health and social sciences, there has been a significant proliferation of autism research in the past 10 years (Pelicano et al., 2013), with a particular increase in qualitative research (Depape & Lindsay, 2016). From research exploring how caregivers navigate healthcare support systems (Gentles et al., 2019), to research examining how healthcare practitioners such as physiotherapists can potentially enhance PA participation among adolescents with ASD (Campos et al., 2019), qualitative inquiry is increasingly gaining traction. Nevertheless, much of the research focused on adolescents with ASD to date has been conducted with adults, such as caregivers, teachers, and healthcare providers (Depape & Linsday, 2016). Despite calls to include the perspectives of individuals with ASD in research (Bolte 2014), there have been few related studies (Depape & Lindsay, 2016), and even less research conducted with adolescents (Jachyra et al., 2018). Given that the views of adolescents can differ from the proxy perspectives of adults (Grover, 2004; Gladstone et al., 2006; Teachman & Gibson, 2012), including adolescents with ASD in research is important to develop a more nuanced understanding of their everyday lives and needs. Collaborating with adolescents opens new possibilities to expand understandings of their daily lives, and has the potential to generate new insights regarding their PA participation that otherwise might not be generated with other stakeholders.

Although there are likely multiple reasons for the paucity of qualitative research conducted with adolescents with ASD, one contributing reason is the lack of description, development, and guidance regarding the selection of methods that might be optimally suited to their needs. Participating in research using traditional methods, such as an in-depth face-to-face semi-structured interview, may be difficult for adolescents with ASD who can experience challenges with verbal communication, and with grasping and responding to social cues (Harrington et al., 2014). Despite preliminary insights suggesting the avoidance of figurative language (Ellis, 2018) and the use of pictures to facilitate communication during individual interviews (Humphrey & Lewis, 2008), there has been little work that has explicated research processes and methodological decisions when working with adolescents with ASD (Ellis, 2017). As a result, there is a lack of well-described strategies, approaches, and/or reflexive accounts regarding how qualitative data were co-produced. Nor has there been work describing methods and approaches that may be adopted to facilitate working with adolescents with ASD (Jachyra et al., 2019).

Given these knowledge gaps, this chapter serves as a point of departure to address these knowledge gaps by describing the qualitative methodology and methods implemented in the study. To address the study aims, I combined digital storytelling (DS) and multiple in person, semi-structured face-to-face interviews to optimize the engagement of adolescents with ASD, and co-produce in-depth data. I highlight the procedures, strategies, and my own learning developed during the study.

*Methodology and Methods*

Consistent with the critical social science approach which framed the study, a critical qualitative methodology was deployed. Critical qualitative inquiry is rooted in exposing and critiquing power relations and the various forms of obvious and systematized discrimination which operate in daily life (Garoian & Gaudelius, 2008). With a commitment to questioning assumptions and the taken for granted, critical inquiry interrogates rationalist truth claims and grand narratives, and also questions conceptual and theoretical bases of knowledge and methods (Denzin, 2017). As a result, critical inquiry is interpretive in nature which recognizes that 'reality' and science are mediated by human interpretation and meaning, socio-political processes, language, discourses, institutions and social-structures, and positionality of the researcher (Denzin, 2017).

Informed by this critical qualitative methodology, a multi-method critical qualitative study was designed that included two face-to-face interviews and the creation of a digital story with each participant. The first interview was designed to explain the study, build rapport with each participant, and talk through the processes for creating digital stories. Following this introductory interview, digital stories were then created with each participant over the course of three facilitated workshops. The second interview occurred after the digital stories were created. Using the participant's digital story to ground discussions, this interview explored the participant's conceptualizations of PA, their attitudes, beliefs and experiences related to PA participation. I also generated observational fieldnotes during all interviews and digital storytelling workshops to document the research process, my reflections, and initial analytical impressions. Before describing the study procedures in detail, I first introduce digital storytelling as a methodology and discuss the rationale for its use in the study.

*Digital Storytelling:*

Digital Storytelling (DS) was initially developed by the Centre for Digital Storytelling in Berkeley, California during the 1990s to mobilize the individual voices and stories of 'ordinary' people (Bundon & Smith, 2017). DS often takes place in a structured, workshop-based format and draws on multi-media content (text, music, images, video, and artwork) and digital tools (video editing software, digital cameras, computers) to produce short visual narratives known as digital stories (Vivienne, 2011). Digital stories often range from two to four minutes in duration (Bundon & Smith, 2017), and a central component of DS is sharing the stories with others for further dissemination. As such, it is not uncommon for stories to be shared with members of the workshop, with family and friends, and digitally through electronic media such as the internet or a DVD.

While DS is a relatively new research method in the field of health studies (Lal et al., 2015), it is increasingly gaining traction (Gladstone & Stasiulis, 2017) and has been deployed in numerous ways. For example, in arts-based health research and community-based participatory research frameworks, researchers have deployed digital stories as a tool to bring the voices of individuals to the fore (Gubrium, 2009). Additionally, DS has been deployed as a research method in studies examining mental health practices (Baker et al, 2015), and experiences of illness (Willis et al, 2014). Others have employed DS as a knowledge translation tool (Ferrarri et al., 2015).

In the context of this study, DS was selected as a method to generate an in-depth understanding of adolescents' daily lives, their practices, experiences, and meanings of PA participation. Furthermore, DS was strategically selected to facilitate rapport building with study participants. In my experience conducting qualitative research with adolescents with ASD developing rapport can be challenging, especially if generating data with participants during a single encounter. Recognizing this challenge, I sought a method that was structured with multiple participant interactions that enabled data to build from previous interactions. In this vein, DS was selected as a research tool given that multiple and sustained engagements with participants over time presented increased potential to establish trust and rapport, while also creating rich data in a safe and enjoyable manner.

Not only did I seek a method that would help establish rapport over time, I also sought a multi-modal method that would support the wide-ranging communication needs and abilities of adolescents with ASD. Given that digital stories inherently include both verbal and non-verbal forms of communication, DS was optimally suited to participant needs as there can be high variability in verbal proficiency among adolescents with ASD. Finally, DS was selected as an elicitation method to facilitate discussion during subsequent interviews. By creating a digital story, I hoped that adolescents would be more inclined to share their PA experiences by reflecting on their experiences of creating the story, and using the story content as a resource to support our discussions.

*Study Participants*

The study was approved by the University of Toronto Health Sciences Research Ethics Board, and the hospital ethics board where the study was conducted (See Appendix 1). Recruitment criteria were as follows: a) had a diagnosis of ASD as per Diagnostic and Statistical Manual of Mental Disorders (5$^{th}$ ed., DSM-5 2013) criteria, supported by the Autism Diagnostic Observation Schedule (Lord et al., 2012); b) were aged 12-19 years; c) demonstrated verbal proficiency in English; d) were capable of allowing turn-taking and discussion of experiences; and e) demonstrated capacity to independently provide consent to participate in the study. Participants were recruited from a large Canadian children's hospital in southern Ontario. Adolescent boys with ASD aged 12-19 years were specifically recruited as research suggests that children with ASD become even less active during adolescence (Pan et al., 2011). Although there are no standardized rules regarding sample size in qualitative research (Smith & McGannon, 2018), I sought to recruit between 8-10 boys to develop a detailed, contextualized, and in-depth examination of PA participation among adolescents.

Recruitment proceeded as follows. Prospective participants were identified through a clinical database from the children's hospital (See Appendix 2). Adolescent boys who met the study criteria received a study invitation package in the mail (See Appendix 2), and were asked to mail back a form indicating their interest in the study (See Appendix 3). After returning their expression of interest (Appendix 4), prospective participants then were screened during a phone call to assess suitability to participate by revisiting study including criteria. Prospective participants who met the study inclusion criteria were invited to participate in an in-person

meeting to review the study, and to assess capacity to consent (See Appendix 5) in order to participate in the study. Prior to meeting with each participant, adolescent boys received an electronic picture storybook (Appendix 6) which outlined: the details of the study, nature of their participation, potential risks/benefits, duration of involvement, along with information regarding the sequence of events that would take place during the in-person meeting. Storybooks have previously been used in research with adolescents with ASD to convey study information, and outline the nature of events to make the research experience more predictable where possible (Kuoch & Mirenda, 2003). The study storybook included a photo of me, along with some biographical information in an effort to facilitate rapport building.

During the first meeting, consent to participate in the study was sought (See Appendix 7). Consent was informed by a relational framework whereby consent was not conceptualised as a static process limited to decision-making moments (Carnevale, Teachman, & Boggosian, 2017). Rather, consent was conceptualized to be processual in nature as an on-going engagement such that consent was re-evaluated throughout the study through verbal 'check ins' and observation of non-verbal cues (See Appendix 5). This process was repeated until 10 adolescent boys with ASD were recruited.

*Study Methods: Integrating Interviews and Digital Storytelling*

In what follows, I explain each method that was used and how it was deployed in the study to co-produce data with study participants. Interviews were conducted prior to and following the creation of digital stories. All interviews were conducted with participants at a location of their choosing. Eight participants were interviewed in their home, and two participants were interviewed at the children's hospital. In an effort to optimize participation, adolescent boys had the option of including their parents in the interview. In total, 2/10 parents (all mothers) were present during the first interview, and one mother was present during both interviews.

*Interview One:*

The first interview was conducted during the initial in-person meeting. This first meeting sought to learn about each participant's communication preferences for the interviews (See Appendix 8 for interview guide). Participants were encouraged to communicate in ways that best suited them, including communicating through alternate means such as the use of pictures, drawings,

and or props. Despite offering a variety of communication options, participants primarily used verbal communication, and at times used props or pictures to help illustrate, and explain a point they were making. The interview also focused on learning about participants' daily routines, participation in daily structured/unstructured activities, and mapping their engagements with social settings, spaces and places. Given the propensity for some individuals with ASD to interpret questions literally, participants were encouraged to tell stories regarding their thoughts and conceptualizations of PA. Utilising this storytelling strategy not only provided more depth and nuance, but also prepared participants to become comfortable with storytelling as a central component of the DS workshops. Some participants told stories which described their previous PA engagements, while other participants told stories which described how PA sounds like, looks like, and feels like when they were asked to think about it.

The interviews unearthed restricted and repetitive interests for some participants. Restricted and repetitive interests are associated with ASD where an individual might have obsessions or strong interests in a particular topic, or display ritualistic/habitual patterns of behaviour such as fiddling (APA, 2013). In this vein, some participants highlighted their expertise of e.g., reptiles, mammals, airplanes, history of World Wars, and video games such as Fortnite. One participant outlined every public transit route in the City of Toronto. Interestingly, when speaking about their particular areas of interests, four participations quizzed my related knowledge of their particular interest. When I (frequently) had little knowledge in these areas, participants suggested that they should 'teach' me more, and continued teaching me about their particular area of interest. While it was difficult at times to redirect participants to the interview discussion at hand, learning about their special interests also helped build rapport with participants throughout the study, and also served as a topic of discussion during subsequent interactions. Following each interview, detailed field notes were written immediately (See Appendix 9). As an analytic device, the notes detailed my interpretations of tone, posture, body language, what was said, but also what was unsaid, and the nature of interactions with participants. Finally, the notes also included my preliminary analytical thoughts, which then were amalgamated into a narrative summary written for each participant.

*Digital Storytelling Workshops*

At the end of the first interview participants were loaned an encrypted digital video camera for 14 days (longer if needed) in order to take pictures and videos featuring their conceptualizations, participation, and experiences in PA. To facilitate generation of digital data, participants received written suggestions (see Appendix 10) for taking photographs and videos, and were also encouraged to use visual digital media from their existing personal archive. Before ending the first visit, the general itinerary, for the first digital storytelling workshop was reviewed to help participants prepare. Once digital data was generated, the camera was retrieved from each participant, their data downloaded onto a secure server, and then made available to them at the workshops.

The workshops took place at Digital Storytelling Toronto and were designed with two expert storytelling facilitators. Prior to the workshops, I met with the facilitators on two occasions to review the aims of the study, discuss any potential challenges or suggestions for working with study participants, and to help plan the workshops. Given the varying needs and abilities of participants, meeting with the facilitators was invaluable as we sought to ensure the workshops would be highly participatory, fun, and most importantly, allowed participants to work at their own pace. Consistent with the codified process originally developed by the Centre for Digital Storytelling in California, digital stories were created through a series of workshops. Although digital stories are typically created during three-to-four consecutive days of workshops so that participants can fully absorb the workshop experience (Gubrium, 2009), I modified the traditional workshop structure to allow for breaks, given the large time commitment required to create the digital stories. We held three, bi-weekly, workshops over a period of 6 weeks in May-June 2017. Each workshop was 5 hours in duration (10am-3pm) with multiple breaks included.

The first workshop commenced with a storytelling circle to facilitate introductions among study participants and workshop facilitators. During this time, workshop participants and facilitators participated in a name game, and were each asked to share a story about themselves. Storytelling circles are an integral component of DS workshops as they seek to develop group cohesion, and seek to teach workshop participants how to show and tell stories (Gubrium, 2009). With the goal of developing individual and group confidence, storytelling circles are designed to be safe and comfortable where participants share stories, thoughts, and ideas, and also receive feedback from

peers, and facilitators (Gubrium, 2009). During the storytelling circle, participants watched a few sample digital stories, and also learned about the seven elements of digital storytelling (see Figure 1) which guide participants to create effective and engaging stories. The first workshop culminated with a brainstorming session where participants browsed through their digital data (pictures/videos) and began conceptualizing the story they sought to tell.

Figure 1: Seven Elements of Digital Storytelling (see Gladstone & Stasiulis, 2017).

| | |
|---|---|
| 1. Point of view | What do you want to say? |
| 2. Dramatic question (story structure) | How can you say it best? |
| 3. Emotional content | Helping your audience care. |
| 4. Voice | Only you can tell your story. |
| 5. Soundtrack | Add music and other auditory elements for impact. |
| 6. Economy | Keep it simple when it comes to words & images. |
| 7. Pacing | Give viewers time to take in the story. |

During the second workshop, participants created a visual storyboard which outlined the pictures/videos to be included in the digital story. Drawing on the seven digital story elements outlined in Figure 1, participants also wrote a script to accompany the visual aspects of the story. Several draft scripts were written as needed. Reflecting the heterogeneity of ASD, some adolescents were highly independent, while others required assistance with conceptualizing and constructing the storyboard, help with script writing, and technical assistance with the software. The degree of assistance varied between participants, and producing the digital story was also a site and source of contention at times. For example, during the storyboard creation, one participant, Daniel (all names are pseudonyms), really struggled with conceptualizing and

expressing his vision of the digital story. Despite the facilitator's efforts in working with him to guide the process, Daniel became agitated and frustrated, suggesting that the ideas proposed by the facilitator did not match the interests and vision of his story. Standing up from his seat, and raising his voice, he walked out of the room. While Daniel and I eventually re-joined the workshop after taking a break, this interaction highlights the importance of flexible approaches, ongoing support, and rapport building for my participants.

For the third and final workshop, participants assembled and edited their digital story. To do so, participants created and then added a voice-over recording to narrate the story, and some included music and sound effects to accompany the story. Using computer software (Windows Movie Maker and Adobe Premiere), they worked with facilitators to edit the digital story and ensure the voice-over narration was synchronized with the digital content of the story.

There was great variation in the content of the digital stories. Some participants included their family members in the story, while others featured only the participant-storyteller. Some stories featured favourite PA activities, while other participants highlighted how their physical impairments such as joint hyper-laxity, or asthma, at times curtailed their PA participation. Once all digital stories were completed, the workshop concluded with a screening of all stories with all participants in the storytelling circle.

During the workshops, my role was fluid, and varied greatly where I took on multiple positions. For example, at times I was on the periphery and simply observed interactions among participants the workshop facilitators, and the space. At other times, I directly interacted with participants throughout the workshops, facilitated the creation of their storyboards, and assisted with editing the digital stories. Not only did I shift between these two roles during each workshop, other times I was forced to draw on my status as an authoritative adult to resolve conflicts between participants. For instance, on one occasion, I asked a participant to stop humming and moving around in his chair as it was irritating other participants around him. On another occasion, I accompanied and tried to calm down a participant who walked out of the digital storytelling session when another study participant sat at the computer he had used during the first workshop. Despite my best efforts to anticipate potential challenges during each workshop, and provided needed supports, adapting to the unpredictable demands, needs, and interactions that arose was of upmost importance.

**Interview Two**

A second interview was conducted with each participant following the creation of digital stories. Prior to each interview, I previewed each digital story to help individualize the interview guide to each participant and develop preliminary points of discussion. To begin, each interview commenced by asking participants to discuss their thoughts and experiences of creating a digital story (See Appendix 11). This introductory question worked to ease participants into the interview (Kvale, 1996) and was notably successful with six participants whose tone of voice transitioned from an initial quiver to a more relaxed tenor. All adolescents expressed excitement about creating digital stories, and the majority of participants (7/10) identified that they learned a new skills such as understanding what makes a good story, and how to use audio, visual, and video editing software. Other participants (especially the three oldest boys) highlighted that they already had working knowledge of how to create movies and digital stories, but it was nevertheless "cool to meet some new kids, and put these skills to use" (Allan).

Following this introductory discussion, the digital story was watched with each participant (and their parent if present). After doing so, participants were asked to describe the meaning and background of the digital story, along with the message they sought to convey. The discussion also included asking participants about their motivations, intentions, and decisions for including particular photos, video, and audio in the digital story. When discussing their decision-making process, I also asked if there was any significance attached to particular images, objects, topics, or narrative devices and probed for additional details. For example, if participants included PA activities in their digital story, they were asked to describe the place where PA activities took place. Asking such probing questions not only generated further discussion about their PA experience, but also provided significant contextual details about what their daily lives looked like, sounded like, and felt like. Integrating the digital story into the interview therefore not only served as an elicitation technique to help participants illustrate a point they were making, but also stimulated further discussion regarding their attitudes, beliefs, conceptualizations, and experiences of PA participation. The integration of these methods produced rich data. The digital stories not only complimented the interview data that was generated, it informed the interviews and revealed complexity, contradiction and insights into the daily lives of adolescents with ASD that would likely have not been gleaned by only interviewing participants, or only creating digital stories.

**Integrated Data Analyses**

Data generation and analysis were conducted concurrently to explore new insights, questions, and developments as data generation proceeded (Green & Thorougood, 2014). Analysis was completed in consultation with my advisors through formal meetings and informal discussions. With interdisciplinary expertise in critical disability studies, intellectual disability, qualitative methodology, digital storytelling, autism research, mental health and neurology, these multiple meetings helped refine conceptual categories, and facilitated the identification of patterns and interpretations of the data. The data for analysis consisted of:

- Verbatim interview transcripts from two face-to-face interviews (n=20)
- 10 digital stories
- All observational field notes generated during the interviews and digital storytelling. workshops. In total, 23 field notes were written (20 generated from interviews and 3 generated from the digital storytelling workshops). When all field notes were combined, there were 109 pages of field notes.
- 10 narrative summaries written for each participant. Each narrative summary was approximately 16 pages long, and consisted of write-ups of the analyses. These narrative summaries facilitated the fleshing out of concepts, thoughts, patterns, and contradictions from each individual participant. Narrative summaries served as the bases of the analyses and allowed me to document how the analyses were taking shape, documenting concepts, along with thoughts and ideas. Analytical insights gleaned from the field notes and multiple viewings of the digital stories were included in a narrative summary written for each participant.

Data analysis was driven by techniques described by Miles and Huberman (1994) that included a flexible coding system, and an analytic guide (see Appendix 12). The analytic guide was composed of a set of sensitizing concepts derived from the research questions, aims of the study, overarching critical social science approach, and Norbert Elias' Figurational Sociology. The analysis was performed in two phases, and the analytical guide was revised accordingly during each phase. Phase One of the analysis satisfied the first aim of the study which was to explore adolescents' attitudes, beliefs, conceptualizations, and experiences of PA participation. Phase Two of the analysis was driven theoretically, and drew on Norbert Elias' Figurational Sociology to examine how broader micro and macro level interactions (socio-cultural processes) shape PA, and to examine how bio-physical, psycho-behavioural, and socio-cultural process interweave to shape participation. The analysis is presented in two sections to help illustrate this phased

approach. Nevertheless I recognize that the phases of analysis were fundamentally interconnected and inseparable.

*Phase One*

Analysis commenced by viewing the digital stories created by each participant. Although there is little consensus if, and, how digital stories should be analyzed for research purposes (Gubrium, 2009), digital stories were approached as analyzable events that reflect participants' internalized perceptions, and in turn representations, of their positions in, and understandings of, the social world. Analysis of digital stories were driven by Gibson's (2005) procedures for analyzing video accounts. The following questions were asked while watching the digital stories:

> What audience is the digital story directed to? How are identities being portrayed by participants? Who was involved in directing the video, and what does this reveal about the participant and/or his relationship? What role(s) does the participant express or perform? What was not included in the digital story, and why? (adapted from Gibson, 2005).

As part of the analytic process, digital stories were re-watched several times, and I was interested in exploring participant conceptualizations and perspectives of PA, along with gaining further insights into their daily lives and presentation of self in the digital story. Reflections in response to my questions and interests were elicited in a narrative summary written for each participant. To add further context, depth, breadth and nuance of the interpretations of the digital stories, my three detailed field notes from each of the digital storytelling workshops were re-read when reflecting on the analytic questions. Analytical insights gleaned from the field notes and multiple viewings were included in a narrative summary written for each participant.

Following the analysis of digital stories, interview transcripts and field notes from the two interviews were read multiple times. While reading the transcripts and field notes, segments of data were coded. As an analytical tool, coding was used to simply, reduce, and manage the data, and also used as a heuristic device (Seidel & Kelle, 1995) to interact with, open up, and think about the data in different ways (Coffey & Atkinson, 1996, p. 29). Initial coding explored experiences; frequency, location of activities; type of participation; beliefs and representations of PA; structure of their daily lives; family supports and participation, and participants'

participation in individual, and/or group based activities and settings. After this initial coding, codes were grouped into categories with central themes, and integrated into the narrative summaries written for each participant following the analysis of digital storytelling. The generation of these narrative summaries helped advance the first aim of the study, which described adolescents' attitudes, beliefs, conceptualizations and experiences of PA participation, and to contribute detailed descriptions of their lives.

*Phase Two*

The second phase of analysis was centred on analyzing how wider socio-cultural processes shaped participation (second aim of the study), and to theorize how these social-cultural processes intersected with bio-physical, psycho-behavioural processes to shape PA participation. Analysis continued by reading each narrative summary to identify preliminary patterns, contradictions, and postulations. Analysis was driven by the Eliasian conceptual framework to explore how PA was positioned within the broader social, political and cultural spheres which shape daily lived contingencies. As such, the following questions were asked when reading each narrative summary:

- How do learned (socio-cultural process, psycho-behavioural processes) and unlearned (bio-physical processes) processes shape PA participation for this participant?
- What is the nature of the relationship between socio-cultural process, psycho-behavioural, and bio-physical processes?
- How is PA positioned, valued, accommodated, and/or resisted in the context of daily life?

Following the analysis of each narrative summary, they were compared and contrasted with the narrative summaries of all the study participants in a cross-case analysis. The purpose of this cross-case analysis was to seek new ways of seeing and analyzing the data, take the data in unexpected and fertile directions (Smith, 2016), to examine depth, breadth and nuances, and to stimulate theoretical curiosity. Multiple analytical cycles of the cross-case analysis were conducted to identify patterns and recurring relationships between concepts. Exceptions (or negative cases) (Phoenix & Orr, 2017) which contradicted the plotline of the study findings were employed as a form of methodological multiplicity to examine what potentially was being omitted. The use of exceptions in the analysis in turn provides an opportunity for further analytic

insight, added depth/breadth to the analysis. The combination of the analytic process described above generated two overarching themes which encapsulated the study findings. These themes are outlined in Chapter 5 and 6. In Chapter 5, the results describe the attitudes, beliefs, conceptualizations, and experiences of PA among 10 adolescent boys with ASD. In providing detailed descriptions of their PA participation and insights into their lives, I interpret their accounts to examine how broader socio-cultural processes shape their PA participation. In doing so, this chapter addresses the first two aims of this study, and argues that PA participation was shaped beyond individual level mediators which have commonly been reported in the literature.

In **Chapter 6**, I build on, and extend the findings presented in Chapter 5 to address the third aim of the study which served as the primary findings of my analysis. Drawing on Elias' concept of the hinge, I analyze how PA participation was shaped by the interweaving of bio-physical, psycho-behavioural and socio-cultural processes. In doing so, I argue that PA participation is not reducible to any one of these processes in isolation. Rather, the interaction of these processes and interactions within particular 'figurations' shaped each participant's habitus, and their predilections toward PA participation.

*Research Rigour:*

In this study, a variety of procedural and analytic strategies were used to enhance study rigour. In terms of procedural rigour, I conducted all data generation with study participants. Conducting data generation in this way provided deep immersion in the data, and enabled me to gain close familiarity not only to outputs (such interview transcripts and the final digital stories) but all the processes, interactions, body gestures, sensory experiences that are integral to the data and its interpretations. Furthermore, working closely with participants over time enabled me to develop individual rapport and trust which allowed for a deeper engagement, and provided the ability to customize methods and strategies with each participant as required. This deeper engagement in turn provided valuable insights for subsequent data generation with other participants.

In addition to these strategies, procedural rigour was enhanced by using expert facilitators to lead the digital storytelling workshops, and by allowing the inclusion of parents during the interview, to support participants who were uncomfortable on their own. To further enhance the procedural rigour of the study, I also held regular meetings with my supervisor, and my program advisory

committee throughout the research process. Regular meetings with my advisory team facilitated the identification, and resolution of challenges encountered throughout the research process. Finally, data generation and preliminary analyses were conducted concurrently in an effort to explore new insights, questions, and developments as data generation proceeded.

To maximize analytical rigour, I engaged in a process of 'crystallization' (Tracy, 2010). As a part of 'crystallization', I drew on multiple forms of data (interview transcripts, fieldnotes, and narrative summaries) which reflected multiple perspectives and aided me in producing layered multi-dimensional interpretations. In addition, multiple iterative cycles of analysis were employed where data were compared and contrasted to discern patterns and ambiguities. It was evident that the digital stories, field notes, and narrative summaries complemented and illuminated the interview data, revealing contradictions, complexity, and insights in ways that interviews alone would not. Furthermore, analytical rigour was maximized by articulating a theoretical framework that informed all aspects of study design, data generation, analysis and representations. By focusing on the multiple and intersecting bio-physical, psycho-behavioural, and socio-cultural processes which shaped PA participation, the study produced theoretical and practical insights that have implications beyond this specific inquiry. Finally, analytical rigour was maximized throughout analysis as I met with my supervisor, and the program advisory committee to further flesh out the study findings. These analysis meetings in turn helped strengthen the depth and breadth of my interpretations, stimulated theoretical curiously, and helped analyze the data in unexpected and fertile directions. With diverse expertise in childhood neurology, autism research, qualitative methodology, digital storytelling, intellectual disability, occupational therapy, and critical disability studies, the expertise of the research team facilitated and strengthened the analysis.

**Case Example**

In what follows, I present an example from one of the study participants (Daniel) to illustrate the types of data that were generated, how these data were integrated into the analyses, and how the combination of the two methods was complimentary in nature. Both interviews were conducted in Daniel's home, and his mother was present for the first interview. At the time of the research, Daniel was 13 years old and was in grade 8. He was an only child, lived with his mother, and spent his weekends with his father. In his digital story, Daniel predominantly included photos of

sports such as basketball, swimming, and weight lifting. He also included a few photos of himself alone, his mom, and his most recent birthday celebration. As part of the voice over of his digital story, Daniel included some biographical information such as his name, age, and the city he lives in. Throughout his digital story, Daniel accentuated that he 'loves swimming', and that swimming was an integral part of his life and his identity.

Daniel's participation in the study accentuated the value of including two interviews. Although I did not anticipate this scenario with Daniel as described below, the study was designed with two interviews in an effort to build rapport with participants over time. During the first interview, Daniel lay down on the sofa in the living room of the apartment, raised up his hand and showed his middle finger. Rather than reacting negatively, I asked Daniel if he was still interested in learning more about the study. After he reaffirmed his interest, I joined Daniel on the sofa with his mother to continue to discuss the study. Within a few minutes of our discussion, he stood up and repeatedly jumped onto and off the sofa. Although I thought of pausing the interview to ask Daniel to sit down and 'focus' on our discussion, I decided not intervene as Daniel was fully immersed in the discussion whilst jumping. Whereas Daniel's behaviours can potentially be interpreted as 'distracting' or 'attention seeking', Daniel expressed that he was very nervous to speak to me because he thought I was "the mean doctor" that Daniel had encountered at the children's rehabilitation hospital. Although I was simply misrecognized, this experience also taught me that Daniel used movement (such as jumping) as a coping mechanism to try to manage stressful situations. With this knowledge in mind, I designed the second interview so that Daniel was not seated, but instead encouraged him to walk and pace as he was talking. This small adaption which I first learned during my time studying to be a health and physical education teacher was immensely fruitful for the second interview where Daniel appeared to be much more relaxed, calm, and comfortable. Designing the study with two interviews therefore was of central importance as the first interview facilitated rapport building, learning strategies regarding what might best engage participants, and learning how to negotiate potentially challenging situations such as described with Daniel.

The integration of interviews and digital stories served as a valuable data elicitation technique where the digital stories helped reveal nuance and contradictions in the accounts that might not have otherwise been surfaced using digital stories or interviews in isolation. For example, although Daniel highlighted in his first interview that he 'adored' the sport of basketball, his

digital story only included his participation in swimming. In his digital story, Daniel featured himself swimming competitively against his peers, discussed the satisfaction of winning, and also included images of him just frolicking in the pool. At the surface, it may appear that Daniel simply enjoyed swimming more than he enjoyed basketball. Our discussion during the second interview however highlighted otherwise, and provided further insights. When asked why he chose to predominantly represent swimming in his digital story, Daniel explained that swimming was his "safe space" and he experienced frequent derision and physical bullying when he played basketball. From being forcefully shoved, to someone throwing a basketball at him, basketball was marred with negative experiences and Daniel noted in the interview that he did not want to relive those experiences by including basketball in his digital story. Not only did this example reveal contradiction in his account, I drew on this contradiction as an analytic opportunity for insight, and mobilized Gibson's (2005) analytic questions into action as part of the analysis. When watching this particular segment of Daniel's digital story, I asked "How is Daniel's identity being portrayed and why is it being portrayed in this way" in an effort to move beyond interpreting his contradiction at face value. In doing so, this question prompted me to consider how socio-cultural processes (bullying experiences) interacted with bio-physical (sensory pleasures of swimming), psycho-behavioural (satisfaction of winning) processes to shape his PA. By asking how Daniel's identity was being portrayed in the digital story, this particular question enabled me to examine how swimming for Daniel was more than just an activity that allowed him to have fun competing with others, or having fun playing on his surf board. Rather swimming also was a space where he sought tranquility, refuge and pleasure, especially when life at times was perceived to be overwhelming as a result of his previous experiences participating in basketball.

The combination of digital storytelling and interviews therefore was an effective tool to gain further in-depth insights. Similar to Gladstone & Stasilius (2017) who used digital storytelling, along with Bagnoli (2009) and Gibson et al (2013) who used visual methods, this case study example with Daniel highlights how the use of visual methods can be a valuable resource to approach difficult or sensitive topics. In what follows, I reflect on the methods and processes that were deployed in the study.

**Reflections on the Methods**

The study design and concurrent integration of methods had three major strengths. Firstly, designing the study to include two interviews was incredibly valuable. Much of the interview research with individuals with ASD has used single interviews (See Healy et al., 2013; Arnell et al., 2018). As highlighted above, including two interviews provided a more detailed and nuanced understanding of participant daily lives and daily routines, along with developing a more contextualized understanding of their attitudes perspectives and conceptualizations of PA participation. As illustrated in the case study with Daniel, the first interview laid a crucial foundation to establish trust and rapport, provided an opportunity to clarify the purposes of the research, and helped to determine communication and collaboration preferences. The second interview built on this rapport to develop a more detailed and nuanced understanding of PA participation, and was useful with all participants.

Secondly, the combination of interview and digital stories provided a method for participants to convey their thoughts through multiple mediums where images, music, a story and the voice narration convey meanings and experiences that might not be otherwise surfaced in an interview. The combination of these two methods also generated nuanced data regarding the socio-cultural processes which mediated PA. As illustrated in the case example above, at the surface it appeared that Daniel simply participated in swimming as he enjoyed the activity. Analysis of his combined accounts however highlight that his habitus was oriented toward participating in swimming given his previous bullying experiences while playing basketball. These socio-cultural processes in turn shaped his participation in numerous ways. This apparent contradiction not only was a key analytical moment, but also highlights how PA participation was situated within, and contoured by the larger social, cultural, and material contexts of everyday life. Similar insights were surfaced across the analyses. The combination of these methods concurrently facilitated a deeper examination of participant narratives, and likely would have not been achieve if these methods were used in isolation.

The third strength lies in the adaptability of the interview methods, and particularly providing participants with the choice to include a parent as part of their interviews. Including parents at times facilitated deeper and more nuanced descriptions of the adolescent's life. In addition, for some participants (2/10), including their parents seemed to contribute to comfort and moral

support, especially during the first interview, even if parents did not verbally contribute to the interview. Including parents as communication partners (2/10) was also helpful for some participants as parents facilitated the recall of life events, and/or prompted their child to share certain experiences. The conversations initiated by parents often commenced with phraseology such as: "*Tell Patrick about the time when*", or "*Remember when you*", or "*What activities did you do last week*". Some participants included a parent during the first interview but not second. It was variable but the flexibility was really important to ease participants, and facilitate trust. Although it is important to acknowledge that including parents in the interview shapes the data produced in multiple ways through social and structural relations that are at play (child/parent relations), it does so no more or less than other, perhaps less obvious contextual differences between interviews (e.g. immediate events preceding the interview, emotional state, time of day). Including parents in the study was a valuable resource, and the flexibility inherent with this approach enabled the tailoring of the methods to the needs, strengths, and preferences of participants.

Despite the many strengths of the study's methodological approach, there were at least two limitations. The first limitation revolves around the potential challenges with gaining access to particular social spaces, and or policies which prohibit photography and video recordings for digital storytelling. For example, one participant was interested in taking photos and videos of himself during his one-to-one swimming lessons to show a new physical activity he was learning. Despite obtaining consent from the instructor to be included in the data, pool policies prohibited all digital pictures and recordings.

Secondly, some participants described feeling pressured to present themselves in ways in that produced the 'right' kind of data (for a similar discussion, see Gibson et al., 2013). Although a list of suggestions was distributed to participants, some adolescent boys expressed experiencing great difficulty at times with deciding what to include. Rather than trying to control the types and quality of data that were generated by the participants, I drew on these occurrences to query how larger social, cultural, and political processes shaped their selection of photos and videos, and also interrogated how others that were not included, or even unthinkable.

Integrating interviews and digital stories not only enabled me to address the aims of the study, but also provided new methodological insights. To my knowledge, this is the first study to use

digital storytelling among adolescents with ASD, and the first study to modify and integrate both approaches as a part of a singular design. This innovative methodology and design opened up new possibilities for adolescents to express themselves, generating in-depth and multi-faceted data. This approach not only was a foray to gain deeper insights into understanding PA participation among this group of boys, but also elicited nuanced and detailed data about their daily lives.

# Chapter 5

# Preface to Chapter 5

In this chapter (a manuscript), the study address the first two aims of the study. The first aim sought to explore the attitudes, beliefs, conceptualizations, and experiences of PA participation among adolescents with ASD, and contribute detailed descriptions of their lives. The second aim sought to interpret the described perceptions and experiences to examine how social, cultural, institutional, and political processes (socio-cultural processes) mediate PA participation. Framed within a critical social science approach, I draw on ten participant accounts to demonstrate how dispositions to be physically active were mediated by broader social, spatial, temporal, and political structures and processes over time. Throughout the analysis, I demonstrate how the interaction of individual dispositions and broader socio-cultural processes in turn enhanced, shaped and curtailed PA participation for these ten adolescent boys.

At the time the dissertation was written, this paper was submitted to the journal "Autism: The International Journal of Research and Practice" as part of the special issue in Autism and Physical Health. Autism is peer-reviewed, interdisciplinary journal focusing on improving the quality of life for individual with autism or autism-related disorders. This manuscript includes all members of the research team.

# 5 Physical Activity Participation among Adolescent Boys with Autism Spectrum Disorder

## Manuscript Abstract

Adolescents with autism spectrum disorders (ASD) are less physically active compared to their age related peers. Despite the many benefits of physical activity (PA), little is known why they are predominantly inactive. To date, there is a paucity of research that has included adolescent's perspectives, and little is known about how wider social, systemic, and policy forces shape PA. The purpose of this study was to explore the perceptions, meanings, and role of PA in the lives of adolescent boys with ASD, and draw on their experiences to examine how social and behavioural processes shaped their participation. Ten adolescent boys with ASD created individual digital stories (similar to a YouTube video), and partook in two interviews. Data was analyzed thematically, and informed by a critical social science approach. Findings highlight that bullying, challenges in community programs, and the prioritization of therapeutic interventions limited participation. Participation was maximized when PA generated meaning, purpose, a sense of identity, and affective pleasures. Study findings illuminate the complexity of PA participation which heretofore have not been described in the literature. Findings suggest potential value in promoting the affective pleasures of movement, along with facilitating social and systemic pathways to enhance PA participation.

Key words: autism spectrum disorder; physical activity; adolescents; qualitative research

**Introduction**:

Research consistently suggests that physical activity (PA) participation for children and adolescents with autism spectrum disorders (ASD) can present a number of physical, psychological, and social benefits. In this vein, research on PA interventions suggest that PA can improve motor skills (Ketcheson, Hauck &, Ulrich, 2017) and motor control (Sowa and Meulenbroek, 2012), enhance aerobic capacity, and overall fitness (Lang et al., 2010). Furthermore, PA has also been demonstrated to reduce maladaptive (Elliott et al., 1994) and stereotypic/self-stimulating behaviours (Sorensen & Zarrett, 2014), and decrease self-injurious behaviour (Sowa & Meulenbroek, 2012). Lochbaum & Crews (2003) note that PA can also contribute toward psychological well-being with observed reductions in stress and anxiety. Finally, PA has been associated with improving social and communication skills (Dillon et al., 2016), adaptive functioning (Redquest, 2019), along with facilitating inclusion in the community (Gregor et al., 2018).

Despite the many benefits of PA, research suggests that children with ASD are predominantly inactive (Healy et al., 2017; Pan et al., 2016), and they often do not meet recommended daily guidelines (Bandini et al. 2013) of 60 minutes of PA. Problematically, research suggests that children with ASD become even less active during adolescence (Pitchford et al., 2013) where a sample of adolescents with ASD in the United States were 60% less likely to participate in PA (McCoy et al., 2016). Compared to their age-related peers, this sample of participants was also 74% less likely to participate in an organized sport (McCoy et al., 2016). Although physical inactivity in isolation does not automatically confer poor health, research suggests that inactivity can potentially contribute to negative physical and mental health outcomes across the lifespan (Humphreys et al., 2014) such as obesity, cardiovascular disease (Biddle & Asare, 2011), diabetes, musculoskeletal disorders, anxiety, and depression (Jansen & LeBlanc, 2010). The higher prevalence and onset of physical and mental health challenges have important ramifications as preliminary research suggests that adults with ASD are at increased risks to die prematurely compared to the general population (see Hirvikoski et al., 2016; Mandell, 2018). Given that PA participation is a modifiable risk factor that can potentially influence physical health outcomes (Healy et al., 2018), there is a need to understand why adolescents with ASD are predominantly inactive, and understand how to facilitate their participation.

To date, much of the PA research among adolescents with ASD has focused on quantitative PA measurement, and has studied the characteristic impairments of ASD that influence PA (MacDonald, Esposito, & Ulrich, 2011). To this end, research has predominantly focused on examining how somato-motor (balance, gait, postural stability, joint flexibility) and behavioural (motivation, perceived skill competence, interest, hyperactivity, difficulties with rules) dimensions influence PA (Eversole et al., 2016; Loprinzi et al., 2015; Ostfeld-Etzion et al., 2016). While the aforementioned research is important in its aims of enhancing PA, qualitative investigations of adolescents' perceptions toward PA is a significantly neglected area of inquiry. Yet, there is a pressing need for this research. Much of the PA research includes the perspectives of caregivers, teachers/coaches and service providers. Despite some preliminary qualitative work (see Healy et al., 2013; Lamb, 2014; Arnell et al., 2018), there is limited research that has generated an in-depth examination of their daily lives, and PA experiences from their own perspectives. As such, little is known about the role, meanings, and forces which shape PA participation for adolescents with ASD. However directly engaging adolescents with ASD has the potential to generate rich insights regarding how to facilitate PA through the design of interventions, programs, supports, and policies that are reflective of their lives, needs, and abilities.

Not only is there a lack of research that has engaged adolescents with ASD, there is also is a paucity of research that has examined how PA is influenced beyond the level of individual physical impairments (gross-motor deficits, sensory factors). Apart from our own preliminary work (Campos et al., 2019; Gregor et al., 2018), there is a dearth of research that has critically theorized and examined how broader systems level social, cultural, community, and public policy forces (hereafter socio-cultural processes) influence PA. Examining how socio-cultural processes shape participation however can elicit novel and original insights to understand how wider social forces interact with biological and psychological dimensions to shape PA participation among adolescents with ASD. Since PA participation among adolescents with ASD is complex and requires addressing barriers at individual, environmental, and systemic levels (Campos et al., 2019), there is a need for this work which heretofore has not yet been described in the literature.

The purpose of this qualitative study was to explore 1) the attitudes, beliefs, conceptualizations, and experiences of PA participation among adolescents with ASD, and contribute detailed

descriptions of their lives, and 2) draw on their subjective experiences to interpret how social, cultural, institutional, and political processes (socio-cultural processes) mediate PA participation.

*Conceptual Framework:*

The study utilized a qualitative design and was driven by a critical social science approach. Critical approaches examine the interplay between personal and environmental factors, examining how individual (behaviours, perceptions, experiences) and micro-level interpersonal factors (social networks) are contoured by broader macro-level (social, institutional, community, and public policy) forces. In this vein, critical approaches acknowledge interdependent recursive relationships between the micro and macro level (Eakin et al., 1996).This dialectical approach seeks to examine how social structures, and social norms influence people's daily lives, what people think and do, and what they imagine is possible (Kincheloe & McLaren 2005). A critical approach was adopted in this study to move beyond merely describing the barriers and facilitators of participation (Yamamoto et al., 2018). By adopting a critical approach, we sought to examine how micro-level, or individual PA perceptions/experiences interconnect with macro-level social structures, values, beliefs at the social systems level to shape PA participation.

## ***Study Design***

*Sampling and Recruitment*

The research described in this article is a part of a series of studies exploring how to best support PA participation by directly working with adolescents, caregivers (Gregor et al., 2018), and healthcare providers (Campos et al., 2019). In this study, adolescent boys with ASD were recruited from a major urban Canadian city. Boys were invited to participate in the study if they: a) had a diagnosis of ASD as per Diagnostic and Statistical Manual of Mental Disorders ($5^{th}$ ed., DSM-5 2013) criteria, supported by the Autism Diagnostic Observation Schedule (Lord et al., 2012); b) were aged 12-19 years; c) demonstrated verbal proficiency in English; d) were capable of allowing turn-taking and discussion of experiences; and e) demonstrated capacity to independently provide consent to participate in the study. Only boys were included in this study given our interest in understanding how masculinity shapes PA participation. To ensure eligibility, all interested participants were initially screened with their caregiver through a telephone conversation. Suitability to participate was re-assessed during the first in-person

meeting. Informed consent was sought from the participant if they met the study inclusion criteria, and agreed to participate. The research study was approved by the Research Ethics Board at the hospital where recruitment took place, and the associated university health sciences research ethics board.

*Methodology and Methods*

In total, 10 adolescent boys (See Table 1 for participant characteristics on page 102) participated in the study. The primary author had extensive experience conducting qualitative research among adolescents with ASD, and conducted all data generation in an effort to facilitate rapport building with participants which enhanced the rigour of the study (Smith & McGannon, 2018). Each participant created a digital story, and participated in two face-to-face semi-structured interviews (for an in-depth description of research methods, Chapter 4). Digital storytelling was originally developed by the Centre for Digital Storytelling in Berkley, California in an effort to mobilize the (often marginalized) voices and stories of 'ordinary people' (Bundon & Smith, 2017). Since its development in the 1990s, digital storytelling has been transformed into a participatory research methodology that combines first-person audio narration, music, video clips, artwork, photographs, text, and drawings to create short, evocative and engaging stories (Gladstone & Staslius, 2017). Drawing on participants' perspectives, digital storytelling has been used as a method of data generation, as a knowledge translation tool (see Ferrarri et al., 2015), and has been used as a medium to engage with difficult or sensitive health-related research topics (see Ferrarri et al., 2015).

Digital storytelling in this study was strategically selected in this study for several reasons. Firstly, it provided participants with a mode of expression (in the form of a visual medium) that creatively highlighted their everyday lives, meanings, practices to highlight their PA experiences. Secondly, given the highly participatory nature of creating digital stories, digital storytelling was selected as we sought to provide participants with an opportunity to potentially develop new strengths, interests, insights, and skills. Thirdly, digital storytelling was selected as a tool to provide the research team with a form of analyzable data. Fourth and finally, digital storytelling was selected as a tool to build rapport with study participants as in our experiences conducting qualitative research among adolescents with ASD, developing rapport can be challenging for both the study participant, and the researcher. In creating a digital story, we hoped that the

multiple interactions during the sessions would help build rapport with participants, and thus facilitate the creation of rich data in a safe and enjoyable manner.

In this study, digital stories were two to three minutes in duration, and were created during three workshops which were 6 hours in duration each (18 hours total). Digital stories were created at a digital storytelling centre, and were guided by digital storytelling facilitators. Following each workshop, detailed field notes were written by the primary author. These field notes articulated the interactions observed among participants, workshop facilitators, and the researcher which in turn added more depth, breath, context, and nuance to the observed interactions. These field notes also were used to guide analysis of the digital stories.

In addition to creating digital stories, each participant engaged in two face-to-face qualitative interviews (n= 20 interviews) prior to, and after producing the digital stories. Participants were interviewed as a location of their choosing, and had the option of including their parents in the interview in an effort to optimize participation. In total, 2/10 parents (all mothers) were present during the first interview, one parent during both interviews, and the remainder of participants (8/10) were interviewed independently. The first interview with each participant was designed to build rapport, and to learn about the intricacies of their everyday lives both within, and beyond the PA context. Questions were guided by a semi-structured interview guide which was designed to elicit discussion about daily and weekly routines, interests in activities/hobbies (which often revealed their restricted interests), including their PA interests and experiences (or lack thereof). Interviews were 45-60 minutes in duration, and all interviews were conducted by the primary author. Field notes were immediately written following each interview to detail the interview setting; tone of language, interactions with participants. Reflexive notes were also written which highlighted initial impressions, conjectures, and analyses.

The second interview was conducted after the creation of digital stories. The digital story was reviewed together to facilitation discussion of the story content. Interviews were 90-120 minutes in duration, and commenced by watching the digital story created by each participant. Participants were then asked to describe why they included particular images/videos in the digital story, along with discussing the personal meaning(s) of the digital story. This interviewing approach served as an elicitation technique to generate rich discussions about perceptions, meanings, role, and of PA. Whereas each method generated novel and original

insights into PA participation, combining these methods revealed complexity, contradiction and insights into the daily lives of adolescents with ASD that would likely have not been gleaned by solely interviewing participants alone. The combination of digital stories and interviews in turn enabled an in-depth analysis of how interdependent macro-level and micro-level forces interacted to enhance, shape, and curtail PA participation.

**Data Analysis:**

All qualitative data (verbatim interview transcripts [n=20], digital stories [n=10], field notes from each interview [n=20] and field notes from each digital story [n=3] workshop) were analyzed thematically. Analysis was driven by techniques described by Miles and Huberman (1994). Analysis was led by the primary author (who was a doctoral candidate and a former physical education teacher), and supported by the research team who possessed expertise in: childhood neurology, autism research, qualitative methodology, intellectual disability, occupational therapy, and critical disability studies. To guide analysis, and analytic guide was used. The analytic guide was derived from the research questions, aims of the study, and the overarching critical social science approach.

Analysis commenced by viewing each digital story created by participants. Digital stories were re-watched several times, and analysis of the digital stories was guided by Gibson's (2005) procedures for analyzing video accounts to help examine how each digital story was constructed. Five analytic questions were used to gain a better understanding of participant's daily lives both within, and beyond PA.

> What audience is the digital story directed to? How are identities being portrayed by participants? Who was involved in directing the video, and what does this reveal about the participant and/or his relationship? What role(s) does the participant express or perform? What was not included in the digital story, and why? (Gibson, 2005).

When reflecting on these analytic questions posed above, field notes from the three digital storytelling workshops also were read several times to add more context, depth, and breadth to the process of data analysis and interpretation. Preliminary thoughts from analysis of the digital stories and field notes were included in a narrative summary written for each participant. After analyzing the digital stories, interview transcripts from the two interviews, and field notes from each interview were read multiple times to develop a sense of the whole (Sandelowski, 1995).

While reading the transcripts and field notes for each participant, codes were used to analyze the: frequency, location of activities, type of PA participation; beliefs, and representations of PA; structure of their daily lives; family interactions; and whether they participated in group based, or independent settings. Codes generated from each participant were clustered together to create larger thematic categories. Overarching thematic categories were then integrated into the individual narrative summaries written during analysis of digital stories. Narrative summaries written during analysis of digital stories and interviews described the perceptions, meanings, and role of PA for each participant, which informed the first purpose of the study.

To analyze how socio-cultural processes enhanced, shaped and curtailed PA participation (second purpose of the study), analysis continued by noting patterns, contradictions and postulations within each participant summary. Narrative summaries then were compared and contrasted with the other participants (cross-analysis) to provide new ways of seeing and analyzing the data and to take data in fertile and unexpected directions (Smith, 2016). Multiple cross-analysis cycles were conducted to identify recurring patterns, contradictions and relationships to examine how macro and micro level interactions shaped PA participation. Analysis was considered complete when the two main themes were established.

**Results**:

The analysis generated two overarching themes: *learning to be inactive,* and the *pleasures of movement*. *Learning to be inactive* highlights how exclusion and bullying, challenges in community programs, and how the prioritization of therapeutic interventions curtailed PA participation. Whereas these socio-cultural processes dissuaded participation, the second theme illustrates the forces that enhanced participation. *Pleasures of movement* illustrates how family identity, affective dimensions of PA, and PA as a quest for excitement increased predilection for participation. Each theme and related subthemes are described in detail below. Taken together, these two themes illustrate the nuance and complexity of participation among adolescent boys with ASD. To protect the identity of participants, all names presented in the paper are pseudonyms selected by participants.

## Learning to be inactive

### *Exclusion and Bullying*

Narratives of exclusion and bullying recurrently came to the fore in participant interviews. For seven participants, exclusion and bullying predominantly occurred in school based health and physical education class (HPE), and was most pervasive in secondary school (14-18 years of age). Across the accounts were stories of both covert and overt forms of exclusion. Covert forms of exclusion were subtle in nature such as being selected last by their peers when teams were being formed for class scrimmages. On the other hand, overt exclusion relegated boys to the sidelines of HPE. At times, peers would preclude their participation by substituting boys with ASD for another player, or they would not be substituted into activities at all. Not only did covert and overt forms of exclusion limit participation, exclusion was tied into physical forms of bullying. Seven boys described being deliberately hit in the face or groin when playing dodgeball, or being deliberately tripped when participating in class warm up activities. Other forms of physical bullying included being body checked to the ground when playing ball hockey, or forcefully shoved out of the way whilst trying to compete for the ball while playing sports such as basketball and soccer. Although teachers often intervened and reminded peers that physical body contact was prohibited, relief from bullying was generally temporary, as bullying was a recurring issue and took take place in subsequent classes. Given these repeated experiences, perhaps it is unsurprising that boys described feeling as if they were proverbial outsiders in class, and at times felt that they did not belong in HPE. Highlighting the impacts of exclusion and bullying, Guido noted:

> I am usually one of the last guys in the draft and chosen last, never in my life been chosen first. What's worse than that is getting hit in the face during dodgeball or getting sacked (hit in the groin). Teachers tell them (peers) to aim below the waist, but they do what they want anyway. It's hard to like gym when you feel like an alien on the wrong planet, like you feel as if you do not belong in gym class.

Physical bullying was often accompanied by verbal taunting, belittlement, and jeers. Although the magnitude and frequency of verbal bullying in HPE varied across participants, seven participants noted that jeers occurred mostly frequently when there were no teachers in the immediate surroundings. Boys were often derided about their (in)ability to execute physical skills and drills in HPE. Derision at times was relatively subtle where Allan recalled one of his

peers laughing at him and saying that he "throws like a girl, and plays soccer with two left feet". Other times however, derision was much more poignant, and was especially pronounced if boys made a performance error that contributed to their team losing an activity. With recollections of HPE experiences from boys suggesting that there was an emphasis accorded to competition, winning, and excellence in physical skills, HPE at times served as a breeding ground for taunting and belittlement. Recollecting a time when he did not score a goal on an empty net and contributed to his team losing in the final game of the class soccer tournament, Romeo's narrative highlights how boys who did not fit into these traditional HPE systemic structures and social dynamics experienced bullying.

> One of the guys came up to me and said that I'm a retard, and a waste of space and am good for nothing. All because I did not score.

Importantly, the data suggests that repeated exclusion, bullying, and derision negatively impacted the enjoyment and experience of HPE. Across the seven participant accounts, boys described a distaste toward HPE. To avoid exclusion, bullying and derision, Romeo and Guido remarked that at times they would deliberately forget their HPE uniforms when the bullying was "really bad" (Jas) during the previous class. Moreover, Miguel that he would book meetings with his guidance counsellor and special education teacher in order to avoid HPE class. Loathing HPE, Miguel and Guido described that at times when the bullying was no longer bearable, they had meltdowns before school in order to avoid HPE. Exclusion and bullying therefore not only limited opportunities to be active, but also had debilitating impacts in other aspects of their daily lives. Lamenting his HPE experiences, and highlighting the impact of bullying on engagement, Allan noted:

> It's hard to enjoy being active when you're always being picked on. You just learn to hate activity. Like there is no point in going to class if all I get out of it is getting hurt. My parents used to doubt me that gym was that bad, until they realized after a meltdown I had that even just the word gym gives me chills down my spine.

Whereas a debilitating social climate in HPE negatively impacted participation, as illustrated below, the interaction of broader macro-level social forces (such as availability of programs interacted) with micro-level processes (such as instructional approaches used in community-based PA activities) also contributed to inactivity.

*Challenges in Community Programs*

In discussing their PA participation from childhood to adolescence, boys described difficulty locating adapted or integrated community-based activities that were responsive to their needs and abilities. Although there was a broad availability of PA activities in their communities, the structure, design, and instructional methods employed at times dissuaded participation. For example, four participants described that PA activities predominantly focused on executing repetitive skills and drills. Given this approach, they described that they were often bored and disengaged, as they spent more time waiting in line to perform the skill, than time engaged in the activity. In addition to the use of autocratic coaching styles emphasizing skills and drills, the predominant use of verbal instructional strategies added an additional layer of complexity for participants. Across the accounts, participants described difficulty comprehending large amounts of verbal instructions shared at one time. Without breaking down the requisite movement patterns into a series of progressions, some boys experienced "information overload" (Miguel) and had a very difficult time understanding, assembling, and then translating instructions into movement patterns. When activities and methods of instruction were not adapted accordingly, PA was perceived to be "overwhelming" (Jas), and "stressful" (Malcolm). The combination of these forces in turn dissuaded participation, and it was not uncommon for caregivers to withdraw boys from activities altogether given these difficulties. Highlighting how these contingencies shaped his participation Jas noted:

> When I was a kid and did t-ball, the coach told me to keep my eye on the ball, so I put my eye on the ball. Turns out, that's not what he meant. I find activity overwhelming sometimes because there is so much new info, so much to remember, all at the same time. It's hard to find an activity and a place where I am comfortable with the activity, the teachers and can understand what they want me to do. I keep trying new activities, but keep quitting because they don't work for me.

Limited availability of PA programs was further complicated by policies from some service providers which mandated personal support workers (PSW) (such as siblings, parents, or hired professionals such as behaviour therapists, or recreation therapists) to accompany adolescents. While such policies at the surface may seek to improve and facilitate integration in PA activities, they also had unintended effects of precluding some participants from PA altogether. For example, despite locating an activity they were interested in, three boys were withdrawn from the activity by the service provider as they were unable to secure a PSW to accompany them. For

these particular boys, macro level forces (policy) interacted with micro level (individual preferences) to curtail participation. Although limited community opportunities and policy considerations dissuaded PA, participation was also shaped by a recursive relationship between family values, and the prioritization of therapeutic interventions. It is to this discussion that we now turn.

*Prioritization of Therapeutic Interventions*

Across the accounts, adolescent boys highlighted that living with ASD presented unique strengths, opportunities, challenges, and additional activities such as participating in therapeutic interventions. In recollecting their childhoods, adolescent boys noted that they had spent a substantial amount of their time during engaged in therapeutic interventions. From behaviour and occupational therapy, through to speech language pathology, participants described that their families (re) directed substantial amounts of their time and resources toward therapy during childhood. For six participants, therapy was ascribed social and familial priority as participating in therapeutic interventions took precedence over other life activities including PA. For example, Jas, Allan, Seper and Daniel noted that they missed organized PA activities to attend therapy. Other participants noted that they were late, or left PA activities early in order to maximize the amount of time engaged in therapy. The accounts suggest that PA was not merely an individual based behaviour. Rather, individual dispositions interconnected with broader social determinants and family contexts where caregivers were tasked with negotiating competing demands, family interests, and values. Capturing this complexity, Miguel remarked:

> As a kid, I did a lot of therapy, but not a lot of physical activity. Sometimes we would plan to do active things, but then my mom would tell me that the OT (occupational therapist) was coming. So then physical activity like always was just pushed off to the side. Not like once or twice, like all the time. It seemed like there never was enough time to do active things because therapy always got in the way and was more important.

With a predominant focus on intervention during childhood, there often was less time to develop sustained PA interests, habits, and patterns of participation. Given these time constraints, there was little consistency in their participation. Six participants described that participation entailed many starts, stops and diversions as they often were withdrawn from PA to accommodate

therapy. Highlighting the multiple (and sometimes unintended) effects of privileging formal therapies, Guido's quote illustrates the complexity of inactivity:

> My parents put me in swimming, basketball, soccer, and t-ball. I would start activities for a few weeks but then they pulled me out as soon as they got me off the therapy waitlist. I never really developed an interest in anything, never really had the time or a chance to do so. Now, I am too afraid to try new things.

The theme learning to be inactive highlights that PA participation was a multi-faceted and complex issue. As illustrated by the subthemes exclusion and bullying, challenges in community-based PA, and the prioritization of therapy over activities, PA participation was shaped by socio-cultural processes interconnected at the macro and micro level. Whereas the socio-cultural processes described above dissuaded participation, the analysis suggest that the pleasures of movement drew boys toward PA. It is to this second theme that we now turn.

**The Pleasures of Movement**

*Family Identity:*

Similar to the ways in which familial prioritizations of therapy influenced participation, family identities played an important role in shaping PA interests, habits, and patterns of participation. By identity, we mean the shared habits, values, and preferences of a family in relation to activity. Family identity in turn shaped how families devoted their time, efforts and resources such as engaging in PA. Some boys in the study noted that their parents, siblings and family unit did not engage in PA during their leisure time. Jas for example noted that he does not come from a "sporty family" as his family spent much of their leisure time attending museums, learning about history, and learning about ancient artifacts. Whether it was spending time with the family at home, cooking, or attending music, theatre, or the arts, some boys and their families devoted their leisure time to pursuits other than PA.

Whereas some participants and their families engaged in non-active pursuits, for others PA participation was an integral component of family life. For these particular boys, PA was a central component of their family life, and was a part of the social fabric of their family identity. From participating in weekly family activities such as walks to the park, and family bike rides, through to hiring personal support workers in community settings, some families invested significant time and resources to facilitate PA participation. Perhaps unsurprisingly, boys from

families who valorized PA adopted and reproduced self-identity as ‘physically active’. A physically active self-identity was a resource used to make sense of their lives, interactions with others, and with the world. For example, four boys took pride in being physically active and noted that PA contributed to a sense of responsibility (such as taking neighbourhood dogs for a walk to the dog park. When analyzing participant’s accounts, boys who were active also were praised by teachers, families, and peers alike. For three boys, participation in PA also elicited social status, and they used this social status to distinguish themselves from other adolescents with ASD who were not physically active. In his digital story, Mark for example featured four photos of himself without his shirt on, and included one photo in which he flexed his arm, chest, and abdominal muscles. When asked in his interview about his decision to include those photos, Mark's narrative illustrates how these self-representations and a physically active identity were central to his sense of self, and facilitated participation.

> I tried to show that kids with autism also can be fit and active. I work hard for this body and its something that I am damn proud of. Plus, I am known as the muscle guy at school, around my family and my friend. You might as well flaunt it if you have it. Keeping this body is what keeps brining me back to doing active things.

*Affective Pleasures of Movement*

In analyzing perceptions and experiences of PA, the concept of pleasure recurrently came to the fore and was multi-dimensional in nature. On the one hand, pleasure elicited the affective dimensions of PA participation. Affect and pleasure were not dichotomous, but fundamentally interconnected as boys noted that PA participation elicited a sense of joy, amusement, and made them “feel alive” (Miguel). When individual abilities aligned with social environments that met their needs, PA contributed to a spirit of fun and elicited a sense of connectedness and belonging. For five boys, these affective dimensions contributed to both immediate and prolonged gratification and shaped dispositions toward activity as they sought to (re)create these experiences in subsequent PA engagements. The interconnected nature of PA, and emotions, was illustrative in Allan’s account:

> I had nothing until I found swimming. I felt like a complete misfit. When I found swimming that all changed. Swimming gives me a focus that I've never had, it is fun and it feels so good having the water on my skin. I feel tired after swimming, but that feeling also is what gets me coming back to the pool.

Further to these affective dimensions, PA also created an aura of exciting significance and served as a controlled form of emotional release. For some boys, PA provided an outlet from their relatively predictable, structured, repetitive, and prescriptive lives which often featured attending school, completing school/homework, and then doing it "all over again, the next day" (Seper). Although some boys found solace and comfort in structure and routine, the controlled decontrolling of emotions elicited by PA attracted boys toward participation. Participation in PA enabled boys to temporarily disengage from the monotony of everyday life, and was particularly experienced in non-sport activities such as going for walks, participating in cultural rites, and or completing home/garden work. For these particular boys, PA offered temporary freedom from the mundane features of daily life, and enabled them to (re)create their lives in other, and some times, more exciting ways. Seper's narrative highlights how PA was shaped by the interaction of affect and broader macro (daily structures such as attending school) and micro (affect and pleasure) level forces:

> I do the same thing every single day. Being active is the only time where I feel free. Free from always been told what to do, how to do it, when to do it. Free from teachers, therapists, and parents telling me how to live my life. Free from doing the same routine of school, home, doing homework, being a loner, getting beat up. Going for walks with my dog gets me to my happy place. Being active just allows me to be, me.

Not only did affective dimensions invite and incite participation, the affective pleasures of movement also contributed to management of externally imposed life rhythms that at times were anxiety producing or overwhelming. For some boys, PA provided a dedicated time and space to detach from difficult features of life such as broader experiences of bullying, or isolation. For three boys in particular, PA was an outlet to "take a break from pretending to be normal" (Daniel) in social situations as they drew on coping strategies and techniques to camouflage what they perceived to be 'abnormal behaviours'. Whereas boys described that the success of pretending to be normal was physically and emotionally exhausting, PA provided an opportunity to loosen habits of self-restraint and a temporary space to move beyond normative social expectations. Although detachment from these features of life was fleeting, PA provided a sense of tranquility that at times was absent in other aspects of their lives. These aspects of PA drew

boys closer to participation. Participation in PA therefore not only included physical aspects, which influenced participation, but also included psychological ones which helped maintain well-being. Highlighting how emotions and pleasures of movement shaped his participation, Daniel said:

> I try so hard and spend so much time and energy trying to fit in to be normal. I can't help myself from rocking back and forth, or times when I start banging my head against the wall. I've tried mindfulness, deep breathing and behaviour therapy to find some calm in my life but none of those worked. Doing taekwondo allows me to be me, and even if I start rocking or head banging, I don't feel like I am always being judged by people because they just get it.

As illustrated across the two key themes, PA participation was enhanced, shaped, and curtailed through interdependent macro and micro level forces. These interdependent socio-cultural processes shaped PA in numerous ways, and illustrate the complexity of participation.

**Discussion**:

Our analysis demonstrates that adolescent boys with ASD had both negative and positive experiences in PA. Their experiences and nature of participation was shaped by interdependent relationships between individual (pleasure, emotions), family (values, prioritization of therapy, identity), and social forces (bullying, availability of programs, policy). Jettisoning static and monolithic conceptualizations of (in) activity, the findings suggest that PA participation was not merely an individual behaviour determined by cognitive forces such as volition, motivation, or self-efficacy. Rather, PA was shaped relationally, such that interdependent relationships between biological, psychological, and socio-cultural processes interact to enhance, shape, and or curtail participation. This relational understanding illustrates the unique complexity of PA participation for adolescents with ASD, which heretofore has not been described in the literature. In addition to calls for research and interventions oriented at enhancing biological and psychological dimensions of PA (Lloyd et al., 2013), the findings suggest that efforts at the social and systemic level are also required to enhance participation. Findings of this study serve as a point of departure in mapping out possible ways forward on how to enhance PA participation among adolescent boys with ASD.

Our exploration of PA participation among adolescent boys with ASD revealed that exclusion and bullying (especially in HPE class) was rampant and a shared experience. Despite the large

corpus of research studying bullying among children and adolescents with ASD (see Morton et al., 2019; Maiano et al., 2015), research on exclusion and bullying in PA curiously have been absent. Apart from two studies that briefly identified bullying in PA (Healey et al., 2013; Avyzoglou et al., 2015), bullying has been overlooked as a mechanism that can shape PA participation. The findings however highlight that repeated exclusion and bullying experiences can have a deleterious impact on the enjoyment and experience of PA. Whereas exclusion and bullying dissuaded PA participation in the short term, research among adults without ASD suggests that negative experiences such as bullying can potentially dissuade predilection to be active during adulthood (Ladwig et al., 2018). Although associations between negative experiences and decreased participation in adulthood appear to be modest, our findings suggest that there is a need to minimize bullying in an effort to potentially enhance the enjoyment and experience of PA participation.

In addition to policy (Cappadocia et al, 2012), universal bullying prevention programs (Pepler et al., 2006), and intervention efforts from adults (Frankel et al., 2010), we suggest that efforts at the level of pedagogy are also needed given the rampant descriptions of bullying in school based HPE class. Given that boys with ASD were often bullied about their physical (in) abilities to perform PA skills, and drills, we suggest that there is a need to move beyond traditional HPE pedagogies which predominantly focus on technical skills, reproducing isolated drills, and participating in class scrimmages (Hopper, Butler, & Storey, 2009). For example, a possible alternative model for HPE in potentially decreasing bullying, and enhancing HPE participation for adolescents with ASD is adventure based learning (ABL). ABL utilizes highly structured physical activities coupled with periods of reflection (debrief) to promote social and personal development. Drawing on cooperative activities, ABL seeks to develop interpersonal and intrapersonal relationship skills to build an ethic of care and a sense of community among students and teachers (Stuhr et al., 2018). ABL may also be well-suited to needs of children with ASD as it provides high amounts of opportunities to participate in PA at their own skill level and pace, without incessant pressure of competition and winning. With very preliminary research suggesting that ABL can potentially decrease bullying in HPE (Battey & Ebbeck, 2013), further exploration of ABL among adolescents with ASD is warranted.

A lack of community programs, challenges with instructional methods, and policy issues also curtailed PA participation. Consistent with Ayvazoglu et al., (2015), our findings suggest that

there were difficulties locating PA opportunities that were responsive to the diverse needs and abilities of children with ASD. Whether it was difficulties adapting and explaining activities to the diverse needs of participants, or policies mandating external support workers, study findings suggest that adolescent boys with ASD were not only drawn to sedentary activities as has been reported in previous research (Obrusnikova & Miccinello, 2012). Rather, individual needs, preferences and abilities interacted with broader socio-cultural processes (instructional methods, policy) to curtail participation. In light of research suggesting that children with ASD participate in fewer recreation programs than their peers (Solish et al., 2010), our study highlights the need for training and policy efforts implemented to potentially enhance their participation. With a noticeable gap in training resources for community service providers, one immediate resource that can be of value is the Canucks Autism Network (Canucks Autism Network, 2017). Drawing on research evidence and principles of applied behavioural analysis, CAN provides autism awareness training for recreation leaders, tip sheets regarding rapport building, conversation tool kits, crisis management, and motivation strategies. All of these resources are online, and free of charge, and serve as a point of departure in building capacity to increase access to community PA activities. In addition to community training resources, our findings suggest that work at the level of policy is also required. In this vein, we suggest that further work is needed to develop funding mechanisms to support PA, recreation activities, and access to clinicians to enhance gross motor skills. Supporting and recognizing PA as a valuable pursuit at the level of policy can be a part of a holistic approach to facilitate physical health and well-being across the lifespan.

The findings highlight that PA was also shaped by family dynamics, values, and identities. The qualitative methodology employed in this study elicited the complexity of participation, which has not been described in the literature. Whereas previous research suggests that familial forces such as parental education, employment, family income, family size/number of siblings influence PA, (Jones et al., 2018), our findings highlight that these familial variables and physical (in) activity did not exist in isolation. Rather, PA participation was shaped relationally, such that raising a child with ASD was shaped by interdependent macro and micro level relationships. From competing family interests such as prioritizing therapy (macro level), through to family identity (e.g. ‘sporty family’) (micro level), these novel findings highlight how negotiating the multiple demands of raising a child ASD shaped PA in multiple ways. Importantly, our findings also identify how privileging therapeutic interventions over other aspects of life such as

participating in PA, had multiple, and sometimes unintended effects. In our study, families often valorized therapeutic interventions where PA was often substituted for more time engaged in therapy. The predominant focus on intervention during childhood however adversely impacted PA for some boys, as there was less time and exposure to develop sustained PA interests, habits, and patterns of participation. Our intent is not to criticize parents for prioritizing therapeutic interventions over PA, nor to downplay the widely documented benefits of various therapeutic interventions for children with ASD (Lai et al., 2018). Rather, the findings prompt us to reflect on, and bring attention to thinking how we can maximize therapeutic, developmental, and health outcomes without losing sight of other aspects of life such as PA participation. Taken together, our study findings suggest that there is a need to reflect how therapeutic interventions can potentially be balanced with other aspects of life in order to support the physical health and development of the 'whole' person.

The pleasures and affective dimensions of movement centrally influenced PA. In addition to the cognitive (motivation) and bio-physical forces (gross-motor impairments) which have been described in the literature, our findings highlight that the pleasures of movement shaped participation. From generating meaning and identity, through to experiencing emotional pleasures, the findings add nuance to the literature as the pleasurable and affective dimensions of PA have not been discussed in the literature among individuals with ASD. Although that the concept of pleasure is under-researched and under-theorized in PA (Phoenix & Orr, 2014) and health related research more broadly (Coveney & Bunton, 2003), the affective dimensions of PA elicited in this study highlighted new ways of thinking about PA promotion for adolescents with ASD. Whereas the literature often cites the physical dimensions and benefits of PA (cardiovascular disease, diabetes, obesity) which are important, findings suggest there may be merit in also promoting the emotional pleasures of movement. In addition to promoting the physical health benefits of PA, promoting fun, joy, tranquility, satisfaction, and participation in all forms of physical activity (unstructured activities such as going for walks, cultural rights, and not just sport related activities) can be a tool to promote the pleasures of movement. Given that the pleasurable and affective dimensions of PA have largely have been absent from PA promotion/policy efforts (Phoenix & Orr, 2014), we argue that it is also important to recognize and promote affective pleasures of PA alongside physical health and functional outcomes. We also suggest that perhaps we conceptualize participation in PA as a pleasurable end in and of

itself, where PA where can elicit the dimension of the human experience such as experiencing freedom, creativity, spontaneity, adventure and risk. In this vein, we suggest that physical activity prescription and promotion not only should attend to the physical health benefits of participation, but also take into socio-cultural circumstances and affective dimensions in an effort to promote and enhance PA participation among adolescents with ASD.

**Limitations and Future Directions:**

Despite the many strengths of this research, study limitations present opportunities for future research. First, the study sample was limited to the perspectives and experiences of adolescent boys with ASD. In light of emerging research suggesting that girls with ASD are underdiagnosed and underrepresented in the ASD literature (Lai et al., 2011), future work needs to include girls and women to understand potential gender differences. Conducting this work is crucial to understand how to optimize their participation in PA. Second, the sample only included participants who possessed verbal conversational skills (albeit in a wide range). Future research with non-verbal adolescents, along with enhancing ethno-cultural diversity (age, socio-economic status) is needed to examine how to best support their needs. Thirdly and finally, our findings suggest that future research is needed to explore if ABL would be an amenable pedagogy to teach HPE and PA for children and adolescents with ASD.

**Conclusion**

This study examined the perspectives, meanings, and experiences of PA, along with the socio-cultural processes which enhance, shape and curtail PA participation for adolescent boys with ASD. With a paucity of knowledge in this area, study findings provide an innovative and original contribution to the understanding of physical (in)activity among adolescents boys with ASD. The findings illuminate the complexity of PA, and highlight the need to identify pathways at social and systemic levels to facilitate participation.

Table 1:

Participant Characteristics

| Name | Age | Self-described Physical Activity Status | PA Frequency per week |
|---|---|---|---|
| 1. Manuel | 15 | Highly active | 3-4 times/week |
| 2. Malcolm | 18 | Predominantly inactive | 1-2 times/week |
| 3. Mark | 17 | Highly active | 5-6 times/week |
| 4. Allan | 12 | Predominantly inactive | 0-2 times/week |
| 5. Seper | 14 | Highly active | 3-4 times/week |
| 6. Daniel | 13 | Highly active | 3-4 times/week |
| 7. Miguel | 18 | Predominantly inactive | 1-2 times/week |
| 8. Jas | 12 | Predominantly inactive | 0-2 times/week |
| 9. Guido | 15 | Predominantly inactive | 0-2 times/week |
| 10. Romeo | 13 | Predominantly inactive | 1-2 times/week |

# Chapter 6

# Preface to Chapter 6

In Chapter 6 (a manuscript), I address the third aim of the study which analyzed how socio-cultural processes interact with bio-physical and psycho-behavioural processes to enhance, shape, and curtail PA participation. In the manuscript, I draw on examples from three participants to highlight how the internalization of risk, and anxiety not only had bio-physical and psycho-behavioural dimensions, but also were concurrently shaped socio-culturally. Drawing on Elias' concepts of figuration, habitus, and hinge, I highlight how these processes interacted within an interdependent relationship. Throughout the paper, I argue that the interrelationships of these processes in turn enhanced, shaped, and curtailed PA participation for adolescents with ASD in this study.

This manuscript will be submitted to the journal "Social Science and Medicine". This is an international and interdisciplinary journal which publishes sociological articles on all aspects of social science and health. The journal endeavors to inform current research, policy and practice in all areas relevant to social scientists, health practitioners and policy makers.

# 6 Physical (In)activity Among Adolescent Boys with Autism Spectrum Disorder

Manuscript Abstract:

Despite the many benefits of physical activity participation (PA), adolescents with autism spectrum disorder (ASD) consistently have been reported to be less physically active compared to their age related peers. Little is known however why they are predominantly inactive, and how their PA activity is shaped by wider social, systemic, cultural, and policy processes (socio-cultural processes). The purpose of this study was to examine how socio-cultural process shape PA, and examine how socio-cultural process interact with bio-physical and psycho-behavioural processes to enhance or curtail participation. Ten adolescent boys with ASD were interviewed twice, and each created a digital story. The study was undergirded by a critical social science approach, and analysis was driven with Nobert Elias' concepts of figurations, hinge, and habitus. Findings suggest that PA participation was not merely an individual behaviour determined by bio-physical or psycho-behavioural forces in isolation. From the internalization of discourses of risk and pedagogies centred on normalizing human movement, through to the bio-psycho-social production of emotions and the valorization of particular masculinities, PA participation reflected the social conditions that were placed upon participants. Findings suggest that PA participation cannot be separated from the complex web of interdependencies between socio-cultural, bio-physical and psycho-behavioural processes. This work draws attention to the socio-cultural processes that mediate PA participation which heretofore have not been discussed in the literature.

Keywords: autism spectrum disorder; physical activity; Norbert Elias; adolescents

**Introduction**:

Despite the reported positive mental, physical, and social outcomes of physical activity (PA) participation (Poitras et al, 2016), research consistently suggests that children and adolescents (hereafter adolescents) with autism spectrum disorder (ASD) are less physically active compared to their age-related peers (Healy, Haegele, Grenier & Garcia, 2017; Pan and Frey, 2006). For example, a sample of adolescents with ASD in the United States were 60% less likely to participate in PA, and 74% less likely to participate in an organized sport (McCoy et al., 2016). Although there are increasing calls to enhance PA participation among adolescents with ASD (Healy et al., 2018; McCoy et al., 2016), it remains unclear why they are predominantly inactive. To date, research examining (in)activity among adolescents with ASD has focused on the bio-physical and psycho-behavioural dimensions that shape their participation (Campos et al., 2019). From a bio-physical standpoint, adolescents with ASD are said to be less likely to be active if they experience gross-motor impairments, delays in acquiring fundamental motor skills, and or sensory sensitivities (Redquest, 2019). Psycho-behaviourally, research suggests that adolescents are less likely to be active if they lack motivation, have low perceived motor skill competence (Loprinzi et al. 2015), or have a disinterest in PA (Eversole et al. 2016). Despite the research examining physical (in)activity among adolescents with ASD, there is a paucity of research that has examined how PA participation is shaped beyond the level of individual. To this end, little is known how broader social, cultural, and political processes mediate PA participation (hereafter socio-cultural processes). Furthermore, there also is very little research that has considered how these socio-cultural processes interweave with bio-physical and psycho-behavioural processes to shape PA. Rather, much of the research to date has examined each of these processes in isolation. Given that socio-cultural processes do not exist independently from the lived physical, affective, cognitive, and existential dimensions of the body, there is a need for research to consider how these processes interact to shape PA, and to generate a more nuanced understanding of physical (in)activity.

To address these knowledge gaps, a critical qualitative study was designed to 1) examine the socio-cultural processes enhance, shape and or curtail PA participation among adolescents with ASD, and 2) analyze how these socio-cultural processes intersect with bio-physical and psycho-behavioural processes to enhance, shape, and curtail PA. In what follows, the paper begins with a

brief overview of Norbert Elias' Figurational Sociology, and I explain how his concepts of figurations, hinge and habitus guided my analysis. I then describe the study, and demonstrate how the internalization of risk, and bio-psycho-social experiences of anxiety interact to enhance, shape and curtail PA participation. I conclude this paper by suggesting a need to critically reflect on how PA participation is promoted among adolescents with ASD.

**Norbert Elias and Figurational Sociology**

Consistent with the critical qualitative methodology and critical approach which undergirded my study, I drew on Norbert Elias' Figurational Sociology to explore how PA was shaped by broader socio-cultural processes, and to examine how physical (in)activity is shaped by the simultaneous interweaving of bio-physical, psycho-behavioural, and social processes. Figurational (or process based) sociology involves understanding individuals and society in relational pluralities. In this vein, Elias proposed that any unit of investigation (such as human beings) cannot be understood or analyzed in isolation (Elias, 1978a). Rather one must situate human beings within a long-term perspective to examine how interdependent social, historical, psychological, biological, and institutional processes shape their affective, physical, existential, and cognitive dimensions. For Elias, the goal of sociology resides in understanding individuals and society in relational pluralities, and processes, where the researcher examines the fluid interrelationships and interdependencies of a particular unit of investigation (Elias, 1987a). To guide the analyses of these interdependencies, Elias developed the concepts of figuration, hinge, and habitus.

The concept of figuration bridges the structure and agency divide to highlight how humans are embedded a system of (not necessarily equal) relations involving mutually oriented and interdependent people. A figuration exists anywhere where there is a social connection, or an interdependency of any sort. Entangled webs and networks of group and individual interdependencies (Atkinson, 2012) come together to form figurations. The inter- and socially connected nature of human life runs the life course as human beings are born into sets of interrelationships (figurations), develop within them, to an extent shape their dynamics, structure, and help create them, and then die within the interdependent ties they share with others (Jarvie & Maguire, 1994; Dunning, 1999). Examples of a figuration include: the military, a state, a city, a family, economy, a political context, a school, students in a classroom, a

workplace, a community (Atkinson, 2012). In this study, adolescent boys with ASD are a part of, and interacted with, several figurations. For example, boys with ASD were a part of the autism figuration as their related symptoms grouped them together with a clinical diagnosis of ASD. Their diagnostic label in turn shaped their lives and trajectories as it provided access to support embedded in other figurations such as healthcare (therapy), and school-based services (educational support). In addition to this autism figuration, boys were also a part of their family figurations, health and physical education class figurations, and PA figurations. Although each of these figurations have a unique structure, logics, practices, and are influenced by systems of power relations.

The concept of figuration is closely connected to the concept of the hinge which also has an explicit focus on interdependencies. Bridging the nature and nurture divide, the concept of the hinge proposes that social and biological aspects of human beings are situated within a recursive, interconnected, and interdependent relationship. Instead of approaching social, physical and psychological (existential, cognitive, affective) dimensions of human beings as separate entities, the hinge proposes that natural (biological) and social processes are fundamentally and deeply entangled. By connecting human nature (biology) with society, Elias' sought to highlight how social processes (society) and learned individual dispositions (human-self) blend with (unlearned) biological aspects (nature) to shape human conduct and human existence in everyday life which he called the habitus.

The habitus involves schemes of perception, and or a mode of orientation that guides thought, perception, tastes, preference, performances, action, and (inter)action within the social world. The development of one's habitus commences at birth, and these dispositions become deeply habituated (Jarvie & Maguire, 1994). Given that dispositions are deeply seated, the habitus is most often beneath the level of conscious awareness and control (Jarvie & Maguire, 1994). The habitus is a heuristic, a mode of perception and orientation in which human beings make sense of their (inter) actions within the social world. As illustrated in the findings below, these conceptual tools guided the analyses to examine how PA participation was shaped by broader socio-cultural processes, and the simultaneous interweaving of bio-physical, psycho-behavioural, and social processes.

**Methods**

Using a critical qualitative methodology (Denzin, 2017), data was generated with 10 adolescent boys with ASD (aged 12-19) who each created a digital story, and participated in two face-to-face interviews. The combination of these methods generated multiple forms of data to examine how subjective experiences interacted with broader social, cultural and political processes to shape PA participation. Adolescent boys with ASD were recruited from a children's hospital in a major urban Canadian city. Only boys were included in this study as part of a program of research investigating how masculinities shape PA participation (see Jachyra, 2016; Jachyra & Gibson, 2016). Boys with ASD were invited to participate in this study if they: a) had a diagnosis of ASD as per Diagnostic and Statistical Manual of Mental Disorders (5th ed., DSM-5 2013) criteria, supported by the Autism Diagnostic Observation Schedule (Lord et al., 2012); b) were aged 12-19 years; c) demonstrated verbal proficiency in English; d) were capable of allowing turn-taking and discussion of experiences; and e) demonstrated capacity to independently provide consent to participate in the study. Research ethics approval was obtained from the Research Ethics Boards at the hospital where the research took place, and the associated university.

A novel qualitative methodology employing digital storytelling and semi-structured interviews was used. Two interviews were conducted with each participant at a location of their choosing. The first interview sought to build rapport with study participants, explain the details of the study, and to discuss the process of creating digital stories. Next, digital stories were created over the course of three workshops conducted with expert digital story facilitators. Digital stories are short videos, often two to four minutes in duration (Bundon & Smith, 2017) and draw on multi-media content (text, music, images, video, and artwork) and digital tools (video editing software, digital cameras, computers) to produce short visual narratives. Digital storytelling was strategically selected in an effort to build rapport and generate rich data as the workshops provided multiple opportunities to interact with participants. Digital storytelling was also selected as it aligned with the study's critical approach which posits that individuals cannot be expected to explain their habitus, that is, how social structures interweave with biological capacities to produce dispositions which shape their daily practices. Finally, a second interview was conducted after the digital storytelling workshops. Digital stories were integrated into the second interview in an effort to stimulate further discussion regarding participants' attitudes,

beliefs, conceptualizations and experiences of PA participation. Finally, observational fieldnotes were generated during all interviews, and the three workshops. These notes documented the research process, my reflections and initial analysis of the data.

Analysis of the data was driven by techniques described by Miles and Huberman (1994) that included the creation of an analytic guide and a flexible coding system consistent with the study purposes and the Eliasian conceptual framework. Narrative summaries were written for each participant by integrating participants' digital stories, interview accounts, and observational field notes. Following the analysis of each narrative summary, the summaries were compared and contrasted with other participants (cross-analysis) in an effort to seek new ways of seeing and analyzing the data, and to take the data in fertile and unexpected directions (Smith, 2016).

**Results of the Analysis**

The analysis of digital stories and interviews generates an in-depth understanding of how socio-cultural processes shape PA participation among adolescent boys with ASD. Drawing on Elias' concepts of the hinge, habitus and figuration, I draw on examples from three participants to highlight that PA participation was not merely an individual behaviour determined by cognitive forces such as volition, motivation, or self-efficacy. From the internalization of discourses of risk and pedagogies centred on normalizing human movement, through to the bio-psycho-social production of emotions and the valorization of particular masculinities, PA participation reflected the social conditions that were placed upon participants. Together, the interaction of these processes and interactions within particular figurations shaped one's habitus, and participant's predilections toward PA participation. Findings suggest that PA participation cannot be separated from the complex web of interdependencies between socio-cultural, bio-physical and psycho-behavioural processes. To further contextualize the analysis in the sections below, I first provide further information about the adolescent boys who participated in this study.

In the study, all participants had a diagnosis of ASD, were aged 12-19 years, and all boys lived at home with at least one parent. At the time of the research, eight boys were in high school, and two were in senior years of elementary school (grade eight). Across participants, there was wide variability in PA participation. Generally the boys can be divided into one of two groups. Based

on their self-descriptions, one group was ‘highly active’ where four boys noted that they participated in PA activities 3-5 times per week. On the other hand, the other group of six boys were predominantly inactive, participating in structured PA activities between 0-2 days per week. Notably, all boys described experiences participating in community-based PA activities, and all had the shared experience of being enrolled in school based health and physical education (HPE) class. For the eight participants who were in high school, only one continued to take HPE class after a mandatory year of enrollment.

At the time of the research, one participant was engaged in paid part-time work, one participant was a volunteer at a local church, and one participant volunteered at a pet shelter. In what follows below, I draw on these contextual details to sketch out how PA was shaped by socio-cultural processes and the interaction of these processes with bio-physical and psycho-behavioural processes.

**Socio-Cultural Production and Internalization of Risk**

In this study, PA participation was not merely driven by ones physical skills in PA, or motivation to be active. Rather, PA was enhanced, shaped, and curtailed by the interaction of socio-cultural (social, norms, assumptions, and practices), bio-physical, and psycho-behavioural processes interacting together within PA figurations. Although these interdependencies were omni-present among participants, the interactions of these bio-psycho-social interdependencies and their impacts on PA participation were particularly evident in Allan’s account. For Allan, PA participation was shaped by his daily life living with Ehlers-Danlos syndrome (bio-physical), but also mediated by wider socio-cultural processes in which he was immersed. At the time of the study, Allan was 18 years old. In addition to his ASD diagnosis, he was diagnosed with Ehlers-Danlos syndrome at age six, a hereditary disorder that typically increases in severity throughout the life-course. Ehlers-Danlos syndrome contributes to weak connective tissues, weak muscle tone, and hypermobility of joints. Hypermobility of joints in particular can be a concern as it increases risks for dislocation, falls, and injury. Allan experienced hypermobility in his knees, ankles, and elbows and at the age of 12 years, dislocated his knee while playing soccer with his friends. To illustrate his hypermobility and how it impacted his daily life and PA participation, Allan included the photo below of his elbow in his digital story.

Although Allan's hypermobility had a bio-physical basis and limited his PA participation as he had an increased risk for injury and dislocation, his participation in PA was also contoured socio-culturally through his interactions with family, rehabilitation professionals, and the logics of practice within each of these figurations. Across the accounts, Allan described that he was predominantly inactive throughout his life. Despite expressing an interest in sport and PA, in his digital story, Allan noted that his "interests to become a pro athlete was a pipe dream as soon as I got that diagnosis". Throughout his life, rehabilitation professionals and physicians advised that he engage in low weight-bearing PA activities such as activities in the water, elliptical running, or using free-weights, but to avoid "sports with any body contact as it increased risk for injury". Recommendations from rehabilitation professionals were internalized and reproduced by his parents. From explaining to Allan that participating in PA was "just too dangerous" throughout his life, through to enrolling him in "less risky" activities such as arts, crafts, music, reading, and film as recommended by rehabilitation professionals, the discourse of risk was present in all aspects of Allan's life. Messages of risk, hypervigilance, and mitigation strategies also carried over to the school context as teachers were aware of his increased risk for dislocation and injury. Whether it was walking up the stairs, or playing outdoors during recesses, Allan recounted that his teachers warned him daily "to always be careful". Although these precautions from Allan's parents, rehabilitation professionals and teachers were well intentioned to minimize his potential risk of injury, consistent messaging to avoid potential injury within these figurations had multiple (and perhaps unintended) effects, and shaped his PA habitus. Given the constant surveillance and potential for injury, Allan internalized these structural, social and cultural discourses regarding the omnipresent risk for injury, and the need for 'inactivity`. As such, he noted that he constantly worried about dislocations. Although Allan identified that rehabilitation professionals encouraged him participate in PA as is one of the best treatments for Ehlers-Danlos

syndrome, Allan's internalization of socio-cultural processes which positioned PA as "dangerous and to be avoided at all costs", generated dispositions to avoid PA participation.

> Exercise is good for me, but I got to be careful because I can get hurt. All my life everyone has told me to be careful so that I don't end up in hospital. Even now as almost an adult, my parents and physio remind me to avoid exercise if I can so that I don't dislocate my knee again.

Given that the habitus is located within the individual, ones habitus embodies structural, social and cultural discourses that become internalized over time (Elias, 1939). As illustrated in the quote above, Allan's PA participation was not merely the result of a lack of motivation, or an individual preference. Rather his bio-physical risks for injury and dislocation interacted with broader socio-cultural processes described above (the hinge), and together, formed dispositions and preferences to dissuade PA participation. Although the habitus is malleable and subject to change over time, it produces enduring particular patterns of thoughts, behaviour and actions to guide (inter)actions within the social world. A habitus oriented away from PA for Allan was deeply seated and reinforced when Allan dislocated his knee. Although Allan noted that his knee dislocation was "freak accident", it contributed to a fear of subsequent dislocations. As such this knee injury contributed to strengthening a fear of PA altogether. This fear and (hyper) vigilance of his knees was articulated in his digital story where he included a photo of a knee in a brace (pictured below). The potential risk for injury and subsequent dislocations in turn shaped his schemes of perception toward a habitus of avoiding PA as he internalized that being cautious about his knees and avoiding PA would be the best option to prevent another knee dislocation. In highlighting his conceptualizations of PA, Allan narrated his digital story in the following way:

> The dislocation confined me to crutches and braces for months, and even basic actions such as going downstairs became a task. When I recovered, I wasn't quite the same. I lost the ability to run and I needed to be more cautious of my knees.

Allan's repeated emphasis on taking his "hyperlaxity more seriously" and being "more cautious of my knees" carried over into school based HPE class, and impacted his participation. Psycho-behavioural processes such as his fear of dislocation and internalization of risk was amplified after he had a few "close calls" with peers during HPE class. Although body contact was prohibited, Allan was body-checked to the ground while playing ball-hockey with his peers on two occasions, and was routinely name called as "soft" and "weak". HPE was a hostile environment for boys like Allan who did not measure up and reproduce traditional markers of masculinity where athleticism, strength, competitiveness and aggressiveness were valorized by peers. These close calls as Allan called it however had a negative impact on his HPE participation as he developed a "paralyzing fear of dislocating his knee again". Given these socio-cultural conditions, and psycho-behavioural internalization of fear, Allan was often relegated to the sidelines of HPE as he described that preferred to "watch and not participate". What seems to be a rational choice at the surface to "watch and not participate" in fact is the deeply seated nature of the habitus where the paralyzing fear of injury is more than just a rational calculation of risks and benefits. Rather, it suggests a deeper and embodied emotional (psycho-behavioural) aversion that now equates PA with harm, produces (unconscious) choices of avoidance, and dispositions in which PA is internalized as an activity that 'is not for the likes of me'. As articulated in his quote below, these particular experiences shaped Allan's habitus toward inactivity.

> After getting nailed [body checked] a few times, I decided it was best not to get in the way of the jocks in the class. It was best for me to just sit out and hang out on my own in class, then to put myself in a spot where I can get hurt again. I can't take anymore chances, I have to be careful.

Allan's quotation above reveals a particular understanding of masculine power hierarchies at his school, along with his particular place within these figurations. These internalized understandings interact with the biological risks of harm (bio-physical processes), paralyzing fear (psycho-behavioural processes) his experience of pain and disability, and multiple injunctions to 'stay safe' (socio-cultural processes) from the adults that surround him. Together, each of these processes interact and produces a habitus of avoidance for Allan.

**Anxiety and Emotions**

For adolescent boys in this study, the propensity to be active not only was mediated by one's physical capabilities, but also mediated by socio-cultural dimensions (social, norms, assumptions, and practices) within PA figurations. Across the accounts were multiple examples of these processes in relation to the interdependencies between physical activity and emotions. Although these interdependencies were present among all study participants, these interdependencies and their impacts on PA participation were particularly evident in the accounts of Jas and Mark who both lived with a clinical diagnosis of anxiety.

Jas was 14 years old and was the eldest child in a family of three children. Despite his self-described low levels of PA participation, across his data, Jas spent a significant amount of time outlining the benefits of PA participation. From explaining that "exercise keeps you healthy" to "exercise can make you happy", Jas went to great lengths to explain the benefits of PA during his interviews. The benefits of PA participation were also expressed in his digital story where he included a photo of his daily step count data and remarked that "you need at least 10,000 steps per day". The health promoting benefits of PA were also expressed by Jas at the end of his digital story as he stated: "Everyone should do exercise, it is good thing and helps people get fit. I want to do it more often".

Despite his internalized knowledge regarding the benefits of PA, analysis of Jas's accounts highlight that cognitive forces alone did not shape his participation. Although not explicitly stated by Jas, his clinical diagnosis of anxiety can be seen to have had a profound impact on his PA participation. Jas's experiences of anxiety in PA however were not merely bio-physical in nature, but rather were also contoured socio-culturally in structured PA figurations such as team sports. With a predominant focus on instilling repetitive, predictable and normalized movement patterns inculcated through skills and drills, Jas described PA to be an "overwhelming experience" as his physical abilities did not align with normalized movement patterns that were expected. For example, in describing his PA experiences, Jas spent much of his time worrying if he was "failing at exercise". From worrying whether he correctly executed movement patterns, to worrying if he would "screw up" if his peers passed the ball to him when playing sports such as basketball, hockey or soccer, PA was an anxiety provoking experience. For Jas, the focus on inculcating repetitive, predictable, and normalized movements in PA figurations was anxiety producing, and was subsequently internalized which emanated from his repeated failure in PA. A repeated sense of failure was reproduced in the school context as Jas tried out for five school teams/activities, but was never selected. Repeated failure across these figurations however had a debilitating impact on his PA participation. Rather than making him 'happy' as highlighted in his quote above, the socio-cultural processes described above interacted with the bio-physical and psycho-behavioural aspects of anxiety via the hinge in a feedback loop to exacerbate his underlying anxiety. In this vein, Jas described that he often commenced PA with feelings of tension, and often ended participation with head and muscle aches. Participation in PA for Jas was an overwhelming and exhausting experience, and generated a habitus toward PA avoidance in structured PA figurations. In highlighting the hidden emotional labour, associated with PA participation, Jas noted:

> I just find exercise so stressful especially in gym class. I get there and I don't want to be there. I am there and then I just shut down because it's just too much. All I worry about it is if I am doing things right and who is judging me. I leave with muscle pain and a headache. I think it's just better if I don't go.

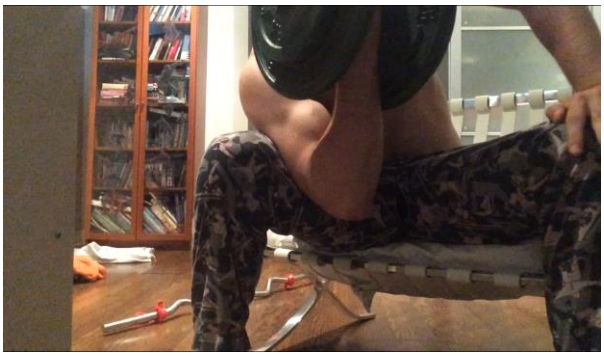
Not only did challenges with adapting to normalizing movement patterns contribute to the overwhelming nature of PA and dissuaded participation, negative interactions with peers also

shaped his habitus toward disengagement. As with the example of Allan presented above, recounting his experiences, Jas noted that he was subject to frequent taunting and belittlement. Verbal jeers were most pronounced in school based HPE, and often revolved around his lack of skill and lack of traditional markers of masculinity. When asked to describe the nature of verbal jeers during the second interview, Jas recalled being repeatedly told that he "played sports like a girl", was "a sissy" and "a fat-ass". In an effort to resist stereotypical notions of masculinity, Jas attempted to talk to his peers about the history of war as a way to gain masculine status. However, there was little room to negotiate this alternate masculinity as a proverbial outsider (lack of masculine status) to this established group (hegemonic forms of masculinity). Equally problematic as the verbal jeers about his physical abilities were jeers about his repetitive behaviours. Given the anxiety producing nature of PA described above by Jas, at times Jas would shred paper, pace, or repeat phrases to himself aloud. These behaviours however were specific expressions of the biological propensities of ASD in response to broader socio-cultural conditions where Jas was stigmatized and recalled being called a "retard", freak", or "alien". This derision and bullying from peers heighted Jas's anxiety further, and worked to generate dispositions away from PA participation in team or group activities. This analysis again highlights the hinge where the bio-physical components of anxiety, and ASD interacted with socio-cultural processes of experienced failure and bullying to produce PA participation. When asked if he was interested in pursuing PA again, Jas noted:

> Being active is just not for me. I've tried it. Don't like it. Get made fun of all the time. Called all these horrible things I told you. I don't see the point in doing exercise, especially in since I just fail at all these things. I feel horrible after and feel like I am going to be anxious always.

Whereas PA was anxiety producing and shaped a habitus that shaped PA participation as 'just not for me', similar socio-cultural processes drew Mark into participation. At the time of the research, Mark was 18 years old and had been highly active for most of his life. From doing sit-ups before bedtime as a child as a way to calm himself down as a child, to trying several sports such as soccer, swimming, cycling, and running, Mark was predominantly physically active throughout his life. At the time of the research, Mark participated in boxing where he would complete two technical session of boxing (punching) per week, and two days of physical fitness

conditioning. Mark's digital story recounted his boxing experiences where he labelled his story "Revenge in the Ring" in which he outlined his boxing routine, and his goal of seeking revenge on an appointing after losing to him in a sparring match.



In contrast to Jas's experiences of PA described above, Mark's accounts suggest that he utilized boxing as a tool to curtail his anxiety. For Mark, boxing was an outlet from the anxieties of everyday life and seemingly mundane tasks such as making decisions about what clothing to wear, or what food to eat. Across his accounts, the bio-physical, sensory components of boxing were described as calming. In this vein, Mark highlighted that he enjoyed the feeling of "exhaustion, and sweat on his skin", sound of "punching the bag", smell of the "chalk on his hands when punching the bag", and the reverberations of his "feet hitting the ground". For Mark, boxing and training elicited bio-physical sensory pleasures such as feelings of excitement. These bio-physical sensory features elicited a sensory connection between the activity, the individual, and their environment, and drew Mark into PA. He noted:

> There is no better feeling than punching the shit out of the bag. Just letting it all out. I am always exhausted after boxing, but it's the best thing because it is my outlet and helps me calm down in so many ways. It's like my drug, I need it so that I don't explode when my anxiety is bad. I love all the different feelings it brings.

Whereas Mark's quote highlights the calming bio-physical dimensions of boxing, bio-physical components also interacted with broader socio-cultural processes to shape his PA habitus and enhanced his participation. For example, Mark's enjoyment of PA afforded him particular social and cultural resources as a result of his fit, strong and muscular body as Mark was often met with

praise for his body, and was known as the "muscly guy" among his family and friends. His body morphology in turn afforded a particular social status which was reinforced in PA environments which value fit-active bodies, which in turn produced dispositions or preferences to participate in PA. The privileging of his body and subscription to traditional markers of masculinity were reproduced in his digital story as he included four photos of his muscles, and two of which he was shirtless, and was flexing his muscles. To this end, while the sensory and emotional components of PA drew him into participation and helped alleviate his anxiety, Mark's habitus was also shaped by these socio-cultural processes which contributed to feelings of what Mark called "success". Although feelings of success can elicit a psycho-behavioural response, feelings of success are only produced and shared within wider social values such as traditional markers of masculinity. As illustrated in Mark's quote, 'flaunting' his body suggests that it is a valorized and masculinized body that is rewarded socio-culturally through flaunting. These socio-cultural conditions in turn produce dispositions to continually maintain a particular body shape, and highlight how the interactions of bio-physical and socio-cultural processes meet and blend together.

> In my digital story, I tried to show that kids with autism also can be fit and active. I work hard for this body and its something that I am damn proud of. Plus, I am known as the muscle guy at school, around my family and my friend. You might as well flaunt it if you have it. Keeping this body is what keeps brining me back to doing active things.

Despite underlying anxiety for Jas and Mark, their PA participation differed greatly. Although the socio-cultural, bio-physical, and psycho-behavioural mechanisms of anxiety are the same, PA participation was shaped by participant-specific ASD related symptoms, rules and figurations at play in each case. As such, PA participation was shaped through the hinge, and the formation of the habitus.

**Discussion**

Drawing on Elias' Figurational Sociology, the analysis of participants' accounts delivers two novel and original contributions to the literature regarding physical (in)activity participation among a group of adolescent boys with ASD. First, this study illuminates how socio-cultural processes shape PA participation. With much of the research to date suggesting that adolescents

with ASD are predominantly inactive as a result of decrements in gross-motor skills (Ming et al., 2007), and or a lack of motivation (Loprinzi et al. 2015), this research draws attention to consider how socio-cultural processes shape participation. The findings suggest that PA participation was not merely an individual behaviour determined by cognitive forces such as volition, motivation, or self-efficacy. Rather, the analysis illuminates how socio-cultural processes enhance, shape, and curtail PA participation in particular ways. These socio-cultural process in turn entailed the internalization of discourses of risk and pedagogies centred on normalizing human movement, valorization of particular masculinities, and interactions of bio-psycho-social elements of emotions. PA participation therefore reflected the social conditions that were placed upon participants. These broader socio-cultural processes in turn add nuance to the literature and suggest that adolescent boys with ASD in this study were not simply or 'naturally' lazy or merely have a preference for sedentary activities as has been described previously in the literature (Healy, 2018). Rather, PA participation was shaped by collective, socio-cultural processes which had multiple (and sometimes unintended) effects. The socio-cultural processes identified in the findings highlight the relational nature of PA, which heretofore has been missing from the ASD research literature.

A second contribution of the study draws attention to the complexity of PA participation. In this research, I drew on Elias' concept of the figuration, hinge, and habitus from three participants to illustrate how socio-cultural processes interacted with bio-physical and psycho-behavioural process to shape PA. The analysis demonstrated how the internalization of risk and experiences of anxiety not only had bio-physical and psycho-behavioural dimensions, but were shaped socio-culturally. For example, socio-cultural processes shaped the expression and experience of anxiety in PA settings. As the first study to examine these interconnections, findings demonstrate how PA participation cannot be separated from the complex web of interdependencies and socio-cultural relations. Physical (in)activity is not reducible to any one of these processes but rather they are interconnected from the outset, and work together to shape the habitus of individuals with ASD.

Given the little research that has explored these interconnections, findings of this study serve as a point of departure to re-consider current efforts aimed at increasing PA. To date, much of the efforts have sought to increase participation through programs using behavioural strategies

(Bassette et al., 2018), and by enhancing gross-motor skills (Redquest, 2019). While research efforts in these domains are important, there has been little work that has sought to address broader socio-cultural processes as a vehicle to potentially enhance PA participation. Given this limited research, findings suggest that there is a need to consider broader socio-cultural issues from the outset when designing PA programs and opportunities. In this vein, I suggest there is a need to move beyond the use of predominant sport and rehabilitation based frameworks centre on repetitive skills, drills and scrimmages. As such, I argue there is a need to attend to the broader socio-cultural processes which focus on what a child can do, rather than what they can't do. By coaching the "athlete, and not the disability" (Townsend, 2017, p. 130), there are new conditions of possibility to re-imagine PA for adolescents with ASD.

Despite the potential value of designing PA programs and interventions within a particular developmental framework used in traditional sport and PA contexts (Pusharenko, 2019), findings highlight the need to also develop programs specific to the needs and preferences of adolescent and family circumstances. As highlighted in the study findings, the interaction of bio-physical, psycho-behavioural and socio-cultural processes produced different choices and preferences among participants. Given this diversity of interdependent processes among participants, there is a need for programs to offer high levels of flexibility in how activities are conceptualized, offered, and delivered in an effort to meet the heterogeneous needs of adolescents. As such, in addition to promoting and offering sport related PA opportunities, findings suggest potential benefit in also promoting non-sport activities that can be implemented by families such as: going for a walk, completing home/garden work, live action-role playing, dancing, climbing, yoga, tai-chi, individual fitness, Zumba, stretching, or martial arts. Broadening our conceptualizations of PA to move beyond sport has the potential to meet the diverse needs and circumstances of adolescents with ASD, and their families.

## Conclusion

In this paper, I have applied Elias' concepts of figuration, hinge, and habitus to examine the lives and PA participation of a group of boys with ASD. By adopting these Eliasian concepts, the study provided new insights into adolescent's choices, but also the socio-cultural processes, and social relations which enhance, shape and curtail PA participation. To date, little research has examined how socio-cultural processes shape participation, and even less research that has

examined how socio-cultural processes intersect with bio-physical and psycho-behavioural processes to shape PA. Given this limited research, there is a need for more research that examines the broader social and material processes that directly influence PA participation, and the daily lives of children with ASD. In developing a novel qualitative methodology which facilitated the optimization of data generated with participants, and interpreting the accounts of adolescents in relation to their social, political, and cultural contexts, this study serves as a point of departure to address these gaps.

Table 2: Participant Characteristics

| Name | Age | Self-described Physical Activity Status | PA Frequency per week |
|---|---|---|---|
| 1. Manuel | 15 | Highly active | 3-4 times/week |
| 2. Malcolm | 18 | Predominantly inactive | 1-2 times/week |
| 3. Mark | 17 | Highly active | 5-6 times/week |
| 4. Allan | 12 | Predominantly inactive | 0-2 times/week |
| 5. Seper | 14 | Highly active | 3-4 times/week |
| 6. Daniel | 13 | Highly active | 3-4 times/week |
| 7. Miguel | 18 | Predominantly inactive | 1-2 times/week |
| 8. Jas | 12 | Predominantly inactive | 0-2 times/week |
| 9. Guido | 15 | Predominantly inactive | 0-2 times/week |
| 10. Romeo | 13 | Predominantly inactive | 1-2 times/week |

# Chapter 7

# 7. Discussion and Implications

## 7.1 Summary of Key Contributions

This dissertation makes six key contributions to the fields of rehabilitation science, ASD research, and qualitative methods. The first four contributions are substantive, the fifth contribution is theoretical, and the sixth contribution highlights advancements in qualitative method. Each contribution is summarized below.

1. This study added novel and rich data by engaging adolescent boys with ASD in describing their lives and circumstances (See Chapter 5 & 6). This is an important contribution to the literature because as noted in Chapter 2, there has been a paucity of research that has been conducted directly with adolescents with ASD. Knowledge of the attitudes, beliefs, perceptions and experiences of PA has the potential to guide the design of interventions, programs, supports, and policies that are reflective of their lives, needs, and abilities. This research contributes new knowledge to this area, and serves as a point of departure to address this knowledge gap.

2. Study findings highlight that PA was not merely a behaviour determined by the individual. As illustrated in Chapter 5 and 6, my analysis illuminated how PA was shaped by wider social values, norms and assumptions about ASD, as well as practices, and interactions within particular social spaces. The socio-cultural processes in turn influenced the (conscious and unconscious) choices and preferences of participants in their particular social contexts, and daily lives. These socio-cultural processes in turn shaped PA participation in numerous ways, and shaped one's habitus toward PA (dis)engagement.

3. The study highlights that socio-cultural processes do not exist, or function in isolation. Conceptually driven with Norbert Elias' concept of the hinge, the interaction of bio-physical, psycho-behavioural, and socio-cultural processes interacted to enhance, shape and curtail participation in numerous ways. Drawing on examples regarding the internalization of risk, and the bio-psycho-social manifestations of anxiety, my analysis demonstrates that PA participation among adolescents with ASD is highly complex, and

cannot be reduced to understanding anyone of these processes in isolation. In this vein, this study adds nuance to the literature and suggests a need to consider these interdependent relationships when studying, conceptualizing and developing PA programs, opportunities, and interventions.

4. Whereas the study illuminated some of the benefits of PA participation, findings also suggest that PA can have multiple, and sometimes unintended, effects. Whereas some participants thrived in PA, others also experienced profound bullying, exclusion and stigma with PA spaces. These experiences in these particular social conditions shaped a habitus toward PA disengagement for some boys. Given these findings, this study draws attention to the need to consider, and critically interrogate, what might be some of the unintended effects when promoting PA among adolescents with ASD. Despite the many benefits of PA participation, there is also a need to consider potential harms. Findings of this study invite us to think critically about PA participation, rather than unreflexively extolling its positive virtues.

5. Theoretically, this study adds to the application of Nobert Elias' Figurational Sociology. To my knowledge, this is the first study to employ a Figurational approach in ASD research, and also it is the first study to apply the concept of the hinge in relation to PA participation among individuals with ASD. With a unique application of the concept of the hinge, the study highlights how bio-physical, psycho-behavioural and socio-cultural processes interacted together to enhance, shape and curtail PA participation. Further details about this particular contribution are outlined in section 7.2.1.

6. Finally, my work contributes to advancing qualitative methodology. With a lack of research that has described potential strategies and techniques that might be suited to the diverse needs of adolescents with ASD, this dissertation adds new insights regarding adaptive methods that integrate semi-structured interviews and digital stories that might be suitable for adolescents with ASD. Contributing to critical qualitative inquiry, this study highlights how the combination of these methods were complimentary in nature, facilitated participation, facilitated rapport building, and generated high quality data.

Having summarized these main contributions of the research, I now discuss in more detail 1) the theoretical contributions of this study, and 2) implications for rehabilitation science and beyond.

## 7.2 Implications of the Research

### 7.2.1 Theoretical Implications

As noted, this dissertation contributes to Norbert Elias' Figurational Sociology in a new direction by applying his concepts in ASD research. To my knowledge, there is no previous research that has used Elias' conceptual tools to gain insights into the lives of individuals with ASD. Applying Elias' concepts in this research illustrates the relational aspects of PA participation which heretofore have not been described in the literature.

Whereas PA participation among adolescents with ASD has predominantly been conceptualized as individually motivated (Townsend, 2018), Elias' sensitizing concepts bring attention to how PA is shaped by multiple interacting forces, and not solely at the level of the individual, or at the level of the family. For example, whereas a lack of time has been identified to negatively impact PA participation (Must et al., 2015), analysis driven with Elias' conceptual tools highlighted that 'a lack of time' was not merely an individual choice made by adolescent boys or their families. Rather, this lack of time was contextualized and shaped by broader socio-cultural processes where therapeutic interventions were prioritized, and accorded greater social value than PA participation. The predominant focus and valorization of intervention during childhood however adversely impacted PA for some boys, as there was less time and exposure to develop sustained PA interests, habits, and patterns of participation. Elias' sensitizing concepts therefore served as a resource to examine how to move beyond individual level theorizations of (in)activity to examine how participation was shaped by broader temporal, political, social, and spatial processes such as the prioritization of therapeutic interventions. By adopting a deep relational perspective, Elias' conceptual tools helped illuminate that PA participation is the product of associations between interdependent human beings, and non-human 'transactors' such as social norms, values, and assumptions. Findings of this study suggest that it is insufficient to simply ask adolescents with ASD why they are inactive or to describe their habits, patterns and interests without examining and interpreting the dynamic social fields (figurations) in which adolescents with ASD are immersed. Such a relational analysis of PA is the first of its kind in the literature.

In addition to bringing attention to theorizing the socio-cultural and relational dimensions of PA, deploying Elias' Figurational Sociology also generated a new application of his concept of the hinge. Although the concept of the hinge has been used in the physical cultural studies to describe, for example, the sensuality of sweat (Atkinson, 2018), discourses of aging (Evans et al., 2015), and retired servicemen's experiences of ageing bodies (Williams et al., 2017), this is the first study to explicitly examine how the hinge mediated PA participation. In the context of this study, I drew on the concept of the hinge to move beyond merely examining the 'experiences' of PA participation. While there are increasing calls for research to examine the experiences of individuals with ASD (Bolte, 2014), I would argue that this concept is uncritically used, and is not adequately theorized. In most iterations, 'experience' does not take into account how history, temporality, social practice, and the interactions between bodily and non-bodily forces. Driven with Elias's concept of the hinge, findings illuminate how experiences of PA participation were driven by the interrelations of bio-physical, psycho-behavioural, and socio-cultural process of participation. Furthermore, simply researching the experiences of adolescents with ASD without using a robust theoretical approach such as Elias' concept of the hinge reinforces the splicing of the body into separate categories of mind, body and the social. In keeping with Elias' rejection of dichotomizing the body and society into separate entities, my employment of the concept of the hinge worked to reveal the interrelationships between an individual's social position, their bodily potentialities, and dispositions developed over time. The result of this robust and theoretical analysis suggests that physical (in)activity cannot be reduced to any one of these interrelationships in isolation. Rather, I have argued and demonstrated that PA participation is produced as a result of these interconnections which are developed over time, and arise through one's emplacement in the social world. In doing so, the use of Elias's conceptual tools helped identify the complexity of PA participation among adolescent boys with ASD.

This dissertation therefore elicits a theoretically-informed and a novel contribution to studying PA participation research and that to my knowledge, is the first to employ Elias' concept of the hinge in this direction. I look forward to further refining my theorization of PA participation and am I interested to explore how the concept of the hinge can serve as a conceptual tool to examine the interconnections between physical activity and mental health among adolescents with ASD as part of my broader program of research.

### 7.2.2 Substantive Implications

In this section, I draw on the study findings to discuss implications of this study for research, practice, and PA promotion. As argued throughout this dissertation, participant 'choices' to be active or not were shaped via the habitus, where the internalization of broader social structures, norms, assumptions and beliefs intersected with bodily potentialities to enhance, shape, and curtail PA participation in numerous ways. Recognizing these interdependencies identified in the study, I join a growing body of researchers (see Edwards et al., 2014; Gibson; 2016; Hammell, 2006; Teachman, 2016) calling for the need to move beyond a restrictive focus on individual level processes to consider the wider forces that shape health and PA participation. In an effort to generate a more detailed and nuanced understanding of PA, I suggest there is a need to not only attend to the socio-cultural process which shape ability and disability, but to also consider how bodily and non-bodily processes interact together.

Drawing on Elias' Figurational Sociology, I suggest that there is a need for rehabilitation, along with school and community contexts to move beyond a *homo clausus* understanding of PA participation in which human beings are conceptualized as self-contained, self-determining, and 'closed' from other people, society and structures. Rather, I suggest there is a need to consider how human beings are understood in *homines aperti* (relational pluralities) to not only recognize the role of society and social structures, but to also acknowledge the interdependencies between socio-cultural, bio-physical and psycho-behavioural processes. To move toward a *homines aperti* understanding of PA participation, I draw on Margarit Shildrick's (2005) idea of an 'ethic of openness'. Consistent with my critical Eliasian approach, an ethic of openness does not refer to mainstream conceptualizations of ethics such as ethical judgement, ethical reasoning, or procedural research ethics. Rather, Shildrick's ethic of openness is a critical approach that seeks to challenge predominant ways of knowing and thinking, avoiding stasis, and generating new possibilities for practice (Shildrick, 1997). An ethic of openness is an ethic of doubt (Gibson, 2016) in that it can be used as a tool or a lens to examine the effects of practices and seeks to rethink and reimagine predominant conceptual orientations. By thinking against the grain in rehabilitation, an ethic of openness recognizes the multiple intersecting "psychological, social, material, historical, and discursive mediators of practice" (Gibson, 2016, p.140). By accepting uncertainty, and challenging assumptions, such an approach resists closure and is not fixed in

any way. A critical ethic of openness generates creative ways to rethink PA promotion, and potentially enhance PA participation among adolescents with ASD. Three specific examples are provided below.

*Re-framing PA Participation*

Across the study findings, much of participants' PA participation predominantly involved structured sport-based activities in HPE class, and in the community. While PA participation in structured team sport based activities worked well for some participants, for others, participating in team and sport based PA was debilitating. Given these study findings, I suggest the need to provide alternative' forms of PA and unstructured activities among adolescents with ASD in school and community based settings. Thinking against the grain, there may be merit in promoting non-sport activities such as going for a walk, completing home/garden work, live action-role playing, dancing, climbing, yoga, tai-chi, individual fitness, Zumba, stretching, or martial arts. These are all ways to potentially draw adolescents with ASD (and their families) into activity. To clarify, I am not suggesting that we abandon sport-based PA activities altogether. Rather, I suggest that a variety of traditional and alternative PA options in community and school-based contexts should be promoted and presented to families and adolescents with ASD in an effort to promote participation throughout the life course. Re-thinking and broadening our conceptualizations of PA and moving beyond traditional sport-based conceptualizations of PA which reign supreme in school and community based settings has the potential to support the needs and interests of adolescents with ASD, and their families. One model that might potentially be of value is adventure based learning (ABL).

Moving beyond traditional pedagogies which predominantly focus on technical skills, ABL utilizes highly structured physical activities coupled with periods of reflection (debrief) to promote social and personal development. Drawing on cooperative PA activities, ABL seeks to develop interpersonal and intrapersonal relationship skills to build a sense of community among students and teachers (Stuhr et al., 2018). ABL may be well-suited to needs of some adolescents with ASD as it provides high amounts of opportunities to participate in PA at their own skill level, pace, and without incessant pressure of competition and winning. Given this approach, ABL may also be well-suited as activities can be individualized, and tailored to the needs of each participant. Apart from one study examining ABL among adolescents with ASD in an

intervention context (see Zachor et al., 2017), I suggest there is value in conducting further research in this area. Below, I illustrate an example of ABL in action, and draw on a recreational program I developed for adolescents with ASD. This particular example builds on the study findings which demonstrated how the interaction of bio-physical, psycho-behavioural and socio-cultural processes produced different choices and preferences among participants, and therefore, PA participation cannot be reduced to a one-size-fits all approach. Driven by an ethic of openness, the example highlights how individualization of activities is an open approach in which there is a high level of flexibility in how the game is played, and that there are no set of physical or social outcomes which drive the program. Rather, the program is designed to support adolescents with ASD with their particular needs and abilities at this point in time.

The Extraordinary Youth Council is a program, free of charge for adolescents aged 12-19 years with developmental disabilities such ASD. The program is organized as a drop-in program to acknowledge complexity in everyday life for some participants, and to reduce pressures to attend weekly. The program is three hours in duration, and participants meet every Friday evening to engage in both unstructured and structured activities such as various forms of PA, arts and crafts, socializing with peers, gain cooking experience, volunteering in the community, and participating in community events. One of the most popular activities is the game: Giants, Wizards and Elves. The game involves two teams and three characters: giants, wizards, and elves. Participants act out the following roles: giant-participants stand on their tippy toes and raise their arms up like a giant; wizards: wave fingers as casting a spell; elves: crouched down. In this game, giants beat elves, elves beat wizards and wizards beat giants. Teams quickly strategize to determine which character they will use. Teams then meet together at the centre and after counting up to three, each team acts out their character. As teams act out these characters, the losing team must run back to their ‘safe zone’ while the other team chases them and tries to tag the opposing members to bring the characters into their team. If both teams show the same character, no one wins, and the countdown is repeated. Integrating the principles of ABL, a brief period of reflection is held to discuss the game, and participants then continue with the other elements of the program.

*Re-conceptualizing PA Participation: Pleasure and Affect*

Across the literature, PA has been predominantly positioned as a "modifiable risk factor that can affect health outcomes" (Healy et al., 2018, p. 818) among adolescents with ASD. As such, much of the PA promotion has centred on highlighting the physical health benefits of PA. Despite researching highlighting the potential of PA to decrease risks of heart disease, diabetes, and depression (Sowa & Meulenbrook, 2012), merely conceptualizing PA to prevent, manage, and intervene in aspects of health de-emphasizes the socio-cultural, embodied, and affective dimensions of PA that were highlighted by study participants. Although the pleasurable and affective dimensions of PA largely have been absent from PA promotion/policy efforts (Phoenix & Orr, 2014), an ethic of openness prompts us to re-think PA promotion efforts which have predominantly focused on the health dimensions associated with PA. In this vein, I suggest that PA promotion not only attend to the individual level physical health benefits of PA, but to also promote fun, joy, tranquility, satisfaction, freedom, creativity, spontaneity, and adventure that can be associated with various forms of PA. Moving beyond conceptualizations of PA as a health outcome oriented activity has the potential to promote PA to be a pleasurable end in and of itself which can be associated with free expression, pleasure, and emotion. Conceptualizing PA in this way draws attention to the relational dimensions of movement identified in this study where bio-physical, psycho-behavioural, and socio-cultural interact together to shape PA participation. To clarify, I am not suggesting that promoting the health benefits of PA participation is entirely problematic. Remaining open to PA in numerous ways however also values PA as a form of expression and indulgence, luxury and creativity, as well as rest and repose (Nichols et al, 2018). These alternative potentialities often are not readily discussed in the literature. Considering how bio-physical, psycho-behavioural, and socio-cultural processes interact together to shape the emotional pleasures of movement, has the potential to support the development of the 'whole' person.

*Redressing PA Participation*

While the benefits of PA are consistently presented across the literature, this study however also highlighted some of the multiple and negative effects of participation. From physical, emotional, and verbal bullying experiences, to significant distress experienced by some adolescent boys, this research highlighted some of the (unintended) other consequences of PA participation. Given

these effects, findings of this study prompt us to reflect on the putative goodness of PA as always and necessarily beneficial. Rather than simply extolling the positive virtues of PA (Abramsky et al., 2018), I suggest that there is a need to interrogate whether the harms that can be associated with PA, outweigh some of the benefits of participation, how so, for who and in what contexts or circumstances. Despite calls for research to examine how to enhance PA participation (Healy et al, 2018), findings of this study prompt us to reflect whether we should honor the preferences of some adolescents with ASD who potentially prefer to be inactive. As illustrated in this study, adolescent boys who were inactive were not naturally lazy, or predominantly drawn to sedentary based activities. Rather, there were multiple reasons for their in(activity), and were highly complex in nature. As such, the point is for stakeholders involved in the field of PA promotion and participation to understand this complexity, and to work with adolescents to identify activities that they may enjoy, rather than trying to fit adolescents with ASD into a particular mold of PA participation. As a result, this study draws attention to consider the importance of letting go of PA promotion efforts where needed without considering their inactivity to be the result of a moral failure of the child, their parents, teachers or healthcare professionals.

To move toward letting go of these fixed and deterministic ways of PA promotion, I suggest that there is a need to adopt an ethic of openness when thinking about physical (in)activity among adolescents with ASD. Adopting an ethic of openness prompts us to interrogate the seemingly mundane, quotidian and obvious benefits of PA participation, and to redress assumptions about physical (in)activity. By letting go of predetermined notions of the right and the good, an ethic of openness serves as a point of departure in interrogating whose interests are being served, whose interests are being marginalized, which socio-cultural processes are making things possible, and what is being denied. Openness therefore is a commitment to work with people where they are at in a non-judgmental supportive way to recognize that not everyone might engage with PA, or may do so at some times in their lives and not others. In doing so, not only is there the potential to increase PA participation, but to also respect the interests, needs and values of adolescents with ASD and their families in a non-judgmental manner.

### 7.2.3 Research Considerations and Future Research

In this section, I highlight some of the study considerations, and also discuss avenues for future research. Before delving into these considerations, it is important to recognize that mine is a

particular interpretation of the data that was co-constructed with a group of adolescent boys with ASD. Although I have sought to produce a rigorous representation that adds to the knowledge base, I recognize that this work is one possible interpretation. As such, other researchers, and the use of other theoretical frameworks in turn would have produced different interpretations. For example, my work could have drawn on Pierre Bourdieu's theory of practice to examine how particular social spaces (concept of field) interact with social values (concept of capital) to produce PA participation choices (concept of habitus). Although similarities between Elias and Bourdieu have been noted (see Depealteau, 2013) through their similar concepts of habitus and social space, the advantage of drawing on Elias' Figurational Sociology was that Elias' work took into account how bodily (bio-physical) and non-bodily potentialities interact together. The emphasis and interdependencies between bio-psycho-social aspects of life draw attention to the complexity of PA participation that would have arguably been missed through Bourdieu's more 'deterministic' approach (Depealteau, 2013) to understanding social life. Therefore, Norbert Elias' Figurational Sociology was well suited for the purposes of this research.

As part of my broader program of research, I was initially interested in exploring how masculinity shaped PA participation among adolescent boys with ASD. While I briefly illustrate how masculinity shaped PA participation among participants in the study findings located in Chapter 6, I did not conduct a robust analysis of gender effects as this would have required a study on its own, and would have been a separate doctoral dissertation. Furthermore, despite the merits and values on conducting a robust gender analysis, conducting such an analysis would have taken the analysis away from the central aims of this study. Although a robust gender analysis was not included as part of this dissertation research, future research examining how gender mediates PA can provide further insights in understanding how socio-cultural processes shape PA participation among adolescent boys with ASD. I intend to conduct this research as part of my post-doctoral studies given my interest in examining the interconnections between PA participation and mental health among adolescents with ASD.

Despite the many strengths and contributions of this research, this study is limited by its in-depth examination of a localized group of adolescent boys with ASD, from one particular context. Although this in-depth analysis sacrificed a broader investigation which may differ across different contexts, this in-depth analysis nevertheless emphasises the details of the processes which shape PA participation among adolescent boys with ASD. As such, I would expect that

these broader bio-psycho-socio-cultural processes would operate in similar ways across Westernized, industrialised contexts. As a result of these contingencies, it may be suggested that the study generates stronger theoretical, than practical implications of this research. However, given the little research that has examined how bodily and non-bodily processes interact together to shape PA participation among adolescent boys with ASD, this study is a rigorously produced, and theoretically informed analysis that draws on rich data to explains the processes of PA participation. To this end, this work elicits a novel, original, and valuable contribution to further advance inquiry and investigation in this area.

The study has important implications for future research. An important extension of this study would be to explore PA participation across the life course of people with ASD. As such, research examining PA participation among adolescents into adulthood is of central importance as there is scant research that has examined PA in adults. Furthermore, future work is needed in the area of mental health and PA participation. Despite research highlighting that PA can enhance mental health among adolescents with ASD, working with participants in this study revealed high levels of anxiety, fear and apprehension in this population. However, little work has considered how PA participation and mental health are interconnected. Given this paucity of research, I am interested in examining how bio-physical, psycho-behavioural and socio-cultural processes interact together to shape the mental health of adolescents with ASD.

In relation to PA practices specifically, findings of this research highlight potential value to examine how teaching and coaching practices can be conducive to the needs of adolescents with ASD. Based on my own experiences and illustrated in Chapter 5 and Chapter 7, there may be merit in examining how adventure based learning might be suitable to move beyond the dominant sport based pedagogies in school. More research in this domain is required.

Finally, my work could be extended by exploring PA participation among families as a whole. For participants who included their parents in the interviews, parents were often very eager to share their insights with me. From my interactions with parents, they had important insights to share, and it was clear to me that they thought of these issues before.

## 7.3 Conclusion

This dissertation provides important information regarding the PA participation of adolescents with ASD, and generated a understanding of physical (in)activity. As highlighted throughout the study, inactivity among these particular participants was not because they were naturally inactive, or drawn to sedentary activities as has been reported in the literature. Rather, participants generated a habitus of participation based on their interactions within various figurations such PA, family, school and the clinic. Informed by Elias' concept of the hinge, I've suggested that PA should not be reduced merely to bio-physical, psycho-behavioural or socio-cultural processes in isolation. To move beyond a reductive understanding of physical (in)activity among adolescents with ASD, I argue there is a need to consider the complexity of participation and consider the how bio-psycho-social interconnections interact to shape PA. Doing so provides a more nuanced understanding of PA participation which frames how PA is conceptualized, deployed, and implemented among adolescents with ASD.

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# Appendices

Appendix 1: Study Approval

**Holland Bloorview**
Kids Rehabilitation Hospital

Holland Bloorview
Kids Rehabilitation Hospital
150 Kilgour Road
Toronto ON Canada M4G 1R8
T 416 425 6220
T 800 363 2440
F 416 425 6591
www.hollandbloorview.ca

A teaching hospital affiliated with the University of Toronto

Holland Bloorview Research Ethics Board
**Ethics Approval Notification**

The Holland Bloorview Research Ethics Board operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans, the Ontario Personal Health Information Protection Act, 2004, ICH Good Clinical Practice Consolidated Guideline E6, and Health Canada Part C Division 5 of the Food and Drug Regulations

**Study Title:** Exploring physical activity participation among Canadian adolescents diagnosed with Autism Spectrum Disorder
**File Number:** 16-638
**Principal Investigator:** Barbara Gibson
**Co-Investigators:** Patrick Jachyra, Evdokia Anagnostou, Rebecca Renwick, Brenda Gladstone
**Original Approval Date:** August 5, 2016
**Expiry Date:** August 5, 2017
**Review Type:** Full Board

August 5, 2016

Dear Dr. Gibson,

The Holland Bloorview Research Ethics Board (REB) has reviewed the above named study. This was a full board review. The board is granting ethics approval for a period of one year. The approval of this study includes the following documents:

- Protocol (version dated July 27, 2016)
- TAHSN form received July 27, 2016
- Expression of Interest to Participate in Phase 2 (version dated July 27, 2016)
- Physical Activity Participation Questionnaire (version dated July 27, 2016)
- Demographic Questionnaire (version dated July 27, 2016)
- Cover Letter for DSS (version dated July 27, 2016)
- Informed Consent Form – Phase 1 DSS (version dated July 27, 2016)
- Cover Letter for POND (version dated July 27, 2016)
- Informed Consent Form – Phase 1 POND (version dated July 27, 2016)
- Invitation to Participate in Phase 2 (version dated July 27, 2016)
- Thank you and reminder survey follow-up Post-Card (version dated July 27, 2016)
- Telephone Script for Phase 2 – Study Invitation Phone Call One (version dated July 27, 2016)
- Social Story Outlining first meeting with Patrick (version dated July 27, 2016)
- Determination of Capacity to Consent Phase 2 (version dated July 27, 2016)
- Informed Consent Form – Phase 2 (version dated July 27, 2016)
- Sample Interview Guides – Visit One (version dated July 27, 2016)
- Suggestions for Taking Photos and Videos (version dated July 27, 2016)
- Interview Guide – Visit Two (version dated July 27, 2016)
- Outline for Interview Field Notes (version dated July 27, 2016)
- Initial Qualitative Data Analysis Guide (version dated July 27, 2016)

This study must be conducted in accordance with the description in the application and any supplementary documents for which ethics approval has been granted. The REB needs to be notified of any unanticipated or unintentional divergence or departures from the protocol through a "Protocol

Deviation Form". Any intentional changes to the protocol need be submitted through an "Amendment Form" to the REB for approval *before* the changes are implemented, except where necessary to eliminate immediate hazards to the participants.

Any adverse events that occur as a result of your study must be reported to the REB by submitting an "Adverse Event/Unanticipated Problem Form".
If the study is expected to continue beyond the new expiry date, you must request another renewal, at least thirty days prior to the expiry date, by submitting an "Annual Renewal Form". When the study is completed or terminated, you need to submit a "Study Closure Form" to the REB.
Best wishes for the successful completion of your project.

Sincerely,

Stephen Ryan, PhD, PEng
Chair, Research Ethics Board
P: 416 425 6220 x3526
sryan@hollandbloorview.ca

UNIVERSITY OF TORONTO

OFFICE OF THE VICE-PRESIDENT, RESEARCH AND INNOVATION

PROTOCOL REFERENCE # 33424

September 7, 2016

Dr. Barbara Gibson
DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE

Mr. Patrick Jachyra
DEPT OF PHYSICAL THERAPY
FACULTY OF MEDICINE

Dear Dr. Gibson and Mr. Patrick Jachyra,

Re: Administrative Approval of your research protocol entitled, "Exploring physical activity participation among Canadian adolescents diagnosed with Autism Spectrum Disorder"

We are writing to advise you that the Office of Research Ethics (ORE) has granted administrative approval to the above-named research protocol. The level of approval is based on the following role(s) of the University of Toronto (University), as you have identified with your submission and administered under the terms and conditions of the affiliation agreement between the University and the associated TAHSN hospital:

- Graduate Student research - hospital-based only
- Storage or analysis of De-identified Personal Information (data)

This approval does not substitute for ethics approval, which has been obtained from your hospital Research Ethics Board (REB). Please note that you do not need to submit Annual Renewals, Study Completion Reports or Amendments to the ORE unless the involvement of the University changes so that ethics review is required. Please contact the ORE to determine whether a particular change to the University's involvement requires ethics review.

Best wishes for the successful completion of your research.

Yours sincerely,

Daniel Gyewu
REB Manager

**Research Oversight and Compliance Office - Human Research Ethics Program**
McMurrich Building, 12 Queen's Park Crescent West, 2nd Floor, Toronto, ON M5S 1S8 Canada
Tel: +1 416 946-3273 ● Fax: +1 416 946-5763 ● ethics.review@utoronto.ca ● http://www.research.utoronto.ca/for-researchers-administrators/ethics/

Appendix 2: Recruitment Details

*Enhancing physical activity participation among youth with Autism Spectrum Disorder*

**Principal Investigator**: **Barbara Gibson,** Senior Scientist, Bloorview Research Institute, Toronto. 416-425-6220 ext 3342; bgibson@hollandbloorview.ca

**Co-investigator** and **Primary Contact* for the study:**
Patrick Jachyra, University of Toronto. 416-425-6220 ext; 3271 pjachyra@hollandbloorview.ca

***** This study is being done by Patrick Jachyra as part of his PhD. He is supervised by four senior researchers who make up the research team.

**Additional Co-Investigators:**
Evdokia Anagnostou, Holland Bloorview Kids Rehabilitation Hospital and University of Toronto

Rebecca Renwick, Occupational Science and Occupational Therapy, University of Toronto

Brenda Gladstone, Dalla Lana School of Public Health, University of Toronto

**What is this research study about?**

You are being invited to participate in **Phase 1** of this two part research study. Information about Phase 2 of this study can also be found at the end of this letter.

The **purpose** of the study is to explore the physical activity experiences of adolescents diagnosed with Autism Spectrum Disorder (ASD). Physical activity is any sort of movements you make with your body. Physical activity can include gardening, walking, riding a bike, sports, swimming, yoga, dancing, or fitness exercises such as lifting weights or jogging. Physical activity can be something you do with a coach or a teacher, or it can be done on your own, with a family member or a friend.

Adolescents with ASD tend to be less physically active than other kids their age which can affect their health. We are interested in learning about the kinds of activities that adolescents like you do and what things made it easier or harder for you to do them. Doing this research will help improve physical activity programs, and will create better physical activity opportunities for adolescents diagnosed with ASD.

**Who is being invited and how will I be involved in this study?**

We are inviting you to complete the survey that is included in this package. The survey is called the Physical Activity Participation Questionnaire. Your parents/caregivers can help you complete the survey. The questionnaire is to be completed when most convenient for you and does not have to be completed in one sitting. In total, we are inviting 625 girls and boys ages 12-19 years to participate in this study. It is important to that we hear from as many people as possible from across Ontario to get an accurate idea of the activities adolescents like you enjoy.

The survey asks questions about your physical activity. For example there are questions that ask which physical activities interest you and where you complete these activities. There are no 'right' or 'wrong' answers.

In this mail package, you will find a stamped envelope you can use to return the survey. When you are finished completing the survey, please put the survey into the stamped envelope and drop off the envelope to any Canada Post mailbox. Please return the envelope with the survey inside the envelope **within 1 week of receiving** this package. We will also mail you a post-card on two occasions to remind you to mail back the survey.

**Is it private?**

The survey is anonymous. Your name will not be on the survey and no one will know the answers you give. We will collect all the answers from participants and add them together. Only these collected responses will be shared with others.

By returning the survey, you are indicating that you/your parent consent to participate in

in Phase 1 of this research study. If you have any questions, please contact Patrick at 416-425-6220 ext 3271, or pjachyra@hollandbloorview.ca. If you have any questions about your rights as a research participant or about the study, please contact the Holland Bloorview Research Ethics Board Office at 416-425-6220 ext 3507.

If you decide to complete the survey, we thank you very much for your assistance. Your interest and assistance in this study is greatly appreciated!
Sincerely,

Patrick Jachyra

Appendix 3: Invitation to Participate in Research Phase 2

## Invitation to Participate in Phase 2

In addition to completing the survey, we are seeking **10 adolescent boys** between 12-19 years to participate in **Phase 2** of the study.

**Phase 2** participants will engage in two face- to-face interviews and attend three workshops to create a digital story about their physical activity preferences and experiences. A digital story is a short video about you. You will create this digital story with our help.

Participants will receive a $50 dollar gift card, and a copy of the digital story they create in acknowledgement of their participation.

To be eligible to participate in Phase 2 boys must meet the criteria here below:

- Be 12 to 19 years old
- Communicate verbally in English
- Comfortable to participate in a 60 minute verbal interview
- Live in the Greater Toronto Area
- Have experience using a video camera
- Have experience using a computer
- Can provide independent consent to be a part of the study

If you meet the criteria and are interested in participating in **Phase 2**, **please complete the information on the first page of the survey, and return it with the survey in the envelope.** Patrick will then contact you over the phone with further information and answer any questions you may have. You can still choose not to participate after this phone call. If you agree to participate in Phase 2 of this study, you also complete a consent form for Phase 2.

If you have any questions about the study, you may contact the study Coordinator Patrick Jachyra at 416-425-6220 ext 3271 or pjachyra@hollandbloorview.ca.

Thank you very much for your time and help. We look forward to hearing back from you. Your interest and assistance in this study is greatly appreciated!

Appendix 4: Information Form to Participate in Research Phase 2

## Information Form Phase 2

**Study Title**: *Enhancing physical activity participation among youth with Autism Spectrum Disorder*

**Principal Investigator**: **Barbara Gibson,** Senior Scientist & Research Chair, Bloorview Research Institute, Toronto.

**Co-investigator** and **Primary Contact* for the study:**
Patrick Jachyra, University of Toronto. 416-425-6220 ext 3271; pjachyra@hollandbloorview.ca

***** This study is being done by Patrick Jachyra as part of his PhD. He is supervised by four senior researchers who make up the research team.

**Additional Co-Investigators:**
Evdokia Anagnostou, Holland Bloorview Kids Rehabilitation Hospital and University of Toronto

Rebecca Renwick, Occupational Science and Occupational Therapy, University of Toronto

Brenda Gladstone, Dalla Lana School of Public Health, University of Toronto

### What is this study about?

The **purpose** of the study is to explore the physical activity experiences of adolescents diagnosed with Autism Spectrum Disorder (ASD). Physical activity is any sort of movements you make with your body. For example, physical activity can include gardening, walking, riding a bike, tai-chi, sports, swimming, yoga, dancing, or fitness exercises such as lifting weights or jogging. Physical activity can be something you do with a coach or a teacher, or it can be done on your own. Some adolescents do physical activity with a family member or a friend.

Adolescents tend to be less physically active than other kids their age which can affect their health. We are interested in learning about the kinds of activities that adolescents like you do, and what things made it easier or harder for you to do them. Completing this research will help improve programs and services, and create better physical activity opportunities for adolescents that meet your preferences and abilities.

You are being invited to participate in **Phase 2** of this study. The study will include twenty boys and twenty girls diagnosed with ASD between the ages of 12-25 years.

**How will I be involved in this study?**

In Phase 2, participants will create a digital story (similar to a YouTube video) about themselves and the activities they do. A digital story is a video that you will create with our help. There are 5 components to the study: 2 interviews and 3 digital storytelling workshops.

The total time of participation is approximately 15-20 hours in **Phase 2**. Each component of the study is explained below in detail. The chart below also provides you with an idea of what you will be doing.

1. **Participate in an introductory discussion**:
   Patrick Jachyra will meet with you and your parent/caregiver at a date and time that best works for you. This meeting will allow you to get to know me, and for me to get to know you as well. This meeting will take place at your home or any other location you would like. During this meeting, I will provide you with more information about the study and answer any questions you may have. You have the choice if you would like to participate in this study. If you agree to participate and understand what the study is about, you will be asked to sign the consent form that is below.

   After we discuss the details of the study, we will then have a chance to chat. I will ask you to describe what sorts of activities you do during the week. I will also ask if you have any favorite physical activities. You will also be able to ask me if I have any physical activities I enjoy. This discussion will take about 1 hour. It will be recorded and written out later so we can remember what you said. There will be plenty of time for you to take a break during the interview. You can take as many breaks as you need.

2. **Attend First digital storytelling workshop**:
   After I meet you, I will let you know a date and time to meet me and the other participants in the study to attend the first digital storytelling workshop in downtown Toronto. During this workshop, staff from the Digital Stories Toronto will explain how to create a digital story. Staff will also show you examples of a digital story, and will explain how you will create your own. During the workshop, Patrick and the Digital Stories Toronto staff will provide you with a guide that will give you some ideas about what sorts of videos and photos you might want to include in your digital story. The first workshop will be 3 hours long. There will be plenty of time for you to take a break during the workshop as well. You can take as many breaks as you need. **It is important to attend all 3 digital storytelling workshops when they are scheduled.**

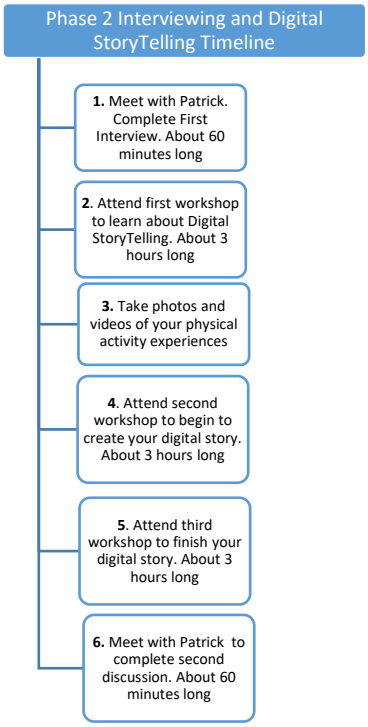
   After the first workshop Patrick will meet with you and lend you with a camera that can take both videos and photos. You will have two weeks to take videos and photos of the places, activities, and people as they relate to physical activity outside of school time. When you are done this part, Patrick will collect the camera from you. He will bring your photos and videos to the next digital storytelling workshop so that you can create your digital story.

3. **Attend Second digital storytelling workshop:**
   During this second workshop, you will look through your videos and photos, and decide which ones you would like to include in your digital story. The staff at Digital Story Telling Toronto will help you write a script of your digital story. They will also record your voice reading the script. Your voice will tell the person who is watching your video what is going on in the digital story. A draft version of your digital story at the end of the second workshop will be created. This second workshop will be 3 hours long. There will be plenty of time for you to take a break during the workshop as well. You can take as many breaks as you need.

4. **Attend Third digital storytelling workshop:**

During this final workshop, the Digital Storytelling Toronto staff will help you edit your digital story. Your digital story will be around 2 to 3 minutes long. You can make your digital story shorter than 2-3 minutes if you would like to. You will be able to keep a copy of your digital story and use it however you like. This final workshop will be 3 hours long. There will be plenty of time for you to take a break during the workshop as well. You can take as many breaks as you need.

5. **Final Meeting and Discussion with Patrick:**
The second discussion will happen after the third and final digital storytelling workshop. The discussion will take place at your home, or any other location you choose. We will first watch your digital story together, and then discuss it. I will ask you questions about how you were feeling when you took the videos and photos. I will also ask you to tell me about some of the things you included in your story. When we are finished the interview, I will give you a $50 dollar gift certificate and a DVD copy of your digital story to thank you for participating in this study. This final visit with you will be about 1 hour. There will be plenty of time for you to take a break during the interview if you would like one.




**Will anyone know what I say or do in this study?**

All information we collect about you and your family will be kept private. Your name will not be used. Instead, I will ask you to choose a pretend name for yourself (a pseudonym) for the study. This way, your identity will not be available to anyone. If you do not want to choose a pretend name for the purposes of the study, I will choose one for you.

During our discussions, I will use a voice recorder to record the interviews. I will then transfer the audio-recordings to a secure computer at Holland Bloorview Kids Rehabilitation Hospital. The recording on the device will be written out word for word and then deleted from the voice recorder to keep your information private. Only researchers who are a part of the project will know what you said. No names or any other information that identifies you will be included in any documents. All information we collect will be kept in a locked cabinet and on a secure server

at the Bloorview Research Institute at Holland Bloorview Kids Rehabilitation Hospital. I will delete all information seven years after the study ends. I will not make public anything that might identify you or your family, unless legally required to do so.

During the digital storytelling sessions, we will do everything we can to keep your information private. When study findings are published or publically presented for education purposes, your name and identifying characteristics will not be used. I will take all necessary steps to protect your identity. If you do not want to have your digital story used as a way to share the findings of the study please put a checkmark in the NO box of the consent form. To help keep your information private, Patrick will only provide the Digital Storytelling Toronto Staff your first name. While I will work to keep all of your information private, it is important to understand that your privacy is not guaranteed when working with the other adolescent girls and boys in this study. It may be possible that some of the other study participants share information about themselves with you. To minimize the sharing of information, Patrick and the Digital Storytelling Toronto Staff will remind all study participants to keep information they learn about others private.

**Do I have to participate?**

Taking part in this study is completely voluntary. Participating in this study will not affect the care you receive from Holland Bloorview Kids Rehabilitation Hospital. You can change your mind and stop participating in this study at any time. No one will be upset with this decision. If you choose to withdraw from the study, you will be asked if you want all your data (interviews, digital stories) to be removed from the study. If you choose to remove your data, it will be destroyed.

**What are the risks and benefits?**

There are no direct benefits to participating in this study. If you become uncomfortable during the discussions in your home or digital story making, then you can take a break or stop the interview/digital story creation at any time you wish. There is a small chance you could become upset when talking about some of the challenges of participating and or not participating in physical activity. Time will be included in sessions to discuss any issues, and the interview will be stopped if needed. If you become upset in the interview, we will stop the interview and ask your parent/guardian, or someone else you choose, to join us to talk about your feelings. If necessary, I will refer you to a social worker at Holland Bloorview Kids Rehabilitation Hospital. By agreeing to participate in this study, you have not waived any rights to legal recourse in the event of any research-related harms.

**What if we have questions?**

If you have any questions about the study, you may contact Patrick Jachyra at 416-425-6220 ext 3271, or pjachyra@hollandbloorview.ca. If you have any questions about your rights as a research participant, please contact the Holland Bloorview Research Ethics Board Office at 416-425-6220 ext 3507.

Thank you very much for your time and help.

Sincerely,

Patrick Jachyra

Appendix 5: Capacity Assessment Guide

## DETERMINATION OF CAPACITY TO CONSENT PHASE 2

Prior to seeking consent, Patrick Jachyra will determine if the adolescent is capable of providing consent to participate in the study. This assessment will also be used in part to determine the child's ability to engage in study activities and what supports may be needed. Participants will be reminded that we need to determine eligibility to participate by assessing their understanding of the study. If they are assessed as incapable, they will be informed that they are ineligible and will be directed to the Holland Bloorview Kids Rehabilitation Hospital website 'participate in research page' for information on other active studies if they are interested. During the scheduled appointment, Patrick Jachyra will engage in the following activities with the participant:

1. Introductions
2. Provide an overview of the visit
3. Review the information letter and study details in conversation with the child and caregiver.
4. Encourage and answer all questions and re-explain any information that is not clear.

The following conversation will be used to asses capacity to consent along with the following questions.

- Can you tell me what the study is about?
- Who can be a part of this study?
- Why do you think we are doing this study?
- How will we keep your name private?
- Who will know what you say?
- Do you have to join the study?
- Can you change your mind later about being part of the study?
- Who can tell you more about the study if you have questions?

Note, an 'incorrect' answer will not necessarily be construed as incapacity but will cue the study coordinator to re-explain and reassess. A final determination about capacity to consent will be made by Patrick Jachyra.

Appendix 6: Social Story Outlining first meeting with Patrick

Participating in Research about Physical Activity

Hello. My name is Patrick.  I am a researcher from Holland Bloorview Kids Rehabilitation Hospital. I am doing a study to learn how adolescents like you move and play in physical activity.

Physical activity is any movement you make with your body. For example, physical activity can include gardening, walking, riding a bike, sports, swimming, tai-chi, yoga, dancing, physical fitness exercise such as lifting weights or jogging. Sometimes these movements make you hot, sweaty and tired. Physical activity can be something you do with a coach or a teacher. Physical activity can also be done by yourself. Some adolescents also do physical activity with a family member, or a friend.

In the next few weeks, I will be coming to your home to meet with you. This meeting will allow you to get to know me better. The meeting will also allow me to get to know you better.

When I come to visit you, I will ask questions to see if you understand what the study is about. If you understand the study and would like to take part in the study, then I will ask you to sign an informed consent form. If you change your mind during my visit and decide you do not want to participate in the study, that is okay. No one at Holland Bloorview Kids Rehabilitation Hospital or in your family will be upset or angry with you if you decide you do not want to participate. You can stop being a part of the study at any time.


If you agree to be a part of the study, we will talk about which physical activities interest you. We will also discuss what sorts of physical activities you are currently doing, have done in the past or would like to do in the future. After talking about which physical activity you find

interesting, we will talk about how you will create digital stories as part of this study. For more detailed information about the study, please read the informed consent form I have sent to your parent/guardian. If you have any questions before our meeting or about the study please call me at 416-425-6220 ext; 3271 or email me at pjachyra@hollandbloorview.ca

Thank you for helping me with this study. I look forward to meeting with you and learning from you.

Appendix 7: Consent Form Phase 2

**Study Title**: *Enhancing physical activity participation among youth with Autism Spectrum Disorder*

By signing this form, we agree that:

1) I have read the information package dated [ ] and understand what this study is about. All of my questions have been answered.
2) I understand the known risks and benefits of participating in this study.
3) I am free now, or in the future to ask questions about the study.
4) I understand that I may drop out of this study at any time for any reason.
5) I agree to participate in the study.
6) I would like to have my digital story used for future research purposes (please circle the yes or no box).

☐ Yes ☐ No

_____ _____ _____

Participant's Name (please print) Signature Date

I as the parent of _____ (Print child's name) support my child to participate in this research study.

_____ _____ _____

Parent's Name (please print) Signature Date

_____ _____ _____

Investigator's Name (please print) Signature Date

Version date: July 27, 2016 REB#: 16-638

Appendix 8: Interview 1-Sample Interview Guide

**Visit One-** Interview guide for a sample participant

Today, I'd like to get to know you a little bit. Together, you will also get to know me a little bit better as well. We are going to talk about some of your favorite activities and physical activities outside of school time.

1. Tell me about yourself
   - Who is in your family? Probe re: extended family and friends, pets, caregivers?
   - What kinds of things do you really like to do? Do you have any activities or interests that you really like? What are you really good at? Which activities make you feel really good about yourself?
2. What are some of the activities you do on a weekday and weekend? Ok, now let's talk about what a school day usually look like for you.
   - Probe getting up and ready for school, including timing, school location, transportation, social and communication networks at school, classroom type, assistance/support at school, fieldtrips, clubs or extracurricular activities, school peers/friends/helpers, favourite/least favourite subjects, general accessibility issues
   - What do you usually do after school – typical evening routines and activities, with who, where in home, tightly structured care routines vs. variable and relaxed, time for leisure

   Now let's think about a usual week – are there differences between the days of the week?
3. What about weekends? Tell me about some of the things you do on the weekends. What does it look like for you.
4. What are some of your favorite physical activities at school, outside of school?
5. Do you do physical activities on your own, with friends, or as part of a team?
6. Where do you usually do physical activities?
7. When do you do physical activities? –Afterschool, on the weekend?
8. How often do you usually do physical activities?
9. After you finish doing physical activities, how do you usually feel?
10. Does anyone else in your family do physical activities?
11. What are the things that make enjoy physical activity?
12. What are some of the things that make not like physical activity?
13. Ask participant if they have any questions for Patrick about his favorite activities?
14. End with review of next session – Remind participant about attendance at digital story telling workshop.

Appendix 9: Outline for field note taking procedure

**Exploring physical activity participation among Canadian adolescents diagnosed with Autism Spectrum Disorder**

Study Pseudonym: _____ Date/Time: _____

Length of Interview:

Who was present?

Description of location and people:

Off tape Observations and non-verbal interactions:

Summary (primary issues/ themes):

Reflections on Process and Content (what worked well and what didn't, what was going on):

New Issues (e.g., change wording or order of questions, any other issues):

Other:

Appendix 10: Suggestions for taking photos and videos

What you will do for two weeks:

- Take videos and photos of the places, activities and people where you do physical activity outside of school time. Physical activities are movements you create with your body and can be done alone, in a group setting or in a team setting. Some examples include: swimming, horseback riding, dancing, yoga, sports, gardening, walking, weightlifting, or martial arts.

What Videos/Photos should I take?

- You can take the videos /photos yourself, or ask someone else to take them for you. But you should decide what videos/photos to take. You can be the director and also put yourself in the photos. It is up to you.
- There are no right or wrong videos or photos we are looking for. All is welcome.
- If you participate in organized physical activity/sport (being on a team or having lessons), please also include those videos/photos.
- If you do not participate in organized physical activity (being on a team or having lessons), please include what sorts of things you do to be physically active.
- Include activities that made you feel really good AND not so good about yourself.
- You can include your own photos that you have taken before that tell important things about your life.

Some Suggestions For Taking Videos/Photos:

- The place where the physical activity or physical activities takes place such as your home, recreation centre, friend's home.
- You doing the activity.
- People such as friends, instructors, coaches, parents who are with you when doing physical activities.
- Videos and photos that shows how you imagine physical activity to look like, sound like, and feel like.
- Videos and photos that show what physical activity means to you and if it is important or not to you.

How often should I take photos during the two weeks?

- Try to take videos/photos at least once each time you do some sort of physical activity outside of school time. For example, if you are doing things at home, at a relative's house, or at a recreation centre, then try to bring the camera and take photos in each those places.

- Take videos/ photos that tell important things about YOU. A few videos/photos that tell about you, your daily routines and the places and people that life will be better than a hundred photos of everything you see.
- Think about taking 10 – 20 video clips and photos.

* IMPORTANT**

You NEED TO explain the study to anyone you want to include in your videos/photographs and get their permission first. This includes teachers, coaches, friends, family members. You can tell them that you are participating in a research study to learn more about physical activity experiences among adolescents.

If they do not agree to be in the video/photo, please DO NOT include them in your photo.

If anyone has any potential questions about with study, please provide them with my business card and they can contact me.

**CALL OR EMAIL ME IF YOU HAVE ANY QUESTIONS**

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Appendix 11: Interview 2-Sample Interview Guide

**Interview Guide for a Sample Participant**

**[individualized according to the digital story data generated by the participant]**

1. You took a lot of videos and photos inside and outside of your home when doing physical activity.

    - How did you choose which parts of your home you wanted to include in the film?

    - How did you choose which photos you wanted to take inside of your home? Can you tell me about your home?

2. Can you tell me about the physical activity you did with your younger sister and her friend?

    - Was there anyone else with you?

    - How often do you guys spend time together?

    - What made you choose this physical activity?

    - What made you do complete this activity with some friend and not alone?

    - Imagine being back with your sister and her friend. Think about what if felt like. What should the title be for this part of the digital story if you were to give it a title? *[show participant a couple of generic captioned photos of youth like the example below to explain the concept if needed]*

    - What are some good things about the place, group or activity in the photo? What are some 'not so good' things that you feel?

    - Do you do other activities together with these people? (what kinds of things and where)

3. You included a long part of the digital story showing you doing yoga in a park alone. Can you tell me about this part of the digital story?

    - What made you choose yoga to show you being physically active?

    - Where did you learn to do yoga?

    - Why that particular park? What is in that surrounding environment that makes you comfortable to do yoga there?

    - Why yoga and not another activity such as hockey or walking your dog?

    - How do you feel after doing yoga? Physically (relaxed) and emotionally (grounded)?

    - What are some of things that encourage you do to yoga?

- What are some of the things that might get in the way of you doing yoga?
- How does yoga fit in your daily life? When do you usually do it- before school, afterschool?
- Is physical activity important to you? Why?
- What does doing a physical activity like yoga give you that you cannot receive or achieve when playing on the IPAD or a computer game?
- If a friend asked you to suggest a physical activity to them, what would that be?
- Do physical activities have to structured based on what a doctor told you like you said in the digital story, or can it be more open where you create physical movements with your body?

ABOUT TAKING THE VIDEOS AND PHOTOS

- How did you find making the digital stories? Probe: Hard, easy, fun, boring
- Was this the first time you took videos/photos?
- Did it make you think of those people, places or activities differently?
- How did you decide to take the videos/photos you took?
- Did anyone help you? How?
- Did you do things or go places where you didn't take photos (outside of your home)? What were some of the reasons why you couldn't/didn't want to take some photos?

**General questions**

- What or who is potentially missing?
- Are there ideas in these digital stories that you would want to share with other people? What are the most important things that these digital stories tell about? How would you change the story told in your digital story to make it better for YOU?
- Are there things in the digital story (or part of your life but not in the digital story) that you wish you could change? Can you tell me about that?
- Is there anything else that we haven't talked about today that you think I should know about?

Appendix 12: Qualitative Data Analysis Guide

**This is an initial, not complete, listing of questions, topics and issues that will 'asked' of the data during the coding of analysis.**

1. What are the everyday routines of these adolescents? What do they look like?

2. What are the material conditions of their everyday lives e.g. housing, modes of transportation, school placement, socioeconomic status.

3. What are the ways that adolescents self-identify? Same, different, able/disabled, part of which groups, outside of which groups. How do they describe themselves? How do they relate to labels such as disabled, disordered, impaired, special needs? Do they identify with 'mainstream' physical activity or different stream?

4. Who is part of their social and physical activity networks, how often, in which settings?

5. How are adolescents exposed to physical activity? By whom: self-initiated, parents, teachers, peers, therapists.

6. What sorts of physical activities are adolescents participating in?

7. Where do adolescents go to participate in physical activity, when and how often? Are these activities individual, collective? Are physical activities recreational or competitive?

8. How do youth describe experiences of physical activity participation? What terms do they use, do they enjoy or dislike physical activity? Why and how so? Are there specific places where they enjoy or do not enjoy being physically active? What ambiguities or contradictions are found in their interviews and digital stories.

9. Do adolescents diagnosed with ASD potentially prefer to be inactive, and is this okay?

10. How and where is power enacted in their everyday lives? By who, how do those in power enable or constrain adolescents in physical activity? How do youth access and use power to meet their goals, and or objectives.