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Participation and inclusion in extracurricular physical activities: An ethnographic study alongside children with disabilities

Katherine Westwood

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Declaration

I Katherine Westwood declare that this thesis has been solely composed by myself. Additionally, the thesis has not been previously submitted, in part or whole for a previous degree application. The work in the thesis is my own, except where there is reference or where it is stated as such.

Katherine Westwood
30. 11. 21

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Abstract

The aim of this thesis is to explore how children with disabilities experience their participation in extracurricular physical activities. The thesis closes a gap in literature by contributing an in-depth year-long collection of lived experiences of extracurricular physical activities which was developed alongside children with disabilities in London Ontario. Knowledge was created alongside 10 children with disabilities by utilizing an ethnographic methodology. Multi-site ethnography was adapted for each participant's needs and communication methods. The methodology contributes to literature by a creative adaptation to interviewing children and having a flexible approach to methods which was chosen by the children themselves.

The thesis answers what inclusion looks like as a lived experience in extracurricular physical activity environments, along with how adults and children create opportunities and constraints for children's recognized participation. The analysis identified that there is a gap in understanding between literature of participation and inclusion and children with disabilities knowledge and preferences. Additionally, findings indicate that children with disabilities that communicate non-verbally experience inclusion differently than children with disabilities who communicate verbally. The knowledge created builds on literature of various attitudes and beliefs of children with disabilities by providing a further in-depth connection to lived experience, participation and inclusion opportunities.

The thesis concludes by emphasizing a flexible approach to creating knowledge alongside children with disabilities, and more specifically advocating for more inclusion of children who communicate non-verbally in research. The thesis suggests an emphasis for continuous communication to understand changing perceptions of participation and inclusion from the perspectives of children themselves and how it is shaped by the surrounding environment and interactions.

Lay Summary

The thesis focuses on the experiences of children with disabilities in extracurricular physical activity environments, specifically regarding their participation and inclusion. There were 11 physical activity environments, some examples include, horseback riding, hockey, skiing, swimming, lawn bowling and baseball. For data gathering a multi-site ethnography was used relying on observations, interviews and fieldnotes.

Through the experiences of 10 children with disabilities and their coaches, parents and volunteers, key themes emerged around participation and inclusion. Ethnography allowed for the discussion of the processes regarding choice, participation and inclusion in relation to the experiences of children with disabilities in these extracurricular physical activities.

Motivations of key participants, training and understandings of one another played a role in the interactions that took place. It was observed that participation happens through a process of negotiations. Based on the observations, interviews and fieldnotes, there are findings that will have implications for training of coaches, provision of adaptations for children in extracurricular physical activities, and the importance of listening to the children's voices.

The thesis gathered new data on the perspectives and understanding of implementing inclusion. The various perspectives of the stakeholders did not always align, and the thesis calls for inclusion to be defined by the participant who is experiencing inclusion or exclusion. The thesis found that inclusion and exclusion can co-exist, and at the forefront of any analysis should be the views of the person experiencing the inclusion or exclusion.

The underlying aim of the thesis is knowledge exchange, to bridge the gap between theory and practice, by incorporating understandings of inclusion, participation and bringing

children's rights further into society. It is recognized that there may not be a one size fits all approach towards inclusion and participation, and the emphasis should be on information sharing techniques to improve relationships, based on mutual respect, with a common goal of furthering a participation and inclusion agenda.

Chapter One: Exploring Literature: Participation Theories for Children and Young People

1.1 Reflecting on my experiences that directed me towards the thesis

The thesis takes an ethnographic approach to learning and understanding, alongside children with disabilities about participation in extracurricular physical activities. Through the various stages of the ethnography, reflexivity allowed me to question my position in the knowledge creation process (Berger 2015, Rose 1997). Therefore, before the details of the thesis begin, I will reflect on my own life experiences and introduce myself as I will be situated in the ethnography. I consider this important as my life experiences invariably have shaped my approach to this thesis and the motivations towards researching this topic.

The journey of my experiences in relation to this thesis began when I was 14 years old having started to volunteer at a therapeutic horseback riding centre for people with disabilities. I was a horseback rider myself and I needed volunteer hours to graduate high school, I saw this as a great opportunity to do something I enjoyed and to be around horses. I began at the centre as a volunteer, gradually progressing to coaching and earning national certification for coaching therapeutic horseback riding in Canada. Through this process, and in many different roles, I observed various was in which the environment of this extracurricular physical activity choose to engage with children with disabilities. Starting as a child myself at 14, I was perplexed at the difference in how coaches would talk to myself and how they would talk to people with disabilities. As a volunteer I was tasked with supporting the coaches, coaches would sometimes vent their frustrations about people with disabilities to myself. I remember feeling uncomfortable when they would discuss positive or negative

developments about people with disabilities with myself as I thought even as a child that the person with a disability should be included in this conversation. My passion for improving the connection between the coach and participant started, I pursued my certification in coaching to hopefully start to close this gap. With over a decade of experience coaching, I noticed that an accepted and encouraged top-down approach to the coaching of people with disabilities was not effective for all. I observed that many coaches would leave people with disabilities out of conversations about their goals for horseback riding, approaches to inclusion and adaptability. The approach rarely encouraged the coach to seek the views of the athlete regarding their experience which raised my curiosity about the process of participation and inclusion. These early observations prompted me to my undergraduate interest in childhood studies and social institutions and disability studies. As I started to learn more about children's rights, disability rights, and participation theories, I began making links between the literature and practice. I noticed that often when discussing participation and inclusion in extracurricular physical environments, the process and perspective of children with disabilities was often missing. There was seemingly no desire to include children with disabilities in the conversation about their participation and inclusion. When I became a coach, I would sometimes encourage them to have conversations with their students about their preferences for participation and inclusion, this was often met with a push back as coaches positioned themselves as the experts. I was hoping that the research could show opportunities for flexibility of coaches, volunteers, parents, and children with disabilities and where inclusion and participation is working for all. I wanted to continue my exploration and understanding about the gaps between theory and practice, in particular from the perspective of children with disabilities which led me to a MSc in Childhood studies at the University of Edinburgh, and further to this PhD thesis. Whilst I explored more academic

theory, I became more interested in understanding what the lived experience of participation and inclusion was.

1.2 Aims of the Chapter

The initial chapter provides an overview of the literature and theories that are linked to the exploration of participation, specifically in childhood. The concept of participation is frequently ill-defined, incorporating multiple meanings that result in a "variable construct" (Percy-Smith and Thomas 2010a, p.357). The exploration will review participation through a rights context, in literature, various theoretical models, and agency. The chapter will not offer a single definition of participation, but instead offers differing opinions on what is currently known about participation to understand key tensions and recurring themes.

The starting point for the discussion on the term participation will be through the UN Convention on the Rights of the Child (UNCRC) (1989). The focus on participation rights to begin is important as it influences the 'new sociology of childhood', which has had an impact on literature, implementation, and research. The section will discuss key considerations and tensions between the UNCRC and practice.

The chapter moves onto discuss participation models that have been prominent in literature, offering different understandings of how participation is experienced amongst children. The models provide insight into different viewpoints on how participation should be labelled.

There will then be a discussion on children's agency and the interplay of adult-child relations. Children's agency is often talked about in relation to participation and is important in understanding why children may act. The section concludes with a discussion on lived experiences and how the understanding has further developed this research study.

Throughout the chapter I identify gaps and tensions in the literature and understandings of participation that have guided the formation of the research questions.

1.3 Exploring, Implementing and Understanding Participation (Approaches to Participation?)

The purpose of this section is to develop an understanding of varying approaches to the term participation and its impact on childhood. The focus will be on the United Nations Convention on the Rights of the Child (1989), as it is widely cited in literature, and Canada ratified the UNCRC in 1991. For context, I first explored what the UNCRC states regarding participation, followed by the links between the UNCRC and literature, specifically when discussing views of children.

1.3.1 Participation according to the UNCRC

The UNRC consists of fifty-four articles, and three Optional Protocols, that encompass cultural, civil, economic and social rights (Hill and Tisdall 1997). The rights surround four fundamental elements: best interests of the child, respect for children's views, non-discrimination and right to life and development (James and James 2012). Additionally, these rights have been grouped by '3P's' which are participation in their community and in their families, protection against abuse and neglect, and provision of basic needs (Alderson 2000).

The UNCRC introduced and recognized participation as a right (UNCRC 1989), although the phrase 'children's participation' is not in the text (Sinclair 2004). However, children's participation is not new and can be seen historically in different settings such as schools, homes, communities, and work (UNICEF 2003, p.3). Article 12 of the UNCRC is often cited in regards to children's participation:

> 2 "States parties shall assure to the child who is capable of forming his or her own views the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.
> 3 For this purpose the child shall in particular be provided the opportunity to be heard in any judicial and administrative proceedings affecting the child, either directly or through a representative or an appropriate body, in a manner consistent with the procedural rules of national law."
> (UNCRC 1989, Article 12)

The specific requirement to ensure that children's views are considered, was an addition (Tisdall et al. 2014). The 'participation right' of the child is significant, as it is in addition to the rights of protection that assures the welfare of the child (Quennerstedt 2010, p.627), Furthermore, the convention states the importance of children's perspectives and stresses the need to consider when decisions are being made which affect their lives (Krappmann 2010, p.512).

The UNCRC has been debated in the literature as some argue that participation was not clearly defined (Tisdall 2014). In response, the United Nations General Assembly in 2009 clarified the definition of participation in relation to Article 12 of the UNCRC.

> "This term has evolved and is now widely used to describe ongoing processes, which include information sharing and dialogue between children and adults based on mutual respect and in which children can learn how their views and those of adults are taken into account and shape the outcome of such processes."
> (UNCRC 2009, p.3)

The General Assembly comment presents a view of children as a subject rather than an object needing help from adults (Freeman 2011). Cornwall and Coelho (2007) also defined participation similarly as "…a process over time, animated by actors with their own social and political projects" (Cornwall and Coelho 2007, p.10). The General Assembly's definition includes respect, learning, and dialogue adding to the importance placed on participation.

With the relevance of Article 12 of the UNCRC to children's participation, it will be cited regularly within this thesis. There are other articles of the UNCRC that support and strengthen Article 12, such as Article 13 freedom of expression, Article 14 freedom of thought, Article 15 freedom of association, and Article 17 the right to information (Flekkoy and Kaufman 1997; UN Committee on the Rights of the Child 2009, Tisdall 2015b). Furthermore, within the preamble the UNCRC states:

> "everyone is entitled to all the rights and freedoms set forth therein, without distinction of any kind, such as race, colour, sex, language, religion, political or other opinion national or social origin, property, birth or other status."
> (UNCRC 1989, preamble)

The preamble provides that the convention covers all children, which is an important clarification, that all children have the same rights.

The UNCRC definition of participation is a good first step to understanding participation; however, the UNCRC is "not something to preach, but something to analyse" (Quennerstedt 2010, p.239) The following sections of the thesis will start an analysis on the UNCRC through key themes and tensions.

1.3.2 Key Themes

One criticism of the UNCRC is that it ignores a child's culture by being embedded in an "abstract universalism", meaning it incriminates certain cultures (Nieuwenhuys 2008, p.4). This is problematic, because inclusion, from a rights perspective, can be described as every citizen having the right to participate, and this right is community encompassing (Jerlinder 2010). For human rights to be contextually relevant, De Feyter (2007) suggests human rights need to be contextual and localized through a bottom-up perspective that reflects the needs of the local community. As well, children at this local level would ideally be able to be impacted by the international implementation of rights from a rights based perspective (Hanson and Nieuwenhuys 2012). The living rights concept is critical, as it takes into account

this power dynamic, of a global perspective and a local concern, of what children's rights should be (Hanson and Nieuwenhuys 2012). It challenges the idea that children are rights holders (Hanson et al. 2016) and are granted agency because of universal international institutions, which ignores their experiences of exercising their rights prior to knowledge of rights (Hanson and Nieuwenhuys 2012). As seen through living rights, the UNCRC can be contradictory to specific cultures, traditions, and societies. It has been argued that the UNCRC has emerged out of a Westernized, romanticized, developmental and paternalistic view of childhood (McNamee 2016, Woodhead 2006). Westernized views of children can be problematic, an example being child workers in the 'Global South' as the right to 'protection from labour' may have serious consequences for children's lives (Liebel 2008). Children may then work illegally, or in unregulated work environments, as they may need or want to earn (Wall 2016).

In relation to Article 12 of the UNCRC, it is worth noting the adults' ability to determine a child's capability of forming their own views (Hanson 2012, p.63) and the adults' ability to define appropriate age and maturity (UNCRC 1989, p.5). The terms of age, maturity, due weight, capability of forming their own views, and even what is deemed to be matters that affect the child, can be the subject of debate by adults. "Age is frequently used as a proxy for competence" (James and James 2012, p.30). This may be a false equivalence, as competence can be linked to social experiences rather than a chronological age. It has been suggested that competence could be seen as, "the ability, capacity or qualification to perform a task, fulfil a function or to meet the requirements of a role to an acceptable standard" (James and James 2012, p.29). There is a tension between the right to express a view in decision making and the inclusion of a safeguarding caveat for maturity and age (Majstorovic 2014, Warming 2017). The UNCRC decision to leave the decision making power with adults in regard to participation has sometimes been limiting, as adults continually underestimate

children's competencies (Lansdown 2005). Age discrimination laws have been implemented for elderly populations, although for children there has not been a similar practice (Liebel 2014).

The UNCRC is written with a top-down rights based approach, which some adults believe is reflecting an acceptable form of childhood (Frankel 2017). McNamee (2016) offers the idea that inverting the way the UNCRC is written would offer a different perspective to the rights. A visualization of this was created by Frankel which can be seen in Figure 1.
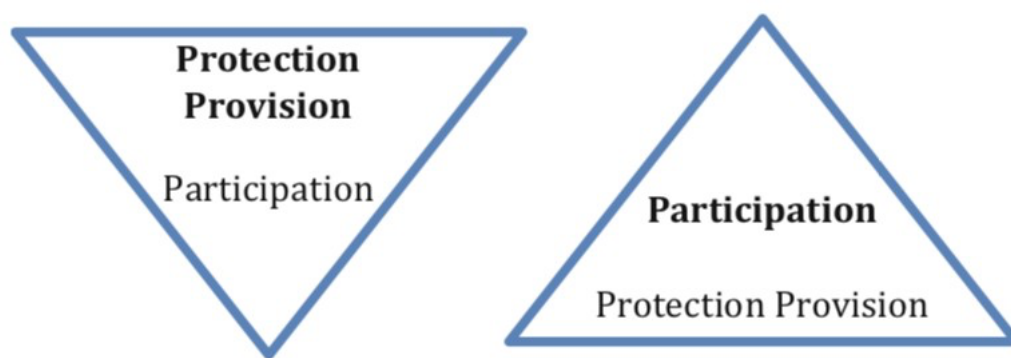
Figure 1 Visual of reconceptualizing the UNCRC (Frankel, 2017 p.253)

Figure 1 highlights that participation has been developed out of provision and protection, reflecting adults' control over child's engagement in participation (Frankel 2017). It has been suggested that participation is often approached in this top-down way (Malone and Hartung 2010). In the development of the UNCRC, children had no involvement (Wyness 2018). Top-down approaches to participation are often described more accurately as 'consultation' (Thomas 2007b). When moving participation to the top of the triangle, children would be in a position of power to develop their protection and provision rights offering a new starting point with children's agency at the forefront (Frankel 2017). This is of importance as protection and provision have defined participation and "enables a model in which adults maintain control over the nature of children's engagement in society" (Frankel 2017, p.254). Additionally, as children were previously excluded from human rights' agendas, children having their own convention, is in itself reinforcing the differences

between adults and children (Cockburn 2013). If the triangle was inverted, children would have been involved in the development of the UNCRC.

> "It is only by engaging with the child that we can overcome adult assumptions about children's best interests and start to engage with children on a level that really starts to ask them what is in their best interests and offers models through which this can be converted into practice."
> (Frankel et al. 2015, p.43-44)

There is a gap noted between the Convention and practice (Blaisdell and Bolger 2020, Freeman 2000, Konstantoni and Patsianta 2019), which includes the creation of the UNCRC as during the creation, children were not involved. However, there are more implementation tensions surrounding the UNCRC which will be discussed in the following section.

1.3.3 Key Tensions

Globally projects, have been developed to promote children's participation (Percy-Smith and Thomas 2010a). There have been numerous activities at local, national, and international levels that facilitated children's participation in the decision-making processes (Tisdall et al. 2014). An emphasis has been placed on children's collective decision making; however, children's participation as a concept also included individual decision making (Cleophas and Assim 2015, Taylor et al. 2007, Tisdall 2015b). It has been argued that there is a potential lack of reflection on children's experiences:

> "Participation is generally seen as 'a good thing', and different participation projects are uncritically accepted as making a positive contribution to the (undefined and assumed) purpose."
> (Cairns 2006, p.218)

The UNCRC is seen as implementing participation into children's lives; however, "it is far from being realised in our actions" (Pascal and Bertram 2009, p.261). One reason children's participation is viewed as being limited is when the discussion is based on just "talking, thinking and deciding" (Alderson 2008, p.79). This limitation has been criticized, as

it can leave out certain groups of children such as young children and children with disabilities (Alderson 2008).

Ratifying the UNCRC makes it legally binding for the particular country; the convention has been ratified by most countries, excluding the United States of America (McNamee 2016, Thomas and Stoecklin 2018). Some see the overwhelming rate of ratification being due to its lack of effective enforceability (Tisdall and Punch 2012). The United Nations Committee on the Rights of the Child's report (2012) on Canada's progress on implementation had various criticisms; it recognized the discrepancies between provincial implementations and the call for federal guidelines and support (UN 2012, White 2014). It noted a concern that children who contacted institutions for protection and promotion were often unaware of the UNCRC (UN 2012). Finally, there was no mechanism for children to voice their concerns when they felt their perspectives were not being considered (UN 2012). Impact of the UNCRC is dependent on whether it is implemented into countries' laws, how legal systems are shaped, and the effort countries put into ensuring implementation (Lundy et al. 2013). It has been argued that governments ratified the convention with little thought and consideration given to 'laws and practices' that would be needed to implement (Freeman 1996, p.4).

In Canada, there was a lack of knowledge of children's rights (Frankel et al. 2015), which is another way to control the implementation in practice. This implementation can be done when adults decide what rights are relevant and worthy of importance (Frankel 2017). As seen by the discrepancies in Canada across provincial child advocate offices, there are different views and priorities for engaging with children (White 2014).

According to the UNCRC, there is an obligation for adults to ensure the implementation of children's rights (Lansdown 2001), however, children are the subject of the rights not an active contributor. The implementation of children's participation rights has

been seen as hard to implement (Tisdall 2015a). Children's voices, although may have legitimacy due to the UNCRC, have little or no effective power (Thomas and Stoecklin 2018). Participation can become problematic when children and young people are only invited to share their views when it suits adults, organizations, and services rather than the inclusion of their perspectives when it suits the children and young people (Percy-Smith 2010). Furthermore, the relationship between adults and children makes implementing rights difficult to navigate. As an example, a child's wish to exercise its right of freedom to religion can be overridden by their community and parents.

Perspectives of the child are seen as important when discussing decisions about their lives (Tisdall and Punch 2012). It is important to note a difference in 'seeking views' of children and 'the direct involvement of children in decision making' (Hill et al. 2004). This is echoed by Woodhead:

> "Participation isn't just about adults 'allowing' children to offer their
> perspectives according to adults' view of their 'evolving capacities',
> their 'age and maturity' or their 'best interests'"
> (Woodhead 2010, p.xxii)

Participation can perhaps be defined differently from the perspectives of a child and adult. When thinking about participation, it should be seen in terms of how power is exercised, rather than adults empowering children by 'giving' them power (Gallagher 2008).

The term 'powerful self' refers to a situation where there is a realization of a lack of power; there are opportunities to demonstrate it by negotiating and acting in their social space (Bacon and Frankel 2014), leaving participation in the social process fluid, flexible and unending. Another aspect is the public demonstration of agency; this ties in with children needing to be heard and visible (Bacon and Frankel 2014). Although the models in section 1.2 of participation include children having direct participatory practices, one needs to reflect about where the amplification of children's voices is, as it ideally creates greater impact.

Children's rights scholars have been focused on the 'implementation gap' between the UNCRC and practice while striving to close it (Reynaert et al. 2015). The current thesis is also interested in the gaps and successes of implementation of participation in practice specifically for children with disabilities. The UNCRC is often discussed in childhood studies literature and impacts the field's view of the child, which will be discussed in the following section.

1.3.4 Impact of UNCRC on literatures conceptualization of children

The concept of childhood throughout history has evolved and has resulted in changes to laws, policies, social practices and how childhood is defined (James and James 2012). Debates in the 1970s and 1980s started to question the views of children that were centred on developmental and socialisation perspectives (Mayall 2012). The sociology of childhood then emerged during the late 1980s and early 1990s, during the time of adoption of the UNCRC (Mayall 2015). The "socially constructed child" depends on the child's lifeworld; childhood is not finite, it is variable, and it is shaped by the context of its historical, moral, social, and political surroundings (James et al. 1998, p.27).

The view of children was changing to an understanding of children as social actors rather than subjects (Sinclair 2004). A new paradigm was proposed for the subsequent study of childhood, the key features outlined are:

> 1."Childhood is understood as a social construction. As such it provides an interpretive frame for contextualizing the early years of human life. Childhood, as distinct from biological immaturity, is neither a natural nor universal feature of human groups but appears as a specific structural and cultural component of many societies.
> 2.Childhood is a variable of social analysis. It can never be entirely divorced from other variables such as class, gender, or ethnicity. Comparative and cross-cultural analysis reveals a variety of childhoods rather than a single and universal phenomenon.

3.Children's social relationships and cultures are worthy of study in their own right, independent of the perspective and concerns of adults.
4.Children are and must be seen as active in the construction and determination of their own social lives, the lives of those around them and of the societies in which they live. Children are not just the passive subjects of social structures and processes.
5.Ethnography is a particularly useful methodology for the study of childhood. It allows a more direct voice and participation in the production of sociological data than in usually possible through experimental or survey styles of research.
6.Childhood is a phenomenon in relation to which the double hermeneutic of the social sciences in acutely present. That is to say, to proclaim a new paradigm of childhood sociology is also to engage in and respond to the process of reconstructing childhood in society."
(James and Prout 1997, p.8)

Notions that children were 'developing', 'incompetent', and their childhood being 'universal' were all critiqued through the 'new' paradigm (Woodhead 2009). The paradigm was seen as a "step forward", as children were being viewed as competent social actors (Vandenbroeck and Bouverne-de Bie 2006). The answer to the question of what a child is, requires an interdisciplinary approach; the answer is dependent on a contextual understanding of the cultural, societal, historical, and theoretical positions (McNamee 2016). Childhood experienced across time is impacted by social class, race, gender, ethnicity and disability (Konstantoni and Emejulu 2017). It is useful to understand in full the features of the new paradigm of childhood studies, as the thesis is rooted in the understanding of children as social actors (Sinclair 2004). The paradigm shift changes how research was conducted in childhood studies, as it was shifting away from previous understandings of childhood (Tisdall and Punch 2012). It offers a context in which to examine everyday interactions, engaging with the structural impact and the understandings of how meanings are created (Frankel 2017).

The new paradigm of childhood studies views children as social actors. A summary of how children are conceptualized is shown below:

"Children as Welfare Dependants
 - Children are Dependants
 - Children are incompetent and vulnerable
 - Children need care, protection and control
 - Children's childhoods are determined by adults

Children as Young Citizens
 - Children are People
 - Children have strengths and competencies
 - Children need recognition, respect and participation
 - Children influence their own childhoods"
(Neale and Flowerdew 2007, p.26) Also discussed in Neale (2002)

The above notes offer an understanding of childhood from a different perspective, one which understands children as dependents and one which views children as young citizens. An important difference in perspectives should be noted, the welfare model of children's experience is being applied rather than children taking part. The shift of thinking of children has emerged "within a mutual interdependence, recognition and respect for children and their views and experiences" (Fitzgerald et al. 2010, p.300). Children's citizenship takes into account the cultural and social negotiations children experience (Warming 2017). Children as citizens incorporates the viewpoint that children should be entitled to equal rights to adults (Hanson 2012). Importance has been placed on the active roles of participation and negotiation through which children assert their citizenship (Cockburn 2013). Previously, views of children were shaped by adults; the shift recognizes that children can also be "shaping the way in which their community functions" (Miller 2000, p.28). However, children's citizenship has been criticized, as only being accepted when adults are able to control it (Frankel 2017).

The incorporation of the views of children builds on the idea that children create meaning in their lives and can shape their experiences. The term co-participant has been suggested for children by Frankel. Co-participant has been defined as "not only the acknowledgment of children as social agents but also actively create opportunities for their participation including change making activities with adults" (Frankel 2018, p.166).

Children's competence goes beyond the opportunities 'given' to them by adults but is about children being actively engaged. Children are a part of shaping structures, practices, and surroundings (Frankel 2017). A social actor has been understood as children being "active in the construction of their own lives, the lives of those around them and of the societies in which they live" (James and Prout 1990, p.8). The two terms (co-participant and social actor) are very similar as children are seen to change and construct their surroundings; co-participant, however, includes working with adults, as an equal partner, as a next step for action in the co-production of meaning.

1.3.5 Section Summary

This section of the chapter provided an overview of the UNCRC in relation to 'participation rights.' The overview cited key examples from the UNCRC to understand the meanings suggested for participation rights. The section continued with themes and tensions of the UNCRC in implementation and literature. Key themes included the UNCRC being written from a top-down approach, adult and child relations and the impact on participation. Themes identified in childhood studies literature started with the 'new' paradigm of childhood emerging. Additionally, this chapter begins to position children in this thesis as co-participants whose participation impacts their surroundings.

As such, the considerations of this thesis are: (1) a critical examination of 'good' participation practices, (2) an examination to further understanding how participation is conceptualized, (3) an exploration of gaps between rights and practice, and (4) an examination of the relationships between adults and children. The chapter will continue with a discussion of childhood studies literature to further explore the considerations of the thesis.

1.4 Models of Participation

The following section will discuss different approaches and models of children's participation from literature. A critical examination of each will attempt to highlight gaps in understandings surrounding identifying and labelling different levels of participation. Approaches that will be discussed are; Hart's Ladder of Participation (1992), Treseder's Degrees of Participation (1997), Cornwall and Coelho (2007) Participatory Sphere, Sheir's Levels of Participation (2001), White (1996) and Wall's (2008) ideas on where to start participation, and Lundy's (2007) Four Elements to Participation. Although this is a comprehensive review of a range of participation theories, with various perspectives that are worth discussing, the thesis has not explored all participation theories.

1.4.1 Climbing the Ladder

In 1992, Hart's Ladder of Participation emerged; he adapted his ladder from Arnstein's 1969 citizen participation ladder, as this was a useful starting point for thinking about children and young people's participation. The ladder was designed to be a tool for children's participation in community development; however, it has also been noted as a useful tool for looking at children's impact in a variety of decision-making processes (James and James 2012). Hart's Ladder of Participation can be seen in Figure 2 below.
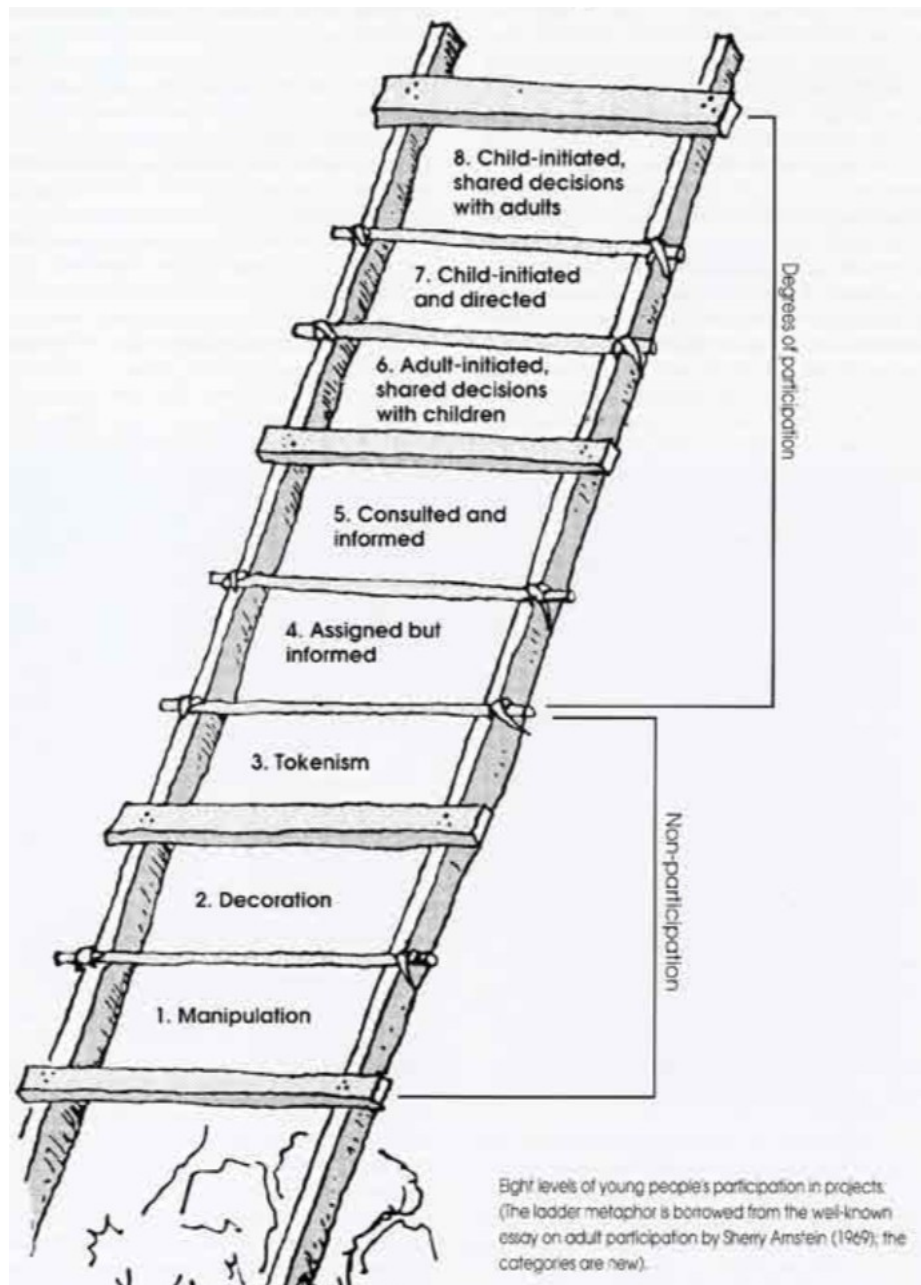
Figure 2 Hart's Ladder of Participation (Hart, 1992, p.8)

The bottom three rungs are meant to represent what participation is not

("manipulation, decoration, and tokenism") and the top five rungs are meant to represent

degrees of participation ("assigned but informed, consulted and informed, adult-initiated

shared decisions with children, child-initiated and directed, and child-initiated shared

decisions with adults") (Hart 1992, p.8). Tokenism is problematic when children and young

people participate in collective decision-making, as it is not sustainable, and it has limited

impact (Tisdall 2017). Hart cautions that the ladder is not "a simple measuring stick of the quality of any programme" (Hart 1992, p.11). An example of viewing it as such, is a criticism that suggests changing the highest rung of the ladder to 'children in charge' (Melton 1993). This is also echoed through Franklin's work with the ladder, as her version changes the order as well as placing of children in charge at the top while removing lower rungs to add "adults rule, and adults rule kindly" (Franklin 1997, p.53). Although these criticisms or suggestions might seem valid, for children to participate fully, they need to be in charge without adults. Part of Hart's reflections later on suggests that having children in charge, as the highest rung, may not be correct, because it is appropriate sometimes to invite others into the decision making as matters may also affect them as fellow citizens (Hart 2008). With the general comments on participation from the UN General Assembly including "information-sharing and dialogue between children and adults based on mutual respect" (UNCRC 2009, p.3), this supports Hart's perspective. Hart recognizes that people have used the ladder as a comprehensive tool rather than what he meant it to be, a metaphor and a jumping off point for individual reflection (Hart 2008). The ladder becomes problematic, because taken literally, it suggests the highest rungs are superior to others, which is not always the case, especially across different settings and cultures (Hart 2008). The suggestion instead is to communicate these options of participation to children to stimulate a discussion (Hart 2008). Taking Hart's Ladder of Participation to open one's mind about participation results in this tool becoming useful. However, if using this tool becomes the only source of information about participation, it becomes problematic, as it is doubtful there can be a hierarchy of participation that is relevant across all settings. If adults are not engaging in a dialogue with children about participation and deciding for them based on a model, it defeats the purpose of participation.

Within literature there has been an emphasis on children participating collectively in decision making, and Hart's Ladder incorporates individual and collective decision making. However, models of participation that are limited to "talking, thinking and deciding" exclude some groups such as young children (Alderson 2008), children with disabilities (Martin and Franklin 2010), and children with mental health issues (Dadich 2010).

The Ladder is to be utilized by organizations and adults to gain a greater understanding of participation. Critiques of a top-down approach have been discussed in the previous section sometimes seen as consultation (Thomas 2007b), however, on the Ladder, consultation is labelled as non-participation. Hart recognizes at the top of the Ladder, there is an opportunity for children and adults to work alongside each other which aligns with the 'new' paradigm of childhood.

1.4.2 Removing the Foundation

Following from Hart's Ladder of Participation, Treseder (1997) reframed the understanding of the ladder to further promote participation. He suggests five degrees of participation being laid out in a circular format which includes: child-initiated, shared
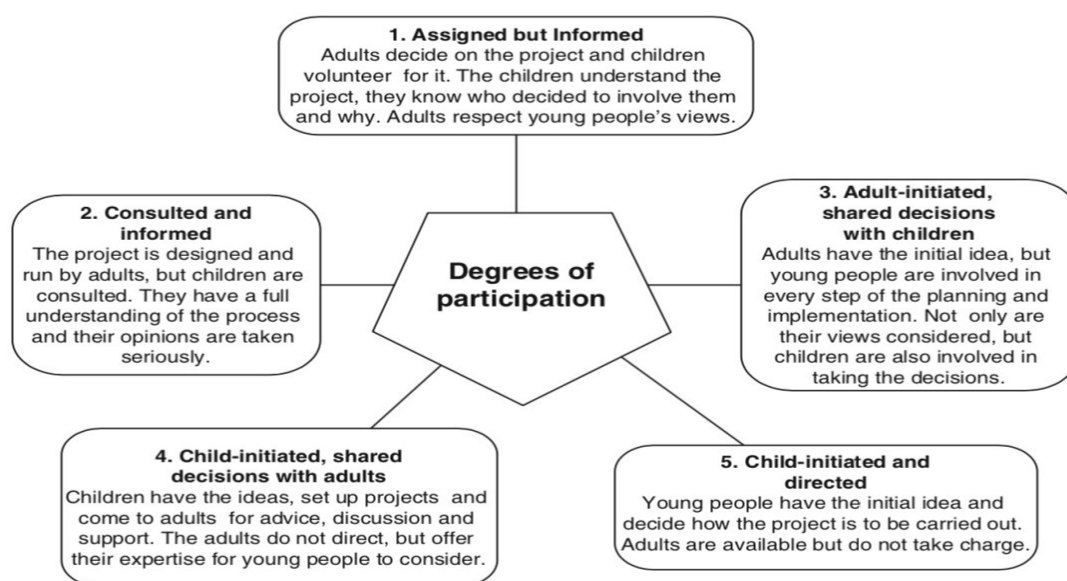
Figure 3 Degrees of Participation (Treseder, 1997, p.7)

decisions with adults, consulted and informed, assigned but informed, adult-initiated shared decisions with children, and child-initiated and directed (Treseder 1997, p.7). The model can be seen in Figure 3.

Treseder's work is an adaptation of Hart's Ladder and his ideas surrounding participation. Treseder has developed a manual for the promotion of involving children and young people in decision-making. The idea for placing these degrees in a circular layout was to transform the ladder proposed by Hart from a hierarchal ranking and a step procedure to a discussion about what is best in a particular circumstance. Treseder suggests that child-initiated is not the best form of participation in every circumstance, thereby modelling different types of participation as equal (Treseder 1997). The lowest rungs were also removed from the ladder, and the promotion of the levels of participation are meant to ensure that practitioners do not feel that they have failed if they do not reach the highest rung (Treseder 1997). Decision-makers need to be willing to share some responsibility with children and young people for this process of participation to create change (Treseder 1997). The bottom rungs of the participation ladder were removed (as they are not actually participation), and it is important to note that these methods could be used without the realization that they are not participatory.

For a successful project, decisions need to be made at the start about when and how children and young people will be involved in the decision-making processes (Treseder 1997). The idea of the circular format was to show that these forms of participation are equal, although different practices of children's participation (Treseder 1997). To break down barriers of participation, Treseder suggests reflecting upon: ensuring real access to decision making, awareness of potential negative attitudes, changing work practices to limit negative attitudes, providing real access to information, and ensuring financial resources (Treseder 1997, p.28).

1.4.3 Stepping Stones

The section will now offer a participation model that is different from Hart's Ladder, Sheir's model of participation. Sheir (2001) offers another model of participation that has five levels and fifteen questions in a logical order for the planning stages of incorporating participation, as seen in Figure 4.

Levels of participation ↓

Openings >Opportunities >Obligations

5. Children share power and responsibility for decision-making.

| Are you ready to share some of your adult power with children? | Is there a procedure that enables children and adults to share power and responsibility for decisions? | Is it a policy requirement that children and adults share power and responsibility for decisions? |

4. Children are involved in decision-making processes.

| Are you ready to let children join in your decision-making processes? | Is there a procedure that enables children to join in decision-making processes? | Is it a policy requirement that children must be involved in decision-making processes? |

This point is the minimum you must achieve if you endorse the UN Convention on the Rights of the Child ●

3. Children's views are taken into account.

| Are you ready to take children's views into account? | Does your decision making process enable you to take children's views into account? | Is it a policy require-ment that children's views must be given due weight in decision-making? |

2. Children are supported in expressing their views.

| Are you ready to support children in expressing their views? | Do you have a range of ideas and activities to help children express their views? | Is it a policy requirement that children must be supported in express-ing their views? |

1. Children are listened to.

START HERE

| Are you ready to listen to children? | Do you work in a way that enables you to listen to children? | Is it a policy requirement that children must be listened to? |

Figure 4 Levels of Participation (Sheir, 2001, p.107)

The levels include: "children are listened to, children are supported in expressing their views, children's views are taken into account, children are involved in the decision-making processes, and children share power and responsibility for decision-making" (Sheir 2001, p.107). At each one of these levels, there are questions to help the reader reflect on their participation planning and practice. To stimulate this reflection, the questions help to analyse how committed a person is to participate through a series of questions about "opening,

opportunity and obligation" (Sheir 2001, p.110). These questions address: opening (at the beginning of each stage when or if a person is ready to commit to participation at that level), opportunity (including the development of new procedures, training, gathering of resources and knowledge), and obligation (operation at this level by policy, and obligation of staff). It is interesting to note here that adults have the choice to include children, rather than asking if children are ready. This is a common experience within participation that hierarchical constraints can block or hinder children's choices on participation (Baraldi and Cockburn 2018). Adults do not always know what is best when it comes to children's participation (Lansdown 2006,2010). To encourage participation, children should be seen as entitled to equal participation opportunities and being a part of decision-making processes (Bjerke 2011).

A major difference between Sheir and Hart's participation model is that Sheir has nothing equivalent to the three bottom non-participation rungs of Hart's Ladder. Within Sheir's model, there is a clear indication of meeting the requirements of the UNCRC (after level 3 and what is beyond). It is different to Hart's model in that it is not as rigid a placement of where participation practices lie. As Sheir's model is something that individuals or organizations can reflect upon, look back at, re-evaluate, and strive to towards the next question or level of participation. For children to be included in the decision-making stages, individuals need to be reflecting on the role of the child. They need to be perceiving children as experts, knowledge creators and co-producers of knowledge (Tisdall 2017) to understand the current hierarchy of knowledge production. At the end of each level, it asks if there is a policy in place to sustain that level of participation in decision making. The following section will explore participation from a bottom-up perspective.

1.4.4 Gap of Voices

Although theorized in a democratic arena, this emergence of space is relevant for empowerment from the bottom-up perspective of participation to include a diversity of interests (Cornwall and Coelho 2007). A "participatory sphere" emerged in 2007 through the work of Cornwall and Coelho to empower people to participate, as they saw a gap between "normative expectations and empirical realities" (Cornwall and Coelho 2007, p.5). The participatory sphere is attempting to fill this gap by inclusion and voice representation (2007). In a democracy sense, the ideal result would be to improve public policy through citizens and states communicating and negotiating effectively (2007). This bottom up approach allows for the implementation across various settings, forms of power and cultures (Gaventa 2007). The relationship of this participatory sphere with the government and civil society is only partial, because they are outside of the formal political institutions and as well as outside of everyday life (Cornwall and Coelho 2007). Commonalities such as ideas, beliefs, social networks, and prejudices may be shared by the state actors within the participatory sphere (Heller 2001). These heterogeneous actors (state, civil society, and others) negotiate and communicate looking at constraints at local and political levels to facilitate an action by opening areas of decision-making and creating spaces in which people can take part in political life (Cornwall and Coelho 2007).

Physical space is not the only thing that children and young people need to participate in effectively, young people need space to develop the skills in addition to ongoing support (Donoghue et al. 2002). "Children's ability to participate is limited to clearly defined social spaces, most of which are policed and regulated by adults" (James and James 2008, p.92). These spaces of power, in which various practices and exercises of power may silence certain actors or exclude them from these spaces entirely (Gaventa 2005). People produce spaces, they are not pre-existing, and spaces can shape people rather than spaces being neutral (Gallagher 2006).

In order for marginalized and excluded populations to participate, they need more than an invitation; they need to recognize themselves as citizens and be aware of what their participation is going to be promoted as (Cornwall 2004). Children and young people can be disempowered before they participate, because they have a smaller network of knowledge than adults, and accessible materials may be filled with jargon (Treseder 1997). Children are in need of their own space to ensure their voices are not overruled by adults (Cornwall 2008). It is not only about having collaboration between children and adults but also having an environment where children and young people feel comfortable participating with and alongside adults (Wyness 2013).

Figure 5 Human Rights in Light of Children (Wall, 2008, p.540)

Participatory spheres should be open to anyone wanting to participate; however, there is a risk that citizens who participate may not be able to fully identify with the questions at hand (such as middle class people attending a process on poverty) (Cornwall and Coelho 2007). There is a danger in respect of creating these 'invited spaces' that they will be embedded with the power of the people who have created them (Cornwall 2002), although these spaces can also be where citizens assert their rights and just not passively accept the space by adapting to engage effectively (Cornwall and Coelho, 2007).

1.4.5 Where to Start, From the Bottom or the Top?

Rights need to be re-thought through a perspective of responsibility to one another, not necessarily about agency, autonomy or entitlement (Wall 2008). Wall (2008)

characterizes participation rights from a bottom- up perspective, versus a top down (protection rights) or developmental (provision), see Figure 5.

The bottom-up approach implies that views of the people at the bottom of the power structure are to be considered in decision-making, as they are the people affected, while top down implies the imposition of decisions on the lower structure without considering the views of the affected people. Children's rights cannot be simplified to one right alone, as they are all intertwined with one another (Wall, 2008). The model is in a circle to reflect the responsibility to one another, which is a cycle of "both passive responsiveness and active responding" (Wall, 2008, p.16). It is inclusive of children in the way they are able to engage and shape their networks and social worlds (Wall, 2008).

When looking at top-down and bottom-up interests in relation to participation, Hanson and Nieuwenhuys (2012) stress that there is a circular process of children's rights with changing and unforeseen circumstances that cannot be translated into a top-down or bottom up activity.

White (1996) provides four forms and functions of participation by looking at the relationships, of the different actors involved, as top-down and bottom-up participation does not always match up neatly. The four forms that White includes are: "nominal participation" (less powerful people want to be involved, top-down actors want legitimization for decisions), "instrumental participation" (community members are involved, however the cost is on them), "representative participation" (top-down actors have more effective results, bottom-up members have a 'voice' in decisions), and "transformation participation" (both participants aim for empowerment) (White 1996). Participation interests from these categories can be seen in Figure 6.

Form	Top-Down	Bottom-Up	Function
Nominal	Legitimation	Inclusion	Display
Instrumental	Efficiency	Cost	Means
Representative	Sustainability	Leverage	Voice
Transformative	Empowerment	Empowerment	Means/End

Figure 6 Interests in Participation (White, 1996, p.7)

Different forms of participation are shown in line with their related interests. Participation is a power dynamic through a negotiation and construction of interests which has potential to challenge patterns of power, or to reproduce existing ones (White, 2008). Participation rights unlike protection policies can challenge power relationships (Tisdall 2017). Shifting participation in Figure 6 shows that interests can move from being cost effective, which does not challenge power relaitonships, to one where empowerment is the goal. White suggests that participation needs to be discussed in respect to the desired ways to participate, not just about enabling people to participate (White 1996). The knowledge exchange between children and adults is important for participatory practices to work and to respect everyone's input needs to be demonstrated, as voice does not equate to inclusion or an outcome (Percy-Smith 2006). To solve the problem of just enabling people to participate, transformative participation would be the ideal, as it brings both parties together empowering one another. However, it leaves a lot of room for different implementations to reach this, and it does not include a piece to be reflexive about the process. Although it is important to be aware of where a participatory practice may fall, this does not go far enough to ensure constant improvement and implementation.

1.4.6 Participation Elements

To conceptualize Article 12 of the UNCRC, Lundy (2007) presents four elements for impact: space, voice, audience, and influence (Lundy, 2007, p.933). The elements can be found in Figure 7 as being intertwined with children's rights. The model is showing elements that are interrelated and overlapping and can only be fully understood when it is in relation to other elements of the UNCRC (Lundy, 2007). "*Space* - Children must be given the opportunity to express a view; *voice* - children must be facilitated to express their views, *audience* - the view must be listened to and *influence* - the view
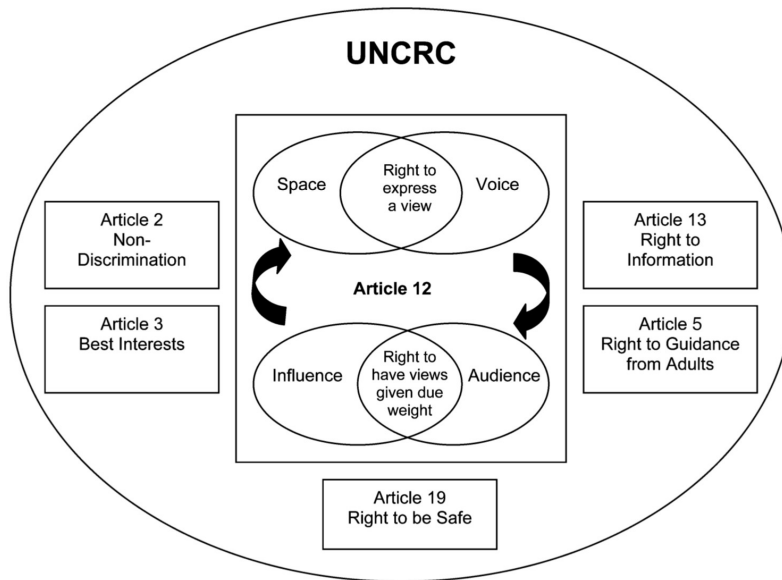
Figure 7 The Lundy Model of Participation (Lundy, 2007, p.932)

must be acted upon, as appropriate" (italics added, Lundy 2007, p.933). It is still being argued that for meaningful participation, children need to be visible and their voices need to be heard (Frankel et al. 2015). Voice has been critiqued further that there is a need to have a presence within society (Moosa-Mitha 2005). Lundy recognizes that a criticism of Article 12 is that it is easy for adults to not only listen to children, but to also take their views seriously (Lundy 2007). Conceptualizing participation in this way means that children may through participation decide the issues, at some point children's views may be the most relevant and erase the assumption that adults should always have input in a decision (Lundy, 2007). As a good practice, it is important that adults give children feedback about what role their voice played in decision-making (Lundy, 2007). This practice would include children, because it would show them how their voice and audience assisted in making changes in participation

more sustainable, because it would feedback into creating a space that encourages children to participate.

It is important to note that space in practice can also be restricting, as seen through forbidding spaces, such as staff rooms or floors being blocked off (Gallacher 2005). Additionally, children are sometimes required to "be in the right place at the right time" (Harden 2012), leaving children's space to participate and engage as sectioned off time. Sometimes space for children with disabilities is inaccessible and it has been mentioned in literature that space perhaps should include technology, as it opens potential for expression and perspectives of children with disabilities rather than a focus on voice (Lankshear and Knobel 2011).

In Lundy's model there is no attempt for children to 'prove' their capabilities, or autonomy which is adhering to the UNCRC preamble, that all children are included. There is an understanding of a process of participation that is built on communication and interactions (Lundy 2007). However, a piece missing is learning participation, a process of enquiry that would make improvements or changes to the participation process itself (Percy-Smith 2018). The lack of reflection in the model from children may challenge the understanding of it being a 'good thing' (Cairns 2006). As enforceability is lacking (Tisdall and Punch 2012), it is important to include children's feedback on the participation experience itself for improvements and to ensure implementation expectations are being met.

1.4.7 Section Summary

This section of the Chapter discussed different participation models on how one may understand and conceptualize participation. The models discussed were Hart's Ladder of Participation (1992), Treseder's Degrees of Participation (1997), Cornwall and Coelho (2007) Participatory Sphere, Sheir's Levels of Participation (2001), White (1996) and Wall's

(2008) ideas on where to start participation, and Lundy's (2007) Four Elements to Participation.

The participation models generally looked at 'talking, thinking and deciding' in regard to participation that may leave out children with disabilities (Martin and Franklin 2010), which is of importance for this thesis. Additionally, models were developed by adults leaving children out of a participatory process. Furthermore, there is an addition needed for feedback for children to discuss potential changes to their participation processes.

The section is highlighting a need for further understanding of (1) children's agency, (2) relationships between adults and children, (3) the interplay of participation and agency, and (4) what does participation look like in the everyday context. The gaps of understanding will be explored in the next section of this Chapter.

1.5 Unpacking children's lived participation experiences

The following section will unpack the role children have in participation as a lived reality. The section will start with the understanding of the relationship between adults and children. The following is a discussion on agency, as the term is important to understand within childhood studies, and for a full understanding of participation. The section will then conclude with key themes that have shaped the research questions.

1.5.1 Relationships between adults and children

In 1994, Qvortrup theorized two different ways children were being viewed as a result of a social construction of childhood either as a "human being" or a "human becoming" (Qvortrup 1994, p.2).

> "…adulthood is regarded as the goal and end-point of individual
> development or perhaps even the very meaning of a person's

childhood. They are however revealing for the maybe unintended message, which seems to indicate that children are not members or at least not integrated members of society. This attitude, while perceiving childhood as a moratorium and a preparatory phase, thus confirms postulates about children as "naturally" incompetent and incapable."
(Qvortrup 1994, p.2)

Adults, defined as beings, place them as competent providers and in control (Qvortrup, 1994). Where children, as becomings, are "less than fully human, unfinished or incomplete" (Jenks 1996, p.10). Adults are seen as a 'finished' being which is often associated with autonomy (Arneil 2012, Mayall 2015). This interpretation of human becomings can be seen through a developmental psychology lens; a blank slate being filled by society with a sense of children needing to adhere to the social norms or to be at risk of being labelled deviant (McNamee 2016). Children are seen as a future being and not yet rational (McNamee, 2016). The becoming period of life is protected and ideally free from adult responsibilities (Bjerke, 2011), so children can play and enjoy this period of life (Aitken et al. 2007).

Socialization theory, as described by Waksler, "leaves out both what children are doing when others are socializing them, and when others are not. It neglects the worlds that children design by themselves for themselves" (Waksler 1991, p.21). This exclusion of children from adulthood leaves a divide between children and adults showcasing children as different and enabling the power divide (Frankel 2017). Contradicting the notion of human becomings as a concept has been due to children being "not simply the product of universal biological and social processes, but are active participants in their social worlds and in those of adults" (James and James 2004, p.24). The belief that adults may know best in comparison to children is a hierarchal belief that creates a barrier to children's participation (Lansdown 2006,2010).

To transition effectively, society should not base competence on age or as being a 'complete' human, but rather it should be about seeing all humans (adults and children) as being fundamentally incomplete and dependent (Lee 2001, Prout 2005). Adulthood should not be assumed to be stable, rather it can be changed, adapted and flexible (Lee 2001, Prout 2011). Instead of separating adults and children with adjectives, such as knowledgeable and developing, one can view all humans as both human beings and becomings (Bacon and Frankel 2014, Invernizzi and Williams 2008). Humans are better viewed as both beings and becomings working together as collaborators and partners in a co-construction of change to the dominant societal structures (Frankel 2017); this creates a meaningful space encouraging participation (Cornwall and Coelho 2007).

Participation in social structures therefore varies "and reflects ambiguities as well as uncertainties of what it means to be a child citizen […] moving on a line from being *equal* to being *different*" (Kjørholt and Lidén 2004, p.64). Viewing children as differently equal, responsible beings when participating responsibly in society (decision-making, trusted to be unaccompanied) allows them to improve their power, status and autonomy (Bjerke 2011). When children do things responsibly (maturely with trust), they are able to access more responsibility in their lives, such as being home alone and choosing when to do chores (Such and Walker 2004). When children demonstrate their capacity through being responsible, they are able to participate in their community (Lister 2008). When not presented opportunities to show that they are responsible beings, it leads to further exclusion from being able to participate in "doing responsible things" (Bjerke 2011), and learning opportunities to develop competencies (James and James 2012). Acting responsibly and being self-reliant can be seen as a construction of agency by utilizing power and knowledge (Smith 2012), it increases the 'participating child' which instead of it being liberating, can become a reason for adults to justify more surveillance (Smith 2012).

The relationship between adults and children is complex, as how they navigate participating together is influenced with the wider context. Politics of communities and neighbourhoods, social norms, and different views of children all influence how adults and children interact (Percy-Smith 2006). Participation literature has left adults out, as it is argued that children create their own practices and spaces (Mannion 2007). However, it is argued that understanding these complex relationships is important for fully comprehending the implications for children's participation (Mannion 2007). It is important to understand the different roles adults and children have in participatory processes for a full picture of the children's worlds (Wyness 2015). The relationship between adults and children is imperative to unpack and continue to reflect upon. To further the understanding, the next section will discuss structures and children's agency and their parts to play within these relationships.

1.5.2 Agency

The current chapter highlights participation understandings, which is consistent with the sociology of childhood, as it has been a topic of importance for a long time (James and Prout 1990). Similar importance has been placed on children's agency (James et al. 1998), which is different than participation, it is assumed to be exercised by children when they are participating (James and James 2004, Wyness 2015). However in childhood studies, it is often treated as needing limited explanation, as it is a characteristic of humans (Prout 2005). Agency can be looked at as children's ability to act autonomously from their surrounding structures (James and James 2008) focused on their capabilities and influences on the surrounding environments (Oswell 2013). This view on agency suggests that children are able to act in a way that is not determined by adults (Baraldi 2014). The term agency has been critiqued and highly promoted in childhood studies which this current section will start to unpack.

'The age of children's agency' has been of high importance on policy agendas in the twentieth century (Oswell 2016). Agency has been seen as a role that children have as social actors (James and James 2008). Research looking at children's agency and participation on Western societies has been focused in institutional settings (examples; Thomas 2007b, Wyness 2009). It is worth noting that other contexts have been explored such as with sports teams (Cockburn, 2017), domestic violence in family settings (Katz 2015) and new global society settings (Clemensen 2016, Percy-Smith and Thomas 2010a).

'Simple agency' can be thought of as a basic level of children's actions that they can modify and change sequences of events (Giddens 1984). This view of agency can be seen in the context of children's participation is subordinated to the authority of adults, where hierarchical social order is present, and there is a level of cooperation (André and Godin 2014, Clemensen 2016). Cooperation with the power structures theorizes children as accepting the status quo rather than showing the availability of action opportunities or choices to make change (Baraldi and Cockburn 2018). It has been argued that children's participation within interactions with their surroundings, and as well as with adults and peers, will change future interactions as they navigate various relationships and power structures (Hutchby 2007). Additionally, it has been difficult to fully label agency within interactions, as sometimes it can be observed as children's involvement in asking questions or it may be minimal signals in their environments (Muftee 2015).

Participation and agency in childhood studies often go hand in hand. As agency can be used to critically look at whether participation is authentic, by looking at access, whether children have been a part of the decision-making processes and practices which may or may not be driven by children's interests (Wyness 2018). Additionally, this critical look can review the options children have available to participate. Children's agency can be based on the availability of choices for action, which could then perhaps offer different action

opportunities (Baraldi 2014). Availability of choices of action, individual's judgement to act, and the choices one makes to act can be ways to observe agency (Baraldi 2014,2015, Bjerke 2011, James 2009, James and James 2008, Percy-Smith 2010). Children's active participation can be described as children practising agency rather than just having a voice (Amadasi and Ievese 2018, Iervese and Baraldi 2014). This view then suggests that agency can be a transformational view of participation (Mayall 2002). In relation to research, children's participation in decision making is ideal rather than children's consultation (Clark and Percy-Smith 2006, Hill et al. 2004, Percy-Smith 2006). Children's agency within the decision-making process is a direct link to participation (Baraldi and Cockburn 2018).

The first theory of agency that will be discussed is the Continuum of Agency showing a range of actions that may be requested, forced, automatic or self-initiated. Degrees of agency have been discussed on a continuum as: no agency, little agency, 'secret' agency, and 'public' agency (Bell et al. 2007). First, no agency can be described as having no choice in a matter and being forced to act. Second, little agency is where there is little choice, and one is acting on the basis to survive. Third, secret agency is acting to resist adult control subtly. Finally, public agency is acting alongside adults. The Continuum of Agency also notes that agency is experienced differently by whom and where they are and what they are doing (Bell et al. 2007). Moreover, their agency can change throughout the continuum depending on different contexts (Robson et al. 2007).

Understanding agency on a continuum is also discussed in the understanding of thick and thin agency (Klocker 2007). Thick agency would be understood as having the ability to act through a range of options, and 'thinned' is often looked at in everyday contexts which have little options to act as they are in restrictive settings (Klocker 2007). Thick agency has been implied that there is participation in social change (Baraldi and Cockburn 2018). Agency is looked at through 'structures, contexts, and relationships that can act as dynamic

'thinners' or 'thickeners' of 'individuals' agency, by constraining or expanding their range of viable choices (Klocker 2007). A *thinning* of agency can be in relation to poverty, gender, and lack of opportunities. Ansell (2009) discusses how children are limited with their agency combining this with thick and thin agency, thin would be at a macro level (policies) and thick agency could be seen at local levels (Tisdall and Punch 2012). However, agency can still be present, as children can "actively negotiate the expectations and power relations that surround them" (Klocker 2007, p.85).

In childhood studies, it has been noted that looking only at individual agency is problematic (examples; Frankel 2017, Gallagher and Gallacher 2008, Tisdall 2012), as childhood is complex. Agency is often discussed alongside understandings of competence, instead of understanding the complex network of actors and shifting relationships (Oswell 2013). Agency is shaped through relationships, as it is negotiated through constraints and opportunities (Leonard 2016) emphasizing the process rather than outcomes (Valentine 2011). Similarly, a difference has been highlights as an actor "is someone who does something; the agent is someone who does something with other people" (James 2011, p.41). Children and adults alike do not escape 'structural constraints' (Bluebond-Langner and Korbin 2007). Through this resistance, children can gain power over adults by creating possibilities, powering themselves (self-respect) and powering by acting in a group as a process of empowerment (Samman and Santos 2009). However, as has been argued, children are able to move between hierarches and boundaries (James and Prout 1995), to do this, they use 'strategic flexibility' (Bacon and Frankel 2014). Children use strategic actions in their everyday lives by engaging with power structures through navigating complex and multi-layered relationships sometimes gaining identity, power and capital (Frankel 2017). Therefore, there is a need to understand agency further through the context of children's environments.

1.5.3 Contextual Agency

The previous subsection discussion of agency suggests the need for further exploration on how the structure, social, cultural, and environmental factors affect children's agency. The exploration of agency in childhood studies is often reliant on individual notions of "authentic choice of self-direction action" (Valentine 2011, p.348). Further the "isolated human individual" who is showing "individual agency" is missing the larger context (Oswell 2013, p.50). The identification of agency can be "by positioning children in their own contexts and looking at the micro level of peer interactions" (Vanderbroek and Bouverne-de Bie 2006, p.128). This viewpoint has become a "point of departure for many contemporary studies of children's everyday lives" (James 2009, p.11). Additional arguments suggest that agency is also "dynamic and constantly shifting" (Robson et al. 2007, p.135) and a more in-depth understanding is needed.

It has been argued that agency, as a term in childhood studies, often offers a minimalist definition as 'to act purposively' and further that the focus is on individuals' choices and actions (Valentine 2011, p.349). Similarly, this is viewed as 'isolated human individual' and therefore is 'individualized agency' (Oswell 2013, p.50). A different view of agency is offered that instead of discussing agency, as the individual acting or labelling it as such, looking at it more relationally.

> "thinking about agency, not as located within the individual child
> faced against social structure, but as itself distributed across a
> network of agents of actors, both human and non-human."
> (Oswell 2013, p.69)

The approach to understand agency as between groups and individuals that are interdependent is comparable to others (examples; Burkitt 2016, Konstantoni 2012, Moosa-Mitha 2005). The term agency has been seen as problematic when describing children as independent social actors (Gallagher and Gallacher 2008). In the field of sociology,

children's agency is discussed in the context of the significance of diverse experiences (Morrow 2006). It has also been noted that there has been a tendency to generalize and group childhood experiences such as being 'all boys' or 'all girls' (Morrow 2006). Children's participation has been modelled in different forms and are associated with 'lived' social relations (Percy-Smith 2010). It has been clear that agency and participation needs to be observed in children's social and cultural lives (Baraldi and Cockburn 2018). Additionally, children's actions, power, and negotiation of meanings in the lived contexts of social relations can show participation as agency (Baraldi and Cockburn 2018).

First, when promoting children's agency, it is important to recognize adults are "facilitators rather than technicians" additionally "both children and adults are co-constructors of knowledge and expertise" (Hill et al. 2004, p.84). Taking children's views into account requires a dialogue which is based on "mutual interdependence, recognition and respect for children and their views and experiences " (Fitzgerald et al. 2010, p.300). It is important to understand the adults' role in how they are constraining or enabling children's differing expressions of agency, as this impacts their everyday lives (Leonard 2016). As often adults run and develop organizations, the structure of activities are important to acknowledge as there are perhaps practices and assessments that may hinder or enable children's right to make choices and participate in their environments (Baraldi and Cockburn 2018). It is perhaps important for children's agency to be recognized in a rights-based approach, as a way of looking at how children affirm and achieve specific rights that go beyond an agency and protection divide (Alanen 2009). Unavoidable components of social life are hierarchical constraints and structures that block children's participation and choices of action (Baraldi and Cockburn 2018). Blocking children's choices for action may hinder their ability to make a greater social change within their environments.

Second, it is important to view children's' experiences as being a part of an

interaction of social context within specific environments, prior experiences, and children's

life history (Valsiner 1998). Children's interpretations, purposes and meanings of their

actions should be analysed in different social contexts (Kumpulainen and Ouakrim-Soivio

2019). As children are embedded in generational relationships and social positions that "all

offer different opportunities and constraints for children to act and, in doing so, exercise their

agency" (James 2009, p.43). However, it has been argued that the term agent could be used

as well:

> "The term agent suggests a further dimension: negotiation with
> others, with the effect that the interaction makes a difference – to a
> relationship or to a decision, to the workings of a set of social
> assumptions or constraints."
> (Mayall 2002, p.21)

James further argues that "there are any number of understandings, ambiguities and

difficulties that children need to resolve and interpret on the way" making agency therefore

"what it means to act" (James 2009, p.41). There is a downside to viewing children this way,

in that participation can then become over-regulated and put pressure on children (Hartas

2008). Due to this pressure on children to participate, a choice should always be available, if

children choose not to assert their agency, or to participate (Tisdall and Punch 2012), and

there are measures in place to ensure truly voluntary participation (Hill 2006). Tisdall and

Punch (2012) go on to question this view of children as being agents, because it replaces

seeing children as vulnerable, and what then happens to those vulnerable populations. An

example used, shows tensions of poverty, and government structure through child soldiers, if

children were agents able to construct their lives (James and Prout 1990) and have the ability

to push back against power structures (Frankel 2017) should they be responsible for

committing violent acts? This analysis leaves agency as a double-edged sword for children.

When children assert their agency, there are "… circumstances in which children's agency is

perceived as negative, challenging or problematic" (Tisdall and Punch 2012, p.258).

Additionally, children can exercise their agency "by actively using their resources and abilities in their relations with others in both positive and negative ways" (Bjerke 2011, p.94). Similarly, there is attention needed for when participation becomes challenging, such as when different voices collide, and how young people are being responded to, so as to ensure effectiveness of conveying young people's realities (Percy-Smith 2006).

By examining the literature, children's agency needs to be viewed and conceptualized through a relational understanding of participation. Agency is produced through different environments and social relations which is ever changing and can be expressed in various ways. Therefore, there is starting to be a development of the idea that children's' lives need to be explored through their lived experiences to fully understand their participation.

1.5.4 Lived experience

The following subsection will suggest understanding participation as a negotiated and lived experience for children which can include children's agency, relationships, social and cultural contexts. Childhood is not a fixed concept; children's rights should also not be a fixed concept, as they are constantly changing, incomplete and being reinvented, they should be 'lived' (Hanson and Nieuwenhuys 2012), by making the most of their daily living situation. Through active engagement and confronting challenges faced, they created living rights even before laws are implemented (Hanson and Nieuwenhuys, 2012). These lived realities and practices of rights means that they are experienced and realized by people well before national and international laws, therefore, the experience of rights is alive (Hanson and Nieuqenhuys, 2012). When children are viewed as expressing agency, this becomes a lived citizenship where children are viewed as citizens (James 2011); this fits with the view that children are social actors, as children shape their rights in their social worlds (Hanson and Nieuwenhuys 2012). These social practices that children shape in their worlds through action become their living rights (Hanson and Nieuwenhuys, 2012). The instability of right and

wrong exists through practices and lived experiences, which can be translated into law; these translations are not always free from political and legal deliberations (Nieuwenhuys et al. 2016). From this position, children are viewed as actors, as they "can make their own lives rather than have their lives made for them" (Freeman 2007a, p.8). A living rights example showing universal rights do not always reflect specific contexts is street children who have been vocal about not wanting to be "rescued" taking actions such as marches asking for safe conditions, not the banishment (Nieuwenhuys et al. 2016). This perspective is showing how children's rights are being experienced and received on the ground and how children are being challenged (Vandenhole 2012). Disagreements will happen, as the rights are alive, and should not be seen as a weakness (Nieuwenhuys et al. 2016). Social movements are visualizations of children being critical of current practices to challenge who is excluded from the making of laws and practices (Nieuwenhuys 2009).

Another relevant position in support of living rights is the concept of "children's rights from below" (Liebel 2012, p.14), which also positions children as social actors transforming their social worlds. "Rights thought up and formulated by children themselves have a more direct and concrete connection to their lives and their ideas of a just and equitable existence" (Liebel 2012, p.14). Rights can only exist through people and people construct their rights for a social purpose that is a reflection of the relationships between agency, actors and structures (Stammers 2012). There is an understanding that there is variations of children's lives and how different experiences can be interpreted and explored. Therefore, a different viewpoint to understand rights is perhaps

> "an imperfect compromise negotiated at a certain moment in time
> and in specific contexts by individuals representing different local
> and organizational interests and possessing different kinds of
> knowledge, skills and power."
> (Hanson and Nieuwenhuys 2012, p.10)

Exploring children's' rights at a local level and how they are actually practised and negotiated can give a greater understanding (Desmet et al. 2015, Reynaert et al. 2015). It is important for researchers to study different views of stakeholders such as parents, children and other key personal to develop a multifaceted view of participation (Reynaert et al. 2015). The living rights perspective aims to develop a "thick understanding" of children's experiences and lived realities (Desmet et al. 2015, p.419). This understanding can create a complex interweaving recognition of community, relationships, responsibilities and rights (Abebe 2013).

Lived childhood takes into account intersectionality of their experiences such as through social class, ethnicity, gender and disability (Baraldi and Cockburn 2018). Children may be categorised into one of these groups, however, lived experience takes into account all of the individuals cultural, social and personal identities (Baraldi and Cockburn 2018). These identities are 'multiple and shifting positions' (Kustatscher et al. 2015) and this perhaps affects children's lived participation experiences. There is a need for a greater understanding of children's identities in interactions (Connolly and Morrow 2006), and in understanding exclusionary and inclusionary practices (Devine and Kelly 2006). People are constructing their realities, engaging with meaning-making through social interactions, lived experiences and understandings (Lincoln and Guba 2000). Ensuring context is incorporated through the understanding of the process of participation will create a more in-depth understanding. Participation can be understood as through children's 'lived' social relations (Percy-Smith and Thomas 2010b) showing children's meaning negotiations, the complexities of day to day life and their process of power and action (Davis and Smith 2012). The thesis is interested in understanding this 'lived' participation experience, to do so it required the unpacking of participation relationships, outcomes, structures and aims (Davis and Smith 2012, p.59).

1.5.5 Section Summary

The current section aim was to explore gaps in understanding of children's agency, child and adult relationships, and what participation looks like in everyday contexts. The section looked to expand the often-minimalist definition of agency to a relational understanding taking into account the entire setting followed by the analysis of lived childhoods taking into account the 'real' lives of children (Baraldi and Cockburn 2018). Lived realities can give insight to the diverse development of voice, agency, participation, everyday interactions, practices, and relationships.

The importance of the section for the thesis is to understand agency, lived experiences and adult-child relationships to further explore the topics in the field. Lived experience of children's everyday practices will allow for an in-depth analysis that incorporates all aspects of the participation processes.

1.6 Chapter One Conclusion

The current chapter has discussed children's participation according to the UN Convention on the Rights of the Child (1989) followed by participation theories. Participation generally has been seen as 'good' through policy, literature, and research. As seen in the first section of the chapter, there are implementation gaps between theory and practice. The UNCRC had impacts on the literature and how children are conceptualized. The section starts to discuss the idea of living rights, as a criticism of the UNCRC which has been written from a top-down perspective. Additionally, the way in which children are viewed and conceptualized has an impact on how children participate in terms of opportunities and constraints. It is important for the thesis to understand different views, as in the field there will be varying views of children at play.

In discussions surrounding participation theory, I illustrated that children's perspectives were not consulted when developing the participation models. The models show what is and what is not participation. Furthermore, some include aspects that are needed in order for participation to take place. The discussion built on the participation ideals from the previous section and gave overviews of models that strive to achieve participation alongside children. The models highlight the importance for children's perspectives on participation, and my thesis will utilize the models as a starting point for understanding children's participation. The last section of the current chapter discussed the relationship between adults and children. Children's agency was discussed simply and then more in-depth to understand how children's agency can be relational. The importance was demonstrated by looking at the whole picture of children's actions to understand their position, aims and wishes. The section finished with a discussion of lived experience and the importance of context which is everchanging and renegotiated between children, adults, and structures. Lived experiences for the thesis will offer an interpretation of children's participation and how it is negotiated in everyday contexts through power, and relationships.

The following chapter will explore the topics of disability models and inclusion. The various disability study models will highlight key themes, tensions, and gaps. Inclusion will also be explored through different definitions, including the understanding of inclusion in relation to the environment of physical activity. The chapter will also link the topics of disability and inclusion to the Canadian context.

Chapter Two: An Overview of Disability and Inclusion - Key Considerations

2.1 Introduction

This chapter aims to explore key themes, gaps and tensions in which this thesis may contribute towards a further the understanding of disability. Disability can be understood through various approaches such as the medical, social, human rights and social relational along with other models. The chapter will begin with an overview of some disability models whilst highlighting key debates in the field. The various disability models discussed provide an overview of contrasting views and objectives to begin to understand the vast differences in perspectives. In the first section, the UN Convention on the Rights of Persons with Disabilities (UNCRPD 2007), will be discussed to make links between theory and policy.

The chapter will then discuss the implications of the context in which this thesis takes place. The section will identify considerations of being a child with a disability in a Canadian context and in an extracurricular physical activity context. The context has an impact on the construction of how the knowledge is created throughout this thesis.

The last section of this chapter will provide a discussion of inclusion from various perspectives, including tensions in definitions of what inclusion means in sport environments, the delivery of inclusion, social justice and social inclusion. The overview of inclusion will highlight key considerations of this thesis.

The chapter will conclude by identifying key considerations taken from the literature that have shaped the research questions of this thesis.

2.2 Approaches to Understand Disability

'Models' of disability have shaped human rights for people with disability, disability studies and disability politics over the past 40 years (Lawson and Beckett 2021). The objective of this section is to develop approaches and understandings in respect of the models of disability. The main models discussed will be the medical, social, human rights, social relative and relational and critical models of disability. By exploring the contrasting theoretical frameworks of disability, the thesis will attempt to address the different understandings of social and individual consequences of disability, what should be done and where disability originates (Smart 2009).

2.2.1 Medical Model of Disability

The medical model of disability is important to discuss, because historically, within the fields of research, disability has been categorized and described through the medical model of disability (Smith and Perrier 2014a). Disability viewed through a biological understanding has been a dominant view in such fields as rehabilitation and health care (Hammell 2006). Additionally, within schools, the medical model is engrained through the provision of classification and identification (Benson 2014) and medical explanations and resolutions of difference are often embraced by schools and parents (O'Connell 2016).

The medical model focuses on the individual's impairment as a defect which needs to be changed with an emphasis on society's desire for diagnosis and treatment (Oliver 1996). The focus is on the limitations of the body with disability being typically defined by the impairment (Fitzgerald 2012). Impairment becomes the defining feature of the individual (Goodley 2011c) which places the burden of the impairment on the individual, and it is the duty of the individual to conform and adapt to society.

Within the medical model, disability is seen as something needing intervention and fixing, which is a way to *other* somebody; the disability is seen as a construction deviating from the norm (DePauw 1997, Smith and Perrier 2014a,b). Medical views of an individual's body can invalidate them when their body does not conform (Loja et al. 2013); they are then seen as deviant, inferior and abnormal (Campbell 2008).

The individualization of disability is framed by the medical model as "significant bodily and/or cognitive variation from those who meet the cultural expectation of embodied normality" (Thomas 2004, p.28). People with physical and mental impairments can be viewed as not 'normal', and less than ideal, which leads to negative stigmatization (Goffman 1963). The negative stigmatization may result in a preconceived view that these children are difficult to communicate with, unknowing, dependant and vulnerable (Richards and Clark 2018). Additionally, this view may leave individuals in a powerless position to separate their identity from this negative perspective (Davis 1995).

The construction of disability through the medical model historically has been described narrowly, as it is seen as a personal limitation and a biological malfunction (Imrie 2004). Other models have argued that the medical model ignores the lived experience of impairment and the individuals' perspective (Owens 2015). There is a gap in the medical model, as it leaves the social world and lived experiences of people with disabilities unchallenged (Smith and Perrier 2014b). This knowledge gap results in the medical model lacking information outside of the medical field.

Oliver (1983) suggests when introducing the medical (or the individual) and social models of disability, the individual model should not be abandoned, because it may add to a comprehensive understanding of disability. The suggestion is that the social model may offer a framework that is more all-encompassing where everything happening to people with

disabilities may be explained or understood (Oliver 1983). To close the gap on understanding of the social world, the social model of disability will be discussed next.

2.2.2 Social Model of Disability

In literature, the social model is often cited as one of the two key models of disability which have emerged through discourse, the medical and social models of disability (Goodley 2011c). The social model can be seen as the opposite of the medical model (Ayling 2018). The main shift from the medical model, where the focus is placed on the 'deviant, personal tragedy' of the individual's body, is to an emphasis on the disabling environment through the social model of disability (Oliver 2013, Oliver and Barnes 2012). Disability, through the social model of disability, is seen as a societal responsibility, not a personal one (Oliver 1990,2013, Shakespeare 2006b, Shakespeare and Watson 2001). The social model makes a distinction between 'impairments' which are biologically determined and 'disabilities' which occur due to exclusionary practices and discrimination (Oliver 1996, Shakespeare 2006b).

The British social model originated in the 1970s through the British disabled people's movement (Campbell and Oliver 1996). The approach distinguishes between impairment (biological) and disability (social); here disability is a result of the environment, which restricts people using barriers placed in their way (Berg et al. 2015).

The United Kingdom (UK) and United States of America (US) views' of the social model stress that disability is a social construction (Hahn 2001). In the UK, the view is that there is an emphasis on 'oppression' which highlights conceptual orientation and political economy, whilst in contrast the US addresses these similar problems by looking into discrimination in laws and through the legal system (Hahn 2001). North America is more concerned with issues of "psychology, identity, personal affirmations and moral development" where the UK is concerned with the issues surrounding "equality in political

and material participation" (Meekosha 2004, p.722). The US social model is challenged when

trying to add individual experience of impairment, the political struggle becomes diluted

resulting in a greater struggle to overcome barriers in society (Oliver 2001). In contrast, the

UK model looks at a 'risk-management' state which is designed to prevent problems rather

than trying to compensate for them afterwards (Giddens 1998). Through this social model,

the difficulties and barriers (social and physical), restrict participation in society by policy

and cultural processes (Barnes and Mercer 2006,2010, Oliver 2009). However, it is argued

that whilst reducing the view of barriers to social ones, the social model may run a similar

risk as the medical model, by reducing impairment to individual characteristics (Watson

2012). Experiences of children with disabilities cannot be the sole analysis of environmental

and social barriers (Watson 2012).

As the social model views disability as a social construct (Oliver 1996,2013), which is

not too dissimilar to the social construct argued for childhood. The social model, "... 'speaks'

from the standpoint of disabled people and therefore voices an opinion that has, throughout

modernity, been silenced by the paternalism of a non-dis-abled culture" (Patterson and

Hughes 2000, p.35). Children and adults with disabilities are connected in the ways that they

are marginalized and disempowered. Children and adults with disabilities are not solicited for

their views on things that affect their lives due to a paternalistic society (Richards 2018).

Oliver (1996) argues the social model has the power to "transform consciousness" by

the connection of professional practice to personal experience. This research aims to do just

that, by connecting the extra-curricular inclusive environments to the understanding of

participation for young people with disabilities. One of the arguments against the social

model is its failure to address the realities of impairment, such as illness, body pain and

dysfunction (Degener 2016, Martin 2013). It ignores the cultural dimensions of disability by

using a limited view of structural disablism (Reeve 2004). By focusing on the social model,

researchers are eliminating the restrictiveness of the medical model allowing for exploration beyond the structural oppression of disability. It has been argued that the social model fails to recognize that impairments may also directly disable people (Shakespeare 2013). The impairment itself is perhaps also socially constructed as determined by a bodily difference (French and Swain 2001). Social identities are not easy to define and are complex, although society may label individuals as being 'disabled', they may not feel that way.

Beckett and Campbell (2015) suggest understanding the social model as a 'oppositional device' through

> "Foucault's genealogical approach understood as description of that which needs to be resisted and the social model understood as a description of a process which needs to be resisted: disablement."
> (Beckett and Campbell 2015, p.272)

The approach is suggested because the social model is repeating similar goals and styles of practice. However, how people with disabilities are resisting practices of disablement, and how this repeating needs to be explored (Beckett and Campbell 2015). Through resistance practices people with disabilities are engaging in producing subjectivity (Proust 2000), and through collective creative forces regulating norms (Campbell 2013, Ewald 1990). Foucault rejects transcendental analysis and instead discusses 'ideas' described as a co-production of knowledge and the process of subjectivation (Beckett and Campbell 2015).

> "If there was no resistance, there would be no power relations (…) it would simply be a matter of obedience (…) So resistance comes first, and resistance remains superior to the forces of the process."
> (Foucault 1996, p.625)

Resistance is not just refusal, it can be transformative (Beckett and Campbell 2015). The social model allows for the understanding of barriers, and challenges ableist society by asking questions about life conditions (Campbell 2009). Applying the oppositional device to

further the model in understanding the present, how being with others is (re)produced, and

acknowledging injustices to come (Beckett and Campbell 2015).

> "Would rest upon an understanding of knowledge as something
> practiced in mundane and specific situations and power as diffused
> throughout society, being relational rather than centred only on the
> organs of the state."
> (Beckett and Campbell 2015, p.273)

The medical model and the UK social model may not be able to capture the full

complexity of disability, as these perspectives offer a limited window in how to examine the

lives of children with disabilities (Berg et al. 2015). The social model showcases the divide of

people who are, and who are not disabled (Shakespeare 2006b). There is a complex interplay

between society and individuals which is not limited to the cause of difficulties or

impairment (Traustadóttir and Smith 2015). The social model should be seen as a tool (Oliver

2013) that has challenges, discriminations and marginalization(s) (Owens 2015).

2.2.3 United Nations Convention on the Rights of Persons with Disability

The social model has been acknowledged to have played a role in how the United

Nations Convention on the Rights of Persons with Disability (UNCRPD 2007) was

developed (Lawson and Beckett 2021). The UNCRPD was adopted by the United Nations in

2007 and was ratified in 2010 by Canada. This convention contains a 25 paragraph preamble

and 50 separate articles. The signatories to the convention undertake to promote and monitor

the rights for people with disabilities. The introduction of the UNCRPD was met with

enthusiasm, resulting in one of the most widely ratified conventions (Kaiser 2013). The

preamble of the UNCRPD defines disability in paragraph 5.

> *"Recognizing* that disability is an evolving concept and that
> disability results from the interaction between persons with
> impairments and attitudinal and environmental barriers that hinders
> their full and effective participation in society on an equal basis with
> others."

(UNCRPD 2007, Preamble)

The UNCRPD approach acknowledges disability as a social construct, as it is created when societal barriers interact with impairment (Degener 2016). The UNCRPD approach to disability is similar to the social model of disability and the understanding that disability is different from impairment (Lawson and Beckett 2021). However, within literature it has been noted that there is continual confusion between disability and impairment (French and Kayess 2008).

It has been argued that the UNCRPD will help with the implementation of equal rights, promote an inclusive environment, and raise the importance of disability in politics (Bickenbach 2009). The most important achievement of the UNCRPD may be that there has been a step towards the encouragement of equal participation (Bickenbach 2009). The UNCRPD reflects the importance of the rights of people with disabilities to participate in decisions that affect them and for this reason has been cited as "one of the most progressive developments in human rights law provided by the UNCRPD" (Stein and Lord 2010, p.698). The requirement is shown in the preamble to the convention:

> "Persons with disabilities should have the opportunity to be actively
> involved in decision making processes about polices and programs,
> including those directly concerning them."
> (UNCRPD 2007, Preamble)

The requirement continues in article 4(3):

> "Closely consult with and actively involve persons with disabilities,
> including children with disabilities, through their representative
> organizations when developing and implementing policies and
> legislation concerning persons with disabilities."
> (UNCRPD 2007, Article 4(3))

However, others believe that although this is an important advancement, the goals of the UNCRPD are far from being met, as there are gaps between policy, and what happens in practice and what is being monitored (Groce et al. 2011). This gap is due to three challenges: (1) a lack of effective policies for implementing the UNCRPD; (2) a gap between national

policies and local community practice; and (3) policymakers not having the desire for full

implementation (Groce et al. 2011). Additionally, the convention is complicated to interpret

causing the implementation to be uneven (Aldersey and Turnbull 2011). Challenges of the

convention are not unique to the UNCRPD, many UN conventions face similar issues

(Hoffman et al. 2016).

In Canada some critics have noted that "there is a gap between this vision [of the

UNCRPD] and the lived experience of Canadians with disabilities" (Kerzner 2011, p.4).

Perhaps this gap is related to the inconsistent nature of implementation of the UNCRPD's

goal of equality and autonomy for persons with disabilities in decision-making (Wildeman

2013). Substitute decision making is a practice where a representative or a guardian decides

or gives consent when a person with a disability is deemed to lack capacity (Caivano 2015),

contrasting to supported decision-making, where friends, allies, or family help with

communication and decision-making whilst assuming the person with a disability has

capacity (Hoffman et al. 2016). Article 12 states that "persons with disabilities enjoy legal

capacity on an equal basis with others in all aspects of life" (UNCRPD 2007, Article 12).

Canada has a specific reservation for Article 12, to protect the substitute decision making

(Wildeman 2013). In practice, substitute decision making has resulted in a lack of respect for

people with disabilities and negative implications for achieving equality (Hoffman et al.

2016). As it may not be possible for an individual to obtain rights which are under the

UNCRPD due to legal capacity requirements (Arstein-Kerslake 2017). Legal capacity

recognizes the right that a human being has that they can make decisions for themselves

(O'Donnell and O'Mahony 2017, Quinn 2010). In practice, this disregard is seen in the

Province of Ontario's Substitute Decisions Act (Government of Ontario 1992), as an

example, when persons who seem to lack capacity, there will be a third person appointed to

make decisions (Bach and Kerzner 2010). It has been noted by academics that this practice

does not consider people who have fluctuating capacity in decision making (Cera et al. 2017). This practice is possible because of the UNCRPD's 'deceptively simple language'; this permits each country to interpret the meaning, and in so doing, denying people with disabilities autonomy in decision making (Caivano 2015). As shown in this Ontario Act, Canadian implementation is inconsistent as the responsibility for upholding the UNCRPD principles are at the provincial level, not federal (Walker 2013). In the Canadian federal system, the provincial jurisdictions are responsible for: healthcare, support services, education programs and accessibility (Walker 2013), although some responsibilities under the UNCRPD such as provisions of goods, services, employment, (Canadian Human Rights Act, 1985), interpreters in judicial proceedings, tax credits (Government Canada 2014b), and aboriginals affairs fall under federal law (Hoffman et al. 2016). There are often battles between the federal and provincial governments over who has jurisdiction which complicates issues when changes are needed (Hoffman et al. 2016). In Chapter Three (Methodology) of this thesis, there will be discussed decisions about consent, thesis methodology, and the data analysis. Therefore, it is important to recognize the autonomy and capacity of children with disabilities; this should become a main priority in practice, rather than deferring to parents and caregivers.

2.2.4 Human Rights Model of Disability

The human rights and social model of disability have been utilized synonymously (Kanter 2003), however, have also been presented to contrast each other (Degener 2016,2017, Stein and Stein 2007). A definition of the human rights model is:

> "The human rights model focuses on the inherent dignity of the
> human being and subsequently, but only if necessary, on the
> person's medical characteristics. It places the individual centre stage
> in all decisions affecting him/her and, most importantly, locates the
> main 'problem' outside the person and in society."
> (Quinn and Degener 2002, p.13)

The human rights model highlights disability as a society constructed concept, similar to the social model; it is society's responsibility to remedy exclusion on the basis of disability (Stein and Stein 2007). The human rights model builds on the social model, as the human rights model is interested in key elements of procedures, practice and policy (Lawson and Beckett 2021).

Degener (2016) outlines six differences between the social model of disability and the human rights model of disability. Degener outlines these differences as seen below:

1. "Disability is a social construct, but human rights do not require a certain health or body status.
2. Human rights are more than anti-discrimination.
3. Impairment is to be recognized as human variation.
4. Multiple discrimination and layers of identity are to be acknowledged.
5. Prevention policy can be human rights sensitive.
6. Poverty and disability are interrelated but there is a roadmap for change."
(Degener 2016, p.3-13)

First, human rights are unconditional rights (Degener 2016); the human rights model is applicable to everybody who is experiencing a denial of rights (Lawson and Beckett 2021). In the preamble of the UNCRPD, the rights are affirmed for all people with disabilities (2007). The human rights model extends the social model's concern with relations in society (Oliver 1996) and into anti-discrimination legislation and civil rights (Degener 2016).

Second, the human rights model of disability would extend the anti-discrimination policy and encompass human rights, political, civil, social, cultural and economic (Degener 2016), with the understanding that people with disabilities are right-holders that perhaps need support. An example is in Article 30 of the UNCRPD (2007), the right to participation in recreation, sport and leisure with access to support information in accessible formats.

Degener's third proposition is:

"the social model of disability neglects the fact that disabled persons might have to deal with pain, deterioration of quality of life, and

> early death due to impairment (…) the human rights model of
> disability acknowledges these life circumstances and demands them
> to be considered when social justice theories are developed."
> (Degener 2016, p.6)

However, Oliver, an advocate and founder of the social model, denies that pain has

been disregarded and rather:

> "(…) it has been a pragmatic attempt to identify and address issues
> that can be changed through collective action rather than
> professional and medical treatment"
> (Oliver 1996, p.42)

Fourth, there is value in diversity identity; it allows space for cultural and minority

identification. A disability factor may be a congenital or an acquired impairment which

results in unique experiences. Women have criticized disability studies for excluding other

features of identity (Fine and Asch 1997, Morris 1991, Thompson 1997) and people of colour

with disability (Bell 2011). The reflection of different identity features are acknowledged in

the UNCRPD (2007) in the preamble to the convention including gender, race, religion,

language, ethnic, political, social origin, indigenous and age. Support for participation in

impairment related culture is recognized: "specific culture and cultural identity, including

sign languages and deaf culture" (UNCRPD 2007 Article 24).

Fifth, in public health policy, prevention of impairment has been criticized, as it can

be seen as discriminatory or stigmatizing (Oliver 1996). It has been noted that impairment

prevention policy for people with disabilities may be needed, and it is not all bad

(Shakespeare 2014). Although the UNCRPD does not discuss primary prevention, it

suggests secondary prevention to "prevent further disabilities including among children and

older persons" (UNCRPD 2007 Article 25(b)).

Finally, there is a link between disability and poverty (Oliver 1996). The human rights

approach suggests that people with disabilities are rights-holders and should have a say in

how resources are distributed (Degener 2016). There is a need for people with disabilities to

have access to equal and active participation in programs and development strategies to mitigate the discrimination on people with disabilities (Degener 2016).

The human rights model of disability adds to the social model, the models are both valuable for achieving participation, inclusion, equality, dignity and quality of life for people with disabilities (Lawson and Beckett 2021). However, the various models of disability have been deemed confusing rather than helpful (Oliver 2009). The human rights model values human beings with rights to be included in the community, education, family life and leisure, with value placed on their preferences and choices (Lawson and Beckett 2021). The social model is a model exploring disability, and the human rights model is exploring disability policy resulting in the two models being complementary (Lawson and Beckett 2021).

2.2.5 Social Relative and Relations Model

The social model divides impairment and disability; however, the Social Relative (Nordic Model) and Relations model sees impairment and disability as interacting (Traustadottir and Egilson 2009), This model sees impairment and disability on a continuum posing a relationship between the environment and the individual through interaction or an exchange (Owens 2015). The understanding of disability in the Nordic model has its focus on the interplay of the societal surroundings and the person through interactions between "the individual and the socio-cultural, physical, political and institutional aspects of the environment" (Berg et al. 2015, p.21). The Nordic approach may have a similar understanding to disability as the United Nations Convention on the Rights of Persons with Disabilities (2007). Thomas (2007a) argues that disability studies should:

> "engage both with social structure (order) and social agency (action) and should therefore accommodate analyses of social relations and social forces that construct, produce, institutionalise, enact and perform disability and disablism. The *lived experience* of both disablism *and* impairment should have its place."
> (Thomas 2007a, p.181-182)

Illness and impairment are portrayed as separate in the UK social model of disability, thereby perhaps neglecting the social relational nature of illness and impairment (Owens 2015). The social relationship between people expands the knowledge of impairment and disablism (Smith and Bundon 2018, Thomas 2007a). People can experience multiple forms of social oppression including indirect, direct and structural disablism (Smith and Bundon 2018). The model incorporates lived experiences of people with disabilities, exploring social oppression, wellbeing and impairment whilst understanding the body as social, cultural and biological (Smith and Bundon 2018).

The understanding of disability in the Nordic model has its focus on the interplay of illness and impairment. The Nordic relational approach may sometimes explain experiences of people with disabilities better (Mallett and Runswick-Cole 2014). This model understands disability through three main assumptions:

1. "Disability is a person-environment mismatch that occurs because the environment is not adapted to accommodate the whole range of people;,
2. Disability is situational or contextual thus specific impairments can become disabling or not due to concrete situations and
3. Disability is relative, as the cut-off point in impairment based definitions of disability to some extent arbitrary."
(Berg et al. 2015, p.22, Gustavsson et al. 2005, TØssebro 2004)

An individual may be 'impaired', but they may not receive a diagnosis of 'illness' until later on or the individual may have an 'illness' for an extended time before they receive a diagnosis which may be defined as an 'impairment' (Charmaz 2010). Similarly, in the human rights model, disability did not require a health status (Degener 2016).

The Nordic model explores the relationship of interactions and exchanges between people with disabilities and their environments (Owens 2015). Some interactions may include: societal attitudes, cultural constructions of disability, oppression, classification, impairment effects, opportunities and access, and well-being (Breslin et al. 2017). There is an

understanding that barriers to participation can include individual barriers such as lack of time and physical strength, social barriers which can be seen in the social model of disability, and societal assumption of disability can play a role in how an individual behaves (Breslin et al. 2017). The model accounts for internalized (negative feelings of oneself) and external (access) forms of oppression (Thomas 1999).

Impairment effects are described as impairment directly affecting the restriction of activity for a person living with impairment (Smith and Bundon 2018). Restriction of activity can also be due to social oppression undermining participation (Thomas 2007a). An example being a person with a disability experiencing pain due to their impairment, and a coach disregarding the impairment effects to 'push through' or leave the team (Beacom and Brittain 2018, Smith and Sparkes 2008, Wendell 1996).

A gap of knowledge noted for this thesis to explore is within disability physical activity research, coaches' learning has been explored in isolation from their participants' (Culver and Duarte 2014, Culver et al. 2012), specifically from the athletes perspective (Culver and Werthner 2018, Townsend et al. 2015) . Coaches have been shown to have knowledge as an able-bodied coach or athlete (Bloom et al. 2012, Cregan et al. 2007). The complex interactions between the coach and athlete shape the experience of participation through a relational process (Allan et al. 2019). Social-relational understandings of how coaches' shape experience in physical activity is important and the thesis will explore the effects coaches' actions and words have on participants' (Shirazipour et al. 2017).

The social relative model has been seen as complicated when used for analysis (Owens 2015, Smith 2013a,b), although it has been found useful when applying with other disability approaches (Smith 2013a,b). Martin (2013) specifically calls for more discussion linking the social relative model and physical activity, as it highlights the complexities of impairment, disability and disablism (Goodley and Runswick-Cole 2015, Martin 2013). The

exploration of lived experiences of children with disabilities participating in physical activities to produce understandings of wellbeing, impairment and social oppression in relation to internal and external relational factors will close a knowledge gap.

2.2.6 Critical Model of Disability

The critical model of disability is the next and final theoretical model to be discussed. The critical model of disability emerged in the mid 2000s which aimed to produce accountable action(s) addressing inequalities (examples include; Flynn 2017, Goodley 2012,2014,2016, Goodley et al. 2019, Mallett and Runswick-Cole 2014, Moeller 2015, Peers 2017, Slater 2015). The critical model has an emphasis on understanding the complex cultural, economic and social conditions that underpin the experience of exclusion for people with disabilities (Runswick-Cole and Goodley 2016). Importance is placed on an individual's own subjective experience and how that then connects to the wider understandings of social meanings, cultural and political discourse (Milton 2014).

The field of critical disability studies is interested in action to destabilize ideas surrounding disability whilst acknowledging power dynamics and questioning how assumptions are created (Vehmas and Watson 2014). Beliefs and assumptions of disability are reflected in policies, practices and actions, that if questioned and exposed, would create a possibility for action toward change (Eakin et al. 1996). In doing this, there is an exposing of how people with disabilities are marginalized and excluded in everyday life (Curran and Runswick-Cole 2013). The importance of this questioning is to recognize that there is a norm of power and privilege towards people without disabilities in cultural, political and social environments (Campbell 2009, Goodley 2014).

Not only is the understanding of how people with disabilities are excluded, the understanding of multiple identities (examples may include: ethnicity, gender, race,

sex/sexuality, class, age and disability) and the process of multiple exclusion processes

important to explore (Crenshaw 1991, Moodley and Graham 2015). In navigating various

identities, Goodley asserts that the purpose of critical disability studies is "to start with

disability but never end with it: disability is *the* space from which to think through a host of

political, theoretical and practical issues that are relevant for all" (Goodley 2016, p.157). An

aim of critical disability studies is perhaps emancipation (Meekosha and Shuttleworth 2009)

rather than a narrow focus on disability (Campbell 2009). However, it is argued that

"disability obtains its meaning through its relationship to the Other" (Campbell 1999, p.77),

and through ableist practices, 'able' bodies are preferred and deemed 'normal'.

There has been a call for a focus on the interdisciplinary nature of disability

(Annamma et al. 2019, Castrodale 2019, Yoshizaki-Gibbons 2019). The significance of this

can be seen in the following explanation:

> "Critical disability studies uses the tools of disciplines that at first
> sight seem to have nothing to do with disability, including
> philosophy and anthropology, history and sociology, ethnology and
> archaeology, literary studies and linguistics, medica studies and
> religious studies. They have opened new worlds of knowledge that
> have changed our understanding of dis/ability."
> (Waldschmidt 2019, p.71)

Dis/ability is split as disability/ability, always reliant on each other, and although

people with disabilities are often compared to what they lack, ability should be at the

forefront (Goodley et al. 2019). In addition to critical disability studies being an

interdisciplinary field, there is a reflexive and self-critical component to navigate multiple

components of experience (Goodley et al. 2019). It has been highlighted that some studies

have minimized understanding of impairments without an understanding of impacts to the

body and mind leaving out psychological and physiological realities (Shakespeare 2013).

Furthermore, people with disabilities who lack a diagnosis are perhaps excluded from critical

disability studies which "both reflects and reinforces their marginalised position in a variety

of forms" (Holt 2016, p.148). The importance for this thesis is to be aware and understand the lived experience of children with disability from an interdisciplinary perspective.

2.2.7 Defining Disability

The previous subsections in this chapter discussed different ways to theorize disability. There have been attempts to define disability, although attempting to define the true meaning of disability can be at times a problematic and confusing task (Thomas 2014). This section will compare and contrast a few definitions of disability to highlight a gap in the universal understanding, including the United Nation Convention on the Rights of Persons with Disability (2007), International Classification of Functioning Disability and Health (2001), and definitions found within disability studies literature.

First, the United Nations Convention on the Rights of Persons with Disability (2007) understands disability as an interaction between people with impairments and environmental and attitudinal barriers that hinder full participation in society (UNCRPD 2007, preamble). The definition is also comparable to the Nordic model where impairment evolved and is context specific (Berg et al. 2015) and the social model of disability (Oliver, 1996). Furthermore, the UNCRPD definition has similar goals to the human rights model of disability as it strives to address key elements such as policy, procedures and practice (Lawson & Beckett, 2021). However, the UNCRPD definition of disability contrasts with the medical model understanding of disability.

Second, the International Classification of Functioning, Disability and Health (ICF) (2001) takes a different approach to the UNCRPD (2007). The terms 'impairment' and 'disability' have been defined in different ways. 'Impairment' defined by the International Classification of Functioning (ICF) refers to "problems in body function and structure as a significant deviation or loss"; the body structure is defined as "anatomical parts of the body

such as organs, limbs and their components" and the bodily function is stated as "the physiological functions of body systems (including psychological functions)" (ICF 2001, p.9). The definition of impairment is similar to the definition of disability as seen through the medical model in subsection 2.2.1, above. Similarly, in Canada disability can be defined as "any severe and prolonged condition that inhibits a person from performing normal and routine daily activities" (Government of Canada 2014a, p.1). Through definitions such as this, disability highlights a 'deficit' where there is an implied sense of 'normal' for individuals into which people with disabilities do not fit. This is the category of *different* that often people with disabilities are identified as (Harris and Roulstone 2011).

However, it has been argued that disability encompasses much more, including barriers as seen in the following definition:

> "… disability is always the combination of a certain set of physical or mental attributes, in a particular physical environment, within a specified social relationship, played out within a broader cultural and political context, which combines to create the experience of disability for any individual or group of individuals."
> (Shakespeare 2006a, p.58)

Similarly, Thomas (2012a) further argues that:

> "the social imposition of avoidable restrictions on the life activities, aspirations and psycho-emotional well-being of people categorized as 'impaired' by those deemed 'normal'"
> (Thomas 2012a, p.211)

The above definitions found within disability literature fall in line more with the UNCRPD (UNCRPD 2007) definition than the ICF (2001). The definitions go further by including that definitions and experience of disability can vary across institutions and agencies (Laudan and Lorprest 2012), which is in line with social relation theories of disability. There is also a recognition that there is significant diversity to the disability experiences across domains such as physical, psychological and cognitive impairments (Susman 1994). Although there is literature that cautions neither the social nor medical model

of disability are absolute, the applications of each model can be used to describe disability (Shakespeare 2006a).

To understand social agency, structure, forces and relations that construct and produce disability, there is a need for the understanding of lived experience (Thomas 2007a). The definition of disability is diverse and varies; it can be argued that the full understanding of disability experiences is dependent on the individual's philosophical view (Michailakis 2003). Impairment can affect individuals in different ways; therefore, it is important to note that disability is not a homogenous group and it may be experienced differently by adults and children (Sherry 2016). Importance should be placed on the individual's subjective experience which complements critical disability theory (Runswick-Cole and Goodley 2016). It should be noted that children with disabilities were not consulted in the creation of these definitions. This thesis will aim to understand what disability means for the participants in this study to further knowledge by adding the voices of children with disabilities and therefore, I will not necessarily be adhering to any definition of disability.

2.2.8 Approaches to Understand Disability - Section Summary

The aim of the section is to understand different theories of disability and the implications that they have on the individual and society. The medical model, social model, Nordic model and critical models of disability were discussed, including a comparing and contrasting of several definitions of disability. The analysis of the disability theories and models in this chapter have shown that there is a gap in the universal understanding of disability. This gap has significant implications for this thesis, as during the research, there may be different perspectives and experiences.

The chapter started with the medical model of disability which has a focus on the individual's impairment and how they can change to fit into society. The social model

followed with a contrasting view that society is the one that needs to change to include people with disabilities. The Nordic model of disability was then discussed adding that disability is an evolving concept which can be experienced differently across various contexts (Berg et al. 2015). Critical disability studies were then discussed, and an emphasis was placed on individual experiences and how it is connected to wider cultural, political and social meanings (Milton 2014).

Then there was an exploration on the definitions of disability and the difference between impairment and disability. International definitions of disability from the UNCRPD (2007) and ICF (2001) were discussed and linked to the disability models. The section argued that disability is diverse in experiences and understandings, and experiences should be explored from the individual's viewpoint (Michailakis 2003).

To summarize, the section developed an understanding of disability theories and definitions which helped to develop the research questions of this thesis. Children with disabilities' perspectives were left out in the creation of these theories and definitions; these perspectives should be included as seen through participation rights in Chapter One. Key considerations for the thesis are: (1) factors that contribute to disability formation through lived experience; (2) power relationships; and (3) tensions when various perspectives co-exist. Additionally, it is important to explore if the theories discussed are still relevant through lived realities or if a more updated understanding is needed. The following section of this chapter will discuss the context in which these models will be explored.

2.3 Context

The aim of the following section is intended to develop an understanding of the context within which the data collection has taken place. The section will begin by linking childhood studies and disability studies, followed by a discussion of the Canadian context

and an exploration of the different understandings of the term 'voice', as it relates to children with disabilities. Finally, this section will explore the context of physical activity for children with disabilities.

2.3.1 Childhood Disability

Childhood can be viewed as a life stage, where children move through and develop from vulnerable and immature on the way to adulthood (Boggis 2018a). Children who do not progress through these stages are often seen as 'atypical' (Boggis 2018a). Children with disabilities often experience increased surveillance from adults denying them the ability to develop the attributes of competence and agency (Richards et al. 2016). The view of children as dependent on adults and vulnerable is often similar to the view of people with disabilities (Priestley 1998). Contrasting to discussions in Chapter One, children in childhood studies are being recognized as being active participants, and having agency (James and James 2004).

A child with disabilities is often characterized with a single term as being a 'disabled child' or a 'child' rather than a child with agency and individuality (Boggis 2018a). Social categorization has been argued to be flawed as a "focus on group membership, instead of personal qualities" (Jones et al. 2014, p.28). Embracing a simplistic view of individuals and diversity perhaps has "consequences for the identity formation of young people" (Papatheodorou 2007, p.43-44). The categorization of children with disabilities is common, as there is often a focus on "identification, categorisation" and then suggestions to "repair" children with disabilities (Penketh 2014, p.1487). As a consequence, children with disabilities are viewed as inferior to able-bodied children which "distances one group from another, sets up barriers of 'them' and 'us' and serves to undermine notions of community and togetherness" (Greene, 1991 in Cassidy and Jackson 2005, p.446). An alternative would be to view children with disabilities as diverse. Diversity is a celebration of "difference" and

acceptance incorporates diverse people in different groups such as disability, lifestyle, age, race, social class and gender (Ayling 2018).

Research of children with disabilities has found that children with disabilities have been shown to have fewer friendships, are less accepted and have lower self-esteem than peers without disabilities (Koster et al. 2009, Koster et al. 2010). Additionally, children with intellectual disabilities experience less social support, more social isolation and weaker social networks in comparison to children with physical disabilities (Lippold and Burns 2009). In context specific research, children with disabilities participating in physical education have been shown to be recipients of bullying and negative peer interactions (Fitzgerald 2005, Goodwin and Watkinson 2000, Haegele and Sutherland 2015, Healy et al. 2013, Moola et al. 2011). A research study in Canada found that children with disabilities felt that having friends, the feeling of being a legitimate participant and a fun activity were the most important factors in the development of self-worth and feeling included (Spencer-Cavaliere and Watkinson 2010). For children with disabilities, having friends was found to decrease their feelings of being lonely, improve feelings of self-worth and enhance independence (Goodwin and Staples 2005, Price and D'Eloia 2018). Children with communication or speech impairments were found to participate in fewer activities outside of school with friends than other impairment types (Raghavendra et al. 2011). It has been noted that inclusive physical education can increase social interactions between children with and without disabilities leading to potential friendship (Bloom et al. 2009). Although the focus of the research is not negative experiences of children with disabilities, the thesis recognizes that children with disabilities may experience some negative interactions during the research process.

It has been acknowledged in the academic community that there is often a passive acceptance that children with disabilities are victims of bullying (Mepham 2010). "Indeed,

bullying can be represented as one of the means by which children with impairments or particular needs become "disabled"" (Chatzitheochari et al. 2014, p.4). Bullying has been suggested in qualitative accounts of children with disabilities to be an unwelcomed daily experience (Connors and Stalker 2002, Liddiard et al. 2018, Norwich and Kelly 2004). When children with disabilities are labeled as 'different' or 'special' the 'othering' language can lead to further social exclusion, because they are being viewed 'with strangeness' (Stevenson 2008). A suggestion has been to replace negative connotation language such as 'special needs' (Martin 2011), as in an educational context it leads to exclusionary practices (Hodge and Runswick-Cole 2009). Instead of the words 'needs' and 'rights' could be used (Sayers 2018). The word 'rights' is important, as it values the rightsholder and identifies that the individual is entitled to rights, respect and dignity (Freeman 2007b, Sayers 2018).

It has been suggested that "disabled children should first and foremost be viewed as children" (Berg et al. 2015, p.27). Rather than viewing children with disabilities through medical concepts which previously took preference, there is an emphasis to prioritize childhood concepts (McLaughlin et al. 2008, Runswick-Cole et al. 2018b). The previous medical view in research resulted in little attention to the lives of children with disabilities, as they are often excluded from "the expectations, opportunities and aspirations afforded to the so-called typically developing children" (Goodley et al. 2015, p.6). Additionally, research has been preoccupied with the presumption of dependency, service use, impairment and vulnerability (Avery 1999, Curran 2010). Furthermore, parent and professional voices have been the focus while the voices of children with disabilities have been frequently excluded (Berg et al. 2015). Recently there has been an increase in research involving the perspectives and views of children and youth with disabilities to enhance the understanding of their experiences and lives (Examples: Allan et al. 2019, Brien 2018, Einarsdottir 2007, Phelan

and Kinsella 2013, Shirazipour et al. 2017, Stalker 2012, Whitburn 2016, Wickenden 2018, Ytterhus 2012).

2.3.2 Canadian Context

The current thesis will conduct research in a Canadian context, specifically the City of London, Ontario and surrounding area. During the 1970s and 1980s, people with disabilities in Canada were represented in law and statutes expressing that they were entitled to the same rights as all other people (Tardif-Willams et al. 2009). In 1982, equal rights were enshrined in the Charter of Rights and Freedoms which included equal rights for people with physical or mental impairments (Tardif-Willams et al. 2009). Prior to recognition of equal rights, children with disabilities were often educated under a separate curriculum, and often in different schools away from non-disabled populations (Weber and Bennett 2004). There was a push to 'mainstream' children with disabilities into schools, but success was questionable, as the children with disabilities were "in their neighborhood school, but not really of it" (Weber and Bennett 2004, p.14). Specific criticisms noted that children with disabilities were in segregated classrooms and experienced isolation from non-disabled students.

The Government of Canada has created the Accessible Canada Act (ACA) (Government of Canada2019) which aims to protect rights and dignity of people with disabilities, to ensure full inclusion and citizenship. The ACA came into force in 2019 with a vision of a barrier-free Canada by 2040 through identifying, preventing and removing barriers. However, with the last national data set of Canadian Participation and Activity Limitation Survey being in 2006, there is no recent national quantification of barriers. This 2006 survey concluded that amongst children under the age of 15, 10.9% had a disability (Statistics Canada2006b). Children in Canada have experienced inequalities such as unequal access to education, healthcare and social services (Green et al. 2005, WHO 2011). It has also

been found that children with disabilities participate less in social leisure activities within their community in comparison to children without disabilities (Engel-Yeger et al. 2009). More specifically, for children with disabilities, participation in various leisure activities gets even more reduced as they get older (Law et al. 2006, Majnemer et al. 2008, Shikako-Thomas et al. 2012).

The Policy on Sport for Persons with a Disability was created with the vision of people with disabilities being able to have access to full participation at "all levels and in all forms, to the extent of their abilities and interests" whilst contributing to "social inclusion through these activities" (Heritage Canada 2006a, p.2). Participation has been deemed important in sport as "children acquire skills and competencies, achieve physical and mental health, and develop a sense of meaning and purpose in life" (Standing Senate Committee on Human Rights 2012, p.6). With 4.4 million Canadians having a disability, one study estimates that 3 percent of these individuals are participating in organized and regular physical activities (Heritage Canada 2006a). Some barriers noted were: a lack of accessible programs, a lack of information about sporting opportunities, the costs for transportation and equipment, attitudinal barriers and a lack of people who knew how to assist people with disabilities in sport (Heritage Canada 2006a). In addition, in Canada "37 percent of children and youth with disabilities never take part in organized physical activities compared to just 10 percent amongst those without disabilities" (Geoffery et al. 2016, p.128). Therefore, it is important to understand the perspectives of children with disabilities regarding their own participation, in an effort to perhaps contribute to the understanding of this participation gap.

In Canada there are specific barriers to physical activity such as the logistical challenge of distance from facilities which results in parental choice of activity based on "how far is too far" (Loitz and Spencer-Cavaliere 2013, p.1130). Additionally, weather is a logistical barrier found especially during winter months when transportation becomes

difficult (Loitz and Spencer-Cavaliere 2013). It is more likely that children with disabilities are living in poverty in comparison to their peers (Petrenchik 2008) which may result in unmet needs and opportunities (Law et al. 2007, Petrenchik 2008). Parents of children with disabilities have reported difficulty with accessing special education for their children (Statistics Canada 2008b). Some children with disabilities require assistive technology; however, over half of the children do not have access to this technology due to barriers such as costs (Statistics Canada 2008a).

Person-first language for 'people with disabilities' rather than 'disabled people' suggests that people should be first rather than their impairment (Lawson and Beckett 2021). There is a divide between identity-first and person-first language, the goal is the same which is to ensure access and rights for people with disability (Collier 2012, Davis 1995). Person first language is used throughout policy in Canada such as the Accessible Canada Act (Government of Canada2019), and The Policy on Sport for Persons with a Disability (Heritage Canada2006a). A review of "people-first" language in Canadian society in 2001 identified the terminology as the dominant linguistic formulation (Eales et al. 2014, Titchkosky 2001, Withers 2012). The thesis will use context specific person first language, until directed by participant preferences.

2.3.3 Children's Voices

In Chapter One, the emphasis was placed on ensuring children's voices in matters are heard that affect their lives. Engaging with the 'voice' of the child has been examined in childhood studies literature (James 2007, Moran-Ellis 2010, Tisdall and Punch 2012). This is a result of the stance that children are experts in their own lives and can contribute valuable knowledge (Clark and Moss 2011). However, there has been an exclusion of children who do not communicate verbally and perhaps a privileging to verbal communication (Tisdall 2012).

Children's 'voices' as positioned in research has been questioned, and a caution has been placed on ensuring that linguistic, textual or verbal communication is not privileged (Komulainen 2007). Non-normative voices such as actions and noises are perhaps more revealing voices (Komulainen 2007, MacLure 2009, Rogers et al. 2005, Spyrou 2018, Tudge and Hogan 2005). The approach was developed with an understanding that 'voice' is socially constructed which results from social interactions (Komulainen 2007). Arguing that "ideals of 'normal' and good communication that prefer rational, abstract thinking and actions, discriminate between different groups of people even through the aims were to meet the needs and individual rights of children" (Komulainen 2007, p.23). Komulainen (2007) draws on the work of Bakhtin to suggest voice is co-constructed instead of fixed, clear, linear or straight forward. This contrasts to the suggestion of 'literal listening' focusing on audible communication (Schnoor 2012). Schnoor (2012) suggests that from a very young age, children are able to communicate their needs and perspectives; children's voices are present rather than needing to be constructed.

The concept of children's voices can be understood through spatial elements (Mannion 2007), which suggest a wide lens when discussing children's voices as adults' intergenerational relationships with children, and different practices, contexts and cultures, shape children's voices. An example can be seen in highly structured schools where children may choose to use more official voices to provide a 'correct answer' rather than how they choose to interact in the neighbourhood or with their friends (Spyrou 2018). Voice is viewed as being produced through social spaces and relations which should not be ignored (Mannion 2007). Haw (2008) states that "in different relationships different voices are articulated, prioritized and privileged" (Haw 2008, p.195).

Similarly, children's voices have been described as "evolving in dialogue with adults" (Graham and Fitzgerald 2010, p.350), rather than the researcher 'giving' voice to children

which is perhaps viewing children as objects. The process is a multidimensional construction that is messy rather than the child voice being a fixed concept (Elden 2012). Extracting quotes from children quickly to collect data for analysis perhaps does not produce meaningful insights into children's life worlds (James 2007, Spyrou 2018).

Warming has suggested that "some children's voices and perspectives are heard and recognized, while others are not even acknowledged" (Warming 2011, p.48). Children with disabilities who are non-verbal or who experience communication difficulties have been excluded from participating in research (Alderson and Morrow 2008). The non-voiced or silent are often ignored and deemed to be non-data but should be viewed as purposeful, meaningful and an aspect of voice (Mazzei 2003,2004,2007,2009). However, children who are non-verbal may experience difficulty in self-advocating, as they may have been taught instead of initiating conversations to respond to prompts (Potter and Whittaker 2011). This emphasizes the importance of understanding space and relations of the construction of voice (Mannion 2007).

Non-verbal communication is important: "respect for non-verbal forms of communication including play…. through which very young children demonstrate understanding, choices and preference" (UN Committee on the Rights of the Child 2009, p.7). The approaches to voice and communication can be seen as an "interdependent and a mediated coproduction between persons and, in some instances, technologies" (Teachman et al. 2018, p.38). The production of voice is complicated and an entanglement of humans, materials, linguistic, visual and oral dimensions (Elden 2012). It is important to note in research that there is often a focus to clarify and confirm meanings from voice which requires a performative aspect (Mazzei 2009). A different approach is to go beyond 'voiced' or verbal language and explore the understanding that if one does not audibly voice their opinion, perhaps they are communicating in a different way (Mazzei 2003,2009).

Voices and competencies of children with disabilities have been questioned for factors, such as presumed lack of maturity, communication clarity, and misconceptions (Richards et al. 2015). Additionally, voices of children with disabilities have been excluded because of the unconventionality of expression and adult's perceptions of capacity (Boggis 2018c). Although the UNCRC suggests that children with disabilities should be heard, often their social position regards them as vulnerable leaving them with a limited opportunity to be heard (Thackray 2018). As an example, parents of children with disabilities may believe that their child does "not have sufficient understanding or communication to take part, or they would be too anxious to interact with a researcher" (McNeilly et al. 2015, p.270). Exclusion of children with disabilities from research, and being reliant on parental perspectives, perhaps means that the voices of children remain unheard (McNeilly et al. 2015, Meerwald 2013).

2.3.4 Sport

A gap in current literature exist as research to date on understanding participation in sport by people with disabilities has often focused on physical education in school (Examples, Coates 2012, Fitzgerald and Stride 2012, Healy et al. 2013, Moola et al. 2011, Qi and Ha 2012, Reuker et al. 2016, Wang 2019). This thesis aims to start closing that gap by focusing on physical activities outside of school.

Children with disabilities should have the same rights and opportunities to join activities as their peers per Article 31 of the UNCRC (UNCRC 1989). People with disabilities can experience social exclusion in sport (Kay and Collins 2014, Misener and Darcy 2014, Spencer-Cavaliere and Kingsley 2015) as indicated by organized sports having a lower participation rate for people with disabilities as compared to people without disabilities (Finch 2001, Klenk et al. 2018, Si et al. 2017, Sotiriadou and Wicker 2014, Ullenhag et al.

2012c). Barriers cited in literature for people with disabilities accessing physical activities include:

> (a) intrinsic barriers (lack of motivation, lack of energy);
> (b) resources (cost, lack of knowledge of available programs); and
> (c) structural barriers (accessibility and knowledgeable instructors).
> (Adapted from, Bedini and Thomas 2012)

Additionally, other factors may be a lack of transportation, and not knowing how to do an activity (Jackson and Scott 1999, Rimmer et al. 2010), staff training issues, policies and procedures being out of date in the facility or community, equipment and information barriers (Rimmer et al. 2004), limited inclusive sport groups (Howe and Kitchin 2014), and fear of getting hurt or being teased (emotional and psychological barriers) (Moran and Block 2010). Children with disabilities may experience more barriers due to parental fears or concerns (Bedini and Thomas 2012). It has been argued that a main barrier for children to participate in physical activities in misperceptions of what participation would entail from the participant and service provider (Bedini and Thomas 2012).

Structured community programs for children with disabilities were found to promote and develop attachments amongst children with similar impairments through their participation (Willis et al. 2016) and similarly suggested by Parkyn and Coveney (2013) in their research with boys diagnosed with muscular dystrophy, where in a familiar environment, children of similar age and impairment reacted positively to skill and social development. This finding may support the argument that children with disabilities, whilst participating in segregated activities amongst other children with disabilities, perceive the interactions as safe, comfortable and non-threatening (Goodwin et al. 2004). The increased attachment to a disability community and skill building can result in the transfer of attitudes and skills to other environments such as school and home (Willis et al. 2016).

In a community of sport, it was found that children with disabilities experienced great pride when having success (Anderson 2009, Anderson et al. 2008, Heah et al. 2007, Lyons et

al. 2009). These experiences have a positive effect on children's activities by increasing their sense of pride, activity choices, development of competence, persistence and overall enjoyment (Anderson 2009). On the other hand, children with disabilities and adolescents may try to separate themselves from the disability community to fit within society, whilst denying their disability identity and adopting society's negative attitudes towards people with disabilities (Dunn and Burcaw 2013, Smart 2001, Tajfel and Turner 1979, Thornicroft et al. 2007).

Formal activities have been described as organised and structured, having goals or rules directed by an instructor or coach which differs from informal activities with no or little prior planning (King et al. 2006, King et al. 2003). Formal activities include clubs, groups, skill-based activities, organized sports and organizations (King et al. 2009). Physical activity can be organized or spontaneous (Jakobsson et al. 2019). Sport generally is an exercise by a team or individual where there is a defined goal (Khan 2011). However, Suits (2007) suggests various elements that are needed for sport. It is suggested that sporting games adhere to rules and are goal-directed, the game requires skill, specifically physical skill, and sports have a following becoming institutionalized (Suits 2007). Physical skill separates games such as chess from a sporting game (Kobiela 2018). A contrasting view is that sport is defined by rules only, as they are "embedded in overall theories or accounts of sport as a practice" (Simon 2000, p.7). Rules perhaps make sport possible but agreeing to follow them is just as important (Brittain 2018, Fraleigh 1984).

The Canadian Sport Policy (2012) sets out a framework for sport in Canada which incorporates 5 goals:

1. "Introduction to sport: Canadians have the fundamental skills, knowledge and attitudes to participate in organized and unorganized sport.
2. Recreational sport: Canadians have the opportunity to participate in sport for fun, health, social interaction and relaxation.

3. Competitive sport: Canadians have the opportunity to systematically improve and measure their performance against others in competition in a safe and ethical manner.
4. High performance sport: Canadians are systematically achieving world-class results at the highest levels of international competition through fair and ethical means.
5. Sport for development: Sport is used as a tool for social and economic development, and the promotion of positive values at home and abroad."
   The Canadian Sport Policy, (Government of Canada, 2012s.2.1.1)

The policy for sport in Canada contrasts with literature such as having to be institutionalized (Suits 2007), as sports can be unorganized. Additionally, there is not a requirement of a game (Suits, 2007). The policy does seem to compare in the understanding that there is a need for rules in sport (Fraleigh 1984, Simon 2000, Suits 2007). To understand the different levels or categories of sport engagement potentially available a Sport Integration Continuum presented by Winnick in (1987) is helpful, as shown in Figure 8 below.
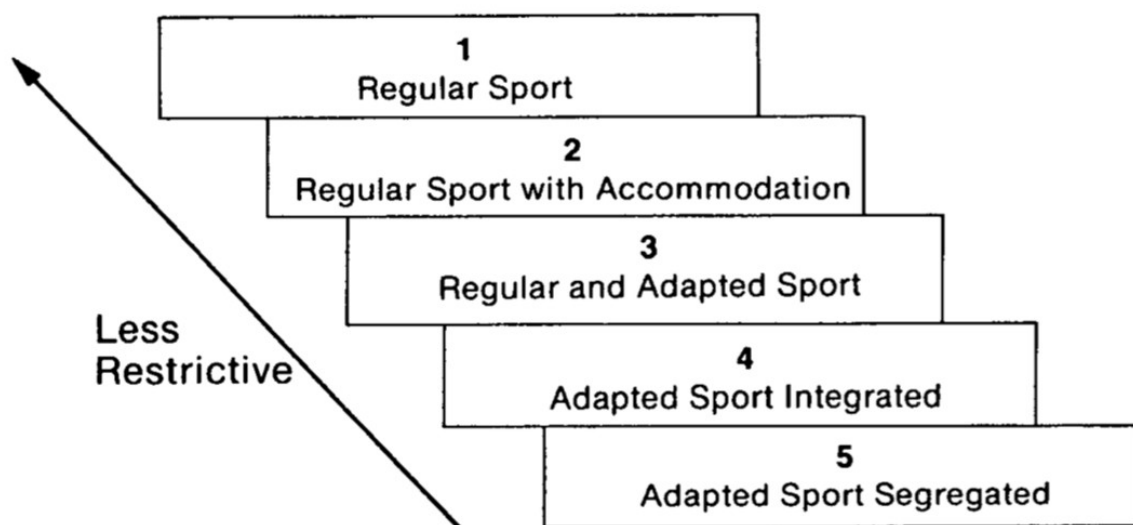
Figure 8 Sport Integration Continuum (Winnick, 1987, p.158)

1. *Regular sport* is where children with disabilities would participate without any support alongside able-bodied participants.
2. *Regular sport with accommodations* is where a person with a visual impairment horseback riding with 'live letters' whilst riding around the arena while someone tells them where they are. A challenge may be to find reasonable adjustments to the physical extracurricular activity for children with disabilities to permit safe enjoyment (Pickering 2018).

3. *Regular and adapted sport* is where there is flexibility for both able-bodied participants and participants with disabilities to participate in sports, such as a person with a visual impairment participating in goalball and 'regular' bowling.

4. *Adapted sport integrated* is looks like reverse integration where able-bodied and people with disabilities participate in an adapted sport, such as sledge hockey.

5. *Adapted sport segregated* is where people with disabilities separated from able-bodied participants, such as in the Special Olympics.

Participation in disability sport has been described as being "about choice across a continuum" (Misener and Darcy 2014, p.3). per the Inclusion Spectrum model seen below in Figure 9.
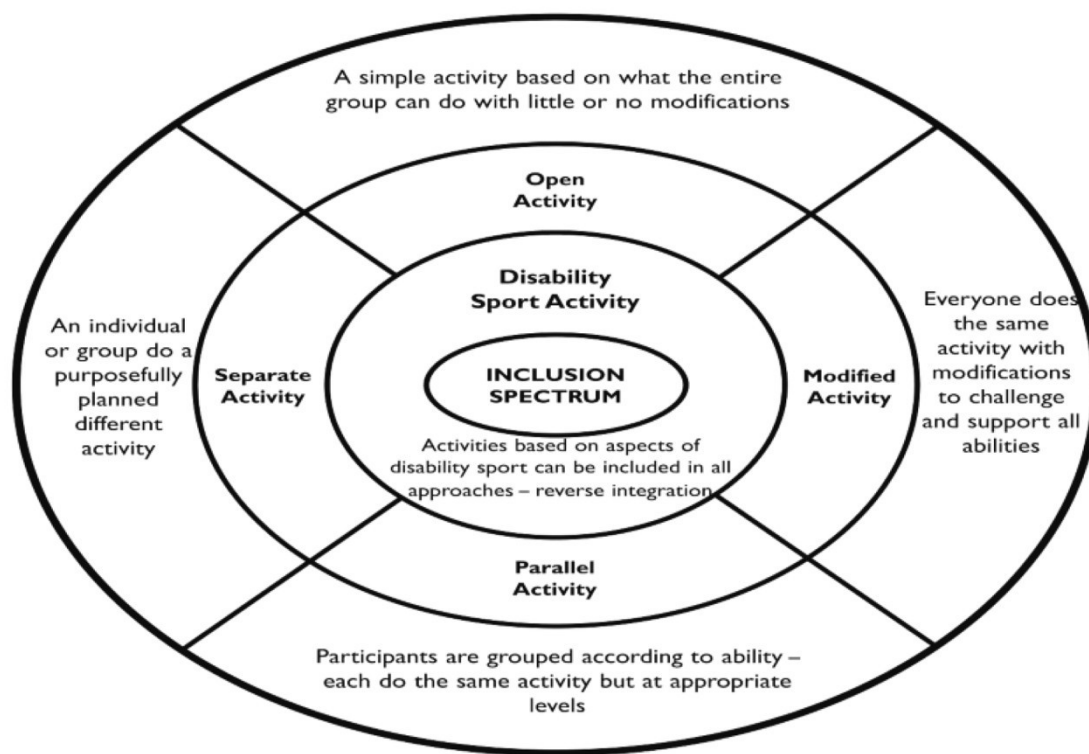
Figure 9 The Inclusion Spectrum Model (Misener & Darcy, 2014, p.3)

The Misener & Darcy model is similar to the Winnick model but with different terminology. The models have evolved with people of disability being integrated and included in mainstream sports (Howe and Kitchin 2014). Sport for people with disabilities is

often segregated, as there is discrimination from mainstream sport (Jeanes et al. 2017, Patel 2015). When children with disabilities experience success in activities, there is perhaps a positive effect which may contribute to overall enjoyment, choice of activity, and persistence (Anderson 2009). An individual's choice of physical activity is an important part of the process, rather than selection of these activities by professionals (Kiuppis 2018). People with disabilities choosing their own sport, how they want to participate and with whom should be the goal (Misener 2014). Applying the UNCRC and the UNCRPD rights of children with disabilities to have a say in matters that affect their lives, this should include which sport they participate in and where on the inclusion spectrum they participate. This thesis will extend this work in investigating the role choice has in physical activity for children with disabilities.

2.3.5 Context - Section Summary

This section of the chapter provided insights into the context in which this study will take place. It has discussed the intersection of childhood and disability experiences and highlighted tensions of exclusionary practices and lived experiences that participants perhaps live through. Knowledge creation will be led by children's experiences. Second, the Canadian context was discussed including policies and research that has been conducted in Canada providing a background knowledge of national goals and tensions discovered in research findings. Barriers to participation were discussed, along with Canadian participation considerations. Third, the concept of voice was discussed where themes were identified.

The understanding gained moves beyond participation of children in matters that affect their lives and how voice is constructed. Voice was understood to be a construction that is not a linear process, and where value should be on all communication rather than preference to verbal communication. Finally, the context of sport was discussed through different models defining integration, inclusion and segregation within physical activities.

The thesis will expand research into physical activities that take place outside of a school setting.

Considerations for this study can be identified as: (1) the construction of children's voice across different contexts; (2) relationships between children, adults and environments; and (3) understanding of children's agency and navigation through context. The next section of the chapter will discuss definitions and theories of inclusion.

2.4 Inclusion

The aim of the current section is to establish key themes and gaps within inclusion literature. Inclusion is a popular term widely used in practice, policies and international discussions. The importance of this section is to highlight that people with disabilities can face barriers to participation in society such as psychological, sociocultural and structural (Halder 2008, Halder et al. 2017).

2.4.1 Defining Inclusion

The goal of full inclusion for people with disabilities has been disseminated through international documents (UNCRPD 2007; ICF, 2001). People with disabilities in Western society have been often regarded as a highly marginalised group (Hall 2005, Koh 2004, Overmars-Marx et al. 2014, Pitonyak 2007). The term 'inclusion' is difficult to challenge, as the term strives for an ideal acceptance of what is morally 'right' within society. The Western world views inclusion as almost universally agreed upon as a goal that should be worked towards.

The term inclusion is a primary focus and area of discussion in the field of education (Kiuppis 2018). Inclusion is "about the participation of all children and young people and the removal of all forms of exclusionary practice" (Len Barton, as quoted in Armstrong 2003,

p.3). Allman (2013, p.1), criticizes the view of inclusion, as inclusion benefits those who already included more than those who are in need of inclusion. The social model of disability is represented in this definition, as it has the aim to remove barriers. A similar definition, inclusion is where:

> "special education programs are placed in general education classes (also known as 'integration'). For others, it is a process of identifying, understanding and breaking down barriers to participation and belonging often by addressing institutional factors and work generally on school development. Inclusion is about the quality of children's experience; how they are helped to learn, achieve and participate fully in the life of the school."
> (Devecchi 2014, p.955)

This philosophical approach believes in the capability of the individuals, and responds to their needs appropriately (Farrell 2017). It has been argued that this approach is dependent on the capabilities and understanding of those staff that work with children with disabilities (Rioux 2014). Additionally, there is a need for staff to "appreciate the child, before the difference" (Elvidge 2013, p.144), as contributions by children with disabilities in reality are rarely valued (Qvortrup 1994).

Inclusion, in education has emerged as the opposite of special education (Thomas 2013). Although some education practices are perhaps labeled as inclusive, children with disabilities may be separate from their peers without disabilities (Norwich 2014). The Figure 10 below is a visual example of inclusion, exclusion, segregation and integration.
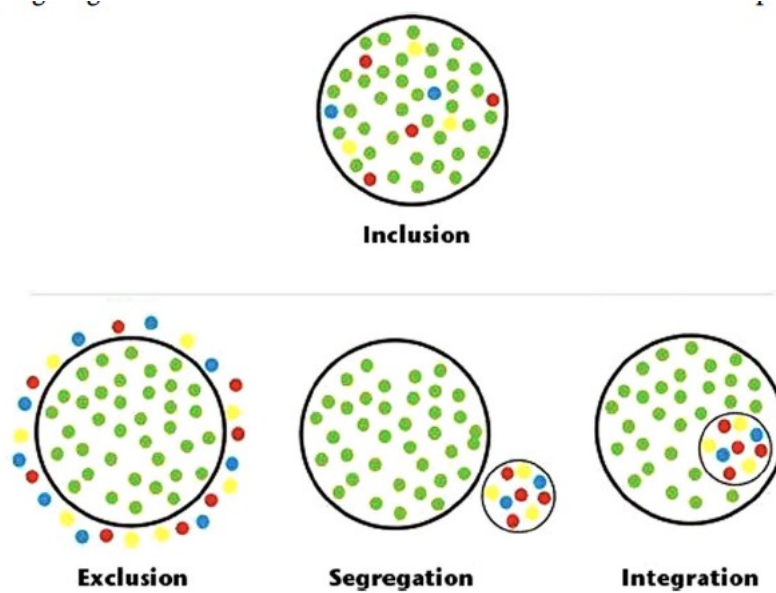
Figure 10 Inclusion Diagram (DeBeco, 2016, p.46)

Figure 10 shows 'exclusion' as people with disabilities being separate, 'integration' people with disabilities are interacting with people without disabilities but are regrouped together, and 'segregation' people with disabilities are separate from people without disabilities but are grouped together (De Beco 2016). Integration of children is seen in practice as being put into a pre-existing environment (Ainscow et al. 2006, Booth and Ainscow 2002). A state of 'perfect' inclusion in education perhaps does not exist; however, instead of identifying problems of children with disabilities, recognizing abilities, adapting to all needs and embracing human differences (De Beco 2016).

Adults with disabilities define social inclusion as being able to participate on their own terms and having the freedom to choose (Hammel et al. 2008). Inclusion is the idea that people with disabilities feel valued, incorporated and welcomed into society without any limitations (Price and D'Eloia 2018). This is similar to the definition as "a sense of belonging, feeling respected, valued, feeling a level of supportive energy and commitment from others so that you can do your best" (Miller and Katz 2002, p.7). However, notions of

inclusion that are 'warm and inviting' overlook present and past lived experiences, as they are future-orientated (Edwards et al. 2001).

It is fundamentally important that inclusion practices, inclusion lived experiences, and the processes of inclusion are critically examined from the perspective of people with disabilities (Spencer-Cavaliere and Watkinson 2010, Susinos 2007). It has been highlighted that inclusion is 'iridescent' as it is "something that looks quite different depending on the viewpoint of the observer" (Roulstone 2000, p.428). Rather than thinking of inclusion as a unidirectional journey by disabled people toward mainstream contexts, these scholars and researchers call for decentring inclusion so that "instead of being either included or excluded, we are all, at once, both half in and half out" (Titchkosky 2011, p.21).

Critical scholars suggest that radically rethinking inclusion requires deconstructing the normative centre from which exclusion processes are derived, where the normative is naturalized, and the 'other' is named and excluded (Cook and Swain 2001, Slee and Graham 2008).

Other research with women living in poverty in the health sector demonstrated inclusion is not experienced as a simple binary of inclusion or exclusion, nor is it stable or necessarily desirable (Ponic and Frisby 2010). Instead, women said they experience 'moments' of inclusion that co-exist alongside experiences of exclusion. The women's account challenged portrayals of marginalized groups as passive recipients of inclusion processes (Ponic and Frisby 2010). The process of inclusion included various elements such as relational, psychosocial, organizational and participatory dimensions (Ponic and Frisby 2010). The process of inclusion cannot be oversimplified, as it incorporates active agents participating (O'Reilly 2005), as the relationship of inclusion and exclusion is complex, contradictory, and fluid (Labonte 2004, Ponic and Frisby 2010). In line with "people's

interpretations and their resulting actions must become the core subject of empirical

research" (Vobruba 2000, p.609).

2.4.2 Inclusion in Sport

Sport has the potential to foster opportunities for belonging and connection, whilst

engaging young people to perhaps lessen social exclusion (Kay and Collins 2014). The terms

'disability', 'sport' and 'participation' are often referred to when discussing inclusive

physical education (Coates and Vickerman 2010, Goodwin 2009). The term inclusion in

physical education is all encompassing covering all levels of access, participation and

achievement (Slee 2006).

Youth with disabilities often experienced sport in three common settings. First,

disability sport which is a segregated setting comprised of a homogenous setting with youth

with disabilities or a setting with children without disabilities (Goodwin and Peers 2012).

Second, integrated mainstream which includes youth with and without disabilities (Goodwin

and Peers 2012). Third, alternative settings which is perhaps reverse integration (Goodwin

and Peers 2012), although mainstream environments may attempt to promote inclusion,

exclusion and marginalization are more common (Spencer-Cavaliere et al. 2017). There has

been criticism towards segregated settings as inclusion values all participants (DePauw and

Doll-Tepper 2000). Segregated settings have reported findings of experiencing a sense of

belonging, learning new skills (Wynnyk and Spencer-Cavaliere 2013), developing an athletic

identity and developing relationships with their peers (Shapiro and Martin 2010). In regard to

youth sport, segregated settings are commonly practiced (Goodwin and Peers 2012).

Segregation is not the same as separation, segregation has the potential to be away from ablist

assumptions and values (Campbell 2008, Hodge and Runswick-Cole 2013). Unlike in school

settings where a professional will choose what a person with disabilities will be entitled to in

regard to segregated, integrated or inclusive settings sport, segregation is perhaps about the right of choice (Kiuppis 2018). The goals may include supporting people with disabilities in making independent choices of where, how and with whom to participate (Misener 2014).

Facilitators and sport providers have been criticized for failing to translate inclusive policy into practice (Fitzgerald et al. 2003). Coaches have a significant role in shaping sport environments, to be inclusive or exclusive (Spencer-Cavaliere et al. 2017). Inclusive practices facilitated by coaches were the result of authentic connections, expectations, views of disability being competitive and adaptations and diversity (Spencer-Cavaliere et al. 2017). Similarly, when people with disabilities were asked their preferred characteristics for a coach, the answers included: trustworthy, patient, prepared to share ideas, good communicator and listener, knowledgeable and flexible (Black 2011). Sports instructors can be seen as positive role models for children with disabilities in formal sport activities (Willis et al. 2016).

Sport inclusion and exclusion can be represented on a spectrum, and exclusion can be seen as a process of othering an individual (Macdonald et al. 2012). Inclusion when observed may view children simply being put 'in' the game, which resulted in not always leading to inclusion for the individual (Spencer-Cavaliere and Watkinson 2010). The representation that sport is a level playing field is not accurate of the ways in which sport has the potential to exclude (Evans and Bairner 2013). For example, children from lower income families participate in less organised sport than children from higher income homes (Hylton and Totten 2013, Kay and Collins 2014, Spencer-Cavaliere et al. 2017). Peers is another factor, as children were found to interact with children with disabilities in social activities, but in athletic and academic contexts it was less likely (Gasser et al. 2014). Children may base their inclusive practices on how they perceive children with disabilities which may impact or interfere with their activity (Diamond and Tu 2009).

2.4.3 Delivery of Inclusion

Inclusion as a pedagogical approach was presented in 1994 at the World Conference on Special Needs Education in Salamanca as a promising new approach (UNESCO 1994). Following the conference, there was a global movement of 'Education for All' (UNESCO 2000). The movement believed in education not being segregated (O'Brien 2002), and all children being a part of the school community regardless of 'weaknesses' (Judge 2003). The attendance of all children in mainstream schools was stated to be an effective way to meet the inclusive education goal and counteract discriminatory attitudes (Krischler et al. 2019). The agenda of inclusion has been seen to be a political process (Allan 2008), which is often pursued through a top-down approach (Coles and Hancock 2002), that is seen as a component of government planning (Corbett 2001).

This movement called for 'full' inclusion, arguing all students should be grouped with their same-aged peers regardless of any differences. Full inclusion was set out as a basic human right, and as morally superior to the provision of segregated classrooms within mainstream schools. This stance on full inclusion was considered radical by many, and continues to be vigorously debated in relation to which types of 'placements' are in the best interests of disabled children (Tardif-Williams et al. 2009). The adoption of the inclusion discourse attempts to conceal the exclusion of children with disabilities in special education (Best et al. 2019). Some educators have advocated for 'meaningful inclusion' rather than 'full inclusion' as children with disabilities although having access to the space of a mainstream classrooms, do not necessarily achieve belonging, acceptance, interdependence or a sense of community (Tardif-Williams et al. 2009). The mainstream schools that children with disabilities were placed into were not designed for inclusion, and all-encompassing provisions (Slee 2008).

Inclusion practices have been criticized, for example, when attempting to implement a standard one-size-fits all approach (Gordon 2006, Slee 2008, Warnock 2006). These approaches increase pressure for children with disabilities to fit into the societal perception of 'normal' whilst promoting homogeneity (Valeo and Bunch 2004). The burden to 'fit in' is perhaps causing harm, especially if children with disabilities are expected to fit into these environments on their own (Cook and Swain 2001). Although children with disabilities may be physically in mainstream social spaces, it does not automatically result in positive interactions (Holt 2003, Milner and Kelly 2009). Instead, classrooms and schools should be adapting to "meet the needs of all children" to begin the process of inclusion (Loreman et al. 2005, p.2). Additionally, there is limited choice for children with disabilities when being obligated to fit into standardized procedures. Encountering inclusion as one of the "paradoxes of forced choice" and "of freedom to do what is necessary", so long as pupils "do exactly what they are expected to do" (Žižek 2009,p.25). Here, inclusion is not located in choice, it is not a human right, but rather is forced participation (Hodkinson 2011).

Generally, inclusion is a sought after ideal; however, in practice, it is sometimes found that integration is taking place (Jahnukainen 2015). 'Inclusion' could be argued as symbiotic, as it is presented by the show of children with disabilities being in attendance (Hodkinson 2011). Over time the ideological commitment to inclusion became an administration project (Žižek 2009). Definitions of inclusions that are broadly used in literature continue to lack clarity (Armstrong et al. 2011, Nilhom and Göransson 2017). Differing definitions are important to explore as different approaches to inclusion will result in differing attitudes towards it (Kruse and Dedering 2018, Nilhom and Göransson 2017), resulting in differing teaching behaviours (Fazio and Roskos-Ewoldsen 2005).

An approach to inclusive education has been suggested that emphasizes everyone has access to quality education (Florian 2019), as a problem with equity is raised:

> (…) equity demands that differentiated approaches are needed to accommodate individual differences between learners, such approaches create problems when the inherent bias within bell curve thinking produces and reinforces school structures that are designed for 'most' students on the ground that something different can be available to 'some'.
> (Florian 2019, p.695)

Florian (2019) argues the logic of special needs education is a process of repeating exclusion, as it is targeting individual difference and treating them differently. Florian's 'rights-based notion of inclusion' is reliant on teachers' practices, decision making and shifts of thinking to educate for all (Florian 2008,2019). The removal of difference by Florian has been criticized, as it ignores positive features of diversity and identities (Ravenscroft et al. 2019). Further, the generic 'education for all' (Florian 2019), fails to engage with notions of difference (Ravenscroft et al. 2019). Children with disabilities have been noted to provide knowledge on the promotion of fairness, equity and restructuring learning environments (Bizas et al. 2014, Deponio and Davis 2014, Ravenscroft et al. 2019), although Florian (2019) suggests a rights-based approach. There is tremendous disregard of Article 12 of the UNCRC and the UNCRPD preamble in which children and people with disabilities have a right to participate in matters that affect their lives.

2.4.4 Social Justice

The social justice movement believes that people who are oppressed have the right to share the benefits of society and receive fair treatment on the premise of equality for everyone, as a human right (Loewen and Pollard 2010, Longmore 2003, Miller 2001, Waddington and Diller 2000). Social justice can be extended to all parts of life to ensure opportunities are being fairly distributed (Cunningham and Lee 2019). Some of the various issues social justice literature incorporates are racism, heterosexism, ableism, classism, agism and sexism (Johnson 2006). Once injustice is recognized, there is a obligation to change

towards ensuring equity (Toporek and Williams 2006). Social justice incorporates the principles of social equality and meaningful roles in communities for everyone (Goodley and Runswick-Cole 2014).

Social justice goals include inclusivity, fairness, equity and effective participation (Pham and Molla 2019). There are different approaches to equality, and whether the focus should be on opportunity, process or outcome (Riddell 2009). Equality as a term has been used "to refer to the approach of treating people with fairness" (Arshad 2008, p.225). This contrasts with the idea of 'equal treatment' (Arora 2005, p.6). Arshad continues to state that offering

> "equal access and rights but does not always take into consideration
> the additional steps required to obtain, as far a s possible, equivalent
> experiences that might allow for equal outcomes"
> (Arshad 2008, p.225)

Understanding diversity, different requirements and various needs as equality results in treating people with fairness (Arshad 2008), there are several challenges to equality for people with disabilities, as problems may go beyond social oppression and exclusion (Badar and Kauffman 2014a,b, Kauffman and Anastasiou 2011,2012,2013). Additionally, equality of outcomes, access and the process of equality are changing (Valli et al. 1997). Sapon-Shevin (2003) stated that "[b]y embracing inclusion as a model of social justice, we can create a world fit for all of us" (Sapon-Shevin 2003, .p28). Social justice continues to challenge practices and policies for fairness (Miller 2001).

A two-dimensional model of social justice has been called the status model (Fraser 1997). Fraser describes social justices playing out through cultural norms and social institutions. Injustice happens when social actors are excluded or seen as unequal through misrecognition or social interactions (Fraser 1997, p.107). Second, Fraser argues for resources to be distributed fairly in a way to ensure individual voice and independence (Fraser 1997, Fraser and Honneth 2003). The model calls for recognition of social actors, and

distribution of resources that is equal with all needs met (Fraser 1997, Fraser and Honneth 2003). Research has excluded children with cognitive impairments, as researchers may not have the skills or training to incorporate their views (Franklin and Sloper 2009). When applying this to Fraser's model, children are excluded and misrecognized into a lower status position, resulting in inequalities and injustice.

Disability rights movements were able to identify access and attitudinal barriers which are now described as a socio-political issue (Waddington and Diller 2000). The understandings of social barriers were outlines in the social model of disability (Oliver 1990). The social model of disability is comparable to the social justice understanding, as the aim is to remove barriers. However, through the social model, if the barriers were removed, people with impairments would no longer be disabled (Riddell 2009). Additionally,

> "because of their unique social and personal needs and special interests, many exceptional people become part of a cultural group composed of individuals with similar exceptionalities. For some, this cultural identity is by ascription; they have been labeled and forced into enclaves by virtue of the residential institutions where they live. Others may live in the same communities or even neighborhood by their own choosing"
> (Gollnick and Chinn 2013, p.174)

Difference in ability, race, language, gender, religion, ethnicity creates diversity (Anatasiou and Keller 2014). Critical disability studies' main concern is social justice for people with disabilities and being inclusive from their perspective (Van Aswegen and Shevlin 2019), which is frequently linked to political and moral transformation, justice and power issues (Goodley 2014).

2.4.5 Social Inclusion

The term 'social inclusion' is mainly a subjective construct which is multifaceted (Croucher and Le Boutilier 2010). Social inclusion has been explained as the opposite of 'social exclusion', specifically marginalization or stigmatization associated with groups

which are based on, but not limited to, gender, race, disability, origin or socioeconomic status

(Koller et al. 2018). Social inclusion for children with disabilities often means dealing with

hurdles of economic, political and social barriers to achieve meaningful participation in

society (Hill et al. 2004). A definition offered for social inclusion from the UN states:

> "social inclusion is defined as the process of improving the terms of
> participation in society, particularly for people who are
> disadvantaged, through enhancing opportunities, access to resources,
> voice and respect for rights."
> (UN 2016, Leaving No One Behind Report, p.17)

A similar definition from the Commission of the European Communities states:

> "social inclusion is a process which ensures that those at risk of
> poverty and social exclusion gain the opportunities and resources
> necessary to participate fully in economic, social, political and
> cultural life and to enjoy a standard of living that is considered
> normal in the society in which they live. It ensures that they have
> greater participation in decision making which affects their lives and
> access to their fundamental rights"
> (European Commission 2003, p.9)

The second definition added that social inclusion should lead to an overall well-being

of an individual which is a basis for being a contributing and valued member of a society

(Mâsse et al. 2012, Murray and Greenberg 2006). Disability barriers through social inclusion

see the disabling being caused by the environment rather than the individual's body (Purdue

2009), which is how the social model of disability views barriers. Understanding the process

of social inclusion acknowledges that attitudes and experiences change due to the setting that

they are experienced in (Fisher and Purcal 2017, Murfitt et al. 2018). Social inclusion is

acceptance of marginalized groups in various contexts, but it also explores how those

individuals experience and control their own involvement (Cobigo and Martin 2011,

Cummins and Lau 2003).

A study conducted that explored how adults with disabilities view social inclusion

described that there was not a specific definition, however social inclusion was referred to as

freedom to choose and being able to participate on their own terms (Hammel et al. 2008). A

similar study found adults with disabilities saw social inclusion as being included beyond a disability label, participating in activities, being employed, appropriate housing, reciprocal relationships and receiving support (Cobigo and Martin 2011). Although these are views from adults with disabilities, according to my search, I did not find any studies discussing how specifically children with disabilities would define social inclusion, but if there are any, they are few. Whereas there is research about children with disabilities experiencing social exclusion which often cite reasons as lack of adaptation and lack of awareness (examples; Hamilton 2005, Houghton and Taylor 2008, Humphrey and Symes 2010, Krull et al. 2014, McPherson and Lindsay 2012, Pijl and Frostad 2010, Rotheram-Fuller et al. 2010). Specifically, children with disabilities in Canada in integrated activity settings did not feel included despite the promotion of social inclusion (Spencer-Cavaliere and Watkinson 2010). Further research into the perspectives on inclusion in activity settings of children with disabilities is important for the understanding of inclusion (Block 2007). Social inclusion has been stated to be a critical component of physical activity for children with disabilities (Taub and Greer 2000).

Impairment specific variables play a role in social inclusion and how children with disabilities experience social inclusion (Kobal Grum and Seničar 2012). Children with disabilities who have multiple impairments, and behavioural/emotional impairments generally experienced more difficulties than children with impairments that were physical, hearing, visual or speech (McCoy and Banks 2012). Other factors relating to social exclusion that are child specific include shyness (Frederickson and Jones 2010), predicted aggression (Kemp and Carter 2005, Odom et al. 2006), and social withdrawal (Odom et al. 2006). North American studies show that social exclusion is experienced by children with disabilities more than their peers (Hanvey 2001, Snowdon 2012). Peer relationships and participation in activities in the community are valued by children with disabilities, although it is reported

they have experienced low levels of social integration (Frazee 2003). Social integration and close proximity of children with and without disabilities does not guarantee social inclusion (Alant et al. 2017).

2.4.6 Inclusion - Section Summary

This section has discussed the concept of inclusion through the examination of definitions, in the context of sport, delivery of inclusion, social justice and social inclusion. People with disabilities are generally excluded from conversations about inclusion, despite an emphasis on the need for people with disabilities' views and experiences of inclusion and exclusion. Inclusion is complex and is different depending on the viewpoint and experiences of the observer. In the context of sport, various participation opportunities were discussed including a spectrum of choice. The delivery of inclusion has been shown to need to move past a 'one size fits all' approach. Social justice in relation to inclusion was discussed as striving for equality for everyone, by redistributing the resources, as inclusion is a human right. Finally, social inclusion was discussed as it relates to economic, social, cultural and political rights.

Key considerations to be explored are: (1) how children with disabilities view inclusion; (2) how children with disabilities act within various segregated, integrated and inclusive contexts; and (3) broader social and environmental factors. The key considerations will shape the research questions for the thesis.

2.5 Chapter Two Conclusion

The chapter has provided an overview of disability models, the context of the thesis and inclusion. The chapter started with an overview of disability models including the medical, social, Nordic, and human rights models. Factors that were highlighted for the thesis

were further exploration of factors contributing to the understanding of disability through lived experiences, power relationships and the tensions of disability perspectives in practice.

The second section of the chapter discussed the context where the thesis takes place. Canadian policy, terminology and barriers to participation were considered. The non-verbal communication of children was understood as a non-linear construction and the context of sport was considered. Key considerations were understanding the negotiation of contexts, relationships of children, adults and environments and the construction of children's voice in various contexts.

The chapter closed with a section focused on inclusion, starting with various definitions of inclusion. Inclusion is complex and the views and experiences of people with disabilities are needed to co-construct further knowledge. Key considerations for the thesis will explore relational factors, participatory actions or inactions, and the lived experience of children with disabilities in physical activities.

The chapter identified key considerations taken from the literature that have shaped the research questions for this thesis. The interplay of power, environment, participation, policy, practice and relationships will be explored through lived experiences to (re)produce meaning.

As a result of this review, research questions were developed alongside the review from Chapter One. The following Chapter will illustrate the research methods utilized, ethical considerations, and how the data was analyzed. Furthermore, the introduction of the participants the research was conducted alongside of will occur. The Chapter will conclude with a clear understanding of how the data was gathered.

2.6 Literature Review Conclusion: Linking Participation, Disability, and Inclusion Models

The section aims to link models of participation, disability and inclusion to create a clear understanding of the links between theories and their importance of these theories in navigating the thesis. The various models are vital to understanding the full lived experience of children with disabilities in extracurricular physical activities.

Hart's model of participation (1992) is useful in understanding what would be labeled participation and non-participation. The participation understanding is furthered by Lundy's elements of participation (2007) in exploring the various factors at play which could create opportunities or constraints for participation such as audience, influence, voice and space. As the participation models help label and guide participation forward in the research, agency and strategic flexibility are important to acknowledge within these. The thesis will analyze participation in various environments and seek to explore experiences of the agency continuum and where agency experiences are thickened or thinned by their environment (Klocker, 2007). Children with disabilities co-participate in their experiences whilst navigating boundaries and hierarchies through strategic flexibility (Bacon & Frankel, 2014); this will be important in the analysis of the process of inclusion and participation. Whilst utilizing strategic actions, children with disabilities in their everyday lives can navigate power structures and complex multi-layered relationships (Frankel, 2017). Exploring the lived experiences of agency and strategic flexibility make for a rich understanding of participation.

For this research, the importance of participation models is clear, especially in relation to disability models. The medical model of disability is important for this thesis, although has been critiqued when viewing people with disabilities through this model as

abnormal or inferior (Campbell, 2008). For this thesis it is important in extracurricular physical activities and in the research process to acknowledge that certain supports and adaptations for some impairments are required. The medical model in extracurricular physical activities has been shown to be important, as coaches need an understanding of what supports and what adaptations are required. Additionally, parents and children felt more comfortable if the coaches and organizations took the time to really understand their impairments, abilities and limitations. Although the medical model does not show the whole experience, it is an important piece to be acknowledged. Building onto the medical model understandings of impairment, the Nordic model incorporates the lived experience of people with disabilities and explores the exchanges and interactions between the environment and people with disabilities (Owens, 2015). The models together assist in understanding participation barriers such as social, physical strength, and assumptions others may have about disability (Breslin et al., 2017); social barriers are also understood in the social model of disability (Oliver, 1996). The understanding of other potential barriers to inclusion and participation regarding disability experience is important and is acknowledged.

An understanding of inclusion as the "removal of all forms of exclusionary practice" (Len Barton, as quoted in Armstrong, 2003, p.3) is also represented in the social model of disability with the goal to remove all barriers (Oliver, 1996). Removing barriers is important for the understanding of inclusion; however, it is important to understand what inclusion experiences may look like in practice. DeBeco's (2016) Inclusion Diagram is a visual representation of inclusion, exclusion, segregation, and integration which can be found on page 97 of the thesis; this will be helpful in labelling the various practices occurring. The diagram clearly shows from an outside perspective what inclusion might be in relation to people with disabilities. However, there is an important perspective being left out when

discussing inclusion, people with disabilities. This missing perspective is highlighted by participation understandings that children should be included in all matters that affect their lives (Tisdall and Punch, 2012). The understanding will also seek to include the participation, agency, choices, and strategic flexibility utilized by children with disabilities themselves to navigate the inclusion opportunities and constraints.

The critical model of disability is important, as it will reframe the understanding of knowledge alongside children with disabilities as it places the importance on the individual's experience (Runswick-Cole and Goodley, 2016). Placing the importance of understanding from the participant viewpoint will reshape how participation and inclusion are understood. Understanding the complexity of these interactions will be through an understanding of lived experience where children are viewed as shaping practices, social worlds, and their rights through their actions (Hanson and Nieuwenhuys, 2012). This understanding is important as the process of participation and inclusion are navigated by children with disabilities and to fully understand the individual social, cultural and personal identities (Baraldi and Cockburn, 2018). There is a vast amount of theoretical literature discussed in the first two chapters, because the literature is important to understand the complexity of the lived experiences in extracurricular physical activities.

Chapter Three: Methodology and Research Design

3.1 Introduction

The current chapter will discuss the ethnographic methodology that has been utilized for this research study. To start, the chapter will discuss the research questions that will be explored, following the key themes from Chapter One and Chapter Two. The chapter will then begin with a general discussion surrounding children, and children with disabilities in research.

There will then be a review of what is ethnography and why is it being used to answer the specific research questions. In this chapter, there will be an in-depth look at how the multi-site ethnography was conducted. The multi-site ethnography tool was utilized to explore the lived experience of extracurricular activities which provided a thick description of participation and inclusion. A thick description was achieved in the field as I actively participated in the lives (Hammersley and Atkinson 2007) of children with disabilities in extracurricular physical activities.

The chapter then shifts to understand the study process that will be described in detail including discussions of recruitment, consent, rapport, and the data collection process. There is a discussion on how knowledge was produced through the ethnographic approach. The section will look at observations, fieldnotes, interviews, data validity and analysis. The section will describe exactly where and how the data was produced for this thesis, including an understanding of the different contexts and spaces that knowledge was created in. Through this description the section provides reflexive accounts of how knowledge was produced.

The fourth section of the chapter is an introduction to the findings that looks at participant group descriptions and research settings in general. Participants' views on how

they would prefer to be described is discussed. The section is followed by children's biographies, which discusses demographics and routines children have in the research settings. Children's biographies are important as they shape children's lived experiences in the data analysis which provides for an in-depth look into their lived realities. The chapter then comments on what took place after data collection including feedback, dissemination and reflection on the methods utilized. Finally, the chapter will conclude with an understanding of how knowledge was produced for the purposes of this thesis.

3.2 Research Questions

The key themes that were identified through the literature review were used to develop a broad aim for this research study which is to explore how children with disabilities navigate their participation in extracurricular physical activities with an emphasis on their lived experiences. The goal is to contribute to knowledge by providing a detailed understanding and description of lived experiences of children with disabilities in extracurricular physical activities.

To guide the exploration of the broad research aim, the following research questions were developed:

> **Question 1:** How do adults and children create opportunities and constraints for children's recognized participation?
>
> **Question 2:** How do children with disabilities navigate (or live through) the process of inclusion in extracurricular physical activities?

The section will discuss the methodological approaches that were taken to answer the research questions.

3.3 Research Foundation

The following section will provide a general understanding of research with children and children with disabilities. The section will then move into specifics about ethnography as an approach to answering the research questions.

3.3.1 Research with Children

The view of children, as described in Chapter One, is of active participants in the construction of their lives (James and Prout 1990, p.8) and children should be seen as co-producers and creators of knowledge in an expert position (Tisdall 2017). As the first two chapters concluded with this view of children, another ontology should be considered, as the relationship between 'researcher' and 'participant' is desired to be more equal.

Throughout childhood studies' literature there is a concern that researchers need to ensure the children's own perspectives are heard striving for "a more direct voice and participation in the production of sociological data" (James and Prout 1997, p.8). Including children's voices within research challenged the way research was traditionally conducted for children. Children's knowledges was often excluded, as the children were considered unreliable while the views of adults were considered reliable and included (Hogan 2005, Punch 2002). This view of children left adults speaking on behalf of children (Christensen and James 2008a), resulting in children as objects to study whilst their voices were excluded from research (James and Prout 1997).

However, there has been a growing amount of literature discussing research with children rather than research on children. As a result, there have been researchers that have directly engaged with the 'voice' of the child (examples, James 2007, Moran-Ellis 2010, Tisdall 2012, Tisdall and Punch 2012). Although there has been an increased inclusion of children's voices in research, there is still debate on how best to involve children's

perspectives. With the rise of participatory methodologies, it is important to note that participatory methodologies may provide a route to "better knowledge, be more ethical and more inclusive" (Tisdall 2015b, p.11). Additionally, the view that because they are children, they need different methodologies perhaps should not be the automatic assumption (Thomson 2007). Punch (2002) argues that assuming creative methodologies are better comes with built-in assumptions, such as children will enjoy participation, children lack attention span to participate in other methodologies, and children are competent. Punch (2002) argues further:

> "It is misleading to talk about 'child' and 'adult' research methods, since the suitability of particular methods depends as much on the research context as on the research subject's stage in the life course. The choice of methods not only depends on age, competence, experience, preference and social status of the research subject but also on the cultural environment and the physical setting, as well as the research questions and the competencies of the researcher."
> (Punch 2002, p.338)

Similar arguments have been made against "prioritizing of methodologies" (Qvortrup (Qvortrup 2008, p.67), while acknowledging that there is nothing exceptionally peculiar regarding children that would require them to use a specific creative methodology (James, 2008, p.2). Qvortrup (2008) further argues that perhaps a variety of methods would help to produce rich in-depth data. Although children's voices are being included in research, it is less common to find the same regarding children with disabilities. I will discuss data collection methods for children with disabilities within this study, as part of the consideration of the ethnographic approach. The next section will discuss children with disabilities in research.

3.3.2 Research with Children with Disabilities

With recognition of children's rights being on the rise, there has been a shift toward recognizing that children should be actively participating in research (Veale 2005). However, it has been argued that this has been a slower process when it comes to children with

disabilities (Franklin and Sloper 2009, Sinclair and Franklin 2000). It has been argued that just as children should be participating in research, so should children with disabilities (Moran-Ellis 2010).

It has been argued that children with disabilities are still largely absent from academic literature and research (Boggis 2018c, Davis and Watson 2002). Stalker's (2012) research continued highlighting the lack of children with disabilities and suggested that they may look 'invisible' in research or just be overlooked all together. This view can be summed up by "research is an imperialist, disablist and heteronormative peculiarity of modernist knowledge production" (Goodley and Runswick-Cole 2014, p.215). The voices of children with disabilities are still being marginalised within the context of research (Franklin and Sloper 2009). These voices are being pushed to the sideline, with voices of professionals and parents at the forefront (Connors and Stalker 2003). Additionally, these lived experiences studies of children with disabilities are often in relation to evaluations and provisions of programing (Abbott 2013). Therefore, stories about children with disabilities and their experiences are not being told by the children; they are being told by service providers (French and Swain 2001).

Increasingly, research is including the experiences and views of children with disabilities (examples, Curran and Runswick-Cole 2013, Goodley 2011a, Goodley and Runswick-Cole 2011a,2014, Wickenden 2011). Brunnberg (2005) used interviews highlighting friendship constructions, Boggis (2011) showcased voices of those children who used AACS (Augmentative and Alternative Communication Systems), and Davis and scholars (2008) utilized ethnography to examine social structures and relationships. Researchers have been encouraged to get creative with their methodologies to capture experiences and voices of children with disabilities (Richards and Clark 2018). This PhD thesis looks to ensure that the methods utilized best capture the experiences of children with

disabilities whilst keeping in mind the lessons learned by the previous scholars. The thesis is closing the gap of longitudinal research study by looking into the lived experiences of children with disabilities in extracurricular physical activities. The following section will continue the discussion on research with children with disabilities, however with the focus on non-verbal children.

3.3.3 Research with non-verbal populations

Youth who live with both communication and physical impairments are among the most excluded in disability research (Morris 2001b,2003, Whitehouse et al. 2009). With some exceptions (examples, Batorowicz et al. 2014, Bennett 2011, Mitchell 2010, Rabiee et al. 2005, Raghavendra et al. 2012, Simmons and Watson 2014, Wickenden 2011), there has been minimal research done with this group. Youth with disabilities that utilized ACCS were generally excluded from research due to assumptions that researchers would experience difficulties in engaging with them (Morris 2003). Thus, there is a clear need to include this population in research to fill the existing void. For children with communication impairment, there were questions raised about how 'voices' are represented, especially in research (Komulainen 2007). Komulainen states "ideals of normal and good communication that prefer rational, abstract thinking and actions discriminate between different groups of people even though the aims were to meet the needs and individual rights of children" (Komulainen 2007, p.23). Komulainen continues to argue against the privileging of communication that is verbal, linguistic or textual. Her argument continues that voice is not an individual property, it is a social construction resulting from social interaction. In this context, she places non-verbal utterances and physical movements as perhaps even more important in an exchange than words when previously these non-verbal communications would have been be disqualified. Children and youth who use ACCS and non-verbal communication methods were shown to have networks of communication partners, in most instances support workers

and/or family. Alongside communication partners children and youth were developing unique communication methods (Wickenden 2011). To tap into these non-verbal communication patterns, ethnography has been seen to uncover meaning (Cunningham-Burley et al. 2008).

3.3.4 What is Ethnography?

Before discussing why ethnography was the best choice of amongst methodological approaches for my research, it is important to know what an ethnography might look like. Hammersley (2018) summarizes various definition of ethnography and suggests some key features below:

- "Relatively long-term data collection process,
- Taking place in naturally occurring settings,
- Relying on participant observation or personal engagement more generally,
- Employing a range of types of data
- Aimed at documenting what actually goes on
- Emphasis the significance of the meanings people give to objects, including themselves in the course of their activities, in other worlds culture and
- Holistic in focus."
  (Hammersley 2018, p.4)

Ethnography can be applied in a plethora of research settings; it is reflexive and flexible regardless of discipline, topic or participant (Vine et al. 2018). The ethnographic approach is non-linear and is often "flying by the seat of your pants" (Van Maanen 1988, p.120). As ethnography is a 'style' which is a process of understanding social meanings and activities in various contexts (Brewer 2000, p.11). "Ethnography is neither subjective nor objective. It is interpretive, mediating two worlds through a third" (Agar 1986, p.19). Additionally, through the process of the ethnographic research, researchers are a part of the community as suggested by: "as researchers we cannot detach ourselves from the worlds we study" (Konstantoni and Kustatscher 2016, p.224).

Knowledge creation through ethnography can be seen as:

> "Ethnography usually involves the researcher participating, overtly or covertly in people's daily lives for an extended period of time, watching what happens, listening to what is said, and/or asking questions through informal or formal interviews, collecting documents and artefacts- in fact, gathering whatever data are available to throw light on issues that are emerging focus of enquiry."
> (Hammersley and Atkinson 2007, p.3)

Ethnography, in relation to this thesis, is an overt process that engages with data collecting as suggested by Hammersley and Atkinson (2007). Social worlds in which children negotiate were studied by participating and observing everyday life (Emerson et al. 2011). The ethnographic approach allows the research to 'get right inside' the lived realities of children's lives (Mason 2002, p.55). This is achieved through extensive time within the field (Agar 2008, Creswell 2007, Hammersley and Atkinson 2007, Vine et al. 2018). The 'thick description' created through the time spend in the field is important for this study, as it provides a deep understanding of multiple meanings, and inter-related lived experiences (Geertz 1973).

3.3.4 Why Ethnography?

The reasons why ethnography is an ideal methodology will now be discussed. The four main reasons for choosing ethnography are its ability to tap into the non-verbal communications, reflexive power relationships, the positioning of children in research practices and the knowledge creation process. Ethnography allows for data collection practices for all children with disabilities to answer research questions more fully.

First, ethnography's ability to tap into non-verbal communications is well suited for this research. Ethnography has been used for children with disabilities to help gain access to communication techniques and children's meanings of their diverse identities (Cunningham-Burley et al. 2008). This access is notably more favorable for children who are non-verbal, communicate in a way unknown to adults, or wish to communicate in non-verbal ways (Boggis 2018c). As children with disabilities have the same right to expression, their 'voices'

should be heard (UN General Assembly, 2007, Article 7). Observations are ideal for children who are non-verbal, as verbal and non-verbal actions can construct children's cultures (Corsaro 2005), by being able to observe different expressions, unspoken interests and non-verbal skills (Almeida et al. 2017).

Second, ethnography allows the researcher to be reflexive about the power relationships. Observation is able to dissect imbalances of power between participants and the researcher (McNamee 2016), which is important as child participants are more vulnerable to an unequal power relationship with adult researchers (Alderson and Goodey 1996). To challenge these power relationships, the researcher can minimize their authority and listen to children, so children feel comfortable in expressing their views (Hill 2006). One way of adult researchers being reflexive about their power position in research can be seen through the different roles they take in ethnography. 'Observer as a participant' is an example of an ethnography role the researcher can take, although potentially distracting, this allows the researcher to be integrated in the activity alongside the participant (Bogdewic 1999). Another role the researcher can take is one of 'not knowing' which allows child participants to "explain what they do and why they do it" (Mukherji and Albon 2010, p.76). Ethnography allows time for the researcher to be reflexive about what is and what is not working as their role changes throughout data collection to best adapt to the environment. Often the researcher can navigate 'stormy waters' by being flexible and adaptable to difficulties in maintaining rapport with participants and gatekeepers (Scheer 2017). A 'friend role' involves not telling on children if they misbehave; under the friend role, having children call the researcher by their first name and using body language to be on the same level as children, may help participants open up their experiences (Konstantoni 2010, p.92), while trying to maintain clear boundaries of the relationship and keep rapport with gatekeepers and teachers (Scheer 2017).

Following the ethnographic strength of being able to be reflexive on power relationship between researcher and participant, the positioning of children in ethnographies has another draw for this PhD thesis. Within ethnography children are positioned as:

> "natives of these cultures 'experts in their own lives' while adult researchers are outsiders, novices who need everything to be explained to them."
> (Corsaro and Molinari 2000, p.7)

The position of children as experts through ethnography allows for them to be "recognized as people" and as "research participants" rather than research subjects (James 2002, p.246). Children are in a position where their voice matters in adherence with the UNCRC and UNCRPD. Finally, it is important that participants' views are relied upon as much as possible (Creswell and Poth 2018).

Ethnography requires the researcher to be reflexive which:

> "changes the everyday relationships of research because it provides countless possibilities for the ethnographer to provide his/her respondents with the opportunity to question his/her analysis"
> (Davis 2000, p.11)

Throughout the research process, the researcher can be positioned as a learner whilst children are the experts. As a learner the researcher can shape their interpretations, assumptions and questions with the participants. The knowledge that is created from ethnography provides rich and descriptive accounts of how children understand and interpret a variety of topics and how these understandings are developed (Corsaro 2011, Hagerman 2017).

The topic of the research study navigates experiences of children with disabilities in extracurricular physical activities. As the research is positioning children with disabilities as experts, they will be deciding the environment(s) of extracurricular activities that are important to their experiences for the thesis. Multi-site ethnography will be discussed next to provide a clearer picture on how knowledge will be created.

3.3.5 Multi-site Ethnography

In 1995 George Marcus advocated for the Multi-Site Ethnography in his article "Ethnography in/of the World System: The Emergence of Multi-Sited Ethnography" (Marcus 1995). The article discusses his observations of ethnographies that were breaking away from individual sites and moving towards an understanding over time and space. Multi-site ethnography has a focus on following people, associations, relationships and connections across spaces (Falzon 2015,2016). A multi-site ethnography can be utilized when the social phenomena that is the object of the study cannot be fully captured by a single site (Falzon 2015,2016, Marcus 1995). Multi-site ethnography was a response to suggestions that a single site was insufficient or a partial perspective (Cook et al. 2009).

Multi-sited ethnographies are interested in "investigating the movement of people and objects within the relevant social or transnational space" (Wolff 2015, p.63), and "multiple fields of relations people work through and within their daily lives" (Gatt 2012, p.111), rather than the traditional approach to ethnography of "being there" with in multi-site ethnography, the researcher is "here and there" (Hannerz 2010), whilst mapping connections, relations and associations (Marcus 1995). Ethnographers utilizing a multi-site ethnographic approach can move between two or more spaces (Falzon 2015). Massey (2005) describes space as:

> "space as the product of interrelations; as constituted through
> interactions, from the immensity of the global to the intimately
> tiny… we recognise space as always under construction".
> (Massey 2005, p.9)

The research is 'multifaceted', as it is not contained to one site, rather it begins to understand complex social situations and networks (Horst 2015). Multi-site ethnography in research can look like 'shadowing' research participants across the various spaces they participate in (Czarniawska 2007). This is perhaps useful, as comparisons can be made amongst different organizations (Bechky 2003, Smets et al. 2014, Smets et al. 2012). The

lived experiences of participants in extracurricular physical activities are not limited to one site, as there are various opportunities for participation, and participation across sites which may be missed if the research was only limited to one site.

Multi-site ethnography has an endless number of possibilities and various paths for researchers to follow; the researcher needs an understanding of how to structure what they are following (Van Duijln 2020). "In multi-sited ethnography, 'following' (e.g. persons, objects and events) is used as a device to structure fieldwork" (Van Duijln 2020, p.281). Marcus (1995) suggests in his article that there are six modes of following: "follow the metaphor … follow the plot, story or allegory, … follow the life or biography … follow the conflict, …. follow the people …. follow the thing…" (Marcus 1995, p.90-94). The modes of following attempt to guide and structure of the fieldworker's research. First, following the metaphor is understanding circulation and construction of the metaphor. Second, following the plot suggests understanding the way in which it influences social memory. Third, following of a biography perhaps takes a researcher across various social contexts. Fourth, the understanding of conflict attempts to explore both sides. Fifth, following people is specific to one person or following of people commonly seen in migration studies (Czarniawska 2007). Finally, following a thing is perhaps following the implementations of a report through organizations and departments (Harper 1998). Following of participants will be implemented within this thesis, as they participate in their chosen extracurricular physical activities. However, through following participants other 'followings' will be guided by the participants' emphasis on what is important to them.

A criticism of multi-site ethnography is the suggestion that there is perhaps a lack of 'depth' in the data (Wittel 2000). Lack of depth is discussed, due to the perceived lack of time in the field, as the researcher spreads their time between sites which may result in not being fully immersed in relationships in the field (Hage 2005). This is a concern, because the

understanding of ethnography relies heavily on the time in the field to be fully immersed in everyday life at the site, which perhaps is being limited with the additions of sites (Kenway 2015). Due to time spent between sites, it has been argued that there is less time to build rapport with informants and gatekeepers, and difficulties in implementation when the researchers needs multiple cultural and linguistic competencies. The criticism is that there is perhaps a compromise in the ability to conduct in-depth and rich fieldwork; however, it is argued that the understandings of people in the same community across various networks and contexts provides richness (Horst 2015). It provides a 'thick' description of interplays of relationships, networks, things, activities, people and meanings rather than individual nodes (Horst 2015). Additionally, specific to the thesis, the extent of the observation time in the field reached a saturation point of data. The time spent in the field was limited to participants' preference, and in most cases I was present in the field the whole time that the activity was taking place. As I was in the field for the full time the activities were occurring, it was not possible to be in the field more.

Multi-site ethnography has challenges such as gaining access to multiple fields and the need to negotiate continuously access in various sites (Van Duijln 2020). In relation to this study, access to various sites was not an obstacle. Recruiting participants first and then mutually requesting access to their chosen participation sites may have made the process less challenging. Additional difficulties can be in relation to constructing quality data that is too time consuming or expansive (Horst 2015). The data construction occurred over one-year and although challenges occurred, the expansive data collected is very important for understanding lived experiences.

To summarize, although there have been criticisms and challenges highlighted with utilizing a multi-site ethnographic approach to data collection, it is the only methodological approach that realistically could be utilized for this thesis. Due to the nature of extracurricular

physical activities, and participation of children amongst these to gain a full and comprehensive understanding of their lived experience, the multi-site ethnography is essential. Furthermore, multi-site ethnography allows for flexibility to achieve greater understanding and explore the bigger picture of participation in activities that are not reliant on a single site and one community.

3.3.6 Ethnographic Limitations

In the previous subsection, ethnography's strengths were discussed whereas the current subsection discusses a few downfalls. These downfalls are first, the positivist view of qualitative research as indicating that there is bias in making the research subjective, and second as people with disabilities are not in the planning stages, they may be positioned in a passive way.

First, knowledge created by ethnography through a positivist lens will be seen as 'biased', as it is not objective, although many ethnographers in the past have claimed falsely that they have been neutral (Crapanzano 1986). An argument is that objectivity is not possible, and through ethnography "something far greater is gained: understanding" (Khan 2011, p.202). Findings from ethnography are made through a process where researcher and participant are both part of the knowledge creation (Way 1998). The interaction with participants is the strength of ethnography, by understanding them, not just 'objectively' standing 'outside' to observe them like viewing a snow globe (Khan 2011, p.201). Although from the positivist point of view, this would make data invalid as not objective, social constructivists value the reliance on participant views (Creswell and Poth 2018).

Second, because research is not objective, it may be seen as not 'scientific enough', as it is too subjective (Gilmore and Keeny 2014). There may be researcher biases, and a disturbance of the setting (Carless and Douglas 2012). However, ethnography utilizes the tool of reflexivity to negotiate relationships between the researcher and participant, and to

question the analysis on comparisons and contrasting values placed on data (Boncori 2018). An argument is that participants may stage their interactions. Ethnographic researchers need to be prepared to argue that although their participants may have 'staged or influenced' the observer, these observations still "reveal profound truths about social and or cultural phenomena" (Monahan and Fisher 2010, p.358). The rich amount of data collected, and its interpretation can be brought back to participants to ensure that these themes are relevant and properly represented (Cunningham-Burley et al. 2008, Davis 2000).

Third, research agendas should be decided in consultation with people with disabilities, instead of these people being passive subjects (Wickenden and Kembhavi-Tam 2014). Similarly, people with disabilities should ideally be involved in the planning and be able to alter projects (Barnes 1992, Oliver 1992, Stone and Priestley 1996). People with disabilities should be represented through their own perspectives (Oliver 1992). Because of institutional review boards (IRB) and university requirements, minimal input from participants is routine in the early research stages (Emmerich 2013, van den Hoonaard 2001). Throughout an ethnography it can and has been argued, that children can change the course of the project (Davis 2000). The constant reflexivity and re-understanding of the experience and observation (Oakley 1994), can alter the agenda as the participant needs.

It may take time for researchers to understand the method of communication preferred by children with disabilities (Davis et al. 2017), however, ethnography can invest time to navigate their chosen communication methods, navigate their complex identities, their changing and ongoing relationships, whilst viewing children's capabilities to take action to challenge stereotypes and access issues (Davis and Watson 2002, Davis et al. 2017). However, before the ethnography starts there is discussion alongside participants needed to establish communication preferences.

3.3.7 Section Summary

The current section aimed to provide an understanding generally of research with children, children with disabilities, and non-verbal children. The section then provided a description of ethnography and why it is the methodology that was utilized for this thesis. The section ended with a critical look at ethnography and highlights key considerations. The next section will expand on ethnography and be specific about how ethnography was conducted for the purpose of this thesis.

3.4 Study Process

The section will discuss the research process, including entering the field, consent, role of the researcher, reflexivity and leaving the field. The section aims to provide a clear understanding of how the research was conducted. The section following will discuss how knowledge was produced.

3.4.1 Entering the Field

Following an in-depth review of the background literature on research with children with disabilities, participation, and disabilities studies, I applied to the University of Edinburgh's ethics board and went through the formal approval process for the research study, approval can be found in Appendix A. Following approval, my research was conducted in children's everyday lives, with trusted adults around (coaches and parents); if children did become uncomfortable, they were in a supportive environment. Although my ethical review process was successful (July 2018), ethics does not stop there. The formal ethical review only focuses on a minimum standard of ethics which may be defined as 'do no harm' (Lahman et al. 2010). It has been argued elsewhere that there are two types of ethics: 'procedural ethics' which is the processes of the formal ethical review, and 'ethics in practice', where the researcher is faced with dilemmas in the field (Guillemin and Gillam

2004, Heath et al. 2007). Additionally, there is relational ethics which Ellis argues ethics "requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences" (Ellis 2007, p.3). The process of ethics from this study may be uncertain and messy which requires ethical decision-making and reflection through listening and respecting participants. However, I fully believe that children are co-participants in society, and they are equal humans, which I found to be a good fundamental guide for how I wanted to interact with participants. After the ethical review process, I started to recruit participants, which will be described in the following subsection.

3.4.2 Recruitment of Participants

After my progression board and ethical reviews, I returned to Canada. I conducted research here, as I wanted to work in Canada, wanted to build relationships in the field and already had connections in Canada to some disability organizations. Here I validated my ethical review with King's University College and obtained a Vulnerable Sector Check from the Ontario Provincial Police. Once these tasks were completed, I started the recruiting process. I emailed my poster out to all the organizations associated with London, Ontario's Child & Youth Network which totalled 94 organizations. I went to 32 organisations to hand deliver my poster. From this, I received 3 responses from parents of children with disabilities who were interested in participating in my study. I then posted my poster on Facebook groups using relevant pages in the London area. Only 1 family contacted me from the Facebook posts, but they were not interested in participating after receiving further information. From there, I networked with the 3 families that were interested, and coaches of those organizations to recruit another 7 participants for my study. The process of recruiting participants from trusted participants is called snowballing (Bissett et al. 2018). Other

children were interested in what I was doing and would sometimes ask things like 'what are you writing'. Here I was able to engage children with the idea of being in the research study which was of interest to some. Parents were also able to put a face to a name from my poster and one parent said to me 'it was good to see you around before, because I wasn't too sure about having my child around a stranger, but you're normal!' (Marie's mom, Fieldnote: December 2018). It was easier for me to recruit participants when I was already embedding in the community of their extracurricular physical activities. On my poster as seen in Appendix (B), I was recruiting for participants aged 14-16 years, but this age range was expanded due to interest from younger children. The youngest participant was 12. Additionally, I did not want to discriminate based on impairment type, so all participants that were wanting to participate in my study, were considered.

The recruitment of children with disabilities led me to their network of parents, coaches and organizations. Often parents would email the coaches and organizations with my information, to connect about furthering the recruitment to encompass important key personnel for further understanding.

3.4.3 Consent

After expressing interest in the study, it was vital that potential participants went through the informed consent process. In Canada, children under the age of 16 need parental consent (Government of Canada 2021), to participate in research studies. It has been recognized that often in research with children a researcher has to first navigate consent with adults (Punch 2002). The informed consent process was completed with parents, coaches, volunteers, and children. An example of an important other would be a coach or volunteer that participants were interacting with. Examples of the information sheets are found in Appendix C and consent form examples are found in Appendix D. With the quick change over in sport environments, it was not practical to gain direct consent from all other children

and parents in these environments. As an example of the numbers, in hockey there were 15 new children each week, as they competed against different teams. Executive directors of each organization were told what I was doing, and I left it up to them to inform parents, as they felt necessary. Additionally, I always had my research poster beside me and was happy to discuss with anyone who had any questions.

Informed consent is a top priority; multiple meetings were held with participants before data collection commenced to ensure full understanding. Informed consent of parents, coaches and volunteers was often discussed in one initial meeting. Discussions with children included the right to withdraw their participation and how withdrawal would be accomplished, such as signs, stickers, a stop sign, etc. Ethical research is being "concerned with respecting research participants throughout each project, partly by using agreed standards" (Alderson and Morrow 2011, p.3). Children were part of the consent discussions, and as an example Ben chose a hand sign gesture of 'no' for times I was not allowed to observe. Participants had access to their own information sheets and consent forms, and these documents had contact information for my supervisors and me. I had two consent forms and information sheets depending on which one the child preferred. One was a visual consent form and information sheet and the other was a written one. Having these forms allowed children to ask questions and express concerns at any point through the research process. Multiple meetings were held to allow for a full discussion of the research process amongst participant, parents and organizations. I acknowledge that children with disabilities are not a homogenous group, and therefore consent and ongoing consent with different participants varied (Connors and Stalker 2007).

Ongoing consent was similar to Davis (1998), where ongoing consent is a regular practice in my research and where children were reminded that they could withdraw at any point up until submission of my PhD thesis. This was consistent with parents', volunteers and

coaches consent, and discussed with them regularly. My role was also discussed at the beginning of every data collection segment with all relevant participants. I also ensured that my participants felt comfortable by providing the ongoing knowledge that participants could withdraw, their contribution was meaningful, their choice of communication method for contacting them was respected (email, telephone etc.), and that data collection was in a familiar environment. This study engaged with some children who had multiple disabilities where ongoing consent verbally was not possible. I was seeking children's assent in addition to parental consent alongside research methods that provided options and choices surrounding their participation. This ongoing process required me to be attentive to children's gestures, body language and actions, as they were engaged in research and I provided children opportunities to reassess their participation in the research project (Dockett et al. 2012). Furthermore, I had to be attuned to children's body language and ensure that I was reading it accurately (Einarsdottir 2007, Robson 2011). When assessing body language, I had to constantly reflect on whether my participants were wanting to be included in this research study. Additionally, this involves dissent where children may choose not to participate (Brown et al. 2017, Dockett et al. 2012). Assent involves a decision to take part to while ensuring it is voluntary (Groundwater-Smith et al. 2014). One of the non-verbal participants in this study would give a thumbs up signal, if it was ok for me to be observing or a thumbs down if it was not ok for me to be there. This approach of using assent in some cases for children ensured that the research study could be inclusive of experiences that may have otherwise not been included (Groundwater-Smith et al. 2014).

Important ethical topics have been discussed in literature such as: anonymity, child protection, power relations and consent (Gallagher 2009). Before research with children could begin safety measures were essential, and these were discussed with organizations where data collection was to take place. These measures included a discussion of protocols

with the participants and putting in guidelines on what steps would be taken if children

disclosed abuse or harm. In cases of abuse or harm, the children's confidentiality cannot be

protected, but ideally any reporting to local officials would be done alongside the child. I

provided every participant with contact information for local organizations, if they felt they

wanted to talk to someone (Children's Help Phone, Childreach, Merrymount, etc.). With the

exception just discussed, anonymity is desired and steps taken for this included having

fieldnotes in a locked cabinet, using codes for participants (not their real names), having my

laptop encrypted and using password protected documents (Holmes 2012). Furthermore,

informed consent is a top priority; multiple meetings were held with participants before data

collection commenced to ensure full understanding.

3.4.4 Participant Pre-Research Discussions

The previous subsection discussed consent which took place at the participant pre-

research discussions.

It is important to note that research with children should engage children's views on

how they wish to be involved (Ennew and Plateau 2004). Furthermore,

> "what is important is that the particular methods chosen for a piece
> of research should be appropriate for the people involved in the
> study, for its social and cultural context and for the kinds of research
> questions that are being posed."
> (Christensen and James 2008b, p.13)

I discussed with each participant different data collection methods to be flexible in

relation to participants' specific needs; the ethnographic approach allows for this flexibility:

> "Although ethnographies share some certain characteristics in terms
> of methods, every ethnography is unique and there is no standard
> way to do this."
> (O'Reilly 2012, p.22)

During the discussions with participants the common response was 'just come see' or

'just come be with me'. Importance was placed on ensuring that the process was guided by

the participants themselves. An example of a research method that was discussed was the

Measure of Children's Participation and Enjoyment survey where most participants chose not

to complete. King and colleagues (2004) developed CAPE (Children's Assessment of

Participation and Enjoyment) and PAC (Preferences for Activities of Children) in

Southwestern Ontario to measure participation regarding out-of-school time, including

formal organized sports. CAPE & PAC can be used in an interview style or self-administered

questionnaire addressing views surrounding each of the 55 activities; they can be

administered together, or separately. CAPE measures participation by intensity, location,

enjoyment, and others involved. PAC measures which activities the child prefers to

participate in. The tools were validated by a longitudinal study from 2000-2003 with 427

children with disabilities aged between 6-15, although the tools can be used for ages 6-21.

The CAPE takes approximately an hour to complete, and the PAC takes approximately half

an hour. The use of this study has led researchers to notice some potential drawbacks to using

the CAPE & PAC. First, while using the CAPE study, they were unsure about which

activities were chosen by the parents versus the activities chosen by the children (Anaby et al

2011). Second, the tools document what the child does, not the degree of support the child

needs, or the child's competence in performing an activity (Chwen-Yng & Wuang, 2012).

Third, the findings do not include the child's understanding of their participation, as the

questionnaire leaves no room for individual explanation or response to findings. As the

present thesis is interested in children's everyday experiences with sport, interpretations of

their understandings of participation and the meaning-making experiences in the sport

environment, quantitative generalizations will not fully answer what I am interested in;

therefore, qualitative methods will be essential and will be the focus.

Consent and methods were discussed at each ethnographic data collection setting

throughout the research process. Participants were able to change the role I took, such as

whether I was a participant alongside them or when I could talk to them. Participants also identified key adults that I should interview and gave me consent to ask the key adults about their experiences.

3.4.5 Role, Rapport, and Relationship Negotiation

The next step of my research was to build rapport with my participants. Building rapport with participants was important, as it allows for an opportunity for enhanced capacity of the researcher to gather in-depth data (Anull-Davis 2008). Friendships that may develop between participant and researcher are an element of importance in collecting good data (Oakley 1981). This is important because:

> "The nature of childhood in adult society means that children are used to having to try to please adults, and they may fear adults' reactions to what they say. Time needs to be invested to form a relationship and gain their trust."
> (Punch 2002, p.328)

Initially I found building rapport with verbal participants easier. I had a lot of worries about building rapport with non-verbal children. My communication matched with children who were verbal. I could ask questions and receive answers. I asked them 'where would you like me to be', 'what would you like me to do?', 'what should I wear to hockey.' I could also check with them about my role 'is this ok?'. With non-verbal children, I had to learn a different method of communication. This has been seen to be an important aspect of conducting ethnographic research; these 'cultures of communication' have to be learnt and navigated (Christensen 2004, p.166). Spending almost a year doing field work granted me enough time to build friendships and rapport with participants. Rapport evolved throughout the ethnography (Hammersley and Atkinson 2007, Sherman Heyl 2001). Each participant was different and building rapport took time. Additionally, I agree that having this rapport enabled me to have a better understanding of my participants' perspectives (Fontana and Frey 2005, Hammersley and Atkinson 2007).

During a researcher's time in the field whilst engaging with an ethnographic approach, they become a member of the community that they are in, while exploring and interacting with people. This process leads the researcher to be an insider in the community (Agar 2008). However, researchers have differing views on which role to take whilst doing fieldwork. Some researchers adopt a least-adult role, whilst some take the clear distinction of adults and children as two separate groups (Mandell 1988). The least-adult role has been defined as

> "My role as least-adult included undertaking a responsive, interactive, fully involved participant observer role with children in as least an adult manner as possible. This entailed neither directing nor correcting children's actions. While my size dictated that I could never physically pass for a child, I endeavoured to put aside ordinary forms of adult status and interaction – authority, verbal competency, cognitive, and social mastery – in order to follow their ways closely."
> (Mandell 1988, p.438)

Moreover, it has been argued the role of least-adult allows for the researcher to engage and interact with children's cultures (Mandell 1988,1991). This least-adult role has been argued to perhaps give a better insight into children's views (Holt et al. 2004). I took a similar role, a friend role (Corsaro 2003, Fine and Sandstorm 1988), this role led to the need to be reflexive about my choice. Researchers may shift roles whilst reflecting on power dynamics ideally attempting to empower participants (Davis 2000). This afforded me the flexibility to navigate roles most notably those of a friend, helper, entertainer, learner and mediator (Davis 2000). In practice, I started as a learner, asking lots of questions where I was able. For the rest of the time, I was in a friend role. Everyone knew me as Katie, some participants played with my name calling me 'K' or 'Kate'. However, when appropriate I did take the role of non-participant observer (Fine and Sandstorm 1988). I would ask children where I should sit if they wanted me to observe. Unfortunately, I could not have participated in some of the activities, such as hockey games and speed skating races. I would reflect on this with participants to ensure that they were still comfortable with me just observing. One

response I got was "oh I thought you were cheering me on" reflecting on this, that perhaps is taking a friend role, observing their activities, and supporting them.

Building rapport with child participants was important; however, it was also important to build rapport with the parents, coaches and gatekeepers (Morrow 1999, Punch 2002). The building of this rapport happened throughout the ethnography but most notably through the observations. Understandings of actions and interactions from all perspectives enhances data for 'thick descriptions' (Geertz 1973). Children's experiences were entangled in the relationships they had in their environments, and actions of coaches and parents that were shaped by their understandings of the world were important to explore (Boncori 2018).

3.4.6 Leaving the Field

Relational ethics has been defined as that which "requires researchers to act from our hearts and minds, acknowledge our interpersonal bonds to others, and take responsibility for actions and their consequences" (Ellis 2007, p.3). Decision making surrounding ethics involves uncertainty and internal reflection. Leaving fieldwork was emotional for some participants. One of my participants cried on the last day of observations. When I set an end date for collecting observational data, I was not expecting the interwoven lives I had lived with the participants actually coming to an end. My ethnography was messy (Crang and Cook 2007), it was problematizing (Schwartzman 1993), and boundaryless, non-linear, it involved a "fly by the seat of your pants" experience (Van Maanen 1988, p.120). For these reasons, there was a lot of uncertainty. I could not have imagined at the start of the ethnography the relationships that I had built up, which made it hard leaving. With my participant who cried at the end, we came up with an action plan on what horseback riding would look like without me intertwined in it and how coaches could help support her whilst I was gone. Additionally, whilst transitioning from leaving the field, I have sent postcards to all participants updating

them on the current research stage. At the end of my research, I asked if they would be okay with me sending them the odd postcard, and all participants were excited about this.

There was an impact on the extracurricular activities for the participants when I left. A response from a parent after I left the field suggested that coaches were less attentive to her son and were attempting to take away his iPad for communication, because they felt it was not adding to his experience. I may not have researched the 'natural' setting of the participant as an impact to the research; however, more importantly he may have been afforded more 'rights' whilst I was there and leaving meant potential for them being taken away. It has been noted that researchers need to reflect on the impact their relationships with participants can have on the production of data (Richards et al. 2015). Following up with participants after data collection may highlight important changes in their environments.

3.4.7 Section Summary

The current section summarized how I entered the field, and the ethics involved. However, the ethics were not seen as a tick box exercise and 'ethics-in-practice' was occurring throughout the thesis (Guillemin and Gillam 2004). The section discussed in detail entering into the field, the recruitment process, consent, pre-research meetings, the role I took as a researcher, and leaving the field. The processes of consent were similar for both children with disabilities, parents, coaches and volunteers within the study. Consent is an ongoing process that was reflective and renegotiable throughout the data collection period (Gallagher 2009, Hammersley 2015,2018), and participants were reminded of this practice throughout the data collection. Additionally, the section discussed the importance of anonymity and confidentiality. The following section will discuss how knowledge was produced through the study process.

3.5 Production of Knowledge - Ethnographic Design

The following section will discuss how knowledge was produced and created through multi-site ethnography and the various tools used. Tools that were utilized during the multi-site ethnography include participant observation, fieldnotes, interviews with children, coaches and parents. The section will then conclude with a discussion of data validity and data analysis.

3.5.1 Participant Observation

Observations and participant observations were conducted with 10 participants over a period of 11 months. A significant amount of data for this PhD thesis was generated through fieldwork where observations are the main contributor. In this section, I will discuss what observation looked like for the purposes of this study, the roles I took in the field and the discussion of informal conversations that took place. The next subsection will discuss how I took fieldnotes. Various methods may be used during the ethnographic approach to data generation, such as observations and interviews (Konstantoni and Kustatscher 2016). The term data generation can be used to describe data that develops through differing sources, understandings, experiences, emotions, interactions and conversations (Mason 2002). Mason continues that the researcher becomes part of the setting "experiencing and observing at first hand a range of dimensions in and of that setting" (Mason 2002, p.84). This data is generated by the researcher listening to what people say, asking questions and observing (Gillham 2000). Furthermore:

> "Participant observation-establishing a place in some natural setting on a relatively long-term basis in order to investigate, experience and represent the social life and social processes that occur in the setting- comprising a core activity in ethnographic fieldwork."
> (Emerson et al. 2001, p.352)

This participant observation is important to get "to know the children, developing rapport and reducing power dynamics" (Konstantoni 2011, p.90). During my time spent in the field, I was able to interact with the children during observations to further understand their extracurricular lifeworld. This was important to be in an everyday context of children's lives rather than one created by the researcher, so that I could observe different accounts and actions in place (Hammersley and Atkinson 2007, p.3). Additionally, this approach is perhaps less disruptive to children's everyday lives and activities than other methodologies as it 'fits in' with what they are doing already (Gallagher 2009). This was inclusive of their interactions with coaches, parents and volunteers. Here in the children's own environments, it was important that I did not assume that they would be more comfortable or that they would even want their environment to be invaded (Punch 2002).

Just being there is not enough, people need to participate in an exchange of knowledge (Oakley 1994). The interaction with participants is the strength of ethnography, by understanding them, not just 'objectively' standing 'outside' to observe them like a snow globe, where "something far greater is gained: understanding" (Khan 2011, p.201-202). This is important, because people with disabilities should be represented through their own perspectives (Oliver 1992). Additionally, children could change the course of the project (Davis 2000). Furthermore, the constant reflexivity and re-understanding of the experience and observation (Oakley 1994), can alter research methods and communication preferences as the participant needs. It may take time for researchers to understand the method of communication preferred by children with disabilities (Davis et al. 2017), however, ethnography can afford me time to navigate their chosen communication methods (Davis and Watson 2002, Davis et al. 2017).

Observations in ethnography can be used to seek an understanding of the "everyday interactions in everyday places" which allows for participants to challenge the researcher's

interpretations as the research is live (Davis 2009, p.186), some of the interactions that took place were amongst children, parents, coaches, volunteers and me as the researcher. Observation has been used for children with disabilities, as it helped gain access to communication techniques and children's meanings of their diverse identities (Cunningham-Burley et al. 2008). This access is notably more favourable for children who are non-verbal, communicate in a way unknown to adults, or wish to communicate in non-verbal ways (Boggis 2018a). As children with disabilities have the same right to express themselves, their 'voices' should be heard (UNCRPD, 2007, Article 7). Observations are ideal for children who are non-verbal, as verbal and non-verbal actions can construct children's cultures (Corsaro 2005), by being able to observe different expressions, unspoken interests, and non-verbal skills (Almeida et al. 2017). In addition, observation is beneficial for research with children with disabilities, because:

> "When we are with our non-verbal partners we are going to have to search at a micro-level for every flicker, every movement, every sound and rhythm and also invest meaning in behaviour we might otherwise reject as just something they do."
> (Caldwell 2007, p.19)

Furthermore, Caldwell (2012) suggests that as researchers, we need to 'listen with all of our senses'. To fulfil in-depth observation, fieldnotes will include activities, comments, influence, communication, context, appearance, mannerisms, time and postures. Through this, I was able to uncover narratives of participants experiences; this is what Stones (2005) describes as an internal critique of participants' lives. It was vital for me to remember that the 'problem' that I was having with non-verbal participants in trying to capture their voices was my limitation, not the participants' (Boggis 2018c). I had to adapt to the participants and truly tap into their 'cultures of communications' (Christensen 2004).

Observations and interviews with participants ultimately provided descriptive accounts where data was constructed (Lane et al. 2019).

"Writing descriptive accounts of experiences and observation is not simply a process of accurately capturing as closely as possible observed reality, of 'putting into words' overheard talk and witnessed activities".
(Emerson et al. 2011, p.5)

The reality of the experiences documented were in relation to interactions with others, which were framed by me, as the researcher (Lane et al. 2019). The construction of this knowledge is needing to be understood through a complex construction and power relations (Teachman et al. 2020). However, voice in qualitative research is always relational (Teachman et al. 2020), and should not be understood as a fixed concept (Spyrou 2011, Teachman et al. 2020). The fieldnotes that were constructed in response to observations will be discussed in further detail in the following subsection.

3.5.2 Fieldnotes

All of my data from participant observation in the field was captured in fieldnotes; this was a vital part of participant observation which is a representation of what I was experiencing in the field (Emerson et al. 2001). Experience in the field needs to be written into the text of fieldnotes and tailored to different settings (Hammersley and Atkinson 2007). I wrote notes during observations which one could see as a "note-taker role" (Emerson et al. 2011, p.37), and may have reminded participants in the field that I was a researcher. I would also write notes after activities if I missed something or had a reflection. Reflexivity was important for this research, as I became aware of my presumptions learnt from academic and non-academic life experience and how they fit or conflicted in the research settings (Davis 1998).

Starting with my experiences in the field, these notes provided a wide understanding of what was taking place (Pole and Morrison 2003). I detailed routines and tried to get as much information down as possible and whenever I could (Emerson et al. 2011). I was

familiar with some of the sports, so I had an idea of some of the routines before going into the field. I adapted my fieldnotes, as I progressed into a comprehensive note-taking strategy (Wolfinger 2002), because it was difficult for me to describe everything that was taking place during my observations. I started with impressions of the setting, what the setting looked like, who was there, and the smells and sounds (Emerson et al. 2011). Then I documented as much as I could, including conversations, reactions, emotions, gestures, where people were looking, how many times something happened or did not happen. With the information document, I would add in a question box, if there was clarification needed for any of the fieldnotes and whom I needed to ask.

I would first take notes in the field in a notebook. I had a total of 16 notebooks at the end of the research process. I would then go home and organize my notes and type up these jottings on my computer in greater detail, adding bits that were missed (Pole and Morrison 2003). The jottings I took were messy, although my goal was to get down as much data as possible; I developed some personal abbreviations (Woods 1986). Participants were numbered, 'C' was for coach, 'HBR' was horseback riding, etc. In addition, I also took pictures of the environments and some of the equipment used. I included my emotions in my fieldnotes and reflections that I would have as I relived the experiences while typing them up. Whether a researcher likes it or not, emotions and moods and feelings all influence how we understand and feel what is developing in the field (Stanley and Wise 1993, p.157), although these are important to note and recognize. All of my fieldnotes were typed up on my computer in order of when they occurred (Emerson et al. 2001), and were later printed off and placed in binders specific for the participant.

Fieldnotes were created for each time spent in the research setting with an individual participant. As an example, on Wednesdays in the Winter there would be 5 separate fieldnotes created as 5 different participants were participating in 5 different activities.

Throughout the creation of fieldnotes, I would practice reflexivity and question assumptions. Additionally, at the end of each month I would create a journal of my overall thoughts per participant and summarize what took place.

Being reflexive is a tool to help researchers be aware of their own biases which may challenge their academic, cultural and social perceptions (Davis 1998). A definition of reflexivity is described as:

> "The thoughtful reflection of a researcher upon the impact of her or his research on the participants, their social world, on the researcher her – or him-self, and on the knowledge produced."
> (Tisdall et al. 2009b, p.229)

This awareness is achieved "through detachment, internal dialogue and constant (and intensive) scrutiny" as a process of questioning, meaning construction and interpretations that the researcher develops in the field (Hertz 1997 , p.vii), this is not to say that the research will transform into being objective. Reflexivity is an important part of the research, not only for the researcher, but the research participant as well, as they are central to the interpretation of different meanings (Clark 2017).

During observation and participant observation there was a balancing act amongst observing, listening, talking and recording data to navigate through various settings and appropriate times (Mason 2002). There was a process on a "continuum between complete participant and complete observer, and to understand the implications" (Mason 2002, p.92). It was not possible to be a complete participant in the ethnographic settings all the time due to restrictions of competitions. Additionally, sometimes children would prefer me to just observe a session, and children's preferences were the most important.

'Reflexivity' is a process of being critically aware and self-reflecting (Herr and Anderson 2005), this is important to minimize bias. I need to be self-reflective about how my background (examples; white, female, student, adult, theoretical stances, non-disabled and middle-class) could potentially influence the interpretation of the research data.

Reflexivity, as a principle, is intertwined throughout this thesis, as it is the source of 'individual enlightenment' (Lynch 2000, p.26), and reflexivity in practice is achieved through 'internal conversation' (Archer 2010). Through reflexivity, the complexity of the process of knowledge creation allows for a deeper understanding. To achieve this understanding requires the researcher to undertake the difficult and challenging task of being continuously self-aware, vulnerable and uncertain. Diaries allow for a space to make reflection a priority, to find contradictions and conceptualizations that are developing and may need further clarification and questioning (Healy et al. 2013). For this reason, a diary has been maintained throughout the research project, which is used to track biases, feelings and thoughts. The goal is to use this information in the interpretation phase to ensure that initial hunches do not drive the findings. The long period of data collection has allowed for opportunities to be reflexive (Cunningham-Burley et al. 2008), and time to go back to the participants about emerging themes.

3.5.3 Child Interviews

Although informal conversations took place during observations which allowed me to gain a better understanding of the children's lives (Fontana and Frey 2005), I decided to also conduct interviews. Interviews were developed to support the ethnographic approach which were conducted with child participants, coaches, parents and key volunteers who worked with the children. This subsection will focus on interviews with children. I do not believe that I could have just conducted interviews as:

> "It is necessary to spend prolonged, or repeated, periods with anyone
> in order to get to know them beyond a one-off interview and to gain
> a greater understanding of their views and experiences."
> (Fetterman, 1989 as quoted in, Punch 2002, p.3)

Interviews allow for:

> "a process of jointly constructed meaning. I am not objective and the
> adolescents do not respond objectively or neutrally about their

experiences. Each of my questions and each of their responses was
filled with our own assumptions, expectations and desires"
(Way 1998, p.27)

These images and stories that are described by participants perhaps show us how they would like to be portrayed (Scheer 2017). It also adds a variety of experiences and their interpretations of them (Seidman 2006). This 'voice' of participants is important to note, voice is perhaps a:

"cluster of intentions, hopes, grievances and expectations that
children guard as their own. This voice surfaces only when the adult
has learned to ask and get out of the way."
(Pufall and Unsworth 2004, p.8)

It was beneficial to have done the observations beforehand with the participants. I had learned when to encourage participants and knew when they were thinking to give them space. In previous research, interviewers only had a brief period of time to build rapport with participants and position themselves in a research role (Moore 2001). Although I found interviews useful, as a structured way to get some participant thoughts, I found that children had already found ways through their agentic strategies to portray their feelings and thoughts (Castro 2017). Additionally, the children who were interviewed asserted their own interview protocol (Castro 2017), by telling me to stop, changing the questions, and playing games.

Participants selected the interview location, and I prepared shorter interviews and allowed for breaks to reduce researcher or participant fatigue (Boggis 2011, Carlsson et al. 2007, Gibson et al. 2014, Morris 2003). Before conducting these interviews, I gave the interview questions to each participant. This was ideal, so participants could have a look at the questions, decide if they did or did not want to answer some, go at their own pace and be prepared for the questions.

At the start of the interview, I would explain consent again; they could stop at any point or change their answers. I also started in line with an idea from Tisdall (2009) that I would like to audio record my interviews, because I have a difficult time listening and taking notes at the same time; I really wanted to ensure I was getting everything down they had to say. All participants except one were accepting of the audio recording and agreed it would be hard to take notes and listen. The one participant that did not want to be audio recorded wrote their answers down for me.

By pressing an icon on my phone, participants started their recordings for me, which ideally made the start of the interview a more collaborative process (Weiss 1994). I put my phone between us first and foremost to hear everything, and second it allowed them to be in control of the stopping and starting. Some participants got anxious, if they were taking too long to answer, so they would stop the recording and start it again when they were done their thought process.

I wanted children to feel as comfortable as possible during the interview process. I wanted to make it fun for both of us. I created dice using four colours and four themes of questions to help participants select questions to discuss. I taped my questions onto the whiteboard sides of the dice and said, 'if you'd like to change the question, here is a marker, just rip mine off'. I also was aware that children do not need a fun activity to participate in an interview, so they also had the option for me just to ask them questions. Although these methods may be seen as helpful, it is important to remember that not all children will enjoy them, and some children with impairments may not be able to participate (examples; visual impairment, cognitive impairment, limited use of motor skills) (Wickenden and Kembhavi-Tam 2014). I understand from previous studies that children may have a hard time answering interpretive, double, or long-winded questions (McTague et al. 2017), I attempted to not have any and left the option for children to change the question. In response to answers or

thoughts, I said things such as 'that's cool' or 'that's interesting' to attempt to make the participants feel at ease, making it seem more of an informal conversation (Gast 2017). It was important to be active in the conversation and respond not only to what children were saying, but how they were saying it (Baraldi and Ievese 2014). I would not only have questions that focus on "concrete facts and 'here and now' situations as well as props that attend to kids' comprehension and communication styles" (Kortesluoma et al. 2003, p.438).

One of my interviews took place with a child after their extracurricular physical activity. This was difficult for the same reasons found with interviewing children after school, due to tiredness, being hungry and restless (McTague et al. 2017). I conducted interviews at some of the extracurricular physical activities, some at a coffee shop, and some at the home of participants. I did run into problems similar to McTague and colleagues' research of participant - distractions, phone calls and pets (McTague et al. 2017). I was aware this could have been avoided in some instances by setting guidelines on interview places such as: comfortable, quiet, private, place on neutral ground, etc. (Gallagher 2009). However, I just let the participants choose their interview location.

The general interview questions were provided to participants before the interview. During the interview the participants chose to have questions asked of them or to play a game with the questions. The game utilized four dice in four different colours to represent different themes: (i red) individual questions, (ii yellow) experiences of extracurricular physical activity, (iii blue) inclusion, and (iv green) mix. Some participants threw the dice across the room, chased them, read the question and answered while others held the dice and just rotated it until they found a question they liked. Children switched between dice if they desired a change of topic. The questions were on the dice with sticky notes. If the participants did not like the question or thought it should be changed, they removed the sticky note and wrote on the whiteboard underneath their new question. An image of the dice can be found below.

Figure 11 Interview Dice

I found the dice useful, as they allowed for the participants to have more power in their interview process. The dice did have challenges such as siblings or family pets trying to retrieve the dice. A couple of participants also noted a different game would be better as the dice did not have an 'end', as they were looking for more questions on the dice to see if they had answered them all.

At the end of my interviews I asked, 'could I have done anything different or better?' and 'what should researchers do next time'. I asked this because Hagerman (2010) believes it is important for researchers to ask children what they think about participating in research and to find out if they enjoyed the process. Additionally, I asked parents and coaches, as I was interested in the different perspectives to these questions.

My routine was to return home and transcribed the interviews verbatim. I kept the interview transcripts separate from my fieldnotes, although they are printed off in a participant specific binder.

I wanted to get the full picture of the experience of extracurricular lifeworlds, which is why I included others that were present at the activities such as parents and coaches. I included the coaches that the children participants thought would be good to interview and all parents. I originally only wanted to talk to the children; however, during observations, it was clear that "children construct different meanings and beliefs than do their parents" (Del Mol and Buysse 2008, p.362). When children were present during the parent interviews, they would interrupt and correct their parents asserting their knowledge (Castro 2017). The following subsection will further explore the process of parent, coach and volunteer interviews.

3.5.4 Interviews with Parents, Coaches and Volunteers

Semi-structured interviews were conducted with 14 parents, 18 coaches and 5 volunteers. The key people identified to interview were the parents who attended the activity. The coaches and volunteers were identified by the child participants as key people to speak to.

Interviews with parents, coaches and volunteers allowed the thesis to understand multi-perspective accounts and perspectives (Cook and Hess 2007) of the extracurricular

physical activities. During data collection informal conversations with parents, coaches and volunteers occurred, however, the informal interview allowed for reflection.

All the interviewees were emailed the consent form, thesis information sheet, and general interview questions beforehand. Open-ended questions were utilized during the interviews allowing for more creative responses (Mayall 2008). However, prompts, probes and follow-up questions were also utilized in the interviews to allow for a deeper understanding.

The interviews took place in the person's home, in an office at the extracurricular physical activity or in a local café for convenience of the interviewee. The length of time the interviews took varied ranging from twenty-one to ninety-seven minutes. All coach and volunteer interviews were individual interviews, and 6 parent interviews were individual and 4 parent interviews were with both parents.

All but one of the interviews were voice recorded for ease of transcription later, however one interviewee chose not to have her interview recorded. When I got home from the interviews, I wrote notes, and reflexive notes relating to the interview. All of the interviews but one I transcribed verbatim (Bryman 2012), which allowed me to become more familiar with the data. The interview that was not voice recorded, I wrote down notes during the interview and after the interview. Pseudonyms were utilized for the interviewees and the participants they discussed.

The focus of the interviews was similar to the focus of the interviews with the child participants which was to understand their views and experiences of participation, and inclusion in extracurricular physical activities. Although informal conversations were had with parents, coaches and volunteers throughout, this was a space to further clarify details and confirm observations (Fetterman 2010). Additionally, views of the interviewees were gathered in respect of the interpretations I made during observations. The interviews allowed

for a holistic understanding of children's experiences and further understanding of relevant previous experiences that may have contributed to interactions, choices and adaptations made for or alongside the child participant.

The role I took during the interview process was to learn and understand the different voices, experiences and viewpoints of the various people involved. Although the interview schedule was flexible, power was evident as I directed the interview and led the topics of discussion. However, sometimes parents and coaches changed topics, or asserted the stance that they know best for their child or student.

3.5.5 Data Validity

Working in collaboration with participants for feedback and fact checking was critical for validity. The long-term engagement with participants affords multiple opportunities to the researcher to be reflexive about emerging themes whilst providing the participants time to question the analysis (Davis 2000). Participants evaluated the interpretations, conclusions and analyses to determine whether they were credible and accurate (Creswell and Poth 2018) to their own understandings. Throughout the data collection and analysis stages, children were asked "how well the ongoing data analysis represents their experience" (Hays and Singh 2012, p.206), and what was missed. There was an inherent risk that children may have responded with what they believed I wanted to hear (Gallagher and Gallacher 2008), especially, because I took the friend role. However, there were instances where participants would contradict my assumptions and understanding on the data and stated what actually mattered to their experience (Boncori 2018).

Another way to think about validity is linking it to an ethical standpoint:

> "the reliability and validity, and the ethical acceptability, of research
> with children can be augmented by using an approach which gives
> children control over the research process and methods which are in
> tune with children's ways of seeing and relating to their world."
> (O'Kane and Thomas 1998, p.336-337)

Participants within this study were allowed make changes to the research methods to be more in tune with their ways of seeing the world. Additionally, non-verbal participants have had concerns raised in the past about validity due to the assumption that they are perhaps being 'lent' a voice as interpretations of facial expressions, and gestures are being made on their behalf (Boggis 2011). Further, other participants in the field may expand, interpret or supplement their voice in various ways (Philpin et al. 2005). However, qualitative research as a whole has been concerned with the ways in which participants make meanings, and what they place importance on which has been co-constructed through this research study (Lloyd et al. 2006). Co-construction of knowledge, experience and importance between participant and researcher is a similar process with participants who are verbal and non-verbal.

3.5.6 Data Analysis

The data collection method for my research study was an ethnographic approach and the analysis incorporated a thematic approach. Thematic analysis can be used when compiling the data to identify themes and patterns emergent within the data (Bryman 2008). Thematic analysis was conducted across "multiple sources of evidence" (Gerring 2007, p.17), which includes fieldnotes, interviews, and informal conversations. Throughout the ethnographic process analysis was already taking place and themes were already emerging (Punch 2012).

I followed the Braun and Clarke (Braun and Clarke 2006,2013, Clarke and Braun 2013,2014) ongoing process of thematic analysis. This process consists of six phases "familiarising yourself with the data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, producing the report" (Braun and Clarke 2006, p.35). Although, this is not claimed to be a linear process (Braun and Clarke 2013), the

starting point I used was re-reading the data to ensure I was familiar and to go beyond

obvious views and the surface data. I stored my data in NVivo where I started to organize by

codes (Hammersley and Atkinson 2007). However, with the large amount of data collected, I

decided to print everything off to colour code different themes and important findings. Often

data could fit into more than one theme or code leaving the print off copies very messy. I did

this because I wanted to be very familiar with all the data and read it several times; I felt

more comfortable doing this when it was printed. Here I also found some 'diamonds

scattered in the sand', key pieces and contradistinctions emerging in the data (Emmel 2015).

Throughout the process, I aimed to be as transparent as possible, as the knowledge that I am

producing is situated and partial (Haraway 1988). As stated previously, reflexivity is

important in ethnographic research (Davis 2000, Konstantoni 2011), and reading the data

several times allowed time to reflect on codes, to question themes and to interpret the data

fully. I do recognize however that "methods of data analysis are not simply neutral

techniques" (Mauthner and Doucet 2003, p.415). Throughout the analysis, there are multiple

perspectives and voices that emerge. The process was messy and long however, what

emerged was learning the data in a tremendous detail. The "complexity, messiness,

contradiction, ambiguity and so on" (Mason 2002, p.177), were part of the process of

unpacking fully what the participants were experiencing whilst constructing an analysis.

During the data analysis phase, utilizing thematic analysis there was a loss of the

individual experience. Children's personal lives and how they interact with structures was

seen as important (Frankel 2018, James 2013). Through peer interaction and social structures

children were constructing their lived experience (Frankel 2017,2018). Experiences of

children with disabilities in this study could be analyzed by thematic analysis; however,

children with disabilities are not a homogenous group and the experiences were sometimes

similar but sometimes very different. I found the following table set out in figure 12, a useful

way to help analyze the data.

Part 1 Structural					Part 2 Agentic		
Context	Interactional Setting	Image of Child	Practices	⬌	Personalised Refelction	Meaning Making	Action/ Reaction
							Part 3
⬅		Additional Factors?		⬅			Re-Inform
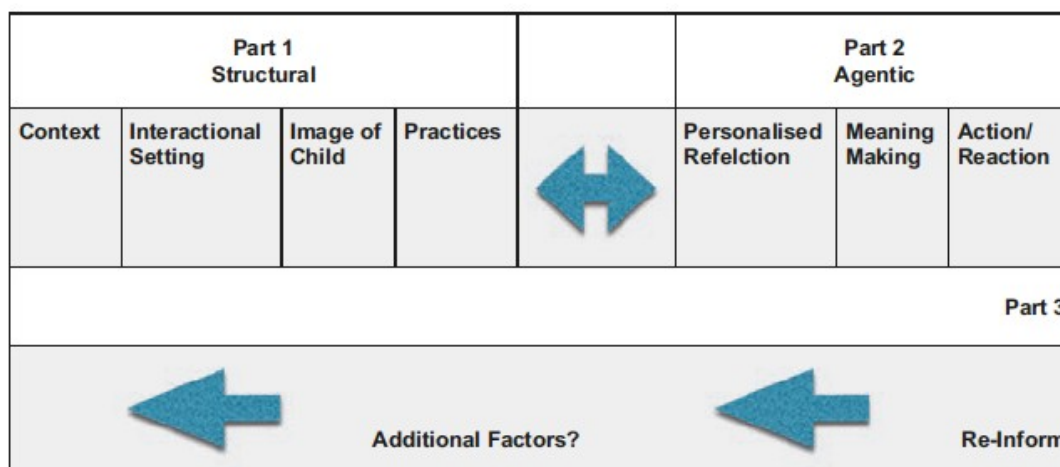
Figure 12 Framework Overview (Frankel 2017, p.43)

Figure 12 above shows another way to understand data. In the figure there are various

factors taken into consideration on how to understand lived experience. The various

understandings for this thesis are useful as there are several contexts, settings, understandings

of childhood and disability, and practices. There is an interlink of the structure of the setting

and assumptions about the child. As part of the thesis, I have explored assumptions about

disability and how that influences the environment. The figure highlights the importance of

participants' reflections, meaning making and actions and how that shapes or influences the

structure. Giddens (1979) also placed importance on understanding how the individual ability

can shape the structure and how actions can create systems of rules. This ethnography is

unique because it covers 11 settings and follows children's participation in various

environments. In relation to analysis, I also argue that although a setting is the same, there are

other factors such as relationships with different coaches, children and volunteers that alter

the setting which creates various differing experiences. This resulted in various networks of

relationships and differences in how agency was impacted. The framework highlights that

children are able to redefine and shape structure, and there are implications for the adult-child

relationships in the various settings (Pendlebury et al. 2014). This confirmed "children are thus involved in the daily 'construction' of their own and other people's everyday relationships and life trajectories" (Alanen 2011, p.160). There was individual meaning making; however, it is seen as multi-layered and their lived experience is not one-dimension (James 2013). Additionally, participants in the study recognized how different their experiences were dependent on impairment, or activity, and even their own experiences across different settings. Agency can be lived out in relation to one's various identities (Smart 2007), this can be specific to an individual, as not all individuals experience disability, gender, childhood etc. the same way. The framework has added to the "thick description" and richness of the data analysis process (Denzin 1989, p.430), and closing a gap in individual experiences.

3.5.7 Section Summary

The section provided an understanding of how knowledge was produced for the purpose of the thesis. Knowledge was produced through observation, fieldnotes, interviews and checking validity with participants. Participant observation occurred whilst participating alongside participants in the study and observation when participant observation was not appropriate in the field setting. Fieldnotes were created whilst spending time in the field for future reference and reflexivity. Interviews were conducted with key people that were present during fieldwork such as, children, coaches, and parents. The section concluded with a process of data analysis and checking validity of findings that have been utilized to interpret the data. The following section will be an introduction to the findings of the thesis.

3.6 Introduction to Findings

This section of the thesis will discuss an introduction to the findings which included participant group descriptions, construction of labels, and an understanding of research settings.

3.6.1 Participant Group Descriptions

The following paragraphs introduce the participants involved in this research project at a group level. I invited participants to participate who were between the ages of 14-16 and had a disability. For the purposes of the research study, I recruited participants that identified as having a disability. I contacted 94 organizations with my poster (Appendix B) and several communities through Facebook groups. The responses I received totaled 11, with 10 of these participating in my study. There were difficulties in generating interest for participation in this study and gaining access to children's worlds which is similar to experiences of other social science researchers (Fothergill and Peek 2015). Some of my participants are younger than my targeted age, as I lowered my target age group to generate enough interest in participation. The target for participants in this study was 15. However, upon reflection, the size could not have been bigger due to timing of activities. The study included 6 females and 4 males. 90% of my participants would like to be referred to with person first language such as 'child with a disability' or 'Moose, who has a disability'. However, 10% of my participants would like to be referred to as 'Kirby with autism'. This is in line with the context of their environment as person first language is the only one used by all of their environments. This person first language can also be seen in policy documents in Canada (examples; Government of Canada, 2019; Heritage Canada, 2006). Overall, my participants participated in a total of 11 different sports. All participants in this study identified as Canadian. Furthermore, 60% of my participants were verbal and 40% were non-verbal.

Additionally, children were asked which pronouns they use, and these have been acknowledged through the data analysis. The decisions that participants made in relation to identity was important for this thesis to incorporate their voice into the creation of their lived experiences.

There were 14 parents, 18 coaches and 5 volunteers that were also involved in observations and interviews. Of the 14 parents, there were 10 mothers and 4 fathers. 2 mothers were single parents. 2 of the families were first generation Canadians. There were 6 male coaches and 12 female coaches. The volunteers consisted of 4 females and 1 male.

3.6.2 Research Settings

In ethnographic research, there is often a focus on "one or a small number" of research settings for in depth data (Hammersley and Atkinson 2007, p.31). However, in this study there are various research settings for this PhD study. The lived experience of children with disabilities is of interest which includes the experience of disability which is in relation to social relationships, political and cultural contexts, physical environments and mental or physical attributes (Shakespeare 2014). Hammersley later states "it is important to remember that behaviour observed in a 'natural' setting with no reactivity may still not be typical of what is done by the same people at other times or in different places" (Hammersley 2018, p.8). The experience can change in various settings, lived experience is multi-factorial and to create in depth data, extracurricular physical activity settings that were of importance to participants were included. This was done as settings evolved and changed due to the seasons and time (Murchison 2010). It is also important to note, all practices, games and competitions were attended except for two practices due to overlapping time schedules. I believe that there was sufficient time given to build a trusting and meaningful research relationship with participants (Enright and O'Sullivan 2012), as I was participating in the research context throughout the whole duration. The heading 'Can Equipment be Provided?' means, can the

organization provide equipment for the participants, if the families cannot provide the

equipment themselves.

Sport Setting	Cost	Can Equipment be Provided?	Transportation	Duration
Horseback riding	$40 per session	Yes	Private	September – June once a week
Hockey	$180 per year	Yes	Private – can take public transportation (bus)	November – April – twice a week
Skiing	$250 for 6 sessions	Yes	Private	January – February once a week
Snowboarding	$250 for 6 sessions	Yes	Private	January – February once a week
Dancing	$3000 per year	No	Private – (can take public transportation)	All year around – 2-3 times per week
Swimming	$225 for 8 sessions	Yes	Private – (can take public transportation)	December – January – once a week
Baseball	$250 for 10 sessions	No	Private – (can take public transportation)	June – August – once a week
Lawn Bowling	$200 per 8 weeks	Yes	Private	July – August – once a week
Track & Field	$180 for 8 sessions	Yes	Private – (can take public transportation)	July – August – once a week
Speed Skating	$340 per year	Yes	Private – (can take public transportation)	November – March – 1-2 times per week
Martial Arts	$25 per month (once a week)	Yes	Private – (can take public transportation)	September – June – once a week

3.7 Children's Biographies

The following section will discuss the individual participants' biographies. All of the names of participants are pseudonyms, which is a common practice to further anonymity and privacy (Truscott et al. 2019). The pseudonyms were also created by the research participants themselves where possible, which has been done previously in research (examples, Breslin et al. 2017, Elliot and Campbell 2013, Townsend et al. 2020, Truscott et al. 2019). The opportunity to select a pseudonym for oneself is seen as important as "personal names do matter" (Hurst 2008, p.351), and rather than researchers having the power to select, the power relationship can be shifted to children (Griffin 2019). During this process no participants wanted to keep their own name in the research findings.

Participants provided their gender for the purposes of demographics. Some participants also provided their diagnosis and the others consented to have their parents tell me, as they did not know specifics.

The discussion of participants' biographies will include, demographics, study specifics, a description and a typical routine for the participant in the research context.

3.7.1 Ben

Demographics: Ben at the time of data collection was a 14-year-old white male who is diagnosed with Global Developmental Delay, Speech Delay and Sensory Processing. Ben communicates non-verbally.

Study Specifics: Ben participated in the study for 10 months in a horseback riding extracurricular setting. Knowledge was generated through ethnography, specifically observation, parent and coach interviews.

Description: Ben communicates non-verbally through facial expressions, gestures and some noises. Ben would occasionally use the word no, would often laugh when happy and

would make horse noises when excited about horseback riding. Ben lives with both of his parents and attends high school in London. At school he is in a segregated classroom for children with disabilities. Ben only participates in horseback riding as a structured physical activity at the time of data collection; however, previously he played soccer and took swimming lessons.

Routine: He has two regular volunteers with him in horseback riding that he jokes around with, as they clearly have a special bond. Sometimes his jokes include taking their hat, pretending to lasso them just as a cowboy would, or after getting off the horse he pretends he needs them to walk him to the gate. Ben loves routine; he has the same routine of going with me to get his helmet on before waiting at the mounting block with his horse. However, sometimes he can be loud and overpowering, so he finds himself in trouble with his parents as their expectation is for him to be well behaved which includes being calm, quiet and listening whilst not playing games. He calls his coach, volunteers, and me 'teachie'. He would also include me in his Mr. Wolf game, which he would frequently want me to be the wolf.

3.7.2 Mickey

Demographics: Mickey at the time of data collection was 16 years old. Mickey is a white male who is diagnosed with Global Developmental Delay and Epilepsy. Mickey communicates non-verbally; however, during the course of data collection, he started to use an iPad for some communication.

Study Specifics: Mickey participated in data collection for 10 months participating in horseback riding. For 3 months Ben (described above) and Mickey were in the same lesson. Knowledge was generated through an ethnographic approach including observation, informal conversations and child, parent and coach interviews.

Description: Mickey communicated non-verbally through gestures and facial expressions. Mickey would also touch people when he wanted to communicate to ensure the person was listening. Mickey lives with both of his parents and his sister. He attends high school in London, in a segregated classroom for people with disabilities. During data collection, he only participated in one structured activity which was horseback riding; however, often he went skiing with his dad in the winter and took bike rides with his family in the summer.

Routine: Mickey waits in the lounge until he sees his horse through the window. Once he sees his horse, he takes my hand and leads me to the rider change room. Here he gets help from a parent to put on his helmet, then he presses the disabled door button and heads out to the arena, where he sits on the bench and waits for his coach. You can tell he is having fun when he tries to hold back a smile or make a half smile, without fail he will be doing this when his horse is trotting.

3.7.3 Kirby

Demographics: At the time of data collection Kirby was 14 years old. Kirby is a white male, is diagnosed with Autism Spectrum Disorder. Kirby communicates verbally, although occasionally requires extra time to respond.

Study Specifics: Kirby participated in data collection for 10 months and during this time participated in various activities which included speed skating, hockey, skiing, snowboarding and track and field. During the ethnography knowledge was created through observations, informal conversations, participant interviews, coach interviews and parent interviews.

Description: Kirby is an only child and his parents are divorced. He spends his weekends with his dad and weekdays with his mom, although they share duties of taking him to his extracurricular physical activities. He attends high school where he is in the band and

on the track and field team. Kirby goes on ski trips with his dad and was one spot away from making the provincial Special Olympics ski team.

Routine: He knows the sport routines very well and the majority of the time follows them. Kirby liked structure and when he is in a structured environment he seemed to thrive. Sometimes when he is being given instruction he moves around and may not always appear to be listening. However, he is on task most of the time following his movements; once he knows what the routine of sport is – as an example, warm up, stretches, activity. He is always there on time ready to participate. If the routine changes, he might be seen biting his gloves or playing with his clothes whilst listening to the changing task.

3.7.4 Charlie

Demographics: At the time of data collection, Charlie was 14 years old. Charlie is a white male; his parents are first generation immigrants from Poland. Charlie is diagnosed with Autism Spectrum Disorder. Charlie has limited verbal communication.

Study Specifics: Charlie participated in data collection for 9 months and during this time Charlie participated in horseback riding, hockey, baseball and skiing. During the ethnography knowledge was created through observations, informal conversations and interviews with parents and coaches.

Description: Charlie has a younger brother who is on his hockey and baseball team. Charlie lives with his parents and attends high school in a segregated classroom for children with disabilities. Charlie is non-verbal, however he started to use an iPad for communication. When he is listening to someone, he makes eye contact. He often attends hockey and baseball with both parents and horseback riding with his mom.

Routine: Charlie's routine is different for different sports. In baseball and horseback riding it is fairly similar to listening to the routine of warm up and activity. However, in hockey, once on the ice, he has his own routine he likes to follow which is different from his

peers. He loves to skate laps around the arena when the other children are playing the game or warming up.

3.7.5 Chloe

Demographics: At the time of data collection, Chloe was 15 years old. She is a white female. Chloe is diagnosed with Cerebellar Atrophy and Anxiety. Chloe communicates verbally.

Study Specifics: Chloe participated in data collection for 8 months during which she participated in horseback riding. Knowledge throughout this duration was created through observation, informal conversations, participant interviews and parent and coach interviews.

Description: Chloe has an older sister and lives with both of her parents. She recently moved from a bigger city into a country house that met accessibility requirements for her. She is very shy when meeting new people, but very talkative when she gets to know someone.

Routine: Each week the coaches would expect that I would tack up and groom Chloe's horse with her. They expected me to supervise her, when in reality I could just go down and chat while she got her horse ready. We would race up to the mounting block and would have lots of chats whilst getting her horse tacked up. Once up on the mounting block, she would become quiet, she would wait for the coach to give her instructions and she would do them. The routine was a warmup stretch, trot and then a course with the horse, then dismounting at the gate. She had 4 different coaches during the year.

3.7.6 Moose

Demographics: At the time of data collection, Moose was 16 years old. He is a white male who is diagnosed with Cornelia de Lange Syndrome. Moose communicates non-verbally.

Study Specifics: Moose participated in data collection for 5 months where he participated in horseback riding. Knowledge was created through observation, informal conversations and interviews with parents and coaches.

Description: Moose has 3 other siblings who he lives with along with his parents. His horseback riding lesson is during the day, so he gets taken out of high school to attend. He attends with his mother, as his father is at work. Moose communicates non-verbally although makes a variety of sounds and body movements to communicate.

Routine: Near the end of his lesson, you will always find that he is leaning to the left, as this is the side, he gets off the horse. He is a wheelchair user, but on the horse, he is able to sit up, lean and then bring his body back to the center. He is very strong such that his volunteers have a hard time moving him a different way than what he would like. He would not trot during his lesson. His warmup would be a faster than a slow walk. They would then do a course the rest of the time which seemed to drag on and be ultra repetitive.

3.7.7 Magic

Demographics: Magic at the time of the data collection was 13 years old, and through the course of data collection turned 14. Magic is a white female who is diagnosed with Coffin Lowry Syndrome, Global Developmental Delay and Sensory processing disorder as provided from her mother. Magic communicates verbally.

Study Specifics: Magic participated in data collection for 7 months where she participated in horseback riding and swimming. Knowledge was created through observation, informal conversations, participant interviews and parent and coach interviews.

Description: Magic has an older sister and is living with her single mother. She is in her last year of elementary school. She never missed a physical activity session. Magic is always making jokes which sometimes gets her into trouble. Magic can also get overwhelmed easily and asks lots of questions to be prepared.

Routine: Each week she helps her horseback riding coach set up the course in the arena, she often gets to pick which toys they play with and where some things go. She gets on her horse from the lower block in the arena. She is very resistant to change and will tell the coach when she does not want to do something. She helps the coach pick warm up stretches and will often complain her horse is walking too slow. After warmups they do a course with the horse and she often gets to ride without a leader, all by herself.

3.7.8 Spyro

Demographics: At the time of data collection, Spyro was 13 years old and turned 14 during the study. Spyro identifies as a white female and is diagnosed with Attention Deficit Hyperactivity Disorder. Spyro communicated verbally.

Study Specifics: Spyro participated in data collection for 6 months, where she was participating in Martial Arts. Knowledge was created through observation, informal conversations, participant interviews and parent and coach interviews.

Description: Spyro is in her last year of elementary school. She lives with both of her parents and is an only child. She is obsessed with Harry Potter. She is always talking and likes to make new friends at her activities. Her father attends Martial Arts with her and they participate together.

Routine: She plays on her Gameboy before she gets to Martial Arts. She often plays tag with her friends in the gym before Martial Arts starts and is often the instigator of this game. If she does not play tag right away, she is sweeping the gym floor to clean it up after the school day. After tag she will get into a circle for warm up stretches. She will follow all the stretches but when it comes to sit ups and push ups, does less than she is supposed to. When listening to instructions she is often moving, playing with her hair or hair elastic on her wrist. In martial arts they practise their belt routine and do another drill. She often plays around during these joking with one of her friends in the class.

3.7.9 Marie

Demographics: Marie was a 15-year-old white female during data collection. Marie is diagnosed with Developmental Delay, Speech Delay, Attention Deficit Hyperactivity Disorder, and Mild Intellectual Disability. Marie communicated verbally.

Study Specifics: Marie participated in data collection for 9 months during which she participated in horseback riding, hockey and lawn bowling. Knowledge was created through observation, informal conversations, participant interviews and parent and coach interviews.

Description: Marie is in high school and her favourite class is math. She lives at home with both of her parents, she has two older siblings who moved out. She attends all of her activities with her mother, and her father will come for the big tournaments. Her mom drives her from a small town 40 minutes from most of her activities.

Routine: After giving coaches, and friends a hug she gets ready for her sports either by putting on the hockey equipment or horseback riding helmet. She is fairly easy going when it comes to changing of coaches, or routines. In hockey they do the same drill to warm up on the ice before each game and she is always one of the first ones to start the drill, and one of the first ones to return the puck to the coach once the referee blows the whistle to start the game.

3.7.10 Aspyn

Demographics: At the time of data collection, Aspyn was 13 years old. Aspyn identifies as a white female. Aspyn has a diagnosis of a hearing impairment and communicated verbally.

Study Specifics: Aspyn participated in data collection for 3 months, during which she participated in horseback riding and dance. Knowledge was created through observation, informal conversations, participant interviews and parent and coach interviews.

Description: Aspyn is in her last year of elementary school. Aspyn lives with her mom and her pet dog. She has convinced her mom to take dance lessons. She sometimes carpools with her friends to dance, as she dances 6 days a week.

Routine: Aspyn's routine in sport was consistent. She is always listening and adapts easily to change. Often dance is getting her kit on with her friends, then chatting with them before the coach comes in. The coach always gets them to sit in a circle for attendance, here the coach asks, 'what would you like to tell me today' and each child gives their answer before they start. They start with warm up dance moves then work on their routine for the end of the year. Once finished she leaves chatting with her friends.

3.8 Following Data Collection

The following section will discuss dissemination and feedback, and reflections on the methods utilized for this thesis.

3.8.1 Dissemination and Feedback

Dissemination is an ethical part of the research process, as children have the right to know that their perspectives were valued and heard (Tisdall and Davis 2004). I have shared initial findings with the participants near the end of the data collection to create a process of checking and critiquing themes. When attempting to disseminate findings to the 11 organizations in this study, only 1 responded. I presented findings to the board of the one organization, 3 out of 10 participants attended that organization. The presentation will be sent to the other organizations.

Initial findings have been presented at King's University College, and at an academic conference at the University of Suffolk.

3.8.2 Reflections on the Methods

For future research and transparency, reflection on ethnography as a method used is important to discuss. First, reflections on methods from participants will be discussed, followed by my own reflections.

An important reflection on the methods was the opportunity for participants to critique the research methods (Davis 2000). During the research process, there were opportunities to alter the ethnography and ongoing discussions were had with participants. Some participants suggested that it would be useful, as part of the study, to see their experiences of physical activity at school, or with their friends after school. I do agree that these are valid experiences to document, however for the scope of the study there was limited time. Additionally, one participant suggested that as a 'participant' in the observation process that I should also be allowed to coach her. Although this may have offered a unique perspective, there were structural constraints within organizations which would have made this impossible. There were various other ideas about changing the structure of the environment of their activity, therefore there is potential for participatory action research. However, for the overall thesis, it was well into the study after building rapport that participatory action was discussed by participants. Perhaps without ethnography as a first step, this would not have been discussed.

My reflection on the methods brought me to the understanding that ethnography was a valuable tool and important research questions to ask. However, 11 settings did make the research process very difficult in terms of scheduling, as extracurricular activities only have a window of time after school. This was especially difficult on Wednesdays were there were 5 activities occurring at different organizations. Recruiting a couple of organizations may have been an easier approach, however, following 10 participants in-depth created rich data that may not have been created otherwise. I originally was going to recruit for verbal participants

only, however, I think the data created with non-verbal participants especially, closed a gap in research by placing importance on their perspectives.

3.9 Chapter Three Conclusion

Chapter Three aimed to give a good understanding into how data was collected through an ethnographic approach. This approach was used to answer my research questions. Data collection was comprised of observations and interviews. These methods were made possible by building rapport with participants and gatekeepers. The multi-site ethnographic method was the best methodological approach to answer the research questions as children directed this approach. Throughout the differing stages of data collection, it was critical to be reflexive about my role as a researcher and how data was being created. Additionally, leaving the field posed challenges for some participants that were used to the routine of me being in the field for such a prolonged period.

The chapter discussed children's biographies and participant group level descriptions which began to introduce how knowledge was constructed amongst participants from their unique perspective and identities. The chapter highlights the importance of children's participation in the creation of knowledge, and the checking of data validity.

The chapter concluded with a reflection on the methods used from a researcher and participant perspective. The following chapters will be an analysis of the data collected by this ethnographic approach.

Chapter Four: Who has the power to choose?

4.1 Introduction

Chapter Four begins to explore how children with disabilities experience, negotiate and participate in extracurricular physical activity environments. The exploration is specific to the Canadian context of London Ontario. This chapter provides an analytical 'thick description' (Emerson et al. 2011), of everyday life in extracurricular physical activity environments. The chapter will begin to answer the following research questions:

> **Question 1:** How do adults and children create opportunities and constraints for children's recognized participation?
>
> **Question 2:** How do children with disabilities navigate (or live through) the process of inclusion in extracurricular physical activities?

The analysis shows the importance for understanding a key theme and finding, choice. As the data supports, choice is a fundamental theme for a complete understanding of the research questions.

The chapter begins with an overview of how children with disabilities become involved in extracurricular physical activities by discussing the information available, and access to activities. The section also discusses the role parents, organizations and children play in deciding the activities children with disabilities participate in. The section contributes to knowledge as it provides an understanding of choice of activity, furthering knowledge of inclusion and exclusion of activities.

The second section of the chapter discusses the lived experience of choice in relation to disability and participation. The section starts to examine the data that shows the different experiences of children who communicate verbally and non-verbally. The findings are

important to highlight as children that communicate non-verbally have previously been excluded from research (Alderson and Morrow 2008), and to provide a comprehensive discussion into lived experience of children with disabilities in extracurricular physical activities, their experience is seen as meaningful.

The chapter aims to provide an understanding of choice in the context of extracurricular physical activities and participation that will be further discussed in the following chapters.

4.2 Introduction of Choice of Extracurricular Physical Activities

The following section aims to provide an understanding of the process of becoming involved in the choosing of extracurricular physical activities and of whose voice matters in the decision-making process.

4.2.1 Information to Choose

For children with disabilities to be able to become involved in participating in extracurricular physical activities, children, families and communities need to be informed of the opportunities. For some families within this study, extracurricular activities were difficult to find which will be further explored in this subsection.

Based on interviews with several parents of the participants, in relation to information about extracurricular physical activity opportunities, a typical comment would be:

> *I wish we would've known about this opportunity [hockey] sooner but because we're out of town, so I just think we don't get what's happening in London. There isn't really any opportunity in our town for Marie to participate in, I don't mind driving through, I wish the schools would help a bit more. I wouldn't have even heard of hockey if it wasn't for other parents.*
> Parent of Marie, interview transcript

Children with disabilities and their families are likely to deal with more inequalities in all areas of their lives (Read et al. 2006, Runswick-Cole et al. 2018a). Here we can notice an

inequality linked to the lack of information, and access to information about after

extracurricular activities. The finding is consistent with previous research suggesting that

there is a lack of resources and information about physical activities for adults and children

with disabilities (Dyck et al. 2004, Gorter et al. 2016, Martin Ginis et al. 2016). There seems

to be a communication gap caused by uncertainty about who should be connecting children

and families with extracurricular physical activity organizations. A solution from this

example is the parent suggesting that the school should be more helpful in linking her child to

appropriate activities. Marie lives in a town which is about a 40-minute drive away from a

larger community; this distance may be another reasoning for not having access to

information. Transportation for youth with disabilities may be seen as hidden parental labour

that is necessary to have access to their wider communities (Goodwin and Ebert 2018), and

transportation should be recognized as a potential barrier (Martin 2013). However, in Marie's

situation, her mother is willing to drive her places to have her involved, the real issue is lack

of communication and information on the activities themselves, not the physical distance.

There is a clear impact on experience driven by rural spaces, class and disability.

Connections parents made with other parents of children with disabilities developed

social networks. Social capital for parents of children with disabilities also helped in other

ways, as seen through comments made by parents during observations:

> *I only found out about funding for speed skates from a parent from*
> *hockey. With all the activities Kirby does we wouldn't be able to*
> *afford expensive skates just to try it out.*
> Mother of Kirby, Fieldnote: December 12, 2018

Social capital amongst parents is seen in this study through a snowballing effect by

talking to other parents. Parents would support other parents in sharing information about

other physical activity organizations that they were involved in. This is consistent with

previous knowledge that the cost of equipment for extracurricular physical activities has been

a barrier to participation in Canada for children with disabilities (Statistics Canada 2006b). In

previous studies such as the CAPE (Children's Assessment of Participation and Enjoyment) a criticism was that there was a lack of a full understanding of the decision process between children and parents used in deciding upon which extracurricular activities the children participated in (Anaby et al. 2012). The thesis, in part, addresses this gap in knowledge. The following section discusses further access barriers for children with disabilities in extracurricular physical activities.

4.2.2 Access

Children with disabilities and their families may run into difficulties achieving access to extracurricular physical activities. Although there may be options for children with disabilities to participate in these programs, they are still often absent due to social, physical, architectural and attitudinal barriers (Darrah et al. 2015, Kehn and Kroll 2009, Rimmer 2005). Structural barriers have been well recorded throughout the literature, such as needing exercise equipment, membership fees, inaccessible facilities, program procedures and policies, limited resources, undertrained staff, and information barriers (French and Hainsworth 2001, Martin 2013, Mulligan et al. 2012). These barriers are witnessed within this study, as some of the barriers experienced by the participants.

> *It used to be like I actually wanted Moose in horseback riding when he was much, much younger. But the only reason why I didn't is because you'd have to still pay for lessons, even if they couldn't come, okay and stuff and he would get sick. All the time in winter is never a good thing for him, so now we don't come in the winter. Usually, we get lucky and someone takes the spot for the winter or we'd have to pay.*
> Mother of Moose, Interview: June 14, 2019

Moose comes from a lower-income family making the idea of paying for something that they could not attend, not a viable option. Participation in supervised activities by children with disabilities from lower-income families ranked the lowest amongst children with disabilities (Mâsse et al. 2012). Canadian children from low income families are less

likely to be physically active (Craig et al. 2010), and 2.5 times less likely than a middle-class family to be signed up for an organized physical activity (Carson et al. 2010). Although there is a tax credit to help lower-income families with these costs, families must have the initial upfront funds to pay for their child's participation in physical activities (Spence et al. 2012); the tax credit is only available through their tax filings after the fees were incurred. This leaves children of lower-income families with the likelihood of being physically inactive (Boyce et al. 2006), supporting Carson et al (2010) findings that 63% of lower-income families spent $0 on physical activity registration (Carson et al. 2010). Moose's family received a scholarship from the extracurricular physical activity organization, so that he could participate in horseback riding, otherwise this opportunity would not be possible. Although Moose was on a scholarship, he was required to pay for his lesson time. In the winter, even though medically it would not be advised for him to ride, he participated in the program for fear of losing his opportunity. Additionally, should a lesson be missed, there was no opportunity to make up the time and the fee was non-refundable.

Although a few participants in this study had difficulties with financing extracurricular physical activities, there were participants who had better access to funding:

> *We've never really had trouble receiving funding, it has not been an issue. With the Autism community I guess I had to look for funding in the beginning, but it was straight forward and all his programs are paid for. I pay for the extras like sweatshirts and transportation but the cost of the programs are covered.*
> Mother of Kirby, Fieldnote: November 12, 2018

Cost has been a barrier for children with disabilities in this study and in other studies (examples; Bedini and Thomas 2012, Geoffery et al. 2016). In the example above, the parent sought out funding in the beginning of participation for her son. However, even when parents do seek out funding, the funding is not always available:

> *Ben doesn't fit into a category really, I can't get funding from the big ones like Autism, or Down Syndrome and he doesn't qualify for Special Olympics. It's really sad actually, I know he benefits from*

activities and they're difficult to find in the first place but then when
I can't afford it, I feel I've let him down and it's not his fault.
Mother of Ben, Fieldnote: October 7, 2018

This example suggests that if Ben was diagnosed with a specific impairment, he would be able to access different funding. In his case, funding was provided by parents for participation. Ben horseback rides, and when asked about the scholarship and if he qualified his mother responded saying "no it's very limited, only 10 children a year and we both work so we're just over the qualifying income" (Mother of Ben, October 7, 2018). Inclusion and participation are discussed in Chapters Five and Six of this thesis but they cannot be answered without knowledge of how children with disabilities access the activities. As seen in the Inclusion Spectrum Model (Misener 2014) discussed in Chapter Two, there are only labels for the activities such as: fully integrated, modified, parallel and adapted activity . There is a need for a wider understanding of inclusion, because as shown in the example, Ben would participate in more activities, but he is unable to have those opportunities due to a lack of funding opportunities. Ben was also asked about his participation in activities and his response can be shown through the example:

I asked Ben what activities he likes to do. He went into his bag and
brought me a toy horse. I asked, 'you like to ride horses?' and he
nodded yes. His mom said, 'I'm sure he'd ride everyday, if he could'
and his face lit up and nodded yes excitedly.
Fieldnote: May 7, 2019

There is no opportunity for Ben to ride more at the current horseback riding facility, as they only offer sessions once a week to participants. Ben also swims and when asked about funding for that his mother said: "it's a very reasonable price in comparison to other activities, so we're able to pay for that without funding" (Mother of Ben, Fieldnote November 9, 2018). Although Ben would ideally participate in horseback riding more, he is unable to do so due to the program, and funding constraints.

The knowledge of these constraints was also perhaps missed in the CAPE (King et al. 2014a) as the study understood times per week of activity but did not comment on why the participation was not more or less. However, understanding the interplay of choices children with disabilities have adds to their participation lived experiences. The thesis found that parents play a key role in the activities their children participate in including the previously discussed funding and information gathering. The thesis will now discuss further ways in which parents play a role in deciding the activities their children participate in.

4.2.3 Parents' Choice?

Looking at the extracurricular physical activities undertaken offers good insights into where parents have options. Within the school system, extensive research has been conducted related to physical activity and children with disabilities where parents have less of a say, because the school is responsible for physical activities (examples; Asbjørnslett and Bekken 2016, Coates and Vickerman 2008, Fitzgerald and Stride 2012, Harvey et al. 2014, James et al. 2011, Wilhelmsen and Sørensen 2017). Research that has been conducted about extracurricular physical activities (examples; King et al. 2006, King et al. 2004, King et al. 2009, Longo et al. 2012, Raghavendra et al. 2011, Ullenhag et al. 2012a, Wuang and Chwen-Yng 2012), has used surveys which have not looked into parents' choice. One of the gaps this research study closes is the process of parents' choice for physical activity for their children with disability. In this current research study, the physical activity is chosen for the participants with disabilities by their parents in all cases.

The age of participant group is between 12 and 16 years; this means for the most part that their parents had decided which activities their child enjoyed and continued to register for these activities. The age group was originally decided upon based on the assumption that participants in an older age group would have more autonomy in selecting their activities.

I wanted to work with an older age group as I had assumed that older children would have picked their extracurricular physical activities. I am surprised at how wrong this assumption was and when talking to parents and children this month, it is very much the parents' choice which activities their children do.
Reflective Notes: October 2018

The parents for the most part would have seen fun and enjoyment from the participants which indicated the child wanted to be in and to continue in those activities. When verbal children within this study were asked if they enjoyed their extracurricular physical activities, most responded positively. There is difficulty in judging if non-verbal participants enjoy their extracurricular physical activities due to their inability to communicate verbally, therefore body language or noises was used as an indicator. An example was participant Moose who cried throughout most of his horseback riding every week. His volunteers would make comments such as "I don't like forcing him to ride" or "he really wants to come off the horse", as he would be throwing his body weight to try and come off the horse.

I'm feeling very uncomfortable watching this. He hasn't stopped crying today while on his horse. He looks like he is frantically trying to get off his horse, grabbing at his volunteers trying to pull himself off. I'm not sure if it is appropriate for me to say something. I guess his mother might say something if he is really in that much pain. It's difficult, because I know children should have the choice to not participate, but is this really my place? I had to ask his mother if he was ok. She barely looked up from her phone and said 'yes, he's fine, just cheer him on and it'll be ok, he needs this physical activity, it's the only thing he does'.
Fieldnote: December 15, 2018

Parents of children with disabilities when discussing non-physical activities have said similar things such as it is "really the only choice" (Teachman 2016, p.132). Moose does not participate in any other activity, because he is perceived as not being able to and his family can only afford one physical activity. Moose's mother is suggesting similar to other studies that say children with disabilities may not be able to independently take advantage of physical activities that are unstructured (Martin and Choi 2009), additionally she has

suggested that emotional support and encouragement from herself and others would be of help (Cox et al. 2011, Zhao and Settles 2014). She is providing transportation for him, so she does not want his session to run short (McManus et al. 2006). She is seemingly ignoring her son's cries because there is a perception that physical activity is important, and for her to get some time off. Potential safety concerns surrounding children with disabilities participating in physical activities (Bloemen et al. 2015), have taken a backseat with this mother, as she has stated "I've read online that horseback riding will help Moose walk". However, his coach contradicts this notion in saying that "I don't understand what she (Moose's mother) wants from me, I'm not a therapist, I can't just make him walk one day" (November 7, 2018). Literature shows that mutual support from parents and service providers is important to enhance the experience (Bergum and Dossetor 2005). However, in this case, the coach and mother rarely communicate, there is seemingly no partnership between Moose and coach or coach and mother yet working together may enhance his participation. With this distance between the coach and parent, there is a limitation to the participation experience that can be offered while opening the conversation may bring reflectiveness on both sides (Goodwin and Ebert 2018). In previous studies about inclusive community programs, it was found that parents may be grateful for having access to programs even when the programs may be inadequately providing for their children's' needs (Mitchell and Snyder 2015). This may be the case, as the mother has also stated 'this is my only time off during the week' and she has a full-time career, so this half-hour time slot may be the only time she gets to shut off. Although parents may choose to have their child participate in an organization's physical activity that does not mean that they will be automatically included. The thesis will now discuss organizations' choice of participation in the following section.

4.2.4 Organizations Choose

The participant requirements for this study were that they already participate in an extracurricular physical activity. Participants had managed to navigate the hurdles of being accepted by organizations into programs; however, it is important to note that organizations do exclude children with disabilities. Two examples from my study are hockey where you had to have an intellectual disability and horseback riding that required an impairment from a long list of impairment types before they were willing to enroll participants in their program, such as spina bifida, amputation and Downs Syndrome to name a few. Consistent with literature that suggests compared to typically developing children, it has been found that children with disabilities are excluded more by service providers causing parents to search for similar opportunities for their children with disabilities (Goodley and Runswick-Cole 2011b, Hodge and Runswick-Cole 2013). When parents entered community recreational sport and physical activity settings, they face the stigma of othering (Green 2007).

Families of children with disabilities experience discrimination, prejudice, and exclusion (Goodley 2011a, Morris 2001a, Schillmeier 2008), which was also found by participants in this study when accessing physical activity organizations due to their inclusion practices.

> *Mother of Ben: It just is not possible for Ben to participate in activities with children without disabilities. We've tried when he was younger but it's always a disaster. Sometimes they sign him up and then they meet him and tell me they can't support him, so I take him home and he's always so upset because we've talked about the activity all week.*
> *Researcher: What about activities for children with disabilities?*
> *Mother of Ben: Yeah, um it's difficult too because some organizations say they are just for children with disabilities but we've had bad experiences really and some people just aren't able to.*
> *Researcher: What do you mean not able to?*
> *Mother of Ben: Well, it's not always their fault but they'll say all the right things but then they just can't take him. Sometimes the coaches are teenagers too and I mean some are good but he has really complex needs and organizations don't recognize it and then when he isn't getting the support he acts out and there's so many kids on the waitlist that they just push him out.*

Mother of Ben, Informal Conversation during Fieldwork: December 12, 2018

The example shows that exclusion can happen from organizations during the process of becoming involved in the activity. The exclusion during this stage was common amongst non-verbal participants:

> *It's disappointing really, Mickey doesn't participate in a lot because he's often told no at the start. Then it's like false hope because he gets a spot and then is not helped or the organizations don't listen to us (parents) and it doesn't go well and then I get told another person would benefit more from the activity and we're out searching for more activities, it's really upsetting.*
> Mother of Mickey, Informal Conversation: January 20, 2019

The experiences shown here are important to recognize, as literature shows that service providers do exclude children with disabilities (Goodley and Runswick-Cole 2011b, Hodge and Runswick-Cole 2013). However, it is rare to understand what that means to the experience of extracurricular physical activities. It is known that people with disabilities are excluded in everyday life (Curran and Runswick-Cole 2013), however, the examples above are from organizations that claim to be suited to people with disabilities. Exclusion was shown not only when applying to activities, but also after acceptance there was still opportunity for exclusion. This created a reaction from parents and children:

> *Chloe: I don't really like trying anything new, I'm happy with horseback riding because I know what's going on but like I hate doing anything new because um like this one time I went on this youth walking thing and I know I can't walk fast but like everyone left me behind and then they said I couldn't go again and I'd just rather not be sad.*
> Fieldnote: March 12, 2019

Another example shows a parent's reaction:

> *Mickey's mom: We aren't planning on trying any new activities, I think at his age now we've tried most in the area and why would I want him to go through it all. Sometimes he likes the activity for the one or two times he's allowed but then I have to tell him he can't go; I just can't deal with that anymore.*
> Parent interview: July 7, 2019

The process of multiple exclusion has been understood in connection to multiple identities (Moodley and Graham 2015). However, the exclusion process here can be shown through an identity of disability exclusion that can be experienced in multiple ways due to physical disability, intellectual or communication preferences. When organizations choose to exclude children with disabilities, the parents and children have little to no choice but to accept the status quo. Agency is difficult to observe as often children are left out of these exclusion conversations and there is often little to no availability of choices to act upon which is shown as 'no agency' on the Continuum of Agency (Bell et al. 2007). It has been suggested that there is limited opportunity for children with disabilities to be heard (Thackray 2018) and these examples have shown this due to children not even being a part of the communication process at the introduction to new activities. The thesis is extending the understanding of the extracurricular physical activity exclusion process, as most research is focused on physical education in schools (Examples, Bloom et al. 2009, Coates and Vickerman 2010, Fitzgerald et al. 2003, Fitzgerald and Stride 2012, Goodwin 2009, Kim 2009, Reuker et al. 2016, Wang 2019, Wilhelmsen and Sørensen 2017). In school, children are already present; however, in extracurricular activities the experience is different, because organizations can exclude on their terms with sometimes inconsistent application. The following section will discuss an aspect of organizations inclusion and exclusion choices where coaches play a role in the process.

4.2.5 Coaches Choose

Coaches are fundamental to an extracurricular physical activity program, coaches need to have an understanding of the physical activity and an understanding of impairment to make alterations and adaptions to rules and tasks (Bantjes et al. 2015). Previously identified, there is a gap in the literature regarding youth with disabilities participating in extracurricular

physical activities and their coaches (Spencer-Cavaliere et al. 2017). This study closes the gap, as the researcher was privy to the interactions through lived experience over an eleven-month study.

The analysis showed various ways in which coaches create opportunities and constraints for participation as shown in the example below.

> *I keep looking at my watch, over and over. I actually feel so unprofessional with how much I am looking at my watch. Both my participants could potentially see me doing this. I'm not bored, I'm just shocked. I'm shocked that one of my participants hasn't been spoken to in 25 minutes. There's only 5 minutes left. My other participant has been talked to the entire time, there has been no moment of dead air. Magic got to make the lesson plan with the coach, get on her horse first, got to choose all the stretches and activities and Charlie hasn't been spoken to once.*
> Fieldnote: October 12, 2018

The example is one excerpt of fieldnotes from Charlie participating in horseback riding that paints a consistent pattern. The pattern with Charlie in horseback riding is also experienced by Mickey and Moose who all happen to be non-verbal participants. Although these participants are non-verbal, and adults may not understand them, they have the right to be able to communicate in ways that they prefer and to be heard by adults (Boggis 2018a). In addition, non-verbal children's feelings and wishes would need to be taken into account through a dialogue with mutual respect (Fitzgerald et al. 2010). People working with children with disabilities need to be skilled in all forms of communication and be skilled in assessment and observation (Hunt 2018). The example shows how structure and hierarchical constraints can block choice and participation (Baraldi and Cockburn 2018), in this case for Mickey by his coach. If the coaches working with these participants are highly skilled in communication, they are choosing not to use their skills in favour of focusing on their verbal participants.

To contrast the above, there is a different gap in literature about understanding the experience of children with disabilities that get pushed too hard in extracurricular physical

activities. Throughout the duration of my longitudinal study, one of my participants, Aspyn quit horseback riding, her reason being:

> *I was having a lot of fun horseback riding when it was just for fun. I kept telling my coach it was just for fun. She just kept moving me to harder groups and wanted me to ride with people in their 20s, I'm 12. I didn't want to compete but she like wouldn't even let me choose. It was actually really awkward, and I just couldn't be there anymore I would rather do anything else.*
> Aspyn, Interview: March 12, 2019

The lack of listening to children with disabilities in extracurricular physical activities will be discussed further in the following sections. In the example above, Aspyn made it clear that she did not want to be pushed and wanted to have fun, but the coach continued to push her which led to her not participating in that physical activity again. Service providers in other studies have also lost sight of the concept of fun and instead have been focused on participation in the activity to build skills, not to have a sense of fun, control, choice and belonging (Gibson et al. 2014). Although Article 12 in the UNCRC does not guarantee that the wishes of the child will be the decisive factor, Aspyn did not understand why she kept being pushed. Her extracurricular time was being changed into something she did not want, and even with her expressing herself, her voice was not considered, and the adult wishes from the coach became paramount. Belonging for Aspyn meant that she wanted to participate alongside friends and not participants that were much older than her (Coates and Vickerman 2008, Li and Chen 2012). Aspyn was very good at her sport, and comfortable in her abilities; this competency could have been fun for her and advancing could mean threatening that degree of achievement (Gibson et al. 2014). However, it is clear from this example of Aspyn quitting that although achievement may have advanced, coaches should not and in this case could not force a child into doing something they did not want to do. Participating with her teammates brought Aspyn joy, and the theme of teammates will be discussed next.

4.2.6 Teammates and Participants Choose

Teammates and participants choose how to interact with each other with the result being their participation and inclusion experience; the following section will discuss in further detail these choices. Inclusion of adolescents with disability into physical activities results in their peers having an important role to play in ensuring inclusion (Anderson 2009). Children with disabilities are more willing to participate in activities with their friends (Coates and Vickerman 2008, Li and Chen 2012). Although organizations group children together for extracurricular physical activities, it is still important to note how children with disabilities choose to interact with one another. The example below is Rosie discussing her relationship with her horseback riding partners.

> *Like no, no offense to Chelsea. But like I want a person who like understands me and who I can talk to during my lesson and Chelsea couldn't really do that, which I understand but I and Chelsea I felt like wasn't on the same like wavelength as me and I feel like Sydney is and Sydney actually inspired me because she rides without like any instructor and like any like later in any like side walkers and that's what I want to do.*
> Rosie, Interview: August 22, 2019

The first teammate Rosie talks about is a non-verbal participant. The coaches had made little to no effort in helping Rosie communicate with Chelsea. When Rosie was switched to a lesson with Sydney, coaches encouraged them to tack up together, and they would play games together on horseback. Coaches may have not wanted to take the time to help a verbal (Rosie) and nonverbal (Chelsea) participant communicate together, or they simply did not know how to do this. In education literature, there is an understanding that children with and without disabilities are treated differently and although can be present in an environment are not always fully apart of it (Weber and Bennett 2004). The example is in an environment for people with disabilities, however, with a similar issue of prioritizing verbal children and putting more emphasis on their experience. People with disability are not a

homogenous group; they do recognize and react to different levels of disability. Rosie also does not try to communicate with Chelsea and prefers a verbal partner to horseback ride with. However, she also states that she likes to ride with someone who is more skilled than herself to push her to be a better horseback rider. Rosie has made a choice to be with a teammate who is verbal, and the following sections will look at children's choices within the extracurricular physical activity environments.

The thesis includes activities where children with disabilities participate alongside typically developing peers. During these activities, there is sometimes a difference of how participant teammates choose to interact. Two examples are shown below.

> *It doesn't really matter to me what Spyro is, she's really nice to me*
> *and we get along.*
> Teammate of Spyro, fieldnote: January 20, 2019

In contrast:

> *Marie has her group of friends at lawn bowling that also identify as*
> *having a disability. All the other groups choose not to interact with*
> *them, and sometimes mean comments and jokes are made at their*
> *expense.*
> Reflective notes: July 2019

When Marie is asked about her experience at lawn bowling, the above example does not seem to impact her experience as she states:

> *I just like being with my friends I don't focus on what others are*
> *doing, I'm just really happy to get to chat and hang out.*
> Fieldnote: August 4, 2019

In the above examples, teammates are making choices about how they interact with the participants in the study. Segregated activities for children with disabilities have been cited to provide a space where interactions with other children are safe and comfortable (Goodwin et al. 2004). The examples support this understanding and suggest that interactions can be comfortable and safe in integrated activities. Spyro is seen by peers as not interfering with the activity which has been understood to influence how children perceive children with

disabilities which may increase inclusive practices (Diamond and Tu 2009). Additionally, observations suggest perhaps an uncomfortable experience; however, when asking the participant themselves, there is perhaps a different explanation as seen by Marie where her focus is placed on her friends.

The section of choice so far has discussed various aspects of how adults and children impact the experience of choice in extracurricular activities. The last subsection will discuss the choice of activity as a whole and where children with disabilities views are implemented in the decisions.

4.2.7 Choice of the Activity

According to the UNCRC, children have the right to participate in play and recreational activities and have the right to express their views in all aspects of their lives (1989). An important aspect of this research project is to look at the degree of adhering to those principles. In research, we see the importance of having individuals choose their physical activity rather than the decision being made by adults (Kiuppis 2018). A researcher even goes as far to say the goal in sport should be individuals being able to make the decision on how they want to participate and with whom (Misener 2014).

In all the parent interviews conducted, there was a question posed about 'who made the decision on [participant's name] participating in [participant's activity]?'. Common answers looked like:

> *We did (reference to both parents being involved in the decision), we heard many of the benefits. Just you know, they call it therapeutic horseback riding for a reason I think and we weren't sure if Mickey well his aunt loves animals because I feel he had a fear of large animals when he was younger, but we didn't even know if this will go well at all, but we heard from other families that their kids have loved it.*
> Mickey's Parents Interview: August 30, 2019

To get a full and accurate picture of this choice, I also asked verbal children a similar question. There is consistency within the interviews from verbal children:

> *Research: Who made the decision about which activities you do?*
> *Rosie: My parents.*
> *Researcher: How do you feel about the choices they made?*
> *Rosie: Hmmm, I obviously love horseback riding now, but I guess it would've been nice to be asked.*
> *Researcher: What about asking now?*
> *Rosie: Yeah, I never really thought about that. I guess it would be nice, because I honestly want to ride every day of the week or just working in a barn really.*
> Fieldnote: November 12, 2018

Through both excerpts, and through many others of similar nature, parents make the decisions on which physical activities their children with disabilities participate in. 'Participation' through what is being described as children just doing what they are told, however, as seen through actions of crying there is resistance taking place. Sheir's (2001) participation model begins with asking the question "are you ready to listen to children?" (Sheir 2001, p.107). However, through the actions of just signing children up for physical activities, parents do not even fall onto the participation chart. Sheir is clear on his participation chart of where the UNCRC participation minimum is; parents would not be adhering to the UNCRC Article 12. Based on the Hart (1992) Ladder of Participation, these decisions would represent the bottom rung of the ladder which is classified as non-participation when decisions are adult-led and children are directed to do the activity, without understanding the purpose (Hart 1992). The model categorizes the method to be manipulation, although Hart cautioned about using the ladder as a measuring stick (Hart 1992, p.11), as the label may not take into account all the factors involved. Franklin's work suggests that the bottom rungs of Hart's ladder should be changed to "adults rule, and adults rule kindly" (Franklin 1997, p.53). However, the inclusion of the parental perspective has been found to undermine the decision-making abilities of people with disabilities (Carey 2010). It is important to note that in addition to parents not including children and young

people in their decision-making processes, parents were unaware of the UNCRC. Starting with non-adherence to the UNCRC, the following sections will discuss choice within the physical activities by children with disabilities in this study.

4.2.9 Section Summary

The current section of the chapter began to discuss the topic of choice in relation to children with disabilities participation in extracurricular physical activities. The subsections discussed how information, access, parents, organizations and teammates influence the various choice experiences. The impact of choice has on the environment in which participants experience their participation is essential in understanding how the structures and interactions are forming.

The section answered in part the research questions as the aspect of choice is directly influencing lived experience of participation and inclusion. The section focused on the role of choices made at the beginning of participation and inclusion experiences when accessing and entering extracurricular physical activities.

The section suggested that there is perhaps power over children's experiences by choices that organizations, peers, and parents make for children with disabilities to access participation opportunities. Parents and organizations face difficulties in being able to offer extracurricular activities for all children and are negotiating access for individual children. There appears to be a lack of opportunities for children with disabilities which leaves organization in a powerful position to pick and choose who can access their space.

In the final subsections of the section, participant's voice and experience is coming to the forefront to demonstrate their perspective of choice of activity, and how the interactions play a role on their experience. There are tensions that arise in the experience of choice and the various relationships children with disabilities have with people and structures.

4.3 Lived Experience of Choice

The following section will start to discuss the lived experience of choice in extracurricular physical activity environments to understanding the beginning of choice as a lived experienced at a base level before moving further into the analysis of participation and inclusion in further chapters.

4.3.1 Medical Model Experience of Extracurricular Physical Activity

In the previous sections of the chapter, it is understood that parents choose extracurricular physical activities, and children with disabilities attended those activities. King and colleagues (2004) researched participation in extracurricular physical activities and one thing they noted was attendance documentation, but they failed to evaluate why there is or is not attendance. In this current thesis, children with disabilities were always in attendance, although they did miss some activities due to illness, family commitments, weather, etc.

Although children with disabilities did not pick their activities, children with disabilities were at the activities and went through the motions of the extracurricular physical activity. The extracurricular physical activity environments seemingly took a medical model stance towards disability (Oliver 1990), as a lot of actions towards children with disabilities seemed to look like the individual was deficient and needing to be 'repaired' (Ayling 2018). There are many examples that place a focus on limitations of children with disabilities, because they see the particular limitation as a disability (Imrie 2004, p.288). This was happening instead of looking at the "lived experiences and desires" from the perspective of the children with disabilities (Goble 2010, p.57).

> *Charlie is looking around the arena, inspecting where he is riding.*
> *Sometimes when a bird dives down near him he starts to chuckle.*
> *The coach starts to notice that he is doing his own thing, steering*

when he wants to and looking around at his surroundings. She snaps
at him and tells him sternly 'look where you are going Charlie' and
she sticks with him, every time he does something that deviates from
what he is supposed to be doing she corrects him in a stern voice
Fieldnote: May 17, 2019

The example shows a continuation of the medical model which showcases children with disabilities as difficult to communicate with, unknowing, dependent, and vulnerable (Boggis 2018c). Throughout his whole horseback riding session, Charlie is not provided an opportunity to communicate what he would like to do. He is consistently told exactly what to do. Although he likes noises, and likes to be curious, he is not afforded the opportunity to perhaps, as the skill development is taking priority for the coach. He is needing to be 'repaired' (Ayling 2018), because he is not fitting the norm of what a 'horseback rider' should look like. Instead of adapting the program to look more like something Charlie would want to do, the only agenda for this activity is from the coach, without adaptation to Charlie's needs.

Choice of extracurricular physical activities for children with disabilities often defaults to the choice of the service providers or parents. As seen through a coach's comment, parents drive decisions about activity.

Parents pay for a service so we listen to what they want the most,
and then sometimes we can work towards different goals they have
and sometimes not.
Fieldnote: December 2, 2018

Further, when asked about feedback from children with disabilities she continued by stating:

We don't really ask children, there's no system for that. Sometimes
children can't communicate, and as coaches we're often the ones
who know the most about what they should be working on.
Fieldnote: December 2, 2018

It has been previously understood that the perspectives of children with disabilities are excluded in favour of professional and parent voices (Berg et al. 2015). Ignoring

individual perspectives and the lived experience of impairment has been a common criticism of utilizing the medical model solely to understand disability (Owens 2015). Instead of viewing extracurricular activities as a fun after school program, they are often viewed as a form of further treatment that focuses on a defect to be changed. When impairment is the focus, the individual's wants and desires end up in the background. The view of children with disabilities is othering them from the norm (Smith and Perrier 2014a,b). To contrast, value has also been placed on children with disabilities who have fit into the norm.

> *Kirby is an excellent athlete, he could compete against kids without*
> *disabilities and he could probably win.*
> Coach, Fieldnote: March 20, 2019

Although through the medical model understanding, people may need fixing as they are deviating from the norm (Smith and Perrier 2014a,b), the example shows that some people with disabilities are perhaps accepted into an environment, if they reach the accepted level of 'normal'. Kirby is often afforded opportunities to engage and with various choices about his extracurricular physical activity participation, however children that communicated non-verbally were rarely afford opportunities to engage with service providers. The medical model understanding of experience of impairment is still relevant to understand, it adds to understanding disability comprehensively (Oliver 1983). Through the social model of disability, ideally the emphasis to change is on the environment rather than the individual with an impairment (Oliver 2013), however, that experience is not always applicable in practice. To further the understanding of choice from a similar interpretation of the medical model of disability, tokenistic experience will be discussed in the next subsection.

4.3.2 Tokenistic

A danger that emerges with participation is potential tokenism (Fleming 2013). Tokenistic behaviours have been seen where children are perceived as vulnerable and

passive, often where adults still work with child developmental models (Punch 2016). Hart

defines tokenism as:

> "Tokenism is used here to describe those instances in which children
> are apparently given a voice, but in fact have little or no choice
> about the subject or the style of communicating it, and little or no
> opportunity to formulate their own opinions."
> (Hart 1992, p.9)

Throughout this research project, a theme of tokenistic participation in extracurricular

physical activity environments emerged. There were many examples of tokenistic choices

taking place within the research. Below is an excerpt from fieldnotes that clearly shows

tokenistic choices at play.

> *From the second Ben walked through the doors today, he has been*
> *told what to do. He was told to put on his helmet, where to put his*
> *legs, where to put his hands, even where to look. I thought he finally*
> *had an opportunity to participate when his coach asked him 'would*
> *you like to steer this time or play a game' although it was only 2*
> *limited options, I was excited for him. The coach pulled out a game*
> *to show him when she asked 'or play a game' his face lit up, and*
> *although he couldn't use his words, it was clear by the massive smile*
> *on his face that was his answer. The coach then said after this*
> *response 'actually no, you have to steer before we do anything you*
> *want to do'. He immediately slouched back down and looked*
> *defeated. At the end of the lesson when the coach brought out the*
> *game again, he didn't even flinch, and chose not to play the game.*
> Fieldnote: October 14, 2018

This tokenistic participation is problematic; it left Ben unsatisfied, frustrated and

disappointed. Missed expectations can make nonparticipation more problematic than a

missed invitation to participate (Gal 2015). This is a regular occurrence with Ben in each

lesson, it is also a regular occurrence that he loses his vibrance and effort to do the things that

he would like to participate in during the lesson. In this example, it also left Ben with

'participation fatigue' where when he was consulted, there was no change made (Cornwall

2008, p.280), and although it just happened once in this example, his inability to make any

choices throughout horseback riding left him defeated. Here he excluded himself to avoid

disappointment and wasting his time again (Cornwall 2008). Once Ben, in the coach's

words, 'tests the boundaries', Ben stops and just complies with what the coach is telling him, whilst looking defeated and not enjoying himself. Additionally, this example shows that the extracurricular physical activity environment for Ben is not adhering to the UNCRC. Ben is not being involved in decisions that affect his life, and when his voice is not heard he has no explanation as to why his voice was not considered. Although Ben is non-verbal, he can comprehend what people are saying with ease, one knows he is comprehending by his non-verbal communication of nodding for yes and slouching with a sad face for no.

During fieldnotes there were times that the coach would ask children with disabilities who communicated verbally questions regarding their participation as shown below.

What stretch would you like to do today first?
Fieldnote: September 20, 2018

Do you think you could drop down to one side walker (support)?
Fieldnote: March 10, 2019

The questions that were frequently asked, such as what stretch a child with disability would like to do, often occurred at the start of the session. However, opportunities for continuous input would stop there. Additionally, stretches were often picked from previous stretches with limited opportunity to be creative. The second example, although engaging with decisions on support preferences, was suggested as there was an absence of volunteer support for that session. Although children with disabilities can participate when coaches ask them questions, there is often hierarchical constraints that can restrict the outcomes. An example of encountering a constraint is shown below as a response to picking a stretch.

Magic: I don't want to do any stretches they're boring.
Coach: I'll pick them then, first we'll take our feet out of the stirrups
and roll our ankles.
[Magic does not do this]
Coach: Well Magic if you don't do the stretch that means you're not
listening and we won't play a game today.
Fieldnote: April 2, 2019

The example shows that Magic has little agency or choice as the coach is providing an environment of having to act a certain way (Robson et al. 2007). Agency and experience can be seen on a continuum depending on the different contexts (Robson et al. 2007). In the current example, an action that Magic takes or does not take will influence her experience. As a result of limiting opportunities for action in a restrictive setting, agency is being 'thinned' (Klocker 2007). The important link of choice to participation is an understanding of how coaches view children with disabilities as that directly impacts the opportunities coaches encourage children with disabilities to participate in. The previous sections show a medical understanding of children with disabilities. The result of this view of children with disabilities is that there is a process of agency and action (Valentine 2011), that is being negotiated through opportunities and constraints (Leonard 2016), and the starting point of negotiation is formed from a restrictive environment. The following subsection will further explore choice and change opportunities in extracurricular physical activities.

4.3.3 Change and Choice in Activity

In the current chapter regarding discussion of choice of extracurricular physical activities, the specific activity has been considered mostly by parents choosing the activity. Within activity environments participants participated in an environment which included parents, volunteers and coaches. In most cases during the research study, children with disabilities and families just had to 'take what they could get'; however, in one case, there was room for a decision.

> *Coach: Hey Rosie so I think we're going to need to switch your coach again (this is the third time in 2 months).*
> *Parent: Does she have to? Change really isn't good with her.*
> *Coach: Yes.*
> *Rosie: I don't like explaining myself to new people all the time.*
> *Coach: Ok well the change is happening next week.*
> *Rosie: I'm only changing if Katie (Researcher) gets to come with me.*
> *Coach: Oh, ok. Katie can you switch times?*

Researcher: I can.
Fieldnote: November 22, 2018

In the example, Rosie had an influence on a decision. Although she was not initially asked for her opinion, she offered a compromise which was heard. She was unable to choose her extracurricular physical activity, but she had an influence on who was around her for her activity. She was able to participate in a respected way by having an opportunity to shape her participation; she generated a small change and had access to information about the change and was part of the process (Graham and Fitzgerald 2010). Although this was not a structured participation opportunity you can see how participation forms in an informal setting where participation was interesting, meaningful, and relevant to Rosie (Thomas 2012b). Unfortunately, decisions that children make are often shaped by adults (Hill 2005), and in this case, although Rosie exerted her voice, there was little opportunity to make an autonomous decision. Her decision was acted upon and her voice was present within the decision (Boyden and Ennew 1997, Tisdall and Davis 2004).

To contrast the above example, more frequently the experience of choice of who is around the children with disabilities in extracurricular activities is as shown below.

> *Because they're often volunteers people can switch all the time, last year Ben probably worked with 25 different volunteers. It's really unsettling for him especially because he doesn't speak, it takes a while for people to get comfortable around him.*
> Mother of Ben, Fieldnote: February 7, 2019

Additionally, from reflective notes:

> *Reflecting on volunteers it seems that it is difficult to recruit volunteers during horseback riding lessons. Especially ones that are during afternoon hours. Many participants have new volunteer(s) weekly. When asking coaches and staff how they are recruited for individuals, there is no real system and no matching process. It is a scramble before lessons, staff often are calling any volunteer to fill the positions in the hours leading up to the lesson. Additionally, this results in not allowing time for informing parents or participants who they will be working with.*
> Reflective notes: October 2018

Negotiation of relationships between children with disabilities and volunteers becomes more basic. This is important to note as lived experience and participation requires the unpacking of structures and relationships (Davis and Smith 2012). The result of continuously changing relationships and expectations has a role for participants in the lived experience of extracurricular physical activities. The changing of volunteers is not desired by the organization; however, it is a reality. In Rosie's example there is an understanding shared with the organization from the participant themselves that the changing of volunteers frequently is having a negative effect on her participation. Continuing the discussion of relationships with coaches and volunteers, the following subsection will discuss in further detail more specifically the role that impairment has on the lived experience of choice.

4.3.4 Too Disabled

Children with disabilities and their families are more likely to experience stigma and social isolation (Akrami et al. 2006). It has been argued that because of social stigma and lack of accommodation created by the wider society, negative aspects describing disability arise (Olkin 1999). In addition, children and young people with disabilities are subject to a stigma that their bodily difference may be interpreted as a moral deficit (Goffman 1963). Sharpiro states that "built social stereotypes, create artificial limitations and contribute to discrimination" (Shapiro 1993, p.30). Although, discrimination towards people with disabilities is not always as overt as above, there is a clear example in this research project.

> *Coach of Moose: I don't understand why Moose is in your study,*
> *you can be there, but it really is pointless.*
> *Researcher: Oh, why is that?*
> *Coach of Moose: I thought you were looking at participation?*
> *Researcher: I am.*
> *Coach of Moose: You know he doesn't participate right? He's too*
> *disabled to do anything really.*
> Fieldnote: November 20, 2018

The coach's negative attitudes towards Moose and her stereotype of him shine through time and time again, as the research continued. The coach sees Moose as lacking status and not having a stake in his surrounding lifeworld (Wyness et al. 2004). Moose is non-verbal; it has been argued that non-verbal children with disabilities speak in ways others might not understand, but they should still have the right to be heard (Boggis 2018c). This marginalization of his non-verbal voice has resulted from the presumption of a lack of competence and maturity (Richards et al. 2015). However, it is difficult for Moose, like other non-verbal children, to advocate for himself, because he has been taught to respond to prompts, not initiating conversations himself (Potter and Whittaker 2011). This leaves Moose in a difficult position of having to comply with the world around him. While the coach does this, she is positioning Moose in her head as having a 'fixed-underachievement' which results in seeing him as a failure and taking the child's self-worth (Ayling 2018). She never pushes Moose to do more, and even describes his activity as 'I just plop him on the horse and hope he stays on' (Fieldnote: June 2019). She does not have any real expectations for Moose and just presumes a lack of competence from him (Richards et al. 2015) negatively affecting his participation. His participation is unchanging and stagnant, because there is no change in sight or positive attitudes surrounding him, no one is advocating for more participation from Moose. During Moose's participation in this study, there was no positive change to regard to him as an individual with a voice.

The understanding of attitudes towards participants in the study is vital in answering the research questions discussed in the following chapters. There is a direct relationship between attitudes of children with disabilities and their experience in extracurricular physical activities. Moose's experience is not an isolated example, another similar experiences can be seen below.

> *Mickey doesn't understand what's going on, I think his parents just*
> *like him coming here"*

Coach, Fieldnote: May 7, 2019

Coach to a volunteer explaining how to work alongside Charlie
"You really just need to remind him of everything, he is constantly
distracted and forgets everything."
Coach, Fieldnote: November 20, 2018

However, there are contrasting experiences:

Aspyn could ride (horseback ride) anywhere, she's so talented. I
pretty much just let her do whatever she wants.
Coach, Fieldnote: February 9, 2019

There is a gap of experience between participants who communicate verbally and those who communicate non-verbally. Non-verbal participants have been excluded from participation opportunities in favour of privileging of verbal participants (Boggis 2018c, Haw 2008). Although, in research it is known to not privilege verbal communication (Komulainen 2007), in practice during extracurricular physical activities there is a privileging. The approach to nonverbal participants is that their participation and success would not be able to reach that of someone who communicated verbally. Voice has been seen to evolve during a dialogue with adults (Graham and Fitzgerald 2010) however, when adults have been unwilling to engage in the process of communication, the perspectives go unacknowledged (Warming 2011). There is a need to adapt to various communication styles which is being missed. Adaptability is vital when working with children, the following subsection will expand on the discussion of adaptability.

4.3.5 Adaptability

Adaptability may be talked about in terms of how inclusive practices can adapt to the needs of children with disabilities (Halder and Argyropoulos 2019). Within this thesis, physical adaptations were almost second nature, different equipment was used, a lift or a ramp was added and extra support was given. However, when it came to emotional and social adaptations that is where a research theme emerged; it was seemingly more difficult for

coaches and organizations to adapt to. The excerpt below shows a coach not adapting to emotional needs of Charlie.

> *Before Charlie got on the horse today, he was crying. The coach is seemingly not acknowledging his feelings. She has not asked him what is wrong, and just keeps telling him what she wants him to do activity wise. She is simply ignoring what he is presenting.*
> Fieldnote: June 11, 2019

Charlie is experiencing a need for something that was not determined, because the coach did not take time to engage in a conversation, rather she simply just continued with the set lesson plan she had in mind. Here Charlie might be showing a stance through emotion (Clark and Richards 2017). It was easy for the coach to add the physical support of a leader to steer for him when he was crying; however, she was unsuccessful in being flexible in adapting to his emotional needs. When the coach was asked after the lesson about Charlie's crying, she stated "what am I supposed to do about it" (Fieldnote: June 11, 2019), and when asked what was wrong, she stated "he didn't tell me" (Fieldnote: June 11, 2019). This may be a case where the coach had not received adequate training to learn communication from nonverbal participants. There is a gap in opportunities to be heard (Thackray 2018).

Adaptability of programs for children with disabilities is important to understand in relation to the research questions discussing participation and inclusion. Inclusion practices that can be facilitated by coaches of extracurricular physical activities include adaptations (Spencer-Cavaliere et al. 2017) and some participants feel this is met.

> *Aspyn: My coach wears an FM microphone so I can hear what she's saying which is good because I don't miss instructions anymore.*
> *Aspyn's mom: She even asked her coach to wear it herself.*
> Fieldnote: February 7, 2019

In the example above, the coach made an adaptation to ensure Aspyn felt more comfortable participating in dance (Spencer-Cavaliere et al. 2017). During Aspyn's lesson the coach will also ask her periodically if the system is working to ensure that Aspyn can hear

everything. The coach is adhering to the social model of disability, as the coach is removing a barrier rather than Aspyn having to adapt to the environment. This has not always been the result for Aspyn, as elsewhere she has stated "some teachers won't wear it so I have to lip read" (Fieldnote: March 20, 2019). Social inclusion also explores the experience marginalized groups have in various contexts (Cobigo and Martin 2011), and although the adaptations are not made for Aspyn everywhere, there is an effort during her dance participation to ensure she has the opportunity to be included. Aspyn did ask her dance teacher to wear the FM system, and the conversation she had with the coach led to a positive change for her experience. The following subsection will further discuss conversations that happen in extracurricular activities for children with disabilities.

4.3.6 Conversation

Conversation is a key component to adhering to the UNCRC Article 12. The opportunity for conversation between adults and children is important, because a "dialogue means a mutual willingness to convince and be convinced to be changed, and to give away one's control over the decision" (Gal and Duramy 2015, p.7). Accessible and inclusive opportunities should be available for all people to have choice in their life and environments, although people with disabilities are struggling for full participation opportunities (Halder and Argyropoulos 2019). Participation determinants have environmental dynamics that may be influenced by activities and interactions in their environments (Halder and Argyropoulos 2019). The below summarizes a conversation had between a coach and their participant.

> *Magic: I would like to trot over poles today.*
> *Coach: Why do you want to do that?*
> *Magic: Because I can.*
> *Coach: Ok we can do it at the end of the lesson because right now*
> *we're focused on two point.*
> *Magic: Ok.*
> Fieldnote: May 7, 2019

Conversations are "ongoing processes, which include information sharing and dialogue" (UNCRC, 2009, p.3). The above excerpt from the fieldnote shows exactly this, Magic was able to have input in her extracurricular physical activity, a compromise was reached between the coach and participant. In addition, this compromise involved the reasoning for when the participant was able to decide for herself, as right at that exact moment they were trying to focus on another task. Magic understood this with the explanation and was ok with waiting until she was able to do what she wanted to do. Conversations amongst children with disabilities and adults according to Sheir (2001) suggest that taking children's views into account meets the requirements of the UNCRC, however for a higher level of participation children should share decision making power. For children who communicate nonverbally, there is sometimes not a willingness to start a dialogue as shown through a couple of quotations below:

> *I don't ask him for his input because he doesn't respond*
> Coach, Fieldnote: October 10, 2018

> *He doesn't have the ability to communicate his wishes, so we have to decide for him*
> Coach, Fieldnote: October 15, 2018

Although the quotes above are discussing children who communicate nonverbally, all children should be included in conversations regarding their participation and inclusion. Ideally children would have their own space to ensure their voices are not overruled by adults (Cornwall 2008), however, in extracurricular physical activities these spaces are very limited. The coach in the second example perhaps believes her decisions are in the best interest of the participant. However, to adhere to the UNCRC, there are other rights that are perhaps ignored such as Article 13, right to information, and Article 2 non-discrimination. Lundy (2007), also suggests that children's conversations should be facilitated to help them express their views, and in these examples the opportunity for children's perspective is not being heard. Although sometimes children with disabilities, opportunities for conversation with adults in

extracurricular physical activities is limited, children also take actions to be heard as seen in the subsection below.

4.3.7 Self-Advocacy

Children self-advocate in extracurricular physical activities when their voices are not being recognized. Children with disabilities can use 'strategic flexibility' (Bacon and Frankel 2014) to navigate the power structures and relationships in their everyday lives (Frankel 2017). Additionally, children with disabilities have agency, however, in some instances the agency they exert may be seen as challenging, negative and problematic (Tisdall and Punch 2012). Children with disabilities' agency looks different in relation to adults, however that does not mean it is less meaningful or powerful (Castro 2017). Agency can be seen and recognized through non-verbal or verbal actions (Corsaro 2005). Below are two examples of self-advocacy, one verbal and one non-verbal example from the fieldnotes:

> *Coach: We are now going to go through our course, your volunteers*
> *can just lead you through it the first time.*
> *Magic: Actually, no hello.*
> *[no response]*
> *Magic: hello, hello, hello, hello, hello [yells]*
> *Coach: Yes Magic.*
> *Magic: I actually know how to steer; you need to show me where to*
> *go.*
> *Coach: Just have your leader do it.*
> *Magic: hello [yells and stops her horse]*
> *Coach: what?*
> *Magic: I'm not moving until you show me.*
> Fieldnote: April 15, 2019

And the following excerpt is a non-verbal self-advocating action:

> *There are two pictures on Mickey's saddle. One says, 'walk on' and*
> *the other one says 'whoa'. When Mickey wants to go, he will*
> *repeatedly touch 'walk on'. Instead of listening to Mickey's actions,*
> *the coach just continues to talk and is getting a little annoyed. She*
> *says 'just wait Mickey' with no reasoning. Mickey continues to touch*
> *walk on.*
> Fieldnote: December 7, 2018

It is important to let children with disabilities communicate, however, that is not enough for them to be heard (James 2007). Here we see a clear example of this, although children with disabilities were not told to speak, they did, and their communication went unheard. The quotations above show the ability of children with disabilities to make choices but it often goes unrecognized (Davis and Watson 2000). Once again, the UNCRC is not being adhered to because children with disabilities here are communicating their choices but are not being heard or are being disregarded and not told as to why. Children with disabilities may get tired of trying to make changes in their lives and the surrounding environments, if adults continue to not hear the wishes of children with disabilities. It is important to hear and observe, to really be aware of children with disabilities' communications, if wanting to enhance their participation. It should not be seen as a negative (Tisdall and Punch 2012), but the examples should be seen as a positive, their willingness to communicate, and desire to be heard and make a change in their lives. In the examples above, their agency is powerful (Castro 2017), it is powerful because although they did not make a significant change, for a brief moment in time they made adults listen whether they wanted to or not. Children with disabilities in these examples are exercising agency clearly to influence their surrounding environment (Oswell 2013). They utilize strategic flexibility, as they are moving between the boundaries and hierarchies set (Bacon and Frankel 2014) within their extracurricular physical activity setting.

4.3.8 Section Summary

The current section discussed lived experiences of choice for children with disabilities in extracurricular physical activities. The lived experiences of choice start to answer the research questions in relation to participation and inclusion. The section was linked to disability studies literature and participation literature. It was noted that the experiences

varied widely depending on the participant and the environment they were in. Additionally, children with disabilities did exercise agency to change their experiences through negotiation and conversations with coaches.

4.4 Chapter Four Conclusion

The following subsections will provide a summary of the chapter in relationship to answering the research questions, and a further overview of the chapter's contents.

4.4.1 Contributions to the Research Questions

The current chapter explores a main theme of choice that emerged during data analysis and the relevance it has to participation and inclusion. Children with disabilities and adults created opportunities and constraints for children's choice which had an impact on how children participated and reacted. Where choice was constrained, children had different spaces to react. An example being that parents choose the activities children participated in however, children would react whilst participating in the activity to either enjoy it or make it clear through emotions they did not like the activity which often resulted in their parents taking them out of the activity. The understanding of the opportunities and constrains of choice of participation at the start of activities is important to the research question as children are gaining insight into where and how their voice matters and reacting accordingly. The understandings of parents and coaches are also important as their expectations perhaps shift throughout the following data chapters as negotiation of their choices are lived through.

Exploring choice in connection to inclusion in extracurricular physical activities for children with disabilities is also a key theme for research question two. Coaches and parents' views and expectations play a role in the choices they make for inclusion opportunities. Coaches choose to take a position that they are in charge of facilitating inclusion opportunities. The result of this has implications for answering the research question as in the

negotiation process of inclusion, coaches have taken a power position on inclusion, and children will be living through the process created. Instead of defining the experiences as a static experience such as 'tokenistic' or 'participating' in the processes, the data chapters will expand on the initial understandings of choice. This will be done in relation to inclusion and participation whilst living through these experiences with children to gain knowledge on their processes of negotiation, and perspectives.

The current chapters' focus was on a theme of choice in relationship to the research questions. The chapter also started to highlight another main theme of the data emphasizing the differing experiences children have depending on their methods of communication. The following subsection will provide a further summary of the chapter's contents and provide insight into Chapter Five.

4.4.2 Summary of Chapter Four

The chapter aims to support answers to the research questions for the thesis by providing an understanding of a key finding of choice, and how choice experience plays a role in participation and inclusion. The chapter started with an exploration on how extracurricular physical activities are chosen; the section discusses information availability, access to activities, the role parents, organizations and children play into the experience of extracurricular physical activities. Availability of activities and funding was noted to be more difficult for certain children with disabilities. Furthermore, choice of activities was often decided by parents, although there was not a wide availability of activities.

Following this, the chapter discussed lived experience of choice and linked practice with the medical model, tokenistic participation, change and choice in activity, how activities adapt, and conversations amongst children with disabilities and adults in these environments. Although there are key differences in choice experience between children who communicate verbally and non-verbally, the thesis suggests that further research and analysis could be

conducted to further explore the intersectional nature of choice of extracurricular physical activities.

      To conclude, the analyses and arguments from this chapter point to the relationships between adults and children with disabilities having a key role in choice opportunities for extracurricular physical activities and are vital in understanding participation and inclusion in relation to the research questions. Additionally, there is a difference in the process of participation and inclusion for children who communicate verbally and non-verbally which starts at the base level of entering the extracurricular environments as the negotiation of relationships occur. Furthermore, there is a lack of opportunities and resources for organizations to offer extracurricular physical activities to children with disabilities, and support for continuous opportunities to be readily available.

Chapter Five: Participation Opportunities and Constraints

5.1 Introduction

The current chapter is a continuation of data analysis from the ethnographic study alongside children with disabilities, conducted in an extracurricular physical activity setting. In the previous chapter there was discussion around choice and the key personnel who had the power to choose. The aim of this chapter is to answer research question number one which states:

> **Question 1:** How do adults and children create opportunities and constraints for children's recognized participation?

To answer this research question, the chapter will be broken down into four sections which include motivation of key personnel, adaptation within these environments, participation elements, and relationships with children with disabilities. There are various themes raised in this chapter with some of them being agency, power, participation opportunities, participation constraints, and the child's perspective. The themes are in relationship to the opportunities and constraints of recognized participation, differing from Chapter Four when they were discussed in relation to choice. The section discusses the relationships between coaches and children with disabilities which will specifically close a gap in literature identified by highlighting the child's perspective (Spencer-Cavaliere et al. 2017), rather than being excluded in preference of parent and professional views (Berg et al. 2015). Additionally, the chapter aims to close a gap in knowledge between the implementation of the UNCRC and practice (Desmet et al. 2015), specifically amongst children with disabilities, non-verbal communication and participation in extracurricular physical activities.

The current chapter will start with motivations of key personnel, as motivations were found to influence the way in which people interacted with one another. Second, adaptations of extracurricular physical activities will be discussed as the implementation of adaptations had a direct relation to the process of participation. Third participation elements will be examined in relation to the lived experience of participation in extracurricular physical activities. The last section will analyse the negotiation of relationships between adults and children whilst exploring different experiences of participation.

5.2 Motivations of Key Personnel

The current section will discuss motivations of key personal in extracurricular physical activities. The section will discuss coach, volunteer, parent, and child motivations surrounding participation in extracurricular physical activities.

5.2.1 Coach Motivations

The first of the key personnel to be discussed are the coaches of the extracurricular physical activities. Children may be accustomed to adults exerting power over them in other aspects of their lives and being treated not necessarily as equals (Punch 2002), but coaches are the ones with the power to shape a child's structural experience. A view of a coach can be seen through the following example:

> *I mean, nothing in the arena happens unless I'm ok with it. Things*
> *can happen of course but I'm the one in charge.*
> Coach, Fieldnote: September 22, 2018

This example shows how coaches see their role and continue to assert themselves within the extracurricular physical activity environment. Coaches in extracurricular physical activities were seen in a powerful position as they are needed to run the activity sessions for children with disabilities (Shields and Synnot 2016). Additionally, there is an element of

'tracking' demonstrated by exercising power over children's environment whilst not considering alternative approaches to understanding (Foucault 1980).

The reasons why and motivations for becoming a coach for children with disabilities in extracurricular physical activities vary. For many, coaching provides personal, emotional, or internal benefits, such as making coaches feel satisfied, because they think they are giving back to the community, as seen in the following example:

> *I started coaching because I just thought it was important to give*
> *back to the community and to help those less fortunate.*
> Coach, Fieldnote: November 12, 2018

There is an assumption that children, and in this case children with disabilities, are seen as less than adults (Priestley 2003). This assumes that the coach's role in working with children with disabilities is to be more of a caretaker. Children with disabilities in this study have reacted to a coach being more of a caretaker by comments such as: "I can do it myself" (Marie, Fieldnote: September 14, 2018), "you're not my mother" (Magic, Fieldnote: April 2, 2019), and "stop telling me what to do" (Chloe, Fieldnote: May 17, 2019). Through the process of 'identity spread' (Shakespeare 2014, p.95), viewing children with disabilities as a 'deficit' may lead to stigmatization and discrimination (Weis 2014). Here we can see children with disabilities asserting their voices whilst showing clear frustration and anger. Similar to Scott (1990), "relations of domination, are at the same time, relations of resistance" (Scott 1990, p.45).

Emotional compensation was perhaps a motivator for some coaches, as they were often volunteering their time to coach. This type of emotional compensation is sometimes not achieved, and as a result, this may alter a coach's motivations to continue. Coaches can become burnt out, which may lead to a negative view of volunteerism as demonstrated by these two examples:

It's honestly really hard to keep coaching, no one appreciates me, I clearly make no difference. I got sworn at by one of my kids this week and no one does anything. There's no support, none of my kids like me what is the point."
Coach, Fieldnote: March 11, 2019

So, I think burn out is a very real thing…but I think it also needs to be recognized in volunteer work and like especially like so I go as someone who works 9 to 4 or 830 to 4 every day and then I go to volunteer at night by the time I get there I might not have had dinner like it might've been a bad day at work kind of thing. So, like sometimes you're sitting there and it's like this lesson s***, like I don't want to be here like it's crappy and then there's not always enough support. I don't find that there's always appreciation for what you're doing, So there's sometimes like you feel burnt out and then all you kind of need is like one person to be like, hey, like thanks or like, hey you made a different and it's not happening and I mean like that's just basic human feeling, like you want to feel like what you're doing is worth it and like making a difference because like why would you be doing if you're if there's no purpose especially if you're like not getting anything out of it because you're burnt out already.
Coach, Interview: August 15, 2019

To improve the quality of the service offered, 'burn out' needs to be addressed (Casey 2011). A few suggested ways are to create safe working conditions, increase organization support, ensuring that people have an interest in working with people with disabilities, and meaningful training (Casey 2011). When adults that are not operating at their fullest, children in that environment are affected. From study observations, when coaches are experiencing burn out, children took notice. Some questions children would ask their coaches 'are you alright?' (Chloe, Fieldnote: November 12, 2018), 'am I doing something wrong?' (Aspyn, Fieldnote: May 10, 2019), and 'why are you being quiet?' (Magic, Fieldnote: May 22, 2019). Even young children, through understanding body language and facial expressions, have the capacity to recognize and learn different emotions (Rieffe and Wiefferink 2017). Children with disabilities are showing their awareness of these emotions and agency in a highly structured environment (Castro 2017), by showing some compassion or concern for their coach.

Coaches' motivations to coach children with disabilities in extracurricular physical activities vary. These motivators and the preconceived notions about children with disabilities that the coaches bring will shape the lived experience of the children with disabilities participating in the activities.

Coaches throughout the delivery of the extracurricular physical activity rely on volunteers to support them in their vision of the activity taking place. Volunteers may not have disability specific expertise but may be found offering physical support, setting up the activity, and working one-on-one with a child participant (Thomas and Smith 2009). The following subsection discusses volunteer motivations.

5.2.2 Volunteer motivations

Volunteers are an integral part of a child with disability's experience in extracurricular physical activities. Although coaches may also be volunteers, as seen in the previous section, for the purpose of this section volunteers will be discussed as people who take direction from coaches and add additional support for children with disabilities. An example of this may be, one-on-one support for the child with a disability to reiterate instructions and add physical or emotional support.

The majority of the volunteers within this study were children. In the province of Ontario, high school students must complete a total of 40 volunteer hours before they are eligible to graduate (Ontario Ministry of Education, 2019). The motivation to complete these volunteer hours was the starting point for some of the volunteers encountered.

> *I started volunteering because I was looking around at places to get*
> *my volunteer hours and I love horses, so this seemed like a good fit.*
> Volunteer, Interview: June 2019

As shown in this example, the volunteer started with a motivation to complete the required volunteer hours, the motivation to stay was in relation to the participants they were supporting. An example of volunteers staying with extracurricular physical activities due to the bond they build with children with disabilities is seen below:

> *For like Mickey when he was in a lesson with (other rider's name) all the attention would be on like (other rider) and not Mickey he would be completely forgotten because (other rider) was the bigger priority or he required more attention. And so, it was if I wasn't in the lesson with that kid, they would just be forgotten about all together. I think because (other rider) was louder and verbal and Mickey was nonverbal and couldn't communicate that he maybe wanted the attention and I feel like it often became like when I was with him me having to direct the others (volunteers) to being like oh, like helping this way has helped like oh hand-over-hand and do this because there's no prompting from the instructor, I just had to figure out what worked on my own.*
> Volunteer, Interview: July 8, 2019

This volunteer continued with the program because of the bond or friendship she developed with the children. There was an empathy for Mickey's experience.

As already noted, children with disabilities have the right to speak for themselves (UN, 1989 Article 12), but at first glance it may appear children are unheard. Here there may be a proxy, whilst creating a bond with this volunteer who he would smile at, touch her, and have eye contact with. This bond was built through a reciprocal relationship that was built over time (Bessell 2009), where Mickey's volunteer realized his capabilities instead of assuming his incompetence (Mason 2009, Noble-Carr 2007). She understood that he has something to communicate and it is worthy (Morris 2003), and that it was up to her to help communication occur.

The way a person views a child with a disability has an impact on how that person then treats a child with a disability (Hahn 2001). The volunteers interviewed in this study were already working alongside children with disabilities; therefore, this study may have not

fully grasped the changes or consistency in view volunteers have toward children with

disabilities. However, volunteers do grow into their own unique views of the children that

they work with, an example is shown below:

> *I think adults need to know about children like about the
> participants. I think that they need to remember that it's still a
> person and that's it. Yeah, it's real to be this person and that one
> disability doesn't mean that they've all disabilities and I think
> because we have a bunch of volunteers to come in who often don't
> have a background with people with disabilities, they automatically
> think other things. Like oh he's nonverbal so he can't hear and
> that's not the case, you need to give them opportunities to show that
> they can do the activities.*
> Volunteer, Interview: June 12, 2019

This volunteer's views of children with disabilities is that they are a human first

which is consistent with the UNCRPD (2006). Children with disabilities should be viewed as

respected and credible individuals (Grech 2012). Viewing children with disabilities in this

way appears to be appreciating them for their capabilities and experiences rather than their

impairment (Fitzgerald and Graham 2009, Mason 2009, Noble-Carr 2007). An example of

understanding capabilities and modifying for children with disabilities is shown below.

> *I think that coming in like as a brand-new volunteer you don't know
> that you can step into that role and sometimes make modifications to
> what the instructor said or just completely change what the
> instructor said. I tell them all the time. If it's not an activity that is
> appropriate for that kid to do because you don't have the knowledge
> going in and understanding of the individual, you're working with so
> you can't know what isn't or is acceptable and I think oftentimes it's
> too much of we're going to get this activity done this way instead of
> trying to have them be successful in what they do.*
> Volunteer, Interview: August 19, 2019

Here the volunteer is suggesting that if children with disabilities do not achieve what

they are supposed to, they will be left behind (James 2002). There is no training for making

these adaptations as a volunteer. The training that volunteers do receive has resulted in not

understanding the impact they can make to the environment. However, from the amount of

time this volunteer spent in the program, she learnt the importance of knowing the individual

participant, the communication requirements, and the verbal and non-verbal cues (Mitchell 2010, Morris 2003). In another example, the volunteer was observed in March 2019 to adapt or change a cue from a coach that was 'thumbs on top' (whilst holding reins on a horse) to 'let's hold ice cream cones' the response to the coach was a minimal change whilst the volunteer got the participant to the result the coach wanted, just with communication the participant preferred.

Volunteers' motivations appear to have an impact on the lived experience of children with disabilities in the extracurricular physical activity environment. Volunteers were seen as vital for these activities to run, as they offered one-on-one support and had potential to become an ally for children with disabilities. Some motivations included a requirement for volunteer hours, a developing rapport with children with disabilities, and a feeling of being needed within the environment.

5.2.3 Parental motivations

Parents of children with disabilities, as seen in Chapter Four, had an imperative role in finding and insuring access to extracurricular physical activity opportunities. This section aims to provide details of parental motivations for participation in these activities. A few of these motivations include the desire for their child to be physically active and be involved in a social setting, as well as providing the parent with a break. A common theme in discussions with parents was the desire to have their child be physically active. Occasionally, physical activity was limited or their child's participation in physical activity was tokenistic in the educational setting (Fitzgerald 2012). Some parents were seeking the health benefits of physical activity (Carson et al. 2010) for their child that were lacking from their lives and turned to an extracurricular option. The parental motivation for physical activities in this study can be seen in the example below:

The goal is I'm hoping he can walk because I know that horseback riding is definitely something that could help with that.
Mother of Moose, Interview: June 11, 2019

Additionally, another example of looking for physical benefits follows:

It helps with her balance of course; she has a weaker core and legs so keeping her moving is really important and hopefully building some muscles might ease pain later on in her life.
Mother of Chloe Interview: August 7, 2019

In both these examples, the parent is looking for a way to improve their child's life through exercise. Physical activity has physical benefits (Rimmer and Rowland 2008, Shah and Diwan 2019) that parents are looking for. In these examples physical benefits are at the forefront and perhaps a measurable outcome of physical activity. Chloe has also made comments on her physical strength: "I like doing things by myself it makes me feel strong" (Chloe, Fieldnote: January 12, 2019), and "I do think horseback riding makes me stronger" (Chloe, Fieldnote: March 20, 2019).

In addition, parents are also looking for social benefits (Breuer et al. 2015) when picking an extracurricular physical activity. These activities have a social element, whether it be with other children with disabilities, coaches, or volunteers. When children are back at school, they may have more to talk about with their peers due to being involved in an activity. Additionally, parents can talk to other parents about their children's sporting activity making it a social benefit for them as well. Here children can interact with others outside of the home and school environment and are ideally able to connect with them in a safe inclusive environment. This motivation theme from a couple of parents can be seen in the following examples:

It's that community, having something and I know that part of the autism he doesn't always seem to really mind that he's on his own or prefers it sometimes not have to deal with other people, but I think it gives him that experience without you know within a structure. So, it's easier. Yeah, it's not just social behaviour going somewhere and

*having to talk to somebody and be social and figure out social cues
and how to talk to people this is giving that interaction a purpose.*
Mother of Kirby, Interview: July 4, 2019

*An inclusive activity would be great but because I do think that
children who don't have a disability need to acknowledge those that
do, and she lost a lot of her social aspects. In activities for children
with disabilities she is beyond social I think she just goes to be
social and I'm so proud when I see that.*
Mother of Marie, Interview: August 12, 2019

For parents it was clear that they wanted their children to connect with others and perhaps even make friends based on a mutual common experience. The examples show that the children are deriving the desired social benefit which keeps the child and parent coming back to the activity. Here, positive and negative social factors can shape the experience lived by children with disabilities (Curran and Runswick-Cole 2014). Additionally, sociability was sought amongst parents as a skill set that children are able to learn in these environments. The potential for group work may provide children with disabilities emotional support from their peers and may result in greater social inclusion (Ajodhia-Andrews 2016, Thomas and O'Kane 1998). To contrast the social motivations, Kirby has suggested that it is not one of his big motivators "I don't really care about chatting, I need to focus" (Fieldnote quote Kirby: February 7, 2019). However, Marie places an importance on her social experience of extracurricular physical activities "my favourite thing is hanging out with my friends and making new ones" (Maire, Fieldnote: June 7, 2019).

In the case of children having access to physical activity within an inclusive and safe environment, the motivation may be to afford parents with the opportunity to take a break. Being able to take a 'break' occasionally for parents whilst their children were in a productive environment was another motivation amongst parents which can be seen:

*I don't like sitting out there with Moose all the time, this is my one
time of the week I get a break you know. I love these 30 minutes; I'll
take anything I can get really. I just want to sit and not have to be
running around.*

Mother of Moose, Fieldnote: March 4, 2019

Families of children with disabilities may find themselves acting on the child's best interests and ensuring their needs are met (Williams 2013). Moose's multiple disabilities may have also led to parental stress (Hall et al. 2007), which increased the desire for a break. This mother is the full-time caregiver for Moose and enjoys having a break whilst he is in a safe environment. Although some parents may have used this time to have a break, some parents utilized this time to bond with their children. Sometimes parents participate in the same sport that their child is now participating in, so they can connect. In another instance children were participating in a new activity that their parents knew nothing about causing the parent to learn alongside their child.

> *I've had experiences in the past where one parent has been absent and never really around for their child. It's pretty common actually, it's hard for some people to understand disability. But then in some cases they must hear that their child is playing hockey, you know, doing something, everybody knows hockey and I always spot them it's easy to spot new people. I'll go up and tell them things they might've missed like oh last week he took a really awesome shot or was being a great team player, you see them light up a little bit of course it takes time. I just keep doing this and more often than not really, I see them in weeks or months down the line in the dressing room and they're talking strategy. Hockey is just something we all know, and it gives parents a chance to understand their child here.*
> Coach, Fieldnote: December 21, 2018

Parental behaviours regarding physical activity, in this case hockey, are significant factors in children's participation in physical activity (Hamm et al. 2016). Parents can be seen to promote the importance of participating in a physical activity (Bois et al. 2005). Here parents can create bonds with their children based on a physical activity; it gives them a chance to connect at a different level. Children with disabilities are perhaps more reliant on support from parents for participating in these activities (Boddy et al. 2015). When children can discuss, debrief, gain support, and strategize for their next session with their parents, it makes the activity more than just something that occurs once or twice a week.

Parental motivations also included children enjoying the activity they were participating in, which resulted in mutual joy.

> *We're able to communicate with Mickey a little bit now which was almost not possible a couple of months ago. We started to use an iPad to see if he would use it, and he doesn't really, it's a learning process. We do watch videos of him riding and he gets excited and will touch 'balloon' on his iPad. It might seem silly, but he loves balloons and I guess we kind of know he must like it and like being able to watch him ride even though it isn't riding time.*
> Father of Mickey, Fieldnote: February 23, 2019

Children and their parents being able to bond over an extracurricular physical activity added to the continuous lived experience. Previously, communication was through body language with Mickey; however, with use of technology Mickey's parents were able to fully grasp the enjoyment their son was getting out of horseback riding. Mickey enjoying the activity was a factor for this family to keep him in this physical activity (Beurskens et al. 2016), and they found that they were able to enjoy the activity through Mickey's eyes.

In some instances, parents lose motivation for their child to participate in a certain activity, if they feel it is not beneficial to their child. The lack of motivation is perhaps a result of a couple factors. One demotivator is if the parents recognize the environment is not adaptable to their child's needs:

> *He had a bad situation with a scare with water, so he wouldn't even get the bathtub alone for awhile. (…) so earlier I mentioned he had a traumatic situation. So, one of the times I put him in traditional developing swimming lessons and there was Ben and 5 other children and I explained to the coach and I was very transparent up front and said to them like, if he were to miss his footing and slip under the water, he would not have the cognitive ware for all to instantly pop up. I was very thorough, I filled out on the information, and they said it wasn't a problem. They wouldn't let me watch from the pool deck, so I had to wait upstairs on the benches, but I could still see. Low and behold I was of course watching from above and I watched Ben go under and I was able to get down the stairs and, in my clothes, jump in the pool and I pulled my son up before the coach could even see that he was missing.*
> Mother of Ben, Interview: July 14, 2019

This is similar to experiences from other parents of children with disabilities in being involved with physical activities where the instructors or coaches lack experience and knowledge of how to support children with disabilities (Beurskens et al. 2016). Parents may become timid or scared to have their children around people they do not find well trained enough. Children with disabilities may then lose out on opportunities for participation because there are not adequate safe choices.

To summarise, parents have various motivations for having their children participate in extracurricular physical activities. Parental motivations for these activities include physical benefits, social benefits, emotional breaks, and bonding opportunities. Parents have considered children's enjoyment in physical activities but only after being confident that their children are properly supported and safe. Although children's views were linked into the sections above, the following subsection will predominately focus on children's motivations for extracurricular physical activities.

5.2.4 Child motivations

Children with disabilities have many different motivations for participating in extracurricular physical activities. A few motivational themes that emerged from the study data included having fun, seeing friends, learning something new and becoming stronger. The way children act around their friends is also different than if they were on their own (McNamee 2016). This section will go into further depth about the themes that emerged with examples throughout the extracurricular physical activity experience.

It was a common occurrence in this study that after a long day at school children with disabilities were motivated to have fun at their extracurricular physical activity. Most of them even looked for opportunities within the structure of their activity to have fun as shown in the examples below.

Once down the snowboarding hill for the third time, he falls over almost looking like he wiped out. However, he is hiding his hands and I can see him starting to make a snowball out of the snow. His coach must think he's fallen and is just lying there he starts to be really still until she gets there and then he throws a snowball at her and starts laughing.
Kirby, Fieldnote: January 11, 2019

The routine in speed skating is warm up, drills, some racing and then it is time to put away the equipment. During the taking down of matts today Kirby decides to place a matt on the ground, he skates away from it then he turns and skates super-fast towards it, jumps on it and then slides across the ice laughing.
Kirby, Fieldnote: November 20, 2018

As shown in these examples, children did not wait for the adults in their environment to make the activity fun, they found creative ways to enjoy themselves. Although there was not an explicit opportunity for decision making around how he is enjoying himself, adults in the environments are just recognizing that this may be his meaningful participation (Frankel 2017). Kirby is actively creating opportunities and changing the way he experiences his participation alongside adults (Frankel 2018). In addition, sometimes when children with disabilities were visibly not paying attention based on eye contact or body language, but when the activity became fun or of interest to them, you could see them paying attention.

Having fun was very linked to Charlie's desire to participate in the extracurricular physical activity.

Charlie looks like he's having a good time although he is not 'engaged' with the other hockey players. He is skating laps around the rink by himself whilst his teammates are doing drills. He is laughing and looking out at the stands. His teammates start a drill where they fall down and get back up. Charlie skated over to his team and joins them for this drill and is laughing even more now.
Charlie, Fieldnote: December 14, 2018

Normative expectations of communication should be left behind, and different expression forms should be accepted as children communicate for understanding (Carroll and Twomey 2018). This means going beyond language, expression and freedom of opinion to enhance communication rights (McLeod 2018). This is an example recognizing his point of

view of when and how he would like to participate. For hockey, Charlie would often not

follow the structure laid out by the coaches and volunteers, unless he was asked a few times,

or it was fun. When it was fun, he joined in, and he would always have a clear huge grin

whilst laughing.

Children with disabilities would also recount times that they had fun in their activity

to their coaches and ask to do what they enjoyed again. While fun was discussed in Chapter

Four, the current discussion is in relation to participation.

> *Spyrou has asked her coach 4 times if they can do a specific*
> *activity an example of the one time she asks is "can we*
> *please do the roll kicky thingy it's the best my hair goes*
> *flying everywhere though". When they eventually did this*
> *drill, she was laughing and having a great time.*
> Spyrou, Fieldnote: February 12, 2019

> *Mickey is nonverbal however; he is pretty good at conveying*
> *what he would like people to know. This session with his*
> *coach when he lays down on his horse that indicates that he*
> *wants to trot. When his coach allows him to trot, he has a*
> *massive smile. He will lay down after a trot or he will use the*
> *sign language word 'more' to keep going.*
> Reflective notes: December 2018

Here you can see a clear motivation to have fun when children communicated to

adults that they would like to do more fun activities. Although adults did not necessarily seek

children's views and it was observed that these spaces were about power over children

(Gaventa 2005), this research study views participants as beings capable of forming views

(Qvortrup 1994), and children were being active in the construction of their lived experiences

by asking for what they would like to do.

Another motivation expressed whilst participating in extracurricular physical

activities was being able to see friends. Similar to having fun in the activity, seeing their

friends made for a more enjoyable experience. As shown below, we see a participant's

experience depends on whether her friends are at the activity.

I think it's like really more enjoyable with friends because you can share that experience with someone else and for example in class when we have breaks like water breaks here just talk to each other and decided dance if we get together, it's fun because we both have that one thing that we can do and it's just very enjoyable because we both kind of enjoy the same things. Hmm, you can also really learn a lot about dancing the other person example of they're stronger in one thing you're strong another you can help each other to kind of you know. I probably wouldn't do as many classes because my classes you do it's a bunch of different people and it's more enjoyable to be with people, you know.
Aspyn, Interview: March 12, 2019

When her friends are at dance class, she seemed to be having a lot of fun, always chatting and laughing. Tonight, her friends are not at dance class and she seems much quieter, she didn't really talk to anybody and it didn't look as fun. When I asked her, what was wrong she said, 'I would just rather be here with my friends'.
Aspyn, Reflective Notes: January 2019

For Aspyn dance class was about having fun. She looked forward to this extracurricular activity as an opportunity to be with her extracurricular friends to share an enjoyable activity. In a Canadian study, it was found that activities where children with disabilities had friends, felt like a valued participant and had fun were important for children's feelings of self-worth and inclusion (Spencer-Cavaliere and Watkinson 2010); these children have greater peer support (Goodwin 2001), more friendships (Bloom et al. 2009, Grenier 2011), and increased acceptance (Grenier 2011). In addition to having more fun whilst participating alongside a friend, making friends also led to being able to participate in activities outside of the structured time.

The dance coach tonight asks children during the attendance 'what is one thing you'd like to share this week' and when it gets to Aspyns' turn she says 'this weekend was really fun because like (3 girls' names in the class) and I all got together and made-up dances and practised the ones for dance classes here'.
Aspyn, Fieldnote: February 14, 2019

Charlie's mother comes up to me at hockey and says 'so something just happened' I respond 'oh what happened?' and she says 'it's never happen before but Charlie just got invited to a birthday party, in 15 years he's never gone to one' I respond 'that's so exciting' and

> *she says 'yes, but I'm worried he's never gone to one so I'm not sure*
> *how he'll react and a little shocked' I respond 'where will the*
> *birthday party be?' and she says 'it's a hockey theme so I'm not sure*
> *but I think that'll help because they all play hockey anyways,*
> *hopefully it won't be too different for him'.*
> Charlie, Fieldnote: November 11, 2018

Extracurricular physical activities were an opportunity to meet new people and develop new connections. Friends were an important part of the extracurricular physical activity environment. These children may have not met the friends they made, if they were unable to access the opportunities. Children with disabilities in a school environment may have limited opportunity to interact with other children with disabilities. This may be one of their environments to meet and bond with people who are similar. This is contradictory to other research that shows physical activity programs face challenges such as being restricted to the activity environment (Bloom et al. 2009) and not being extended to larger community involvement (Castenada and Sherril 1999).

Having a friend in an activity also led to a sense of being required to be there, in some cases children felt they had a duty to be there for their friend.

> *Chloe approaches me after her horseback riding lesson and says*
> *'hey Katie' and I respond 'hey' and she says 'so can I ask you a*
> *favour' and I say 'of course' and she says 'so I'm not going to be*
> *here next week and I feel really bad because (other rider's name) I*
> *think is going to miss me and we help each other tack up and play*
> *games and stuff can you come and help her next week? I honestly*
> *will never miss again'.*
> Chloe, Fieldnote: April 14, 2019

In this example, Chloe feels as though she is needed within her extracurricular physical activity environment which gives her a sense of pride. Often research shows that children with disabilities need support from adults in their environment (Biricocchi et al. 2014, Devine and O'Brian 2007, Devine and Parr 2008, Oriel et al. 2012, Zitomer and Reid 2011), but in this case, children with disabilities may be the ones needing to support each

other (Goodwin 2001). In one of the instances that she had to miss a week, Chloe ensured

that her riding partner knew. Chloe felt a sense a sense of responsibility to her friend, as she

was identifying as part of group or team with her peers. Identifying as someone's friend can

be a positive experience for children with disabilities (Gustavsson and Nyberg 2015). Agency

has the ability to emerge through friendships (Castro 2005), and Chloe is actively making

choices to ensure that she tells her friend when she is going to be away.

Children with disabilities had the motivation of physical benefits from their

participation in extracurricular physical activities.

> *I like being strong, and dance for sure helps me be a lot stronger it was hard to do some of the moves when I started. Being strong helps me do lots of things too like yard work.*
> Aspyn, Interview: March 12, 2019

> *During a rotation tonight at track and field, Kirby is currently doing javelin. The throw he makes is the farthest in his group. He turns around and lets out a roar and puts his arms up to show everybody how much muscles he has. Later in the evening I asked him 'did you enjoy javelin today?' and his response was 'yeah everyone knows how strong I am now' and I said, 'how did you get so strong?' and his response was 'I don't know I guess I just do every sport'.*
> Kirby, Fieldnote: July 26, 2019

> *I never really experience how to walk like a normal person, but hopefully I'll get there. I want to get there and I proved all the doctors wrong when I was born because all the doctors said I couldn't walk and I probably would never be able to but I proved them wrong (…) horseback riding makes my legs a bit stronger and that helps.*
> Chloe, Interview: August 9, 2019

Being strong was seen to be a desirable trait that was achievable for these participants

within the extracurricular physical activity environment. Being strong may help children with

disabilities identify more strongly with an athlete identity in the sports world (Anderson

2009). In addition, this identity development in extracurricular physical activities may help

their identity formation in other areas of life (Anderson 2009, Goodwin and Staples 2005,

Groff and Kleiber 2001), such as 10 being a strong helper at home. In addition, Chloe has a

different view on strength; it is not just about building upon strength but being able to push the limits of her abilities beyond what she was told she would be able to accomplish. This section presented some key motivations that children with disabilities have for participating in extracurricular physical activities. There were themes of having fun, seeing their friends, and enhancing their strength. These themes aim to answer in part research question number one, as they investigate why children continue to participate in these activities and what they feel are important aspects of their time.

5.2.5 Section Summary

Building on the results from Chapter Four, and in conjunction with the opening section of Chapter Five, research question one has begun to be answered. The section explored motivations of key personnel in extracurricular physical activities and their views on children with disabilities participation. The section discussed the motivations of coaches, volunteers, parents, and children. The section identified that motivations of key personnel were not always the same as child participants, and child participants did not always have the same views as each other on what they desired out of participation in extracurricular physical activities.

Further exploration identified importance of comparing children's views with those of key adults in the field. The chapter will discuss relationships between adults and children and the opportunities and constraints these relationships provide. Motivations have proven to be an important aspect of the relationships, as they guide assumptions and expectations of participation.

The following section will explore adaptations for children with disabilities for their participation in extracurricular physical activities. The section will answer in part research question number one by furthering the understanding of opportunities and constraints of

participation in extracurricular physical activity environments. The examination of adaptations for extracurricular physical activities will be compared to previous literature, as well as children's views on implementation.

5.3 Extracurricular physical activity adaptation

The current section will explore various adaptations for extracurricular physical activities for participants in this study. Subsections will include physical adaptations, emotional adaptations, non-verbal communication adaptations, and training of coaches. These subsections are included as they offer key insights into the participation experiences of participants in this study.

5.3.1 Physical adaptations

The following subsections will look at adaptations made by coaches and organizations for children with disabilities to participate in extracurricular physical activities. The purpose of looking at the adaptations will help to answer research question number one because it presents opportunities and constraints to what can and is negotiated for participants participation. The word adaptations refers to adjustments and modifications that the participants in this study may have needed to continue to participate. Children with disabilities may need physical adaptations to participate in their chosen extracurricular physical activities (Shields et al. 2012). Some of these adaptations included ski tethers, different saddles for horses, lighter lawn bowling balls, ramps, or one-on-one helpers providing physical support. The responsibility for the adaptation decisions often falls upon the organization itself, and in the study, the involvement of coaches as decision makers around the adaptations:

*I noticed tonight that the lawn bowling balls have different colours
on them, I asked one of the coaches 'why are they different colours'
and she said, 'well they have different weights so the children can
pick one they feel most comfortable with or if you look over there
actually that boy has foam ones, he is fairly weak so we found him
the lightest ones we could find'.*
Marie, Fieldnote: July 20, 2019

For lawn bowling, the coach knew the rationale for the different coloured balls.

Marie, in this study, would also sometimes switch the colours of her balls depending on

whether she felt tired or more energetic that night. There was an ability for her to pick which

level of support she needed which enabled her to co-participate in the physical adaptation

process (Frankel 2018). To contrast this experience of physical adaptation from lawn

bowling, the example below is from horseback riding. In the example the coach is responding

to a question about a participant having a tall handle on the saddle.

*Um, no. I actually have no idea why he'd have that like he sits up
fine, so I don't know, it's not my decision.*
Mickey, Fieldnote: October 4, 2018

The reasoning behind some equipment was unclear to the coaches who spent a

significant amount of time with the child participants. Children with disabilities in this study

did not always just accept the extra adaptations. Child participants sometimes questioned the

rationale for these adaptation decisions:

*During Magic's lesson tonight, she asks her coach 'why do my
stirrups look different to his (other rider)' the coach responds, 'um I
guess you could have the same ones as him, but I'd need to check
with the program manager'.*
Magic, Fieldnote: May 19, 2019

Magic is a social actor who is actively asking questions, learning and constructing her

lived experience (James and Prout 1990). For change to happen in this environment, Magic

became a creator of knowledge and change rather than as a passive consumer (Treseder

1997). When coaches are looking to make decisions on removing a physical aid from a child,

they need a clearance from someone higher up in the organization.

> *Tonight, I asked the coach 'hey I'm curious to know how you made the decision to take away a volunteer who was offering Charlie physical support?' and her response was 'well we were really struggling to get volunteers for this lesson and he looks pretty balanced right, but I need to get the program manager to clear it first'.*
> Charlie, Fieldnote: November 7, 2018

Sometimes the changes would take weeks to make, because the coaches were unable to connect with whoever was in a position to make decisions in the organization due to scheduling conflicts.

> *Tonight, in Chloe's lesson she asks her coach 'Hey um (coach's name) I thought you said that I could go down in support this week (having a volunteer not hold onto her)' and the coach responds, 'well I can't really do anything without having a program manager who is never here during that time or a therapist come out to say that's ok'.*
> Chloe, Fieldnote: March 12, 2019

Here Chloe is questioning her coach and speaking up to share her views which if properly addressed gives her the opportunity to be a co-participant in this environment (Frankel 2017). The study observed that coaches were the ones responsible for ensuring the implementation of the equipment changes and regularly checking the equipment. There was little room for consultation with children with disabilities within these environments when children who choose to question the rationale for specific equipment were unable to speak to the decision makers. Although children with disabilities took ownership of their experience and being a 'powerful self'(Bacon and Frankel 2014) in questioning authority, they had little power in negotiating their social space. An example below shows an interaction between a participant and coach about a physical adaptation change.

> *Marie has asked her coach this in multiple other lessons before but tries again and asks, 'can I try steering without having a leader?' and the coach says, 'when I say you're ready' and Marie responds, 'how will I know when that is' and the coach says, 'I'll tell you'.*
> Marie, Fieldnote: June 10, 2019

In the previous examples, we saw that coaches were more receptive to hearing what children with disabilities were questioning. The current example is a contrast, as there is clear use of power and authority over Marie (Smyth and Holian 2008). Although power is not necessarily a negative (Knights and Wilmott 1999) in this example, it may lead Marie to feel like an incomplete human as a becoming, rather than a being who is able to understand an explanation or to have a conversation.

In conclusion, within this study there appears little room for children's perspectives on their physical adaptations within the extracurricular physical activity environment. Physical adaptations were made by organizations with the expectation that coaches would follow their guidelines and any changes that were made by coaches were done after consultation with a more senior member of the organization to obtain approval. The following subsection will look further into adaptations in extracurricular physical activities with the focus on social and emotional adaptations.

5.3.2 Social-Emotional adaptations

Social-emotional adaptations are sometimes necessary for children with disabilities to be able to participate in extracurricular physical activities. Unlike the previous section about physical adaptations, emotional and social adaptations are perhaps more difficult to specify, as the need for emotional support can be constantly changing. As the emotional state of the particular child changes, the frontline coach may need to adapt the approach. This section will aim to answer in part, research question number one, as it discusses social and emotional adaptations, the potential for the inconsistent nature of this adaptation, and where children's views are taken into account.

In some cases, emotional adaptation required one-on-one support for a child with a disability to participate in an extracurricular physical activity. In some cases, emotional

adaptation for the child could look like, reassuring the child, giving them extra or repeated

instructions, reminders, a schedule and many more. Some emotional adaptation needs can be

foreseen, in which case, coaches are able to address, such as, obtaining an extra person to

assist, and clearly stating what that person needs to do to support the child emotionally:

> *Tonight, a coach tells a volunteer at the start of the session 'so he's*
> *going to need a lot of support like telling him everything we're*
> *doing, if he's supposed to be listening and he's trying to talk just*
> *ignore that behaviour, he's normally ok though'.*
> Mickey, Fieldnote: October 14, 2018

This example shows a coach reacting to a perceived need to support by assigning a

volunteer to pay extra attention to allow the participant to understand the drills. Behaviours

are sometimes not predictable, and, in this case, the frontline coach would be responsible for

making emotional adaptations during the lesson. The coach recognizes that her participant is

trying to communicate but is actively choosing to ignore what he has to say throughout; the

focus appears to be on getting through the lesson rather than encouraging communication.

Children need to be visible and heard (Bacon and Frankel 2014), and this example shows that

children with disabilities have fewer opportunities to be heard by adults (James and James

2012). Some coaches were able to adapt as the session went on and others struggled, as

shown in the examples below:

> *During Ben's session tonight he seems pretty agitated, there are new*
> *volunteers and a new coach. I don't think he's met this coach before*
> *and every time she asks him to do something he slouches and says*
> *no. He hasn't smiled tonight which is out of character and he often*
> *jokes around which again he isn't doing. The coach is also getting*
> *more agitated with him not doing anything by making her requests*
> *increasingly shorter. She ends up saying 'hold you're reins or I'm*
> *telling your father you're not doing anything and I'm pulling you off*
> *the horse'. She waits a couple of seconds; he does not pick up his*
> *reins. She responds to this by counting down '3, 2, 1' and then says,*
> *'ok time to get off' Ben screams no, and she physically removes him*
> *from the horse.*
> Ben, Fieldnote: May 4, 2019

Contrasting with an example below:

One of Charlie's teammates is lying face down on the ice and he looks like he might be crying. Charlie stops what he is doing which was skating laps by himself which is normal, and he skates over to sit down beside his teammate. He doesn't normally interact with teammates, so this is pretty special. One of their coaches comes over and sits down with both of them asks the child 'what's wrong' and he says 'I can't get up' the coach stands up, helps both of them up and they all go back to what they were doing before.
Charlie, Fieldnote: December 17, 2018

In both Ben's and Charlie's examples, a child is reaching out for some emotional support. The adults involved have completely different reactions. In Ben's example, the adult-child hierarchy is used by the coach to impose her view of the how the lesson will unfold; there is no attempt to adapt to Ben's emotional need. In Charlie's example, the child lying on the ice needed some support beyond being lifted. The coach skated over, asked the child what was going on, and provided the physical support requested. Because of the coach's action was to help the child up, the activity continued which is in complete contrast to Ben's experience.

Children with disabilities' experiences are relative to the support that they receive in their environment. The coaches above took two different approaches to behaviours in their extracurricular physical activity. The coach who observed to understand before he intervened and understood that listening is more than hearing (Roberts 2008), had a more positive result of getting children with disabilities to continue to participate. The other coach lacked important participatory skills, as there was little constructive feedback and information (Morgan 2005) for the participant and his views were not taken into consideration (Smart 2002). Children do have the right to be heard, not disregarded (McNamee 2016).

It is important to note that children with disabilities did not feel that their voices are heard when discussing social and emotional adaptations for their programs, as seen in the examples below.

I guess sometimes they (coaches) know like if I need physical help but no ones asked me other stuff. Like I don't know I'm pretty uncomfortable with new people and I wish I could talk to someone about that.
Chloe, Fieldnote: January 12, 2019

Aspyn: I think I don't need a lot of support but I see sometimes my teammates the coaches know to help with like doing the activity but no one really helps them join in. I guess it's like the focus on doing the movements but I think sports is more like we're supposed to be a team and no one helps some kids besides saying hello join in with us.
Researcher: Which kids do you think no one helps?
Aspyn: Kids who don't speak.
Aspyn, Fieldnote: February 7, 2019

In Chapter Four, it was noted that not all children see extracurricular activities as an opportunity to make friends. However, through the above examples there is seemingly a gap of support for social and emotional adaptations when needed. To further Aspyn's comment regarding a non-verbal communicating participant, an example is shown below.

This month is difficult to reflect on Mickey's social experiences in horseback riding. My fieldnotes show very little interaction with coaches, volunteers, and other children. There are limited adaptations put in place to communicate with him, and the coach insists he waves to his riding partner at the start and the end of the lesson. Besides the start and the end of the lesson there is very little communicate towards Mickey specifically.
Mickey, Reflective notes: October 2018

Childhood has been understood as a 'social construction' (James and Prout 1997), and although there has been a move past viewing children as 'incompetent and developing' in literature (Woodhead 2009), it seems in practice this is not always accurate. More accurately childhood experiences are impacted by disability, social class, gender and race (Konstantoni and Emejulu 2017), and as seen in this example how children choose to communicate. Aspyn in the examples above noted a difference in participation amongst children with disabilities who are verbal and non-verbal. The process of participation is linked to interactions and

communication (Lundy 2007), therefore, when there is little effort to support and socially adapt there is a gap of voices.

Although it is the responsibility of the coaches to adapt to the children's needs, sometimes this role is taken by volunteers. In the example below, we see a volunteer stepping in to offer emotional support:

> *I feel extremely awkward. Charlie has been crying the whole lesson, we're 12 minutes into the lesson and the coach just hasn't acknowledged it. I'm not sure if I should step in, our previous agreement was that I wouldn't distract him but he's clearly very sad and I've never seen him like this before. His volunteer eventually asks the coach 'hey you know he's crying right' and she responds, 'yeah but I don't know why so I'm sure he'll stop eventually' the volunteer then starts to tell him stories of her favourite things about him like 'I remember this one time you called your horse Doug and that was so silly because her name is Indie, do you remember that?' While the volunteer was talking, he would stop crying and looked at her demonstrating he was listening.*
> Charlie, Fieldnote: June 12, 2019

Here we see a coach ignoring a behaviour that is undesirable and a volunteer stepping in to provide emotional support for the service delivery. Coaches are not the only ones that can make a difference in a child's lived experience, other surrounding personnel can step in. In this case, we see a volunteer trying to listen and understand the child's emotions rather than them being disregarded. The act of his volunteer listening to those emotions and actions, while continuing to talk about fun stories when he stops crying means she is listening to what he needs, trying to have a dialogue and ensuring she is giving him respect (UN, 2009).

Children with disabilities sometimes ask for more support when they need it and the ability of the coach to appropriately respond to this need for emotional adaptation is important in determining how a child is experiencing their activity. The example below shows a child asking for more emotional support from the coach:

*Magic has yelled at least 15 times at the coach for help there have
been variations such as 'hello', 'hello why aren't you listening to
me', 'I need help', 'I don't know where I'm going here' and the
coach continued on what she was doing before, didn't look at Magic
after these requests.*
Magic, Fieldnote: May 22, 2019

Due to the evolving nature of emotional support needed by children to participate,

understanding the motivations and views of children is critical. Magic continues to use her

agency to attempt to get her coach's attention. The coach is not engaging with the voice of

the child, although it is presented to her resulting in non-participation (Hart 1992). As Magic

did not receive support when she asked for it, after the lesson I asked the coach why she

chose not to address Magic's request as shown below:

*It's actually annoying, honestly she just wants attention sometimes
you need to let her do it herself.*
Magic, Fieldnote: May 22, 2019

Here we see that although the coach heard the child, the coach chose to ignore the

child without any feedback, again making this non-participation for Magic (Hart 1992).

Instead of offering support the coach chose to ignore an opportunity to engage with a child.

Here the coach is not recognizing participation from Magic in the form of her voice,

expressing what she needs and wants. Her voice is not being heard which is an example of

not adhering to the UNCRC (Frankel et al. 2015). Magic is demonstrating clearly that she is a

social actor and not just a passive recipient of her surroundings (Tisdall and Punch 2012); she

is challenging the norm in her lesson and contributing to a conversation (Bacon and Frankel

2014). However, here we see her unable to escape a 'structural constraint' (Bluebond-

Langner and Korbin 2007) that her coach has placed on her voice.

Emotional adaptations for children with disabilities in extracurricular physical

activities are the responsibility of the coaches to identify and implement. Sometimes the

adaptations that are needed are predictable, and sometimes they are not. The way the coaches

react to the emotional needs affects how children with a disability experience participation in extracurricular physical activity. In the current subsection, there were examples of non-verbal communication adaptation lived experience. However, there is a need to further unpack this experience as the analysis shows a key finding and contribution to knowledge of non-verbal communication lived experiences. A piece of non-verbal experiences is described in the subsection below in an exploration of non-verbal adaptations.

5.3.3 Non-verbal adaptations

One of the reasons why this thesis contributes to knowledge is that almost half of the participants within this study were identified as non-verbal. Non-verbal participants in extracurricular physical activity environments may need individualized support to participate to the fullest. Some similarities can be drawn from emotional adaptations because coaches were also seen as the service provider for this type of support which led to some inconsistencies. During this study, a few of the non-verbal adaptations that were observed were one-on-one support, an iPad for communication, pictures for children to point at, and participant specific non-verbal cues. This section will go into further depth of these lived experiences in practice.

Non-verbal participants still communicate; however, sometimes their coaches may need to take the time to learn each individual's way of communicating. One-way that coaches addressed this challenge was to assign or require one-on-one support, some examples are:

> *I was chatting with Charlie's mother tonight at baseball and I asked*
> *if Charlie's one-on-one support was found by the baseball*
> *organization and her response was 'no she is his worker I have, they*
> *expect us when we signed up that we will find the body' and I said*
> *'oh I didn't know that' and she said 'yes it's getting expensive*
> *paying for him to play and then for worker'.*
> Charlie, Fieldnote: July 14, 2019

> *It can be difficult with volunteers we went through a period where there was constantly someone new. I try to be a good mother and know their names, but it was impossible. Luckily, we've had one really good one that's been coming for 6 weeks now so that's awesome.*
> Mother of Mickey, Fieldnote: April 4, 2019

In the first example, we see that a family is required to take on the responsibility of paying for the extracurricular activity and additionally paying for one-on-one support to be able to participate. For Charlie, the support that was hired for the participant works with him for more than just in baseball and multiple times a week. This is common that parents have often taken on the task of finding, training, and paying for additional support of their children (Goodwin and Ebert 2018). In the second example, we see the difficulties experienced trying to maintain consistency when the volunteers are constantly changing. With non-verbal participants, time is important to learn their unique ways of communicating, the high frequency of volunteer changeover is perhaps unsettling.

Physical supports and non-verbal supports can overlap, especially when looking at the use of iPads or pictures for children to communicate:

> *Mickey is now utilizing his iPad in lessons for communication. Volunteers do need to set it up with 'walk on' or 'whoa' but he does consistently press the button to make it speak. His riding partner brought their iPad this week to try to do the same thing and the coach said, 'um no, that's too much technology for one lesson'.*
> Mickey, Fieldnote: January 16, 2019

Children should be given various options on how they would like to best express themselves in order for their 'voice' to be heard including the option, not to participate (Lundy 2007). Finding a way for participants to communicate is a way that coaches empower their participants. In Mickey's example, once a structure was in place there did not appear to be any opportunity to change the coach's mind; she has placed a value on voice and who is able to access it and who is not. This lack of flexibility does seem to run contrary to the principle that all children have the right to be heard (UNCRC 1989).

Non-verbal cues are not just exclusively from non-verbal participants. Verbal

participants can utilize body language to communicate to adults in their environment:

> *Tonight, Aspyn is not really engaged, she has her head lowered and*
> *isn't smiling. She hasn't talked to her riding partners tonight which*
> *is out of character. The coach ends up asking 'hey how are you,*
> *what's going on?'*
> Aspyn, Fieldnote: February 12, 2019

In this example, Aspyn is demonstrating the body language of someone who does not

want to be there which is uncommon for her. In comparison, we see similar non-verbal

communication in the next example with a non-verbal participant.

> *Ben is really out of it tonight; he didn't greet me when I came in*
> *which was abnormal. He is looking fairly down pretty slouchy and*
> *doesn't look happy which is out of the norm. His coach addressed*
> *his posture by saying 'sit up' and when he wasn't smiling tried to get*
> *him to smile by saying 'smile it isn't that bad riding a horse'.*
> Ben, Fieldnote: October 6, 2018

In this example, Ben, a non-verbal participant is demonstrating the body language of

someone who does not want to be there. The coach recognizes the non-verbal cues and

attempts to cheer Ben's spirit. The examples show similar body language communication

with different responses from the coaches. Communication is to go beyond language,

expression and freedom of opinion to enhance communication rights (McLeod 2018). Aspyn,

a verbal participant, was using her non-verbal signs to communicate that something was

different (Flewitt 2005). In contrast, Ben was seen as a social problem, as he was disturbing

the set lesson plan which is consistent with children with disabilities being seen as a social

problem (Barron 2015). There seems to be a hierarchy of importance on non-verbal

communication throughout the study, perhaps because adults may be able to receive feedback

from verbal participants it might be seen to be more desired, however, that should not make a

voice less than equal.

In section 5.3.2, social and emotional adaptations for non-verbal communicating participants was touched upon in relation to non-verbal participants communication with other children. However, in the current subsection, there has been discussion on simply being able to communicate with coaches and volunteers. It is important to note that other children recognize this, as seen below:

> *Magic: Why are you talking to him (Charlie) like he's a baby?*
> *Coach: He understands simple language.*
> *Magic: You know he's like older than me right?*
> *Coach: Yeah.*
> *Magic: I know I wouldn't like that and he listens to me and I talk to*
> *him normally.*
> Magic, Fieldnote: March 10, 2019

During the analysis, there are various examples of children with disabilities who are verbal questioning the interactions of adults and children who communicate non-verbally. Participation models are often described in a context of 'talking, thinking and deciding' which has left out children with disabilities (Martin and Franklin 2010); however, the analysis of this thesis goes further to understand that opportunities to be heard and respected are even less common for children with disabilities who communicate non-verbally. It is important to fully understand the participatory process and the various roles children and adults play (Wyness 2015), as through this example it is not a linear process. The coach, in this example, is willing to have a discussion and explain to Magic, a child with a disability who speaks verbally, about Charlie who communicates non-verbally; however, she has not explored that same possibility with Charlie. When the coach was asked how she learnt to communicate with Charlie she stated, "I never was taught, I just kind of say simple things" (Charlie, fieldnote: March 10, 2019). Recognition of agency is understanding children's capabilities (Oswell 2013), however, the coach in this example is assuming lack of capacity rather than attempting to communicate in a respectful manner.

The current subsection has explored non-verbal adaptations for children who communicate non-verbally and has suggested that the process of participation is different between children with disabilities dependent on communication. In adult and child relationships between children with disabilities, it is important to acknowledge as the lived experience of participation that negotiation and power vary due to communication. The following subsection will discuss participants' views on their coaches training, and gain insight into feedback children with disabilities regarding their relationships with adults.

5.3.4 Participant view of training of coaches

It can be seen throughout the current section that children with disabilities have little impact on adaptation changes and are not consulted, even at the beginning of participation. In the next paragraphs, there will be a couple of examples provided on how coaches feel about the training provided followed by children giving their experiences with coaches and suggestions for improvement. Feedback is rarely sought from children on how to improve the programs. This may be a valuable take away for programs that participated in this study to understand how children are experiencing their participation.

Before encountering child participants, coaches in all the programs (except one) received training to prepare them for coaching children with disabilities. The examples below show from the coaches' perspectives of what their training looked like.

> *Horseback riding coach: Being a coach you have to train as a volunteer first and learn all that like basic disability stuff, safety stuff. You really just meet with the program manager and she just tells you what to do I guess.*
> Fieldnote: September 22, 2018
>
> *You know what? It's a matter of I think you know (executive director) and (board member) and they have a look at some of the parents that are around, and they have a look at how we evolved as groups. For me it was a matter of I kind of volunteered little bit more secure come on out. For the most part I think they kind of go to*

*those that they think would make pretty decent coaches and you
know, because I being volunteers with a lot of volunteers not
everybody's made to be a coach and maybe I'm one of them but they
just I think basically they just kind of feel out who's around who's
going to be there who's committed every week but I think that's part
of it seeing there first every week and then say, okay this person is
going to be here, you know, they look like they have an idea what
they're doing. Let's see if they can be a coach or help here and in
junior, I was able to be on the bench and oh on the ice with the kids
for a year, so that was kind of a bit of a training if you will for being
a coach because you're kind of getting a sense of what's happening
on the ice. And so that's where I kind of got my training from
himself.*
Coach, Interview: March 9, 2019

The horseback riding coach received some informal sharing of experience from the

program manager, but it was not apparent whether there was ongoing support and

monitoring. The hockey coach was picked from volunteers that were already somewhat

involved. After being observed over a period of time, the program manager would approach

the volunteer to solicit interest in coaching. The hockey coach had no formal training but

was regularly monitored and received ongoing informal guidance from the program manager.

Although the one organization said they did not train coaches as such, there was

training that was done, just in a more kinesthetic way. There was a larger population to select

from and the volunteers graduated to coaching, as they absorbed the culture and norms of the

organization. The other organization lacked the large pool of qualified volunteers to select

from and the transition to coach was not typically from volunteer rather from coaching in

non-disability-oriented programs.

Throughout the ethnographic study, there were opportunities to ask children with

disabilities, what they thought of their coaches. Some of the answers received were:

*Chloe's response: I don't like (a coach's name) because I don't
even think she knows my name, and I like (a coach's name) because
she talks to me like a person and is fun.*
Chloe, Fieldnote: March 8, 2019

> *Aspyn's response: (coach's name) is strict but I learn so much so*
> *that's great and (coach's name) I don't really get along with*
> *anymore. I asked why is that and Aspyn says she just pressures me*
> *to do more and I just want this to be fun.*
> Aspyn, Fieldnote: February 3, 2019

In the examples, Chloe doesn't like her coach, because she does not feel a personal connection; her other coach, by comparison regularly interacts with Chloe creating a fun environment. For Aspyn, she is able to overlook the strict style of coaching, because Aspyn feels the benefit or effectiveness of the participation experience.

Children's responses about their coaches were not being sought by the organizations, and there was limited time for feedback from any family member. Parents either advocate for their child's experience or nothing seems to happen. This is another example of children's lived experience learning that coaches and organizations are not willing to hear their feedback making this loop non-participation (Hart 1992). There was no clear way that children could choose to participate in feedback, even if they wanted to assert their agency (Tisdall and Punch 2012). This research study views participants as beings capable of forming views (Qvortrup 1994); however, coaches made the expression of these views difficult, as they asserted their power over participants regularly. When questioning organizations, if there was opportunity for coach changes or feedback from children with disabilities, the response was that these opportunities were almost non-existent. However, there was some expectation that coaches adapt to each child and how they are behaving that day.

Furthermore, this study allowed for participants to express their observations of participation activity and their appreciation of or frustration with the coaches:

> *Kirby's speed skating coach always seems to know what Kirby is*
> *going to do before he does it. If Kirby starts to look a bit frustrated*
> *or anxious or isn't getting a drill it seems to be his coach is already*
> *there telling him to 'slow down' and 'think' about what he is doing.*

It seems to be working really well for Kirby, he's always going to his coach for high fives and will look for him if he is late for directions.
Reflective Notes: December 2018

Moose today is very floppy on his horse he is falling over volunteers that are holding his hips to stay seated and then his upper body with their other hand to keep him from collapsing. The coach walks away and is looking outside before she comes back over to him and says 'I don't know what you want from me, we can't do this every week' she is clearly frustrated and perhaps out of ideas but is looking like to be ignoring the problem and now setting up for her next lesson.
Moose, Fieldnote: October 20, 2018

The observations reflect two extremes. For Kirby, the coach appears to be fully attuned to Kirby's experience picking up on subtle clues. For Moose, the coach's choice to ignore Moose's performance appears to have created frustration for both the participant and the coach.

Not all coaches in the extracurricular physical activity community have the same skill set and come to programs with different life experiences which may have an impact on how they behave towards children with disabilities. In the above examples, there are two very different interactions for children with disabilities. One coach treats the child as a valued participant which is recognizing that Kirby may need some extra instructions. The other coach reacts differently, and the adult is refusing to listen and gets frustrated. It has been understood that children with disabilities may have a difficult time finding safe and reasonable adjustments to participate in extracurricular physical activities (Pickering 2018).

Regulation of coaches should be considered. There is a range of oversight by the organizations. In one instance, the executive director is always present watching the coaches interact with the participants while in another instance, there is no one observing the coaches, as shown in the examples below:

Hockey is set up in the rink there are 2 ice pads and the executive director's office is like a glass box in the middle of them. He is constantly watching and running out to make changes or offer

support or get a different piece of equipment. It seems like every
potential problem is solved right away.
Reflective Notes: November 2018

At horseback riding, none of the 'program' staff are there when I am
it seems. The executive director, program manager and head
instructor all work during the day so not when lessons are running.
It seems difficult for coaches to get any type of support or feedback.
It seemingly takes weeks for changes to be made or for coaches to
get feedback.
Reflective Notes: October 2018

For the hockey program, the executive director is always onsite when the participants are present. Hockey takes place one-day per week and the facilities are rented. For horseback riding, participation happens in the evenings and over the weekend. The program manager is responsible for the facilities and the operation of the program making constant presence during participation less practical.

In addition, coaches at hockey often reported feeling very supported, and at horseback riding there was a constant clear frustration about the staff. Hockey takes a team approach to participation while it is the horseback riding coaches who need to take ownership of the participation experience. As already noted, there were many cases of burn out with the horseback riding volunteer coaches, and it seemed that children with disabilities were not receiving adequate support staff.

5.3.5 Section Summary

The current section explores adaptations for participation in extracurricular physical activities for children with disabilities. Specific exploration of adaptations included physical, social, and emotional, non-verbal, and training for coaches. The chapter focused on participation, and although ideally children would be heard in decisions surrounding adaptations, that is not frequently the case. Adults and coaches often make adaptation decisions for children with disabilities, and sometimes have not explained to participations

why or how the decisions were made. There is a tension between children with disabilities and adults' interactions with perhaps a lack of recognition for non-verbal communicating participants, as identified by verbally communicating participants.

Adaptations for extracurricular activities are specific to individual participants, with individual experiences of implementations. Implementation was not consistent across all activities. Additionally, there were no policies and little opportunity for feedback from children. Organizations often relied on coaches to be the experts in implementation of adaptations with little to no room for children's views or preferences.

The following section of the chapter begins to explore participation elements in relation to extracurricular physical activities. The section will examine key topics of space, audience, influence, and voice alongside lived experiences of children with disabilities. The examination will explore the process of participation and the opportunities and constraints that children and adults negotiate in practice.

5.4 Participation Elements

The following section discusses participation in extracurricular physical activities in relation to the understanding Lundy's (2007) Four Elements to Participation. The section is divided into the subsections of space, audience, influence and voice to further analyse the data in relation to participation.

5.4.1 Space

Developed in Lundy's (2007) participation model, space is an essential component to ensure Article 12 of the UNCRC is being upheld, specifically the right to express a view. Under the concept of space, Lundy states "children must be given the opportunity to express

a view" (Lundy 2007, p.933). However, in the context of extracurricular physical activities, this opportunity to express a view was rarely given as seen in the following example:

> *Coach: Today we're going to start off with stretches then some*
> *trotting and then we'll do our course and maybe go outside if we*
> *have time.*
> *Magic: Um hello I would actually like to go outside now.*
> *Coach: Ok we need to stop talking and start stretches.*
> *Magic: Great no one listens around here.*
> Fieldnote: June 16, 2019

In this example, horseback rider Magic expresses the desire to direct the activities to be undertaken. Magic's view is either not heard or ignored and Magic verbalises the frustration that no one was listening perhaps indicating that this is a common experience for Magic.

The example highlights that there is no space for feedback or consultancy. We see Magic is resistant to a portion of the adults' control, the coach's decision on what to do' and Magic is not being a passive recipient and is showcasing that she is actually a social actor (Tisdall and Punch 2012). According to the UNCRC, this would not be deemed to be participation, as there is no feedback for the voice Magic is asserting, and it is not through an ongoing conversation (UNCRC, 2009). Space according to Lundy (2007) includes adults seeking views of children, but in this example Magic is expressing a voice however, the coach is not hearing her voice.

The previous example related to the structure of an activity space which is an issue throughout other aspects of activities as well as shown below:

> *Researcher: If you could change one thing about dance what would*
> *it be?*
> *Aspyn: I guess I just wish we could pick some of the moves.*
> *Researcher: What kind of things do you wish you could do?*
> *Aspyn: I don't know I would need some time, but I really like to*
> *make up dances with my friends and it would be fun to do some of*
> *those with the girls in my dance class too.*

Aspyn, Interview: March 12, 2019

In this excerpt, we hear Aspyn's views about her dance class. Although she enjoys her activity, Aspyn would like to have more freedom to self-direct what dances and moves are practised.

We see again that coaches do not seek children's views. Continuously it was observed that these spaces were regulated and policed by adults (James and James 2008). It was observed that these spaces were about power over children and silencing their views (Gaventa 2005). Although they are still participating in the activity, it makes for a grey area of participation as Hart (1992) describes, participation can be children being informed about the decisions whilst they are participating.

Extracurricular physical activities are a defined social space and these defined social spaces are often regulated by adults (James and James 2008). Children with disabilities in extracurricular activities are part of a social space where adults should recognize children's voices and take them seriously (Lundy 2007). However, in the example below this is not always translated into practice.

> *Coach: I sometimes ask children questions about how they like*
> *horseback riding really to see if they enjoy it.*
> *Researcher: Which children do you ask?*
> *Coach: Ones that can respond.*
> *Researcher: Verbally?*
> *Coach: Yes.*
> Fieldnote: December 10, 2018

A contribution to research is recognizing a gap in lived experiences of children with disabilities who communicate verbally, and nonverbally. In the previous examples, there were limited opportunities for space for children to express themselves. However, coaches acknowledge a further divide when non-verbal communication is discussed. In literature there is a suggestion that space should include the use of technology, as it opens opportunities

for various perspectives of children with disabilities instead of being reliant on voice only

(Lankshear and Knobel 2011). Participation is built on a process of interactions and

communications (Lundy 2007), however, in this example there is little attempt at non-verbal

communication inclusion.

Additionally, physical space has been blocked off in extracurricular physical activities

for children with disabilities such as office space where coaches plan lessons. This is similar

to school environments where staff rooms are blocked off (Gallacher 2005). An example of

an implication of this practice is seen below:

> *Chloe is knocking on the glass office door where she sees her coach*
> *sitting behind. The coach answers the door and asks 'can I help*
> *you?'. Chloe responds asking 'can we talk about my lesson today?'*
> *and the coach says 'no, I'm busy right now.' When the coach closes*
> *the door I ask Chloe 'what do you want to talk about?' and she says*
> *'I just thought I could talk to her about trying something different' I*
> *responded and said 'well maybe you can talk to her during your*
> *lesson' Chloe then responds 'no she doesn't like talking then'.*
> Chloe, Fieldnote: February 6, 2019

Physical space has been blocked off for children with disabilities in this environment,

as they are unable to enter the office. It is also the only place in the building with stairs rather

than a ramp, making it physically inaccessible for Chloe. In the example, lesson planning

becomes a place where children with disabilities are physically blocked off. Various times

coaches were asked about input from participants regarding lesson planning and comments

would be similar to "I coach, so I make the lesson plan" (Coach, Fieldnote: October 20,

2019). The specific coach was asked about this experience later that day:

> *Researcher: Did you ever talk to Chloe?*
> *Coach: What do you mean?*
> *Researcher: She came by your office before the lesson.*
> *Coach: Oh, no I didn't ask about it later.*
> *Researcher: During lessons is there time to ask participants their*
> *views?*
> *Coach: On what?*

> *Researcher: Just generally, how they're experiencing the program*
> *maybe.*
> *Coach: I don't ask them, but I can tell if they're enjoying their time.*
> *Researcher: Does the organization ask children?*
> *Coach: No.*
> Chloe, Fieldnote: February 6, 2019

Participation is a learning experience for both children and adults, and a process of enquiry would perhaps support changes and improvements to the process (Percy-Smith 2018). However, in this example it is shown that Chloe first does not feel comfortable engaging in conversation during lesson time, and when she attempted to have a conversation outside of lesson time, the coach did not make the time to listen. It has been noted that enforceability of including space for children with disabilities to express a view is lacking (Tisdall and Punch 2012), however, the organization in this example does not recognize the importance of including space for children's perspectives. Creating a meaningful space for participation requires adults and children working together (Frankel 2017), however, this step has not been taken in some extracurricular physical activities.

To contrast the previous experiences of space of participation, a different view is found in an example below:

> *Kirby: (Coach's name) listens to me when he isn't talking to*
> *someone else, I'm not supposed to interrupt.*
> *Researcher: What do you talk to him about?*
> *Kirby: Well I tell him if I'm having a good day or bad day.*
> *Researcher: Why do you tell him that?*
> *Kirby: If I say bad day he isn't as hard on me but if I say good day*
> *that means I'm ready to work.*
> *Researcher: How does he know that?*
> *Kirby: We've talked about it because he really wasn't understanding*
> *when he first started coaching me.*
> Kirby, Fieldnote: November 15, 2018

The example above contrasts the previous examples in this subsection, as Kirby and his coach have worked together to construct space to communicate and knowledge about participation to change his experience. Kirby feels comfortable with his coach and has had a meaningful conversation to encourage participation (Cornwall and Coelho 2007). Within

Kirby's space, he has negotiated action opportunities (Bacon and Frankel 2014), and he has worked alongside his coach to take action himself each session to reflect on how he will participate that day, and his coach has taken meaningful action to respond.

To summarize, this section answers in part the research question one as adults are regulating the spaces children occupy and shaping their environment to how they see fit. The examples show how adults are either constraining or making opportunities for children's recognized participation. Additionally, children are full of ideas on how to further participation, but their navigation of their environments is sometimes halted which adds to the understanding of the current research question. Participation elements as discussed by Lundy (2007) also include audience which will be discussed in the following subsection as audience is exploring beyond space to ensuring children's views are communicated and listened to.

5.4.2 Audience

Children with disabilities participating and being co-participants in extracurricular physical activities involves having an 'audience' for their views to be safely shared (Lundy 2007). It is not about just having conversations between adults and children, but it is also about children being comfortable participating with adults (Wyness 2013). In order for children to be co-producers of knowledge, children need to be respected and seen as experts (Tisdall 2017). There is a responsibility to listen to children's views. Children with disabilities throughout the study show their agency when they are not being listened to. Participation should not just be a process of allowing children to offer their views (Woodhead 2010, p.xxii), but rather children should be seen as co-participants. In the following example, we see a volunteer who is 16 years of age talking about one of the participants that she works with:

Researcher: How do you think her coaches support or impede her participation?
Volunteer 45: They literally don't do anything too, it's bad. Like I'm trying to think of like everyone as an individual like I've kind of just thinking about (Coach's name) mostly. (Coach's name) did nothing for her at all. Nothing.
Volunteer, Interview: June 7, 2019

This is similar to another interview with a 15-year-old volunteer:

Researcher: Okay. How do you think the coaches support or impede his participation?
Volunteer 124: I think she definitely impedes his participation because the attention gets put on (the other rider) for more advanced things and Charlie's not given the opportunity to practice or try anything that she does. He just sits there really no one talks to him which is kind of sad. That's part of participating right? Talking to him? I don't know what I would do if my coach didn't talk to me.
Volunteer Interview: August 18, 2019

In these two examples, the volunteers assisting with the lessons perceive the coaches as instructing at the participant rather than trying to communicate with the participant. The volunteers question the value that the participants receiving.

When talking about coaching styles to volunteers in this current research study, the volunteers seem to recognize various degrees of participation between the coach and participant. There was no clear way that children could choose to participate, even if they wanted to assert their agency (Tisdall and Punch 2012). This research study views participants as beings capable of forming views (Qvortrup 1994); however, coaches made this difficult to do, as they asserted their power over participants regularly. These coaches have made the decision about who is capable of forming views (Hanson 2012). In the discussion with Charlie's volunteer, he is not as advanced as his riding partner and has been excluded based on the assumption of what he can do (Cockburn 1998). Although volunteers may notice a gap in participation opportunities, they do not often have the power to make decisions on changes to activities.

Children with disabilities understand who is approachable in extracurricular physical activity environments, as shown in the example below:

> *Marie: (horseback riding coach's name) doesn't listen to me at all*
> *really, so I don't really say anything anymore.*
> *Researcher: What about other coaches?*
> *Marie: Yeah my hockey coach always listens.*
> *Researcher: What do you talk to him about?*
> *Marie: Well I get really upset sometimes and need a break and he's*
> *never mad or anything or makes me do anything.*
> *Researcher: What if he made you do something?*
> *Marie: I guess it wouldn't really matter because I know it's for a*
> *reason like if I just lie down in front of the net I'd get hit by pucks so*
> *he won't let me do that.*
> Marie, Fieldnote: January 28, 2019

Marie understands that coaches have the ability to incorporate her views into the decision process or not and her experiences in various activities vary depending on the environment. She feels her 'audience' at hockey is being listened to and although she does not always make the decisions, she feels that her views are considered. Marie in hockey feels she is listened to, and her views are taken into account (Sheir 2001). Marie suggests there may have been feedback about decisions made about her taking a break, as she cites safety reasons for where she takes a break. Marie feels she is a part of a participation opportunity and has some influence on the decision-making process which is encouraging her to participate with her hockey coach rather than her horseback riding coach (Bjerke 2011).

To conclude this subsection answers in part the research question number one as adults are restricting children with disabilities' full participation by shaping the environment which children occupy. Although there is little audience for children with disabilities to express their views in extracurricular physical activities, they still may find ways to do so, as seen in the next section.

5.4.3 Influence

Within this project, children with disabilities that demonstrated agency around

extracurricular physical activities were often left unrecognized or seen as exhibiting deviant

behaviour. It is not only important for children to be able to express their views but also have

their views taken into account in all matters that affect their lives (Tisdall and Punch 2012).

The influence of children's views is important throughout participation models (examples;

Lundy 2007, Sheir 2001, Wall 2008). The following example is of participant Chloe looking

for change from the researcher:

> *Chloe has changed coaches almost weekly, it seems. I had a*
> *conversation with the program manager earlier this week who*
> *called asking if I would be there for Chloe's session this week. I*
> *responded 'yes' and the program manager said, 'ok great because*
> *Chloe's parents are really mad, because she is switching coaches*
> *again, but they wanted to make sure you were there'. After riding*
> *this week Chloe came up to me looking super upset and said, 'tell*
> *that lady that my legs are weak, I was 'terrified'. I responded, 'can*
> *we tell her together what you want?' and Chloe said 'no, I don't*
> *know her, and she clearly doesn't understand or know my*
> *disability'. I said, 'ok what would you like me to tell her' Chloe says,*
> *'just tell her I can't do all that stuff, my legs are too weak and it's*
> *embarrassing telling her I can't do it'. Chloe was getting*
> *increasingly upset so I said 'ok let's go feed your horse an apple and*
> *I promise I will tell your coach what you told me'.*
> Chloe, Fieldnote: January 12, 2019.

In this example, Chloe wants to communicate a message to her new coach, but her

lived experience tells her that her voice will not be heard unless it comes from someone else.

Chloe asks the researcher to her voice creating an ethical dilemma for the researcher whether

to cross from observer to participant. The previous ethical decision was made in the moment

(Wall 2010, Zigon 2008) and was situated and contextualised within this environment

(Simmons and Usher 2002). There was a friendship that was built with Chloe and friendships

have been seen to be of importance in good data collecting (Oakley 1981). The researcher

had put in a good amount of time building rapport with Chloe to gain her trust and build a

relationship (Punch 2002). Unfortunately, this same amount of time was not spent by the

coach in her extracurricular physical activity due to the constant changing of coaches; the person she felt comfortable communicating with was the researcher. As a result, of being in a 'friend' researching role with Chloe, the researcher was her way of finding the result and 'influence' she wanted through her strategically enlisting of another adult's participation in the communication. In this way, Chloe's voice is being heard and she is exerting influence resulting in agency (Lundy 2007), although this happened through the relationship with the researcher. At first, the researcher struggled with this:

> *I'm not sure if this is my place to tell a coach what they should be doing, or what their student is thinking.*
> Reflexive notes: January 13, 2019

> *If I'm taking the 'friend' role, as a 'friend' I would help the process of communication and do everything in my 'power' to help my 'friend' feel comfortable. I've also said I would say something, therefore, potentially making it worse and betraying trust if I don't.*
> Reflexive notes: January 14, 2019

> *At the last session of the year, Chloe's dad says to me. "I don't know what we're going to do without you next year". The friend role is looking like I was too close to the everyday lives of children in my study. I perhaps should have taken a further seat back, because it is now going to be harder for children.*
> Reflexive notes: June 22, 2019

Over the period of the study, Chloe developed a strong friendship with the researcher which would be normal given the extended period of the study and the amount of interaction. The researcher's participation in the activities was as a non-judgmental observer different from other adult interactions that Chloe experienced.

Perhaps by becoming a 'helper' for Chloe, the researcher became more 'powerful' and Chloe became less capable and autonomous (Christensen 1999). Although children should be able to express their views to whomever they want, there could have been more support from the researcher to help her express her views to the 'right' adult who needed the information. By excluding her from the conversation, the researcher continued the divide

between children and adults which enabled the power divide even further (Frankel 2017). Seeing children as co-participants was the researcher's ideal which would have included creating change making activities with Chloe (Frankel 2018); it could have become a self-advocacy project alongside Chloe. Rather the researcher stepped in to aid a 'vulnerable' participant instead of seeing her as a co-participant.

Although the reflexive notes do show that the researcher is questioning, whether assisting with Chloe's communication is ethical, she did put pressure on Chloe to act (Hartas 2008), and additionally, offered a choice of whether to participate in the process of talking to her coach or not (Tisdall and Punch 2012). Granted Chloe most likely had the ability to push back against the power structure (Frankel 2017), which in this case was her coach, the researcher made an in the moment decision on how to act that satisfied Chloe's want to be heard and to create an influence in the moment. This is an example of Chloe navigating her participation through her activity which in part answers research question number one. In addition, Chloe was hopeful that her participation would create change with the adults that shaped her experience of horseback riding which in part answers research question number one.

5.4.4 Voice

Children with disabilities are perhaps more likely to express themselves in informal surroundings (Cockburn 2013). Before service providers are able to see children with disabilities as agentic, they need to recognize their voices. Although this adheres to the UNCRC as seen in previous examples, this was not always the case in the study. Normative expectations should be left behind, and different expression forms should be accepted as children communicate for understanding (Carroll and Twomey 2018). This is to go beyond language, expression and freedom of opinion to enhance communication rights (McLeod

2018). The example below is about a child with a disability who is using non-verbal

expression in a way that cannot be ignored:

> *Today Mickey was not going to be overlooked by anyone. He was*
> *very set on what he wanted from his horseback riding. When he got*
> *onto the horse and the horse started to move without him touching*
> *'walk on' on his iPad he gave a disgusted look to his volunteer who*
> *holds the iPad and then put his hand on her head. She automatically*
> *noticed what she had done wrong and said, 'oh sorry bud you're*
> *right here you go' and gave him his iPad. Next, when the coach was*
> *talking to him like he was a 2-year-old saying 'Mickeyyyy Mickeyy,*
> *look at me look at me' he had enough and just laid down on his*
> *horse. She eventually got the hint and stopped talking to him in a*
> *baby voice. Finally, he's now learnt how to get his horse to trot*
> *which is when he smiles the most. Today when he wanted to trot,*
> *without instruction he would just start to kick his horse to get him to*
> *go.*
> Reflexive notes: May 2019

In this example, Mickey was able to non-verbally communicate effectively with the

volunteer, using an iPad and with the coach using body language. Voice is perhaps socially

constructed whilst privileging spoken communication (Komulainen 2007), sometimes

allowing children's voices to be unheard (Carroll and Twomey 2018). However, in this case,

Mickey presented his voice in a way that was unable to be ignored. Mickey utilized his

agency to be heard and to make changes in his extracurricular physical activity. Mickey is

participating through navigating his experience of horseback riding and changing his

recognized participation.

Children have the right to information to form a view or perspective (Flekkoy and

Kaufman 1997, UNCRC 2009) and information should be shared between adults and children

based on respect (UNCRC 2009). However, through extracurricular physical activities it is

shown that is not always translated to practice.

> *Ben is riding his horse and his coach asks him to put his heels down.*
> *The bottom of his feet look like they are parallel to the ground. His*
> *coach keeps asking him to do this, and he is slouching further and*
> *further down looking disappointed and maybe confused. His*

> *volunteer asks the coach 'like this?' and she says 'no his heels need to go down. The coach seems to be getting frustrated that she's repeating herself and eventually said 'just forget it'. At the end of the lesson I ask 'why were you asking Ben for his heels down?' and she stated 'because if he were to fall with his heels up his foot could get caught in the sitrrup'. I asked her 'does Ben know this?' and she says 'no he won't understand'. I asked her 'how do you know he won't understand?' and she says 'he just won't he can't understand 2 step directions, he won't understand why he has to keep his heels down'.*
> Ben, Fieldnote: October 7, 2018

The coach has not shared information with Ben and the interaction with Ben was not based on mutual respect. Learning, dialogue and respect are included in the definition of the participation process (UNCRC 2009). The coach's view of Ben's understanding is perhaps limited; however, over time and in a language that Ben may comprehend and learn the participation process could be more inclusive. A criticism of the UNCRC is that the power for decision making is up to adults (Lansdown 2005), and in this example, the power the adult is exercising is to exclude Ben from the conversation completely, as the coach has decided his capacity independently. Although children's voices have recognized legitimacy, they have little power (Thomas and Stoecklin 2018), which in this example is shown through no attempt to engage with Ben.

5.4.5 Section Summary

The current subsection builds on the previous findings of motivations and adaptations of extracurricular physical activities as participation elements furthering the understanding of lived experiences of participation. Through participation elements of space, audience, influence and voice the data showed various opportunities and constraints to children's recognized participation in extracurricular physical activities.

Children with disabilities' participation opportunities and constraints were relational to their environment and interactions they had with adults. Organizations did not prioritize opportunities to create space and listen to children with disabilities' views about their

participation. Children were seen to utilize strategic flexibility in some of their environments as a way to change their participation experiences. However, coaches often were unwilling to engage in conversations and dialogue alongside children with disabilities which resulted in hierarchical constraints, and limited opportunities for children to act.

The next subsection of the chapter will further explore the interactions and relationships children with disabilities had with adults in extracurricular physical activity environments as identified as an important theme in the current subsection.

5.5 Relationships and Interactions

For the following subsection, relationships and interactions have been identified as key themes in answering research question number one as shown through participation elements. The subsection will discuss key findings such as time with children, willingness to understand and power.

5.5.1 Time with children

The shortest duration extracurricular physical activity program observed was snowboarding which was scheduled for 6 weeks; however, due to weather conditions there were only 3 weekly lessons. The longest extracurricular physical activity program observed was horseback riding which was 10 months in duration. Building rapport through an ongoing process (Milton 2018) with participants is necessary for not only the participant but for the coach to be continuously motivated to try new things and to add excitement to the activity, as shown in the example below:

> *Hockey coach: I know I can try new things with him, I trust him, and I think he trusts me. It makes a really big difference when there is mutual trust because we can push boundaries.*
> Fieldnote: January 10, 2019

> *Horseback riding coach: I do really enjoy teaching Magic,
> she is my favourite student by far. I don't think I'd still be
> coaching if it wasn't for her. I know she isn't good with
> change, so I like to be here for her and to be sure she likes to
> be here.*
> Magic, Fieldnote: June 10, 2019

Both the hockey coach and horseback riding coach are motivated by seeing their participants succeed. Through the time spent with children, coaches were able to see what they were able to push from their participants and understand their unique forms of communication as shown below:

> *I asked Charlie's hockey coach why Charlie bangs his stick on the
> ice and his response was "It really depends it is on the boards or on
> the surface of the ice, if it's on the boards I think that he is
> distracted and looking out the glass towards his parents. If it's on
> the ice and he's looking at the other kids he wants the puck passed
> to him.' I then asked a further question of 'how did you learn that?'
> and he said 'I've been working with him for two years and I know I
> don't fully understand what he's trying to say but I am trying and
> watching what he does after he makes gestures it just takes time and
> I was frustrated when I started working with him at how long it was
> taking me but I'm just trying to be patient and learn'.*
> Charlie, Fieldnote: January 5, 2019

The hockey coach is viewing Charlie as different, but equal to himself in the participation process (Bjerke 2011). Understanding the complex relationships between children and adults and how it relates to implications for children's participation is important (Mannion 2007), as the process of participation varies from different interactions. The hockey coach is taking a role of learning from Charlie, as he attempts to unpack Charlies different ways of communicating. This is different for Charlie in other environments as shown below.

> *Researcher: How do you communicate with Charlie?*
> *Baseball Coach: I don't really, we require children with multiple
> disabilities to bring staff with them.*
> *Researcher: Does Charlie ever communicate with you?*
> *Baseball Coach: I don't think he can.*
> Charlie, Fieldnote: July 20, 2019

Baseball, as a program is 8 weeks long with sessions once a week, whereas hockey is a program that is 6 months long with sessions twice a week. Although the baseball coach does not take time to learn communication from Charlie, during hockey there is much more opportunity and time to learn communication methods. Charlie also explores opportunities of how to participate as shown below:

> *Charlie has skated up without prompting to be the center of the puck drop three times today, and once hit the puck in the direction of one of his teammates. After doing this he skated to a teammate and bumped his glove to their glove.*
> Charlie, Fieldnote: March 11, 2019

Agency is seen through negotiation of relationships and different opportunities and constraints (Leonard 2016). Charlie took an opportunity to act in the hockey game and gained perhaps some capital and power (Frankel 2017), amongst his teammates which were cheering him along. Charlie does not often engage in the exact structure of a hockey game and is often off to the side, however here he is showing that he can act purposely (Valentine 2011).

Additionally, coaches who spend time with children with disabilities are seen to develop relationships with some participants as seen below.

> *Chloe: (riding partner's name) is the favourite so she gets whatever she wants, anything she wants to do its kinda annoying because I get ignored sometimes.*
> Chloe, Fieldnote: December 20, 2018

A similar example is shown below:

> *Aspyn: I know I'm the favourite at horseback riding and I know I get like more opportunities because she (coach) always lets me go to shows and stuff. It's awkward sometimes because I feel bad for the other riders but I also like it.*
> Aspyn, Fieldnote: February 2, 2019

Children with disabilities have taken note of how much time they are given in comparison to others. The role of the adult is important as in Aspyn's example the coach is enabling different forms of action whereas Chloe's participation is limited (Leonard 2016). Adult run organizations have been shown to potentially hinder children's participation and

choice (Baraldi and Cockburn 2018), however, as both examples show adults may enhance

participation opportunities depending on how the adult views the child. Components of social

life include structures and constrains to participation (Baraldi and Cockburn 2018), however,

it is important to note differences in lived experiences. Through the subsection, the

importance of time spent with children with disabilities has been demonstrated; however,

there is also a need for a willingness to understand children with disabilities' perspectives

which will be explored next.

5.5.2 Willingness to understand

Coaches and volunteers within the extracurricular environment benefit from a

willingness to understand children with disabilities, as individuals. The activities observed

were not always rigidly structured experiences demonstrating a benefit to flexibility in

session planning. Below is an example of willingness to learn and adapt to a child's needs:

> *This one time we had a child that was having such a hard time*
> *moving their hands up and down the stick. Our normal equipment*
> *are gloves but this young lady had two fingers missing so the fingers*
> *of the gloves are so hard, and they were getting in the way. I mean it*
> *might not seem too out of the box, but it took me a week to think let*
> *me just cut those off and sew the glove back together. I'm telling you*
> *there's always a way we just gotta keep thinking.*
> Fieldnote: January 2, 2019

In this example, the coach observed the participant struggling and identified an

adaption, the modification of equipment, to allow full participation. Spending time and the

willingness to seek various opportunities for children to participate led to greater

participation opportunities.

The modification and adaptation of an activity for an individual can create

opportunities for success and make participation easier (Geidne and Jerlinder 2016). In this

case, a simple adaptation to the equipment meant the child was able to go from unable to

perform the activity to a full participant. In contrast to being willing to explore and learn

different techniques, some coaches have a different approach:

> *I don't know why Moose rides here, he doesn't like it and it's not*
> *really safe, like I'm not a therapist.*
> Fieldnote: April 4, 2019

In this example, the coach is clearly frustrated with the lack of success Moose is

experiencing and does not understand why he is still in the program.

Individual physical activities may be easier to adapt to individual needs than group

activities (Grandisson et al. 2012). In contrast to the hockey example, there was no one

taking ownership for exploration of how to make participation for Moose more enjoyable

causing the child to derive little from his presence at the activity.

An important factor to acknowledge is the attitudes towards children with disabilities

and participants in physical activities (Rimmer et al. 2004). Children with disabilities notice

that there are differences between coaches' attitudes towards them as shown in the examples

below:

> *Chloe: I don't know why she yelled at me last week. I've been*
> *thinking about it all week and I just hope that I don't get yelled at*
> *again this week. I am trying.*
> Chloe, Fieldnote: November 19, 2018
>
> *Magic to her mother: 'Hey guess what?' her mother responds*
> *'what' and Magic says '(coach's name) said I was really good today*
> *and I did a good job' and her mother responds, 'that's great!'*
> Magic, Fieldnote: May 22, 2019

In these examples, Chloe appears to dread her lessons, because the coach yells at her.

In contrast, Magic appears quite excited by the positive feedback she is getting. Children

perceive the level of positivity in their environment which translates into their willingness to

participate and benefit. Chloe's views are not taken into account or explored which leaves a

lack of dialogue and a constraint on participation (Fitzgerald et al. 2010). There is an impact

created by coaches' actions on the everyday life of children with disabilities (Leonard 2016), Magic feeling pride from praise, and Chloe feeling confused about criticism.

Furthermore, children with disabilities are active in their negotiation of power relationships around them (Klocker 2007). Children with disabilities are participating and understanding their audience as shown below.

> *Well I know if I just ask (Volunteer's name) she won't do anything*
> *only my (coach's name) can change anything around here.*
> Magic, Fieldnote: March 7, 2019

In this example, Magic is expressing that her coach is the only adult that can make decisions regarding her participation. Additionally, Magic knows how to interact with her coach for her benefit:

> *All you've got to do to get them (coaches) to listen I just yell.*
> Magic Interview: August 7, 2019

Magic has learnt a way to get attention and dialogue from her coaches and utilizes that tool to her advantage. Magic has negotiated with her coaches through the action of yelling, that her coaches respond making her an agent in the interaction (Mayall 2002). Although perhaps utilizing agency in a negative way, Magic is actively changing her experience by utilizing her abilities and resources (Bjerke 2011). Children with disabilities can take action and create opportunities for participation, however, a willingness to understand and engage from adults in the environment of extracurricular activities is important as well. The following subsection will further discuss power relationships between adults and children.

5.5.3 Power in Relationships

Exploring lived experiences of children in extracurricular activities highlighted complex negotiations and the complex process of participation and power (Davis and Smith 2012). The structures of extracurricular physical activities has been discussed, often coaches

are in a hierarchical position of power over children with disabilities participating. However, this subsection will look at a few examples where power is negotiated resulting in opportunities and constraints for recognized participation.

Children understand when they are in a position where they lack power (Bacon and Frankel 2014), as shown in an example below.

> *Spyro: I'm constantly having to follow instructions and I get kinda bored.*
> *Researcher: Do you always follow them?*
> *Spyro: Not always but sometimes if I'm really bored I'll tell one of the coaches another coach told me I could take a break or do a move a different way.*
> *Researcher: Do they ever figure out your trick.*
> *Spyro: No, I don't think they ever really talk because they never find out.*
> Spyrou, Fieldnote: November 29, 2018

Spyro realizes that she is in a position that lacks power; however, she understands her activity that other coaches have power that she can borrow. She has made an opportunity for herself to demonstrate her own power in the social space (Bacon and Frankel 2014). Although her views are not being directly heard, she has negotiated a position where she can choose what movements she wants to do with little questioning. The example shows 'strategic flexibility' and Spyro moved through multi-layered relationships gaining power (Bacon and Frankel 2014).

To contrast with this example, children with disabilities who assert agency have also been seen through a negative view and their behaviours as problematic (Tisdall and Punch 2012), as shown below.

> *During Moose's horseback riding lesson tonight the coach was not overly paying attention to him. She was on her phone and giving limited instructions to Moose's volunteers in order for him to participate. After numerous cries from Moose, perhaps attempting to signal discomfort he drops his weight to one side and tries to slide himself off of the horse. The coach starts to scream at him saying*

> *'you can't do that' and very abruptly pushing him up back on the*
> *horse. She is clearly very upset and states 'I can't teach this lesson*
> *it's too much if you can't even sit up'.*
> Moose, Fieldnote: November 6, 2018

Moose has shown the ability to push back against power structures (Frankel 2017). The coach has become upset and views Moose's behaviour as challenging and problematic (Tisdall and Punch 2012). Moose often has limited opportunities for recognized participation as his volunteers and coach often do not engage with communication of any degree. In this example, Moose's decision to get off his horse was seen by his environment negatively rather than as an attempt to communicate or show agency. The example reaffirms that people with disabilities' views are often not sought (Richards 2018). Additionally, if there was perhaps reflection on the example utilizing the social model (Oliver 1996), there could be an examination of the environment to question how inclusive it is. Power can be understood through examples of lived experiences in the thesis; however, it was important to show the reactions to children with disabilities acting. The following subsection notes an important finding in the change of lived experience when a researcher is added into the participation environment.

5.5.4 Researcher power

Researcher power was discussed in the Methodology Chapter; however, a couple examples below are important to note for the understanding of opportunities and constraints created for the lived experience of participation. Mayall (2008), suggests minimizing the hierarchal relationship of child-adult interactions, which the study followed by placing the researcher as 'friend' and not the 'boss'. In classrooms, the 'boss' is the teacher (Watson 2017), and in this case the 'boss' is the coach. My power relationships with children shifted continuously based on how the particular child perceived me and what that meant for them (Jones et al. 2018). For some participants, they saw this as an advantage:

Coach: Katie: So I know you're looking at participation, what would you like me to do today in the lesson I can do whatever you need me to do.
Researcher: Just continue as normal.
Marie: Actually, shouldn't you be asking me?
Coach: Well, Katie is the researcher, and she's going to be writing about us, so she needs to see some stuff.
Marie: Did you know participation is about children too?
Coach: But you're horseback riding and I'm the coach.
Marie: Katie said I get to make any decision I want about my research.
Researcher: And what would you like to do today?
Marie: Ride backwards.
Coach: I guess we'll do that then.
Marie, Fieldnote: June 14, 2019

In this example, Marie wants to dictate what the horseback lesson will look like. The coach listens to Marie to the extent that Marie's wishes are within the framework of a horseback riding, the goals of lesson, and safety.

In this research study, participants were viewed as participants rather than objects of research, and one way this was done was building a trusting rapport with the children (O'Kane 2008). Although this research study valued the children's perspectives, there was a tension when it came to other adults in the field. Corsaro (1985) suggests that the research should let the children in the study shape and define the ethnographer's role. In this example, I allowed Marie to take the lead after she voiced her need to participate further, with the information she received from my study. I started at a baseline of explaining to participants what participation was to children in this project. Hill (2005), suggests methods that are geared to the understanding of children; an explanation was needed directed at children. However, as Marie points out in the example, with knowledge came the power to tell her coach what she would like to do, because her voice mattered in the context of participation. This answers in part research question number one, as shown adults and children can shape

their experiences. Marie was advocating for herself; she pushed the boundaries of what participation would be allowed within her environment.

5.5.5 Section Summary

The current section built on the previous sections of motivations and adaptations to extracurricular physical activity environments. In the subsection main themes that were discussed included time with children, willingness to understand and power. Lived experiences were shown to vary between participants and environments which resulted in vast differences in participation opportunities and constraints.

Time spent with children with disabilities was imperative to the participation experiences for participants, especially participants who communicated non-verbally as different communication styles needed to be explored. Second, a willingness to understand and explore participation opportunities for children with disabilities was essential. Exploration of opportunities to seek out ways for children to enhance participation opportunities are needed. Finally, power within relationships was discussed and how children with disabilities can utilize strategic flexibility to negotiate their participation through various structures and interactions.

5.6 Chapter Five Conclusion

At the beginning of this chapter, the stated aim was to answer research question number one:

> **Question 1:** How do adults and children create opportunities
> and constraints for children's recognized participation?

The chapter is broken up into the topics of motivation of key personnel, adaptation within these environments, participation elements and interactions with children. Various themes are raised with some of them being agency, participation opportunities, participation

constraints, voice of the child, and the child's perspective. The chapter derives insights from examples of children with disabilities and their lived experiences in extracurricular physical activity environments. The voices and experiences of the children are prioritized in the research to highlight that children with disabilities are not just subjected to their environment but are also able to make changes and express their views through their agency.

The chapter analysed various participation opportunities and constraints that children with disabilities experiences in extracurricular physical activities. This was done by exploring elements of participation such as space, audience, influence and voice. Throughout the chapter, the process of participation was influenced by structure and how that structure can change as seen through the adaptation section. The motivations of key personnel involved was important in understanding how interactions played out and were negotiated over the course of the chapter. Participation opportunities and constraints were explored throughout and were seen as something that was constantly changing over time, negotiation and environments. The process of negotiating participation was embedded in the interactions children with disabilities had with adults, coaches, volunteer, environments, and structures. The following chapter will continue to unpack lived experiences of children with disabilities; however, it will focus on the topic of inclusion within the extracurricular physical activity environments.

Chapter Six: Children with Disabilities experiences of living through the Process of Inclusion

6.1 Introduction

The previous chapter gave an in-depth look into the lived experiences of children with disabilities participating in an extracurricular physical activity environment. Having a good fundamental knowledge base of what is happening day to day in extracurricular environments is an important starting point, as this chapter will narrow the study's focus to inclusion. The lived experiences of inclusion practices will be examined from the participants' perspective with the aim of this chapter being to move the common thinking around inclusion. Western society sees inclusion as worth striving for, as it is universally agreed to be morally 'right' and 'good'. The goal of full inclusion for people with disabilities has been disseminated through international documents (UN, 2006; WHO, 2001) and national legislation (Canadian Disability Policy Alliance, 2009), and it is the aim of organisations involved in the delivery of extracurricular physical activity, as shown in this study. Through these documents, inclusion is seen as a desired achievement to attain. Generally, definitions of inclusion in literature tend to lack clarity (Nilhom and Göransson 2017). An examination of the various definitions of inclusion can be found in Chapter Two of this PhD thesis. To this point, literature has called for an exploration of the perspectives of people with disabilities regarding their lived experiences of inclusion (Spencer-Cavaliere and Watkinson 2010, Susinos 2007). This chapter will address the academic literature gap in respect of the perspectives of children with disabilities about inclusion and their lived experiences of inclusion through answering the following research question.

Question 2: How do children with disabilities navigate (or live through) the process of inclusion in extracurricular physical activities?

This chapter will explore the perspectives and understanding of children with disabilities whilst they live through everyday experiences of inclusion. Some previous research does utilize participatory research methods; however, this chapter will take the inclusion agenda further by ensuring inclusion is looked at through the eyes of the participants in this study. Throughout this study importance has been placed on children's co-participation in all aspects of their lives, and this PhD thesis will ensure children's perspectives are represented by examining the ways in which they see inclusion. The chapter will start with data from participants and coaches about their respective understandings of inclusion. The chapter will also share some lived experiences of inclusion and explore how children with disabilities are shaping inclusion, in practice.

6.2 External Factors of Inclusion

The following section of the chapter will begin to unpack external factors that impact the lived experience of inclusion in extracurricular physical activities for children with disabilities. The section starts with a discussion of organizational factors, followed by parental factors and concluding with the perspectives of children with disabilities.

6.2.1 Organizations' understanding of inclusion

The participation in extracurricular physical activities that was explored for this thesis took place at 11 different organizations. Inclusion was a goal of all the organizations. In literature, it is understood that the goal would be to have all children participate and to remove exclusionary practices (Barton 2013). One interpretation of inclusion is shown below.

> *Coach: Inclusion here is allowing children with disabilities to participate.*
> *Researcher: All children with disabilities?*

> *Coach: Most, but they have to go through a process with a physio*
> *(therapist) and some kids can't if they've had a seizure or they have*
> *other issues.*
> Fieldnote: October 12, 2018

In the example, the coach is insisting inclusion is happening at their organization

simply by having children with disabilities present. This is similar to the implementation of

'inclusion' in mainstream schools where the attendance of children with disabilities was how

inclusion was going to be reached (Krischler et al. 2019). However, there is still a medical

understanding of disability and children with disabilities who fall outside of the accepted

criteria are excluded. Although the space is meant for people with disabilities, there is still

medical understandings and exclusionary based practices occurring. Inclusion in this example

is also at a facility with only children with disabilities participating rather than amongst

children without a disability which would be understood as segregated in literature (De Beco

2016). The contradiction of inclusion understandings between practice and literature was

common in all segregated activities a similar definition from fieldwork can be seen below.

> *Coach: It is inclusive here because we welcome all children with*
> *disabilities to come out and try skiing, we try to make it work for*
> *everyone.*
> Fieldnote: January 7, 2019

Skiing is a separate activity from children without disabilities which continues to

show a contradiction to the definition in literature, as it would not be inclusive for all

children. However, the example shows some aspects of inclusion in that the coach is striving

to welcome children (Price and D'Eloia 2018), and is committed to finding ways for children

to be involved and try their best (Miller and Katz 2002).

Inclusion understanding in a segregated activity was noted to be different than

explanations from activities that had all children participating as shown below.

> *Coach: We're inclusive because I think we try not to see disability*
> *and try to help everyone progress through the levels.*
> *Researcher: Do you think all children could participate here?*
> *Coach: Yes and no, I think you'd need to have some level of physical*

ability, because we are standing up and moving around and you
need to be able to follow directions.
Fieldnote: February 20, 2019

The example is showing that inclusion or integration is happening as children with and without disabilities are participating in the same environment (De Beco 2016). The coach is also attempting to have people with disabilities incorporated into the activity with a positive approach to being able to adapt for all children. However, there is also a limit on the inclusion, as there are requirements for physical ability and being able to follow directions.

During the fieldwork, it was apparent motivation in the organization for labelling the activity, inclusive, shown in the example below.

Coach: We need to show to (funding name) that we're inclusive so
we can continue to receive funding.
Researcher: How do you show that?
Coach: We say how many kids we have with each disability and then
that's kind of it, I guess.
Researcher: Do they ask for anything else?
Coach: No, they must trust us, I guess. I mean they can come and
see but we're an organization for people with disabilities so there's
no reason for us not to have the numbers.
Fieldnote: October 7, 2018

A factor in ensuring that organizations are inclusive towards people with disabilities is a motivation for funding opportunities. The funder, in this example, asks for numbers in categories of impairment for people with disabilities reaffirming a medical model standpoint, rather than being interested in the lived realities of the program. However, a lack of funding is important as a barrier for people with disabilities causing lack of access to physical activities (Bedini and Thomas 2012). It is interesting to note that although organizations receive funding, it does not always directly impact the participation of children with disabilities. In this study, 8 children participated with this organization and 4 of those participants had problems with cost, an example shown below.

We really struggle with how much horseback riding costs, it's a lot
for half an hour. We've thought about taking him out, but the
waitlist is so long to get back in if we change our mind.

Mother of Charlie, Fieldnote: March 11, 2019

The cost is a known barrier for physical activities for people with disabilities in Canada (Heritage Canada, 2006), and although motivations for funders is perhaps further inclusion, the benefits may not reach to lowering cost of activities.

However, it is important to note that there are contrasting motivations, such as:

> *Coach: We're inclusive because it's the way of life, everyone is different, and we all deserve a chance to play hockey.*
> Fieldnote: November 20, 2018

Inclusion is perhaps seen as the morally right thing to do in another organization. Here, the coach is appreciating the child first rather than focusing on their difference (Elvidge 2013). Hockey is also a 'segregated' activity, as it is for people with disabilities only (De Beco 2016). Segregated settings for sport are common for people with disabilities (Goodwin and Peers 2012). The example has some aspects of inclusion, as they embrace difference, adapt to various needs, and recognize the human first (De Beco 2016).

In summary, there are external factors which impact the lived experience of children with disabilities participating in extracurricular physical activities. The organizations' understanding and motivations to be inclusive impact the participation, as what organizations strive for translates into practices and understanding of what children with disabilities should be experiencing. The standpoint organizations start from relate to how they interact with children with disabilities and the service they will provide. The following subsection will explore how these understandings are implemented in practice, specifically who is the target of inclusion.

6.2.2 Targeting Children for Inclusion

Inclusion was identified for children with disabilities, often by the organization themselves. It was observed that some participants needed extra attention to be included for various reasons, such as: limited or no communication, needing extra help to follow

instructions, or help staying in the group setting, thereby aligning with the medical model of disability in identifying an impairment and the desire to treat the impairment to adapt to society (Oliver 1996). Targeting specific children with disabilities for inclusion can be seen in the examples below:

> *Coach: Mickey won't be able to interact with any other kids, may be just wave which we need to facilitate.*
> Fieldnote: October 20, 2018

> *Coach: He just doesn't follow any directions so just constantly remind him about what I'm saying.*
> Coach to Volunteer of Ben, Fieldnote: September 22, 2018

> *Coach: Can you please make sure Charlie doesn't run away, just stay with him the whole time.*
> Fieldnote: July 14, 2019

Coaches have identified children with disabilities that they believe need extra help in extracurricular physical activities. The desired 'inclusion' level in the examples is for children with disabilities to 'fit in' and adapt to the plan of the activity, as they promote homogeneity (Valeo and Bunch 2004). Coaches may believe that they are adapting to meet the needs of the children with disabilities (Loreman et al. 2005), as they are providing support, but there is no real choice, as children are expected to do exactly what they are told.

The approach of having an adult volunteer with a child with a disability for the duration of the activity was a common solution utilized to keep the participant physically included, as follows:

> *I've known Charlie for 9 months now and he does like to wander in other extracurricular physical activities. He is required to have one-on-one support at baseball, this support is an adult worker. Initially the other children would ask the support worker 'who are you' and 'what are you doing here', after the first couple of weeks the questions seemed to be answered and not asked again. As he has this one-on-one support, he is constantly watched. Every time he moves it seems he is corrected into sitting, or standing, or watching, or throwing. He is told when he can interact with other children and when he cannot. Today his worker went over to the bench without Charlie to get a sip of water. A couple of other children seemingly took over for the one-on-one worker and were*

> *asking him to throw the ball back and forth with them. When he*
> *got distracted, they said 'hey Charlie over here, throw it here'.*
> Charlie, Fieldnote: July 12, 2019

In this example, the children saw which supports Charlie needed to participate, and they included him when his worker took a step back. Children here were keen to include Charlie, and although that does not seem to be his experience in horseback riding, hockey, skiing, or in baseball, he is having positive interactions with others. Children are active agents (examples, Frankel 2018, Hanson et al. 2016, James and James 2012, Sorin and Galloway 2006, Tisdall et al. 2009a), and shown through this example when faced with an opportunity to include, children did without the support of coaches. Although the views in this study from participants are that coaches are responsible for inclusion practices, this example shows that children's capabilities also foster inclusion.

To contrast Charlie's experience, there are potential disadvantages to singling a participant out with a label of disability. Some examples are seen below:

> *Teammates talking about Spyro: We have to include Spyro*
> *remember, a child responds I actually like Spyro so I'm going to*
> *go over there with her.*
> Spyrou, Fieldnote: March 3, 2019

> *Teammates talking about Charlie: I don't think he'll understand*
> *anyways he's dumb remember, a child responds, He's not dumb,*
> *he just doesn't like you.*
> Charlie, Fieldnote: April 12, 2019 (Teammate talking about
> Charlie to a coach)

> *Magic talking to coach: I don't have anything wrong with me, so*
> *I don't understand why you tell everyone that the coach*
> *responds, you do, and they need to know when you need extra*
> *help.*
> Magic, Fieldnote: November 19, 2018

A problem with using labels for children with disabilities is that it may place them in a separate group, which is maybe seen as different than what should be 'normal' (Sayers 2018). Additionally, the labelling will aid with 'othering' which simply means an individual that is 'not one of us' in a group (Wendell 1996). The last example shows a medical model

approach with the need to classify and identify impairment (Benson 2014). However, it is important to note that this is not always the case. In the first two examples, children with disabilities experience acceptance (Ayling 2018), by the responding teammates. In literature, it has also been noted that children with disabilities are less likely to have friends and more likely to experience rejection (Crothers et al. 2007). Children with disabilities did in these examples experience a form of 'othering'; however, they also in two examples experienced an ally.

Inclusion is not only about acceptance, but it is important to look at how individuals are in control and how they experience their involvement (Cobigo and Martin 2011, Cummins and Lau 2003). Although there were negative comments made to some of the participants, other children stepped in to defend the participants or the participant themselves used it as a learning opportunity. In these examples, they did not need to be facilitated as to what to do, they are facilitating the experience themselves. Assuming that children need adult facilitators, lessons on how to be inclusive and seeing children as co-participants in the environment are needed, and there needs to be questions about how we know inclusion is happening.

6.2.3 Inclusion as a tick box exercise

Following the previous subsection, it is important to understand how inclusion is happening, and this subsection will look at answering that from the perspectives of coaches. Various informal conversations and observations were made surrounding what was believed to be inclusion in extracurricular physical activity environments. Although some definitions of inclusion may be vague, the people involved in this study often had very set ideas as to what inclusion looked like in their environment. The following discussions happened during fieldwork demonstrating one coach's view of inclusion:

Researcher: How is inclusion possible here?

> *Coach: It's just the environment it just works. Horses bring it out*
> *in people.*
> *Researcher: How do you know that inclusion is taking place?*
> *Coach: Look around, everyone gets involved and really is helping*
> *out the disadvantaged children.*
> *Researcher: Helping children do what?*
> *Coach: Ride horses.*
> *Researcher: And that is automatically inclusion?*
> *Coach: Yes, they can't do it anywhere else.*
> *Researcher: Is there nowhere else in the area? So, then horseback*
> *riding is inclusion?*
> *Coach: Well, we're the only certified place in the area and yes,*
> *they get to ride a horse, so they're included.*
> Mickey's horseback riding coach, Fieldnote: October 12, 2018

Literature surrounding inclusion suggests it is perhaps symbolic when people with disabilities are just present in an environment, as this is not necessarily inclusion (Hodkinson 2011). There were a few coaches in this study who had this view that children with disabilities being present in an environment was inclusion; the children were present in an environment that they otherwise would not be but for the program. Before the inclusion movement , integration of people with disabilities was the goal where people with disabilities were involved with little adaptations made (Weber and Bennett 2004). Additionally, the use of language surrounding children with disabilities as disadvantaged is perhaps a result of inadequate training (Rheams and Bain 2005). Inclusion is often a sought-after goal; however, it can be found to actually be misinterpreted integration (Jahnukainen 2015, Rosenqvist 2005). Integration is often seen as restricted to the intermixing of people or groups previously segregated. In the example, the environment is that of a segregated activity where only children with disabilities participate; it really is not inclusion or integration with others.

It is important to note that upon reflection on some of the questions posed to the coach, my bias and different viewpoint that I do not view children with disabilities as disadvantaged may have been apparent. Additionally, my understanding of inclusion was evident being that meaningful inclusive opportunities which go beyond just having access to

an activity of space (Tardif-Willams et al. 2009). Therefore, there was a potential for missed

data on how and why the differing beliefs came to be.

I reframed my inclusion question for other coaches who had previously said in their

coaching environment inclusion exists, as I wanted to know more about specifics. Below is

an exchange from another coach to solicit views on inclusion:

> *Researcher: How do you know inclusion is happening here?*
> *Coach: We facilitate it.*
> *Researcher: How do you do that?*
> *Coach: Well, some kids have special equipment so they can*
> *participate here.*
> *Researcher: Is there anything else?*
> *Coach: Um yeah, like if no one is talking to someone I'll go over*
> *and talk to them.*
> Charlie's skiing coach, Fieldnote: February 12, 2019

Although this is a similar example to the one above, this is a coach providing

equipment adaptations for Charlie in order for him to be able to participate in skiing.

Inclusion can mean "being allowed or enabled to take part" (Davis and Hill 2006, p.1).

Additionally, there is a debate in literature surrounding the notion of inclusion and what

should constitute integration instead (Fitzgerald and Long 2017). In practice, inclusion has

been criticised for having a standard, one size fits all view (Gordon 2006), and just providing

equipment may not be enough to cause a change. Although one has access to physical space

and physical adaptations that does not equate to being accepted, belonging, or having a sense

of community (Tardif-Willams et al. 2009). However, in these examples, the children are

being allowed and enabled by the adults in the environments, and this chapter will look

further into what else is going on, such as the negotiation of participation in relation to

inclusion and the process of inclusion.

Within the environments observed as part of this study, there was no specific training

provided for children to learn how to include other children. However, coaches when

thinking outside the box and trying something different does not seem to be happening through this example. If inclusion means 'being allowed or enabled to take part' (Davis and Hill 2006, p.1), one may perhaps see the adaptations taken by coaches being enough for inclusion. As when children show up to their activity, they are seen to be included automatically. However, there are more interactions taking place besides an adult to child power imbalance surrounding the ideas that coaches are the only ones facilitating inclusion. As such, my findings confirm previous research that just being physically present does not result in positive inclusive experiences (Holt 2003, Milner and Kelly 2009). The following subsection will continue with external factors of inclusion and explore parental perspectives.

6.2.4 Parents' of children with disabilities understanding of inclusion

Inclusion is a contested topic, and its theory has been extensively discussed and researched including research of its application in various venues such as: the workplace, schools, and playgrounds. 'Social inclusion' amongst their peers for children with disabilities is a subjective multifaceted term (Croucher and Le Boutilier 2010) which is often described as the opposite of 'social exclusion' (Koller et al. 2018). Social exclusion refers to a marginalization or stigmatization of a group; in this study children with disabilities who achieve meaningful involvement perhaps need to overcome economic, social and political barriers (Hill et al. 2004). Social inclusion suggests that one is a valued and contributing member of a community (Mâsse et al. 2012, Murray and Greenberg 2006). Throughout the study, parents did not shy away from discussing inclusion and their concerns or worries about inclusion, as shown below:

> *I just hope that he can make a friend, I know it's difficult because his behaviours do scare some children because they're so sporadic.*
> Mother of Charlie, Fieldnote: October 10, 2018

> *He acts a bit young for his age so they put him with really young*
> *kids sometimes, but I do wish they would let him interact with*
> *children closer to his age.*
> Mother of Mickey, Fieldnote: January 18, 2019

Parents, being close to their children's lived experiences, have views but do not always see an avenue to advocacy. For example, Mickey's mother has asked the organization for him to be partnered with someone close to his age; however, she was often ignored. The program manger complained about the requests and stated, "I don't understand why she cares so much, he doesn't engage anyways" (Fieldnote: February 7, 2019). The program manager is assuming, because Mickey is non-verbal that he does not have the capacity to communicate. At the time, Mickey's partner was 5 leaving a ten-year age gap. Although not all children follow the same age-based development path (James 2005), children that use augmentative and alternative systems to communicate experience social isolation and additional struggles to keep up with their age based peers (Clarke et al. 2011). Mickey is potentially being further excluded on the basis of his difference (Moosa-Mitha 2005), as negative assumptions are being made about him without involving him.

Previous research into parents' perspectives of social inclusion has suggested that parents express concerns about how their child's behaviours may affect inclusion (Recchia and Lee 2004). Children with disabilities are at an increased risk of being bullied or isolated in comparison to typically developing peers (Cummins and Lau 2003, Guralnick et al. 2007, Koster et al. 2010). Parents indicated that there are obstacles to social inclusion encountered from within the child and from the environment which shows a biopsychosocial model (Shakespeare 2006a, Thomas 2004). Parents in the study expressed concerns about a loss of control over the process:

> *We don't really have a say too much, if we want Chloe to participate*
> *in horseback riding, we have to follow their rules. We can ask for*
> *more support for her but we're at the mercy really of the coach.*
> Father of Chloe, Fieldnote: November 22, 2018

> *I think the coaches try and get Ben involved. It is difficult but we've*
> *been told to sit outside the arena and not watch so the coach is just*
> *responsible when he's in there.*
> Mother of Ben, Fieldnote: March 7, 2019

The parents are expressing concerns that they are being excluded from the activity, and in the second statement, the parent has started to assign responsibility for the inclusion experience. Findings show that parents of children with disabilities believe service providers, or coaches in the example, are ultimately responsible for facilitating inclusion (Schleien et al. 2014). When parents have tried to get involved, it has been met with resistance, as shown in the second example where Ben's parent was asked to watch from another room.

The children in this study expressed similar views as to their parents about control in the extracurricular environment, such as:

> *Yeah, I have to say hi to (child's name) because (coach's name) tells me*
> *I have to talk to him.*
> Chloe, Fieldnote: December 11, 2018

> *If I ever feel left out, I think (coaches name) wants me to go to her, but I*
> *won't.*
> Magic, Fieldnote: April 21, 2019

> *If someone doesn't want to include me, it's almost worse if it's like*
> *forced by (coaches name) and it doesn't work they'll just do what they*
> *want again anyways.*
> Aspyn, Fieldnote: June 6, 2019

In these examples, children have a similar understanding to their parents that coaches are the ones in charge of facilitating inclusion, although they may not agree with their methods and there are signs of resentment. Here it can be seen that inclusion can be viewed and understood differently depending on the viewpoint (Roulstone 2000). When coaches offer solutions, such as being 'forced' to include in Aspyn's example, it is attempting to solve a 'problem' which may lead to further segregation. In Magic's example it shows that although coaches may offer a solution, it may be met with resistance.

These experiences contradict research conducted in classrooms that found children with disabilities noted the educators had a vital role in facilitating and ensuring quality social inclusion (McPherson and Lindsay 2012). Children in this study felt that sometimes coaches make the inclusion process more difficult or worse.

Overall, in this study, parents seemed to be grateful that their child has an opportunity to participate, although at the start of the study parents were reporting environmental barriers, trouble with access to services, and negative community attitudes (Ault et al. 2013, Leyser and Kirk 2004, Schleien et al. 2014). When there is a negative experience, parents feel that having their child involved in an activity is better than not and can get stuck when advocating for change. Parents and children had similar views on whom the responsibility of inclusion falls on which is the coach in these environments. The following subsection will look further into the views of children with disabilities in relation to their understandings of inclusion.

6.2.5 Children with disabilities understanding of inclusion

The understanding of inclusion from participant's view is important. The universally 'good' term of inclusion needs to be explored by those who are identified as the excluded (Cook and Swain 2001, Holt 2003, Slee and Graham 2008); the organizations in this study are catering to a potentially excluded group, children with disabilities. The question was asked to some children in this study: 'what does inclusion mean at (their activity)?'. Some responses were:

> *Magic: Does that mean do I feel included?*
> *Researcher: Sure, do you feel included?*
> *Magic: I guess so.*
> *Researcher: Who helps you to feel included?*
> *Magic: Well, I'm friends with my volunteer we get to talk a lot.*
> *Researcher: Are you friends with anyone else?*
> *Magic: Not really.*
> *Researcher: What about other children?*
> *Magic: We're not really allowed to talk; I think that I might distract her.*
> *Researcher: Why do you think that?*

> *Magic: Well (coach's name) doesn't let me talk to (another rider)*
> *because she needs to focus.*
> *Researcher: Can you talk to her other times?*
> *Magic: No not really because I don't know when I'm allowed.*
> Magic, Fieldnote: April 26, 2019)

Throughout this study, Magic does have a relationship with the other rider, and they do start to interact. In my fieldnotes, I had an assumption that children's inclusion was with their peers, perhaps it is important to note that sometimes children can also feel included with adults in their environment. However, the process of inclusion for this child, although wanting to build a relationship with the other child involved, has been challenging as the gatekeeper, the coach, is stopping the interaction. These interactions are important for the development of social capital which may lead to meaningful relationships (Weisel and Bigby 2014). The same question (what does inclusion mean in your activity?) was probed further:

> *Spryo: I think when we're all getting along.*
> *Researcher: Getting along with all the other children?*
> *Spryo: Yeah and no one is left out.*
> *Researcher: How would someone be left out.*
> *Spryo: Umm if someone was being mean to them.*
> Spryo, Fieldnote: March 7, 2019

The base level understanding participants had of inclusion is ensuring that no one was left out, and the majority were aware, if another child was not participating in the same way. Development of future practices and policies of inclusion need to be informed by people with disabilities (Spencer-Cavaliere and Watkinson 2010, Susinos 2007). Throughout all of these conversations with children, coaches were for the most part uninterested in how children were feeling about inclusion. In this example, the environments are set up for adults to be in charge and we get a sense of what inclusion means from the child's perspective.

Implementation of inclusion has also been discussed in this section, children with disabilities have views on the implementations, as shown below.

> *Aspyn: I don't think my coaches really think about inclusion, they*
> *put us together and I know they make adaptations for my hearing*
> *but that's it.*

> *Researcher: What else do you think they could do?*
> *Aspyn: I think they can talk to us about it because like sometimes I*
> *get it, I just want to do my own thing and not really talk to other*
> *kids, but I also don't think it's fair that because I can talk.*
> *Researcher: What's not fair?*
> *Aspyn: Well, I can choose if I talk to other kids and like I guess I'm*
> *thinking of one kid doesn't speak and my coach always thinks she's*
> *bothering us by being around us so tells her to stop but that's not*
> *inclusion. Sometimes I do like doing my own things, but I also think*
> *like she can be with us too.*
> Aspyn, Fieldnote: March 7, 2019

Aspyn notices a privilege to verbal communication (Boggis 2018b, Richards and Clark 2018), specifically in her ability to choose how she participates with other children, where other children do not get to make the same choices. Here there is an example that some children's voices are not even being acknowledged (Warming 2011). The coach reinforces the exclusion by assuming that a non-verbal child is perhaps 'bothering' a verbal child without asking the children themselves. Although children who communicate non-verbally are 'included' and present in extracurricular physical activities, they are also perhaps being excluded within the environment, another child has a similar view, as shown below.

> *Marie: Yeah, I mean if they can't speak it's harder for the coaches*
> *to include them. I always try to just be with them and understand*
> *what they're going through.*
> *Researcher: How do you think the coaches try to include them?*
> *Marie: (laughs) I don't really think they try, but maybe they just like*
> *don't know.*
> *Researcher: How does that make you feel?*
> *Marie: I think sad because we're all kids and like if I was born a*
> *different way I'd be treated differently, I already am and it just*
> *makes me feel bad because they're treated like different.*
> Marie, Fieldnote: August 8, 2019

Impairment can be viewed as socially constructed, as a determination of a difference (French and Swain 2001). Here, Marie identifies that there are multiple layers to discrimination (Degener 2016), as she identifies having a disability and she is treated differently and acknowledges that non-verbal children are treated differently, as well. The human rights model of disability strives for people with disabilities to be active and equal in

participation in strategies for the development of programs (Degener 2016). The example shows a lack of understanding by the coaches in the discrepancies of non-verbal communication, and including the various voices may result in greater levels of inclusion. 'Disability' in this example becomes disability through the relationship with the coach and other children (Campbell 1999), the ableist practices have preferred 'normal' verbal communication.

The subsection starts the understanding of inclusion and inclusion implementation for children with disabilities. There is a gap in practice of the implementation of inclusion for children with disabilities who communicate verbally and non-verbally. Children with disabilities have a desire to include other children; however, sometimes the implementation of inclusion does not always allow for children to communicate their perspectives.

6.2.6 Section Summary

The start of the section began to answer research question number two by identifying external factors to inclusion. External factors of inclusion were discussed in the subsections exploring organization views, inclusion implementations, parental views, and participants perspectives. Inclusion was seen as a goal to be worked towards from all perspectives; however, from the parent and child perspectives, it was determined that inclusion is perhaps not being achieved. A key theme that has been identified is a gap between experiences of children with disabilities who communicate verbally and those who communicate non-verbally. Additionally, perspectives on inclusion were not often sought after by organizations and coaches, as they exercised their power in making inclusion decisions.

Inclusion in extracurricular physical activities has been seen as a tick box exercise. Coaches believe that they are implementing inclusion and are the ones to determine who needs adaptations for inclusion to occur. This is challenged by children with disabilities views, as they view coaches as a gatekeeper for them blocking them from negotiating

relationships with other children. Children with disabilities believe that there are changes coaches can make to be further inclusive of children, specifically non-verbal children.

The section noted some tensions between literature and practice, specifically in the various understandings of what inclusion is. This is an important theme, as the thesis allows for an in-depth look into the lived experience of inclusion and how the understandings of inclusion are processed and negotiated which will be discussed further in section 6.4. The next section will have a focus on the process of inclusion, building on this section looking at how we know inclusion is happening, and various boundaries children with disabilities face.

6.3 The process of Inclusion

The following section will explore the process of inclusion starting with how coaches implement inclusion and how children with disabilities view the implementation. Additionally, it will explore how we know inclusion is happening and inclusion boundaries.

6.3.1 Coaches facilitating inclusion

The following subsection will expand on the previous section exploring further in-depth the implementation of inclusion and the tensions and reactions it may create. In the literature, there are some examples of pairing children up, so they can be included in activities, sometimes by giving support to a child with a disability. Children supporting children is perhaps seen as a more ideal situation, as when adults are paired with children with disabilities, the child can be further excluded by children. An example of one of the participants receiving this buddy support is Chloe, as her horseback riding partner (another child with a disability) is often asked to help her out on various tasks:

> *Coach: Hey (other rider name) can you help Chloe brush her horse*
> *she just isn't as experienced as you.*
> *Other rider: Yeah.*
> *Chloe and I overhear this as we are 2 meters away from this*
> *interaction.*

The other rider now stands and observes Chloe brushing her horse, sometimes correcting her on the technique.

Other rider: No, you're doing that wrong you have to use that in circles like this I'll show you.
Chloe: Oh, ok.

When we were in a different room, I asked Chloe

Researcher: Did you have fun with the (other rider)?
Chloe: Yeah, she knows more than me.
Researcher: You'll learn too.
Chloe: Yeah, one day I just don't like having to be watched by her, I want her to think I'm good too.
Researcher: Why do you think she would think you weren't?
Chloe: Well, you heard (coach's name) she told her I wasn't as good, and I need her help. I think it's just because of my legs I always get helped.
Researcher: How does getting help make you feel?
Chloe: I don't mind when I need it but when coaches tell other kids to help me, I don't think they know when I don't need it. I'd rather just be normal.
Researcher: What do you mean normal?
Chloe: Just not needing to be singled out to other kids.
Chloe, Fieldnote: January 9, 2019

In this example, Chloe appreciates the help of her partner but feels singled out when the coach directs her partner, almost as an extension of the coach needing to assist. People with disabilities often face hurdles to meaningful inclusion and participation such as in this example a social barrier (Hill et al. 2004). Social inclusion views individuals as valued members of the community (Mâsse et al. 2012, Murray and Greenberg 2006), where there is respect of voice. Negative attitudes towards children with disabilities resulting in social exclusion is often found in literature (examples, Hamilton 2005, Houghton and Taylor 2008, Humphrey and Symes 2010, Krull et al. 2014, McPherson and Lindsay 2012, Pijl and Frostad 2010, Rotheram-Fuller et al. 2010). In this example, Chloe's partner is supposed to be a peer which makes Chloe feel belittled in comparison by needing help and having the rest of the group know that she needs help. In physical activities, feelings of inclusion have resulted from participation, access, and achievement (Slee 2006).

In the next example, Spryo is partnered up (asked to assist) with a less experience

participant, something that she was not anticipating before the session.

> *Spryo has been partnered up with a new participant at martial arts*
> *tonight. The coach asked her to get the other participant up to*
> *speed. Throughout Spryo's experience tonight, there were a lot of*
> *comments from the coach that said, 'stop talking' or 'pay attention'*
> *or 'did you hear the instructions'. During a water break, I asked her*
>
> *Researcher: Are you having fun?*
> *Spryo: Not really.*
> *Researcher: Oh, what's wrong?*
> *Spryo: I keep getting into trouble.*
> *Researcher: Why?*
> *Spryo: Well (coach's name) asked me to help out the new girl and I*
> *am but I really want to practise my own routine for grading, but I*
> *know that she needs help so I am, but I have a hard time listening to*
> *instructions on the best of days. I'm really bad at night and I can't*
> *do all these things at once.*
> *Researcher: What do you think would help?*
> *Spryo: Maybe I should've said no to helping the new girl, I really*
> *want to focus on my own stuff.*
> *Researcher: You could be helping her feel included.*
> *Spryo: Yeah, and I like talking to people before and after class but I*
> *want to be included because people think I'm really good and I need*
> *to get my yellow belt, but I can't do that with distractions.*
> *Researcher: So the most important thing for you to be included is*
> *getting to the next level?*
> *Spryo: Yeah I like chatting but here I just want to be good at*
> *something and I'm really trying.*
> Spryo, Fieldnote: March 11, 2019

Spryo, in this example, wants to work on getting good at a skill, part of her identity

that she is good at and succeeds at martial art, but she is asked to help someone new which

takes away from Spryo's goal causing some frustration. In this example, Spryo wants to 'be

recognized' and 'become known' for her skills at martial arts which develops social capital

perhaps leading to more meaningful relationships (Weisel and Bigby 2014). There is a

tension surrounding the experience, as Spryo wants to advance her own experience but is also

supporting someone else. Spryo does not want to exclude the new participant; however, her

choice would be to focus on herself. The example shows how an 'identity' is being placed on

Spryo to be a helper with little flexibility, rather than making purposeful choices on how she

would like to interact in her own lifeworld. Additionally, there is a tension because Spryo does not want to convey an identity surrounding disability. Making the choice to not participate in inclusive practices does not equal exclusion (Jeanes et al. 2014). Being able to make independent choices on how and where to participate is important (Misener 2014), whereas in this example, she is being subjected to a form of control where she feels there is little to no choice to change her experience.

Coaches, as seen in section 6.2, have taken responsibility for ensuring that inclusion of children with disabilities in extracurricular physical activities is happening. The next example shows coaches upholding their promise of inclusion.

> *In hockey today one of the coaches asked a teammate of Charlies to help encourage him to stay with his team as Charlie likes to skate on his own normally laps of the rink. The teammate kept trying to redirect Charlie by saying things such as "Charlie over here", "Charlie, Charlie", "Charlie come over here", "Charlie we're all over here". Sometimes Charlie would smile in the direction of his teammate but was giggling more whilst skating around. Another teammate heard all of this encouragement and said, "it's useless stop trying". Charlie stopped smiling for approximately 10 seconds after hearing this. A coach then jumped in and said to the other teammate, "oh it's ok Charlie can just keep skating around."*
>
> *I asked a Charlie's mom and Charlie's coach about this after the practice.*
>
> *Coach: I don't mind that Charlie skates around, he seems to be having fun and sometimes there's just too many kids that need one-on-one coaching that there isn't enough time.*
> *Researcher: What about other children's views of Charlie.*
> *Coach: Well, they can get frustrated because he's just skating, but I don't think Charlie minds.*
>
> *Mother of Charlie: I do wish that he would interact more with his teammates, I know he isn't like the other children, but he does get really excited to come and he does need social interactions too.*
> Charlie, Fieldnote: January 30, 2019

Inclusion within an activity can often further benefit those who are already included more than those who are in need of inclusion (Allman 2013). The example shows Charlie's teammates bonding by critiquing Charlie's way of participating. For Charlie's teammate, there was social restraint to continue to interact with Charlie. Negative attitudes where

children with disabilities experience social exclusion is well researched (examples, Humphrey and Symes 2010, Krull et al. 2014, McPherson and Lindsay 2012, Pijl and Frostad 2010). Additionally, this is another example of the situation often found in research where children with multiple impairments generally experience more difficulties being included (McCoy and Banks 2012). It is important to note that the choice of not participating does not equal exclusion (Jeanes et al. 2014), and Charlie seems to be making the decision to participate in a different way where he appears to be happy while skating around the arena by himself. He can take part, as he often does at least one faceoff when directed each game. This is perhaps a choice that he is making to participate in his own way.

This section hopes to give insight into how inclusion is being played out by coaches in extracurricular physical activity environments. The following sections will give further examples on how children navigate their experiences of inclusion.

6.3.2 Participant views on the implementation of the coaches' inclusion practices

A look at what children have said about what they believe adults think about inclusion may provide some insights. It is interesting to know what children gathered from adults in these settings about views on inclusion. I asked participants questions similar to 'what do you think inclusion means to your (coach's name)?' or 'what have you learnt about inclusion from (coach's name)?' Some of the responses are:

> *Magic: They just like to talk. Not about anything though, it's the same questions all the time. Like at skiing I have to talk to Olivia and (coach's name) always tells me to ask her about school blah blah blah (whilst rolling her eyes).*
> *Researcher: Is that inclusion?*
> *Magic: No of course not Katie, you should know that, how is that inclusion if I ask the something's all the time being watched like maybe she hates school, but she can't tell me because (coach's name) will tell her to respond differently. I can't be myself or I get in trouble, can't ask the wrong question.*
> *Researcher: Do you feel the same way at horseback riding or swimming?*

Magic: Yeah well, I'm never really allowed to talk at swimming, but you know what happens at horseback riding.
Researcher: I think I do but maybe you see it differently from me.
Magic: Oh my god, ok well you know the guy I ride with doesn't talk which is fine because I can talk for both of us but it's the same, I get told to say hello, he doesn't respond. I go in for a fist bump which he might like but oh no I can't do that.
Researcher: How would you include him?
Magic: Well, I would just ask him to show me what he likes.
Researcher: Is that different from what your coach is asking you to do?
Magic: Yeah, duh. I said show me, also I didn't say ask the same questions. How am I supposed to get to know him by saying hi, that's not going to work? You get to know someone by being allowed to talk to them without a hawk swooping in.
Researcher: If he doesn't talk though, does that make it more difficult?
Magic: Nope nope nope, I talk enough for both of us. He also has an iPad he isn't allowed to use anymore which is weird. Also, he does communicate, and he laughs when my jokes are funny.
Magic, Fieldnote: June 4, 2019

The example will be discussed in relation to the coach's thoughts on inclusion as

shown below.

Coach: It's really hard to implement inclusive practices when there's one verbal kid and one not.
Researcher: Which inclusive practices do you implement with Magic?
Coach: Well, every lesson I get her to say hello to her riding partner and then I'll get her to say goodbye at the end.
Researcher: Do you think they could communicate more?
Coach: No.
Researcher: Do you think they've tried to communicate besides just the hello and goodbye?
Coach: No, (other rider's name) is nonverbal so they can't have a conversation.
Researcher: Is there anything else you'd like to try to promote inclusion?
Coach: No.
Magic, Fieldnote: June 4, 2019

In the above example, we see how a coach utilize a tactic of cueing children with

disabilities to ask the same questions. There are many observation fieldnotes with the same

questions in them such as cueing for 'how was school', 'how are you', and 'what did you do

on the weekend'. These cues would end at each question. The examples above do explain the

implementing of inclusion similarity. However, the understandings from the experience are

very different. Magic explains that her riding partner's communication is not being

acknowledged, and the coach confirms her stance of the child not being able to communicate.

The coach assumes that the child cannot communicate (Boggis 2018c), and is excluded from

an inclusion process. Additionally, in relation to the extracurricular activity, there is often a

barrier of knowledgeable instructors (Bedini and Thomas 2012, Rimmer et al. 2004), which

has been noted by Magic as she is untrained beyond greetings in how to include children with

disabilities who communicate non-verbally. Magic has a desire to continuously try to

communicate with her partner, whereas her coach is unwilling to advance the process.

Inclusion can be seen here as a negotiation process between the children which is being

impacted by the coach not recognizing inclusion. As Magic acknowledges, this process

should go beyond verbal language (MacLure 2009, Mazzei 2003,2004,2007,2009).

The example above could perhaps be viewed differently if with different participants

involved. In the example below, there is a different experience for children with disabilities

interacting and their inclusion desires.

> *Chloe: I don't want to be friends with my riding partner. I come*
> *here for me because I love to be with horses. I'm nice to people all*
> *day at school, I just want my own time.*
> Chloe, Fieldnote: November 2, 2018

In this example, Chloe desires limited interaction with her horseback riding partner

and the greetings required by the coach above would perhaps be ideal for Chloe. Chloe's

interpretation of the coach's implementation of 'inclusion' may have been received as

positive rather than Magic's negative commentary. Chloe not wanting to be friends with her

riding partner to feel included contradicts an aspect previous activity research (Spencer-

Cavaliere and Watkinson 2010). Choice of sport has been seen to be important for people

with disabilities (Kiuppis 2018), and choice of how children participate in sport should be

equally as important.

Children with disabilities can be shown to resist inclusion practices that coaches are implementing as shown below.

> *Aspyn horseback rides with 3 other students who are all older than
> her.*
> *Coach: (to the older students) You guys really need to include Aspyn
> in your conversations it's quite rude to leave her out!*
> *Aspyn: No thanks.*
> *Coach: Why do you want to be left out?*
> *Aspyn: They're talking about high school stuff and I'm not
> interested.*
> *Coach: Oh ok, they can talk about other things.*
> *Aspyn: I'm happy doing my own thing.*
>
> *I asked Aspyn about this after the lesson and she said:*
>
> *Aspyn: I don't understand why it's so important for me to talk to
> kids so much older than me, it might make my coach feel better that
> I'm not like left out, but I don't want to be included.*
>
> *I asked the coach about this after the lesson, and she stated:*
>
> *Coach: I do want Aspyn and the other kids to get along, so I try to
> encourage it.*
> *Researcher: Is it important they get along?*
> *Coach: Maybe not, but it's upsetting she's never included.*
> Aspyn, Fieldnote: January 20, 2019

There is a key theme that emerges with the examples, as there is a disconnect between the wishes and preferences of the participants and the coach's understandings. This creates a tension in the adult-child relationship, as Aspyn is clearly stating her wishes, but the coach is desiring a different result. Although Aspyn is being heard, she is not being listened to, Aspyn's has changed her experience and influenced the environment, and she is choosing not to interact with the other participants (Oswell 2013). She has made a choice to act on her own which has not been determined by an adult (Baraldi 2014), and this has been accepted. It is worth noting that this is not always the experience when children with disabilities express agency, a contrasting example follows.

> *Ben's coach normally gets Ben to wave at the other rider each week
> to signal 'hello'. This week when she asks Ben to 'say hello' and he
> shakes his head no and looks down, away from the coach. The coach*

> *asks 4 times before asking the volunteer leading Ben's horse to stop*
> *the horse, the coach walks over and says "Ben look at me" as she*
> *waits for him to do so, he eventually looks up. She then says, "you*
> *can't walk on with your horse until you wave."*
> Ben, Fieldnote: March 10, 2019

The example contrasts with the previous example, because Aspyn was seen as able to make her own decision about who to interact with. The example confirms that Ben as a non-verbal participant is being told to respond to prompts (Potter and Whittaker 2011), and his agency is being perceived as problematic and negative (Tisdall and Punch 2012). Ben has limited action choices and opportunities available (Baraldi 2014), as the coach insists on him following directions or takes away participation opportunities. Agency is shaped through various relationships and negotiated (Leonard 2016), with a focus on the process (Valentine 2011). However, in Ben's example, the process is lacking as the motivations and understanding of the coach is not working towards a collaborative process. In both examples the children were not a part of the decision-making process on which inclusion practices were to be prompted (Wyness 2018).

To summarize the subsection, a key theme developed identifying a clear gap in communication between children with disabilities and coaches in the implementation of inclusion. Children who communicate non-verbally are being further marginalized by the limited understanding of inclusion, and non-recognizing of the by their coaches. Furthermore, there is a tension that arises about the understanding of inclusion, and if a homogenous label can be placed on what inclusion is, as there are varying desires of children with disabilities. The following section will further explore the child-coach relationship and the roles at play.

6.3.3 Discussing children's experience with boundaries

All the lived experiences being discussed in this PhD thesis are within structured physical activity environments, although recognizing that there are some less structured spaces such as changing rooms, before and after allotted time, in a car time, meetings outside

of the activity, etc. It has been discussed that coaches or instructors are the people in charge

at these activities as noted by parents and children. A few examples of this relationship can

be seen below.

> *Marie: We have to do what (coach's name) says or we can get into trouble.*
> Marie, Fieldnote: January 12, 2019
>
> *Ben's mom: When we arrive, we hand off Ben to whoever the coach is that day and they're in charge from then on.*
> Ben, Fieldnote: September 22, 2018
>
> *Magic: Yeah, the coach is the boss, sometimes I even salute her.*
> Magic, Fieldnote: April 18, 2019

The hierarchical experience that takes place during these activities correlates with

some literature suggesting that there is a barrier to children's agency when child-adult

relationships are based and embedded in hierarchical frameworks (Esser et al. 2016).

Additionally, this barrier is difficult to navigate when the culture and structure of the

environment is inflexible and rigid (Davis and Smith 2012). Within these spaces, there is a

clear forefront of a hierarchy and power relations at play (Davis et al. 2012).

In this study, there are various examples of predetermined boundaries for children

with disabilities. Often these boundaries were determined by the coaches or organizations

without consulting the children. Some of these boundaries specific to inclusion are shown

through two examples below.

> *Ben is non-verbal although he does express himself through noises, sometimes loud noises. He often attempts to interact with the other rider by making noises whilst looking at the other rider, pointing at him and pointing back at himself and waving. He seems to be really happy doing this smiling and laughing. When he does this, he is almost always met with 'stop talking', 'focus', 'I'll remove you from the lesson' from his coach. When he gets really excited often when he receives a wave back, he gets even louder laughing and making cheering noises. When this happens, he often gets a time out which is his horse walking to a wall in the corner and sitting there for a few minutes. After this happened a couple of times, I asked the coach 'why is it so important that Ben stay focused and isn't engaging with the other child?'. Her response was 'he needs to follow the rules and*

> *I find it really impulsive and disruptive'. This struck with me because I feel there are so many missed opportunities for interaction with children with disabilities and it's upsetting watching almost a punishment for trying to talk amongst each other in an activity that's supposed to be fun.*
> Reflective notes: December 2018

A similar example is shown.

> *Researcher: Can you explain what normally happens at Martial arts to me?*
> *Spryo: I get there early so I can talk to some of my friends and play tag um then when we start which is at like 6, we line up then we break into groups for drills and stuff and then it ends at 7.*
> *Researcher: Do you like how it is set up?*
> *Spryo: Most times yeah but I don't like how we can't like talk to our friends if we're in a line waiting anyways. It can't be super loud I know but like I have to sneak a thumbs up sometimes and I can't control it sometimes I get distracted and it's annoying getting in trouble.*
> Spyrou, Fieldnote: February 12, 2019

As viewpoints of children involved in these experiences are being excluded, the rigid system is not allowing for improvements. Inclusion in these spaces have hierarchies and power relationships (Davis et al. 2012). Power in these examples is being used to threaten exclusion and being singled out for those not following the rules to prevent undesirable behaviours (Foucault 1977). There are children that accept conformity, as they feel safe within the structure and some other children choose to rebel (Gallagher 2004 , Tallant 2015). In these examples, children are accepting a suspension of their agency (Hill 2005), however, in other examples this is not always the case. Although it is important to note that these experiences are potentially not relative to all children with disabilities, as teachers or coaches have a variety of differing approaches (Davis and Watson 2001). An example being with Kirby who is verbal, very athletic, and often the coaches' favourite will frequently receive a high five from coaches when saying hi or chatting to his peers.

The extracurricular physical activities in this study had participation from children with disabilities, and some environments had children without disabilities as well. Segregated

activities, as they cater to children with disabilities, perhaps have more experience with working alongside children with disabilities. The following examples are experiences of boundaries within segregated activities.

> *Coach: Charlie you need to stop rocking on your horse that's not*
> *what horseback riders do,*
> Charlie, Fieldnote: April 28, 2019
>
> *Infront of the other participant and Mickey, the coach says to the*
> *volunteer: "You really need to repeat everything to him and if he*
> *doesn't get it just put your hand over his and make him do it."*
> Mickey, Fieldnote: October 16, 2018

In these examples, there is an attempt at following traditional approaches and structure for horseback riding. Coaches are defining boundaries on what is acceptable in their structured environment (Foucault 1977). Additionally, there is an identity that is imposed on children that they are different, and they should be something else (Davis and Watson 2001). This view represents the medical model of disability, as the activity is defining what is normal.

The subsection has looked at the experience of boundaries that children with disabilities may experience in extracurricular physical activities which helps to answer in part research question number two, because it is highlighting the experience of what 'inclusive' activities may look like. Although there are assumptions that inclusion perhaps is the best way forward, there seems to be little to no checks on feedback from children with disabilities and how the power relationships between coach and child are perhaps hindering the participation. The final subsection below explores how we know inclusion is happening in extracurricular physical activity environments.

6.3.4 How do we know inclusion is happening?

The topic of inclusion and the way it is discussed affects the participants in this study; therefore, their views, on how we together process what inclusion is, is important. At the

beginning of the data collection, I discussed with the participants what they know about inclusion. Early on, I noticed a power struggle within myself, as a researcher about how inclusion was going to be discussed, as shown below:

> *I can see all the participants of any given activity in the same space.*
> *I know that in some studies attendance in activities would count as*
> *inclusion. I am also aware of different inclusion practices on an*
> *overall level. I'm feeling quite awkward and avoiding writing about*
> *if any of my participants are included or not because this research is*
> *supposed to be about the children's views. I don't feel I'm capable*
> *of being the judge to what is inclusion.*
> Reflective Notes: November 2018

An important strength about ethnography is that changes can be made to further the depth of the research. Early in the ethnographic notes, I had a standard about whether inclusion was happening; however, the conversation should have started with children's interpretations. An active effort was made to ensure that children's voices came to the forefront of inclusion conversations.

One of the ways this was encouraged was by carving out time to fact check research notes as soon as possible. If the next session went by before being able to fact check my notes alongside the participant, they would sometimes not remember the examples that I would share by stating things such as "um I don't think I remember that happening" (Aspyn, Fieldnote: May 12, 2019), or "I don't know" (Marie, Fieldnote: August 9, 2019). Although I tried to narrate scenarios for participants, they would respond in part with "I guess I would have said hi to him (Magic, Fieldnote: June 10, 2019)", or "Maybe she just wanted time alone" (Chloe, Fieldnote: February 12, 2019).

> *Magic is at swimming tonight. The pool is always full of children and*
> *they are all one on one with a coach. They are all doing different things,*
> *some playing with a ball, some learning strokes, some trying to just get*
> *in the water. There is little to no interaction between children. Magic*
> *has a foam kickboard in front of her and she is being encouraged to kick*
> *her legs to go forward. A ring hits her in the crowded pool from another*
> *child who says 'sorry' Magic responds and says 'I'll get it' as she*
> *reaches over and grabs it and passes it back. When she does this, she*
> *asks her coach 'can I play that game too?' and the coach says, 'no*

*we're working on our kicking'. When she comes out of the pool for a
break, I asked her.*
Researcher: How are you enjoying swimming?
Magic: I'm cold and it isn't really fun.
Researcher: You're pretty good at swimming.
Magic: Yeah, but I wish I could play games sometimes too.
Researcher: What kind of games?
*Magic: I really like (coach's name) but she never lets me talk to any
other kids here.*
Researcher: Hmm do you feel included at swimming?
Magic: Sometimes.
Researcher: When?
Magic: I like my coach she is a lot of fun she makes me tired though,
Researcher: When do you not feel included?
*Magic: Well, she (coach) doesn't listen to me if I'm just going to be with
her, she needs to listen.*
Researcher: Do you wish it was with other people?
*Magic: Yeah, even for like 5 minutes, everyone is here I think it would
be fun to play a game for a little.*
Researcher: How could you be more included?
Magic: Umm.
Magic, Fieldnote: December 18, 2018

It is important to note that the question 'when do you not feel included' is perhaps

directive and may have resulted in a change of response by Magic. The example above gives

insight into what Magic believes being included means for her. Magic wants to be listened to

by whoever she is participating with, and she wants to be interacting with other children.

Magic also notes that having fun is very important to her enjoyment of the activity which has

been cited in previous research (Spencer-Cavaliere and Watkinson 2010). The coach is seen

as a gatekeeper to whom Magic can and cannot interact with. Coaches as gatekeepers was a

theme throughout the examples:

*Researcher: Do you feel more included at dance or at horseback
riding?*
Aspyn: Dance.
Researcher: Can you tell me why?
*Aspyn: Yeah, I guess all my friends are here like we have sleepovers
and stuff too.*
Researcher: Could you make friends like that at horseback riding?
*Aspyn: Not really, we can't really talk but here we get time to like work
on things together and we can practice with each other after class.*
Researcher: You like having time to work on things together?
Aspyn: It's hard to make friends when (coach at horseback riding) is

telling us what to do all the time or not to talk. We can't talk here either sometimes, but we're always given time to practice on our own and I can teach some of my friends the moves if they don't know them.
Researcher: Is having friends the most important thing for you to feel included here?
Aspyn: I think so, no one really knows about my disability here like they do at horseback riding. One of my friends here her dad has a hearing aid too, so no one really cares so I like having friends where I don't need to explain my disability
Aspyn, Fieldnote: March 12, 2019

Aspyn values being included with others, feeling like a legitimate participant, having fun, and making friends leads to her feeling included (Spencer-Cavaliere and Watkinson 2010). It is always important to double check that a participant feels included within the environment before making assumptions as being with others leads to feeling included does not apply to all children with disabilities, as seen in the example below.

Kirby appears to be having a good time snowboarding. His coach is encouraging him to interact with his friend, by asking him to ask him questions such as 'what did you do this weekend'. I asked Kirby during break how tonight was going and he stated 'I told Luke that I don't want to talk tonight, and I'm being forced to'
Kirby, Fieldnote: February 7, 2019

Standardized inclusion practices promote homogeneity, which may result in feeling pressure to fit a preconceived notion of what is 'normal' (Valeo and Bunch 2004). It seemed to be a common theme for coaches to cue children with disabilities to ask the other children participants questions. However, in this example, Kirby was having an off day and did not want to participate in the asking of questions. If a child without a disability just wanted to snowboard, he may have been allowed to. Another example where the subject's and observed experience did not line up was:

Kirby has been interacting a lot with two girls tonight at track and field. They keep coming over and are really nice to him, some examples telling him he is really good at long jump, asking him questions about school, and sitting by him. When it is Kirby's turn to long jump and he gets up, the girls start gossiping about Kirby and telling the coach 'I think he's so weird, I just don't like him' they tell other participants 'he's just a weirdo I wouldn't be friends with him'. At the end of the

> *session, I asked Kirby 'did you have a good time tonight?' and he*
> *responded 'yeah I think I made friends with those two girls over there'*
> Kirby, Fieldnote: July 22, 2019

This example shows that there are so many things happening in an extracurricular physical activity that it is important to understand the whole environment before deciding on what is inclusive. Here Kirby does feel that he was included, making friends, and adding value. Whether Kirby's perceptions match other's observations may not be important, because he felt included. In the first example, Kirby was being 'forced' to talk when he did not want to, and in the second example Kirby wanted to talk to his peers. The idea of inclusion can be seen to change from one experience or environment to another; this has been noted in literature as essential to fully understand the process of inclusion and lived experiences of inclusion of people with disabilities (Spencer-Cavaliere and Watkinson 2010, Susinos 2007). Additionally, inclusion looks different depending on who the observer is (Roulstone 2000), which has been shown through the examples in the subsection. Although Kirby in the last example may have felt included, his peers are also excluding him by their responses to interaction with him, making his experience both inclusion and exclusion (Titchkosky 2011).

The understanding of inclusion is a process and cannot be oversimplified (O'Reilly 2005), as the relationship between inclusion and exclusion is complex (Labonte 2004, Ponic and Frisby 2010). The examples in the subsection begin to show how complex the relationship between inclusion and exclusion are, and how individual views can shift overtime. It is difficult to have a standardized definition of inclusion, as the examples show how fluid inclusion is. Inclusion has been shown to fit with the perspective that inclusion is dependent on who the observer is (Roulstone 2000).

6.3.5 Section Summary

The current section explores the process of inclusion in extracurricular physical activities for children with disabilities. The section starts with an understanding of how coaches implement inclusion and how children with disabilities react to the implementations. The section then discusses boundaries of the child-coach relationship. The section concludes with a discussion of how we know inclusion is happening from the perspective of the participants themselves.

Key themes emerged through this section that answer in part research question number two. The analysis included a comparison of the viewpoints of child-coach and their understanding of inclusion practices. There are implications for literature suggesting that the perception of inclusion and exclusion vary depending on the observer and the person who is experiencing the inclusion or exclusion. Furthermore, there is a lack of communication between the child and coach in understanding of the various perspectives of inclusion and how to implement.

Key tensions have emerged surrounding participation and negotiating of the process of inclusion; to further answer research question number two, the following section will further explore the process. The section will continue to examine the relationship between inclusion and exclusion and the interplay between the two different terms.

6.4 Recognizing participation and negotiation in the inclusion process

The following section will aim to answer in part research question number two. The section will do this by exploring participation and negotiation in the inclusion process starting with inclusion experiences connecting to participation literature and followed by a discussion of choice and inclusion. The section will conclude with a further discussion of the relationship between inclusion and exclusion.

6.4.1 Parallels to participation

Participation of children with disabilities in this study has not been as passive recipients of predefined inclusion practices, and in some instances, there was space for choice and decisions. Additionally, children have been active participants in discussing ways to include other children as shown in the example below.

> *Aspyn notices one of the other children in jazz class is having a hard time tonight. She goes up to her and asks, 'want me to show you?' and the other dancer responds 'yes' and Aspyn begins to count out the moves while doing it with her.*
> Aspyn, Fieldnote: January 12, 2019
>
> *Later, I followed up with Aspyn*
>
> *Researcher: I saw that you helped your friend with some dance moves.*
> *Aspyn: Yeah.*
> *Researcher: That was nice of you, I noted that you asked her if she wanted help first.*
> *Aspyn: Yeah…. Sometimes you don't want help.*
> Aspyn, Fieldnote: January 12, 2019

Here we see that Aspyn has also been respectful to other children in recognizing their choice. She is clearly demonstrating agency by making a purposeful choice on how to include her dance partner (Samman and Santos 2009), and ensuring the opportunity for her partner to make a choice whether to engage. There was no coach's instruction needed in order for Aspyn to make inclusion happen. Although the space has a hierarchy, it is also a process not a static entity and here we see how there is room for children to be involved in the process.

In previous chapters the thesis has a focus on participation, which the data is showing often intersects with inclusion practices, as children are either participating in the inclusion process or not, and they are included or not in the process. None of the organizations had opportunities for formal feedback specific to inclusion; however, the examples below show informal conversations surrounding the topic.

Chloe: I wish my coaches would just ask me how I would like to be included. My coaches switch frequently and sometimes they tell whoever I'm with to talk to me a certain way and sometimes I feel like it comes across that they talk to me slow, and I don't need that.
Chloe, Fieldnote: February 8, 2019

Kirby is one of the fastest hockey players on his team. One of his teammates who is slower to him often taps his stick on the ice when Kirby gets the puck to signal for him to pass to him. When Kirby does pass the puck to him the coach always says positive comments to him from the bench such as 'great team play' or 'great pass'.
Kirby, Fieldnote: December 19, 2018

The first example is a participant who is looking for a conversation with her coach to discuss a plan for her inclusion. Throughout the study, it was not observed that time was made for this conversation resulting in non-participation (Hart 1992). Although Chloe did ask her coach on several occasions such as one time saying, "can I talk to you when you have time?" (Fieldnote: November 24, 2018), the response was similar to the one in this example of "I'm busy can we talk next week?" (Fieldnote: November 24, 2018). Although in theory it is known that the views of people with disabilities should be taken into account regarding inclusion (Spencer-Cavaliere and Watkinson 2010, Susinos 2007), in practice this is not always the case. In the second example, Kirby is being praised for including his teammate where a conversation was not needed, and the positive encouragement led to more positive interactions.

As shown through various examples in the current chapter, children with disabilities are not consulted on their inclusion preferences and their influence over decisions is perhaps limited. The examples below are from interviews with children and the question they are answering is 'how would you change inclusion in (activity)?'.

Aspyn: I do think the coaches need to listen to us, I don't really know other ways to include kids, but I think it's important to talk to us because then everyone will be happy.
Aspyn, Interview: March, 12 2019

Marie: Maybe allowing it to be more fun. I know about all the rules but like if we could have more fun and time to hangout, I think that

we would just all become friends because like if we're shouted at for chatting, I don't think that's good.
Marie, Interview: August 28, 2019

To compare to the participants' views, a parent's answer is below:

Mother of Mickey: I think there should be more training for coaches on how to interact with the kids who are non-verbal. I think the coaches are often scared of Mickey but maybe if there was more training, they would feel more comfortable. And I think talking to him, and us I think if everyone shared information that would be helpful. Coaches often just take Mickey and then when he isn't included people are surprised. I know it will take more effort but to just give up is really annoying.
Parents' of Mickey, Interview: August 9, 2019

The above examples have elements of participation, as there is a desire to have a voice recognized, be listened to, and have an influence over the inclusion experience (Lundy 2007). To experience meaningful participation, it has been argued that children's voices need to be heard (Frankel et al. 2015), and it has been recognized that children's voices are easy for adults not to listen to (Lundy 2007). Children and parents do not feel listened to by the coaches regarding inclusion practices in extracurricular physical activities. Aspyn understands that she may not have an answer for furthering inclusion, but if consulted, a co-constructed solution to further the experience may be found. Additionally, Marie suggests that less structure may help inclusion to take place, such as allowing for chatting to other children might give space for inclusion. Furthermore, the mother of Mickey understands that including children who communicate non-verbally is difficult, however, discussing and interacting with each other may derive some improvements.

It has been argued that children make inclusion themselves, and perhaps do not need intervention from adults. However, participation is needed for inclusion to take place. Communication and feedback on challenges and successes should be valued more which would require a mindset shift from adults to encourage feedback. The following section will explore when inclusion is taking place amongst children but goes unrecognized by adults.

6.4.2 Recognized and unrecognized inclusion

In observing structured activities, it initially seemed hard for children to interact with each other without being watched or told what to do. However, children can be active in their own experiences:

> *Ben and Mickey are both non-verbal. They horseback ride together but after initial instructions to say hi to each other they are often separate. I've asked the coach about this and she says, "they can't talk anyways" or "Ben will get worked up and make loud noises" or "they need to focus on building horseback riding skills". When they sit on the bench together before they get on their horses, they have a couple of minutes by themselves. Sometimes they poke each other and laugh pretending they didn't touch the other. Sometimes Ben will act out a story and Mickey will laugh. Mickey when he has his iPad will touch a button like "balloon" and Ben will pretend to have a balloon. When they get too rowdy the coach asks them to separate and sit quietly.*
> Fieldnote: November 4, 2018

The example shows that the coach assumed that because her students did not use verbal communication, they were unable to communicate. Here, ethnography was a powerful tool to listen (Warming 2005), to the experiences of Ben and Mickey through being able to understand their bodily gestures (Maconochie 2018). After this example, and following similar observations of interactions with the coach and Ben and Mickey:

> *I'm seated in the waiting room waiting for Mickey and Ben to arrive. Ben arrives first and starts to laugh and waves a big high at me. When Mickey arrives, Ben runs over to him and shows him a plastic horse, Mickey smiles at it. When they're ready to go up to the bench to wait for the horses Mickey puts out his hand for me to take and leads me up there with him. Whilst sitting with them, they continue to interact, poking each other, laughing, communicating through bodily gestures. As the coach approaches, she says to me 'you must be bored up there' and I said, 'no I'm not'. After the lesson I approached the coach and asked, 'why do you think I would be bored with Ben and Mickey?' and she responded, 'well they don't talk'.*
> Fieldnote: November 27, 2018

There are many different perspectives in this example, the coach is viewing Ben and Mickey through their impairment, making it their defining factor which suggests a medical

model of disability perspective (Goodley 2011b), however, Ben and Mickey have found a

way to adapt to communicate to each other and strategically use their time not controlled by

their coach to connect. Although they are demonstrating their abilities, these abilities are not

being taken into account by the coach. The coach also coached Marie for part of the year who

is verbal, and had different comments towards her such was "She's so smart, don't you

think?" (Fieldnote: May 2, 2019), "Marie is really doing well this year" (Fieldnote: April 14,

2019), and "I haven't taught Marie in over a year and she's really improved" (Fieldnote:

March 4, 2019). These comments seem to contradict the coach's view of people with

disabilities, as defined by their impairment. Below I ask the coach what the differences are:

> *Researcher: You coach a couple of the participants in my study right now.*
> *Coach: That's right.*
> *Researcher: Are there any differences in how you coach them?*
> *Coach: Yes, Marie is really excelling in her horseback riding skills. Ben and Mickey will not be able to get to that advanced stage.*
> *Researcher: What is your main focus with Ben and Mickey?*
> *Coach: Getting a pony ride and having fun.*
> *Researcher: Do you think about inclusion with them?*
> *Coach: They're riding a horse.*
> *Researcher: Could they be included in other ways do you think?*
> *Coach: They can't really do anything else.*
> *Researcher: You get Marie to interact a lot with her riding partner do you think Ben and Mickey interact a lot?*
> *Coach: No.*
> *Researcher: Why not do you think?*
> *Coach: They're non-verbal I can only get them to wave to say hi really.*
> *Researcher: I wonder if they could communicate in other ways.*
> *Coach: Mickey has a hard time using the iPad but besides that no they're non-verbal.*
> Fieldnote: May 18, 2019

The coach was getting uncomfortable talking about Ben and Mickey's

communication and although being led into perhaps thinking of different communication

types was unwilling to discuss further. His coach is disqualifying non-verbal utterances, body

gestures, eye contact and other forms of communication which has been cautioned against in

research (Komulainen 2007). Inclusion, although perhaps not a goal for the coach, it is for the

organizations and Ben and Mickey are not treated as valued participants making inclusion non-existent (Price and D'Eloia 2018). Similarity, a coach of Moose's said that "he doesn't get anything out of coming here" (Fieldnote: December 8, 2018) and "I literally just put him on a horse" (Fieldnote: November 22, 2018). Attitudes and beliefs of children with disabilities affect how they are treated (Boggis 2018a). Here they are not being viewed as 'becomings' but less than.

The section thus far has discussed coaches' difficulties in understanding different forms of communication that are other than verbal. The examples below are from different moments during a hockey game of Charlie's.

> *Coach: Hey Charlie how's it going today.*
> *There is no response from Charlie, the coach skates in front of him*
> *so he is in Charlie's line of sight.*
> *Coach: Hey Charlie, how are you?*
> *Charlie smiles and lets out a little laugh.*
> *Coach: What drill are we doing today?*
> *Charlie is skating and moving his stick back and forth and the coach*
> *joins him for a couple of laps.*
> Charlie, Fieldnote: January 14, 2019
>
> *Charlie is skating around the arena and not lining up for a face off*
> *where he is supposed to be. A teammate yells over 'yo Charlie' and*
> *Charlie lines up smiling. Once the puck is in play Charlie laughs*
> *and skates towards it.*
>
> *After the game I talked to his mother*
>
> *Researcher: That was a good game?*
> *Charlie's Mom: It was.*
> *Researcher: I saw him smiling and laughing a lot when people were*
> *talking to him.*
> *Charlie's Mom: He really loves that interaction he really likes*
> *coming here, he tries putting on his hockey clothes almost daily*
> *during the week.*
> *Researcher: What makes it so special for him do you think.*
> *Charlie's Mom: I do notice here unlike his other activities they let*
> *the other kids talk to him and I know it isn't always positive but*
> *everywhere else I feel they're scared to engage with him but here he*
> *genuinely is on the team. During the week I see him looking at the*
> *hockey stats and he'll point to names he knows.*
> *Researcher: How do you think they make that possible here?*

> *Charlie's Mom: They don't protect him well they obviously have the equipment so he's safe, but it isn't a big deal when a kid says something to him. He's on the same playing ground, on the ice the same amount of time as everyone else. They're just playing and not focused on oh he can't talk because non-verbal communication is important in hockey.*
> Charlie, Fieldnote: January 14, 2019

Charlie participates in skiing, hockey, baseball, and horseback riding. Charlie has a one-on-one working relationship in all of the activities except hockey where there are two coaches on the ice for all the players. Starting with the example of the interaction between the coach and Charlie, the coach attempted communication and tried again when the first attempt did not work. Additionally, he asked what drill Charlie would like to do and followed through and did it with him ensuring that he had a say in his experience. Charlie's mother believes that they are 'valuing diversity' (Florian 2019), as at hockey the community is perhaps seeing good non-verbal communication as a positive. Attitudes that surround children with disabilities can vary depending on which society they live (Halder et al. 2017) and these examples show varying beliefs in the different environments.

Although both scenarios are different, there is a similarity in that non-verbal children sometimes have difficulty initiating communication themselves, as they are often taught to respond to promptings (Potter and Whittaker 2011). In these examples, Charlie's experience at hockey was better than Ben and Mickey's at horseback riding, however, communication does stop at the bare minimum with Charlie.

The subsection shows that children with disabilities are participating in inclusion practices whether they are recognized or not. Children with disabilities are active in their experiences and influence the environment around them. The following subsection will explore participants' actions further, in relation to choosing inclusion.

6.4.3 To choose or not to choose

As discussed in subsection 6.4.1, parallels to participation, participation which is similar to inclusion should have an aspect of respect for the participant choice. Inclusion is regarded to as 'good' (Cook and Swain 2001, Holt 2003, Slee and Graham 2008), however, inclusion practices should take into account the perspectives of people with disabilities (Spencer-Cavaliere and Watkinson 2010, Susinos 2007). Participation includes having a choice to participate or not, and ensuring that it is voluntary (Tisdall and Punch 2012). The example below showcases a conversation with a coach on the topic of inclusion followed by discussion with the verbal participant.

> *Researcher: What do you think inclusion means for Magic?*
> *Coach: That's a tough one, I'm not too sure what she would think. I hope she thinks that she's welcomed here by me. I haven't thought about it.*
> *Researcher: What about with other children?*
> *Coach: There isn't a lot of time for them to interact because we're doing different things.*
> *Researcher: Why different things?*
> *Coach: Umm well I'm not sure. I guess we want her to learn to ski.*
> Coach, Interview: March 10, 2019
>
> *Magic rolls the interview dice and reads the question.*
> *Magic: What do you want adults to know? That's confusing like all adults?*
> *Researcher: You're right that is confusing, can you tell me what you would like the adults at skiing to know?*
> *Magic: I want them to know I'm not going to the Olympics.*
> *Researcher: Ok, anything else?*
> *Magic: Yeah, I want to have fun and they panic if I go over and talk to Abby. I don't have many friends at school, and I think they should not be so serious.*
> *Researcher: Do you think they'd understand that?*
> *Magic: Uh no but maybe. I mean I like my coach, but I think sometimes she forgets we're kids like I hear kids talking at school and they get to chat to their friends at skiing.*
> Magic, Interview: July 12, 2019

Although inclusion is seen as a 'good' thing, there is a strong theme throughout the quotes that there are different practices at play. Coaches utilize their symbolic capital in these environments to have obedience (Cushion and Jones 2006, Swartz 1997), from the participants to follow their desired outcomes. It is important for children to be able to share

their views and know that they are valued and heard (Tisdall and Davis 2004). However, there seems to be a disconnect in what is allowed to be shared. In another sport, a coach said, "parents don't pay money for their kids to not learn a skill" (Fieldnote: January 3, 2019), although all parents I talked with had similar desires to "I just want Mickey to be happy, if he gets a couple of laughs or talks to someone that's a great day" (Mickey's mom, Fieldnote: November 20, 2018). There seems to be a pressure on coaches to focus on skill development rather than the interactions of the participants.

Inclusion is a choice, just as participation is. However, inclusion, in the data for this thesis from the perspective of coaches, has been a predefined structure and a way of interacting with other children. The examples below illustrate the result when children act in different ways than a predefined structure:

> *There is a new participant at lawn bowling tonight. Marie is the first one to go over and strike up a conversation. Marie asks the coach if they can be in the same group which was agreed. Marie is talking to the new participant during her swing and releases of the ball. Marie gets told "focus Marie or we'll move you to another group". Marie responds, "I just want to have fun and I'm teaching Beth how to do it". Marie ends up getting moved groups.*
> Marie, Fieldnote: July 11, 2019

> *Mickey is non-verbal and when he wants the other rider's attention, he gently places his hand on them sometimes on the shoulder. He is reminded by the coach that there is a hands-off policy and the coach tells the other rider to move away from him.*
> Mickey, Fieldnote: November 7, 2018

Both Marie's and Mickey's behaviour was not tolerated, as it was considered disruptive to the predefined structure of the session. Believing in capabilities of individuals and responding to what each individual may need may lead to greater social acceptance (Farrell 2017), however, in this example capabilities are not taken into account. Adults have left little room for co-creation of inclusion by eliminating the viewpoints of the children. A chance to socialize and focus on fun has been cut to focus on skill development. As children are actively creating their social selves (Nutbrown 1996), and self-esteem can be enhanced by

listening to children (Tallack and Neaum 2002), it is important to engage in a dialogue with children instead of just disagreeing. There is an attitude shift needed with coaches who work with children to create opportunities for joint ideas on how solutions can work to include all viewpoints (Cairns 2006).

The data has shown thus far that the way we think about inclusion needs to transform, especially in practice. As discussed, there is a need for participation within the inclusion process to ensure every viewpoint is taken into account. Below is another example of how Spyro feels about inclusion in Martial Arts.

> *Spyro in an interview rolling the question dice.*
> *Spyro: Where do you feel the most included? Hmmm. Where I don't feel different. When people are like listening to me and I'm being helpful.*
> *Researcher: Do you feel those things at Martial Arts?*
> *Spyro: Sometimes, and sometimes I don't.*
> *Researcher: Could that change to all the time?*
> *Spyro: Yeah I guess, I don't really have lots of problems with the other kids but the coaches I feel like could listen to us although they're the Sensei.*
> *Researcher: Do you feel included by the other children?*
> *Spyro: Yeah they're all really nice and I guess we're all doing the same thing just like waiting for breaks to talk and stuff.*
> Spyro, Interview: July 12, 2019

A repeated theme throughout this chapter is children wanting to be heard and listened to by adults. However, Spyro does feel included by her peers and is excited to talk to them when she is able. It should be of note that most participants when discussing inclusion mentioned their coach as being a part of that process. A reflective note through the research starts to explain why.

> *I have lots of notes about non-verbal participants receiving one-on-one coaching, being singled out by coaches, and having coaches as a gatekeeper to other children. I assumed this was potentially a non-verbal experience, however Aspyn who is verbal said to me this week 'coaches are always there you can't get away from them'. I started to look through my notes and every time something small went wrong they were there or always telling children what to do.*
> Reflective Note: March 2019

Children with disabilities in this study were surrounded by coaches for most of their experience. It seems relevant for participants to include their interactions with their coaches in their inclusion experiences. Adults are often seen as fully competent and in control of the environment (Qvortrup 1994), making space for children's perspectives difficult. Coaches are correcting the children when they do not act in the way in which they desire.

The subsection explores the space in which children with disabilities have the ability to choose during their extracurricular physical activity environments. Coaches play a role in which spaces the process of inclusion can occupy which may result in feeling included and excluded. The following subsection of the chapter will further explore the relationship of inclusion and exclusion.

6.4.4 When inclusion and exclusion co-exist

A portrayal of defined inclusion and or exclusion, as labelled by me as researcher or a participant, was found to be limiting. There were many moments throughout this study where experiences were exchanged sporadically one minute to the next. The portrayal of the experience of a member of a marginalized group, as a passive recipient of a simple binary label as either included or excluded is unsatisfactory and without value (Ponic and Frisby 2010). The following section looks further into the day to day lived experience of inclusion amongst children with disabilities in extracurricular physical activities.

The first example looks at an everyday experience of a structure set up for participation in hockey:

> *Marie is one girl on a hockey team where the rest of the team is male. She gets on the ice at a different time than the rest of the team, because she does not utilize the same change room as they do. The rest of the team talks before getting on the ice. Once on the ice they appear as a team and interact with Marie.*
>
> *Researcher: How do you feel being the only girl on your team?*
> *Marie: I do like it for the most part.*

> *Researcher: For the most part?*
> *Marie: If there was just one other girl I could skate onto the ice with someone or I don't think I'm the fastest.*
> *Researcher: Do you think your teammates like having a girl on the team.*
> *Marie: If I score yeah, but a couple of them don't talk to me a lot. Probably because they think I have cooties.*
> Marie, Fieldnote: November 29, 2018

In further and previous conversations with Marie about participating alongside boys in hockey, she seemed to have an overall positive experience with them. Later in the study, Marie started to get dressed quicker and wait for the boys to come out of the dressing room, so they could go on the ice together. Structurally, Marie is excluded for a portion of the time during hockey, as she is in a different changing room. Marie is excluded from some relationships with the boys at hockey because of her gender. There is an intersectionality of experience of gender in her disability physical activity experience (Baraldi and Cockburn 2018). Although Marie is in a segregated 'disability' activity, there are other factors at play, and in this example, gender plays a part in her lived experience. However, Marie does state that she feels included overall, and there are just moments of exclusion experiences.

There are perhaps intermittent moments in the relationship with being included and excluded, with different overall feelings of inclusion or exclusion. Another example of inclusion and exclusion experiences can be seen below.

> *Moose is the only participant in his horseback riding lesson. Usually after his lesson when the next rider is going into her lesson she will say "Hi Moose" on her way in. Moose looks at the other participant when she says Hi. When Moose is participating in his lesson there are often discussions in front of him about his capabilities. Some examples "He doesn't do anything so just keep him on the horse", "I think he wants off, but his time isn't up yet", and "just push him up if he's slouching". Moose's communication through his body is often pushing to get off the horse, and crying. His only interactions in his lesson are with his coach and volunteers. Today he had a new volunteer and instead of just moving his body for him she asked him several times throughout the lesson the following "Moose can you sit up", "Moose can you hold on" additionally she spoke to him a couple times about the surroundings. "Hey Moose, it's a pretty nice day today", "Moose I hope you have a good day after this". When*

his new volunteer was talking to Moose, Moose looked in her
direction off to the side, and was not appearing to try and get off the
horse.
Moose, Fieldnote: April 7, 2019

The above example is not inclusion, however there are moments where Moose was being regarded as an individual. Exclusion like inclusion is not stable (Ponic and Frisby 2010), which the above example shows, although social exclusion seems to be pretty stable for Moose in this environment, and sometimes there are new people who try to interact with him. Moose is non-verbal and has physical impairments; researchers have documented that children with these impairments have high levels of social exclusion (Morris 2001a,2003, Smith and Perrier 2014a,b, Whitehouse et al. 2009). A 'normal' individual from the coach's standpoint would be able to sit up on command, and because Moose does not that makes Moose an outsider due to the coach's predetermined normative view (Imrie and Edwards 2003).

During interviews with participants in this study, there were experiences that were recalled about inclusion which can be seen below.

Chloe: I think I feel inclusion. I can't really describe it but like I
know when I feel it and when I don't feel it.
Researcher: Can you describe a time you felt it?
Chloe: Umm yeah. I feel really happy and like I matter when I get
asked if I know something and I do and the coach will be happy I
know it and then the other kids can see that I'm smart.
Researcher: That must be really nice.
Chloe: Yeah but it's scary also because if I don't know the answer I
look really dumb and like I could get made fun of for not knowing.
Chloe, Interview: August 9, 2019

Furthermore, a similar example:

Kirby: People often think I'm not being included.
Researcher: Why is that?
Kirby: Well I don't like talking to a lot of people, I do my own thing.
Researcher: That's ok.
Kirby: I guess but it's also a problem.
Researcher: Why is that?
Kirby: People then ignore me and then when I do want to talk to
people, they've all made friends already.

Kirby, Interview: July 4, 2019

In the first example above, Chloe discusses that she likes to be included, but it can result in some worries about not being included. In the second example, Kirby suggests that he chooses to be alone, but sometimes he would like to interact with others and finds that process difficult later. Chloe and Kirby both suggest that they experience inclusion but also exclusion, and both are suggesting that there is a process of inclusion in their activities. The goal of choosing how they participate and with whom (Misener 2014), is almost achieved with Kirby, as he made the choice to be on his own, however, re-joining the group could be identified as an inclusion process to improve. Improvement could be discussed amongst Kirby and the coach to find a solution together. There is a tension between the choice of participation made, and how that affects Kirby's inclusion. The results may appear to be moments of inclusion that co-exist alongside moments of exclusion. The motivations for the choice of participation vary, for Chloe access to inclusion in this example shows being knowledgeable, and Kirby's is interacting with others. This could contradict with the feelings they have during their participation, as shown below.

> *Chloe: I really like talking to (other rider) she makes me feel like so welcomed and I haven't really made friends here before so it's exciting.*
> Chloe, Fieldnote: February 7, 2019

> *Kirby: Did you see me throw that?*
> *Researcher: I did!*
> *Kirby: It was amazing right; I think everyone here thinks I'm the best at javelin.*
> *Researcher: Do you think so?*
> *Kirby: Yeah, they're all going to want me on their team.*
> Kirby, Fieldnote: July 20, 2019

In the examples of inclusion during fieldwork, it may contrast with the individual's interview preferences. The journey of inclusion is different for each individual throughout the thesis, and the process is important to reflect upon. Preferences can change over time, and vary from one moment to the next proving that inclusion is very different depending on the

observer (Roulstone 2000). For example, in this case the observer could be the child, the coach, the assistant or the other children. Children with disabilities are active agents participating and changing their actions and viewpoints, the process of inclusion cannot be oversimplified (O'Reilly 2005).

Children with disabilities acting in the process of inclusion may not always result in a linear process to inclusion, as shown in the examples below.

> *Mickey is sitting on the bench next to a new student tonight. He reaches over and puts his hand on the student and smiles. This is something Mickey regularly does to the student he normally rides with. This time the student jumps up and says, 'don't touch me this guy is weird'.*
> Mickey, Fieldnote: January 28, 2019

A contrasting example is shown below.

> *Ben has a different interaction with his riding partner tonight. When the other rider does something that Ben thinks is good, he cheers him on by making a cheering noise and then giving him the thumbs up. The other rider reacts to this by saying 'thank you' with a big smile, and when Ben keeps doing this the rider says, 'I appreciate it man' and 'you're really cool.'*
> Ben, Fieldnote: November 22, 2018

The examples above show that participation choices of inclusion practices can have differing results, as there are various actors at play. In the first example, Mickey made a choice to say hello like he normally does but to a new student. The result was perhaps not one that was desired, however, it is important to note that participation choices can lead to forms of exclusion. To contrast, the second example shows that participation choices can also lead to forms of inclusion. Both participants communicate non-verbally, however, they have very different experiences. Although children with disabilities have opportunities to act and make purposeful choices in their inclusion experiences, there are negotiations and a process to be had. A few weeks after Mickey's experience above, the following happened.

> *The other rider goes up to Mickey and says, 'please don't touch me and I know you don't talk but I think I just prefer a high five'.*

> *Mickey looks at the other rider. The other rider holds his hand up to invite for a high five and Mickey touches his hand and smiles.*
> Mickey, Fieldnote: February 10, 2019

Mickey's first action to promote inclusion with his peers did not work, however, as time passed there was a door open to inclusive experiences. The negotiation from a touch to a high five was a simple one, but it took time for the other rider to process what Mickey wanted, and what he was comfortable with. Although exclusion may have been experienced, the experience changed even for a moment to an inclusive experience where both children were happy. The process of inclusion has elements such as participatory, relational, and psychosocial (Ponic and Frisby 2010).

The subsection looks at various experiences and viewpoints on inclusion and exclusion. The subsection highlights a tension, as inclusion is constantly changing from the viewpoint of the person experiencing inclusion or exclusion. Additionally, children with disabilities are active in their experiences and negotiation of inclusion.

6.4.5 Section Summary

The current section aim was to answer in part research question number two by exploring the negotiation of inclusion. To answer the research question, the section was divided into four parts. First, inclusion was discussed in relationship to participation, and a key theme of limited communication and a feedback loop in child-coach relationships. Second, inclusion can be recognized and unrecognized depending on the observer. A key theme of children's perspectives was discussed. To understand and recognize the process of participation it is important to explore the lived realities of the individuals experiencing inclusion. The third subsection explores the aspect of choice in relation to inclusion and the changes children with disabilities are able to create. Finally, the section concluded with a discussion of the relationship of inclusion and exclusion. The section provided examples of when the two terms can co-exist, and how children can navigate between the two. There is a

consistent tension throughout the subsections that inclusion and exclusion experiences are changing from the viewpoint of the person experiencing the inclusion and exclusion. The tension of the process of being included and excluded changes due to preferences, environment, relationships, expectations, actions, and motivations. The section provides lived experiences and examples of these tensions to understand how children with disabilities navigate and live through the inclusion process at various stages throughout their participation.

6.5 Chapter Six Conclusion

The current chapter's aim was to answer research question number two of the thesis which states:

> **Question 2:** How do children with disabilities navigate (or live through) the process of inclusion in extracurricular physical activities?

The chapter answered this question by looking at coaches' practices of implementing inclusion, parents' perspectives, children's perspectives, and children's lived experiences through participating in inclusive activities. Rethinking is needed on how researchers discuss inclusion. Inclusion and exclusion can co-exist, inclusion can be a choice and inclusion can look very different depending on the individual. Children with disabilities can feel that they are being excluded in some aspects of an activity and included in others. The process of inclusion has been similar for participants in this study, as they make their own inclusion experiences and are able to navigate power structures to engage with their peers. Similar to participation seen in other chapters, there are many different ways for a child to feel included and all those different ways should be equally valid. Predefined structures and definitions have not seen great success through the data calling for a mindset shift of these organizations to include the voice of the child. The lack of communication often leaves limited space for children to act and make choices on their inclusion experience as that does not seem to be the

overall aim of the coaches. Integration of children with disabilities in these extracurricular activities is occurring, with moments of inclusion.

The chapter focused on examples of how children with disabilities are navigating the inclusion process. Inclusion and exclusion were influenced by external factors such as parental, and organizational factors as described in the first section. The factors played a key role as they set boundaries, and goals for inclusion although often without input from the children.

Additionally, the chapter showed how children with disabilities understand the meaning of inclusion and how that can change for them over time or in different environments. The chapter also explored examples of coaches implementing inclusion practices and how children reacted to those implementations. Children provided feedback on the coaches' implementation strategies and offered a way to perhaps improve on inclusion goals.

The following chapter, Chapter Seven, aims to offer practical solutions to help willing coaches learn more about engaging with children. Furthermore, it will offer concluding thoughts and future suggestions for inclusion.

Chapter Seven: Conclusion on how children with disabilities navigate their experiences in extracurricular physical activities

7.1 Introduction

The overall aim of this thesis was to explore and create an understanding of how children with disabilities experience and navigate their participation in extracurricular physical activities. The reason for this exploration was the lack of evidence and understanding in respect of the lived reality of participating in extracurricular physical activities from the perspective of children with disabilities. The data from this study has added to this knowledge through incorporating lived experiences from multiple perspectives including children with disabilities, coaches, and parents. To understand these perspectives, the research study focused on the following research questions:

> **Question 1:** How do adults and children create opportunities and constraints for children's recognized participation?

> **Question 2:** How do children with disabilities navigate (or live through) the process of inclusion in extracurricular physical activities?

The research questions were explored using a participant led ethnography methodology which was conducted alongside children with disabilities in London, Ontario, Canada. The research was conducted over an eleven-month period, with ten participants across eleven extracurricular organizations. The thesis answered the research questions from the perspectives and lived experiences of ten children with disabilities. As the ethnography method did not only rely on spoken communication, it was utilised over an extended period allowing time to engage with all participants. Additionally, I was able to experience

extracurricular physical activities environment alongside the participants to co-create in-depth knowledge. Throughout the ethnography, I observed how the views of various coaches, organizations, parents, and children were similar and how they contrasted on the topic of what experiences were actually taking place.

In this final chapter of my doctoral thesis, I will review the findings of my research beginning with a summary of my findings based of my two research questions. I will then discuss the implications this research has for literature, policy, and practice. Following this, I will reflect on the limitations of this study, my role and beliefs, children's positions and perspectives, and my research methods.

7.2 Summary of findings

This section will summarize each finding of the research in order. The research questions were developed whilst identifying gaps in the literature to understand how children with disabilities navigate their participation in extracurricular physical activities. In-depth answers to the research questions can be found in my finding chapters four through six.

7.2.1 The Role of 'Choice' in extracurricular physical activities for children with disabilities

The fieldwork has expanded and improved the understanding of how choices are made in the extracurricular physical activity spaces. It was important to start with the concept of choice and a look at how children with disabilities were involved in the process of deciding which activities to take part in.

This section summarizes and discusses the findings in respect of the thesis (the full discussion is found in Chapter Four). The key themes of the research findings for question one and two are the:

- Context surrounding the experience of choice,
- Parent-child relationship in the process of choice,
- Coach-child relationship in the process of choice, and

- Participant's impact on the choice made.

These key themes will be discussed in order.

First, I will discuss the context of choice regarding finding extracurricular physical activity opportunities. The study participants experienced difficulty in finding activities where they would be accepted after considering their impairment or specific impairment type. In London Ontario and surrounding areas, there was typically only one program for each sport that was specific to those with disabilities. Throughout the data, there is a theme of choice that being the particular activity is "really the only choice" (Teachman 2016, p.132). This is significant for choice, because if there was a negative experience at an activity, there was an overall feeling of not wanting to give up on the limited opportunity afforded to the participants. More specifically from the data it was found that non-verbal participants, or participants with challenging behaviours (as defined by the organizations) experienced this 'only choice' more. Access to specific programs is limited, so even with a negative experience, participants and parents do not want to give up their position. Additionally, the application process to get on a waiting list was time consuming, so participants did not want to get caught between programs, for a concern having no activity. Parents found there to be a lack of information and resources to assist for children with disabilities to identify and facilitate participation in physical activities (Dyck et al. 2004, Martin Ginis et al. 2016). There were barriers such as membership fees, inaccessible facilities, limited resources, program policies and procedures and undertrained staff (French and Hainsworth 2001, Martin 2013, Mulligan et al. 2012). The thesis builds on the previous research and shows the tensions between children and their parents when navigating the process of activity choosing.

Second, the understanding of the parent-child relationship surrounding choice was found to have an impact on the opportunities and constraints of experiencing extracurricular physical activities. In Chapter Four, it was shown that parents often picked the activities that

children with disabilities were participating in. Parents were found to protect their children from navigating access by not informing them when an activity was too expensive or when they were rejected or asked to not come back to an activity. Parents often did not consult children about the activities that they were searching for stating that they did not want to get their children's hopes up.

Parents of children with disabilities were found to have the final say in the choice of the extracurricular physical activity their child participated in. When making the choice of which activity, data showed findings similar to previous research that identified motivations for parents included rehabilitation, fun, and belonging (Gibson et al. 2014, King et al. 2014b). However, parents were often paying for the activities, and providing transportation to the activities, resulting in limitations from parents on which activities and when their children could participate due to logistics.

Third, the relationship between coaches and participants had an impact on choice. Coaches are often the first point of contact for children, as they enter the extracurricular physical activity space. My analysis, in Chapter Four of this thesis, starts by showing that children with disabilities are sometimes offered tokenistic choices by coaches on how their experience generally will be framed. Choices are sometimes offered and taken away, or it is made clear that there would only be one right choice. Some participants experienced goal setting with their coach, although in many cases the goals were forgotten about. Tokenistic consultation or choices led to 'participation fatigue', as if they were consulted, there were often no changes (Cornwall 2008, p.280). Children with disabilities would often not seek out choice opportunities as frequently with some coaches, as they learned who was willing to consider their perspective seriously.

When children with disabilities tried to navigate their choices and assert their agency, coaches can see this as 'testing boundaries'. Coaches talk to other coaches and have often

labelled children that were navigating their agency in the space as 'difficult to work with' or 'does not take direction', rather than viewing children with disabilities as competent individuals to learn from. This becomes problematic as the culture around the child becomes one of expecting them to 'act up', so coaches become stricter to counteract the behaviours. Relationships between coaches and children with disabilities who communicated non-verbally were more difficult. Coaches were sometimes timid to allow non-verbal participants in their programs, as they were described as being difficult to communicate with (Boggis 2018c). Children with disabilities have the right to be able to communicate in ways that they prefer and to be heard (Boggis 2018c), for non-verbal participants, people working with them need to be skilled in observation and assessment (Hunt 2018). The data repeatedly highlights views and assumptions from coaches that non-verbal participants lack competence and maturity (Richards et al. 2015). These views and assumptions are a continuation of the narrative that children with disabilities having various communication methods are a 'problem'.

Participants in this study were involved in various physical abilities. Some participants were seen by coaches as not being able to achieve a high level in the activity, and a couple of participants were seen as exceptional and were pushed to excel. A participant voiced that she wanted to participate to have fun, but her coach decided to push her to develop her ability resulting in her leaving the activity. Choice, belonging, and fun were lost by service providers who focused on the activity to build skills instead (Gibson et al. 2013). This study is building on the idea that after a choice of activity is made, there are still opportunities for choice about how the activity is going to be experienced.

Finally, this summary looks at participant's own impact on choice. The thesis furthers knowledge surrounding extracurricular physical activities for children with disabilities which had previously looked at what activities they participated in and attendance rather than

children's viewpoints of the choice (examples, Coates and Vickerman 2008, King et al. 2006, King et al. 2004, Longo et al. 2012, Ullenhag et al. 2012a, Ullenhag et al. 2012b, Wuang and Chwen-Yng 2012). It is important for individuals to have choice of activity (Kiuppis 2018), and people with disabilities should have the opportunity to choose their sport (Misener 2014). Participants in this study expressed that they would have liked to be consulted before the picking of their activities. In regard to the viewpoint of children with disabilities on the choices made for them, they for the most part enjoyed the activity chosen. In other cases children with disabilities expressed their perspectives of non-enjoyment by visibly being upset at an activity. Some examples of not enjoying an activity looked like crying, taking a while to get ready, dragging their feet, or verbally saying things such as 'I don't want to be here'. The responses to participants not wanting to participate in activities are significant, because there is a disconnect on whose responsibility it is to listen between the coach and the child and the parent and the child. Coaches would say things, such as, 'their parents are paying for them to be here, so we have to keep them here' whilst parents would make comments, such as, 'well at least they're doing something'. Overall, this work extends literature that looks at how attendance in activities reflects on the role participants have in choice of activity and choice of how they want to experience their activity.

To conclude, the thesis closes gaps in literature by looking at the process of choosing a physical activity while taking into account different perspectives, which adds to the field by giving a rich account of how physical activity choice is made for children with disabilities, and their role in the decision-making process.

7.2.2 The lived experience of participation and how it unfolds amongst children with disabilities and adults in extracurricular physical activities

Chapter Five of the thesis explored the topic of the lived participation experience of children with disabilities in extracurricular physical activities. The purpose of this chapter was to discuss and answer research question number one. The key themes of the research findings for Question one are:

- Participation, motivations, and views of parents, coaches, and children with disabilities and how these motivations facilitate or hinder participation;
- Different types of adaptations for participants to participate and how the adaptations work in practice;
- The influence that context and environment have on participation; and
- Comparison of experiences of participation for children with disabilities who communicated verbally versus non-verbally.

The section will now discuss in order the key findings which in part answer research question number one.

First, I began the overview of the lived experience of participation with a discussion of participation motivations and views of coaches, parents, and children with disabilities and exploring how that motivation hinders or facilitates participation. Starting with the coaches' view of their role in extracurricular physical activities as being fully in charge. A few coaches made comments that represented the view of children being less than adults (Priestley 2003), or needing to be protected and cared for, rather than viewing the children with disabilities as having capabilities (Fitzgerald and Graham 2009).

In line with other research, the motivations expressed by parents for their children with disabilities to participate in physical activity were for the health benefits (Carson et al. 2010), social benefits (Breuer et al. 2015), enjoyment (Beurskens et al. 2016), and personal respite. Additionally, this finding supports that parents can change their motivation for participation in these activities, if parents get the impression of a lack of support, knowledge, and experience (Beurskens et al. 2016). As parents live through their children's positive and negative social experiences, it shapes their views on participation. Some parents were unwilling to have their children participate in activities alongside children without

disabilities, as previous attempts resulted in negative experiences. Additionally, parents also found themselves in the position of advocating for positive experiences in both segregated and integrated activities. The data shows that some parents were at times unable to enjoy their children participating in physical activity reporting feeling 'on edge' and being 'ready to jump in' to either advocate for more positive participation experiences or to educate people about their child's needs to ensure their needs are met (Williams 2013).

Overall children with disabilities in this study reported motivations for participation in extracurricular physical activities as wanting to have fun, seeing their friends, becoming stronger and learning new things. Wanting to participate alongside friends was important, as it led to them feeling like a valued member of the activity which is consistent with other research done in Canada (Spencer-Cavaliere and Watkinson 2010). Data showed that some friendships extended beyond the activity's environment which contradicts other research that showed friendships being restricted to specific environments (Bloom et al. 2009). Bonds amongst participants also led to supporting one another (Goodwin 2001), which sometimes resolved a previous understanding for the need of adults to support children with disabilities (Biricocchi et al., 2014; Zitomer & Reid, 2011; Oriel et al., 2012). The friendship relationships are significant, as they add a positive experience to participation (Gustavsson and Nyberg 2015).

Participants actively found opportunities to create fun in their different environments, which changed the way participation was experienced (Frankel 2018). For participants, having fun was a way of connecting and participating with their peers which could be expressed by non-verbal communication.

From motivations of participants, the role of identity emerged, as the activities provided an opportunity to be recognized for something other than their disability. One desirable identity was that of an athlete (Anderson 2009). Through participation in physical

activities, there was space for development of identities that would extend to other aspects of their lives (Anderson 2009, Goodwin and Staples 2005, Groff and Kleiber 2001). It became a sense of pride for some participants, as they gained knowledge and skills which could translate to teaching others what they had learned. Additionally, teaching other children their skills in their current environment built up their self-esteem by being identified as being skillful and succeeding in an activity. However, there were occasions where children with disabilities wanted to focus on their own activity rather than helping others.

Second, participation in extracurricular physical activities for children with disabilities is often experienced with surrounding adaptions. In literature, it is known that some children with disabilities may need physical adaptations to participate in physical activities (Shields et al. 2012). The data added that sometimes children with disabilities are able to pick what physical adaption that they feel they need for that specific session without asking for permission. However, there is contrasting data that showed children were unaware of why they had a physical adaptation and were not consulted when deciding what was best for them. Additionally, sometimes coaches did not know the reason for the adaptation which led to frustration from children when trying to understand why they were different. Emotional adaptation was implemented more inconsistently, and it was very relative to who was providing the support, where the support was being provided and the views of the child. Some coaches did not take into account the participants' views (Smart 2002), whilst some coaches took time to observe to understand (Roberts 2008). There were various examples in Chapter Five about coaches not willing to take into account participants' views, or if they were shared, they were sometimes ignored. As children's needs change, it would be important to ensure that there is room for expressing the needs and wants of the child. Sometimes children would be consulted about minor decisions, but they were not consulted for major ones.

Adaptations for non-verbal participants were often having to be organized and funded by parents (Goodwin and Ebert 2018). Non-verbal participants found the experience of support to be challenging, as it was often the case that their personal helpers and coaches were changing frequently. It takes time to learn the unique ways of communicating causing non-verbal participants to restart the process with each new person that was introduced to their environment. Unlike the other adaptations, non-verbal adaptations are unique in that they seemed to be less important to the organizations and coaches. If there was a problem in securing the specific adaptation for the activity, the default was to not find other solutions but to just say 'he'll be fine for today'. Non-verbal cues can be similar between non-verbal and verbal participants; however, there seemed to be a big disconnect in the desire to recognize these communications. The attempts to communicate and get attention, if not being recognized, would be seen as a social problem and disruptive (Barron 2015). As adaptations have an impact on how participation is experienced by children with disabilities, it is important to explore the context further to imagine a fuller picture.

Third, a theme of Chapter Five in answering research question one was the importance that context and environment had on what experiences actually unfold in extracurricular physical activity environments. Unpacking participation as a lived experience from the start of data collection was challenging, as there were a lot of differing perspectives and tensions surrounding participation. The vast majority of participants did not know about their rights. Similarly, most coaches and parents did not know about children's rights, while some parents made their concerns known about educating their children on their rights. The culture around children's rights in Canada is important to recognize because participation experiences can be shaped by the culture itself.

The extracurricular space for physical activities exists in a clear hierarchy of power with the coach being in control. The environments are regulated and policed by adults (James

and James 2008). However, there were many examples where children with disabilities are not just passive recipients and resist the control (Tisdall and Punch 2012). During observations, there was little to no explicit opportunities for expressing participant viewpoints. Some participants reported being uncomfortable when expressing their views to coaches, suggesting a lack of a safe space for information sharing. Although there were various actions from children that showed they were capable of forming a view (Qvortrup 1994), the coaches instead made their own decisions on whom they thought capable (Hanson 2012). It is commonly known that children should be involved in matters that affect their lives (Tisdall and Punch 2012), however, this viewpoint is not being incorporated in practice. The understanding in literature surrounding participation often cites the UNCRC, however, none of the coaches or organizations had heard of the UNCRC before the study. For children's perspectives to be incorporated in practice there will need to be an understanding by the organization of why children's voices are important to incorporate.

The analysis shows the difference between protection of children with disabilities in their ongoing participation versus support. How coaches view children with disabilities is a key contributor as to whether they are protecting or supporting participants.

In the thesis, I have strived in my researcher role to understand how the process of participation was changing and how the culture was hindering or supporting the process. The research placed an importance on how the individuals in each environment interacted, and of equal significance understanding and deconstructing the attitudes towards children with disabilities (Rimmer et al. 2004). Some coaches were very explicit about not wanting to teach certain children, these children were often non-verbal which resulted in children who communicated non-verbally to be treated differently than their verbal peers, some examples included non-verbally communicating children being ignored, coaches assuming a lack of

competence, assumptions and that the children's communication was a form of 'acting up' causing a disregard their ability to communicate.

Finally, an important theme throughout this research is the differing perspectives from verbal and non-verbal participants. Four participants in this study communicate non-verbally, which is a significant contribution of knowledge, because often their perspectives are excluded from studies. Literature promotes that children with disabilities should be seen as capable rather than viewing them through their impairment (Fitzgerald and Graham 2009, Mason 2009, Noble-Carr 2007). Some verbal participants experienced being viewed as capable; however, it was extremely rare that non-verbal participants were viewed as capable. Even if children were expressing the same non-verbal communication, such as looking in the direction of the person speaking, verbal participants were assumed to be listening on all occasions. Non-verbal participants would be asked questions, such as, 'are you even listening to me?'. Spoken language is continuously preferred and therefore privileged (Komulainen 2007). Non-verbal communication is not respected as a legitimate form of communication and the coaches' preconceived notions are leading to participant perspectives not being recognized. Coaches made comments about verbal and non-verbal participants that could be described as harsh or at least insensitive, and coaches would make these comments in front of non-verbal participants. When questioned, coaches would just assume that the participant did not understand. When children with disabilities are excluded from conversations, this furthers the power divide between adults and children (Frankel 2017).

In conclusion, research question one was answered through the key themes of motivations of parents, coaches and children with disabilities, adaptations, context specific impact and verbal versus non-verbal communication experiences.

7.2.3 Experiences of children with disabilities through the inclusion process

Scholars have highlighted that there is a need to explore inclusion from the perspectives of people with disabilities (Spencer-Cavaliere and Watkinson 2010, Susinos 2007). Chapter Six of the thesis is contributing experiences and perspectives of inclusion from children with disabilities to further understand inclusion in practice. During the Chapter Six discussions on research question two, a few key themes emerged which are:

- Various perspectives of inclusion from parents, coaches, and children with disabilities,
- Context of the culture and motivations surrounding inclusion, and
- Lived experiences of inclusion.

The key themes are summarized in order.

First, the data shows the perspectives of parents, coaches, and children with disabilities about inclusion. Parents viewed inclusion as what is often described in literature as social inclusion which is being a contributing and valued member of the community (Hickingbotham et al. 2021, Mâsse et al. 2013, Mâsse et al. 2012, Murray and Greenberg 2006). Parents expressed worries about their children not being included and often felt they had to advocate for their children to have a meaningful presence in extracurricular physical activities. Parents of non-verbal children experienced this more often, as they were further excluded on the basis of communication (Moosa-Mitha 2005). Similarly, parents with children who had behavioural challenges felt that this affected inclusion for them (Recchia and Lee 2004).

Coaches had a different view of inclusion which was sometimes reduced to being the same as attendance. All the organizations where the activities took place had claimed to be inclusive. In society, inclusion is seen as a goal, and funding for programs is often tied to being inclusive. Attendance previously has been measured as inclusion; however, literature shows that attendance is not enough for inclusion to occur (Tardif-Williams et al. 2009) which was confirmed in the data of this thesis. Other coaches believed that provision of

special equipment facilitated inclusion which was seen to be through a medical model perspective of disability (Oliver 1996).

Children with disabilities in this study believed that inclusion was "felt". They believed that they could feel inclusion from their peers and not their coach or vice versa. Inclusion was discussed in literature as having meaningful relationships with others which sometimes resulted from social capital (Weisel and Bigby 2014). Additionally, children did feel similar to their parents in their desire to be meaningful in their environment and contribute (Mâsse et al. 2012, Murray and Greenberg 2006). However, there were occasions where children with disabilities did not prioritize making friends or feeling included, rather, they wanted to practice skills.

To understand the complexity of interconnection of inclusion perspectives amongst children with disabilities, parents and coaches in inclusion practices, ethnography was a necessary tool. There are similarities and differences surrounding the understanding of inclusion amongst the coaches, parents and participants which plays a role into the lived experiences of inclusion.

Second, building on the theme of how key people view motivations and culture surrounding inclusion will be summarized. Extracurricular physical activities as a space has a hierarchy where children with disabilities, parents and coaches believe that coaches are in charge. It was believed that coaches were in charge of ensuring and facilitating inclusion from the perspectives of parents, children with disabilities and the organizations. The structures of extracurricular activities were found to be rigid making the environment difficult for children with disabilities to navigate (Davis and Smith 2012). Data in the thesis shows that children with disabilities attempted to connect with their peers in their environment and sometimes would get in trouble for their unstructured attempts, as they were

seen as disruptive. Power is used by coaches to limit undesirable behaviours (Foucault 1977), whilst at the same time limiting potential for social relationships.

The goal is to have inclusion; coaches are placed in charge, and they feel capable to include children with disabilities because sessions are advertised as 'inclusive'. One method that was observed in the data collection was coaches singling out certain children by telling the other children about their impairment and asking them to be inclusive. This method serves to reinforce that those children with disabilities are different from the 'normal' (Sayers 2018). The 'othering' language would reinforce exclusion from the group (Wendell 1996), and it reinforces to the other children that it was permissible to use the same language. Children with disabilities in this study believed that sometimes coaches made the inclusion process worse. Some children in this study preferred to identify with other labels such as their name rather than the coach explaining to other children and volunteers their impairment first. Discussing a label of impairment first rather than a skill sometimes left children frustrated by some of the labels. These experiences did not reflect a valuing of individuality, rather it is attempting to conform children to be 'normal' (Valeo and Bunch 2004).

Coaches' views varied on inclusion resulting in varying approaches (Davis and Watson 2001). Children with disabilities who were excelling athletically were often allowed more freedom to engage with other children leading to more social capital and seemingly making it more desirable for other children to be friends with them. This finding supports literature that has said inclusion within activities benefits those who are already included more than those who need inclusion (Allman 2013). However, my study builds on the idea that space is also a process and not a static entity (Christensen et al. 2015). Space changed throughout the study as relationships were built, children had new teammates or coaches, the time of the activity varied, new equipment was utilized, and various other factors led to space changing constantly.

Third, the lived experience of inclusion is an important addition to knowledge, as it provides observations of how inclusion is experienced over an extended period. Inclusion can be viewed and understood differently depending on the viewpoint (Roulstone 2000), making it a subjective and a multifaceted term (Croucher and Le Boutilier 2010). It is important to understand specifically from the perspective of participants how inclusion was being experienced.

For some children with disabilities in this study, it was clear that they were not experiencing inclusion. Labeling inclusion or non-inclusion within these environments became very limiting. Non-verbal children were not seen as valued participants throughout the study which makes inclusion non-existent (Price and D'Eloia 2018). Beliefs and attitudes of children with disabilities have a direct influence on how they are treated (Boggis 2018a), and included.

Inclusion was also experienced as co-existing with exclusion from one moment to the next. Observations showed engagement in activity followed by exclusion. It seemed difficult for children with disabilities to navigate the ever-changing rules of engagement. The data also showed that children with disabilities would include other children by making strategic and purposeful choices to include (Samman and Santos 2009), especially occurring in spaces that were not overlooked by coaches. In these spaces children would often interact and would sometimes express the frustration of not being allowed to have fun with each other in front of their coaches.

The summary of Chapter Six answers the research question number two through inclusion perspectives, the context of extracurricular physical activities and lived experiences. The analysis shows the importance exploring the term inclusion that is universally understood as 'good' through the perspectives of those who are previously identified as excluded (Cook and Swain 2001). The data shows that children with disabilities

can question if their experience is really inclusion. Numerous participants were unsure on whether to say they were included or not, as a whole.

7.3 Implications for literature, policy, practice, and future research

Following the data summary of the answers to the thesis's research questions, I will now discuss the implications for literature, policy, practice and future research.

7.3.1 Implications for literature

The thesis is adding to literature and has theoretical implications to fields of childhood studies, disability studies and inclusion literature. The following implications will be discussed below:

- Rethinking inclusion,
- Participation is uncertain and ever changing, and
- Inclusion of non-verbal participant perspectives.

First, there is a need for literature to rethink the way in which inclusion is defined. Inclusion is currently defined and labelled by people who are not experiencing exclusion. It is often discussed as being a goal for the future to work towards; however, it needs to be talked about in the present as well. The thesis attempts to give a wholistic approach to examining inclusion by looking at the process of inclusion, and different perspectives of inclusion. Additionally, inclusion should be continuously researched through lived experience, as inclusion and exclusion may co-exist and understanding the interplay between the two is necessary. Furthermore, choices for children with disabilities and their role in their own lived experience of inclusion and exclusion should be given weight as their choices have value. To summarize, the thesis has direct implications for literature as the understanding of the fluidity of inclusion and exclusion should be acknowledged. The understanding of inclusion should be from the perspective of the child who is experiencing inclusion and exclusion.

Secondly, the data adds to the field of children's participation literature, as it highlights participation being uncertain and changing. The data aligns with the criticisms that participation can be treated as a technical exercise (Hinton 2008, Malone and Hartung 2010). The thesis provides implications for literature, furthering the importance of researching participation amongst children, specifically children with disabilities and acknowledging their role in their lifeworld.

Thirdly, the research methodology of ethnography was utilized to widen the diverse perspectives of participation experienced in extracurricular activities. This has implications for future research, as children who communicate non-verbally should be included more in research as shown through this study, their perspectives are unique and sometimes different from the overall disability population. Children who are non-verbal are often excluded from research, and the thesis clearly shows an extremely unique lived experience that needs to be acknowledged.

7.3.2 Implications for policy

The thesis points to implications for policy in Canada regarding participation of children with disabilities in extracurricular physical activities. The key implications for policy are:

- Inclusion of children with disabilities perspectives,
- Enforceability, and
- Adaptations

First, it is important that work on policy is furthered to include the experiences and views of children with disabilities. There is a need for policy to incorporate their perspectives on participation and inclusion. Additionally, it should be policy to evaluate and ensure that children's participation is at the forefront of their experiences in their lifeworld. Evaluation and feedback on the current policy effectiveness to translate into inclusive practice or its impact on children's experiences falls short.

Second, children with disabilities are often limited in choice of extracurricular physical activities as some activities where all children were allowed to participate had limitations. Segregated activities also had limitations which made activities more challenging to access. Although Canada in policy terms is moving towards aspiring to achieve greater inclusion, there is an oversight in not identifying who is accountable for the changes to be made. Additionally, when discrimination is faced, parents and children risk losing their participation opportunities, if they speak up to the organization. The thesis suggests that there should be an avenue for support in finding activities for children with disabilities, and a place where their voices can be heard to adapt their experiences to make it overall more positive.

Third, adaptations made in physical activities were often made for children with disabilities rather than working alongside children with disabilities for solutions. In policy, there should be an understanding that assumptions should not be made about children with disabilities and their perspectives should be gathered about adaptations. Additionally, adaptations on how coaches interact with children with disabilities should be understood from the children, such as their preferred method of communication, what they would like to be disclosed to volunteers and other parties, and how they identify. The implication of these policy changes is important, as respect for children with disabilities needs to be demonstrated from the initiation of interactions.

7.3.3 Implications for practice

In childhood studies literature, it is commonly discussed that children should be able to participate in meaningful ways in their everyday lives (Percy-Smith and Thomas 2010a). However, my data shows that theory does not always translate into practice. The key themes for change are:

- Mindset shift on the view of children with disabilities,
- Feedback, and
- Choice.

First, one of the thesis's implications for practice are about the need to change those who are in charge. My research demonstrates the importance for a mindset shift into viewing children as co-participants who have value to shape whether they are verbal or non-verbal. Organizations need to encourage coaches to learn more about how to interact with children with disabilities generally and those who are non-verbal specifically. Although children with disabilities were viewed in various ways by coaches and organizations, there is a clear need for a baseline understanding on how to interact with children with disabilities. The implications of a mindset shift to perhaps viewing children with disabilities as children first may change how people interact with children with disabilities. Instead of viewing children with disabilities as 'needing' support, children may be encouraged to have fun and their perspectives taken more seriously.

Second, there is a need to include the views of children with disabilities through using consistent feedback on their participation in extracurricular physical activities. Organizations were contacted near the end of my fieldwork to inquire, if they would like to receive a summary of findings, only one organization said yes. Feedback was sent to all organizations, with only one response. The lived experience examples in the thesis highlighted that feedback from children with disabilities was rarely important. However, children with disabilities also expressed very important and impactful perspectives that should be heard and valued. The thesis highlights the implication that there is a need for a space for children to share their views, and to be heard.

Third, whilst including children's perspective of their experience, there needs to be a recognition that choice is ok. Children with disabilities, sometimes did not want to be included in the traditional sense with their peers and should have the option to choose. Additionally, children with disabilities sometimes wanted to focus on skill building, instead of teaching other children. Hearing children with disabilities preferences, it should be

acknowledged that children should also have a say in how they participate. Coaches sometimes assumed that parents wanted education goals, rather than a fun activity. However, children with disabilities should be entitled to have 'fun' rather than a continuation of a school like instruction. The implications for practice would be to allow for children to be co-participants in their experience by allowing them to shape their experience.

7.4 Reflections

The chapter is now shifting into a reflexive account of the thesis overall. Throughout the thesis, a reflexive approach was taken and intertwined in the data. The following will look at the impacts of the thesis through a reflection on the methods used, limitations of the study, and my impact on the participations.

7.4.1 Reflecting on limitations of the study

Ethnography generated rich and in-depth data for this thesis. However, there were only 10 participants resulting in only 10 perspectives being reflected. Due to time limitation and nature of extracurricular activities such as weeknights and weekends, it would have been impossible for me to add any other participants to the study under the existing design. However, more perspectives or sports may have added depth to the research conducted.

The research was limited to the context of extracurricular physical activities, and although there are dialogues with participants discussing their other environments, it would have been interesting to see other contexts.

Participants included in this study had access to extracurricular activities which means funds, transportation, parental approval, and acceptance into programs. It would have been interesting to explore how children with disabilities navigate extracurricular time without these supports.

The age group of participants targeted for the data collection was not young children. For future research, it would be interesting to do a similar study to understand if experiences are similar at different ages. I assumed at the start of my study that older children would have a bigger say about which activities they participated in, which was not always the case. There were reflections from participants about discriminatory practices in integrated programs in their earlier childhood which led participants to sometimes prefer disability participant only programs. It would be worthy research to follow these lived experiences firsthand to see how coaches, parents, and children navigate the experience.

7.4.2 Reflecting on my role and beliefs

I began the thesis journey with a belief that the experience children with disabilities live through in extracurricular physical activities matter. Throughout my previous studies, I was constantly thinking back to the ten years of volunteering or coaching with children with disabilities. I felt that participation needed to be explored in these settings.

My 'personal, political and intellectual autobiography' shaped the research process and data creation (Mauthner and Doucet 1998, p.121). I am a middle class, white, female, coach, PhD student, daughter, and sister. I believe that children with disabilities should be seen as co-participants. In Chapter Three, I discussed further my identity and the lived experience that may have shaped the way I understand the lived experiences of participants.

Before recruiting participants for the study, I was apprehensive of working alongside non-verbal participants. I believed that they should be included in the study; however, I was nervous about learning various methods of communication. In practice and the world in which non-verbal people live, this is a common experience. Working alongside all the participants, ethnographic research was also looking at non-verbal language of all children. Once in the field, I found that non-verbal participant data to be vital. It was helpful that non-

verbal participants were interacting with others during the fieldwork, as I was able to observe communication and learn actively.

I also found the data collection inspiring while working alongside children with disabilities following their journeys of meaning-making and reflections. It is an important process to document and not rush into.

I found the data chapters difficult to write. I was a part of other people's families celebrating successes and watching them navigate challenging situations for an extended period. The researcher role did not end in fieldwork. As I took on a 'friend' role during data collection, it was important that I reflect on all the data presented to ensure I am representing the participants contributions in a respectful manner.

Participation has been an interest for me, especially how to further participation opportunities. Data from the fieldwork shows that children with disabilities are navigating their spaces and creating participation opportunities. I choose to label and categorize various participation elements surrounding the perspective of children with disabilities. However, I did not label adults' actions as 'resisting child control' or 'becomings' as they learn participation processes through living rights. Adults are in a position of power throughout the study, they can be seen to stop participation, not acknowledge participation, define the rules of engagement of participation or limit participation opportunities. Although it may not just be a result of a hierarchy, the hierarchy may continue to exist because of how coaches and parents view children. The communal view on children with disabilities in these environments needs to change for the culture in these spaces to shift to focus on recognizing participation.

7.4.3 Reflecting on children's position, perspectives, and research relationship

Asserting a judgment on children's positions and perspectives throughout this thesis has been challenging, as I am an adult commenting on their life experiences. Throughout the study it was vital to continue to check ongoing findings with participants to ensure their perspectives were being represented appropriately. I asked a couple of the participants how they felt about me writing up their experiences and a couple answers were "Well I don't want to do your homework" (Magic, Fieldnote: April 12, 2019) and "You're here all the time so I think you have a pretty good idea about what to say" (Chloe, Fieldnote: June 4, 2019). The data created through this research study adds to research by showcasing different and further understandings of the experiences of children with disabilities in extracurricular physical activities.

Participants that were in this study took on a role of teaching me about their everyday experiences. They seemed to get enjoyment in teaching me about their activity, checking my notes and telling me things I was missing. The majority of the participants, like me, were white, middle class and growing up in an area I knew well. This is perhaps a limitation of the research and a gap that future research could cover. I was able to connect with participants talking about extracurricular physical activities, different schools they went to, and different local activities. During the data collection, some participants would tell me straight away that something was important by saying things such as 'Katie are you getting this?', or 'did you just see that?'. On some occasions, children requested I take less active roles, as I was researching with them one on one, they wanted their free time to be allocated to other activities.

During the fieldwork, children with disabilities raised questions about the importance of participation which may or may not have shaped the way they navigated their spaces, some of these questions can be found below.

- "Why are you the only one that writes down what I say?" (Chloe, Fieldnote: December 10, 2018)

- "You always talk about participation but what does it matter if we can't talk to coaches and have them actually like listen? I don't like that … Look at how that can create more awkward things and I'm just trying to not make waves. It's not just us like do you talk to bric walls?" (Magic, Fieldnotes: March 22, 2019)

At the start of the study both participants above did not know about children's rights or about participation rights. As part of my knowledge creation with participants, I would introduce meanings of participation that adults had come up with such as definitions, participation diagrams and working through the '7 Golden Rules for Participation' from the Young People's Commissioner Scotland. Once understanding how participation *should* look or work between children and adults, similar questions would arise about the importance of participation. When asking what would be more important to learn about, some answers are shown below.

- "I know it's like chatting right but like it's also like I don't know. What do you do when you chat? I mean maybe you don't I don't know. When I chat it's like I actually care and like listen and like you need to start there." (Magic, February 18, 2019)
- "Where to start ummm I think like my coach thinks it's participation because I'm here which like kinda. But I don't know it's more right? And sometimes like I don't want to participate and it's ok if they don't want to sometimes either." (Marie, November 10, 2018).
- "Well, it's simple you're going to need to know what's right and what's wrong." (Aspyn, October 6, 2018)

Participants' views on participation are not just about describing what participation looks like but what participation can feel like as well, having morality and terms of engagement. Participation is bigger than the label that it is given in research. Further, participation knowledge does not always create a culture or space that practise participatory mindsets. Participation does not happen in a bubble, for participation to occur the wider issues surrounding views of the child in practice need to catch up with the theoretical knowledge.

The views of coaches from participants in this study were overall seen as 'others'. There were subjective views of coaches, of themselves and the other way around as well how coaches viewed themselves and how they viewed the participants. The differing views of how one views themselves versus how they are being viewed shapes the experience. When

coaches saw children with disabilities as not being competent versus participants seeing themselves as competent, there was irritation all around. When two parties are not on the same page, it became frustrating for participants.

7.4.4 Reflecting on research methods

The main research method used in this study was ethnography. The two research questions were to be explored alongside participants with various communication methods. Ethnography gave me the ability and time to learn different communication methods. Although, at the beginning of my research process, I asked participants which research method they would like to engage with, participants felt the best way to understand their experiences was for me to be with them.

Over the course of the research, I developed a rapport with each of the participants in the study which often took on a friend role. The role was difficult to navigate as in ethnography, there is a whole community involved. Often coaches questioned why I was being friendly and spending a lot of time talking and learning from participants.

Although the research methodology was through a participatory focus, upon reflection the research methods could have gone further in having children be a part of the whole research process. Children perhaps could have been co-researchers or children could have been involved in the dissemination of the data. Additionally, children could have come up with research questions, or suggested different areas of their life as important to explore.

Living through the research process in a highly structured space with little to no free time added challenges to the ethnography. Participants were required to follow a series of instructions and focus on the task at hand. That meant one of the challenges I faced was sometimes not having the ability to ask questions right away. On fieldnotes, I wrote down questions I wanted to ask participants when there was a spare moment. However, sometimes the opportunity did not occur, as parents were eager to leave after the activities. A couple of

the participants were able to think back and reflect on specific questions I had, while others had difficulty remembering. I could have gone further in creating more data such as writing questions down for participants to take home and reflect upon.

I found the journey of a researcher challenging, specifically when I did not agree with how children with disabilities were being treated, or when I saw opportunities for improvements. Other research methods would have potentially resulted in more objective data.

I acknowledge that my role as a researcher had influence on the setting and the data that was being created (Connolly 2008), especially at the start of the research process, parents and coaches seemed unsure of how to act or what to say around me. They seemed to be searching for the 'right' answer. However, as time went on, people felt more comfortable to share their more typical expressions and experiences.

7.4.5 Leaving the field

The research occurred for some participants over an eleven month period of time. I was with participants for all their extracurricular physical activities. It was difficult for me to transition to being back in an office all of a sudden, without the interaction with the people that I had become accustomed. Due to research being in Canada and finishing my studies in Edinburgh, it made it difficult to remain in contact with various participants.

Participants included in this study also found the change difficult. I received emails from participants wishing I could come visit them. Additionally, it was hard to explain that their perspectives still matter. In some cases, I was encouraging participants to share their thoughts, feelings, and reflections more than they had previously. Leaving the field meant that participants were no longer creating data with me which had become a part of their routine.

With a couple of participants, there were tears when final goodbyes were said. It did make me question my involvement in their lives. Ethically researchers are not supposed to cause any distress to participants. Additionally, there is an importance placed on the impact, as their time and experiences have made a difference. I believe that children participating in research should see some sort of impact. The children received findings of the study; they may not feel there is an impact, but there is a big impact, as I write up the findings, especially as PhD thesis' takes time to write up. However, leaving the field upon reflection could have been done by creating some sort of action research for children to continue to share their views in their environments. Another suggestion for future research is finding programs for participants to join after or during data collection that engage with the notion of expressing their views to create community impact.

7.5 Concluding reflections

This thesis has explored how children with disabilities navigate their participation in extracurricular physical activities through the lived experience of ten participants in London, Ontario, Canada. The purpose was to explore the complex lived realities of the participants and highlight their lived experiences. Key contributions from the thesis include:

- Contributing to a further understanding of lived experiences of children with disabilities, inclusion, and participation
    - Unlike other research, this research experiences alongside participants, multiple extracurricular physical activities providing rich and in-depth day to day accounts. Multiple participants participated in a couple or more activities which allowed for greater understanding of how space impacts how practical inclusion and participation are experienced.
    - Children with disabilities are active co-participants in their experiences during their attendance at extracurricular physical activities, although coaches often disregard engaging or learning participatory processes. Theoretical analysis of participation does not result in changes in practice in extracurricular physical activities. There is a need for the presence of the child to add value.
    - Inclusion in extracurricular physical activities can co-exist with exclusion. Inclusion is a process not a static state, which should be seen as a fluid and ever-changing whilst actors are responding to the surroundings. Inclusion and exclusion should include participant perspectives rather than pre-set labels and criteria.

      o   Contribution of non-verbal perspectives.

There is a need for policy and research to collaborate with parents, coaches, and children with disabilities to create ongoing meaningful dialogues for enhancing participation engagement competencies. Additionally, there is a need for practical training and dialogue surrounding different perspectives to come together to create a culture that is based on knowledge exchange, feedback, and recognition of rights. Upholding participation rights is challenging, maintaining a high standard without help and guidance from all parties involved is a daunting task. The thesis also recognizes that a rights-based approach may not be the best way to achieve meaningful engagement and collaboration between children with disabilities and adults.

I hope that this thesis will spark discussions by challenging the importance of predefined labels such as inclusion and participation whilst closing the research gaps between policy and practice, and to shift more towards a culture that prioritizes challenging assumptions, values diverse perspectives and whilst working collectively to continuously learn and improve upon processes of participation and inclusion.

References

1985. Canadian Human Rights Act.

ABBOTT, D. 2013. Who says what, where, why and how? Doing real-world research with disabled children, young people and family members. *In:* CURRAN, T. & RUNSWICK-COLE, K. (eds.) *Disabled children's childhood studies.* Hampshire: Palgrave Macmillan.

ABEBE, T. 2013. Interdependent rights and agency: the role of children in collective livelihood strategies in rural Ethiopia. *Reconceptualizing children's rights in international development: Living rights, social justice, translations*

AGAR, M. H. 1986. *Speaking of Ethnography,* London, Sage.

AGAR, M. H. 2008. *The professional stranger: an informal introduction to ethnography,* Bingley, Emerald.

AINSCOW, M., BOOTH, T., DYSON, A., FARRELL, P., FRANKHAM, J., GALLANNAUGH, F., HOWES, A. & SMITH, R. 2006. *Improving schools, developing inclusion,* London, Routledge.

AITKEN, S. C., LUND, R. & TRINE KJØRHOLT, A. 2007. Why Children? Why Now? *Children's Geographies,* 5**,** 3-14.

AJODHIA-ANDREWS, A. 2016. Reflexively conducting research with ethnically diverse children with disabilities. *The Qualitative Report* 21**,** 252-287.

AKRAMI, N., EKEHAMMAR, B., CLAESSON, M. & SONNANDER, K. 2006. Classical and Modern Prejudice: Attitudes Towards People with Intellectual Disabilities. *Research in Developmental Disabilities,* 27.

ALANEN, L. 2009. Generational Order *In:* QVORTRUP, J., VALENTINE, W., CORSARO, W. & HONIG, M. (eds.) *The Palgrave handbook of childhood studies.* Basingstoke: Palgrave.

ALANEN, L. 2011. Generational order. *In:* QVORTRUP, J., CORSARO, W. & HONIG, M. (eds.) *The Palgrave handbook of childhood studies.* Basingstoke: Palgrave Macmillan.

ALANT, E., SAMUELSON, B. & OGLE, L. 2017. Empathetic Communication: Bridging Differences in a Global Context. *In:* HALDER, S. & CZOP ASSAF, L. (eds.) *Inclusion, Disability and Culture: An ethnographic perspective traversing abilities and challenges.* Springer.

ALDERSEY, H. M. & TURNBULL, H. R. 2011. The United Republic of Tanzania's national policy on disability: A policy analysis. *Journal of Disability Policy Studies,* 22**,** 160-169.

ALDERSON, P. 2000. UN Convention on the Rights of the Child: some common criticisms and suggested responses. *Child Abuse Review,* 9**,** 439-443.

ALDERSON, P. 2008. *Young Children's Rights: Exploring Beliefs, Principles and Practice* London, Jessica Kingsley Publishers.

ALDERSON, P. & GOODEY, C. 1996. Research with Disabled Children: How Useful is Child-Centred Ethics? *Children & Society***,** 106-116.

ALDERSON, P. & MORROW, V. 2008. Ten topics for consideration in carrying out social research with children and young people. *Children's Geographies*.

ALDERSON, P. & MORROW, V. 2011. *The Ethics of Research with Children and Young People,* London, Sage.

ALLAN, J. 2008. *Rethinking Inclusive Education: The Philosophers of Difference in Practice,* Dordrecht, Springer.

ALLAN, V., EVANS, M., LATIMER-CHEUNG, A. & CÔTÉ, J. 2019. From the Athletes' Perspective: A Social-Relational Understanding of How Coaches Shape the Disability Sport Experience. *Journal of Applied Sport Psychology*, 546-564.

ALLMAN, D. 2013. *The Sociology of Social Inclusion*, SAGE Open.

ALMEIDA, A., CARVALHO, D. & DELICADO, A. 2017. Accessing Children's DIgital Practices at Home Through Visual Methods: Innovations and Challenges. *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methodological Issues, Strategies, and Innovation.* Emerald Publishing Limited.

AMADASI, S. & IEVESE, V. 2018. The Right to be Transnational: Narratives and Positionings of Children with a Migration Background in Italy. *In:* BARALDI, C. & COCKBURN, T. (eds.) *Theorising Childhood: Citizenship, rights and participation.* Palgrave Macmillan.

ANABY, D., LAW, M., HANNA, S. & DEMATTEO, C. 2012. Predictors of change in participation rates following acquired brain injury: results of a longitudinal study. *Developmental Medicine & Child Neurology*, 339-347.

ANATASIOU, D. & KELLER, C. 2014. Cross-National Differences in Special Education Coverage: An Empirical Analysis. *Exceptional Children,* 80.

ANDERSON, D. 2009. Adolescent girls' involvement in disability sport: Implications for identity development. *Journal of Sport & Social Issues,* 33, 427-449.

ANDERSON, D., WOZENCROFT, A. & BEDINI, L. A. 2008. Adolecent girls' involvement in disability sport: A comparison of social support mechanisms. *Journal of Leisure Research,* 23, 78-103.

ANDRÉ, G. & GODIN, M. 2014. Child labour, agency and family dynamics: The case of mining in Katanga (DRC). *Childhood,* 21, 161-174.

ANNAMMA, S., FERRI, B. & CONNOR, D. 2019. Cultivating and explaning disability critical race theory *In:* ELLIS, K., GARLAND-THOMSON, R., KENT, M. & ROBERTSON, R. (eds.) *Manifestos for the future of critical disability studies.* Routledge.

ANSELL, N. 2009. Childhood and the politics of scale: descaling children's geographies? *Progress in Human Geography,* 33, 190-209.

ANULL-DAVIS, C. 2008. *Reflexive Ethnography, a Guide to Researching Selves and Others,* London, Routledge.

ARCHER, M. S. 2010. *Conversations about Reflexivity: Ontological Explorations,* Abington, Oxon, Routledge.

ARMSTRONG, D., ARMSTRONG, A. & SPANDAGOU, I. 2011. Inclusion: by choice or by chance? *International Journal of Inclusive Education,* 15, 29-39.

ARMSTRONG, F. 2003. Researching the Practice and Processes of Policy Making. *In:* ARMSTRONG, F. (ed.) *Spaced out: Policy, Difference and the Challenge of Inclusive Education.* New York: Kluwer Academic.

ARNEIL, B. 2012. Becoming Versus Being: A Critical Analysis of the Child in Liberal Theory *In:* ARCHARD, D. & MACLEOD, C. (eds.) *The Moral and Political Status of Children* Oxford University Press.

ARORA, R. 2005. *Race and Ethnicity in Education,* Hants, Ashgate Publishing Limited.

ARSHAD, R. 2008. *Teacher Activism in Equity and Anti-discrimination in Scotland: An interpretive study,* PhD Thesis, University of Edinburgh.

ARSTEIN-KERSLAKE, A. 2017. Legal Capacity and Supported Decision-Making: Respecting Rights and Empowering People. *In:* O'MAHONY, C. & QUINN, G.

(eds.) *Disability Law and Policy: An Analysis of the UN Convention.* Dublin: Clarus Press.

ASBJØRNSLETT, M. & BEKKEN, W. 2016. Openness to difference: Inclusion in sports occupations for children with (dis)abilities. *Journal of Occupational Science,* 23**,** 434-445.

AULT, M., COLLINS, B. & CARTER, E. 2013. Congregational participation and supports for children and adults with disabilities: parent perceptions *Journal of Intellectual and Developmental Disability,* 51**,** 48-61.

AVERY, D. M. 1999. Taking 'tragedy': identity issues in the parental story of disability. *In:* CORKER, M. & FRENCH, S. (eds.) *Disability Discourse.* Buckingham: Open University Press.

AYLING, P. 2018. Diversity, Equality and Rights. *In:* BOGGIS, A. (ed.) *Dis/Abled Childhoods? A Transdisciplinary Approach* Palgrave Macmillan.

BACH, M. & KERZNER, L. 2010. *A new paradihm for protecting autonomy and the right to legal capacity* [Online]. Law Commission of Ontario Available: http://www.lco-cdo.org/disabilities/bach-kerzner.pdf. [Accessed 2021].

BACON, K. & FRANKEL, S. 2014. Rethinking Children's Citizenship. *International Journal of Children's Rights,* 22**,** 21-42.

BADAR, J. & KAUFFMAN, J. 2014a. Better thinking and clearer communication will help special education. *Exceptionality,* 22**,** 1-16.

BADAR, J. & KAUFFMAN, J. 2014b. Instruction, not inclusion, should be the central issue in special education: An alternative view from the USA. *Journal of International Special Needs Education,* 17**,** 13-20.

BANTJES, J., SWARTZ, L., CONCHAR, L. & DERMAN, W. 2015. Developing Programmes to Promote Participation in Sport among Adolescents with Disabilities: Perceptions Express by a Group of South African Adolescents with Cerebral Palsy. *International Journal of Disability, Development and Education,* 62.

BARALDI, C. 2014. Children's participation in communication systems: A theoretical perspective to shape research *In:* WAREHIME, M. (ed.) *Sould of society: A focus on the leaves of children and youth* Bingley: Emerald.

BARALDI, C. 2015. Promotion of migrant Children's epistemic statue and authority in early school life. *International Journal of Early Childhood* 47**,** 5-25.

BARALDI, C. & COCKBURN, T. 2018. Introduction: Lived Citizenship, Rights and Participation in Contemporary Europe. *In:* BARALDI, C. & COCKBURN, T. (eds.) *Theorising Childhood: citizenship, rights and participation.* Palgrave Macmillan.

BARALDI, C. & IEVESE, V. 2014. Observing children's capabilities as agency. *In:* STOECKLIN, D. & BONVIN, J. M. (eds.) *Children's rights an the capability approach: Challenges and prospects.* Springer.

BARNES, C. 1992. Qualitative research: valuable or irrelevant? *Disability, Handicap & Society,* 7**,** 107-124.

BARNES, C. & MERCER, G. 2006. *Independent futures: Disability services in the 21st century,* Bristol, Policy Press.

BARNES, C. & MERCER, G. 2010. *Exploring Disability,* Cambridge, Palgrave.

BARRON, K. 2015. Social Inclusion as a Theoretical Concept and a Social Practice *In:* TRAUSTADOTTIR, R., YTTERHUS, B., BERG, B. & EGILSON, S. (eds.) *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging.* Basingstoke: Palgrave Macmillan.

BARTON, L. 2013. *Disability, Politics and the Struggle for Change,* Independence, Independence : Taylor and Francis.

BATOROWICZ, B., CAMPBELL, F., VON TETZCHNER, S., KING, G. & MISSIUNA, C. 2014. Social participation of school-aged children who use communication aids: The views of children and parents. *Augmentative and Alternative Communication,* 30**,** 237-251.

BEACOM, A. & BRITTAIN, I. 2018. Introduction. *In:* BEACOM, A. & BRITTAIN, I. (eds.) *The Palgrave Handbook of Paralympic Studies* London: Palgrave Macmillan.

BECHKY, B. 2003. Sharing meaning across occupational communities: The transformation of understanding on production floor. *Organizational Science,* 14**,** 312-330.

BECKETT, A. & CAMPBELL, T. 2015. The social model of disability as an oppositional device. *Disability & Society,* 30**,** 270-283.

BEDINI, L. A. & THOMAS, A. 2012. Bridge II sports: A model of meaningful activity through community-based adapted sports. *Therapeutic Rescreation Journal,* 46**,** 284-300.

BELL, C. 2011. *Blackness and Disability,* Münster, Lit Verlag.

BELL, S., KLOCKER, N. & ROBSON, E. 2007. Conceptualizing agency in the lives and actions of rural young people. *In:* PANELLI, R., PUNCH, S. & ROBSON, E. (eds.) *Global Perspectives on Rural Childhood and Youth: Young Rural Lives.* New York, London: Routledge.

BENNETT, A. B. 2011. "Freedom herself is very agile, very co-dependent and a lovely person": The school identities of high school aged youth with communication differences. *Disability Studies Quarterly,* 31**,** 1-13.

BENSON, D. 2014. Education (School). *In:* CAMERON, C. (ed.) *Disability studies: A pupil guide.* London: Sage Publications.

BERG, B., EGLISON, A. T., YTTERHUS, B. & TRAUSTADOTTIR, R. 2015. *Childhood and Disability in the Nordic Countries* Basingstoke, Hampshire: England, Palgrave Macmillan

BERGER, R. 2015. Now I see it, now I don't: Researcher's position and reflexivity in qualitative research *Qualitative research,* 15**,** 219-234.

BERGUM, V. & DOSSETOR, J. 2005. *Relational ethics: The full meaning of respect,* Hagerstown, University Publishing Group.

BESSELL, S. 2009. Research with Children: Thinking about Method and Methodology *In:* BISHOP, K. & DOCKETT, S. (eds.) *Involving Children and Young People in Research* New South Wales: Australian Research Alliance for Children and Youth.

BEST, M., CORCORAN, T. & SLEE, R. 2019. Disability Studies in Education - Building Platforms to Reclaim Disability and Recognise Disablement. *Journal of DIsability Studies in Education***,** 1-11.

BEURSKENS, J., PISKUR, B., MEUSER, S., JONGMANS, M. J., SMEETS, R., MARJOLIJN, K., CASPARIE, B. & HAARSMA, F. 2016. The lived experience of parents enabling participation of their child with a physical disability at home, at school and in the community *Disability & Rehabilitation,* 38**,** 802-812.

BICKENBACH, J. E. 2009. Disability, culture and the UN convention. *Disability & Rehabilitation,* 31**,** 111-124.

BIRICOCCHI, C., DRAKE, J. & SVIEN, L. 2014. Balance outcomes following a tap dance program for a child with congenital myotonic muscular dystrophy. *Pediatric Physical Therapy,* 26**,** 360-365.

BISSETT, N., SAUNDERS, S. & BOUTEN PINTO, C. 2018. Collaborative Autoethnography: Enhancing Reflexive Communication Processes. *In:* VINE, T., CLARK, J., RICHARDS, S. & WEIR, D. (eds.) *Ethnographic Research and Analysis : Anxiety, Identity and Self.* London: Palgrave Macmillan.

BIZAS, N., RAVENSCROFT, J. & DAVIS, J. 2014. Transition, inclusion and partnership: child, parent- and professional-led approaches in a European research project. *Child Care in Practice,* 21**,** 33-49.

BJERKE, H. 2011. Children as 'differently equal' responsible beings: Norwegian children's views of responsibility *Childhood: A Global Journal of Child Research,* 18**,** 67-80.

BLACK, K. 2011. Coaching disabled children in sport. *Coaching children in sport.* Routledge.

BLAISDELL, C. & BOLGER, T. 2020. Young children's participation as a living practice: The role of material and emotional relations during the transition to primary school. *Exploring Materiality in Childhood.* Routledge.

BLOCK, M. 2007. *A teacher's guide to including students with disabilities in general physical education,* London, Sydney, P. Brookes.

BLOEMEN, M., BACKX, F., TAKKEN, T., WITTINK, H., BENNER, J., MOLLEMA, J. & DE GROOT, J. 2015. Factors associated with physical activity in children and adolescents with a physical disability: A systematic review. *Developmental Medicine & Child Neurology,* 57.

BLOOM, G., REID, G. & SEYMOUR, H. 2009. Friendship in inclusive physical education. *Adapted Physical Activity Quarterly,* 26**,** 201-219.

BLOOM, G., SABISTON, C., TAWSE, H. & REID, G. 2012. The role of coaches of wheelchair rugby in the development of athletes with a spinal cord injury. *Qualitative Research in Sport, Exercise and Health,* 4**,** 206-225.

BLUEBOND-LANGNER, M. & KORBIN, J. E. 2007. Challenges and Opportunities in the Anthropology of Childhoods: An Introduction to "Children, Childhoods, and Childhood Studies". *American Anthropologist,* 109**,** 241-246.

BODDY, L., DOWNS, S., KNOWLES, Z. & FAIRCLOUGH, S. 2015. Physical activity and play behaviours in children and young people with intellectual disabilities: a cross-sectional observational study. *School Psychology International* 36**,** 154-171.

BOGDEWIC, S. P. 1999. Participant Observation *In:* CRABTREE, F. & MILLER, W. (eds.) *Doing qualitative research* Second ed. Thousand Oaks, CA: SAGE Publications.

BOGGIS, A. 2011. Deafening silences: Research with inarticulate children. *Disability Studies Quarterly,* 31.

BOGGIS, A. 2018a. *Dis/Abled Childhoods? A Transdisciplinary Approach* Palgrave Macmillan.

BOGGIS, A. 2018b. *Dis/Abled Childhoods?: A Transdiciplinary Approach* Suffolk, Palgrave Macmillan.

BOGGIS, A. 2018c. Ethnographic Practices of Listening *In:* VINE, T., CLARK, A., RICHARDS, S. & WEIR, D. (eds.) *Ethnographic Research and Analysis.* London: Palgrave Macmillan.

BOIS, J., SARRAZIN, P., BRUSTAD, R., TROUILOUD, D. & CURY, F. 2005. Elementary schoolchildren's perceived competence and physical activity involvement: the influence of parents' role modelling behaviours and perceptions of their child's competence. *Psychology of Sport and Exercise* 6**,** 381-397.

BONCORI, I. 2018. The Salience of Emotions in (Auto) ethnography: Towards an Analytical Framework. *In:* VINE, T., RICHARDS, S., CLARK, J. & WEIR, D. (eds.) *Ethnographic Research and Analysis: Anxiety, Identity and Self.* Palgrave Macmillan.

BOOTH, T. & AINSCOW, M. 2002. *Index for Inclusion: developing learning and participation in schools*, Centre for Studies on Inclusive Education.

BOYCE, W., JANSSEN, I., SIMPSON, K. & PICKETT, W. 2006. Influence of individual and area level measures of socioeconomic status on obesity, unhealthy eating and physical inactivity in Canadian adolescents

BOYDEN, J. & ENNEW, J. 1997. *Children in Focus: A Manual for Participatory Research with Children* Stockholm, Radda Barnen

BRAUN, V. & CLARKE, V. 2006. Using Thematic Analysis in Psychology. *Qualitative Research in Psychology,* 3**,** 77-101.

BRAUN, V. & CLARKE, V. 2013. *Successful qualitative research: A practical guide for beginners*, Sage.

BRESLIN, G., FITZPATRICK, B. & HASLETT, D. 2017. The psychological influences on participation in Wheelchair Rugby: a social relational model of disability *Acta Universitatis Carolinae: Kinanthropologica,* 53**,** 60-78.

BREUER, C., HOEKMAN, R. & NAGEL, S. 2015. *Sport Clubs in Europe: A Cross-National Comparative Perspective,* Berline, Springer.

BREWER, J. 2000. *Ethnography,* Buckingham, Open University Press.

BRIEN, J. 2018. How Can the Right of Young Children with Disability to be Heard be Enacted within the Policy Constructs of Participant Choice and Control? *The International Journal of Children's Rights,* 26**,** 423-445.

BRITTAIN, I. 2018. Key Points in the History and Development of Paralympic Games. *In:* BRITTAIN, I. & BEACOM, A. (eds.) *The Palgrave Handbook of Paralympic Studies.* London: Palgrave Macmillan.

BROWN, H., HARVEY, E., GRIFFITH, S., ARNOLD, D. & HALGIN, R. 2017. Assent and dissent: Ethical considerations in research with toddlers. *Ethics & Behavior,* 27**,** 651-664.

BRUNNBERG, E. 2005. The school playground as a meeting place for hard of hearing children *Scandinavian Journal of Disability Research* 7**,** 73-90.

BRYMAN, A. 2008. *Social Research Methods,* Oxford, Oxford University Press.

BRYMAN, A. 2012. Social Research Methods Fourth ed.: Oxford University Press.

BURKITT, I. 2016. Relational agency: Relational sociology, agency and interation. *European Journal of Social Theory,* 19**,** 322-339.

CAIRNS, L. 2006. Participation with Purpose. *In:* TISDALL, E. K. M., DAVIS, J. M., HILL, M. & PROUT, A. (eds.) *Children, Young People and Social Inclusion: Participation for What?* Bristol: Policy Press.

CAIVANO, N. 2015. Conceptualizing Capactiy: Interpreting Canada's Qualified Ratification of Article 12 of the UN Disability Rights Convention *UWO J Leg Stud* 4.

CALDWELL, P. 2007. *From Isolation to Intimacy: Making Friends without Words,* London, Jessica Kingsley Publishers

CALDWELL, P. 2012. *Listening with All Our Senses,* Brighton, Pavilion.

CAMPBELL, F. 2008. Exploring internalized ableism using critical race theory. *Disability & Society,* 23**,** 151-162.

CAMPBELL, J. & OLIVER, M. 1996. *Disability Politics: Understanding Our Past, Changing Our Future,* London, Routledge.

CAMPBELL, T. 1999. Refreshingly disabled: Interrogations into the corporeality of disabled bodies. *The Australian Feminist Law Journal,* 12**,** 57-80.

CAMPBELL, T. 2009. *Contours of Albeism the Production of Disability and Abledness,* Basingstoke, Palgrave Macmillan.

CAMPBELL, T. 2013. *Dyslexia: The Government of Reading,* Basingstoke, Palgrave Macmillan.

CANADA, G. O. 2012. The Canadian Sport Policy.

CANADA, G. O. 2014a. Canadian Disability Benefits

CANADA, G. O. 2014b. Convention on the rights of persons with disabilities: first report of Canada. *In:* LANGUAGES, C. H. A. O. (ed.). Ottawa.

CANADA, G. O. 2019. Accessible Canada Act.

CANADA, G. O. 2021. Research Ethics Board: Policies, guidelines and resources *Health Canada: Science Advice and Decision Making*.

CANADA, H. 2006a. *Policy on Sport for Persons with a Disability* [Online]. Heritage Canada. Available: https://www.canada.ca/en/canadian-heritage/services/sport-policies-acts-regulations/policy-persons-with-disability.html?_ga=2.98567582.1000898974.1528046317-159748195.1528046317 [Accessed].

CANADA, S. 2006b. The 2006 Participation and Activity Limitation Survey: Disability in Canada.

CANADA, S. 2008a. Participation and Activity Limitation Survey 2006: A Profile of Assistive Technology for People with Disabilities.

CANADA, S. 2008b. Participation and Activity Limitation Survey 2006: A Profile of Education for Children with Disabilities in Canada

CAREY, A. C. 2010. *On the Margins of Citizenship: Intellectual Disability and Civil Rights in Twentieth-century America,* Philadelphia, Temple University Press.

CARLESS, D. & DOUGLAS, K. 2012. Membership, Golf and a Story About Anna and Me: Reflections on Research in Elite Sport. *Qualitative Methods in Psychology Bulletin, Sports and Performance,* 1**,** 27-35.

CARLSSON, E., EHNFORS, M., PATERSON, B. L., SCOTT-FINDLAY, S. & EHRENBERG, A. 2007. Methodological issues in interviews involving people with communication impairments after acquired brain damage. *Qualitative Health Research*.

CARROLL, C. & TWOMEY, M. 2018. Introduction: Why voice and why now? *In:* CARROLL, C. & TWOMEY, M. (eds.) *Seen and Heard: Exploring Participation, Engagement and Voice for Children with Disabilities* Oxford: Peter Lang.

CARSON, V., SPENCE, J., HOLT, N. & DUTOVE, J. 2010. Uptake and effectiveness of the Children's Fittness Tax Credit in Canada: The rich get richer. *BMC Public Heath*.

CASEY, R. 2011. Burnout for Developmental Services Workers *McGill Sociological Review* 2**,** 39-58.

CASSIDY, W. & JACKSON, M. 2005. The need for equality in education: An intersectionality examination of labelling and zero tolerances practices. *McGill Journal of Education,* 40**,** 435-455.

CASTENADA, L. & SHERRIL, C. 1999. Family participation in challenger baseball: Critical theory perspectives *Adapted Physical Activity Quarterly,* 16**,** 372-388.

CASTRO, I. 2005. Children's Agency and Cinema's New Fairy Tale. *Sociological Studies of Children and Youth,* 11**,** 215-237.

CASTRO, I. 2017. Contextualizing Agency in High-Structured Enviroments: Children's Participation in Parent Interviews. *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methodological Issues, Strategies and Innovations.* Emerald Publishing Limited.

CASTRODALE, M. 2019. Disabling militarism: theorizing anti-militarism, dis/ability and dis/placement. *In:* ELLIS, K., GARLAND-THOMSON, R., KENT, M. & ROBERTSON, R. (eds.) *Manifestos for the Future of Critical Disability Studies.* Routledge.

CERA, R., DELLA FINA, V. & PALMISANO, G. 2017. *The United Nations Convention on the Rights of Persons with Disabilities: A Commentary* Springer International Publishing

CHARMAZ, K. 2010. Studying the Experience of Chronic Illness through Grounded Thoery. *In:* SCAMBLER, G. & SCAMBLER, S. (eds.) *New directions in the sociology of*

chronic and disabling conditions: assaults on the lifeworld. New York: Palgrave Macmillan.

CHATZITHEOCHARI, S., PARSONS, S. & PLATT, L. 2014. Bullying Experiences Among Disabled Children and Young People in England: Evidence from Two Longitudinal Studies. *Department of Quantitative Social Science.*

CHILD, U. C. O. T. R. O. T. 2009. *General Comment No. 12 The Right of the Child to be Heard* [Online]. Available: www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC-C-GC- 12.doc [Accessed 2021].

CHRISTENSEN, J., MYGIND, L. & BENTSEN, P. 2015. Conceptions of place: Approaching space, children and physical activity. *Children's Geographies,* 13**,** 589-603.

CHRISTENSEN, P. 1999. *Towards an anthropology of childhood sickness: an ethnographic study of Danish schoolchildren.* Ph.D, University of Hull.

CHRISTENSEN, P. 2004. Children's Participation in Ethnographic Research: Issues of Power and Representation. *Children & Society,* 18**,** 165-176.

CHRISTENSEN, P. & JAMES, A. 2008a. Introduction: Researching Children and Childhood- Cultures of Communication. *In:* CHRISTENSEN, P. & JAMES, A. (eds.) *Research with Children: Perspectives and Practices.* 2nd ed. Abingdon: Routledge.

CHRISTENSEN, P. M. & JAMES, A. 2008b. *Research with children perspectives and practices,* New York, N.Y., New York, N.Y. : Routledge.

CLARK, A. 2017. *Listening to young children : a guide to understanding and using the mosaic approach*, London ; Philadelphia : Jessica Kingsley Publishers.

CLARK, A. & MOSS, P. 2011. *Listening To Young Children: The Mosaic Approach,* London, National Children's Bureau.

CLARK, A. & PERCY-SMITH, B. 2006. Beyong consultation: Participatory practices in everyday spaces. *Children, Youth and Enviroments,* 16**,** 1-9.

CLARK, J. & RICHARDS, S. 2017. The Cherished Conceits of Research with Children: Does Seeking the Agentic Voice of the Child Through Participatory Methods Deliver What it Promises? . *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methodological Issues, Strategies, and Innovations.* Emerald Publishing Limited.

CLARKE, M., NEWTON, C., GRIFFITHS, T., PRICE, K., LYSLEY, A. & PETRIDES, K. 2011. Factors associated with the participation of children with complex communication needs. *Research in Developmental Disabilities,* 32**,** 774-780.

CLARKE, V. & BRAUN, V. 2013. Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The psychologist,* 26.

CLARKE, V. & BRAUN, V. 2014. *Thematic analysis,* New York, NY, Springer.

CLEMENSEN, N. 2016. Exploring ambiguous realms: Access, exposure and agency in the interations of rual Zambian children *Childhood,* 23**,** 317-332.

CLEOPHAS, K. & ASSIM, U. 2015. Child Participation in Family Law Matters Affecting Children in South Africa. *European Journal of Law Reform,* 17.

COATES, J. 2012. Teaching inclusively: Are secondary physical education student teachers sufficiently prepared to teach in inclusive enviroments? *Physical Education and Sport Pedagogy,* 17**,** 349-365.

COATES, J. & VICKERMAN, P. 2008. Let the children have their say: children with special educational needs and their experiences of Physical Education – a review. *Support for Learning,* 23**,** 168-175.

COATES, J. & VICKERMAN, P. 2010. Empowering Children with Special Education Needs to Speak up: Experiences of Inclusive Physical Education. *Disability & Rehabilitation,* 32**,** 1517-1526.

COBIGO, V. & MARTIN, L. 2011. Definitions matter in understanding social inclusion. *Journal of Policy and Practice in Intellectual Disabilities,* 8**,** 276-282.

COCKBURN, T. 1998. Children and citzenship in Britain: A case for socially interdepent model of citizenship. *Childhood,* 5**,** 99-117.

COCKBURN, T. 2013. *Rethinking Children's Citizenship,* Basingstoke, Palgrave Macmillan.

COLES, C. & HANCOCK, R. 2002. *The Inclusion Quality Mark* Croydon, Creative Education.

COLLIER, R. 2012. Person-first language: What it means to be a "person". *CMAJ,* 184**,** 935-936.

COMMISSION, E. 2003. The European Social Fund and Social Inclusion.

CONNOLLY, P. 2008. Race, gender and critical reflexivity in research with young children. *In:* CHRISTENSEN, P. & JAMES, A. (eds.) *Research with Children: Perspectives and Practices.* 2nd ed. Oxford: Routledge.

CONNOLLY, P. & MORROW, V. 2006. Special Issue: Gender and Ethnicity in Children's Everyday Lives. *Children & Society,* 20**,** 87-91.

CONNORS, C. & STALKER, K. 2002. *The views and Experiences of Disabled Children and Their Siblings: A Positive Outlook,* London, Jessica Kinglsey Publishers.

CONNORS, C. & STALKER, K. 2003. *The views and experiences of disabled children,* London, Jessica Kingsley.

CONNORS, C. & STALKER, K. 2007. Children's Experiences of Disability: Pointers to a Social Model of Childhood Disability. *Disability & Society,* 22**,** 19-33.

COOK, J., LAIDLAW, J. & MAIR, J. 2009. What if there is no elephant? Towards a conception of an un-sited field. *Multi-sited ethnography: Theory, praxis and locality in contemporary research***,** 47-72.

COOK, T. & HESS, E. 2007. What the Camera Sees and from Whose Perspective. *Childhood,* 14**,** 29-45.

COOK, T. & SWAIN, J. 2001. In the name of inclusion: 'We all, at the end of the day, have the needs of the children at heart'. *Critical Social Policy,* 21**,** 185-207.

CORBETT, J. 2001. Supporting Inclusive Education: a connective pedagogy. London: Routledge Falmer.

CORNWALL, A. 2002. Making spaces, changing places: situating participation in development.

CORNWALL, A. 2004. Spaces for transformation? Reflections on issues of power and difference in participation in development *In:* HICKEY, S. & MOHAN, G. (eds.) *From Tyranny to Transformation.* London: Zed Books.

CORNWALL, A. 2008. 'Unpacking "Participation": models, meanings and practices Community' *Development Journal,* 43.

CORNWALL, A. & COELHO, V. 2007. Spaces for Change. *In:* CORNWALL, A. & COELHO, V. (eds.) *Spaces for Change.* London: Zed Books.

CORSARO, W. 1985. *Friendship and peer culture in the early years*

CORSARO, W. 2005. *The sociology of childhood* Thousand Oaks, CA, Pine Forge Press.

CORSARO, W. & MOLINARI, L. 2000. Entering and Observing in Chidren's Worlds: A Reflection on a Longitudinal Ethnography of Early Education in Italy. *In:* CHRISTENSEN, P. & JAMES, A. L. (eds.) *Research with Children: Perspectives and Practices.* London: Falmers Press.

CORSARO, W. A. 2003. *"We're friends, right?": inside kids' culture,* Washington, D.C, Joseph Henry Press.

CORSARO, W. A. 2011. *The sociology of childhood* Los Angeles, CA, SAGE Publishing

COX, T., ADDUSO, O., BASKIN, M., LI, K. & DAVISON, K. 2011. Measuring parental support for children's physical activity in white and African American parents: The activity support scale for multiple groups *Preventive Medicine,* 52.

CRAIG, D., CAMERON, C., HRIFFITHS, J. & TUDOR-LOCKE, C. 2010. Descriptive epidemiology of youth pedometer-determined physical activity. *Med Sci Sports*

CRANG, M. & COOK, I. 2007. *Doing Ethnographies,* London, Sage.

CRAPANZANO, V. 1986. 'Hermes' dilemma: The masking of subversion in ethnographic desrcription. *In:* CLIFFORD, J. & MARCUS, G. E. (eds.) *Writing Culture: The Poetics and Politics of Ethnography.* Berkely: University of California Press.

CREGAN, K., BLOOM, G. & REID, G. 2007. Career evolution and knowledge of elite coaches of swimmers with a physical disability. *Research Quarterly for Exercise and Sport,* 78**,** 339-350.

CRENSHAW, K. 1991. Mapping the Margins: Intersectionality, Identity Politics, and Violence against Women of Color. *Stanford Law Review* 43**,** 1241-1299.

CRESWELL, J. 2007. *Qualitative inquiry and research design: Choosing among five traditions,* Thousand Oaks: CA, SAGE.

CRESWELL, J. & POTH, C. 2018. *Qualitative Inquiry and Research Design: Choosing Among Five Approaches,* London: Los Angeles: Melbourne, SAGE Publications

CROTHERS, I., LINDEN, M. & KENNEDY, N. 2007. Attitudes of Children Towards Peers with Acquired Brain Injury. *Brain Injury,* 21**,** 47-52.

CROUCHER, A. & LE BOUTILIER, C. 2010. Social inclusion and mental health *British Journal of Occupational Therapy,* 73**,** 136-139.

CULVER, D. & DUARTE, T. 2014. Becoming a coach in developmental adaptive sailing: a lifelong learning perspective. *Journal of Applied Sport Psychology,* 26**,** 441-456.

CULVER, D., MCMASTER, S. & WERTHNER, P. 2012. Coaches of athletes with a physical disability: a look at their learning experiences. *Qualitative Research in Sport, Exercise and Health,* 4**,** 226-243.

CULVER, D. & WERTHNER, P. 2018. Voices: para athletes speak. *Qualitative Research in Sport, Exercise and Health,* 10**,** 167-175.

CUMMINS, R. & LAU, A. 2003. Community integration of community exposure? A review and discussion in relation to people with intellectual disability. *Journal of Applied Research in Intellectual Disabilities,* 16**,** 145-157.

CUNNINGHAM, G. & LEE, W. 2019. Moving Toward Understanding Social Justice in Sport Organizations: A Study of Engagement in Social Justice Advocacy in Sport Organizations. *Journal of Sport and Social Issues,* 43**,** 245-263.

CUNNINGHAM-BURLEY, S., DAVIS, J. & WATSON, N. 2008. Disabled children, ethnography and unspoken understandings: The collaborative constructions of diverse identities. *In:* CHRISTENSEN, P. & JAMES, A. (eds.) *Research with children: Perspectives and practices.* Oxon: Routledge.

CURRAN, T. 2010. Social Work and Disabled Children's Childhoods: A Foucauldian Framework for Practice Transformation. *Oxford University Press,* 40**,** 806-825.

CURRAN, T. & RUNSWICK-COLE, K. 2013. Disabled Children's childhood studies: A distinct approach? *Disability and Society,* 29**,** 1617-1630.

CURRAN, T. & RUNSWICK-COLE, K. 2014. Disabled children's childhood studies: a distinct approach? *Disability & Society,* 29.

CUSHION, C. & JONES, R. 2006. Power, Discourse, and Symbolic Violence in Professional Youth Soccer: The Case of Albion Football Club. *Sociology of Sport Journal,* 23.

CZARNIAWSKA, B. 2007. *Shadowing, and Other Techniques for Doing Fieldwork in Modern Societies,* Herndon, VA, Copenhagen Business School Press.

DADICH, A. 2010. Participation among Young People with Mental Health Issues: Redefining the Boundaries. *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice.* Abingdon: Routledge.

DARRAH, J., WIART, L., KELLY, M. & LEGG, D. 2015. Community fitness programs: What is available for children and youth with motor disabilities and what do parents want? *Physical & Occupational Therapy in Pediatrics.*

DAVIS, J. 1998. Understanding The Meanings of Children: A Reflexive Process. *Children & Society,* 12**,** 325-335.

DAVIS, J. 2000. Disability Studies as Ethnographic Research and Text: can we represent cultural diversity whilst promoting social change? *Disability & Society,* 15**,** 191-206.

DAVIS, J. 2009. Involving Children *In:* TISDALL, E. K. M., DAVIS, J. & GALLAGHER, M. (eds.) *Researching with Children and Young People: Research Design, Methods and Analysis.* London: SAGE Publications Ltd.

DAVIS, J. & HILL, M. 2006. Introduction. *In:* TISDALL, K., PROUT, A., HILL, M. & DAVIS, J. (eds.) *Children, Young People and Social Inclusion: Participation for What?* : Policy Press.

DAVIS, J. & SMITH, M. 2012. *Working in Multi-Professional Contexts: A Practical Guide for Professionals in Children's Services* London, SAGE Publications.

DAVIS, J. & WATSON, N. 2000. Disabled Children's Rights in Everyday Life: Problematising Notions of Competency and Promoting Self-Empowerment. *The International Journal of Children's Rights* 8**,** 211-228.

DAVIS, J. & WATSON, N. 2001. Where are the children's experiences? Analysing social and cultural exclusion in 'special' and 'mainstream' schools. *Disability & Society,* 16**,** 671-687.

DAVIS, J. & WATSON, N. 2002. Countering stereotypes of disability: Disabled children and resistance. *In:* CORKER, M. & SHAKESPEARE, T. (eds.) *Disability/ postmodernity: Embodying disability theory.* London: Continuum.

DAVIS, J., WATSON, N. & CUNNINGHAM-BURLEY, S. 2017. Disabled children, ethnography, and unspoken understandings: The collaborative construction of diverse identities *In:* CHRISTENSEN, P. & JAMES, A. (eds.) *Research with Children: Perspectives and Practices.* Third ed.: Routledge.

DAVIS, L. 1995. *Enforcing Normalcy: Disability, Deafness, and the Body,* London New York Verso.

DAVIS, R., ROCCO-DILLON, S., GRENIER, M., MARTINEZ, D. & AENCHBACKER, A. 2012. Implementing Disability Sports in the General Physical Education Curriculum. *Journal of Physical Education, Recreation & Dance,* 83**,** 35-41.

DE BECO, G. 2016. Transition to Inclusive Education Systems According to the Convention on the Rights of Persons with Disabilities. *Nordic Journal of Human RIghts,* 34**,** 40-59.

DE FEYTER, K. 2007. Localising human rights *In:* BENEDEK, W., DE FEYTER, K. & MARELLA, F. (eds.) *Economics Globalisation and Human Rights* Cambridge University Press.

DEGENER, T. 2016. Disability in a Human Rights Context. *Laws,* 5**,** 35.

DEGENER, T. 2017. 10 years of Convention on the Right of Persons with Disabilities. *Netherlands Quarterly of Human Rights,* 35**,** 152-157.

DEL MOL, J. & BUYSSE, A. 2008. The phenomenology of children's influence on parents. *Journal of Family Therapy.*

DENZIN, N. 1989. *Interpretive Biography,* Newbury Park, CA, Sage.

DEPAUW, K. P. 1997. The (in)visibility of disability: Cultural contexts and sporting bodies. *Quest,* 49**,** 416-430.

DEPAUW, K. P. & DOLL-TEPPER, G. 2000. Toward progressive inclusion and acceptance: Myth or reality? The inclusion debate and bandwagon discourse. *Adapted Physical Activity Quarterly,* 17**,** 135-143.

DEPONIO, P. & DAVIS, J. 2014. Analysing conflicting approaches to dyslexia on a European project: moving to a more strategic, participatory, strength-based and integrated approach. *International Journal of Inclusive Education,* 18**,** 515-534.

DESMET, E., LEMBRECHTS, S., VANDENHOLE, W. & REYNAERT, D. 2015. Introduction: A Critical Approach to Children's Rights. *In:* VANDENHOLE, W., DESMET, E., REYNAERT, D. & LEMBRECHTS, S. (eds.) *International Handbook of Children's Rights Studies.* Abingdon: Routledge.

DEVECCHI, C. 2014. Glossary. *In:* FLORIAN, L. (ed.) *The Sage handbook of special education.* 2nd ed. London: Sage Publications.

DEVINE, D. & KELLY, M. 2006. 'I Just Don't Want to Get Picked on by Anybody': Dynamics of Inclusion and Exclusion in Newly Multi-Ethnic Irish Primary School *Children & Society,* 20**,** 128-139.

DEVINE, M. & O'BRIAN, M. 2007. The mixed bag of inclusion: An examination of an inclusive camp using contact theory *Therapeutic Rescreation Journal* 41**,** 201-222.

DEVINE, M. & PARR, M. 2008. "Come on in, but not too far": Social capital in an inclusive leisure setting. *Leisure Sciences* 30**,** 391-408.

DIAMOND, K. E. & TU, H. 2009. Relations between classroom context, physical disability and preschool children's inclusion decisions. *Journal of Applied Developmental Psychology,* 30**,** 75-81.

DOCKETT, S., EINARSDOTTIR, J. & PERRY, B. 2012. Young children's decisions about research participation: Opting out. *International Journal of Early Years Education,* 20**,** 244-256.

DONOGHUE, J. L., KIRSHNER, B. & MCLAUGHLIN, M. 2002. Introduction: Moving youth participation forward. *New Directions for Youth Development,* 2002**,** 15-26.

DUNN, D. S. & BURCAW, S. 2013. Disability identity: Exploring narrative accounts of disability *Rehabilitation Psychology,* 58**,** 148-157.

DYCK, I., LEVINS, S. & REDENBACH, D. 2004. Individual and societal influences on participation in physical activity following spinal cord injury: a qualitative study

EAKIN, J., ROBERTSON, A., POLAND, B., COBURN, D. & EDWARDS, R. 1996. Towards a critical social science perspective on health promotion research. *Health Promotion International,* 11**,** 157-165.

EALES, L., SPENCER-CAVALIERE, N. & PEERS, D. 2014. Say What You Mean: Rethinking Disability Language *Adapted Physical Activity Quarterly,* 31**,** 265-282.

EDWARDS, R., ARMSTRONG, P. & MILLER, N. 2001. Include me out: critical readings of social exclusion, social inclusion and lifelong learning. *International Journal of Lifelong Education,* 20**,** 417-428.

EINARSDOTTIR, J. 2007. Research with children: Methodological and ethical challenges. *European Early Childhood Education Research Journal,* 15**,** 197-211.

ELDEN, S. 2012. Inviting the messy: Drawing methods and "children's voices". *Childhood,* 20**,** 66-81.

ELLIOT, D. & CAMPBELL, T. 2013. 'Really on the ball': exploring the implications of teachers' PE-CPD experience. *Sport, Education and Society***,** 1-17.

ELLIS, C. 2007. Telling Secrets, Revealing Lives: Relational Ethics in Research with Intimate Others. *Qualitative Inquiry,* 13.

ELVIDGE, K. 2013. Inclusion. *In:* TAYLOR, K. & WOOLEY, R. (eds.) *Values and vision in primary education.* Maidenhead: OUP.

EMERSON, R., FRETZ, R. I. & SHAW, L. L. 2001. Participant Observation and Fieldnotes. *In:* ATKINSON, P., COFFEY, A., DELAMONT, S., LOFTLAND, J. & LOFTLAND, L. (eds.) *Handbook of Ethnography.* London: Sage.

EMERSON, R. M., FRETZ, R. I. & SHAW, L. L. 2011. *Writing Ethnographic Fieldnotes,* Chicago, University of Chicago Press.

EMMEL, N. 2015. Themes, variables, and the limits to calculating sample size in qualitative research: A response to Fugard and Potts. *International Journal of Social Research Methodology,* 18**,** 685-684.

EMMERICH, N. 2013. Between the accountable and the auditable: Ethics and ethical governance in the social sciences 175-186.

ENGEL-YEGER, B., JARUS, T., ANABY, D. & LAW, M. 2009. Differences in Patters of Participation Between Youths With Cerebral Palsy and Typically Developing Peers. *American Journal of Occupational Therapy,* 63**,** 96-104.

ENNEW, J. & PLATEAU, D. 2004. *How to research the physical and emotional punishment of children,* Bangkok.

ENRIGHT, E. & O'SULLIVAN, M. 2012. Listening to young people's voices in physical education and youth sport research. *In:* O'SULLIVAN, M. & MACPHAIL, A. (eds.) *Research Methods in Physical Education and Youth Sport.* London: Routledge.

ESSER, F., BAADER, M., BETZ, T. & HUNGERLAND, B. 2016. *Reconceptualising agency and childhood: New perspectives in childhood studies,* New York, Routledge.

EVANS, J. & BAIRNER, A. 2013. Physical education and social class. *In:* STIDDER, G. & HAYES, S. (eds.) *Equity and inclusion in physical education and sport.* New York: Routledge.

EWALD, F. 1990. Norms, Dicipline and the Law. *Representations***,** 138-161.

FALZON, M. 2015. *Multisited Field Studies*, Routledge.

FALZON, M. 2016. Introduction: Multi-sited Ethnography: Theory, Praxis and Locality in Contemporary Research.

FARRELL, M. 2017. *Educating special students: An introduction to provision for learners with disabilities and disorders,* Abingdon, Routledge.

FAZIO, R. & ROSKOS-EWOLDSEN, D. 2005. Acting as We Feel: When and How Attitudes Guide Behavior. *In:* BROCK, T. & GREEN, M. (eds.) *Persuasion: Psychological Insights and Perspectives.* Thousand Oaks: CA: Sage.

FETTERMAN, D. 2010. *Ethnography: Step-by-step,* Los Angeles, CA, SAGE.

FINCH, N. 2001. *Disability survey 2000: young people with a disability and sport,* London, Sport England.

FINE, G. A. & SANDSTORM, K. L. 1988. *Knowing Children,* Thousand Oaks, Sage.

FINE, M. & ASCH, A. 1997. Nurturance, Sexuality, and Women with Disabilities. *In:* DAVIS, L. (ed.) *The Disability Studies Reader.* New York: Routledge.

FISHER, K. & PURCAL, D. 2017. Policies to Change Attitudes to People with Disabilities. *Scandinavian Journal of Disability Research,* 19**,** 161-174.

FITZGERALD, H. 2005. Still feeling like a spare piece of luggage? Embodied experiences of (dis)ability in physical education and school sport. *Physical Education and Sport Pedagogy,* 10**,** 41-59.

FITZGERALD, H. 2012. 'Drawing' on disabled students' experiences of physical education and stakeholder responses *Sport, Education and Society,* 17**,** 443-462.

FITZGERALD, H., JOBLIN, A. & KIRK, D. 2003. Valuing the voices of young disabled people: Exploring experience of physical education and sport. *European Journal of Physical Education,* 8**,** 175-200.

FITZGERALD, H. & LONG, J. 2017. Integration or Special Provision? Positioning disabled people in sport and leisure. *In:* LONG, J., FLETCHER, T. & WATSON, B. (eds.) *Sport, Leisure and Social Justice.* London: Routledge.

FITZGERALD, H. & STRIDE, A. 2012. Stories about Physical Education from Young People with Disabilities. *International Journal of Disability, Development and Education,* 59**,** 283-293.

FITZGERALD, R. & GRAHAM, A. 2009. "Young People Big Voice": Relections on the participation of children and young people in a university setting. *In:* YOUTH, A. R. A. F. C. A. (ed.) *Involving children and young people in research: Compendium of papers and reflections from a Think Tank.* New South Wales: New South Wales Commission for Children and Young People

FITZGERALD, R., GRAHAM, A., SMITH, A. & TAYLOR, N. 2010. Children's participation as a struggle over recognition: Exploring the promise of dialogue. *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *Handbook of children and young people's participation. Perspectives from theory and practice.* London, New York: Routledge.

FLEKKOY, M. G. & KAUFMAN, N. H. 1997. *The Participation Rights of the Child,* London, Jessica Kingsley Publishers

FLEMING, J. 2013. 'Young People's Participation- Where Next?'. *Children & Society,* 27.

FLEWITT, R. 2005. Conducting research with young children: Some ethical considerations. *Early Child Development anf Care,* 175.

FLORIAN, L. 2008. Inclusion: special or inclusive education: future trends. *British Journal of Special Education,* 35**,** 202-208.

FLORIAN, L. 2019. On the necessary co-existence of special and inclusive education.

FLYNN, S. 2017. Engaging with Materialism and Material Reality: Critical Disability Studies and Economic Recession. *Disability & Society,* 32**,** 143-159.

FONTANA, A. & FREY, J. H. 2005. The Interview: From Neutral Stance to Political Involvement. *In:* DENZIN, N. K. & LINCOLN, Y. S. (eds.) *The Sage Handbook of Qualitative Research.* 3rd ed. London: Sage.

FOTHERGILL, A. & PEEK, L. 2015. *Children of Katrina,* University of Texas Press.

FOUCAULT, M. 1977. *Dicipline and Punish. The Birth of the Prison,* London, Allen Lane.

FOUCAULT, M. 1980. *Power/Knowledge: Selected Interviews & Other Writings 1972-1977,* New York, Pantheon

FOUCAULT, M. 1996. Clarifications on the Question of Power. *In:* LOTRINGER, S. (ed.) *Foucault Live: Collected Interviews, 1961-1984.* New York: Semiotexte

FRALEIGH, W. 1984. Rights Actions in Sport: Ethics for Contestants. *Champaign, IL,* Human Kinetics.

FRANKEL, S. 2017. *Negotiating Childhoods Applying a Moral Filter to Children's Everyday Lives*, London : Palgrave Macmillan UK : Imprint: Palgrave Macmillan.

FRANKEL, S. 2018. *Giving children a voice: A step-by-step guide to promoting child-centered practice*, Jessica Kingsley Publishers

FRANKEL, S., MCNAMEE, S. & POMFRET, A. 2015. Approaches to promoting ideas about children's rights and participation: Can the education of undergraduate students contribute to raising the visibility of the child in relation to child participation in Canada? *Canadian Journal of Children's Rights,* 2**,** 26-47.

FRANKLIN, A. & SLOPER, P. 2009. Supporting the participation of disabled children and young people in decision-making. *Children and Society,* 23**,** 3-15.

FRANKLIN, B. 1997. The Ladder of Participation in Matters Concerning Children. *In:* BOYDEN, J. & ENNEW, J. (eds.) *Children in Focus: a Manual for Participatory Research with Children.* Stockholm: Grafisk Press.

FRASER, N. 1997. *Justice Interruptus: Critical reflections on the 'postsocialist' condition,* London, Routledge.

FRASER, N. & HONNETH, A. 2003. *Redistribution or recognition? A political-philosophical exchange,* London, Verso.

FRAZEE, C. 2003. *Thumbs up! Inclusion, rights and equality as experienced by youth with disabilities. Laidlaw Foundation Working Paper Series: Perspectives on Social Inclusion,* Toronto, ON, Laidlaw Foundation.

FREDERICKSON, N. & JONES, A. 2010. Multi-informant predictors of social inclusion for students with autism spectrum disorders attending mainstream school. *Journal of Autism and Developmental Disorders,* 40**,** 1094-1103.

FREEMAN, M. 1996. Introduction: Children as Persons. *In:* FREEMAN, M. & ALDERSHOT, M. (eds.) *Children's Rights: A Comparative Perspective.* Dartmouth.

FREEMAN, M. 2000. The future of children's rights. *Children & Society,* 14**,** 277-293.

FREEMAN, M. 2007a. *Article 3: The best intersts of the child. A commentary on the United Nations Convention on the Rights of the Child* Martinus Nijhoff Publishers.

FREEMAN, M. 2007b. Why It Remains Important to Take Children's Rights Seriously. *International Journal of Children's Rights,* 15**,** 5-23.

FREEMAN, M. 2011. Children's Rights as Human Rights. *In:* QVORTRUP, J., CORSARO, W. & HONIG, M. (eds.) *The Palgrave Handbook of Childhood Studies.* Basingstoke: Palgrave Macmillan.

FRENCH, D. & HAINSWORTH, J. 2001. 'There aren't any buses and the swimming pool is always cold!' Obstacles and opportunities in the provision of sport for disabled people. *Managing Leisure.*

FRENCH, P. & KAYESS, R. 2008. Out of Darkness into Light: Introducing the United Nations Convention on the Rights of Persons with Disabilities. *Human Rights Law Review,* 1.

FRENCH, S. & SWAIN, J. 2001. The relationship between disabled peopled health and welfare professionals. *In:* ALBRECHT, G., SEELMAN, H. D. & BURY, M. (eds.) *Handbook of disability studies.* London: Sage.

GAL, T. 2015. Conclusion from social exclusion to child-inclusive policies: towardsan ecological model of child participation *In:* GAL, T. & DURAMY, B. (eds.) *International Perspectives and Empirical Findings on Child Participation: From social Exclusion to Child-Inclusive Polices.* Oxford: Oxford Universiy Press.

GAL, T. & DURAMY, B. 2015. *International perspectives and empirical findings on child participation: From social exclusion to child-inclusive policies*, Oxford University Press.

GALLACHER, L. 2005. '"The Terrible Twos": Gaining Control in the Nursery?". *Childrens Geographies,* 3**,** 243-264.

GALLAGHER, M. 2004 *Producing the Schooled Subject: Techniques of Power in a Primary School* Doctoral, The University of Edinburgh.

GALLAGHER, M. 2006. Spaces of Participation and inclusion? *In:* TISDALL, K., DAVIS, J., PROUT, A. & HILL, M. (eds.) *Children, young people and social inclusion: Participation for what?* Bristol: Policy Press.

GALLAGHER, M. 2008. Foucault, Power and Participation. *The International Journal of Children's Rights,* 16**,** 395-406.

GALLAGHER, M. 2009. Ethics. *In:* TISDALL, E. K. M., DAVIS, J. & GALLAGHER, M. (eds.) *Researching with Children & Young People: Research Design, Methods and Analysis*

GALLAGHER, M. & GALLACHER, L. 2008. Methodological Immaturity in Childhood Research? *Childhood,* 15**,** 499-516.

GASSER, L., MALTI, T. & BUHOLZER, A. 2014. Swiss children's moral and psychological judgements about inclusion and exclusion of children with disabilities. *Child Development,* 85**,** 532-548.

GAST, M. 2017. Researcher as College Coach: Dilemmas and Possibilities in Fieldwork with Adolescents *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methodological Issues, Strategies, and Innovations.* Emerald Publishing Limited.

GATT, C. 2012. Emplacement and Enviromental Relations in Multi-sited Practice/theory. *Multi-Sited Ethnography: Theory, Praxis and Locality in Contemporary Research.*

GAVENTA, J. 2005. *Reflections on the Uses of the 'Power Cube, Approach for Analyzing the Spaces, Places and Dynamics of Civil Society Participation and Engagement', prepared for Assessing Civil Society Participation as Supported In-Country* The Netherlands, MFP Breed Netwerk.

GAVENTA, J. 2007. Claiming Citizenship: Rights, Participation and Accountability. *In:* CORNWALL, A. & COELHO, V. (eds.) *Spaces for Change? The politics of citizen participation in new democratic arenas.*

GEERTZ, C. 1973. *The Interpretation of Cultures,* New York, Basic Books.

GEIDNE, S. & JERLINDER, K. 2016. How sports clubs include children and adolescents with disabilities in their activities. A systematic search of peer-reviewed articles. *Sport Science Review,* XXV**,** 29-52.

GEOFFERY, Z., KOHE, D. & PETERS, M. 2016. High Performance Disability Sport Coaching *Palaestra,* 31.

GERRING, J. 2007. *Case study research: Principles and practices,* Cambridge, University Press.

GIBSON, B., KING, G., KYSHKI, A., MISTRY, B., THOMPSON, L., TEACHMAN, G., BATOROWICZ, B. & MCMAIN-KLEIN, M. 2014. A multi-method approach to studying activity setting participation: Integrating standardized questionnaires, qualitative methods, and physiological measures. *Disability & Rehabilitation,* 36.

GIBSON, B., MISTRY, B., SMITH, B. M., YOSHIDA, K., ABBOTT, D., LINDSAY, S. & HAMDANI, Y. 2013. The integrated use of audio diaries, photography, and interviews in research with disabled young men. *International Journal of Qualitative Methods,* 12.

GIDDENS, A. 1979. *Central Problems in Social Theory : Action, structure and contradiction in social analysis,* London and Basingstoke, The Macmillian Press Limited

GIDDENS, A. 1984. *The constitution of society : outline of the theory of structuration,* Cambridge, Cambridge : Polity Press in association with Basil Blackwell, Oxford.

GIDDENS, A. 1998. *The Third Way: The renewal of Social Democracy,* Cambridge, Polity Press.

GILLHAM, B. 2000. *Case Study Research Methods,* London, Continuum.

GILMORE, S. & KEENY, K. 2014. Work-Worlds Colliding: Self-Reflexivity, Power and Emotion in Organizational Ethnography. *Human Relations***,** 1-24.

GOBLE, C. 2010. Celebrating disability *In:* GAINE, C. (ed.) *Equality and diversity in social work practice.* Exeter: Learning Matters

GOFFMAN, E. 1963. *Stigma,* London, Penguin

GOLLNICK, D. & CHINN, P. 2013. *Multicultural education in a pluralistic society* Boston: MA, Pearson.

GOODLEY, D. 2011a. *Disability Studies an Interdisciplinary Introduction,* London, Sage.

GOODLEY, D. 2011b. Disability Studies: An interdisciplinary introduction. *Sage.*

GOODLEY, D. 2011c. *Disability studies: An interdisciplinary introduction* London, Sage.

GOODLEY, D. 2012. Dis/entagling Critical Disability Studies. *Disability & Society,* 27**,** 631-644.

GOODLEY, D. 2014. *Dis/ability studies: theorizing disablism and ableism,* London, Routledge.

GOODLEY, D. 2016. *Disability Studies: An Interdisciplinary Introduction,* London, Sage.

GOODLEY, D., LAWTHOM, K., LIDDIARD, K. & RUNSWICK-COLE, K. 2019. Provocations for Critical Disability Studies. *Disability & Society,* 34**,** 972-997.

GOODLEY, D. & RUNSWICK-COLE, K. 2011a. The violence of disablism. *Sociology of Health and Illness,* 33**,** 602-617.

GOODLEY, D. & RUNSWICK-COLE, K. 2011b. The violence of disablism. *Sociology of Health & Illness,* 33.

GOODLEY, D. & RUNSWICK-COLE, K. 2014. Becoming dis/human: Thinking about the human through dis/ability. *Taylor & Francis Group,* 37**,** 1-15.

GOODLEY, D. & RUNSWICK-COLE, K. 2015. Critical Disability Studies and Critical Health Psychology: Comrades in Arms? *In:* MURRAY, M. (ed.) *Critical Health Psychology.* 2nd ed. Basingstoke: Palgrave Macmillan.

GOODLEY, D., RUNSWICK-COLE, K. & LIDDIARD, K. 2015. The DisHuman Child. *Discourse: Studies in the Cultural Politics of Education.*

GOODWIN, D. 2001. The meaning of help in PE: Perceptions of students with physical disabilities. *Adapted Physical Activity Quarterly,* 18**,** 189-303.

GOODWIN, D. 2009. *The Voices of Students with Disabilities: Are They Informing Inclusive Physical Education Practice,* London, Routledge

GOODWIN, D. & EBERT, A. 2018. Physical Activity for Disabled Youth: Hidden Parental Labor. *Adapted Physical Activity Quarterly.*

GOODWIN, D., KROHN, J. & KUHNLE, A. 2004. Beyond the wheelchair: The experience of dance. *Adapted Physical Activity Quarterly,* 21**,** 229-247.

GOODWIN, D. & PEERS, D. 2012. Disability, sport and inclusion. *Inclusion and exclusion through youth sport***,** 186-202.

GOODWIN, D. & STAPLES, K. 2005. The meaning of summer camp experiences to youths with disabilities. *Adapted Physical Activity Quarterly,* 22**,** 160-178.

GOODWIN, D. & WATKINSON, J. 2000. Inclusive PE from the perspectives of students with physical disabilities. *Adapted Physical Activity Quarterly,* 18**,** 189-303.

GORDON, S. 2006. Making sense of the inclusion debate under IDEA. *BYU:Education* 189.

GORTER, J. W., GULKO, R., GALUPPI, B., WRIGHT, M. & GODKIN, E. 2016. Consensus Planning Towards a Community-Based Approach to Promote Physical Activity in Youth with Cerebral Palsy *Physical & Occupational Therapy in Pediatrics,* 37**,** 1-16.

GRAHAM, A. & FITZGERALD, R. 2010. Progressing Children's Participation: Exploring the Potential of a Dialogical Turn. *Childhood,* 17.

GRANDISSON, M., TETREAULT, S. & FREEMAN, A. 2012. Enabling Integration in Sports for Adolescents with Intellectual Disabilities. *Journal of Applied Research in Intellectual Disabilities,* 25**,** 217-230.

GRECH, S. 2012. Disability and the majority world: A neocolonial approach *In:* GOODLEY, D., HUGHES, B. & DAVIS, L. (eds.) *Disability and Social Theory* Hampshire: Springer International Publishing.

GREEN, S., DAVIS, C., KARSHMER, E., MARSH, P. & STRAIGHT, B. 2005. Living stigma: The impact of labeling, sterotyping, separation, status loss and discrimination in the lives of individuals with disabilities and their families. *Sociological Inquiry,* 75**,** 197-215.

GREEN, S. E. 2007. We're tired, not sad: Benefitsand burdens of mothering a child with a disability. *Social Science and Medicine,* 64.

GRENIER, M. 2011. Coteaching in physical education: A strategy for inclusive practice. *Adapted Physical Activity Quarterly,* 28**,** 95-112.

GRIFFIN, K. 2019. Participatory Research Interviewing Practices with Children *In:* ECKHOFF, A. (ed.) *Participatory Research with Young Children.* Cham: Springer.

GROCE, N., LANG, R., KETT, M. & TRANI, J. F. 2011. Implementing the United Nations Convention on the rights of persons with disabilities: principles, implications, practice and limitations. *Science Direct,* 5**,** 206-220.

GROFF, D. & KLEIBER, D. 2001. Exploring the identity formation of youth involved in an adapted sports program *Therapeutic Recreastion Journal* 35**,** 318-332.

GROUNDWATER-SMITH, S., DOCKETT, S. & BOTTRELL, D. 2014. Ethical Questions in Relation to Participatory Research with Children and Young People. *Participatory Research with Children and Young People.* London: SAGE Publications Limited.

GUILLEMIN, M. & GILLAM, L. 2004. Ethics, Reflexivity, and "Ethnically Important Moments" in Research. *Qualitative Inquiry,* 10**,** 261-280.

GURALNICK, M., NEVILLE, B., HAMMOND, M. & CONNOR, R. 2007. The friendships of young children with developmental delays: a longitudinal analysis. *Journal of Applied Developmental Psychology,* 28**,** 64-79.

GUSTAVSSON, A. & NYBERG, C. 2015. 'I Am Different, But I'm Like Everyone Else': The Dynamics of Disability Identity. *In:* TRAUSTADOTTIR, R., YTTERHUS, B., EGILSON, S. & BERG, B. (eds.) *Childhood and Disability in the Nordic Countries.* London: Palgrave Macmillan.

GUSTAVSSON, A., SANDVIN, J., TRAUSTADOTTIR, R. & TØSSEBRO, J. 2005. *Resistance, Reflection and Change: Nordic disability Research,* Lund: Sweden, Studentlitteratur.

HAEGELE, J. & SUTHERLAND, S. 2015. Perspectives of Students with Disabilities Toward Physical Education: A Qualitative Inquiry Review. *Quest,* 67**,** 255-273.

HAGE, G. 2005. A not so Multi-sited Ethnography of a not so Imagined Community. *Anthropological Theory.*

HAGERMAN, M. 2017. "The Celebrity Thing": Using Photographs of Celebrities in Child-Centered, Ethnographic Interviews with White Kids About Race. *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methodological Issues, Strategies, and Innovations.* Emerald Publishing Limited.

HAGERMAN, M. A. 2010. "I like being intervieeeeewed!" Kids' perspectives on participating in social research. *In:* JOHNSON, H. B. (ed.) *Children and youth speak for themselves.* Bingley: Emerald Publishing Limited.

HAHN, H. 2001. Attitudes Towards Disabilities: A Research Note on Activists with Disabilities. *Journal of Disability Policy Studies,* 12.

HALDER, S. 2008. Rehabilitation of Women With Physical Disabilities in India: A Huge Gap. *The Australian journal of rehabilitation counselling,* 14**,** 1-15.

HALDER, S. & ARGYROPOULOS, V. 2019. *Inclusion, Equity and Access for Individuals with Disabilties : Insights from educators across World* Palgrave Macmillan.

HALDER, S., CZOP ASSAF, L. & KEEFFE, M. 2017. Disability and Inclusion: Current Challenge. *In:* HALDER, S. & CZOP ASSAF, L. (eds.) *Inclusion, Disability and Culture: An Ethnographic Perspective Traversing Abilities and Challenges.* Springer International Publishing.

HALL, E. 2005. The entangled geographies of social exclusion/inclusion for people with learning disabilities. *Health & place,* 11**,** 107-115.

HALL, S., BURNS, D. & REISS, A. 2007. Modeling family dynamics in children with Fragile X syndrome. *Journal of Abnormal Child Psychology* 35**,** 29-42.

HAMILTON, D. 2005. An ecobehavioural analysis of interactive engagement of children with developmental disabilities with their peers in inclusive preschools. *International Journal of Disability, Development and Education,* 52**,** 121-137.

HAMM, J., PITCHFORD, E., SIEBERT, E. & YUN, J. 2016. Parental perceptions of physical activity benefits for youth with developmental disabilities *American Journal of Intellectual and Development Disabilities,* 121**,** 25-32.

HAMMEL, J., MAGASI, S., HEINEMANN, A., WHITENECK, G., BOGNER, J. & RODRIGUEZ, E. 2008. What does participation mean ? An insider perspective from people with disabilities. *Disability & Rehabilitation,* 30**,** 1445-1460.

HAMMELL, K. W. 2006. *Perspectives on disability & rehabilitation: Contesting assumptions, challenging practice*, Churchill Livingstone.

HAMMERSLEY, M. 2015. *Reflections on Paul Atkinson's for Ethnography* [Online]. Available: https://martynhammersley.wordpress.com/documents/ [Accessed 2019].

HAMMERSLEY, M. 2018. What is ethnography? Can it survive? Should it? *Ethnography and Education,* 13**,** 1-17.

HAMMERSLEY, M. & ATKINSON, P. 2007. *Ethnography: Principles in Practice,* Abingdon, Routledge.

HANNERZ, U. 2010. *"Fields Worries: studying down, up, sideways, through, backward, forward, early or later, away and at home", Anthropology's World: Life in a Twenty-First Centure Disipline,* New York: NY, Pluto Press.

HANSON, K. 2012. Schools of though in children's rights *In:* LIEBEL, M. (ed.) *Children's Rights from Below: Cross-cultural Perspectives.* Basingstoke: Palgrave Macmillan.

HANSON, K. & NIEUWENHUYS, O. 2012. Living rights, social justice, translations. *Reconceptualizing children's rights in international development: Living rights, social justice, translations.*

HANSON, K., VAN DAALEN, E. & NIEUWENHUYS, O. 2016. Children's Rights as Living Rights: The Case of Street Children and a new Law in Yogyakarta Indonesia *The International Journal of Children's Rights,* 24**,** 803-825.

HANVEY, L. 2001. *Children and Youth with Special Needs: Summary Report of Findings* Ottawa, ON, Canadian Council on Social Development

HARAWAY, D. 1988. Situated knowledges: The science question in feminism and the privilege of partial perspective *Feminist Studies,* 14**,** 575-599.

HARDEN, J. 2012. Good Sitting, Looking and Listening: The Regulation of Young Children's Emotions in the Classroom. *Childrens Geographies,* 10**,** 83-93.

HARPER, D. 1998. An argument for visual sociology. *In:* PROSSER, J. (ed.) *Image-Based Research: A Sourcebook for Qualitative Researcher.* London: Routledge Falmer.

HARRIS, J. & ROULSTONE, A. 2011. *Disability, policy and professional practice,* London, Sage.

HART, R. A. 1992. Ladder of participation, children's participation: From Tokenism to citizenship. *Innocenti Essays 4.*

HART, R. A. 2008. Stepping Back from 'The Ladder': Refl ections on a Model of Participatory Work with Children. *In:* REID, A., JENSEN, B. B., NIKEL, J. & SIMOVSKA, V. (eds.) *Participation and Learning: Perspectives on Education and the Environment, Health and Sustainability.* Dordrecht: Springer Netherlands.

HARTAS, D. 2008. The Right to Childhoods: Critical Perspectives on Rights, Difference, and Knowledge in a Transient World.

HARVEY, W., WILKINSON, S., PRESSÉ, C., JOOBER, R. & GRIZENKO, N. 2014. Children say the darndest things: physical activity and children with attention-deficit hyperactivity disorder. *Physical Education and Sport Pedagogy,* 19**,** 205-220.

HAW, K. 2008. 'Voice' and video: Seen, heard and listened to? *In:* THOMSON, P. (ed.) *Doing visual research with children and young people.* London and New York: Routledge.

HAYS, D. G. & SINGH, A. A. 2012. *Qualitative inquiry in clinical and educational settings* New York, NY, Guilford Press.

HEAH, T., CASE, T., MCGUIRE, B. & LAW, M. 2007. Successful participation: The lived experience among children with disabilities. *Canadian Journal of Occupational Therapy.*

HEALY, S., MSETFI, R. & GALLAGHER, S. 2013. 'Happy and a bit Nervous': the experiences of children with autism in physical education. *British Journal of Learning Disabilities,* 41**,** 222-228.

HEATH, S., CHARLES, V., CROW, G. & WILES, R. 2007. Informed consent, gatekeppers and go-betweens: negotiating consent in child and youth-orientated institutions. *British Educational Research Journal,* 33**,** 403-417.

HELLER, P. 2001. Moving the state: the politics of democratic decentralization in Kerala, South Africa, and Porto Alegra. *Politics & Society,* 29**,** 131-163.

HERR, K. & ANDERSON, G. L. 2005. *The Action Research Dissertation: A Guide for Students and Faculty,* California, SAGE Publications.

HERTZ, R. 1997 Introduction. *In:* HERTZ, R. (ed.) *Reflexivity and Voice.* London: SAGE Publications.

HICKINGBOTHAM, M., WONG, C. & BOWLING, A. 2021. Barries and facilitators to physical education, sport and physical activity program participation among children and adolescents with psychiatric disorders: a systematic review. *Translational Behavioral Medicine,* 11**,** 1739-1750.

HILL, M. 2005. Ethical considerations in researching children's experiences. *In:* GREENE, S. & HOGAN, D. (eds.) *Researching Children's Experience.* London: Sage Publications

HILL, M. 2006. Children's Voices on Ways of Having a Voice: Children and Young People's Perspectives on Methods Used in Research and Consultation *Childhood,* 13**,** 69-89.

HILL, M., DAVIS, J., PROUT, A. & TISDALL, K. 2004. Moving the Participation Agenda Forward. *Children & Society,* 18**,** 77-96.

HILL, M. & TISDALL, K. 1997. *Children & Society* Harlow, Prentice Hall

HINTON, R. 2008. Children's participation and good governance: Limitation of the theoretical literature. *International Journal of Children's Rights,* 16**,** 285-300.

HODGE, N. & RUNSWICK-COLE, K. 2009. Needs or Rights? A Challenge to the Discourse of Special Education. *British Journal of Special Education,* 36**,** 198-203.

HODGE, N. & RUNSWICK-COLE, K. 2013. 'They never pass me the ball': Exposing ableism through the leisure experiences of disabled children, young people and their families. *Children's Geographies,* 11.

HODKINSON, A. 2011. Inclusion: a defining definition? *Power and Education,* 3**,** 179-185.

HOFFMAN, S. J., SRITHARAN, L. & TEJPAR, A. 2016. Is the UN Convention on the Rights of Persons with Disabilities Impacting Mental Health Laws and Policies in High-Income Countries? A Case Study of Implementation in Canada. *BMC International Health and Human Rights,* 16.

HOGAN, D. M. 2005. Researching "The Child" in Developmental Psychology. *In:* GREENE, S. (ed.) *Researching Children's Experiences: Methods and Approaches.* London: SAGE.

HOLMES, L. 2012. Guidance for Ensuring Confidentiality and the Protection of Data. *In:* BRYMAN, A. & FERGUSON, H. (eds.) *Understanding Research for Social Policy and Social Work: Themes, Methods, and Approaches.* Bristol: Policy Press

HOLT, J., HOLT, L. & PELHAM, T. 2004. *The Hockey Life: The Good, the Bad and the Ugly* Acadia University.

HOLT, L. 2003. (Dis)abling children in primary school micro-spaces: Geographies of inclusion and exclusion. *Health & Place* 9**,** 119-128.

HOLT, L. 2016. Young People with Socio-Emotional Differences, Theorising Disability and Destablising Socio-Emotional Norms. *In:* HALL, E. (ed.) *Towards enabling geographies: disabled 'bodies and minds in society and space'.* Abingdon: Routledge.

HORST, H. 2015. Cultivating the cosmopolitan child in Silicon Valley. *Identities,* 22**,** 619-634.

HOUGHTON, S. & TAYLOR, M. 2008. Difficulties in initiating and sustaining peer friendships: perspectives on students diagnosed with AD/HD. *British Journal of Special Education,* 35.

HOWE, P. & KITCHIN, P. 2014. The mainstreaming of disability cricket in England and Wales: Integration 'One Game' at a time. *Sport Management Review,* 17**,** 65-77.

HUMPHREY, N. & SYMES, W. 2010. Peer-group indicators of social inclusion among pupils with autistic spectrum disorders (ASD) in mainstream seconday schools: a comparative study. *School Psychology International,* 31**,** 478-494.

HUNT, G. 2018. Early Interventions *In:* BOGGIS, A. (ed.) *Dis/Abled Childhoods? A Transdisciplinary Approach* Palgrave Macmillan.

HURST, A. 2008. A healing echo: Methodological reflections of a working class researcher on class. *Qualitative Report,* 13**,** 334-352.

HUTCHBY, I. 2007. *The discourse of child counselling,* Amsterdam, John Benjamins.

HYLTON, K. & TOTTEN, M. 2013. Developing 'sport for all'. *In:* HYLTON, K. (ed.) *Sport development: policy, process and practice.* New York: Routledge

ICF 2001. World Health Organization: International Classification of Functioning, Disability, and Health.

IERVESE, V. & BARALDI, C. 2014. Observing children's capabilities as agency. *In:* STOECKLIN, D. & BOVIN, M. (eds.) *Children's rights and the capability approach. Challenges and prospects.* Dodrecht: Springer.

IMRIE, R. 2004. Demystifying disability: A review of the International Classification of Functioning, Disability and Health *Sociology of Health & Illness,* 26.

IMRIE, R. & EDWARDS, C. 2003. Disability and bodies as bearers of value. *Sociology,* 37**,** 239-256.

INVERNIZZI, A. & WILLIAMS, J. 2008. *Constructions of Childhood and Children's Experiences,* London, Sage.

JACKSON, E. & SCOTT, D. 1999. Constraints to leisure *In:* JACKSON, E. & BURTON, T. (eds.) *Leisure studies: Prospects for the Twenty-First Century.* Venture.

JAFFER, M. & BRAZEAU, P. 2012. *Standing Senate Committee on Human Rights: Level the playing field: A natural progression from playground to podium for Canadians with disabilities* [Online]. Available: https://sencanada.ca/content/sen/committee/411/ridr/rep/rep07jun12-e.pdf [Accessed].

JAHNUKAINEN, M. 2015. Inclusion, integration, or what? A comparative study of the school principals' perceptions of inclusive and special education in Finland and in Alberta, Canada. *Disability & Society,* 30**,** 59-72.

JAKOBSSON, J., MALM, C. & ISAKSSON, A. 2019. Physical Activity and Sports - Real Health Benefits: A Review with Insight into the Public Health of Sweden. *Sports* 7.

JAMES, A. 2002. Ethnography in the Study of Children and Childhood *In:* ATKINSON, P., COFFEY, A., DELAMONT, S., LOFTLAND, J. & LOFTLAND, L. (eds.) *Handbook of Ethnography.* London: Sage Publications.

JAMES, A. 2005. Life Times: Children's Perspectives on Age, Agency and Memory across the Life Course. *In:* QVORTRUP, J. (ed.) *Studies in Modern Childhood: Society, Agency, Culture.* Basingstoke: Palgrave MacMillan.

JAMES, A. 2013. *Socialising children,* Basingstoke, Palgrave Macmillan.

JAMES, A. & JAMES, A. L. 2012. *Key concepts in childhood studies,* Los Angeles, Calif. ; London, SAGE Publications Ltd.

JAMES, A. & PROUT, A. 1997. A New Paradigm for the Sociology of Childhood? Provenance, Promise and Problems. *In:* JAMES, A. & PROUT, A. (eds.) *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood.* . second ed. London: Falmer Press.

JAMES, A. L. 2007. Giving voice to children's voices: Practices and problems, pitfalls and potentials *American Anthropologist,* 109**,** 261-272.

JAMES, A. L. 2009. "Agency" *In:* QVORTRUP, J., CORSARO, W. & HONIG, M. (eds.) *The Palgrace Handbook of Childhood Studies.* New York: Palgrave Macmillan.

JAMES, A. L. 2011. To be (come) or not to be (come): Understanding children's citizenship. *The Annals of the American Academy of Political and Social Science,* 633**,** 167-179.

JAMES, A. L. & JAMES, A. 2004. *Constructing childhood: Theory, Policy and Social Practice*, Macmillan.

JAMES, A. L. & JAMES, A. 2008. *Key Concepts in Childhood Studies,* London, SAGE Publications Ltd.

JAMES, A. L., JENKS, C. & PROUT, A. 1998. *Theorizing Childhood,* Cambridge, Polity Press.

JAMES, A. L. & PROUT, A. 1990. *Constructing and Re-constructing Childhood*, Basingstoke: Falmer Press.

JAMES, A. L. & PROUT, A. 1995. Hierachy, boundary and agency: towards a theoretical perspective on childhood. *Sociological studies of children,* 7**,** 77-99.

JAMES, A. R., KELLMAN, M. & LIEBERMAN, L. 2011. Perspectives on Inclusion from Students with Disabilities and Responsive Strategies for Teachers. *Journal of Physical Education, Recreation & Dance,* 82**,** 33-38.

JEANES, R., MAGEE, J. & SPAAIJ, R. 2014. *Sport and Social Exclusion in Global Society* Abingdon, Routledge

JEANES, R., SPAAIJ, R., MAGEEB, J., FARQUHARSOND, K., GORMANE, S. & LUSHER, D. 2017. 'Yes we are inclusive': Examining provision for young people with disabilities in community sport clubs. *Sport Management Review*.

JENKS, C. 1996. *Childhood,* London, Routledge.

JERLINDER, K. 2010. Social Justice in Inclusive Physical Education for Pupils with Physical Disabilities- Reality or Utopia? *Studies from the Swedish Institute for Disability Research* 33.

JOHNSON, A. 2006. *Privilege, power, and difference,* New York, McGraw-Hill.

JONES, A., POTTER, H. & WATSON, D. 2018. Expressive Eyebrows and Beautiful Bubbles: Playfulness and Children with Profound Impairments. *In:* RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies.* London: Palgrace Macmillian

JONES, J., DOVIDIO, J. & VIETZA, D. 2014. *The psychology of diversity: Beyond prejudice and racism,* West Sussex, Wiley Blackwell.

JUDGE, B. 2003. Inclusive Education: principles and practices. *In:* CRAWFORD, K. (ed.) *Contemporary Issues in Education.* Dereham: Peter Francis.

KAISER, H. A. 2013. Law and psychiatry in the age of the Convention on the Rights of Persons with Disabilities (CRPD). *In:* BLOOM, H. & SCHNEIDER, R. D. (eds.) *Law and mental disorder: a comprehensive and practical approach.* Toronto: Inwin Law.

KANTER, A. 2003. The Globalisation of Disability Rights Law. *Syracuse Journal of International Law and Commerce,* 30**,** 240-248.

KATZ, E. 2015. Beyond the physical incident model: How children living with domestic violence are harmed by and resist regimes of coercive control. *Child Abuse Review,* 25**,** 46-59.

KAUFFMAN, J. & ANASTASIOU, D. 2011. A social constructionist approach to disability: Implications for special education. *Exceptional Children,* 77**,** 367-384.

KAUFFMAN, J. & ANASTASIOU, D. 2012. Disability as cultural difference: Implications for special education. *Remedial and Special Education,* 33**,** 139-149.

KAUFFMAN, J. & ANASTASIOU, D. 2013. The social model of disability: Dichotomy between impairment and disability. *Journal of Medicine & Philosophy,* 38**,** 441-459.

KAY, T. & COLLINS, M. 2014. *Sport and social exclusion,* London, New York, Routledge.

KEHN, M. & KROLL, T. 2009. Staying physically active after spinal cord injury: A qualitative exploration of barriers and facilitators to exercise participation. *Biomed Central Public Heath.*

KEMP, C. & CARTER, M. 2005. Identifying skills for promoting successful inclusion in kindergarten. *Journal of Intellectual and Developmental Disability,* 30**,** 31-44.

KENWAY, J. 2015. Ethnography "is not what it used to be": rethinking space, time, mobility, and multiplicity. *In:* BOLLIG, S., HONIG, M., NEUMANN, S. & SEELE, C. (eds.) *MultiPluriTrans in Educational Ethnography: Approaching the Multimodality, Plurality and Translocality of Educational Realities.*

KERZNER, L. 2011. *Paving the way to full realization of the CRPD's right to legal capacity and supported decision making: a Canadian perspective,* Vancouver, University of British Columbia.

KHAN, S. R. 2011. *Privilege: The making of an adolescent elite at St. Paul's school. ,* Princeton, NJ, Princeton University Press.

KIM, S.-Y. 2009. Assessing Physical Activity Levels of Students with Disabilities in Physical Education? *Journal of Physical Education, Recreation & Dance,* 80**,** 3-4,51.

KING, G., GIBSON, B., MISTRY, B., PINTO, M., GOH, F., TEACHMAN, G. & THOMPSON, L. 2014a. An Integrated Methods Study of the Experiences of Youth with Severe Disabilities in Leisure
Activity Settings: The Importance of Belonging, Fun, and Control and Choice. *Disability and Rehabilitation,* 36**,** 1626-1635.

KING, G., LAW, M., HANNA, S., KING, S., HURLEY, P., ROSENBAUM, P. & PETRENCHIK, T. 2006. Predictors of the leisure and recreation participation of children with physical disabilities: a structural equation modeling analysis. *Children's Health Care,* 35**,** 209-234.

KING, G., LAWM, M., KING, S., ROSENBAUM, P., KERTOY, M. & YOUNG, N. 2003. A Conceptual Model of the Factors Affecting the Recreation and Leisure Participation of Children with Disabilities. 23:1**,** 63-90.

KING, G., LAWM, M., KING, S., ROSENBAUM, P., KERTOY, M. & YOUNG, N. 2004. A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics,* 23**,** 63-90.

KING, G., MCDOUGALL, J., DEWIT, D., PETRENCHIK, T., HURLEY, P. & LAW, M. 2009. Predictors of Change Over Time in the Activity Participation of Children and Youth With Physical Disabilities. *Children's Health Care,* 38**,** 321-351.

KING, G., RIGBY, P., BATOROWICZ, B., MCMAIN-KLEIN, M., PETRENCHIK, T., THOMPSON, L. & GIBSON, M. 2014b. Development of a direct observation Measure of Environmental Qualities of Activity Settings *Developmental Medicine & Child Neurology***,** 763-769.

KIUPPIS, F. 2018. Inclusion in sport: disability and participation. *Sport in Society,* 21**,** 4-21.

KJØRHOLT, A. & LIDÉN, H. 2004. Children and youth as citizens: Symbolic participants or political actors *In:* KAMPMANN, J., BREMBECK, H. & JOHANSSON, B. (eds.) *Exploring Contemporary Childhoods in the Nordic Welfare Societies.* Fredriksberg Roskilde University Press.

KLENK, C., ALBRECHT, J. & NAGEL, S. 2018. Social participation of people with disabilities in organized community sport. *Ger J Exerc Sport Res,* 49**,** 365-380.

KLOCKER, N. 2007. An exmaple of 'thin' agency: Child domestic workers in Tanzania

KNIGHTS, D. & WILMOTT, H. 1999. *Management Lives: Power and Identity in Organisations* London, Sage.

KOBAL GRUM, D. & SENIČAR, M. 2012. Self-concept and social support among adolecents with disabilities attending special and mainstream schools. 48**,** 73-83.

KOBIELA, P. 2018. Should chess and other mind sports be regarded as sports? *Journal of the Philosophy of Sport,* 45**,** 279-295.

KOH, H. 2004. Different But Equal: The Human Rights of Persons with Intellectual Disabilities Available from: https://digitalcommons.law.yale.edu/fss_papers/1779/.

KOLLER, D., LE POUESARD, M. & ANNEKE RUMMENS, J. 2018. Defining Social Inclusion for Children with Disabilities: A Critical Literature Review. *Children & Society,* 32**,** 1-13.

KOMULAINEN, S. 2007. The Ambiguity of the Child's "Voice" in Social Research *Childhood,* 14**,** 11-28.

KONSTANTONI, K. 2010. *Young children's perceptions and constructions of social identities and social implications : Promoting social justice in early childhood.* Thesis (Ph.D.)--University of Edinburgh, 2011.

KONSTANTONI, K. 2011. Young children's perceptions and constructions of social identities and social implications: promoting social justice in early childhood. PhD Edinburgh University.

KONSTANTONI, K. 2012. Children's peer relationships and social identities: exploring cases of young children's agency and complex interdependencies from the Minority World. *Children's Geographies,* 10**,** 337-346.

KONSTANTONI, K. & EMEJULU, A. 2017. When intersectionality met childhood studies: the dilemmas of a travelling concept. *Childrens Geographies,* 15**,** 6-22.

KONSTANTONI, K. & KUSTATSCHER, M. 2016. Conducting ethnographic research in early childhood research: questions of participation. *In:* FARRELL, A., KAGAN, S. & TISDALL, K. (eds.) *Sage Handbook of Early Childhood Research.* London: Sage.

KONSTANTONI, K. & PATSIANTA, K. 2019. Young children's rights in 'tough' times: Towards an intersectional children's rights policy agenda in Greece and Scotland. *The Routledge International Handbook of Young Children's Rights* Routledge.

KORTESLUOMA, R. L., HENTINEN, M. & NIKKONEN, M. 2003. Conducting a qualitative child interview: Methodolgical considerations. *Journal of advanced nursing.*

KOSTER, M., NAKKEN, H., PIJL, S. & VAN HOUTEN, E. 2009. Being part of the peer group: A literature study focusing on the social dimension of inclusion in educations. *International Journal of Inclusive Education,* 13**,** 117-140.

KOSTER, M., PIJL, S., NAKKEN, H. & VAN HOUTEN, E. 2010. Social participation of students with special needs in regular primary education: in the Netherlands. *International Journal of Disability, Development and Education,* 57**,** 59-75.

KRAPPMANN, L. 2010. The wright of the child's view: Article 12 of the Convention on the Rights of the Child. *International Journal of Children's Rights,* 18**,** 501-513.

KRISCHLER, M., POWELL, J. & PIT-TEN CATE, I. 2019. What is meant by inclusion? On the effects of different definitions on attitudes towards inclusive education. *European Journal of Special Needs Education,* 34**,** 632-648.

KRULL, J., WILBERT, J. & HENNEMANN, T. 2014. The social and emotional situation of first graders with classroom behaviour problems and classroom learning difficulties in inclusive classes. *Learning Disabilities - A contemporary journal,* 12**,** 161-190.

KRUSE, S. & DEDERING, K. 2018. The Idea of Inclusion: Conceptual and Empirical Diversities in Germany. *Improving Schools,* 21**,** 19-31.

KUMPULAINEN, K. & OUAKRIM-SOIVIO, N. 2019. "My Treasure Box": Pedagogical Documentation, Digital Portfolios and Children's Agency in Finnish Early Years Education. *In:* ECKHOFF, A. (ed.) *Participatory Research with Young Children* Springer

KUSTATSCHER, M., KONSTANTONI, K. & EMEJULU, A. 2015. Hybridity, Hyphens, and Intersectionality: Relational Understandings of Children and Young People's Social Identities. *In:* PUNCH, S., VANDERBECK, R. & SKELTON, T. (eds.) *Familites, Intergenerationality and Peer Group Relations* Singapore: Springer.

LABONTE, R. 2004. Social inclusion/exclusion: Dancing the dialectic. *Health Promotion International,* 19**,** 115-121.

LAHMAN, M. K. E., GEIST, M. R., RODRIGUEZ, K. L., GRAGLIA, P. & DEROCHE, K. K. 2010. Culturally Responsive Relational Reflexive Ethics in Research: The Three Rs'. *Quality & Quantity,* 45**,** 1397-1414.

LANE, D., BLANK, J. & JONES, P. 2019. Research with children: Context, power, and representation. *The Qualitative Report,* 24**,** 693-704.

LANKSHEAR, C. & KNOBEL, M. 2011. *New Literacies,* New York, Open University Press

LANSDOWN, G. 2001. *Promoting Children's Participation in Democratic Decision Making,* Florence, UNICEF Innocenti Research Centre.

LANSDOWN, G. 2005. *The Evolving Capacities of the Child*, UNICEF Innocenti Research Centre.

LANSDOWN, G. 2006. International Developments in Children's Participation: Lessons and Challenges. *In:* TISDALL, K., DAVIS, J., HILL, M. & PROUT, A. (eds.) *Children, Young People and Social Inclusion: Participation for What?* Bristol: The Policy Press.

LANSDOWN, G. 2010. *The realisation of children's participation rights.*, Children & Society.

LAUDAN, A. & LORPREST, P. 2012. Disability and the Education System. *The Future of Children,* 22**,** 97-122.

LAW, M., KING, G., KING, S., KERTOY, M., HURLEY, P., ROSENBAUM, P. & HANNA, S. 2006. Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology,* 48**,** 337-342.

LAW, M., PETRENCHIK, T., KING, G. & HURLEY, P. 2007. Perceived Environmental Barriers to Recreational, Community, and School Participation for Children and

Youth With Physical Disabilities *Archives of Physical Medicine and Rehabilitation,* 88**,** 1636-42.

LAWSON, A. & BECKETT, A. 2021. The social and human rights models of disability: towards a complementarity thesis *The International Journal of Human Rights,* 25**,** 348-379.

LEE, N. 2001. Children and Society: Growing up in an Age of Uncertainty *Issues in society series* Maidenhead: Open University Press.

LEONARD, M. 2016. *The Sociology of Children, Childhood and Generation,* London, SAGE.

LEYSER, Y. & KIRK, R. 2004. Evaluating inclusion: an examination of parent views and factors influencing their perspective. *International Journal of Disability, Development and Education,* 51**,** 271-285.

LI, C. & CHEN, S. 2012. Exploring experiences of physical activity in special school students with cerebral palsy: A qualitative perspective. *European Journal of Adapted Physical Activity* 5.

LIDDIARD, K., CURRAN, T. & RUNSWICK-COLE, K. 2018. Concluding Thoughts and Future Directions. *In:* RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies.* Palgrave Macmillan.

LIEBEL, M. 2008. Citizenship from below. *In:* INVERNIZZI, A. & WILLIAMS, J. (eds.) *Children and citizenship.* London/Thousand Oaks: Sage.

LIEBEL, M. 2012. *Children's rights from below: cross cultural perspectives* New York, Palgrave Macmilian.

LIEBEL, M. 2014. From evolving capacities to evolving capabilities: Contextualizing children's rights. *In:* STOECKLIN, D. & BONVIN, J. M. (eds.) *Children's rights and the capability approach: Challenges and prospects.* Dordrecht: Springer.

LINCOLN, Y. & GUBA, E. 2000. Paradigmatic controversies contradictions, and emerging confluences. *In:* DENZIN, N. & LINCOLN, Y. (eds.) *Handbook of Qualitative Research.* 2nd ed. Thousand Oaks, CA: Sage Publications.

LIPPOLD, T. & BURNS, J. 2009. Social Support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research,* 53**,** 463-473.

LISTER, R. 2008. Investing in children and childhood: A new welfare policy paradigm and its implications *Childhood: Changing Contexts* Emerald Group Publishing Limited.

LLOYD, L., BORNMAN, J. & ALANT, E. 2006. Issues in AAC research: How much do we really understand? *Disability & Rehabilitation,* 28**,** 143-150.

LOEWEN, G. & POLLARD, W. 2010. The Social Justice Perspective *Journal of Postsecondary Education and Disability,* 23.

LOITZ, C. & SPENCER-CAVALIERE, N. 2013. Exploring Barriers and Facilitators to Children's Active Transportation to and From School From the Perspectives of Practitioners. *Journal of Physical Activity and Health,* 10**,** 1128-1135.

LOJA, E., COSTA, M. E., HUGHES, B. & MENEZES, I. 2013. Disability, Embodiment and ableism: Stories of resistance *Disability and Society,* 28**,** 190-203.

LONGMORE, P. 2003. The second phase: From disability rights to disability culture. *Disability and Proud.*

LONGO, E., BADIA, M., ORGAX, B. & VERDUGO, M. 2012. Cross-cultural validation of the Children's Assessment of Participation and Enjoyment (CAPE) in Spain. *Child: care, health and development,* 40**,** 231-242.

LOREMAN, T., DEPPELER, J. & HARVEY, D. 2005. *Inclusive education: a practical guide to supporting diversity in the classroom,* London, RoutledgeFalmer.

LUNDY, L. 2007. 'Voice' is not enough: conceptualising Article 12 of the United Nations Convention on the Rights of the Child. . *British Educational Research Journal,* 33**,** 927-942.

LUNDY, L., KILLKELLY, U. & BYRNE, B. 2013. Incorporation of the United Nations Convention on the Rights of the Child in Law: A Comparative Review *International Journal of Children's Rights,* 21**,** 442-462.

LYNCH, M. 2000. Against Reflexivity as an Academic Virtue and Source of Privileged Knowledge. *Theory, Culture and Society* 17.

LYONS, S., CORNEILLE, D. & CORKER, P. 2009. A miracle in the outfield: The benefits of participation inorganized baseball leagues for children with mental and physical disabilities *Therapeutic Rescreation* 43**,** 41-48.

MACDONALD, D., PANG, B., KNEZ, K., NELSON, A. & MCCUAIG, L. 2012. The will for inclusion: bothering the inclusion/exclusion discourses of sport. *In:* DAGKAS, S. & ARMOUR, K. (eds.) *Inclusion and exclusion through youth sport.* London: Routledge.

MACLURE, M. 2009. Broken voices, dirty words: On the productive insufficiency of voice. *In:* JACKSON, A. & MAZZEI, L. (eds.) *Voice in qualitative inquiry.* Routledge.

MACONOCHIE, H. 2018. Making Space for the Embodied Participation of Young Disabled Children *In:* LIDDIARD, K., CURRAN, T. & RUNSWICK-COLE, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies* London: Palgrave Macmillan.

MAJNEMER, A., SHEVELL, M., LAW, M., BIRNBAUM, R., CHILINGARYAN, C., ROSEBAUM, P. & POULIN, C. 2008. Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology,* 50**,** 751-758.

MAJSTOROVIC, I. 2014. Children's participation in family mediation: An example of new challenges for non-discrimination. *In:* KUTZAR, D. & WARMING, H. (eds.) *Children and non-discrimination. Interdisciplinary textbook.* Estonia: University Press Estonia.

MALLETT, R. & RUNSWICK-COLE, K. 2014. Approaching Disability: Critical Issues and Perspectives. *Canadian Journal of Disability Studies,* 4.

MALONE, K. & HARTUNG, C. 2010. Challenges of Participatory Practice with Children *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice* London: Routledge.

MANDELL, N. 1988. The Least- Adult Role in Studying Children. *Journal of Contemporary Ethnography,* 16**,** 433-467.

MANDELL, N. 1991. The Least-Adult Role in Studying Children. *In:* WAKSLER, F. (ed.) *Studying the Social Worlds of Children: Sociological Readings.* London: Falmer Press.

MANNION, G. 2007. After Participation: The Socio-Spatial Performance of Intergenerational Becoming *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice.* London: Routledge.

MARCUS, G. E. 1995. Ethnography in/of the World Systems: The Emergence of Multi-Sited Ethnography. *Annual Review of Anthropology,* 24**,** 95-117.

MARTIN GINIS, K., MA, J., LATIMER-CHEUNG, A. & RIMMER, J. 2016. A systematic review of review articles addressing factors related to physical activity participation among children and adults with physical disabilities. *Health and Psychology Review,* 10**,** 478-494.

MARTIN, J. J. 2013. Benefits and barriers to physical activity for individuals with disabilities: A socio-relational model of disability perspective. *Disability & Rehabilitation,* 35**,** 2030-2037.

MARTIN, J. J. & CHOI, Y. 2009. Parents' physical activity-related perceptions of their children with disabilities *Disability and Health Journal,* 2.

MARTIN, K. & FRANKLIN, A. 2010. Disabled Children and Participation in the UK: Reality or Rhetoric? *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice.* Abingdon: Routledge.

MARTIN, N. 2011. Brief Reflections on Disability Theory, Language, Identity, Equality and Inclusion. Available from: https://blogs.lse.ac.uk/equityDiversityInclusion/2017/02/national-self-injury-awareness-day-social-justice-user-led-interventions-and-challenging-stigma/ 2021].

MASON, J. 2002. *Qualitative researching,* London, Sage.

MASON, J. 2009. Strategies and issues in including children as participants in research on children's needs in care: A case study *In:* BISHOP, K. & DOCKETT, S. (eds.) *Involving children and young people in research: Compendium of papers and reflections form a think tank.* New South Wales: Australian Research Alliance for Children and Youth.

MÂSSE, L., MILLER, A., SHEN, J., SCHIARITI, V. & ROXBOROUGH, L. 2013. Patterns of participation across a range of activities among Canadian children with neurodevelopmental disorders and disabilities. *Developmental Medicine & Child Neurology,* 55**,** 729-736.

MÂSSE, L. C., MILLER, A. R., SHEN, J., SCHIARITI, V. & ROXBOROUGH, L. 2012. Comparing participation in activities among children with disabilities. *Research in Developmental Disabilities,* 33**,** 2245-2254.

MASSEY, D. 2005. *For Space,* London, Sage.

MAUTHNER, N. & DOUCET, A. 1998. Reflections on a Voice-Centred Relational Method: Analysing Maternal Domestic Voices. *In:* EDWARDS, R. & RIBBENS MCCARTHY, J. (eds.) *Feminist Dilemmas in Qualitative Research: Public Knowledge and Private Lives.* London: SAGE.

MAUTHNER, N. & DOUCET, A. 2003. Reflective Accounts and Accounts of Reflexivity in Qualitative Data Analysis. *Sociology,* 37**,** 413-431.

MAYALL, B. 2002. *Towards a Sociology of Childhood: Thinking from Children's Lives,* Buckingham, Open University Press.

MAYALL, B. 2008. Conversations with Children: Working with Generational Issue. *In:* CHRISTENSEN, P. & JAMES, A. (eds.) *Research with Children: Perspectives and Practices.* New York: Routledge.

MAYALL, B. 2012. An Afterword: Some Reflections on a Seminar Series. *Children's Geographies,* 10**,** 347-355.

MAYALL, B. 2015. The Sociology of Childhood and Children's Rights'. *In:* VANDENHOLE, W., DESMET, E., REYNAERT, D. & LEMBRECHTS, S. (eds.) *Routledge International Handbook of Children's Rights Studies.* Abingdon: Routledge.

MAZZEI, L. 2003. Inhabited silences: In pursuit of a muffled subtext. *Qualitative Inquiry,* 9**,** 355-368.

MAZZEI, L. 2004. Silent listenings: Deconstructive practices in discourse-based research. *Educational Researcher***,** 26-34.

MAZZEI, L. 2007. *Inhabited silence in qualitative research: Putting poststructural theory to work,* New York, Peter Lang.

MAZZEI, L. 2009. An impossibly full voice. *In:* MAZZEI, L. & JACKSON, A. (eds.) *Voice in Qualitative Inquiry: Challenging conventional, interpretive, and critical conceptions in qualitative research.* New York: Routledge.

MCCOY, S. & BANKS, J. 2012. Simply academic? Why children with special educational needs don't like school. *European Journal of Special Needs Education,* 27**,** 81-97.

MCLAUGHLIN, M., GOODLEY, D., CLAVERING, E. & FISHER, P. 2008. *Families Raising Disabled Children: Enabling Care,* Basingstoke, Palgrave Macmillan.

MCLEOD, S. 2018. Communication rights: Fundamental human rights for all *International Journal of Speech-Language Pathology,* 20**,** 3-11.

MCMANUS, V., MICHELSEN, S., PARKINSON, K., COLVER, A., BECKUNG, E., PEZ, O. & CARAVALE, B. 2006. Discussion groups with parents of children with cerebral palsy in Europe designed to assist development of a relevant measure of enviroment. *Child: Care, Health and Development,* 32.

MCNAMEE, S. 2016. *The Social Study of Childhood: An Introduction*, Palgrave Macmilian.

MCNEILLY, P., MACDONALD, G. & KELLY, B. 2015. The Participation of Disabled Children and Young People: A Social Justice Perspective. *Child Care in Practice,* 21**,** 266-286.

MCPHERSON, A. & LINDSAY, S. 2012. Experience of social exclusion and bullying at school amongst children and youth with cerebral palsy. *Disability & Rehabilitation,* 34**,** 101-109.

MCTAGUE, T., FROYUM, C. & RISMAN, B. 2017. Learning About Inequality from Kids: Interviewing Strategies for Getting Beneath Equality Rhetoric. *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methogological Issues, Strategies, and Innovations.* Emerald Publishing Limited.

MEEKOSHA, H. 2004. Drifting down the Gulf Stream: navigating the cultures of disability studies. *Disability and Society,* 19**,** 721-733.

MEEKOSHA, H. & SHUTTLEWORTH, R. 2009. What's so 'critical' about Critical Disability Studies? *Australian Journal of Human Rights,* 15**,** 45-75.

MEERWALD, A. 2013. Researcher | Researched: Repositioning Research Paradigms. *Higher Education Research and Development,* 32**,** 43-55.

MELTON, G. 1993. Review of 'children's participation: from tokenism to citizenship' *The International Journal of Children's Rights,* 1**,** 263-266.

MEPHAM, S. 2010. Disabled children: The right to feel safe. *Child Care in Practice,* 16**,** 19-34.

MICHAILAKIS, D. 2003. The Systems Theory Concept of Disability: One is Not Born a Disabled Person, One is Observed to Be One. *Disability and Society,* 18**,** 209-229.

MILLER, D. 2000. Citizenship:What does it mean and why is it important? . *In:* PEARCE, N. & HALLGARTEN, K. (eds.) *Tomorrow's citizens. Critical debates in citizenship and education* London: Institute for Publich Policy and Research

MILLER, D. 2001. *Principles of social justice,* Cambridge, MA, Harvard University Press.

MILLER, F. & KATZ, J. 2002. *The Inclusion Breakthrough: Unleashing the Real Power of Diversity* Berrett-Koehler Publishers, Inc.

MILNER, P. & KELLY, B. 2009. Community Participation and inclusion: People with disabilities defining their place. *Disability & Society,* 24**,** 47-62.

MILTON, D. 2014. Becoming Autistic: An Aut-ethnography: Cutting Edge Psychiatry in Practice. *Autism Spectrum Disorder,* 4**,** 185-192.

MILTON, D. 2018. Autistic Development, Trauma and Personhood: Beyond the Frame of Neoliberal Individual *In:* RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies* London: Palgrave Macmillan.

MISENER, L. 2014. Managing disability sport: From athletes with disabilities to inclusive organisational perspectives. *Sport Management Review,* 17**,** 1-7.

MISENER, L. & DARCY, S. 2014. Managing disability sport: from the athletes with disabilities to inclusive organisational perspectives. *Sport Management Review,* 17**,** 1-7.

MITCHELL, D. & SNYDER, S. 2015. *The biopolitics of disability: Neoliberalism, ablenationalism and peripheral embodiment,* Ann Arbor, MI, University of Michigan Press.

MITCHELL, W. 2010. 'I know how I feel': Listening to young people with life-limiting conditions who have learning and communication impairments. *Qualitative Social Work: Research and Practice,* 9**,** 185-203.

MOELLER, M. 2015. Pushing Boundaries of Normalcy: Employing Criticaldisability Studies in Analysing Medical Advocacy Websites. *Communitcaion Design Quarterly Review,* 2**,** 52-80.

MONAHAN, T. & FISHER, J. A. 2010. Benefits of 'observer effects': Lessons from the field. *Qualitative Research,* 10**,** 357-376.

MOODLEY, J. & GRAHAM, L. 2015. The Importance of Intersectionality in Disability and Gender Studies. *Agenda,* 29**,** 24-33.

MOOLA, F., FUSCO, C. & KIRSH, J. 2011. 'What I wish you know': Social barriers towards physical activity in youth with congenital heart disease (CHD) *Adapted Physical Activity Quarterly,* 28**,** 56-77.

MOORE, V. A. 2001. "Doing" racialized and gendered age to organize peer relations: Observing kids in summer camp. *Gender & Society,* 15**,** 835-858.

MOOSA-MITHA, M. 2005. A Difference-Centred Alternative to Theorization of Children's Citizenship Rights. *Citizenship Studies,* 9**,** 369-388.

MORAN, T. & BLOCK, M. 2010. Barriers to participation of children with disabilities in youth sport. *TEACHING Exceptional Children,* 6.

MORAN-ELLIS, J. 2010. Reflections on the Sociology of Childhood in the UK. *Current Sociology***,** 186-205.

MORGAN, R. 2005. Finding what children say they want: Messages from children. *Representing Children,* 17**,** 180-189.

MORRIS, J. 1991. *Pride against Prejudice* Philadelphia, New York Publishers.

MORRIS, J. 2001a. Social exclusion and young disabled people with high levels of support needs. *Critical Social Policy,* 21.

MORRIS, J. 2001b. Social exclusion and young disabled people with high levels of support needs. *Critical Social Policy,* 21**,** 161-183.

MORRIS, J. 2003. Including all children: Finding out about the experiences of children with communication and/or cognitive impairments. *Children & Society,* 17**,** 337-348.

MORROW, V. 1999. Conceptualising Social Capital in Relation to the Well-Being of Children and Young People: A Critical Review. *The Sociological Review,* 47**,** 744-765.

MORROW, V. 2006. Understanding Gender Differences in Context: Implications for Young Children's Everyday Lives. *Children & Society,* 20**,** 92-104.

MUFTEE, M. 2015. Children's agency in resettlement: A study of Swedish cultural orientation programs in Kenya and Sudan. *Children's Geographies,* 13**,** 131-148.

MUKHERJI, P. & ALBON, D. 2010. *Research Methods in Early Childhood: An Introductory Guide,* London, Sage.

MULLIGAN, H., HALE, L., WHITEHEAD, L. & BAXTER, G. 2012. Barriers to physical activity for people with long-term neurological conditions: A review study. *Adapted Physical Activity Quarterly.*

MURCHISON, J. 2010. *Ethnography Essentials: Designing, conducting, and presenting your research,* San Francisco, John Wiley & Sons.

MURFITT, K., CROSBIE, J., ZAMMIT, J. & WILLIAMS, G. 2018. Employer Engagement in Disability Employment: A Missing Link for Small to Medium Organizations. A Review of Literature. *Journal of Vocational Rehabilitation,* 48**,** 417-431.

MURRAY, C. & GREENBERG, M. 2006. Examining the importance of social relationships and social contexts in the lives of children with high-incidence disabilities. *The Journal of Special Education,* 39**,** 220-233.

NEALE, B. 2002. Dialogues with children: Children, divorce and citizenship. *Childhood,* 9**,** 455-475.

NEALE, B. & FLOWERDEW, J. 2007. New structures, new agency: The dynamics of child-parent relationships after divorce. *International Journal of Children's Rights,* 15.

NIEUWENHUYS, O. 2008. Editorial: The ethics of children's rights. *Childhood: A Global Journal of Child Research,* 15**,** 4-11.

NIEUWENHUYS, O. 2009. Is there an Indian childhood? *Childhood,* 16**,** 147-153.

NIEUWENHUYS, O., HANSON, K. & VAN DAALEN, E. 2016. Children's Rights as Living RIghts: The Case of Street Children and a new Law in Yogyakarta, Indonesia *The International Journal of Children's Rights,* 24**,** 803-825.

NILHOM, C. & GÖRANSSON, K. 2017. What is meant by inclusion? An analysis of European and North American journal artices with high impact. *European Journal of Special Needs Education,* 32**,** 437-451.

NOBLE-CARR, D. 2007. *Engaging Children in Research on Sensitive Issues: A literature Review, Institute of Child Protection Studies*, ACU National for the ACT Department of Disability, Housing and Community Services

NORWICH, B. 2014. How does the capability approach address current issues in special education needs, disability and inclusive education field? *Journal of Research in Special Education Needs,* 14**,** 16-21.

NORWICH, B. & KELLY, N. 2004. Pupils' Views on Inclusion: Moderate Learning Difficulties and Bullying in Mainstream and Special Schools. *British Educational Research Journal,* 30**,** 43-65.

NUTBROWN, C. 1996. *Children's Rights and Early Education,* London, Chapman Press.

O'BRIEN, T. 2002. *Enabling Inclusion: blue skies…dark clouds,* London, Optimus.

O'CONNELL, K. 2016. Unequal Brains: Disability Discrimination Laws and Children with Challenging Behaviour. *Medical Law Review***,** 1-23.

O'DONNELL, S. & O'MAHONY, C. 2017. The UN Convention on the Rights of Persons with Disabilities: Exploring the synergy between Article 12 and Article 19. *In:* O'MAHONY, C. & QUINN, G. (eds.) *Disability Law and Policy: An Analysis of the UN Convention.* Dublin: Clarus Press.

O'KANE, C. 2008. The Development of Participatory Techniques: Facilitating Children's Views about Decisions Which Affect Them *In:* JAMES, A. & CHRISTENSEN, P. (eds.) *Researching Children: Perspectives and Practices.* Second ed. New York Routledge.

O'KANE, C. & THOMAS, N. 1998. The ethics of participatory research with children. *Children & Society,* 12**,** 336-348.

O'REILLY, D. 2005. Social Inclusion: A philosophical anthropology. *Politics* 25**,** 80-88.

O'REILLY, K. 2012. *Ethnographic methods*, Routledge.

OAKLEY, A. 1981. Interviewing Women: A contradiction in Terms. *In:* ROBERTS, H. (ed.) *Doing Feminist Research.* London: Routledge.

OAKLEY, A. 1994. Women and children first and last: Parallels and differences between women's and children's studies. *In:* MAYALL, B. (ed.) *Children's childhoods: Observed and experiences.* London, UK: Farmer Press.

ODOM, S., ZERCHER, C., LI, S., MARQUART, J., SANDALL, S. & BROWN, W. 2006. Social acceptance and rejection of preschool children with disabilities: a mixed-method analysis *Journal of Educational Psychology,* 98**,** 807-823.

OLIVER, M. 1983. *Social Work with Disabled People* Basingstoke, Macmillian

OLIVER, M. 1990. *The politics of disablement* UK, Macmillan.

OLIVER, M. 1992. Changing the social relations of research production. *Disability Handicap & Society,* 7**,** 101-114.

OLIVER, M. 1996. *Understanding disability: From theory to practice* London, Macmillan Press.

OLIVER, M. 2001. Images of the body from popular culture: engaging adolescent girls in critical inquiry. *Sport, Education and Society,* 6**,** 143-164.

OLIVER, M. 2009. *Understanding Disability: From Theory to Practice,* Hampshire, Palgrave Macmillian.

OLIVER, M. 2013. The social model of disability: Thirty years on. *Disability and Society,* 28**,** 1024-1026.

OLIVER, M. & BARNES, C. 2012. *The New Politics of Disablement* Tavistock, Palgrave-Macmillan.

OLKIN, R. 1999. *What psychotherapists should know about disability,* New York, Guildford.

ONTARIO, G. O. 1992. Substitute Decisions Act. *Legislative Assembly of Ontario*.

ORGANIZATION, W. H. 2001. *International Classification of Functioning, Disability and Health* [Online]. Available: https://www.who.int/standards/classifications/international-classification-of-functioning-disability-and-health [Accessed 2021].

ORIEL, K., MARCHESE, V., SHIRK, A., WAGNER, L., YOUNG, E. & MILLER, L. 2012. The psychosocial benefits of an inclusive community-based aquatics program. *Pediatric Physical Therapy,* 24**,** 361-367.

OSWELL, D. 2013. *The Agency of Children From Family to Global Human Rights,* Cambridge, Cambridge University Press.

OSWELL, D. 2016. Re-aligning children's agency and re-socialising children in childhood studies. *In:* ESSE, F., BAADER, M., BETZ, T. & HUNGERLAND, B. (eds.) *Reconceptualising agency and childhood: New perspectives in childhood studies.* London: Routledge.

OVERMARS-MARX, T., THOMÉSE, F., VERDONSCHOT, M. & MEININGER, H. 2014. Advancing social inclusion in the neighbourhood for people with an intellectual disability: an exploration of the literature. *Disability & society,* 29**,** 255-274.

OWENS, J. 2015. Exploring the critiques of the social model of disability: The transformative possibility of Arendt's notion of power.

PAPATHEODOROU, T. 2007. Difference, culture and diversity: Challenges, responsibilities and opportunities. *In:* MOYLES, J. (ed.) *Early years foundation: Meeting the challenge.* Maidenhead: Open University Press.

PARKLYN, H. & COVENEY, J. 2013. An exploration of the value of social interaction in boys' group for adolescents with muscular dystrophy. *Child, Care, Health and Development,* 39**,** 81-89.

PASCAL, C. & BERTRAM, T. 2009. Listening to young citizens: the struggle to make real a participatory paradigm in research with young children. *European Early Childhood Education Research Journal,* 17**,** 249-262.

PATEL, S. 2015. *Inclusion and exclusion in competitive sport. Socio-legal and regulatory aspects,* London Routledge.

PATTERSON, K. & HUGHES, B. 2000. Disabled Bodies. *In:* HANCOCK, P., HUGHES, B., JAGGER, E., PATERSON, K., RUSSEL, R., TULLE-WINTON, E. & TYLER, M. (eds.) *The body, culture and society* Buckingham: Open University Press.

PEERS, D. 2017. Cramping Our Style: Critical Disability Studies as Axiological Affinities. *Disability Studies Quarterly,* 37.

PENDLEBURY, S., HENDERSON, P. & JAMIESON, L. 2014. Unsettling notions of participation: A view from South Africa. *In:* TISDALL, K., GADDA, A. & BUTLER, U. (eds.) *Children and young people's participation and its transformative potential* Basingstoke: Palgrave Macmillan.

PENKETH, C. 2014. Invention and repair: Disability and education after the UK Coalition Government. *Disability & Society,* 29**,** 1486-1490.

PERCY-SMITH, B. 2006. From consultation to social learning in community participation with young people. *Children Youth and Enviroments,* 16**,** 153-179.

PERCY-SMITH, B. 2010. Councils, consultation and community: Rethinking the spaces for children and young people's participation. *Children's Geographies,* 8**,** 107-122.

PERCY-SMITH, B. 2018. Participation as Learning for Change in Everyday Spaces: Enhancing Meaning and Effectiveness Using Action Research *In:* COCKBURN, T. & BARALDI, C. (eds.) *Theorising Childhood: citizenship, rights and participation.* Palgrave Macmillan.

PERCY-SMITH, B. & THOMAS, N. 2010a. Conclusion: Emerging Themes and New Directions. *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice.* Abingdon: Routledge.

PERCY-SMITH, B. & THOMAS, N. 2010b. *A Handbook of Children and Young People's Participation,* London and New York, Routledge.

PETRENCHIK, T. 2008. Childhood Disability in the Context of Poverty. *CanChild Centre for Childhood Disability Research***,** 1-27.

PHAM, L. & MOLLA, T. 2019. Capital and capability: reimagining social justice in and through education. *Policy Futures in Education,* 17**,** 575-581.

PHELAN, S. & KINSELLA, E. 2013. Occupation and Identity: Perspectives of Children with Disabilities and Their Parents. *Journal of Occupational Science*.

PHILPIN, S., JORDAN, S. & WARRING, J. 2005. Giving people a voice: Reflections on conducting interviews with participants experiencing communication impairment. *Journal of Advanced Nursing,* 50**,** 299-306.

PICKERING, D. 2018. The Embodiment of Disabled Children and Young People's Voices About Participating in Recreational Activities: Shared Prespectives. *In:* RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies.* London: Palgrave Macmillan.

PIJL, S. & FROSTAD, P. 2010. Peer acceptance and self-concept of students with disabilities in regular education. *European Journal of Special Needs Education,* 25**,** 93-105.

PITONYAK, D. 2007. The Importance of Belonging.

POLE, C. J. & MORRISON, M. 2003. *Ethnography for education,* Buckingham, Open University Press.

PONIC, P. & FRISBY, W. 2010. Unpacking assumptions about inclusion in community-based health promotion: Perspectives of women living in poverty. *Qualitative Health Research,* 20**,** 1519-1531.

POTTER, C. & WHITTAKER, C. 2011. What does the 'voice of the child' mean for children with complex learning and communication impairment? *In:* JONES, P. & WALKER, G. (eds.) *Children's rights in practice.* London: Sage.

PRICE, P. & D'ELOIA, M. 2018. Sense of belonging: is inclusion the answer? *Sport in Society: Cultures, Commerce, Media, Politics,* 21**,** 91-105.

PRIESTLEY, M. 1998. Childhood, disability and disabled childhoods - Agendas for research. *Childhood - A Global Journal of Child Research,* 5**,** 207-223.

PRIESTLEY, M. 2003. Symposium on Disability and the Life Course: Introduction to the Symposium. *Disability Studies Quarterly,* 23.

PROUST, F. 2000. Introduction to De La Résistance. *Hypatia,* 15**,** 18-22.

PROUT, A. 2005. The Future of Childhood: Towards the Interdisciplinary Study of Children. *The future of childhood series.* London: Routledge.

PROUT, A. 2011. Taking a Step Away from Modernity: Reconsidering the New Sociology of Childhood. *Global Studies of Childhood,* 1.

PUFALL, P. & UNSWORTH, R. 2004. The imperative and the Process for Rethinking Childhood. *In:* PUFALL, P. & UNSWORTH, R. (eds.) *Rethinking Childhood* New Brunswick: Rutgers University Press.

PUNCH, S. 2002. Research with Children: The Same or Different from Research with Adults? *Childhood: A Global Journal of Child Research,* 9**,** 321-41.

PUNCH, S. 2012. Hidden struggles of fieldwork: Exploring the role and use of field diaries. *Emotion, space and society,* 5**,** 86-93.

PUNCH, S. 2016. Exploring Children's Agency across Majority and Minority World Contexts *In:* WYN, J. & CAHILL, H. (eds.) *Handbook of Children and Youth Studies* Singapore: Springer.

PURDUE, K. 2009. Barriers to and facilitators to inclusion for children with disabilities in early childhood education. *Contemporary Issues in Early Childhood,* 10**,** 133-143.

QI, J. & HA, A. 2012. Inclusion in physical education: a review of literature. *International Journal of Disability, Development and Education,* 59**,** 257-281.

QUENNERSTEDT, A. 2010. Children, But Not Really Humans? Critical Reflections on the Hampering Effect of the "3 p's". *The International Journal of Children's Rights,* 18**,** 619-635.

QUINN, G. 2010. Personhood & legal capacity: Perspectives on the paradigm shift of Article 12 CRPD. *HPOD Conference.* Boston.

QUINN, G. & DEGENER, T. 2002. *Human Rights and Disability,* New York and Geneva, United Nations.

QVORTRUP, J. 1994. Childhood Matters: Social theory, practice and politics *In:* QVORTRUP, J., BARDY, M., SGRITTA, G. & WINTERSBERGER, H. (eds.) *Childhood Matters: Social theory, practice and politics* Brookfield: Avebury.

QVORTRUP, J. 2008. Microanalysis of Childhood. *In:* JAMES, A. & CHRISTENSEN, P. (eds.) *Research with Children: Perspectives and Practices.* Second ed. New York: Routledge.

RABIEE, P., SLOPER, P. & BERESFORD, B. 2005. Doing research with children and young people who do not use speech for communication. *Children & Society,* 19**,** 385-396.

RAGHAVENDRA, P., OLSSON, C., SAMPSON, J., MCINERNEY, R. & CONNELL, T. 2012. School participation and social networks of children with complex communication needs, physical disabilities, and typically developing peers. *Augmentative and Alternative Communication,* 28**,** 33-43.

RAGHAVENDRA, P., VIRGO, R., OLSSON, C., CONNELL, T. & LANE, A. 2011. Activity participation of children with complex communication needs, physical disabilities and typically-developing peers   Developmental Neurorehabilitation,.

RAVENSCROFT, J., DAVIS, J., BELGIN, M. & WAZNI, K. 2019. Factors that influence elementary school teachers' attitudes towards inclusion of visually impaired children in Turkey. *Disability and Society,* 34**,** 629-656.

READ, J., CLEMENTS, L. & RUEBAIN, D. 2006. *Disabled Children and the Law: Research and Goods Practice.,* London, Jessica Kingsley Publisher.

RECCHIA, S. & LEE, Y. 2004. At the crossroads: overcoming concers to envision possibilities for toddlers in inclusive child care. *Journal of Research in Childhood Education,* 19**,** 175-188.

REEVE, D. 2004. Psycho-emotional dimensions of disability and the social model. *In:* BARNES, C. & MERCER, G. (eds.) *Implementing the social model of disability: theory and research* Leeds: The Disability Press.

REUKER, S., RISCHKE, A., KÄMPFE, A., SCHMITZ, B., TEUBERT, H., THISSEN, A. & WIETHÄUPER, H. 2016. Inclusion in physical education. An overview of international research results from 2005 to 2014. *Sportwissenschaft,* 46**,** 88-101.

REYNAERT, D., VANDENHOLE, W., LEMBRECHTS, S. & DESMET, E. 2015. Conclusions: Toward a Field of Critical Children's Rights Studies *In:* VANDENHOLE, W., DESMET, E., REYNAERT, D. & LEMBRECHTS, S. (eds.) *Routledge International Handbook of Children's Rights Studies.* Abingdon: Routledge.

RHEAMS, T. & BAIN, S. 2005. Social interaction interventions in an inclusive era: attitudes of teachers in early childhood self-contained and inclusive settings. *Psychology in the Schools,* 42**,** 53-63.

RICHARDS, S. 2018. Policy, Provision and the Historical Context. *In:* BOGGIS, A. (ed.) *Dis/abled Childhoods? A transdisciplinary Approach* Palgrave Macmillan.

RICHARDS, S. & CLARK, J. 2018. Research with Disabled Children: Traving the Past, Present and Future *In:* BOGGIS, A. (ed.) *Dis/ Abled Childhoods?: A Transdisiciplinary Approach* Ipswich, UK: Palgrave Macmillan.

RICHARDS, S., CLARK, J. & BOGGIS, A. 2015. *Ethical research with children: Untold narratives and taboos,* London, Palgrave Macmillan.

RICHARDS, S., CLARK, J. & BOGGIS, A. 2016. *Ethical research with children: Untold narratives and taboos,* London, Palgrave Macmillan.

RIDDELL, S. 2009. Social justice, equality and inclusion. *Scottish education Discourse,* 30**,** 283-297.

RIEFFE, C. & WIEFFERINK, C. 2017. Happy faces, sad faces: Emotion understanding in toddlers and preschoolers with language impairments *Research in Developmental Disabilities,* 62**,** 40-49.

RIMMER, J. 2005. The conspicuous absence of people with disabilities in public fitness and recreation facilities: Lack of interest of lack of access? *American Journal of Health Promotion*.

RIMMER, J., RILEY, B. & WANG, E. 2004. Physical activity participation among persons with disabilities: Barriers and facilitators. *American Journal of Preventive Medicine,* 26**,** 419-425.

RIMMER, J. & ROWLAND, J. 2008. Physical activity for youth with disabilities: A critical need in an underserved populaiton *Developmental Neurorehabilitation,* 11.

RIMMER, J., WANG, E., YAMAKI, K. & DAVIS, B. 2010. Documenting disparities in obesity and disability. *FOCUS Technical Bried,* 24.

RIOUX, M. 2014. Disability rights in education. *In:* FLORIAN, L. (ed.) *The Sage handbook of special education.* 2 ed. London: Sage Publications Ltd.

ROBERTS, H. 2008. Listening to children: And hearing them *In:* CHRISTENSEN, P. & JAMES, A. L. (eds.) *Research with Children (Second Edition).* London: Falmer.

ROBSON, C. 2011. Real world research: A resource for social-scientists and practitioner-researchers. Third ed. Oxford: Blackwell Publishing.

ROBSON, E., BELL, S. & KLOCKER, N. 2007. Conceptualising agency in the lives and actions of rural young people. *In:* PANELLI, R., PUNCH, S. & ROBSON, E. (eds.) *Global perspectives on rural childhood and youth: young rural lives.*

ROGERS, A., CASEY, M., EKERT, J. & HOLLAND, J. 2005. Interviewing children using an interpretative poetics. *In:* GREENE, S. & HOGAN, D. (eds.) *Researching children's experience: Approaches and methods.* London: Sage.

ROSE, G. 1997. Situating Knowledges: Positionality, Reflexxivities and Other Tactics. *Progress in Human Geography,* 21**,** 305-320.

ROSENQVIST, J. 2005. Some themes within the realm of research on special education *In:* GUSTAVSSON, A., SANDVIN, J., TRAUSTADOTTIR, R. & TØSSEBRO, J. (eds.) *Resistance, Reflection and Change: Nordic Disability Research.* Lund: Studentlitteratur.

ROTHERAM-FULLER, E., KASARI, C., CHAMBERLAIN, B. & LOCKE, J. 2010. Social involvement of children with autism spectrum disorders in elementary school classroms. *Journal of Child Psychology and Psychiatry,* 51**,** 1227-1234.

ROULSTONE, A. 2000. Disability, dependency and the new deal for disabled people. *Disability & Society,* 15**,** 427-443.

RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. 2018a. Introduction. *In:* RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies.* Sheffield: Palgrave Macmillan.

RUNSWICK-COLE, K., CURRAN, T. & LIDDIARD, K. 2018b. *The Palgrave handbook of disabled children's childhood studies*, London : Palgrave Macmillan UK : Imprint: Palgrave Macmillan.

RUNSWICK-COLE, K. & GOODLEY, D. 2016. Understanding this thing called Autism. *In:* RUNSWICK-COLE, K., MALLETT, R. & TIMIMI, S. (eds.) *Re-Thinking Autism: Diagnosis, Identity and Equality.* London: Jessica Kingsley Publishers.

SAMMAN, E. & SANTOS, M. 2009. *Agency and Empowerment: A review of concepts, indicators and empirical evidence* [Online]. Available: http://www.ophi.org.uk/wp-content/uploads/OPHI-RP-10a.pdf [Accessed 2018].

SAPON-SHEVIN, M. 2003. Inclusion: A matter of social justice *Educational Leadership,* 61**,** 25-28.

SAYERS, D. 2018. Rights Not Needs: Changing the Legal Model for Special Education Needs (SEN). *In:* LIDDIARD, K. & RUNSWICK-COLE, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies.* Palgrave Macmillan.

SCHEER, A. 2017. Maneuvering the Stormy Waters of Ethnography in an Inner-City School: Reflections from the Field *In:* CASTRO, I., SWAUGER, M. & HARGER, B. (eds.) *Researching Children and Youth: Methodological Issues, Strategies, and Innovations* Emerald Publishing Limited.

SCHILLMEIER, M. 2008. Time-spaces of In/dependence and Dis/ability. *Time & Society,* 17.

SCHLEIEN, S., MILLER, K., WALTON, G. & PRUETT, S. 2014. Parents perspectives of barriers to child participation in recreational activities. *Therapeutic Recreastion Journal,* 48**,** 61-73.

SCHNOOR, O. 2012. Early childhood studies as vocal studies: Examining the social practices of 'giving voice to children's voices' in a crèche. *Childhood,* 20**,** 458-471.

SCHWARTZMAN, J. 1993. *Ethnography in Organizations,* London, Sage.

SCOTT, J. 1990. *Domination and the Arts of Resistance: Hidden Transcripts,* New Haven and London, Yale University Press.

SEIDMAN, I. 2006. *Interviewing as Qualitative Research: A Guide for Researchers in Education and the Social Sciences,* New York and London, Teachers College, Columbia University.

SHAH, S. & DIWAN, S. 2019. Physical Fitness, Physical Activity and Academic Achievement in School Going Children: A Narrative Review. *International Journal of Physiotherapy and Research,* 7.

SHAKESPEARE, T. 2006a. *Disability rights and wrongs,* London ; New York New York, London ; New York : Routledge.

SHAKESPEARE, T. 2006b. The social model of disability. *In:* DAVIS, L. (ed.) *The disabilities studies reader.* 2nd ed. New York: Routledge.

SHAKESPEARE, T. 2013. The social model of disability. *In:* DAVIS, L. J. (ed.) *The Disability Studies Rwader.* fourth ed. New York, NY: Routledge.

SHAKESPEARE, T. 2014. *Disability rights and wrongs revisited,* London, Routledge.

SHAKESPEARE, T. & WATSON, N. 2001. The social model of disability: An outdated ideology? Exploring theories and expanding methodologies. *Research in Social Science and Disability***,** 9-28.

SHAPIRO, D. R. & MARTIN, J. J. 2010. Athletic identity, affect, and peer relations in youth athletes with physical disabilities. *Disability and Health Journal,* 3**,** 79-85.

SHAPIRO, J. P. 1993. *No pity: People with disabilities forging a new civil rights movement,* New Yrok, Random House.

SHEIR, H. 2001. Pathways to participation: openings, opportunities and obligations. *Children & Society,* 15**,** 107-117.

SHERMAN HEYL, B. 2001. Ethnographic Interviewing. *In:* SEALE, C. (ed.) *Researching Society and Culture.* London: Sage.

SHERRY, M. 2016. A sociology of impairment. *Disability & Society,* 31**,** 729-744.

SHIELDS, N. & SYNNOT, A. 2016. Perceived barriers and facilitators to participation in physical activity for children with disability: a qualitative study. *BMC Pediatrics,* 16.

SHIELDS, N., SYNNOT, A. & BARR, M. 2012. Percieved barriers and facilitators to physical activity for children with disability: a systematic review. *British Journal of Sports Medicine,* 46**,** 989-997.

SHIKAKO-THOMAS, K., DAHAN-OLIEL, N. E., SHEVELL, M., LAW, M., BIRNBAUM, R., ROSENBAUM, P., POULIN, C. & MAJNEMER, A. 2012. Play and Be Happy? Leisure Participation and Quality of Life in School-Aged Children with Cerebral Palsy. *International Journal of Pediatrics*.

SHIRAZIPOUR, C., EVANS, M., CADDICK, N., SMITH, B., AIKEN, A., GINIS, K. & LATIMER-CHEUNG, A. 2017. Quality participation experiences in the physical activity domain: Perspectives of veterans with a physical disability. *Psychology of Sport and Exercise,* 29**,** 40-50.

SI, Q., WANG, L., LIU, H., LOPRINZI, P. & CARDINAL, B. 2017. A Systematic Review of Physical Activity among People with Disabilities in Mainland China: From 1992 to 2013. *International Journal of Sports and Physical Education,* 3**,** 17-25.

SIMMONS, B. & WATSON, D. 2014. *The PMLD Ambiguity: Articulating the life-worlds of children with profound and multiple learning disabilities,* London, UK, Karnac Books.

SIMMONS, H. & USHER, R. 2002. *Situated Ethics in Educational Research,* New York, Routledge.

SIMON, R. 2000. Internalism and Internal Values in Sport. *Journal of the Philosophy of Sport,* 27**,** 1-16.

SINCLAIR, R. 2004. Participation in Practice: Making It Meaningful, Effective and Sustainable. *Children & Society,* 18**,** 106-118.

SINCLAIR, R. & FRANKLIN, A. 2000. *Young people's participation, quality protects research briefing no.3,* London, Department of Health.

SLATER, J. 2015. *Youth and Disability: A Challenge to Mr Reasonable,* Burlington, Ashgate.

SLEE, R. 2006. Teacher Education, Government and Inclusive Schooling: The Politics of the Faustian Waltz. *In:* ALLEN, J. (ed.) *Inclusion, Participation and Democracy: What is the Purpose?* New York: Kluwer Academic.

SLEE, R. 2008. Beyond special and regular schooling? An inclusive education reform agenda. *International Studies in Sociology of Education,* 18**,** 99-116.

SLEE, R. & GRAHAM, L. 2008. An illusory interiority: Interrogating the discourse/s of inclusion. *Educational Philosophy and Theory,* 40**,** 277-293.

SMART, C. 2002. From children's shoes to children's voices. *Family court Review,* 40**,** 307-319.

SMART, C. 2007. *Personal life,* Cambridge, Policy Press.

SMART, J. 2001. *Disability, society, and the individual,* Gaithersburg, MD: Aspen

SMART, J. F. 2009. The Power of Models of Disability. *Journal of Rehabilitation,* 75**,** 3-11.

SMETS, M., BURKE, G., JARZABKOWSKI, P. & SPEE, P. 2014. Charting new territory for organizational ethnography: Insights from a team-based video ethnography. *Journal of Organizational Ethnography,* 3.

SMETS, M., MORRIS, T. & GREENWOOD, R. 2012. From practice to field: A multi-level model of practice-driven institutional change. *Academy of Management Journal*

SMITH, B. 2013a. Disability, Sport, and Men's Narratives of Health: A Qualitative Study. *Health Psychology,* 32**,** 110-119.

SMITH, B. 2013b. Sporting Spinal Cord Injuries, Social Relations, and Rehabilitation Narratives: An Ethnographic Creative Non-Fiction of Becoming Disabled Through Sport. *Sociology of Sport Journal,* 30**,** 132-152.

SMITH, B. & BUNDON, A. 2018. Disability Models: Explaining and Understanding Disability Sport in Different Ways. London: Palgrave Macmillan UK.

SMITH, B. & SPARKES, A. 2008. Changing Bodies, Changing Narratives and the Consequences of Tellability: A Case Study of Becoming Disabled Through Sport. *Sociology of Health & Illness,* 30**,** 217-236.

SMITH, B. M. & PERRIER, M. J. 2014a. Disability, sport, and impaired bodies: A critical approach. *In:* SCHINKE, R. & MCGANNON, K. R. (eds.) *The psychology of subculture in sport and physical activity: A critical approach.* London: Psychology Press.

SMITH, B. M. & PERRIER, M. J. 2014b. Understanding disability, sport and exercise: Models and narrative inquiry. *In:* EKLUND, R. C. & TENENBAUM, G. (eds.) *Encyclopedia of sport and exercise phychology.* CA: Sage.

SMITH, K. 2012. Producing governable subjects: Images of childhood old and new. *Childhood,* 19**,** 24-37.

SMYTH, A. & HOLIAN, R. 2008. Credibility Issues in Research from within the Organisations *In:* SIKES, P. & POTTS, A. (eds.) *Researching education from the inside.* New York: Taylor & Francis

SNOWDON, A. 2012. *Strengthening Communities for Canadian Children with Disabilities,* Toronto, The Sandbox Project.

SORIN, R. & GALLOWAY, G. 2006. Construct of childhood: Constructs of self. *Children Australia,* 31**,** 12-21.

SOTIRIADOU, P. & WICKER, P. 2014. Examining the participation patterns of an ageing population with disabilities in Australia. *Sport Management Review,* 17**,** 35-48.

SPENCE, J., HOLT, N., SPRYSAK, C., SPENCER-CAVALIERE, N. & CAULFIELD, T. 2012. Non-refunable Tax Credits Are an Inequitable Policy Instrument for Promoting Physical Activity Among Canadian Children *Canadian Journal of Public Heath*

SPENCER-CAVALIERE, N. & KINGSLEY, B. 2015. The exclusionary practices of youth sport. *Social Inclusion,* 3**,** 24-38.

SPENCER-CAVALIERE, N., THAI, J. & KINGSLEY, B. 2017. A Part of and Apart from Sport: Practitioners' Experiences Coaching Segregated Youth Sport. *Cogitatio,* 5**,** 120-129.

SPENCER-CAVALIERE, N. & WATKINSON, E. J. 2010. Inclusion Understood from the Perspectives of Children with Disability. *Adapted Physical Activity Quarterly,* 27**,** 275-293.

SPYROU, S. 2011. The limits of children's voices: From authenticity to critical, reflexive representation. *Childhood,* 18.

SPYROU, S. 2018. The Production of Children's Voices. *In:* THOMAS, N., SPYROU, S., CURTIS, P. & TWUM-DANSO IMOH, A. (eds.) *Disclosing Childhoods: Research and knowledge production for a critical childhood studies.* London: Palgrave Macmillan.

STALKER, K. 2012. Researching the lives of disabled children and young people. *Children & Society,* 26**,** 173-180.

STAMMERS, N. 2012. Children's rights and social movements: reflection from a cognate field. *Reconceptualizing Children's Rights in International Development: Living Rights, Social Justice, Translations***,** 275-293.

STANLEY, L. & WISE, S. 1993. *Breaking out: Feminist Consciousness and Feminist Research,* London, Routledge and Kegan Paul.

STEIN, M. & LORD, J. 2010. Monitoring the Convention on the Rights of Persons with Disabilities: Innovations, lost opportunities and future potential. *Human Rights Quarterly,* 32**,** 689-728.

STEIN, M. & STEIN, P. 2007. Beyond Disability Civil Rights. *Hastings Law Journal,* 58.

STEVENSON, S. 2008. (M)Othering and Autism: Maternal Rhetorics of Self-Revision. *In:* O'STEEN, M. (ed.) *Autism and Representation.* New York: Routledge.

STONE, E. & PRIESTLEY, M. 1996. Parasites, pawns and partners: disability research and the role of non-disabled researchers. *British Journal of Sociology,* 47**,** 699-716.

STONES, R. 2005. *Structuration Theory,* Basingstoke, Palgrave Macmillan.

SUCH, E. & WALKER, R. 2004. Being responsible and responsible beings: Children's understanding of responsibility. *Children & Society,* 18**,** 231-242.

SUITS, B. 2007. The elements of sport. *In:* MORGAN, W. (ed.) *Ethics in sport.* Champaign, IL: Human Kinetics.

SUSINOS, T. 2007. 'Tel me in Your Own Words': Disabling Barries and Social Exclusion in Young Persons. *Disability & Society,* 22**,** 117-127.

SUSMAN, J. 1994. Disability, stigma and deviance. *Social Science and Medicine,* 38**,** 15-22.

SWARTZ, D. 1997. *Culture and Power: The Sociology of Pierre Bourdieu,* Chicago, The University of Chicago Press.

TAJFEL, H. & TURNER, J. 1979. The social psychology of intergroup relation *In:* AUSTIN, W. & WORCHEL, S. (eds.) *The social psychology of intergroup relation* Monterey: CA: Brools/Cole.

TALLACK, J. & NEAUM, S. 2002. *Good Practice in Implementing the Pre-School Curriculum,* Cheltenham, Nelson Thorne's.

TALLANT, L. 2015. Framing Young Children's Humour and Practitioner Responses to it Using a Bakhtinian Carnivalesque Lens. *International Journal of Early Childhood,* 47**,** 251-266.

TARDIF-WILLAMS, C., TRENT-KRATZ, M. & DONATO, K. 2009. Rights and Education. *In:* OWEN, F. & GRIFFITHS, D. (eds.) *Challenges to the human rights of people with intellectual disabilities.* London: Jessica Kingsley Publishers.

TARDIF-WILLIAMS, D., TRENT-KRATZ, M. & DONATO, K. 2009. *In:* OWEN, F. & GRIFFITHS, D. (eds.) *Challenges to the human rights of people with intellectual disabilities.* London: Jessica Kingsley Publishers.

TAUB, D. & GREER, K. 2000. Physical activity as a normalizing experience for school age children with physical disabilities. Implications for legitimation of social identity and enhancement of social ties. *Journal of Sport & Social Issues,* 24**,** 395-414.

TAYLOR, N., TAPP, P. & HENAGHAN, M. 2007. Respecting Children's Participation in Family Law Proceedings. *The International Journal of Children's Rights,* 15**,** 61-82.

TEACHMAN, G. 2016. *Interrogating inclusion: Critical research with disabled youth who use augmentative and alternative communication.* Doctor of Philosophy University of Toronto.

TEACHMAN, G., GLADSTONE, B. & FACCA, D. 2020. Working the Limits of "Giving Voice" to Children: A Critical Conceptual Review. *International Journal of Qualitative Methods,* 19**,** 1-10.

TEACHMAN, G., MCDONOUGH, P., MACARTHUR, C. & GIBSON, B. 2018. A critical dialogical methodology for conducting research with disabled youth who use augmentative and alternative communication. *Qualitative Inquiry,* 21**,** 35-44.

THACKRAY, L. 2018. Anonymity, Confidentiality and Informed Consent: Exploring Ethical Quandaries and Dilemmas in Research with and About Disabled Children's Childhoods. *In:* CURRAN, T., RUNSWICK-COLE, K. & LIDDIARD, K. (eds.) *The Palgrave Handbook of Disabled Children's Childhood Studies.* London: Palgrave Macmillan.

THOMAS, C. 1999. *Female forms: experiencing and understanding disability* Buckingham, Open University Press.

THOMAS, C. 2004. Rescuing a social relational understanding of disability. *Scandinavian Journal of Disability Research,* 6**,** 22-36.

THOMAS, C. 2007a. *Sociologies of Disability and Illness,* London, Palgrave.

THOMAS, C. 2012a. Theorising disability and chronic illness: Where next for perspectives in medical sociology? *Social Theory & Health,* 10**,** 209-228.

THOMAS, C. 2014. Disability and impairment *In:* SWAIN, J., BARNES, C. & THOMAS, C. (eds.) *Disabling barriers - Enabling enviroments.* 3rd ed. London: Sage.

THOMAS, G. 2013. A Review of Thinking and Research about Inclusive Education Policy, with Suggestions for a New Kind of Inclusive Thinking. *British Educational Research Journal,* 39**,** 473-490.

THOMAS, N. 2007b. Towards a Theory of Children's Participation. *The International Journal of Children's Rights,* 15**,** 199-218.

THOMAS, N. 2012b. Love, Rights and Solidarity: Studying Children's Participation Using Honneth's Theory of Recognition. *Childhood: A Global Journal of Child Research,* 19**,** 453-466.

THOMAS, N. & O'KANE, C. 1998. The Ethics of Participatory Research with Children. *Children & Society,* 12**,** 336-348.

THOMAS, N. & SMITH, A. 2009. *Disability sport, and society: an introduction* New York, Routledge.

THOMAS, P. & STOECKLIN, D. 2018. Recognition and Capability: A New Way to Understand How Children Can Achieve Their Rights? *In:* BARALDI, C. & COCKBURN, T. (eds.) *Theorising Childhood.* Palgrave Macmillan.

THOMPSON, R. 1997. Feminist Theory, the Body, and the Disabled Figure. *In:* DAVIS, L. (ed.) *The Disability Studies Reader.* New York: Routledge.

THOMSON, F. 2007. Are Methodologies for Children Keeping them in Their Place? *Children's Geographies,* 5**,** 207-218.

THORNICROFT, G., ROSE, D., KASSAM, A. & SARTORIUS, N. 2007. Stigma: Ignorance, prejudice or discrimination *The British Journal of Psychiatry,* 190**,** 192-193.

TISDALL, E. K. M. 2015a. *Addressing the Challenges of Children and Young People's Participation: Considering Time and Space*, Oxford University Press.

TISDALL, E. K. M. 2015b. Children and Young People's Participation:A critical consideration of Article 12. *In:* VANDENHOLE, W., DESMET, E., REYNAERT, D. & LEMBRECHTS, S. (eds.). Routledge.

TISDALL, E. K. M. 2017. Conceptualising children and young people's participation: examining vulnerability, social accountability and co-production. *The International Journal of Human Rights,* 21**,** 59-75.

TISDALL, E. K. M. & DAVIS, J. 2004. Making a difference? Bringing Children's and Young People's Views into Policy-Making. *Children & Society,* 18.

TISDALL, E. K. M., DAVIS, J. & GALLAGHER, M. 2009a. Introduction. *In:* TISDALL, E. K. M., DAVIS, J. & GALLAGHER, M. (eds.) *Researching with Children & Young People: Research Design, Methods, and Analysis* SAGE.

TISDALL, E. K. M., DAVIS, J. & GALLAGHER, M. 2009b. *Researching with Children and Young People: Research Design, Methods and Analysis,* London, SAGE Publications Ltd.

TISDALL, K. 2009. Dissemination - or Engagement? *In:* TISDALL, E. K. M., DAVIS, J. & GALLAGHER, M. (eds.) *Researching with Children and Young People: Research Design, Methods and Analysis.* London: SAGE.

TISDALL, K. 2012. Taking forward children and young people's participation. *In:* HILL, M., HEAD, B., LOCKYER, A., REID, B. & TAYLOR, R. (eds.) *Children's services: working together.* Harlow: Pearson.

TISDALL, K. 2014. Children Should be Seen and Heard? Children and Young People's Participation in the UK. *Children and Young People's Participation and Its Transformative Potential.* London: Palgrave Macmillan

TISDALL, K., GADDA, A. & BUTLER, U. 2014. Introduction: Children and young people's participation in collective decision-making *In:* TISDALL, K., GADDA, A. & BUTLER, U. (eds.) *Children and Young People's Participation and Its Transformative Potential.* Basingstoke: Palgrave Macmillan.

TISDALL, K. & PUNCH, S. 2012. Not so 'new'? Looking critically at childhood studies. *Children's Geographies,* 10**,** 249-264.

TITCHKOSKY, T. 2001. Disability: A Rose by Any Other Name?"People-First" Language in Canadian Society. *The Canadian review of sociology,* 38**,** 125-140.

TITCHKOSKY, T. 2011. *The question of access: Disability, space, meaning*, University of Toronto Press.

TOPOREK, R. & WILLIAMS, R. 2006. Ethics and professional issues related to the practice of social justice in counseling psychology. *In:* TOPOREK, R., GERSTEIN, L., FOUAD, N., ROYSIRCAR, G. & ISRAEL, T. (eds.) *Handbook for social justice in counseling psychology: Leadership, vision, and action.* Thousand Oaks, :CA: Sage.

TØSSEBRO, J. 2004. *Exploring the living conditions of disabled people,* Lund: Sweden Studentlitteratur.

TOWNSEND, R., SMITH, B. & CUSHION, C. 2015. Disability sports coaching: Towards a critical understanding. *Sport Coaching Review,* 4**,** 80-98.

TOWNSEND, R. C., HUNTLEY, T., CUSHION, C. J. & FITZGERALD, H. 2020. 'It's not about disability, I want to win as many medals as possible': The social construction of disability in high-performance coaching. *International Review for the Sociology of Sport,* 55**,** 344-360.

TRAUSTADOTTIR, R. & EGILSON, S. 2009. Participation of Students with Physical Disabilities in the School Enviroment. *The American Journal of Occupational Therapy,* 63**,** 264-272.

TRAUSTADOTTIR, R. & SMITH, E. 2015. Childhood Disability, Identity and the Body. *In:* TRAUSTADOTTIR, R., YTTERHUS, B., EGILSON, S. & BERG, B. (eds.) *Childhood and Disability in the Nordic Countries: Being, Becoming, Belonging.* Basingstoke, Hampshire: England: Palgrave Macmillan.

TRESEDER, P. 1997. *Empowering Children and Young People,* London, Children's Rights Office and Save the Children

TRUSCOTT, J., GRAHAM, A. & POWELL, M. 2019. Ethical considerations in participatory research with young children *In:* ECKHOFF, A. (ed.) *Participatory Research with Young Children* Cham: Springer.

TUDGE, J. & HOGAN, D. 2005. An ecological approach to observations of children's everyday lives. *In:* GREENE, S. & HOGAN, D. (eds.) *Researching children's experiences: Approach and methods.* London: Sage.

ULLENHAG, A., ALMQVIST, L., GRANLUND, M. & KRUMLINDE-SUNDHOLM, L. 2012a. Cultural validity of the Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children (CAPE/PAC). *Scandinavian Journal of Occupational Therapy,* 19**,** 428-438.

ULLENHAG, A., BULT, M., NYQUIST, A., KETELAAR, M., JAHNSEN, R., KRUMLINDE-SUNDHOLM, L., ALMQVIST, L. & GRANLUND, M. 2012b. An international comparison of patterns of participation in leisure activities for children with and without disabilities in Sweden, Norway and the Netherlands. *Developmental Neurorehabilitation,* 15**,** 369-385.

ULLENHAG, A., BULT, M., NYQUIST, A., KETELAAR, M., JAHNSEN, R., KRUMLINDESUNDHOLM, L. & GRANLUNG, M. 2012c. An international comparison of patterns of participation in leisure activities for children with and without disabilities in Sweden, Norway and the Netherlands. *Developmental Neurorehabilitation,* 15**,** 369-385.

UN 2012. United Nations Committee on the Rights of the Child: Consideration of reports submitted by States parties under article 44 of the Convention: Concluding observations: Canada.

UN 2016. Leaving no one behind: the imperative of inclusive development. *United Nations: Economic & Social Affairs*.

UNCRC. 1989. *UN Committee on the Rights of the Child: Convention on the Rights of the Child. Office of the United Nations High Commissioner for Human Rights* [Online]. United Nations. [Accessed].

UNCRC 2009. General comment No.12 (2009): The right of the child to be heard.

UNCRPD. 2007. *UN General Assembly: Convention on the Rights of Persons with Disabilities* [Online]. UN General Assembly. Available: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/convention-on-the-rights-of-persons-with-disabilities-2.html [Accessed 2021].

UNESCO 1994. The Salamanca Statement and Framework for Action on Special Needs Education: World Conference on Special Needs Education: Access and Quality. *United Nations Education, Scientific and Cultural Organization.*

UNESCO 2000. Dakar Framework for Action, Education for All. *UNESCO, Paris.*

UNICEF 2003. The State of the World's Children.

VALENTINE, K. 2011. Accounting for Agency. *Children & Society,* 25**,** 247-358.

VALEO, A. & BUNCH, G. 2004. Student Attitudes Toward Peers with Disabilities in Inclusive and Special Education Schools. *Disability & Society,* 19**,** 456-474.

VALLI, L., COOPER, D. & FRANKES, L. 1997. Professional Development Schools and Equity: A Critical Analysis of Rhetoric and Research. *Review of Research in Education,* 22**,** 251-304.

VALSINER, J. 1998. *The guided mind: A sociogentic approach to personality,* Cambridge, Harvard University Press.

VAN ASWEGEN, J. & SHEVLIN, M. 2019. Disabling discourses and ableist assumptions: Reimagining social justice through education for disabled people through a critical discourse analysis approach. *Policy Futures in Education,* 17**,** 634-656.

VAN DEN HOONAARD, W. 2001. Is Research-Ethics Review a Moral Panic? *Canadian Review of Sociology,* 38**,** 19-36.

VAN DUIJLN, S. 2020. Everywhere and nowhere at once: the challenges of following in multi-sited ethnography. *Journal of Organizational Ethnography,* 9.

VAN MAANEN, J. 1988. *Tales of the Field,* Chicago, Chicago University Press.

VANDENBROECK, M. & BOUVERNE-DE BIE, M. 2006. Children's Agency and Educational Norms: A tensed negoitation. *Childhood,* 13**,** 127-143.

VANDENHOLE, W. 2012. Localizing the Human Rights of Children. *In:* LIEBEL, M. (ed.) *Children's Rights from Below.* Basingstoke: Palgrave Macmillan.

VANDERBROEK, M. & BOUVERNE-DE BIE, M. 2006. Children's Agency and Educational Norms: A tensed negoitation. *Childhood,* 13.

VEALE, A. 2005. 'Creative methodologies and thier use in a participatory research project in Rwanda'. *In:* GREENE & HOGAN (eds.) *Researching Children's Experiences.* London SAGE Publishers

VEHMAS, S. & WATSON, N. 2014. Moral wrongs, disadvantages, and disability: A critique of critical disability studies. *Disability & Society,* 29**,** 638-650.

VINE, T., CLARK, J., RICHARDS, S. & WEIR, D. 2018. Introduction. *In:* VINE, T., CLARK, J., RICHARDS, S. & WEIR, D. (eds.) *Ethnographic Research and Analysis.* London: Palgrave Macmilan.

VOBRUBA, G. 2000. Actors in processes of inclusion and exclusion: Towards a dynamic approach. *Social Policy & Administration,* 34**,** 601-613.

WADDINGTON, L. & DILLER, M. 2000. Tensions and coherence in disability policy: The uneasy relationship between social welfare and civil rights models of disability in American, European and international employment law. *International Disability Law and Policy Symposium.*

WAKSLER, F. 1991. Studying the social worlds of children. *Sociological readings.* London: Falmer Press.

WALDSCHMIDT, A. 2019. Why critical disability studies needs a cultural model of dis/ability. *In:* ELLIS, K., GARLAND-THOMSON, R., KENT, M. & ROBERTSON,

R. (eds.) *Interdisciplinary approaches to disability: Looking towards the future.* Routledge.

WALKER, J. 2013. The United Nations convention on the rights of persons with disabilities: an overview. Ottawa: Library of Parliment.

WALL, J. 2008. Human Rights in Light of Childhood. *The International Journal of Children's Rights,* 16**,** 523-543.

WALL, J. 2016. *Children's rights: Today's global challenge,* Lanham, Boulder, Rowman & Littlefield.

WALL, L. 2010. *Ethics in Light of Childhood,* Washington, Georgetown University Press.

WANG, L. 2019. Perspectives of students with special needs on inclusion in general physical education: A social-relational model of disability. *Adapted Physical Activity Quarterly,* 36**,** 242-263.

WARMING, H. 2005. Participant Observation: A Way to Learn About Children's Perspectives. *In:* CLARK, A., KJ ØRHOLT, A. T. & MOSS, P. (eds.) *Beyond Listening: Children's Perspectives on Early Childhood Services.* Bristol: The Policy Press.

WARMING, H. 2011. Getting under their skins? Accessing young children's perspectives through ethnographic fieldwork. *Childhood,* 18**,** 39-53.

WARMING, H. 2017. Trust and power dynamics in shaping of children's lived citizenship and participation in globalised societies. *Open Journal of Social Sciences*

WARNOCK, M. 2006. Introduction. *In:* FARRELL, M. (ed.) *Celebrating the special school.* London: Routledge.

WATSON, K. 2017. *Inside the 'Inclusive' Early Childhood Classroom: The Power of the 'Normal',* New York, Peter Lang.

WATSON, N. 2012. Theorising the Lives of Disabled Children: How can Disability Theory Help? *Children & Society,* 26**,** 192-202.

WAY, N. 1998. *Everyday courage: The lives and stories of urban teenagers,* New York, NY, New York University Press.

WEBER, K. & BENNETT, S. 2004. *Special education in Ontario schools,* Thornhill, Highland Press.

WEIS, R. 2014. *Introduction to abnormal child and adolescent psychology,* London, Sage.

WEISEL, I. & BIGBY, C. 2014. Being recgonised and becoming known: Encounters between people with and without intellectual disability in the public realm *Environment and Planning,* A 46.7**,** 1754-1769.

WEISS, R. S. 1994. *Learning from strangers: The art and method of qualitative interview studies.,* New York, NY, The Free Press

WENDELL, S. 1996. *The Rejected Body: Feminist Philosophical Reflections on Disability* London, Routledge.

WHITBURN, B. 2016. The Perspectives of Secondary School Students with Special Needs in Spain. *Research in Comparative and International Education* 11**,** 148-164.

WHITE, C. 1996. Depoliticising development: the uses and abuses of participation. *Development in practice,* 6**,** 6-15.

WHITE, L. 2014. Understanding Canada's lack of progress in implementing the UN convention on the rights of the child: The intergovernmental dynamics of children's policy making in Canada. *The International Journal of Children's Rights,* 22**,** 164-188.

WHITEHOUSE, A. J. O., WATT, H. J., LINE, E. A. & BISHOP, D. V. M. 2009. Adult psychosocial outcomes of children with specific language impairment, pragmatic language impairment and autism. *International Journal of Language & Communication Disorders,* 44**,** 511-528.

WHO 2011. World Health Organization & The World Bank: World report on disability.

WICKENDEN, M. 2011. 'Talk to me as a teenager': Experiences of friendship for disabled teenagers who have little or no speech. *Childhoods Today,* 5**,** 1-35.

WICKENDEN, M. 2018. 'I have a lot to say!': A human rights perspective on recognizing the voices of disabled children globally. *In:* TWOMEY, M. & CARROLL, C. (eds.) *Seen and Heard: Exploring Participation, Engagement and Voice for Children with Disabilities.* Oxford Peter Lang.

WICKENDEN, M. & KEMBHAVI-TAM, G. 2014. Ask us too! Doing participatory research with disabled children in the global south.

WILDEMAN, S. 2013. Protecting rights and building capacities: challenges to global metnal health policy in light of the Convention on the Rights of Persons with Disabilities. *Journal of Law, Medicine and Ethics,* 4**,** 48-73.

WILHELMSEN, T. & SØRENSEN, M. 2017. Inclusion of Children With Disabilities in Physical Education: A Systematic Review of Literature From 2009 to 2015. *Adapted physical activity quarterly : APAQ,* 34**,** 311.

WILLIAMS, V. 2013. *Learning disability policy and practice,* Basingstoke, Palgrave Macmillan.

WILLIS, C., GIRFLER, S., THOMPSON, M., ROSENBERG, M., REID, M. & ELLIOTT, C. 2016. Elements contributing to meaningul participation for children and youth with disabilities: A scoping review. *Disability & Rehabilitation,* 21**,** 1-14.

WINNICK, J. P. 1987. An Integration Continuum for Sport Participation. *Adapted Physical Activity Quarterly,* 4**,** 157-161.

WITHERS, A. 2012. *Disability, politics and theory,* Black Point, NS, Fernwood.

WITTEL, A. 2000. Ethnography on the move: from field to net to internet. *Qualitative Social Research,* 1**,** 1-9.

WOLFF, S. 2015. Experiences with multi-sited ethnographies in transnational studies. *Educational Ethnography***,** 57-78.

WOLFINGER, N. 2002. On Writing Fieldnotes: Collection Strategies and Background Expectancies. *Qualitative Research,* 2**,** 85-95.

WOODHEAD, M. 2006. Changing Perspectives on Early Childhood: Theory, Research and Policy. *International Journal of Equity and Innovation in Early Childhood,* 4**,** 1-43.

WOODHEAD, M. 2009. Childhood Studies: Past, Present and Future. *In:* KEHILY, M. (ed.) *An Introduction to Childhood Studies* 2nd ed. Maidenhead Open University Press

WOODHEAD, M. 2010. Foreword. *In:* PERCY-SMITH, B. & THOMAS, N. (eds.) *A Handbook of Children and Young People's Participation: Perspectives from Theory and Practice.* London and New York: Routledge.

WOODS, P. 1986. *Inside schools: ethnography in educational research,* London, Routledge.

WUANG, Y. & CHWEN-YNG, S. 2012. Participation patterns and enjoyment in adolescent with Down Syndrome. *Research in Developmental Disabilities,* 33**,** 841-848.

WYNESS, M. 2009. Children representing children: Participation and the problem of diversity in UK Youth Councils. *Childhood,* 16**,** 535-552.

WYNESS, M. 2013. Children's participation and intergenerational dialogue: Bringing adults back into the analysis. *Childhood,* 20**,** 429-442.

WYNESS, M. 2015. *Childhood,* Cambridge, Policy Press.

WYNESS, M. 2018. Children's Participation: Definitions, Narratives and Disputes *In:* COCKBURN, T. & BARALDI, C. (eds.) *Theorising Childhood: citizenship, rights and participation.* Palgrave Macmillan.

WYNESS, M., HARRISON, L. & BUCHANAN, I. 2004. Childhood, politics and ambiguity: Towards an agenda for children's political inclusion. *Sociology,* 38.

WYNNYK, K. & SPENCER-CAVALIERE, N. 2013. Children's social relationships and motivations in sledge hockey. *Adapted Physical Activity Quarterly,* 30**,** 299-316.

YOSHIZAKI-GIBBONS, H. 2019. Engaging with ageing: a call for the greying of critical disability studies *In:* ELLIS, K., GARLAND-THOMSON, R., KENT, M. & ROBERTSON, R. (eds.) *Manifestos for the future of critical disability studies.* Routledge.

YTTERHUS, B. 2012. Everyday segregation amongst disabled children and thier peers: A qualitative longitudinal study in Norway *Children & Society,* 26**,** 203-213.

ZHAO, J. & SETTLES, B. 2014. Enviromental correlates of children's physical activity and obesity. *American Journal of Health Behavior,* 38.

ZIGON, J. 2008. *Morality: An Anthropological Perspective,* Oxford, Berg.

ZITOMER, M. & REID, G. 2011. To be or not to be-able to dance: Integrated dance and children's perceptions of dance ability and disability. *Research in Dance Education,* 12**,** 137-156.

ŽIŽEK, S. 2009. *In Defense of Lost Causes,* London, Verso.

Appendix
3.1 A. Ethics Approval

THE UNIVERSITY *of* EDINBURGH
Moray House School of Education

Our Ref: 1599

Katherine Westwood
PhD candidate
Institute of ECS
Moray House School of Education & Sport

Date: 16 July 2018

Dear Katherine,

Title: Participation in inclusive extracurricular physical activities constructed by the perspectives of children with disabilities

The School of Education and Sport Ethics Sub-Committee has now considered your request for ethical approval for the studies detailed in your application.

This is to confirm that the Sub-Committee is happy to approve the application and that the research meets the School Ethics Level 3 criterion. This is defined as "applies to novel procedures, research without consent, sensitive personal data, or the use of atypical participant groups. Also projects in which ethical issues might require more detailed consideration but are unlikely to prove problematic".

You are reminded that if the research changes in any way from that described on your application form, you may need to re-apply for approval.

Should you receive any formal complaints relating to the study you should notify the MHSE Ethics Committee immediately by email to MHSEthics@ed.ac.uk

Yours sincerely

On behalf of:
Dr Ailsa Niven
Convener, School Ethics Sub-Committee

3.2 B. Recruitment Poster

PARTICIPANTS NEEDED FOR RESEARCH ON HOW CHILDREN WITH DISABILITIES UNDERSTAND THEIR PARTICIPARTION IN EXTRACURRICULAR PHYSICAL ACTIVITIES

I am looking for volunteers to participate in a study as part of my PhD research project that looks at how children with disabilities understand their participation in extracurricular physical activities. Children meeting the following criteria are eligible:

- Have a disability and are between 14-16 years of age and
- Currently participate in extracurricular physical activity in the London and surrounding areas

If you agree to participate:

- A range of methods will be available to suit your preferences (interviews, photographs, observation, blogs, tours, etc.).
- Your participation in terms of session timing and length will be tailored to suit you.
- Your identity will be protected.

If you are interested, please message me directly using the contact information below. For more information about this study please contact:

Katie Westwood
Moray House School of Education, University of Edinburgh
Telephone: (519) 854 – 0396
Email:

Project supervisors:
John Ravenscroft at
Moray House School of Education
University of Edinburgh, Charteris Land 2.08
EH8 8AQ, Edinburgh, United Kingdom

Kristina Konstantoni at
Moray House School of Education
University of Edinburgh , St John's Land (Room 2.15)
EH8 8AQ, Edinburgh, United Kingdom

Sally McNamee at
King's University College at Western University, 266 Epworth Avenue
N6A 2M3, London Ontario

3.3 C. Information Sheets

Research Information Sheet for Child Participants

Hello_____!

My name is Katie Westwood and I am contacting you to ask if you would be interested in being a participant in my research project. I will first tell you a little bit about myself. I grew up in London Ontario area and was a student at Medway Secondary School (for my first 3 years) and then Lucas Secondary School (for my last year) of high school. Outside of school, I enjoyed playing soccer, horseback riding and swimming. Fast forward to 7 years later, I am working on a research project as part of my PhD program for my school in Scotland which is 5,499 km away!

My research project is called Participation in Inclusive Extracurricular Physical Activities constructed from the perspectives of children with disabilities. Therefore, I am looking for participants to help me understand how children participate in different sports outside of school.

As a participant, you will help me choose how I do this. I can come with you to watch your afterschool activities, you can fill out answers to questions, you can give me a tour of your environment, taking pictures of your surroundings, we can even think of more ideas that you might like better! Me being a part of your environment while I observe and take notes is called an ethnography. I'll be taking lots of notes of everything you do in these environments such as talking, playing, what you are interested in, and anything that is important to you. Ideally, I would spend 2-3 hours with you once a week for 3-4 months. However, if that's too much for you, we can shorten either of those times!

I promise not to mention your name in my research and you can even pick the name to use for the research if that interests you. I promise to give you feedback about themes that arise from the data collection. And if you decide at any point during my research that you don't want to participate anymore, that is completely fine!

If this is something you think might be interesting, please send me an email and we can have a chat about my research before you decide! My email is kwestwo2@uwo.ca .

Thank you for taking the time to consider my information sheet,

Katie Westwood

Information Sheet for Guardian

For the research project: *Participation in inclusive extracurricular activities constructed by the perspectives of children with disabilities.*

Dear _____,

I am Katie Westwood and I am interested in exploring how children with disabilities understand their participation in extracurricular physical activities. From 14 to 22 years of age, I participated in various volunteer and staff roles at SARI therapeutic riding which helped form my passion for seeing children as active contributors to their surroundings. After graduating from Western University, I have spent the last two years continuing my studies with an enhanced focus on children's participation.

Currently, I am a PhD Education student at the University of Edinburgh. For the research component of my studies, I am exploring how children with disabilities understand their participation in extracurricular activities. I have come back to London, because my goal is to do research in the community where I grew up.

I am looking for participants with disabilities aged 14-16 that are participating in extracurricular physical activities who would like to share their experiences with me!

For my research project I am going to use an ethnography. An ethnography, is where I observe what is happening in an extracurricular physical activity environment and I interpret what I see. I am therefore seeking permission to observe specific children at these locations! A range of methods may also be used based on child preference. Some examples of these methods include: interviews, photographs, observations, drawings, tours, map making, blogs etc. I will ask the children to help me pick the methods that best suits their interests. Quotes, body language and communication techniques will be analysed from these. I want my participants to be as comfortable as possible, so I would like meetings to take place where they are most comfortable, such as, at home, a coffee shop, a sport environment, etc. You will be informed at all times where such meetings will take place and why. My current plan is to allow approximately 8 months for data collection, meeting approximately once every other week. Resulting in approximately 16 meetings. However, we can discuss this!

Children and people close to the children may be able to identify the child based on particular sport or disability. Therefore, we can have a discussion on whether or not to include impairment type. Throughout research, if a participant becomes uncomfortable or looks like they would withdraw, the data collection will stop.

I will also be asking for ongoing consent as the research project progresses. You may withdraw your child's consent up until July 2019.

August 2019 I will share my initial findings with you. I will be using the data for my PhD thesis, presentations and journal articles.

Contact Information. I can be reached by my email kwestwo2@uwo.ca for any further enquires or questions.

Katie Westwood

My supervisors can also be reached at:

John Ravenscroft at
Moray House School of Education
University of Edinburgh
Charteris Land 2.08
EH8 8AQ, Edinburgh, United Kingdom

Kristina Konstantoni at
Moray House School of Education
University of Edinburgh
St John's Land (Room 2.15)
EH8 8AQ, Edinburgh, United Kingdom

Sally McNamee at
King's University College at Western University
266 Epworth Avenue
N6A 2M3, London Ontario

Ethics approval. This research proposal was reviewed and approved by the Moray House Ethics Board (University of Edinburgh) in July 2018 and King's University College (Western University) in August 2018.

Organization Information Sheet

For the research project: *Participation in inclusive extracurricular activities constructed by the perspectives of children with disabilities*.

Who am I? I am Katie Westwood and I am interested in exploring how children with disabilities construct their participation in extracurricular physical activities. I am a current PhD Education student at the University of Edinburgh. For the research component of my studies, I want to explore how children with disabilities construct their participation in extracurricular physical activities.

How I'm going to do it? For my research project I am going to use ethnography. An ethnography, where I observe what is happening in an extracurricular physical activity environment and I interpret what I see. I am therefore seeking permission to observe specific children, coaches and volunteers at these locations! Some examples of these methods include; interviews, photographs, observations, drawings, tours, map making, blogs etc. I am going to have the children help me pick some of these to suit their interests. Therefore, children may wish for me to observe them in your organization.

What part will you play? I am looking for consent from different organizations to observe children with disabilities participating in extracurricular physical activities. We can have a discussion deciding what that will look like to minimize disruption (whether I participate in activities or sit on the sidelines). I may also talk to coaches and staff for a better idea about the participants participation in sports. I'd like your permission to look at interactions that take place between coaches, children and volunteers. The everyday interactions interest me, some things I will be taking notes of are interactions, relationships and conversations that take place. I am also looking for help in recruiting participants, therefore, if you could help pass on information to my research project it would be appreciated.

When would my research take place? Initial steps of the research process will commence in August 2018 allowing for time to discuss research methods with participants and creating the timeline for data collection together. The length of time for data collection is dependent on the methods chosen, but my current plan is to allow approximately 8 months for collection. I would be observing (participants' name) a total of 5 times.

What are the risks? In respect of risk to privacy, confidentiality and autonomy are a main priority and how this will be accomplished will be part of our upfront discussion. I will change the names of participants and places where participants participate. Therefore, your organization will not be mentioned by name. Additionally, if the researcher notices that the participant is uncomfortable, the data collection will stop.

Can I withdraw my participation? Yes! Ensuring ongoing consent is a priority; therefore, you can withdraw consent at any point, up until July 2019. You may withdraw from any specific aspects, or from the research as a whole.

Will I know what is being done with my data? Yes! In August of 2019, you will receive the initial analysis of the data broken down into themes; this information will be provided in person, by email or mail depending on your preference. You may also receive (upon successful completion) a copy of the PhD thesis which is targeted to be completed in October 2020. During this process, the raw data will be secured in a locked cabinet and electronic

versions will kept in an encrypted format. Physical copies and electronic files will be destroyed after successful completion of the PhD thesis by the University of Edinburgh's IT team.

Contact Information. I can be reached by my email k.westwood@ed.ac.uk for any further enquires or questions.

My supervisors can also be reached at:
John Ravenscroft at
Moray House School of Education
University of Edinburgh
Charteris Land 2.08
EH8 8AQ
Edinburgh, United Kingdom

Kristina Konstantoni at
Moray House School of Education
University of Edinburgh
St John's Land (Room 2.15)
EH8 8AQ
Edinburgh, United Kingdom

Sally McNamee at
King's University College at Western University
266 Epworth Avenue
London, Ontario
N6A 2M3

Ethics approval. This research proposal was reviewed and approved by the Moray House Ethics Board (University of Edinburgh) July 2018, and King's University College (Western University) August 2018.
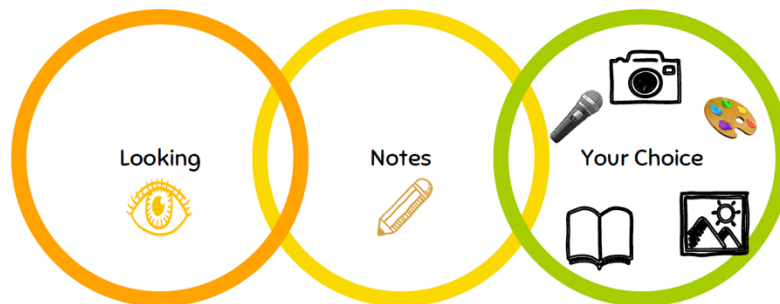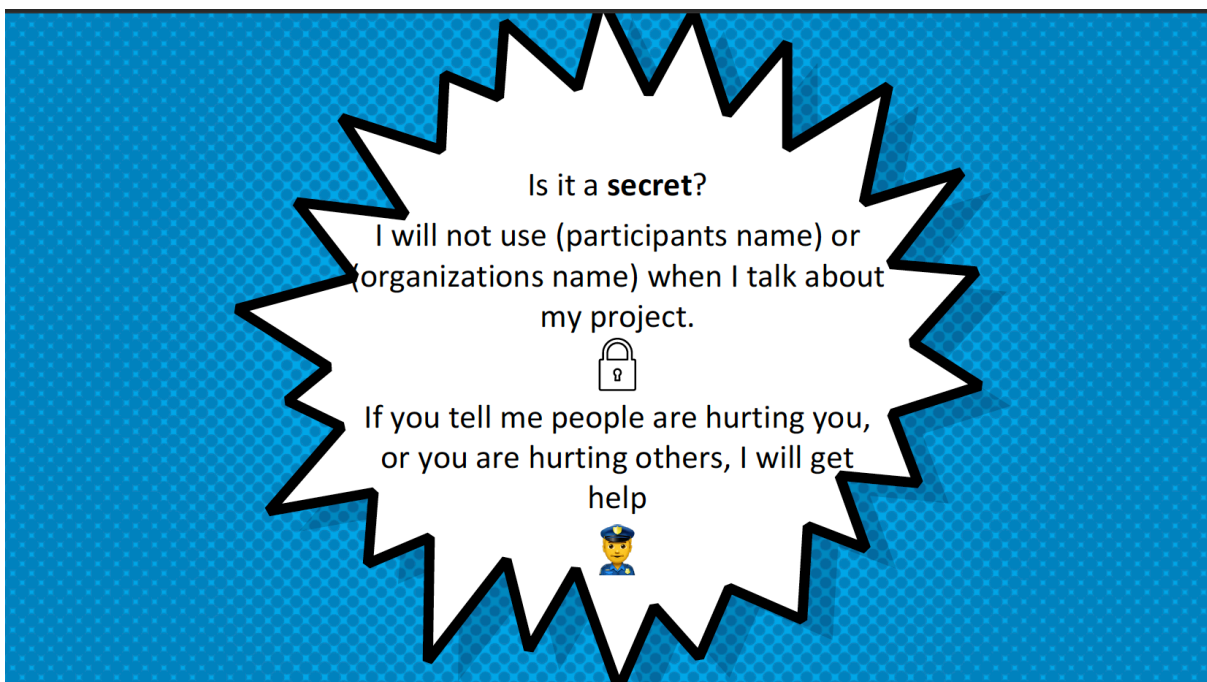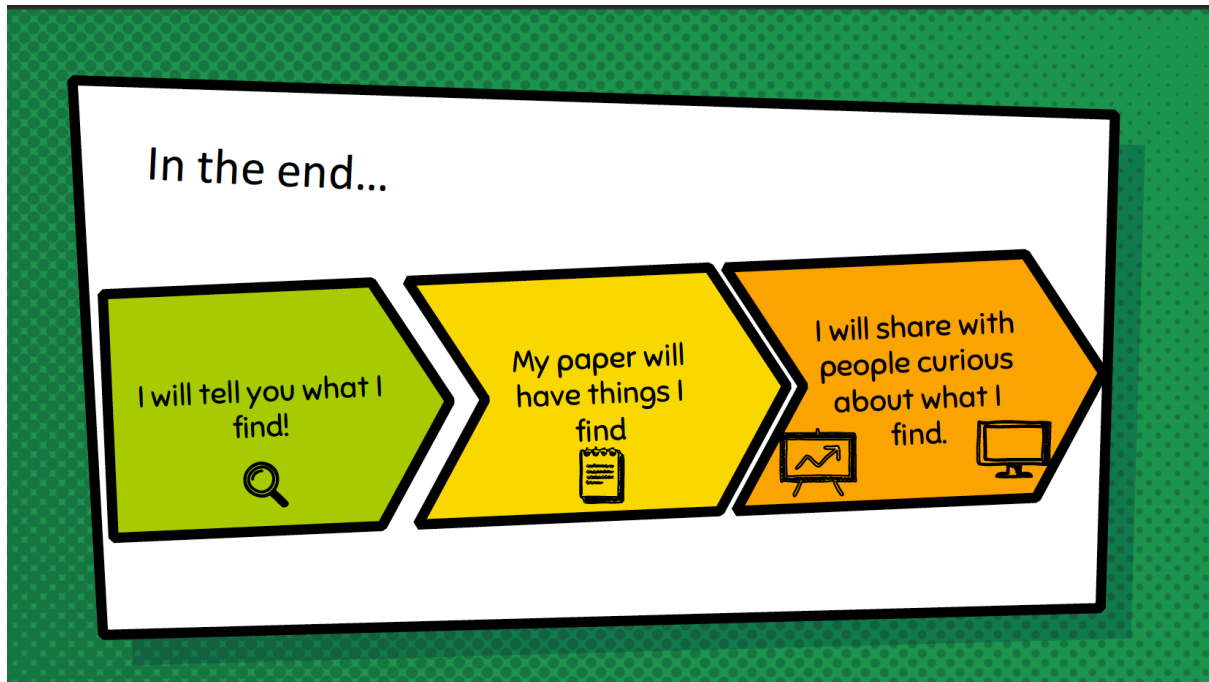
3.4 D. Consent Forms

Participant Informed Consent Form

As the participant, _____, I give my consent to participate in Katie
Westwood's PhD research project. This research project is entitled *Participation in inclusive
extracurricular activities constructed by the perspectives of children with disabilities*. There
are three supervisors for this research project; two at the University of Edinburgh, Scotland,
UK (John Ravenscroft, and Kristina Konstantoni) and one at King's University College,
London, Ontario (Sally McNamee). For the following statements, please check that you agree
and understand the following;

- o I have read and understood the information sheet (see attached).
- o I understand that participation is voluntary, meaning I can withdraw at any time
  without providing a reason, even though I have signed the consent form.
- o I understand that if I do withdraw this will not affect my participation in my chosen
  activity.
- o I will keep the original of all of any visuals that I make (pictures, drawings, maps
  etc.); however, Katie may take a picture of the original for analysis.
- o I understand that these visuals may be used anonymously for the research project
- o I understand that if Katie records our conversations, these will be written down word
  for word for use in the project. She will make them these conversations anonymous
  by not revealing my name, or activities that I participating in.
- o I understand the long term nature of the project.
- o I understand that what Katie finds she may use in her thesis, future presentations and
  publications
- o I understand that this research project aims to place me as the expert, and my choices
  in the project will have a high importance.
- o I understand that my words may be reproduced.
- o I am aware that the information I provide will be kept strictly confidential*.
  Unless there is disclosure of abuse, or harm, these will need to be reported to the local
  authority.

If I have any questions or concerns at any point. the researcher, Katie can be reached at
kwestwo2@uwo.ca or alternatively, her supervisors: John Ravenscroft at
john.ravenscroft@ed.ac.uk; Kristina Konstantoni at kristina.konstantoni@ed.ac.uk or Sally
McNamee at smcnamee@uwo.ca (mailing addresses can be found on the information sheet)

_____
Print Participant's Name:

_____
Participant's Signature:

_____
Date:

Research Site Informed Consent Form

As the coach/ instructor/ staff at _____, I give my consent for my participation in Katie Westwood's PhD research project. This research project is entitled *Participation in inclusive extracurricular activities constructed by the perspectives of children with disabilities*. There are three supervisors for this research project: two at the University of Edinburgh (John Ravenscroft, and Kristina Konstantoni) and one at King's University College (Sally McNamee). For the following statements, please signify that you are in agreement with each.

- o I have read and understood the information sheet (see attached).
- o I understand that participation is voluntary, meaning I may withdraw at any time, even though I have signed the consent form.
- o I understand that visuals may be made (examples; pictures, drawings, maps etc.). The original copy will be property of the participant; however, the researcher may take a picture of the original for data analysis.
- o I understand that these may be used anonymously for the research project.
- o I understand that there may be audio recordings made, and these will be transcribed. Anonymous excerpts may be used for the research project. Recordings will be destroyed after the completion of the PhD project.
- o I understand the potential longitudinal nature of the project.
- o I understand that what Katie finds she may use in her thesis, future presentations and publications
- o I understand that this research project aims to place the participant as the expert in the field, and their choices in the project will have a high value placed upon them.
- o I understand that my words may be reproduced.
- o I am aware that the information I provide will be kept strictly confidential*. Unless there is disclosure of abuse, or harm, these will need to be reported to the local authority.

If I have any questions or concerns at any point, the researcher, Katie, can be reached at kwestwo2@uwo.ca or alternatively, her supervisors; John Ravenscroft at john.ravenscroft@ed.ac.uk; Kristina Konstantoni at kristina.konstantoni@ed.ac.uk or Sally McNamee at smcnamee@uwo.ca (mailing addresses can be found on the information sheet)

_____
Print Participant's Name: Participant's Signature:

_____
Date: Email:

_____
Address

Guardian Participant Informed Consent Form

As the guardian of _____, I give my consent for my participation in Katie Westwood's PhD research project. This research project is entitled *Participation in inclusive extracurricular activities constructed by the perspectives of children with disabilities*. There are three supervisors for this research project: two at the University of Edinburgh, Scotland, UK (John Ravenscroft, and Kristina Konstantoni) and one at King's University College, London, Ontario (Sally McNamee). For the following statements, please signify that you are in agreement with each.

- o I have read and understood the information sheet (see attached).
- o I understand that participation is voluntary, meaning I may withdraw at any time, even though I have signed the consent form.
- o I understand that visuals may be made (examples; pictures, drawings, maps etc.). The original copy will be property of the participant; however, the researcher may take a picture of the original for data analysis.
- o I understand that these may be used anonymously for the research project.
- o I understand that there may be audio recordings made, and these will be transcribed. Anonymous excerpts may be used for the research project. Recordings will be destroyed after the completion of the PhD project.
- o I understand the potential longitudinal nature of the project.
- o I understand that this research project aims to place the participant as the expert in the field, and their choices in the project will have a high value placed upon them.
- o I understand that my words may be reproduced.
- o I understand that what Katie finds she may use in her thesis, future presentations, and publications
- o I am aware that the information I provide will be kept strictly confidential*. Unless there is disclosure of abuse, or harm, these will need to be reported to the local authority.

If I have any questions or concerns at any point, the researcher, Katie can be reached at kwestwo2@uwo.ca or alternatively her supervisors: John Ravenscroft at john.ravenscroft@ed.ac.uk; Kristina Konstantoni at kristina.konstantoni@ed.ac.uk or Sally McNamee at smcnamee@uwo.ca (mailing addresses can be found on the information sheet)

_____

Print Participant's Name: Participant's Signature:

_____

Date: Email:

_____

Address:

Guardian Informed Consent Form

As the guardian of _____, I, hereby, give my consent for him/her to
participate in Katie Westwood's PhD research project. This research project is titled
*Participation in inclusive extracurricular activities constructed by the perspectives of
children with disabilities*. There are three supervisors for this research project; two at the
University of Edinburgh in Scotland, UK (John Ravenscroft, and Kristina Konstantoni) and
one at King's University College, London, Ontario (Sally McNamee). For the following
statements, please signify that you are in agreement with each.

- I have read and understood the information sheet (see attached).
- I understand that participation is voluntary, meaning the participant can withdraw at
  any time, even though a signed consent form has been submitted.
- I understand that visuals may be created (examples; pictures, drawings, maps etc.),
  and the originals will be property of the participant; however, the researcher may take
  a picture of the original for data analysis.
- I understand that these may be used anonymously for the research project
- I understand that there may be audio recordings made, and these will be transcribed
  for purposes of documenting the research. Anonymous excerpts may be used for the
  research project. At the completion of the project, these recordings will be destroyed.
- I understand that the participants words may be reproduced
- I understand the potential longitudinal nature of the project.
- I understand that what Katie finds she may use in her thesis, future presentations, and
  publications
- I understand that this research project aims to place the participant as the expert in the
  field, and their choices in the project will be highly valued.
- I am aware that the information the participant provides will be kept strictly
  confidential*.
  Unless there is disclosure of abuse, or harm, these will need to be reported to the local
  authority.

If you or the participant have any questions or concerns, the researcher, Katie can be reached
at kwestwo2@uwo.ca, or alternatively, her supervisors; John Ravenscroft at
john.ravenscroft@ed.ac.uk; Kristina Konstantoni at kristina.konstantoni@ed.ac.uk or Sally
McNamee at smcnamee@uwo.ca (mailing addresses can be found on the information sheet)

_____
Print Participant's Name:

_____
Guardian's Printed Name: Guardian's Signature:

_____
Date: Email:

_____
Address: