Adapted Physical Activity Camps: Family Experiences and Implications for Family Relationships

Youngblood, Jessica

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Adapted Physical Activity Camps:
Family Experiences and Implications for Family Relationships

by

Jessica Youngblood

A THESIS
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Abstract

Children with disabilities tend to be less active than typically developing children and barriers to participate in activities may cause strain on family relationships. Families caring for a child with a disability face higher levels of stress, burnout, and feelings of isolation. The purpose of this thesis was to better understand family members’ perspectives regarding family relationships as they relate to participation in an adapted summer camp for children and adolescents living with a disability. This thesis was informed by the Social Relational Model of Disability and Bowen’s Family Systems Theory. A constructivist epistemology and relativist ontology provided the foundation for two collective case studies examining interactions and relationships among families participating in adapted physical activity (PA) camps. The first study examined a camp where children and adolescents with disabilities have the opportunity to participate in a variety of adapted sports. The second study focused on a camp where children and adolescents with disabilities have the opportunity to participate in physical activities with their parents and siblings. In both studies, focus groups were conducted with each family at one time point with questions regarding their perceptions of their family relationships as they related to participation in the camps and their perspectives regarding the suspension of these recreation programs as a result of the COVID-19 pandemic. Thematic analysis was conducted to identify themes and examine similarities and differences in the families’ reported experiences. While experiences in the two contexts varied, themes included family members’ perspectives regarding what the child living with a disability is able to achieve, conversations surrounding disability, support for managing daily stressors, an understanding of one another, shared experiences and memories, sibling bonding, and pride in the child with a disability. Families also noticed that the confidence and independence experienced by the child living with a disability was meaningful
for interactions within their families. The loss of the camps due to COVID-19 was associated with families experiencing isolation, worry, and frustration. The findings from these studies can be used to better understand family members’ experiences regarding adapted PA as it relates to family relationships.
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Dedication

To my family, thank you for always encouraging me and inspiring me to pursue my passions. I wouldn’t be who I am today without your love and support.
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Chapter 1: Introduction

1.1 Problem Statement

Children and adolescents living with a disability may need more assistance from their parents when performing everyday tasks than typically developing children (Patterson, 1991). As a result, children and adolescents living with a disability may also rely on their parents more to facilitate their physical activity (PA) involvement. Accessing recreation can be difficult for children and adolescents living with a disability because many community programs are not accommodating of their impairments (Scholl et al., 2003). As a result, parents who have a child living with a disability may face barriers when trying to find appropriate recreation programs for their child living with a disability (Williams et al., 2004). These barriers may include environmental barriers such as inadequate transport or facilities, poorly maintained outdoor areas, and lack of the assistance necessary for their child to meaningfully engage in PA. (Williams et al., 2004). Because society rarely adjusts to the impairment of individuals with disabilities, there are limited spaces and opportunities for PA participation (Martin, 2003). This difficulty to find appropriate recreation for children with a disability may have an impact on family relationships (Patterson, 1991).

There may be profound impacts on a family when one child has a disability. As a result of the individual’s impairment and the societal barriers that the child faces, a large proportion of family resources may go towards that child (Haefner, 2014). Societal barriers such as not being able to access adequate health care or recreation programs make it difficult for parents raising a child with a disability (Patterson, 1991). Families raising a child living with a disability face a variety of challenges during everyday life such as an inability to access transportation, supporting the child’s self-care needs, and addressing the health needs of the child (Green,
2007). As a result of these barriers, parenting a child with a disability may be more time consuming, expensive, and physically exhausting than parenting a typically developing child (Green, 2007). Because of these barriers, families raising a child living with a disability may have to advocate for their child in a variety of settings due to lack of accommodations. The need to consistently advocate for their child’s needs may leave parents with little time or energy to find appropriate recreation opportunities for their child (Scholl et al., 2003; Martin, 2013).

1.2 Research Purpose

The purpose of this research was to better understand family members’ perspectives regarding family relationships as they relate to participation in an adapted summer camp for children and adolescents living with a disability.

1.3 Research Questions

The following research questions will be addressed in two studies:

(1) How are family members’ perceptions of family relationships affected following participation in an adapted physical activity camp?

(2) What are families’ experiences regarding family relationships after losing the opportunity to participate in adapted physical activity camps due to COVID-19?

1.4 Rationale

PA has numerous physical and psychosocial benefits for children and adolescents living with a disability, including enhanced self-esteem and self-efficacy (Martin, 2013). There is limited research examining how the potential psychosocial benefits from PA may impact family relationships. Research examining experiences with adapted PA tends to focus on the perceived impacts on the child living with the disability and less on the perceived impacts on other family members and/or as a whole. It is important to expand the focus to examine how recreation
experiences impact not only the child or adolescent living with a disability but also the experiences of their family members (Patterson, 1991). Families tend to be more involved in the PA of children and adolescents living with a disability because of the barriers they face (Martin, 2013). As such, the benefits of adapted PA for children and adolescents may have a perceived impact on family relationships and we can examine if adapted PA can be an effective mechanism leading to a perceived reduction in the daily stressors that families with a child living with a disability may face.

The COVID-19 pandemic has led to fewer recreation opportunities for many children and adolescents living with a disability, due to program cancellations. This provides a rare opportunity to examine the experiences of families who lost the opportunities to participate in certain recreation programs due to COVID-19. Families with a child who is living with a disability reported perceived increases in stress and lower levels of social support than families with typically developing children during the pandemic (Neece et al., 2020). It’s important to consider the experiences of family members after a child or adolescent with a disability participated in an adapted PA programs and their experiences regarding family relationships as they relate to losing the opportunity to participate in programs.

This thesis will be framed by the social relational model of disability and Bowen’s family systems theory. This thesis includes two studies, focusing on two adapted summer camp environments. One camp provided opportunities for families with children and adolescents with disabilities to participate in PA, and especially outdoor recreation activities together as a family. The second camp examined provided opportunities for PA participation for children and adolescents with disabilities. The goal of this camp is to increase long term engagement in adapted PA, and it provides opportunities to participate with other children and adolescents with
disabilities. Conducting these two studies allowed me to examine aspects of each camp and the experiences of families in these camp environments.

Adapted PA has positive impacts for families with a child living with a disability. Participating in PA together may increase family communication and marital satisfaction (Mactavish & Shliene, 2004). Family participation can be a facilitator for the PA involvement of children and adolescents living with a disability and can be used as an effective tool to increase the long-term participation of the child or adolescent living with a disability (Shields & Synott, 2016). Participating in adapted PA increases the willingness of children and adolescents with disabilities to participate in PA long term (Goodwin et al., 2009). There is little research examining families’ experiences of participating in PA together. This research may be important because participating in PA together may be a positive context for family interactions. Understanding families’ experiences in adapted PA could help practitioners design programs to make them more impactful for families.

It is important to clarify how language related to family members and their relationships is used throughout this thesis. All families who participated in the studies in this thesis include at least one child (under 10 years of age; World Health Organization, n.d.) or adolescent (10 to 19 years old; World Health Organization, n.d.) living with a disability. When referring to prior research on the experience of young people living with a disability, we use the terms children and adolescents, as relevant to the study being discussed. However, “child” also refers to the relationship between an individual and their parent, and therefore when discussing relationships among participants in the families who participated in this study, we refer to the individual living with a disability as the child living with a disability (regardless of whether they are a child or adolescent), and their brothers and sisters as siblings, because we are referring to their positions
within the family. While it is recognized that families are diverse, and can include individuals other than parents and children, all of the families who participated in this study defined their family in terms of parents (including mothers, and sometimes also fathers) and children (including the child with a disability, and sometimes also brothers and/or sisters).

1.5 Summary of Thesis Format

This MSc thesis includes the examination of how family members in families with a child living with a disability view family relationships as they relate to participating in an adapted PA summer camp. The structure of the thesis is as follows: this chapter provides a general introduction and a description of the objective of the studies. The second chapter includes a description of the theoretical framework used and a review of relevant literature. The third chapter includes a study which examines the perspectives of family members following participating in a family adapted physical activity camp. The fourth chapters includes a study examining the perspectives of family members as they relate to their child participating in an adapted PA summer camp. The fifth chapter includes an overall summary of the findings, implications of the research, and a general conclusion with recommendations for future research.
Chapter 2: Literature Review

2.1 Conceptual Framework

2.1.1 Social Relational Model of Disability

The conceptual framework of this study is informed by the social relational model of disability (Reindal, 2008) and Bowen’s family systems theory (Brown, 1999). The social relational model of disability considers both the biomedical and social roots of disability and suggests that whether an impairment becomes a disablement is influenced by societal factors (Reindal, 2008). One of the main tenants of this theory is the concept of disablism. Disablism can be defined as socially imposed restrictions (Haslett & Smith, 2020). In the context of the social relational model of disability, disability is viewed as the inability to participate in normative activities as a result of the individual’s impairment and societal factors. When participation is restricted it may cause the individual’s impairment to impact their physical body and their functioning within the social world (Smith & Bundon, 2018).

There are three types of disablism that occur in society; structural disablism, psychoemotional disablism, and internalized oppression (Haslett & Smith, 2020; Reeve, 2014). Structural disablism is the inability to participate in opportunities, services, or activities because of an impairment (Haslett & Smith, 2020). Structural disablism leads to psychoemotional disablism when it causes the individual with a disability to miss out on experiences. Psychoemotional disablism can be direct or indirect. Direct psychoemotional disablism occurs when the looks, words, or actions of others are discriminatory, such as when a child with a disability is talked over or ignored because of their impairment. Indirect psychoemotional disablism recognizes the emotional consequences of being unable to participate in PA opportunities. Internalized oppression refers to negative thoughts and feelings individuals with
disabilities may have about themselves as a result of being unable to participate in some normative activities (Haslett & Smith, 2020). These three types of disablism may impact a child’s ability and willingness to participate in recreation programs. Adapted programming may help to reduce these types of disablism that individuals may face when accessing and participating in recreation programs, through creating a more accessible environment for individuals living with a disability.

2.1.2 Bowen’s Family Systems Theory

The social relational model of disability explains some of the societal barriers families may face as a result of having a child living with a disability. Bowen’s family systems theory provides insights into how family members impact on another, within the social context that was laid out by the social relational model of disability (Brown, 1999). Bowen’s family systems theory assumes that all family members are impacted in some way by the disability that one member of the family has. Therefore, it is important to understand how each family member functions in families that have a child living with a disability (Townsend & Van Puymbroek, 2017). Bowen’s family systems theory focuses on the roles each family has within the family system and how these roles are shaped and forged throughout the lifetime (Brown, 1999). Family is defined as an emotional structure where individuals can support one another (Brown, 1999). This theory focuses on patterns in a family that are created and used to reduce a family’s anxiety, and how each family member functions within the family system (Brown, 1999). Anxiety in a family is related to the amount of societal stress families may experience. Societal barriers, such as not being able to access adequate health care or recreation programs, make it difficult when raising a child with a disability and may cause increased stress on the family system (Patterson, 1991). Families have diverse structures including single parent families, two-parent families,
families with one child, families with more than one child, intergenerational families, and many other family structures. This theory suggests that families may be intensely emotionally reliant on one another, therefore, the actions of each individual in the family can impact others within their family unit.

Bowen’s family systems theory is informed by eight interrelated concepts: (1) differentiation of self, where individuals who are emotionally connected to the family begin to make more self-directed choices, (2) triangles, a three-person relationship which is considered the most stable relationship unit, (3) the nuclear family emotional system, identifies relationship patterns and how they may impact emotional functioning within the family, (4) family projection processes, when a parent experiences more anxiety towards one child, (5) emotional cut-off, when an individual who have negative emotions towards their family members disconnects from the family, (6) multigenerational transmission process, how certain roles in relationships are passed down from generation to generation, (7) sibling position, where the age order of children in the family impacts the roles within the family system, and (8) societal emotional process, which refers to how the societal stresses families experience may cause stress on the family system (Brown, 1999; Haefner, 2014). Bowen’s family system theory provides insight into the interaction that occurs in each family system to reduce anxiety. This provides an opportunity to examine how families perceive these interactions following adapted PA participation.

2.2 Physical Activity for Children and Adolescents Living with a Disability

The scope of this literature review will focus on individuals with physical and intellectual disabilities that could benefit from participating in adapted PA. This review does not focus on disabilities that do not impact the individual’s ability to participate in PA. Our society is not well adapted to accommodate the impairments of people living with disabilities. Therefore, children
and adolescents living with a disability may rely on their parents for assistance with everyday tasks more often than typically developing children (Patterson, 1991). This need to rely on family members to support daily functioning can impede a child’s sense of independence (Groff & Kleiber, 2001). PA can be a channel for children and adolescents with disabilities to gain independence through a meaningful and healthy activity (Groff & Kleiber, 2001).

Participation in adapted PA is important to enhance the development of physical and social health of children and adolescents living with a disability (Steinhardt et al., 2021). There are also a variety of psychosocial benefits to PA participation for children and adolescents living with a disability; such as perceptions of self-esteem, self-competence, and self-efficacy (Martin, 2013). Improvements in emotional functioning have also been seen as one of the major benefits to participating in adapted PA (Kosma et al., 2007). Despite a wide array of benefits, children and adolescents living with a disability often do not meet the recommended levels of daily PA (Martin, 2013). PA can play an important role in enhancing quality of life in children and adolescents living with a disability (Martin, 2013).

Many children and adolescents living with a disability may not have the opportunity to enjoy the benefits of PA because they face many medical, psychological, social, and environmental barriers when attempting to access PA opportunities (Martin, 2013). Many community recreation programs are not well equipped to accommodate the needs of individuals with disabilities (Scholl et al., 2003). Environmental barriers such as inadequate transportation or facilities, poorly maintained outdoor areas, and lack of assistance for mobility conditions can contribute to structural disablism and impact participation in recreation programs for children and adolescents with disabilities (Haslett & Smith, 2020; Williams, Vogelsong, Green, & Cordell, 2004).
Since children and adolescents living with a disability face so many barriers when attempting to access PA programs, the responsibility to access these programs typically rests with parents. As a result, parents are seen as the most relevant relationship for facilitating PA involvement (Steinhardt et al., 2021). Parental support has been seen as the most important facilitator to PA involvement for youth and adolescents living with a disability (Steinhardt et al., 2021). However, when raising a child with a disability, barriers arise not only during recreation but also during everyday activities such as transportation, self-care, and addressing the health needs of the child (Green, 2007). As a result, parents often spend considerable amounts of time advocating for their child’s medical and educational needs due to the lack of accommodations provided in these settings. This need to advocate may leave parents with little time or energy to find appropriate recreation opportunities for their child (Scholl et al., 2003; Martin, 2013). Negative parental attitudes and less parental engagement can also be a barrier to the PA participation of children and adolescents living with a disability (Steinhardt et al., 2021). Parents may not encourage their child to participate in an adapted program as an attempt to protect their child from negative experiences and emotions (Steinhardt et al., 2021). It is well known that PA has a wide variety of benefits for children and adolescents living with a disability (Martin, 2013). Thus, it is important that parents have positive experiences regarding their child living with a disability’s PA involvement, so they can continue to encourage PA participation for their child.

2.3 Family Relationships

Family is the primary context where human development takes place (Bronfenbrenner, 1986). There may be profound impacts on the family when one child has a disability. As a result of a child’s impairment and the societal barriers that child faces, a large proportion of family resources tend to go towards that child (Haefner, 2014). Societal barriers, such as not being able
to access recreation programs, make it difficult when raising a child with a disability (Patterson, 1991). Family systems theory assumes that all family members are impacted in some way by the disability that one member of the family has; therefore, it is important to understand how each family member functions in families that have a child with a disability (Townsend & Van Puymbroek, 2017; Trivette et al., 2010). In the presence of adversity, relationships existing in triangles are beneficial when all the individuals lean on each other. However, this reliance on other family members may become problematic when one parent focuses their anxieties on the child with a disability. The other parent or sibling in the triangle may feel left out, or like they aren’t fully included in the relationship (Haefner, 2014; Patterson, 1991). When one parent focuses on the child with a disability it can also undercut the process of self-differentiation of that child (Brown, 1999). The process of self-differentiation may look different for children with disabilities since they may be more reliant on their parents for a longer period of time than typically developing children. The family system may be affected by these adversities faced by the child with a disability and their families.

Since Western society is not always accommodating of individuals with disabilities, families raising a child with a disability may feel as though they face more societal constraints. As a result, families with a child with a disability have reported facing increased social isolation, parental and child stress, and strained parent relationships (Downling & Dolan, 2001; Shields & Synott, 2016). When raising a child with a disability, barriers can arise during everyday activities such as transportation, self-care, and addressing the health needs of the child (Green, 2007). As a result, parenting a child with a disability may be more time consuming, expensive, and physically exhausting than parenting a typically developing child (Green, 2007). If parents do not have access to the necessary social supports, they may find it difficult to interact with their
child in a way that enhances development (Trivette, Dunst & Hamby, 2010). It can be difficult to make connections with other families who understand the challenges that come along with raising a child with a disability (Downling & Dolan, 2001). As a result, families with a child with a disability may find it hard to establish a strong social network, which may lead to these families feeling isolated (Downling & Dolan, 2001).

There are also a variety of positive implications having a child with a disability has on families. Most parents who have a child living with a disability have reported benefits that are related to raising a child living with a disability (McConnell et al., 2015). When sufficient supports are in place, families have reported higher levels of marital satisfaction, family cohesion, stronger family bonds, and less family conflict than families with typically developing children (Townsend & Puymbroek, 2017). As a result of the challenges associated with raising a child with a disability the family may become stronger and more resilient (Townsend & Van Puymbroek, 2017).

Siblings are typically the longest relationship in a person’s life and therefore play an important role in a child’s development (Mandleco et al., 2003; Travers et al., 2020). Ross and Cuskelley (2006) found that siblings of a child with a disability are at a greater risk of developing internalizing behaviour difficulties, and siblings have reported feelings of separation and perceptions of differential treatment compared to the child with a disability (Mandleco et al, 2003). However, parents and teachers of children with a sibling living with a disability often perceive that the typically developing sibling tends to exhibit increased warmth, patience, empathy, maturity, and self-control compared with children who do not have a sibling with a disability (Ross & Cuskelley, 2006; Mandleco, 2003). Further, siblings of an individual living with a disability may report lower levels of conflict and high levels of closeness within the
relationship when compared to typically developing siblings (Zaidman-Zait et al., 2020). In a sibling relationship where one sibling lives with a disability, the typically developing sibling may feel the need to support their brother or sister living with a disability, which may lead the typically developing sibling to put effort into enhancing their relationship with their sibling (Zaidman-Zait et al., 2020). Furthermore, children with disabilities who are older siblings can gain an increased sense of self when they engage in their older sibling duties (Serdity & Burgman, 2012). Sibling relationships are important for children with disabilities, but these relationships may be complicated by the adversities faced by the child with a disability. PA can be a positive channel for siblings to bond, potentially enhancing sibling relationships.

Support from family members is very important to individuals with disabilities (King et al., 2006). Support within the immediate family (parent(s) and child(ren)) is associated with better psychological and emotional well-being. Individuals with disabilities feel particularly supported when their parents and sibling(s) believe in and understand them (King et al., 2006). Lack of support from family members may cause the child with the disability to feel angry, which may decrease their emotional well-being (King et al., 2006). When family members provide individuals with disabilities strategies to overcome adversity it can help them flourish and achieve life goals (King et al., 2006). Participating in positive communication and problem-solving strategies can decrease family stress and has been shown to decrease behavioral problems in children with disabilities and their siblings (Giallo & Gavidia-Payne, 2006; King et al, 2006). Participating in PA together may increase family communication and marital satisfaction (Mactavish & Shliene, 2004). Therefore, PA can be a positive influence to increase support within families who have a child with a disability.
2.4 COVID-19

The COVID-19 pandemic has had a profound impact on family relationships and the ability to access PA in families who have a child living with a disability. The psychosocial benefits of PA such as increased self-esteem and decreased anxiety are important for the emotional development of children and adolescents living with a disability (Aishworiya & Kang, 2020). As a result of the public health restrictions related to the COVID-19 pandemic access to recreation programs for children and adolescents living with a disability has been reduced. Children and adolescents living with a disability have reported experiencing stress and decreased mental health as a result of being less physically active (Theis et al., 2021). Parents reported experiencing anxiety for themselves and their child living with a disability (Ashbury et al., 2020) and worry about the long-term impacts of the pandemic on their child’s mental health and social engagement opportunities (Neece et al., 2020; Ashbury et al., 2020). Adapted PA may contribute to reductions in stress levels and behavioural problems (Yarimkaya & Esenturk, 2020). Thus, losing PA opportunities during the pandemic may have reduced options for managing stress. Parents have reported that the opportunity for families including a child living with a disability to spend more time together was a positive outcome of the pandemic (Neece et al., 2020). But overall, COVID-19 is a challenging time, and may be especially so for families who include a child living with a disability.

2.5 Summary

This research examines family relationships as they relate to adapted PA, informed by the social relational model of disability and Bowen’s family systems theory. The aim of these studies was to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impact their family relationships. As
a result of the COVID-19 pandemic the two camps this thesis focused on were unable to run in the summer of 2020. We therefore also examined family members’ experiences regarding family relationships after being unable to participate in these programs. Families with a child living with a disability tend to face more stress and anxiety than families with typically developing children because of barriers they face on a daily basis and in terms of participating in PA (Martin, 2013), and it is important to understand how adapted PA programs may play a role in their family relationships.
Chapter 3: “We’re stronger as a family”: Family Experiences and Relationships in an Adapted Physical Activity Camp

3.1 Abstract

Family recreation may be an important way to enhance family relationships. The objective of this study was to examine family members’ perspectives regarding family relationships as they relate to participation in an adapted summer camp for families with a child living with a disability. A collective case study was conducted with five families who participated in a summer camp where children and adolescents living with a disability could participate in recreation with their family. A focus group was conducted with each family and thematically analyzed. Participation in the camp was related to families feeling supported and experiencing a reduction in daily stressors, a better understanding of one another, common memories between all family members, and an increase in sibling bonding. These findings can be used to better understand how family participation in PA can impact relationships in families that include a child living with a disability.

Key words: adapted physical activity, family, qualitative, disability, children and adolescents
3.2 Introduction

Children and adolescents living with a disability tend to be less active than typically developing children because they may face limitations when accessing recreation programs (Heah et al., 2006). Families caring for a child living with a disability may also experience greater parental stress, isolation, frustration, and financial challenges compared with families caring for typically developing children (Ono et al., 2019). Conversely, parents of a child living with a disability may see family recreation as a positive way to increase the quality of family life (Mactavish & Schleien, 2004). As a result of COVID-19, families had fewer opportunities to participate in physical activity (PA). Families raising a child living with a disability reported an increase in stress and anxiety during the COVID-19 pandemic (Neece et al., 2020). However, there is limited research regarding families’ perspectives on how recreation programs that provide opportunities for families including a child living with a disability to participate together can impact their interpersonal relationships. A better understanding of these processes could inform future program development to further support family relationships and PA opportunities.

3.3 Conceptual Framework

The conceptual framework for this study is informed by the social relational model of disability (Reindal, 2008) and Bowen’s family systems theory (Brown, 1999). The social relational model of disability considers how disability is viewed within the broader societal context (Reindal, 2008). It also considers the biomedical and social roots of disability and suggests that whether an impairment becomes a disablement is influenced by societal factors (Reindal, 2008). In the social relational model of disability, disability is viewed as the inability to participate in normative activities as a result of the individual’s impairment and societal factors (Haslett & Smith, 2020). It proposes three types of disablism: structural disablism, psycho-
emotional disablism, and internalized oppression (Haslett & Smith, 2020). Structural disablism is the inability to participate in opportunities, services, or activities because of an impairment (Haslett & Smith, 2020). Psychoemotional disablism can be direct or indirect. Direct psychoemotional disablism occurs when the actions of others are discriminatory or patronizing, such as when a child with a disability is talked over or ignored because of their impairment. Indirect psychoemotional disablism recognizes the psycho-emotional consequences of not being able to participate in activities, such as when a child feels isolated after not being able to participate in a recreation program because of their impairment. Internalized oppression refers to negative thoughts and feelings individuals with disabilities may have about themselves as a result of living in a society where they do not always feel welcome (Haslett & Smith, 2020). Adapted programming may attempt to create environments that reduce all three of these types of disablism.

Bowen’s family systems theory provides insight into how family interactions operate and how these processes may influence family relationships, and the individuals within them. Family is defined as “a cohesive relationship between individuals and an emotional structure where individuals can support one another” (Bavel & Segal, 1982). This theory focuses on the structure of a family, individuals’ roles within it, and how these roles are continually forged throughout the lifetime (Brown, 1999). Family systems theory is informed by eight interrelated concepts: (1) differentiation of self, where individuals who are emotionally connected to the family act autonomously and make self-directed choices, (2) triangles, a three-person relationship which is considered the building block of larger relational systems and the smallest stable relationship unit, (3) nuclear family emotional system, which identifies relationship patterns that affect emotional functioning within the family, (4) family projection processes, when a parent’s
anxieties are transmitted onto a child, (5) emotional cut-off, when an individual copes with unresolved negative emotions by disconnecting from the family, (6) multigenerational transmission process, which includes how patterns and roles within relationships are passed down from generation to generation, (7) sibling position, whereby the age order of children impacts their family roles and relationships, and (8) societal emotional process, which refers to societal stress that may cause stress on the family system; Haefner, 2014; Brown, 1999). Family systems theory provides a lens for examining how family members interact and how participation in an adapted PA camp may affect those interactions.

3.4 Physical Activity for Children Living with a Disability

PA can be a channel for children and adolescents living with a disability to gain independence through meaningful and healthy activity (Groff & Kleiber, 2001). The challenge is that children and adolescents living with a disability may face medical, environmental, family, and social barriers to PA (Martin, 2013). Further, many community recreation programs are not well equipped to accommodate the needs of individuals living with a disability (Scholl et al., 2003). Environmental barriers can include inadequate transportation or facilities, poorly maintained outdoor areas, and lack of assistance for mobility conditions can contribute to structural disablism and impact participation in recreation programs (Haslett & Smith, 2020). As a result, there are limited opportunities for individuals living with a disability to participate in PA because our society rarely adjusts to their needs (Martin, 2013).

Parents and peers may impact the child or adolescent’s participation in PA. Negative parental attitudes toward PA are a barrier to participation, particularly for children and adolescents living with a disability because they tend to rely on their parents to facilitate their PA involvement (Shields & Synnot, 2016). Parents often spend considerable amounts of time
advocating for their child’s medical and educational needs due to the lack of accommodations provided in these settings. Moreover, the need to advocate may leave parents with little time or energy to find appropriate recreation opportunities for their child or themselves (Scholl et al., 2003; Martin, 2013). This ability to be able to participate together can make family recreation an effective way to increase the likelihood that the whole family is active.

Parents who have a child living with a disability may see family recreation as a positive way to increase the overall quality of family life and enhance family relationships (Mactavish & Schleien, 2004). However, family recreation may be difficult to plan for all family members due to various interests and abilities within the family (Mactavish & Schleien, 2004). Family recreation typically involves parents and the child with a disability and happens at times when their siblings are either occupied with other activities or at school (Mactavish & Schleien, 2004). It can be difficult for parents to meet the individual needs of each family member, while also addressing the family’s needs collectively, particularly for families who have a child with a disability (Mactavish & Schleien, 2004). Furthermore, finding programs that accommodate the needs of all family members can be taxing for parents of children with a disability (School et al., 2003).

3.5 Family Relationships

Families raising a child who is living with a disability may face more societal constraints because society is not always accommodating of individuals with disabilities. Examples of this may be families with a child living with a disability facing higher levels of social isolation, parental and child stress, and strained parent relationships when compared with families raising typically developing children (Shields & Synnot, 2016). When raising a child living with a disability, barriers can also arise with everyday activities (e.g., transportation, self-care, and
addressing the health needs of the child; Green, 2007). As a result, parenting a child who is living with a disability may be more time consuming, expensive, and physically exhausting than parenting a typically developing child (Green, 2007).

Raising a child that is living with a disability may also have positive impacts on family relationships (Patterson, 1991). Some parents perceive that having a child who is living with a disability has led to greater patience and understanding of others (McConnell et al., 2015). When sufficient supports are in place, parents report higher levels of marital satisfaction and families report higher levels of cohesion, stronger family bonds, and less family conflict than families with typically developing children (Townsend & Van Puymbroek, 2017). These findings suggest that the challenges associated with raising a child who is living with a disability may contribute to the family becoming stronger and more resilient (Townsend & Van Puymbroek, 2017).

The family is an important developmental context because family is the main social group in which we have lifelong ties (Bronfenbrenner, 1986). There may be profound impacts on the family when one child is living with a disability and a large proportion of family resources may go towards that child as a result of the child’s impairment and the societal barriers that the child faces (Haefner, 2014). Family systems theory assumes that all family members are impacted by the disability that one member of the family has; therefore, it is important to understand how each family member functions within their roles of the family (Townsend & Van Puymbroek, 2017; Trivette et al., 2010).

Siblings play a particularly important role in a child’s development because they are social partners and role models for one another (Mandleco et al., 2003). Siblings of a child who is living with a disability are at a greater risk of developing internalizing behaviour difficulties (Ross & Cuskelly, 2006). However, parents and teachers of children with a sibling often report
that the typically developing sibling tends to exhibit increased warmth, patience, empathy, maturity, and self-control compared with children who do not have a sibling who is living with a disability (Ross & Cuskelly, 2006; Mandleco, 2003).

**3.6 Perceived Impacts of COVID-19**

This study took place during the COVID-19 pandemic and therefore in-person recreation programs were suspended. As such, it was important to consider both how family recreation programs affect families and how the loss of recreation opportunities impacts family relationships in families who have a child or adolescent living with a disability. Families with a child who is living with a disability reported increased stress and perceived less social support than families with typically developing children during the pandemic (Neece et al., 2020). Parents reported increased anxiety for themselves and their child living with a disability (Ashbury et al., 2020) and worry about the long-term impacts of the pandemic on their child’s mental health and social engagement opportunities (Neece et al., 2020; Ashbury et al., 2020). Given that increased participation in PA contributes to improved emotional functioning (Martin, 2013), losing PA opportunities during the pandemic may have reduce options for managing stress. Parents have reported that the opportunity for families including a child living with a disability to spend more time together was a positive outcome of the pandemic (Neece et al., 2020). But overall, COVID-19 is a challenging time, and may be especially so for families who include a child living with a disability.

**3.7 Purpose**

The purpose of this study was to examine family members’ perspectives regarding family relationships as they relate to participation in an adapted summer camp for families with a child living with a disability. Children and adolescents living with a disability may rely more on their
families than their typically developing peers, thus it is important to expand the focus to examine how recreation experiences impact not only the child but also the experiences of their family members (Patterson, 1991). The COVID-19 pandemic began during the planning stages of this study. As a result, the 2020 camp was cancelled and this study focused on families who participated in the 2019 adapted summer camp. Families included both children (under 10 years of age; World Health Organization, n.d.) and adolescents (10 to 19 years old; World Health Organization, n.d.) living with a disability. However, while discussing results in this paper we will refer to the individual with a disability as the child living with a disability to identify their role within the family. This study aimed to address the following research questions: (a) how are family members’ perceptions of family relationships affected following participation in a family adapted physical activity camp, and (b) what are families’ experiences regarding family relationships after losing the opportunity to participate in an adapted physical activity camp due to COVID-19?

3.8 Methods

3.8.1 Methodology and Design

A collective case study was conducted in which each family participating in this study was treated as a case (Hodge & Sharp, 2016; Goddard, 2012) and experiences were examined within and across families (Hancock & Algozzine, 2006). Focus groups were conducted separately with each family at one time point. We used a relativist ontology and constructivist epistemology to frame the study. A relativist ontology acknowledges that there are multiple realities, and reality is socially constructed through human experiences (Creswell & Poth, 2013). A constructivist epistemology acknowledges that knowledge is gained through interactions with others (Lee, 2012).
3.8.2 Program

Rocky Mountain Adaptive is a non-profit organization based in Canmore, Alberta. The aim of this organization is to make outdoor activities accessible to individuals with disabilities through a variety of programs. This study focused on their Friends and Family Camp, where families participated in outdoor activities alongside their child who is living with a disability. At this week-long overnight camp families participated in hiking, biking, and kayaking activities during the day. Activities were facilitated by access to adaptive equipment and by staff with experience adapting activities. Families each had their own cabins, where they cooked all their own meals and were able to spend family time when no activities were scheduled. Social hours and campfires are also offered every evening, and gave families the opportunity to socialize with one another. Participants for this study had attended the camp in 2019 and were unable to take part in 2020 due to the program being suspended due to COVID-19.

3.8.3 Participants

Total population sampling (Morse, 1991) was conducted (October 2020 – January 2021), meaning that all nine families who went to the camp in 2019 (August, 2019) were contacted by Rocky Mountain Adaptive and asked for their consent to be contacted about the study. Six families gave consent to contact and five families participated in this study. In these families five mothers, five children living with a disability (female = 3, male = 2), and three male siblings participated. At the time of the focus groups mothers were 45-53 years of age, siblings were 7-12 years old, and the children living with a disability were 10-18 years old. In all cases the siblings were younger than the child living with a disability. All families spoke English as a first language, all mothers, siblings, and the majority of children with a disability identified as Caucasian, with one child with a disability identifying as Latino and Caucasian. Three mothers
were married, one was separated, and one was widowed. Two fathers attended the camp with their family; however, they were unavailable at the time of the focus group. The children had a variety of disabilities including Cerebral palsy, Down’s Syndrome, Cognitive Disability, and Rare Genetic Conditions. One individual with a disability was a wheelchair user, the rest were all ambulatory and all experienced an intellectual disability.

3.8.4 Positionality

I am a Caucasian female in her twenties and has worked with individuals living with a disability in a variety of contexts. I do not have a disability and do not have a family member living with a disability and I am very active in my everyday life. I had worked as a camp coordinator at the adapted program described in 2019 and had previously met all families involved in this study. A reflexivity journal was used to address how the author’s past experience may influence the research process and in turn how the research influenced me (Berger, 2015).

3.8.5 Data Collection

Ethical approval was obtained from the University of Calgary Conjoint Health and Research Ethics Board (REB20-1429). Two adults with personal experience of living with a disability and supporting adapted recreational programs were consulted to review the focus group guide and demographics interview guide. The first author conducted a pilot focus group with a family with a child living with a disability who was not involved in the camp to obtain feedback about the focus group guide questions. Following the pilot focus group, families who attended the camp were contacted via phone by program staff and asked for their consent to be contacted by the researchers. The first author then called each family and invited them to participate in the study. After the families agreed to participate in the study, demographic information was collected by the first author via a 10–15-minute audio recorded telephone
interview with a parent from each family, but in all cases, it was mothers who participated in this interview. All mothers electronically signed a consent form or verbally consented to participate in this study before the start of the interview. This demographic information was collected to learn more about the child’s diagnosis and the family’s backgrounds.

Focus groups were conducted by the first author via Zoom with one family at a time, with all family members who agreed to participate in the study. Since, the mother’s consent was already obtained, consent and assent were collected from the rest of the family’s members prior to the start of the focus group. Audio recorded focus groups lasted 18 – 60 minutes ($M = 36$ minutes). These focus groups followed a semi-structured interview guide comprised of questions regarding the family’s experience at the camp, family relationships and family recreation during and after the camp, and the impact of the suspension of the camp due to the COVID-19 pandemic. Reflexive field notes were written after each focus group to document any potential emerging themes, the family’s interactions during the focus group, and any other aspects of the focus group that stood out to the researcher. Each family was given an alphanumeric code to indicate each family’s study number and family role (mother = M, child with a disability = C, sibling = S).

3.8.6 Data Analysis

All audio-recorded focus groups were transcribed verbatim. The first author analyzed the transcripts using reflexive thematic analysis to identify themes and patterns of meaning across the data set (Braun et al., 2016). Each transcript was first read and re-read to gain an understanding of the overall meaning. Then transcripts were read and initial codes were created to identify meaning pertaining to the research question. Once that process was complete for each family, the themes were compared and contrasted across families. It is important to note that
themes were interpreted in light of Bowen’s Family Systems Theory. The themes were then reviewed to check that coding was consistent across all cases. Names and definitions of the themes were then created. A report was written describing the participants’ perspectives, interpretations of the data across families and in light of theory and incorporating quotations to illustrate the findings (Braun et al., 2016).

3.3.7 Study Rigour

The rigour of this study should be assessed by criteria aligned with our constructivist philosophy, relativist ontology, case study design, and reflexive thematic approach (Burke, 2016). Transparency (which refers to whether readers can clearly understand the research process and demonstrating that research was done in an ethical manner) was addressed through having regular meetings with the second author where the research process was questioned and talked about and all themes were reviewed to help ensure the findings were reflective of the lived experiences of the participants (Burke, 2016). Resonance (which occurs when the readers are able to make connections between the findings and their lived experiences) was addressed through thick description, which refers to writing thoroughly descriptive accounts of the findings and including sufficient contextual information and quotations to evoke understanding of the meaning of the findings and help readers associate the findings to their own lived experiences (Burke, 2016). Credibility (which refers to whether findings represent the lived experiences of the participants) was addressed through a reflexivity journal where I (the first author) addressed how my interpretations and experiences may have impacted the research process and in turn how the research process has impacted me (Burke, 2016).
3.9 Results

There were eight themes describing ways in which the camp influenced family relationships, and three themes related to how family interactions changed as a result of COVID-19 and the suspension of the program.

3.9.1 Camp Influence on Family Interactions

*Reducing Isolation for Mothers Raising a Child with a Disability*

Most mothers discussed how attending the camp made them feel supported because they were around other families who have a child living with a disability. Raising a child who is living with a disability can be isolating, and attending the camp made mothers feel like they were not alone in dealing with challenges resulting from having a child living with a disability.

“Definitely made me feel not alone in our situation and having talked with other families about how they deal with certain things or solve certain problems. Or how they planned for the future, it felt really supportive.” (M4)

Mothers acknowledged that the journey of every family is different, but there are many commonalities, and they cherished being able to relate to other families through the camp.

“…everyone is totally different and unique and everyone has gone through different journeys with their kid but there are some similarities and it was nice to talk to people who had gone through similar things.” (M2)

Mothers appreciated and enjoyed the opportunity to talk about challenges they face with families who understand what it is like to raise a child who is living with a disability. This is a type of support families might not always get when socializing with families who have typically developing children.
Confidence to Participate in Family Activities Beyond the Camp

Families appreciated the opportunity to try new activities in a safe environment at the camp, which led them to greater confidence in their collective abilities to engage in recreation activities outside of the camp as well. As a result, several families now do more recreation as a family, which they really enjoy: “It’s great that I can do other activities now” (C3). Mothers reported that prior to attending the camp they felt nervous about trying activities as a family such as kayaking, hiking, or biking. Their anxiety used to hold them back from participating in activities, but after having the opportunity to try these activities in a safe environment, it increased their confidence and opened up new possibilities for recreational activities.

“…I’m comfortable in a kayak but I hadn’t been comfortable taking [child’s name] out just knowing my own capabilities being able to keep us in the boat and up right and if it were to tip over, having help get us back in the boat which we didn’t have happen thank goodness, but knowing that was there gave us the security to try something different so it was good.” (M4)

The same mother mentioned that they were able to go on a family canoe trip in the summer, something they never would have never thought imaginable if they had not attended the camp. Going to the camp increased their desire to try other activities, not just the ones from the camp. Having the opportunity to try accessible activities in a safe environment was very important to mothers and increased the families’ ability to participate in recreational activities together.

Joy with Seeing Confidence in Child with a Disability and their Siblings

Many families saw a change in the confidence of the child living with a disability. It gave mothers joy to see an increase in their child’s confidence. “It gives me happiness to see her confident and approaching people and talking” (M3). When asked by their mothers and/or
siblings if they feel more confident, most children or adolescents with a disability replied yes. Individuals with a disability may feel less confident in everyday life if they are unable to do many of the things that their family members do, so having an activity where they can participate and be successful may improve confidence. Seeing that increased confidence in the child with a disability also affected the siblings’ confidence in themselves. As one sibling stated, “[the camp] was actually a real self-esteem booster for me. Yeah, actually surprisingly it helped my confidence” (S1B). This increase in confidence seemed very important to the families.

**Reduced Daily Stressors and Anxiety about Physical Activity Increased Family Bonding**

While mothers typically did directly discuss daily stress associated with raising a child living with a disability in the focus group (with their entire family present), it was apparent from the discussions that the mothers typically did a lot of work and dealt with a lot of challenges to take care of their children. Furthermore, the mothers had anxiety regarding their child that is living with a disability participating in PA. Having an activity where they knew their child would be taken care of and safe relieved some of this stress, and allowed them to focus on bonding with their family. Since there were staff and volunteers at the camp to assist their child who is living with a disability, mothers were able to step out of their caregiver role of assisting their child and just focus on bonding with their children.

“It meant a lot to us because [child’s name]’s particular disability just usually means that he can’t participate at the same level. So, skiing or biking or almost any outdoor activity, if [child’s name] comes with us it usually requires me as the single parent to stay with him at all times. So, being part of the camp meant that with other volunteers we were able to. I can enjoy my other children on an activity just as much as being with [child’s name]
‘cause there was somebody else to kind of make sure that he was safe and kept up with the group.” (M4)

The camp gave families time to relax, since everything was taken care of for them. The typical anxiety the mothers felt was relieved while they were at the camp and the decrease in stress was instrumental in helping the families focus on bonding.

**Mutual Understanding, Communication, and Support**

The camp gave families an opportunity to spend uninterrupted time together and experience each other’s company in different PA settings than they were used to. These experiences contributed to a better understanding of each other, an increased willingness to participate in activities together, and feelings that they grew closer and became a stronger family. As one mother stated, “I think from my perspective, we’re stronger as a family” (M1). Family members felt like they improved their understanding of the child’s disability. Mothers discussed how this understanding improved the siblings’ patience with the child with a disability because they now understood more about their sibling personality.

“Yeah, again it’s the slowing down at camp and not having the tight schedule that we sometimes feel like we have here. So, they’re less rushed now when they speak to [child’s name] …And I can see how much more patient they are after having spent quality time with him at camp.” (M4)

This deeper understanding of each other allowed siblings to better communicate with each other, which lead to stronger sibling and family relationships.

**Sharing a Common Experience with the Child with a Disability**

Family members discussed how they are not always able to participate in activities with a child living with a disability because of the accommodations they may need in PA settings. The
camp provided these opportunities to participate together, and it allowed families to develop a common bond and shared memories, which resonated with them. Siblings enjoyed being able to include their sibling living with a disability in activities and it seemed that the siblings felt like they missed out on earlier opportunities to participate in PA with their sibling who is living with a disability. For example, in one focus group there were two typically developing siblings who seemed sad while they discussed how they used to feel as though a lot of their memories from participating in activities were between the two of them and they could not include their sibling who is living with a disability. When talking about participating in activities together one brother stated;

“I really like it and I kind of felt really happy for it because we could actually enjoy something together with our sister (C1). Rather than she enjoying it and [S1B’s name] and I not having a clue what she was doing or talking about. So, I really enjoyed it that we all could share fond memories of it and that we all enjoyed it together.” (S1A)

Many children with a disability also mentioned that they would prefer to participate with their family members rather than doing activities on their own. When asked by their mother “Do you like doing activities on your own like when I drop you off somewhere or do it as a family?” (M5). The child with a disability responded “family” (C5). Conversely though, one child with a disability expressed that they would have rather participated in the camp without their family, because they would have enjoyed the opportunity to have more independence.
Independence of Child with a Disability Impacted Mothers’ Perceptions of Their Child’s Future

Most families saw an increase in independence for the child with a disability, which influenced the families in several ways. One mother discussed how after attending the camp her child now helps more around the house.

“…it makes him so happy; he gets so happy just being able to participate and so proud of himself and even now if he is downstairs watching a movie or playing with Legos, if I call him to tell him the dishwasher is ready to unload he’ll come upstairs right away, he doesn’t want anyone else to do it. That’s kind of his thing and he’s so proud of himself. It, yeah it’s really good.” (M4)

The camp was also a good scaffolding experience for the child to participate in more independent activities. One family discussed how their child who is living with a disability has talked about going to an overnight camp on their own, and how their experience with the family camp gave them an opportunity to see if that experience would be possible for their child.

The children living with a disability also discussed the joy they felt of being more independent, as opportunities for independence were sometimes less available to them. “It feels pretty good that I don’t need help like I used to when I was little” (C3). Mothers discussed how their child’s new found independence gave them relief, and more courage to plan for the future, including things they had not previously imagined.

“[Child’s name is] turning 18 in a couple of weeks …so we’re looking into transitioning into him being an adult which will involve different activities, different volunteer opportunities for him, possibly employment. Which will be a transition for the whole
family but I think the camp kind of helped us prepare for that and prepare for us to do that as a team so it was good.” (M4)

After seeing this increase in independence, it was clear that the mothers felt like their child was capable of more they may have originally thought.

**Sibling Bonding made Parents Comfortable Giving Siblings Responsibility to Support the Child with a Disability**

As the siblings spent more time with their sibling living with a disability and understood and communicated with them better, mothers recognized that their typically developing children were better equipped to support their sibling who is living with a disability. This increase in ability to support led to parents feeling more comfortable giving their typically developing children more responsibilities with their sibling who is living with a disability.

“Yeah, and then last year during the school year they would all go to a day camp.... I didn’t have any aid support to send with [child’s name] so the boys often had to give her extra support or help out a little bit so she was doing what the group was doing. And I think that after the camp and after they saw how maybe to interact in a little bit different way to provide some guidance, it helped out when I needed that help.” (M1).

Mothers expressed relief being able to have their other children help support their sibling who is living with a disability. The camp gave the mothers an opportunity to access this additional support that was already in their household.

**3.9.2 Family Interactions during COVID-19**

**Families Isolated**

The families no longer had the camp or any activity to participate in with other families with children living with a disability. Families felt left out from activities, as there were even
fewer opportunities than were available to families that do not include a child living with a disability during the pandemic. Mothers felt isolated during normal times as a result of raising a child with a disability, but this feeling of isolation had been heightened during the pandemic.

“Just challenges in like, we just haven’t had a break. And it would have been so nice to go camp. Like we can’t, like we just can’t go camp, like regular camping unfortunately. So just not being able to camp. And I know there’s tons of other families that have been going camping and stuff so we just kind of felt left out.” (M2).

Some families were unable to leave their house at all because of their child’s specific medical needs. This feeling of isolation seemed to have a strong impact on the families. Some mothers’ tone of voice expressed a sense of desperation when discussing this isolation, and the lack of certainty about how much longer they would need to carry on in these conditions.

**Effects of the Camp Fading as a Result of the Camp Not Running**

Families noticed that some of the positive impacts the camp had on family relationships were declining as they were not able to attend this year, and their families fell back into old habits. Mothers seemed deflated when talking about how their typically developing children seem to have lost patience for their sibling living with a disability.

“Well, I think those regular intervals of stepping away are super important. And the longer you go between intervals, the easier it is to kind of fall back into your bad habits of normal ways of rushing through things. And when you have a good experience, you can come back home with different intentions and it can last a little longer.” (M4)

Families had fewer opportunities to do activities together. “…this year just seemed really off because we didn’t have that opportunity to go camp. Like we did lots of activities separately.” (M2).
Mothers Exhausted and Defeated by Difficulties Planning Activities for their Children

The children and adolescents with a disability struggled with the lack of activity due to the COVID-19 pandemic. Many of the children expressed how they were feeling lonely.

“How does it make you feel?” (M1)
“I don’t like it, I feel lonely” (C1)
“You feel lonely” (M1)
“I’m so sad.” (C1)

Seeing their child struggle led to mothers feeling pressure to plan developmentally appropriate and engaging activities for their children. It was clear when mothers discussed the effects of the pandemic that they felt exhausted from having to plan all their children’s activities, in addition to the increased workload that all parents faced due to COVID-19.

“It was a full-time job, I went from being busy to, being insanely busy trying to do home schooling, and you know there was less driving so it was actually we had more time to fill. Which can be good and bad trying to just mentally come up with the energy to think of things to do that everyone would enjoy or think of things to do to keep everyone active or at least going outside once a day.” (M4)

The loss of activities due to public health restrictions made it even harder than usual for parents to find appropriate programs and engaging activities for their children with a disability. Mothers seemed as though they were putting a positive spin on the situation when discussing it in the focus group in front of their children, but it seemed that they were exhausted from having to plan everything without the same PA programs that their child would typically participate in.
3.10 Discussion

Family Relationships

The purpose of this study was to examine family members’ perspectives regarding family relationships as they relate to participation in an adapted summer camp for families with a child living with a disability. After attending the camp families felt as though they were able to develop a better understanding of one another, due to an increase in participating in recreation together. This sense of understanding had increased the family members’ abilities to support one another. It especially gave family members a better understanding of how to effectively support the child with a disability. Support from family members is very important to individuals living with a disability because they may not always feel supported because of the different forms of disablism they face in everyday life (King et al., 2006; Martin, 2013). Support within the immediate family is associated with better psychological and social well-being and lack of support from family members may cause the child living with a disability to feel angry, which may then decrease their emotional well-being (King et al., 2006). Support and communication may have an impact on the family members emotional functioning, thus impacting the nuclear family emotional system (Brown, 1999). The camp gave family members the ability to support one another and families experienced changes in family communication and functioning.

Family members grew more patient with the child living with a disability and learned how to communicate with them more effectively. Since family members were not always able to participate in PA with the living child with a disability, attending the camp gave them a better understanding of how to communicate in this type of setting. Communication is an effective way to decrease familial stress and behavioural problems in children living with a disability and their siblings (King et al., 2006). Families experienced positive changes regarding family
relationships, however the camp being unable to run in 2020 led to negative outcomes for family relationships. Families felt as though some of the positive changes they experienced were lost due to not being able to participate in the camp. Not being able to participate in recreation during the pandemic has had a strong impact on family relationships (Neece et al., 2020), which was apparent in how mothers discussed feeling that their family members were becoming impatient with each other.

**Parental Stress**

Families raising a child who is living with a disability tend to face higher levels of stress when finding recreation programs, in part because parents tend to worry that programs won’t be accommodating of their child with a disability (Scholl at al., 2003). Parents engage in a considerable amount of labour to overcome certain barriers to participation (Goodwin & Ebert, 2018). Having an activity where the mothers knew that their child would be safe and well accommodated for decreased the amount that the mothers were transmitting their anxieties onto the child living with a disability (Brown, 1999). Attending the camp was an opportunity where parents could relax knowing their child who is living with a disability would be accommodated. This ability to relax gave mothers an opportunity to step out of their typical caregiving role, which allowed them to focus on family bonding. Having an activity that was accommodated for their child decrease the presence of the societal emotional process, through decreasing the amount of stress society causes on the family system (Brown, 1999). However, finding appropriate programs and activities has become particularly difficult due to the COVID-19 pandemic. Parents are facing increased stress and worry about their child’s opportunities for social engagement (Ashbury et al., 2020). It was clear throughout this study that mothers were
becoming increasingly worried about their ability to provide engaging recreation opportunities for their child.

**Sibling Relationships**

Children and adolescents living with a disability and their siblings do not always have an opportunity to participate in recreation together because of the accommodations the sibling who is living with a disability may need (Mactavish & Schleien, 2004). Having an opportunity to participate in activities together increased the typically developing siblings’ understanding of their sibling’s disability. This understanding contributed to the siblings experiencing patience and communication with their brother or sister. Typically developing siblings often enjoy and value supporting their siblings with a disability in athletic endeavours (Blazo et al., 2014). A similar effect was found in this study in how excited siblings were to have the opportunity to participate in recreation with their sibling living with a disability. In some studies, typically developing siblings have reported unpleasant experiences when participating in PA with their brother or sister living with a disability due to communication difficulties (Pit-Ten Cate & Loots, 2000). In contrast, participants in this study suggested that participating in recreation together when the child with a disability’s needs are accommodated can enhance sibling communication. This increase in communication and understanding led to an increase in the sibling’s responsibility to support the child living with a disability. Since all siblings in this study were younger than the child with a disability, this demonstrates that sibling position and the roles siblings have in those positions may not look the same in families who have a child living with a disability since that child may require additional supports from their younger siblings (Brown, 1999).
3.11 Limitations

The need to conduct all focus groups via Zoom rather than in person due to COVID-19 may have impacted the first author’s ability to establish rapport with the families. Technical issues and not being able to see all family members also limited rapport. Since the focus groups were conducted more than a year after the families were last able to participate in the camp, participants’ may not have been able to recall some details of the camp. However, this time lag may have allowed the participant to reflect on longer-term impacts from participating in the camp. Since the focus groups were conducted with all family members together, participants may not have felt comfortable sharing some perspectives. It seemed that the mothers were holding back some perspectives so as to not hurt or upset their child. However, the focus group design provided the opportunity to examine families interacting with each other. No fathers participated in this study, and therefore the results may not be reflective of fathers’ views. It should be noted that while thick description was attempted there are inherent limitations within the study that made achieving thick description more difficult. We acknowledge that the first author previously knew the families beforehand, and as a result families might have a sense of what she wanted to hear. However, this may have established an increase in rapport between participants and the researcher. These limitations being the limited focus groups and the depth of information provided by the participants.

3.12 Conclusion

The findings from this study suggest that participation in a family adapted PA camp may impact family relationships in families who have a child living with a disability. This can occur through families feeling supported and experiencing a reduction in daily stressors, a better understanding of one another, common memories between all family members, and an increase
in sibling bonding. Further, youth living with a disability experienced higher levels of confidence and independence. In addition to confirming that participating in family recreation can have perceived positive effects on family relationship in families who have a child living with a disability, this study adds to the limited body of research regarding family relationships as they relate to PA by showing the mechanism that may lead to positive impacts on family relationships. Future research should continue to explore how family recreation for families with a child living with a disability can impact family life, through engaging community partners to increasing development of family focused recreation programs.

3.13 Acknowledgments

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Chapter 4: "We're a lot closer, we talk more": Family experiences and relationships following child's participation in an adapted physical activity camp

4.1 Abstract

Children and adolescents with developmental challenges may rely on their parents for assistance with everyday tasks to a greater extent than typically developing children. The objective of this study was to examine family members’ perspectives regarding family relationships as it relates to participation in an adapted summer camp for children and adolescents living with a disability. A collective case study was conducted with eleven families who had a child living with a disability who participated in an adapted physical activity (PA) summer camp. A focus group was conducted with each family and thematically analyzed. Following the camp, families experienced a change in perspectives and pride surrounding adapted PA, child’s confidence changed family conversations about disability, less perceived parental worry and more independence of the child living with a disability, family PA changed child’s bonds with parents and siblings, loss of camp due to COVID-19 associated with frustration and worry, and strained family relationships. These findings can be used to better understand how participation in adapted PA for children and youth with disabilities can impact family relationships.
4.2 Introduction

Physical activity (PA) has numerous physical and psychosocial benefits, including enhanced self-esteem and self-efficacy (Martin, 2013). However, children and youth living with disabilities are less likely to meet PA guidelines when compared to their typically developing peers because they may face limitations when accessing recreation programs, such as environmental barriers such as inadequate transport or facilities, poorly maintained outdoor areas (Williams et al., 2014). Many studies outline the psychosocial benefits of PA, such as an increase in self-esteem for children and youth living with disabilities, but there is little research that focuses on how these potential benefits impact their family relationships. Families caring for children with disabilities may experience greater parental stress, isolation, frustration, and financial challenges compared with families caring for typically developing children (Columna et al., 2020; Ono, et al., 2019). Research regarding adapted PA for children and adolescents with disabilities tends to focus on how adapted PA impacts the child or youth who participates, but there is limited research examining how the benefits gained from PA participation may impact family relationships. There is a need for research that goes beyond these benefits and examines how benefits gained from PA may impact the family relationships of the child who participated. A better understanding of these perceived impacts could inform future programs to better support family relationships. Families can include both children (under 10 years of age) and adolescents (10 to 19 years old; World Health Organization, n.d.) living with a disability. Therefore, when referring to prior research on the experience of young people living with a disability, we use the terms children and adolescents, as applicable. However, “child” also refers to the relationship between an individual and their parent, and therefore when discussing the family context and relationships among participants in this study we refer to the individual living with a disability as
the child living with a disability, and their brothers and sisters as siblings, because we are referring to their positions within the family.

4.3 Conceptual Framework

This study will be informed by both the social relational model of disability (Reindal, 2008) and Bowen’s family system theory (Brown, 1999). This social relational model of disability views disability as something that occurs in the individual but is manifested through social interactions (Haslett & Smith, 2020). This model considers both the biomedical and social roots of disability and states that whether an impairment becomes a disability is due to socially imposed restrictions. (Haslett & Smith, 2020). One key tenant of this model is the concept of disablism. Disablism can be defined as socially imposed restrictions and is a form of social oppression (Haslett & Smith, 2020). In the context of this model, disability is viewed as being unable to participate in certain activities as a result of both the individual’s impairment and societal factors (Haslett & Smith, 2020).

There are three types of disablism discussed in this social relational model of disability; structural disablism, psychoemotional disablism, and internalized oppression. Structural disablism is the exclusion from activities and services due to one’s impairment and a lack of accommodations in those settings. An example of this is when families are unable to find appropriate recreation programs for their child living with a disability (Tsai & Fung, 2009).

There are two sources of psycho-emotional disablism; direct and indirect. Indirect psychoemotional disablism recognizes the psycho-emotional consequences of not being able to participate in opportunities due to one’s impairment. An example of this is when a child is left out and isolated from participating in a certain activity because of their impairment. Direct psychoemotional disablism recognized the emotional consequences when an individual
experiences look, words, or actions that are patronizing towards them, such a child feels ignored as a result of their impairment. Internalized oppression refers to the harsh relationships an individual living with a disability might have with themselves as a result of living in a society that is not well accommodating of their needs (Haslett & Smith, 2020; Reeve, 2014). These types of disablism may impact children and youth living with a disability’s willingness and ability to participate in recreation opportunities. Adapted PA attempts to create a positive environment that is well accommodating of individual impairments and through this accommodation attempts to limit the previously discussed forms of disablism. The disablism experienced by the child living with a disability may impact the entire family.

Bowen’s family systems theory assumes that all family members are impacted in some way by the disability that one member of the family has; therefore, it is important to understand how each family member functions in families that have a child with a disability (Townsend & Van Puymbroek, 2017; Trivette, Dunst, & Hamby, 2010). Bowen’s family systems theory provides insight into how families interact with one another and affect each other within the societal context that was laid out by the social relational model of disability. This theory focuses on patterns in a family that are created and used to reduce a family’s anxiety, and how each family member functions within the family system (Brown, 1999). The amount of anxiety in a family is related to the amount of societal stress families may experience. Societal barriers; such as not being able to access adequate health care or recreation programs, make it difficult when raising a child with a disability and cause increased stress and anxiety on the family system (Patterson, 1991). This theory also discusses the roles each family member has in the family systems and how these roles are forged throughout the lifetime (Brown, 1999). Within the context of this theory family is defined as a relationship where individuals are emotionally reliant
on one another and support each other throughout the lifetime (Bavel & Segal, 1982). This theory suggests that since families are emotionally reliant on one another, the actions of one individual within the family may impact the others in the system. (Brown, 1999).

Bowen’s family systems theory is informed by eight interrelated concepts (1) differentiation of self, when an individual begins to make more autonomous decisions while still remaining emotionally connected to the family; (2) triangles, which are three-person relationships that are less vulnerable to stress than dyads; (3) nuclear family emotional systems, which identify relationships that affect the emotional functioning within the family; (4) family projection processes, which occur when one child is less emotionally separated from the family than the other children in the family and one parent projects their anxiety towards this child; (5) emotional cuttoff, when one individual is no longer emotionally connected to the family; (6) multigenerational transmission processes, when familial roles are forged throughout generations; (7) sibling positions, which refer roles each sibling may have based on their position in the family; and (8) societal emotional processes, which refers to when societal barriers cause stress on the family (Brown, 1999; Haefner, 2014). Bowen’s family system theory provides insight into the interaction that occurs in each family system to reduce anxiety. This provides an opportunity to examine how families perceive a change in these interactions following adapted PA participation.

4.4 Physical Activity for Children and Adolescents Living with Disabilities

There are a number of barriers children with disabilities face that limit their engagement in PA, such as medical, environmental, family and social barriers (Martin, 2013). Many community recreation programs are not well equipped to accommodate the needs of individuals with disabilities (Scholl et al., 2003). Environmental barriers such as inadequate transportation or
facilities, poorly maintained outdoor areas, and lack of assistance for mobility conditions can contribute to structural disablism and impact participation in recreation programs for children and youth living with disabilities (Haslett & Smith, 2020; Williams et al., 2004). Because our society often does not adjust to the impairments of individuals with disabilities there are limited opportunities for PA participation (Martin, 2013).

Parents and peers affect childrens’ and adolescents’ participation in PA. Negative parental attitudes toward PA, such as lack of parental support and parental fear are a barrier to participation, particularly for children with disabilities because they tend to rely on their parents to facilitate their PA involvement (Shields & Synott, 2014). The literature has shown that parents with children with disabilities may value PA and recognize the benefits (Columna et al., 2020). Parents often have little time or energy to find appropriate recreation programs for their child living with a disability because they tend to spend considerable amounts of time advocating for their child in other settings. Such as advocating for their child medical and educational needs, as there may be a lack of accommodations in these settings (Scholl et al., 2003; Martin, 2013).

Having strong social bonds is fundamental to maintaining a positive quality of life (Tsai & Fung, 2009). PA provides opportunities for children and youth with disabilities to increase social connectedness (establishing close relationships with others) and social integration (the process where individuals are incorporated into the social structure of society), and to develop new friendships (Martin, 2013; Lee, Draper, & Lee, 2001; Van Alphen et al, 2010). Furthermore, social bonds may influence sustained and longer-term participation in PA (Tsai & Fung, 2009). However, children with disabilities have found PA participation difficult when they do not have friends and peers with whom to participate in programs (Tsai & Fung, 2009). Adapted recreation programs give children and adolescents with disabilities the opportunity to gain a sense of
belonging through shared experiences with peers who also have a disability. When children and adolescents with disabilities connect with peers who have similar experiences it allows them to feel more comfortable and not worry about judgement from others (Martin, 2003; Willis et al., 2017).

4.5 Family Relationships

Since societal barriers may make it difficult when raising a child with a disability there may be profound impacts on the family when one child has a disability. As a result of the child’s impairment and the societal barriers that the child faces, a large proportion of family resources tend to go towards that child (Haefner, 2014). Raising a child living with a disability may also have profound positive impacts on the family. Most parents who have a child living with a disability have reported benefits that are related to raising a child living with a disability (McConnell et al., 2015). Parents raising a child living with a disability tend to perceive that it has led to an increase in their patience, understanding of others, becoming stronger as a family, and more resilient. (McConnell et al., 2015; Townsend & Van Puymbroek, 2017). Families raising a child with a disability have also reported positive outcomes, such as higher levels of cohesion, stronger family bonds and less family conflict when they have access to the necessary supports and are surrounded by a supportive social network (McConnell et al, 2015; Townsend & Van Puymbroek, 2017).

Siblings play a particularly important role in the development of their brother or sister living with a disability because they are each other’s role models and social partners (Mandelco et al., 2003). Siblings have reported enjoying doing activities with their brother or sister living with a disability. However, siblings have also reported unpleasant experiences when doing things with their sibling living with a disability because of difficulties in communication (Pit-Ten Cate
Individuals who have a brother or sister living with a disability have been shown to show an increase in maturity, self-concept, and tolerance (Pit-Ten Cate & Loots, 2000). Typically developing siblings acknowledge that their brother or sister living with a disability needs more attention because of the barriers they may face on a daily basis but they acknowledge that their parents attempt to treat everyone equally (Pit-Ten Cate & Loots, 2000). Siblings with a brother or sister living with a disability may be at risk of developing internalizing behaviour difficulties (Ross & Cuskelly, 2006).

4.6 Purpose

The purpose of this study was to examine family members’ perspectives regarding family relationships as it relates to participation in an adapted summer camp for children and adolescents living with a disability. Research examining experiences with adapted PA tends to focus on the perceived impacts on the child living with the disability and less on perceived impacts on other family members and/or the family as a whole. Research examining experiences with adapted PA tends to focus on the perceived impacts on the child living with the disability and less on the perceived impacts on other family members and/or family as a whole. For children and adolescents living with a disability the family may be their primary social context, thus it is important to expand the focus to examine how recreation experiences impact not only the child or adolescent living with a disability but also the experiences of their family members (Patterson, 1991). The planning stages of this study occurred during the COVID-19 pandemic. Thus, we found it important to examine how the loss of PA programs for children and adolescents living with a disability impacted family relationships. This study aimed to address the following research questions: (a) how do family members perceive that their family relationships are affected by a child’s participation in an adapted physical activity camp, and (b)
what are families’ experiences regarding family relationships given the cancellation of the adapted physical activity camp due to COVID-19?

4.7 Method

4.7.1 Methodology and Design

A collective case study design was conducted, where each family who participated in this study was viewed as a case (Hodge & Sharpe, 2016; Goddard, 2012). The philosophic approach for this study was framed by a relativist ontology and constructivist epistemology. A relativist ontology acknowledges each individual has their own reality which is formed as a result of the impact of their lived experiences (Creswell & Poth, 2013). A constructivist approach acknowledges that knowledge is gained through the interactions we have with others (Lee, 2012). Through this design we were able to examine and compare and contrast the experiences of each family. Focus groups were conducted at one time point with each family.

4.7.2 Program

The program that was being examined in this study is the Adapted Sport and Recreation summer camp that was conducted through Active Living, Faculty of Kinesiology, University of Calgary, Calgary, Alberta. Children and youth with physical disabilities participated in a variety of adapted programs including tennis, athletics, swimming, sledge hockey, dance, karate, wheelchair rugby, dance, climbing, quidditch, gymnastics, and wheelchair basketball. All activities that were offered at the camp were facilitated by organizations within the city of Calgary that offer these programs. The aim of this camp was to encourage long term engagement in PA for children and youth living with physical disabilities. There were two separate one-week camps that were run: week one is for children entering grades 4-7, and week two is for adolescents entering grades 7-12. A video was provided to each family showing the activities the
children and adolescents were doing at each camp. Due to the COVID-19 pandemic this camp was cancelled in the summer of 2020. As a result, participants for this study were drawn from the children and youth who attended the camp in 2019.

4.7.3 Participants

There were forty children who attended the camp, and twenty-three consented to participate in future research. I (the first author) called all families who agreed to participate in future research and eleven families agreed to participate in this study. Participant recruitment was done between November 2020 and January 2021. Twelve (5 female, 7 male) children living with a disability (in one family both children had participated in the camp), eleven mothers, six fathers, and six (5 female, 1 male) siblings participated. At the time of the focus groups, children living with a disability were aged 11-17, mothers were aged 39-53, fathers were between the ages of 46-59, and siblings were 10-16 years old. In ten of the families the parents were married, with one family having divorced parents. The majority of families spoke English as a first language (8 mothers, 3 fathers, 4 siblings, 11 children living with a disability). Other first languages that were spoken were; Croatian (1 mother), Spanish (1 mother, 1 father), Urdu (1 mother, 1 father, 2 siblings, 1 child living with a disability), and Italian (1 father). The children had a variety of disabilities including cerebral palsy, visual impairment, spina bifida, and one individual was undiagnosed.

4.7.4 Positionality

The first author is a female in her twenties who has worked with individuals living with disabilities in a variety of PA settings. I do not have a disability and do not have a family member living with a disability. PA is a very important aspect of my everyday life as I’m very
passionate about the benefits of PA. I was not able to attend the camp in 2019, therefore have no previous interactions with the participants.

4.7.5 Data Collection

Ethical approval was obtained from the University of Calgary Conjoint Health and Research Ethic Board (REB20-1429). Two adults who worked at the camp and who have personal experience living with a disability reviewed and provided feedback on the focus group guide and demographic interview guide in order to ensure that the questions were relevant to the experience of individuals living with a disability. A pilot focus group was then conducted with a family who has a child living with a disability who were not able to attend the camp to obtain feedback about the clarity and relevance of questions asked. The first author called the parents of each family who had a child who participated in the 2019 camp and had indicated their willingness to be contacted for future research studies, and invited them and their families to participate in this study. Once one parent agreed to participate and provided consent, I (the first author) conducted a 10–15-minute phone interview with a parent, in all cases it happened to be the mother, to collect demographic information about each family.

Since consent was already obtained from the mothers, consent or assent were obtained from the rest of the family members before the focus group started. One audio recorded focus group was conducted via Zoom with each family and lasted 21 – 56 minutes (μ = 38 minutes). Focus groups followed a semi-structured guide, which included questions regarding family relationships after the child’s participation in the adapted sports camp, the experiences of the family members seeing the child with a disability participate in the camp, and the loss of adapted PA camps due to the COVID-19 pandemic. Reflexive notes were taken by the first author after each focus group in order to document how her experiences impacted the study, and in turn how
the study impacted her. Each family was given an alphanumeric code to indicate each family’s study number and family role (mother = M, father = F, child with a disability = C, sibling = S).

4.7.6 Data Analysis

Each audio-recorded focus group was transcribed verbatim. The transcripts were thematically analyzed to identify patterns of meaning across the dataset (Braun et al., 2016). Thematic analysis is conducted in six phases. I (the first author) engaged with the data by reading one family’s transcript multiple times to get a sense of the overall meaning. The transcript was then re-read, and initial codes were created to identify meaning in the data that is relevant to the research question. These two steps were repeated with each family’s transcript. Next, the initial codes identified across all of the transcripts were organized so that codes with similar meanings were grouped together, and initial themes were generated (Braun & Clarke, 2019). Each theme was interpreted in light of Bowen’s family systems theory and the social relational model of disability. Initial themes were then reviewed to check that coding reflected participants expressed meaning and was consistent across the dataset. The themes were then named and descriptions were written. Finally, the report was written, including quotes to provide evidence of interpretations of the data (Braun et al., 2016; Braun & Clarke, 2019).

4.7.7 Study Rigour

The rigour of this study was judged against criteria that align with the relativist ontology and constructivist epistemology used in this study. Transparency refers to the research process being clear to the readers and was addressed through having regular meetings with the second author, where all themes were reviewed to help ensure that the lived experiences of the participants were well represented. This study aimed for resonance, which refers to the readers making connections between the findings and generalize those to experiences they have had in
their own life (Burke, 2016). We attempted to enhance resonance through thick description by attempting to provide a detailed explanation of the study through including quotations and description of contextual data so the reader could find similarities between findings and their lived experiences. Credibility helps to ensure that our interpretations of the data represent the lived experiences of the participants. Credibility was addressed through a reflexivity journal where the I (the first author) documented how I was impacted by the research process and intern how my influence and experiences impacted the study (Burke, 2016).

4.8 Results

Families see the child living with a disability in a different light

Before attending the camp, it was difficult for families to find appropriate recreation programs for their child living with a disability in their community. For some children this was their first time being able to participate in an adapted PA. The parents were overjoyed about having the ability to be able to provide a recreation opportunity for their child.

“I don’t think I’ve ever thought that she was limited. I think she was limited in the areas that she can actually participate. It’s those community services, there aren’t any. So, that’s the limitation, I think she can do a lot more than what she’s done… but again it’s the access part of it is what the limitation is.” (F9)

This new experience of the camp opened the parents’ and siblings’ eyes to how many adapted sports are available for individuals living with a disability. The child living with a disability and their parents were excited by all the sports that were available to the child living with a disability.

Parents and siblings felt proud of the child living with a disability after being able to see them succeed in an adapted PA setting. “It really helped, it gained parental pride that your child
was obtaining a higher level” (F3). Siblings mentioned how seeing the child living with a
disability participate in new activities made them feel very proud of their brother or sister. The
child with a disability was very excited to here that their sibling(s) were proud of them. The child
living with a disability exuded a sense of pride while they were discussing how they were able to
teach their family members about the sports at the camp. The children with a disability were also
very proud that they were able to try so many new sports and that they were able to succeed in
them. This pride seemed to be very important to the child with a disability because for some of
them it was the first time where they were able to not only participate in but succeed in adapted
PA. Family members seemed to bond over this sense of pride. It’s important to note that families
saw less of a change in family relationships and pride within the family if their child living with
a disability was already previously active in adapted PA before the camp.

Child is confident discussing their disability with their family members

All families reported that the child living with a disability seemed more confident after
attending the camp. Families felt that the camp gave children living with a disability the
opportunity to increase their confidence through participating in adapted PA on their own and
through the social interactions they had at the camp. The families felt that the confidence
affected how they discussed the child’s disability and the child’s overall comfort surrounding
their own disability.

“I think he’s, with us has felt more comfortable talking about his disability, like, and just
owning it and it being something that just, you know, it doesn’t, like, if it’s not going to
work for him now, he doesn’t feel like, oh, it has to change for the whole family. He just
says look guys, you know, I need some help with this. Or, I don’t think that’s going to
work, I’d like to try it but like, oh, to be realistic, I don’t think that one’s going to work for us. So, I think he’s found his voice a little more.” (M7)

Parents felt like the change in confidence they saw in their child made their child become more outspoken and comfortable talking their family members.

“He became more outspoken, more willing to approach people. So that would almost link into confidence really. Confidence in himself gave him the ability to talk to different age categories and different people.” (D3)

One mother also mentioned how her child feels comfortable advocating for themself. This was very important to the mother as it was something, she used to always do for her child. The child living with a disability being able to advocate for himself has made the family members believe that he is capable to take care of himself more.

**Parents felt comfortable allowing their child to be independent**

Many of the parents discussed how before the camp they often did not allow their child to participate in activities alone because there were worried about their child’s ability to succeed on their own without supervision or an aid. Attending the camp alone made family members realize that the child living with a disability is more capable of doing things on their own than their family members may have initially thought. Siblings discussed how before the camp they noticed that their family seemed afraid to let the child living with a disability do things on their own.

“It seems like sometimes we stay a bit afraid and we don’t let her do the things that we all know she could do and her doing stuff like that camp really stopped us from being so afraid and now she can do more stuff with us to.” (S10B)
Parents gave their child opportunities to be independent because they did not feel worried and anxious regarding the child’s independence. Mothers realized that it was important for them to let their child do more things on their own.

“I think that she is more capable of things. Instead of going, ‘Oh, let me do that, let me do that,’ I try to wherever I can say, ‘Oh, you try this.’ I will often come at our relationship like she is still a toddler or an infant because in some ways, yes. But I feel like I am giving her chances to try new things. Simple things like meal prep or turning the light off on her own instead of me reaching for it and that kind of thing. Taking the time, because it takes longer. Taking the time and knowing that she can do it and that it’s a good thing.”

(M8)

This independence made families realize that the child living with a disability could live a fuller life than they may have originally thought. Families felt like the child would be more capable of living independently in the future. The children living with a disability were also excited about being able to be independent.

**Family members have bonded with one another through participating in PA together**

Families reported that they do more physical activity together after seeing what the child living with a disability was able to achieve at the camp. Being able to include the child with a disability in family activities was very important for the families. Before participating in the camp, the families would typically find someone to watch the child with a disability when they were participating in physical activities as a family. “It’s just more inclusive. Like, we just don’t have the think like oh if we do this what are we going to do with [C5 Name]. So, it’s just nice at this time in our lives to include him” (M5).
Participating in PA together gave families members something new to talk about with the child living with a disability. As this participating in PA created common experiences and memories between the child living with a disability and their family members.

“I feel like we’ve gotten to know each other better and it’s been fun spending time with her because I don’t really get to see her because we go to different schools and stuff and then with everything going on, it’s just been nice to have some time” (C7)

Siblings were able to spend quality time together while participating in PA with each other. Before the camp siblings didn’t have activities that they participated in together so they spent minimal active time together. Family members also tried adapted sports after the camp. The child with a disability was very excited to be able to teach their typically developing family members about adapted sports. This perceived change family PA was very important to enhance family bonding and relationships.

**Families experienced frustration, worry, and strained family relationships**

Parents were sad and upset that their child was not able to attend the camp in the summer of 2020 as a result of the COVID-19 pandemic, as the camp had been important to their child and their child’s development. Parents were sad and disappointed that they weren’t able to provide their child with an activity or event to look forward to.

“…when you have an opportunity to give someone with disabilities something you look forward to and to not have that anymore, because she truly enjoys trying the new things, after she’s tried them, she enjoys it so being able to have something that she enjoys and looks forward to.” (M9)

Families felt lonely, helpless, and ultimately become impatient with one another. One mother mentioned how she was becoming worried about her child’s mobility as a result of losing
the camp. The children living with a disability were sad not to be able to participate in the camp, and thus, losing the change to participate activities that were designed for them and also not have those social connections they established at the camp. The absence of social interaction from the camp led to families becoming impatient with one another.

“People became a little more impatient with others because you don’t, activities and sport is such a great break to break up the monotony of things and you know it’s a great feeling of physical satisfaction but also it is a mental feeling of satisfaction so I think you miss that and you get into that” (M7)

It was clear that the camp was a big part of many of these families’ years and not having this to look forward to impacted the families in a variety of ways. It was clear that the families were very disappointed about this loss of an opportunity for their child to be physical active in an environment that was designed for them.

4.9 Discussion

The purpose of this study was to examine family members’ perspectives regarding family relationships as it relates to participation in an adapted summer camp for children and adolescents living with a disability. Families experienced a change in family members perceptions of the possibilities available for the child living with a disability, change in conversations surrounding disability, change in levels of parental worry towards child participation in sport, changes in family members perceptions of their ability to participate in family PA. Furthermore, families noticed a change in confidence and independence in their child after attending the camp. Families also experienced feelings of hopelessness and isolation, as a result of being unable to attend the camp in because of the COVID-19 pandemic.
Families mentioned how they now participate in adapted PA more as a family. Family members feel as though this increase in family time has changed their perspective on the bonds with other family members. Parents of a child or adolescent living with a disability may see family recreation as a positive way to increase the overall quality of family life and enhance family relationships (Mactavish & Schleien, 2004). Families who participated in the study experienced closer sibling bonds because they were now spending more time together and now had more things in common after participating in PA together. Before attending the camp, siblings did not typically participate in recreation because families were unaware of how to accommodate certain activities for their child living with a disability. Typically developing siblings often enjoy and value supporting their siblings living with a disability in athletic endeavours (Blazo et al., 2014). For many individuals with disabilities, sharing an enjoyable experience with others is vital for successful participation (Heah et al., 2006).

Family members mentioned how they typically experienced worry and anxiety around the child living with a disability participating in PA on their own. Families raising a child who is living with a disability tend to face higher levels of stress when finding recreation programs, in part because parents tend to worry that programs won’t be accommodating of their child living with a disability (Scholl at al., 2003). This is seen through the family projection process when one parent may project their anxiety onto one individual of the family, this may be the child living with a disability (Brown, 1999). The children living with a disability who participated in this study usually had aids or family members there to help them in recreation settings. Not having aids at the camp allowed parents the opportunity to see what their child was able to achieve on their own. Family members believe this ability to see the child participate on their own is associated with a decrease in parental worry surrounding the child doing things on
their own. PA can be a channel for children and adolescents with disabilities to gain independence through a meaningful and healthy activity (Groff & Kleiber, 2001). Parents reported giving their child living with a disability more opportunities to be independent following the camp. Independence may lead to a child or youth living with a disability’s increased perception of control over their environment (Heah et al., 2006).

Families noticed a change in confidence in their child with a disability after attending the camp. This increase in confidence led to the child living with a disability being more open to talking about their disability with their family members. Open communication surrounding the child’s disability is important since typical developing family members have a different experience than the child living with a disability. Therefore, they may not always be able to understand exactly what the child with a disability need (Caldwell, 2010). Parents may unknowingly contribute to their child’s internalized oppression if they do not communicate with the child and ask what supports they feel they need (Caldwell, 2010). This reported change in comfort surrounding talking about their disability was also reported by families to have led to the child living with a disability to feel more comfortable advocating for themselves. Advocating for one’s self may have a perceived impact on individuals living with a disability positive self-concept and disability identity (Caldwell, 2010). The child living with a disability being more comfortable advocating for themselves made take away the need for parents to regularly advocate for their child. This increase in ability to self-advocate may aid in the child’s differentiation of self (Brown, 1999) through the child making more autonomous choices about their needs and communicating those to others.

After the camp being cancelled due to COVID-19 family members missed the positive experiences they associated with their child’s participation in the camp. Parents were upset that
their child would not have the positive social interactions they previously had at the camp. Families tend to worry about their child’s long term mental health and social engagement (Ashbury et al., 2020). Families experienced strained family relationships, which they felt were connected to this decreased social engagement. Social engagement through PA opportunities can also be an important way to enhance the self-esteem and self-confidence of individuals living with a disability (Martin, 2013). Thus, not having this opportunity may have affected the child’s confidence, and ability to be independent and advocate for themselves.

4.10 Limitations

Limitations in this study include selection bias because we are only getting the perspective of the families who volunteered for this study. Therefore, the findings may not represent the full range of families’ experiences. It was necessary to conduct all focus groups via Zoom rather than in-person due to the COVID-19 pandemic, and this online format made it more challenging to establish rapport with families. The first author was also unable to spend time at the camp to meet the families and develop rapport before conducting the focus groups, because the camp was not offered in 2020 due to COVID-19. Furthermore, since focus groups were conducted over a year after the child’s camp participation in 2019, it may be difficult for family members to remember all of their experiences during the camp. However, this delay between camp participation and the interviews did provide an opportunity to hear about families’ perspectives on the longer-term implications of camp participation. The decision to use focus groups rather than individual interviews also introduced the limitation that some participants may not have felt comfortable sharing their full experience in front of their family members.
4.11 Conclusion

The findings of this study suggest that there may be positive implications for family interactions and relationships associated with participation in adapted PA camps. The ways in which family members experiences changes in their perspectives, conversations surrounding disability, parental worry, and pride in the child with a disability were important to the ways in which they interacted with and understood each other. Further, the confidence and independence experienced by the child living with a disability was meaningful to their own experiences, and interactions within their families. This study adds to the limited body of research regarding family relationships as they relate to a child’s adapted PA participation. Further research should continue to examine how PA for children and youth living with a disability can impact family life, by engaging community programs to offer developmentally enhancing programs for children and youth living with a disability.

4.12 Acknowledgments

The authors gratefully acknowledge Vi Riddell Pediatric Rehabilitation Research Program, at the Alberta Children’s Hospital for providing funding for this study. We would also like to extend our gratitude towards University of Calgary Adapted Sport and Recreation Camp for supporting this research and the participants for sharing their experiences with us.
Chapter 5: Conclusion

5.1 Summary of Findings

The purpose of this thesis was to better understand family members’ perspectives regarding family relationships as they relate to participation in an adapted summer camp for children and adolescents living with a disability. Families in both studies experienced confidence and independence in the child living with a disability, stress reduction, family bonding, increase in family PA, and changes in sibling relationships. They also reported feelings of hopelessness and isolation as a result of being unable to attend the camp because of the COVID-19 pandemic.

Families in both studies experienced confidence in their child living with a disability. Low self-confidence has been cited as a barrier to PA participation for children and adolescents living with a disability (Wright et al., 2019). Therefore, this confidence experienced by the families may be a way to support PA participation in children and adolescents living with a disability. Families who attended the family camp noticed that the confidence experienced by their child living with a disability impacted the child’s willingness and bravery towards participating in PA. The families who had a child who attended the University of Calgary camp noticed that this confidence influenced their child’s ability to communicate about their disability. The children living with a disability felt more comfortable talking to their family about their disability and advocating for themselves. The opportunity to participate in the camp on their own gave the children and adolescents living with a disability the ability to advocate for themselves in a PA setting. The child living with a disability expressed comfort talking with their family about their disability, because they experienced confidence at the camp. Open communication surrounding a child’s disability is important since typically developing family members have a different experience in everyday life than the child living with a disability because they may not
Individuals living with a disability may be viewed as being limited in their ability to be independent because they may rely on their family members to help with daily tasks more than typically developing individuals (Martin, 2013). PA can be a channel for children and adolescents living with a disability to gain independence through meaningful and healthy pursuits (Groff & Kleiber, 2001). In both studies, families remarked at the independence demonstrated by their child living with a disability. Family members were surprised by what the child living with a disability was able to achieve and by how successful the child was in a PA setting. Parents reported giving their child living with a disability more opportunities to be independent following the camp. Independence may lead to perceptions of control over the environment among children and adolescents living with a disability (Heah et al., 2006).

Families raising a child who is living with a disability tend to face higher levels of stress when finding recreation programs, in part because parents worry that programs will not accommodate their child with a disability (Scholl at al., 2003). Parents who have a child living with a disability may not always encourage their child’s participation in PA programs as a way to protect their child from negative experiences they may have in such programs (Steinhardt et al., 2021). In both camps parents experienced lower stress and anxiety surrounding their child living with a disability participating in PA, which may contribute to positive perceptions of PA.
Positive perceptions towards PA are a facilitator of PA involvement of children and adolescents living with a disability (Steinhardt, 2021).

Mothers who attended the family camp commented that their experiences of relatively low daily stress allowed them to focus on bonding with their family. Parents typically feel the need to protect their child living with a disability from the barriers their child may face on a daily basis (Woolfson, 2004). Having an activity where the mothers knew that their child would be safe and accommodated decreased the anxiety the mothers felt towards their child participating in that activity. Appropriately designed and accommodating PA contexts may be an effective way to decrease the amount of anxiety parents transmit on their child living with a disability (Brown, 1999). Mothers had an opportunity to temporarily step back from their caregiver role and focus on bonding with their family. These findings were only discussed by families who attended the Rocky Moutain Adaptive Family Camp. If families perceive that they have strong bonds they may communicate more, which creates opportunities to build resiliency as a family (Al-Krenawi et al., 2011).

Family members participating in more PA together may be an effective way to enhance family bonds. Parents of a child or adolescent living with a disability may see family recreation as a positive way to increase the overall quality of family life and enhance family relationships (Mactavish & Schleien, 2004). Families started participating in more PA as a family after both of the camp experiences. After participating in either of the camp experiences families gained a better understanding of what their child living with a disability was able to achieve in a recreation setting. After this experience the families began to include the child living with a disability in more family recreation activities. For a child or adolescent living with a disability,
having the opportunity to participate in recreation activities with family members is important because it may mean sharing an enjoyable experience with others (Heah et al., 2006).

Children living with a disability and their siblings do not have as many opportunities to participate in recreation together because of the accommodations the sibling who is living with a disability may need (Mactavish & Schleien, 2004). In both studies parents discussed how the child living with a disability and their siblings typically did not participate in PA together because parents were worried about the child living with a disability. Siblings have reported enjoying doing PA with their brother or sister living with a disability (Pit-Ten Cate & Loots, 2000). Because parents felt less stress surrounding their child’s PA participation, parents included the child living with a disability in more family activities. This inclusion gave siblings the chance to spend more quality time with their brother or sister living with a disability. In both studies family members mentioned how the typically developing siblings enjoyed the opportunity to participate with their brother or sister living with a disability. Siblings had opportunities to communicate about and bond over their experiences together. Spending time together may increase the siblings’ positive support and emotional understanding of one another (Stormshak et al., 2009). For families experiencing significant stress, effective communication and problem-solving may also be challenged (Giallo & Gavidia-Payne, 2006). Therefore, siblings participating in PA together may be an effective way to enhance sibling bonds, communication, and support.

Families were disappointed in not being able to access the camps and these benefits due to program suspension during the COVID-19 pandemic. Not being able to participate in recreation during the pandemic has had a strong impact on family relationships (Neece et al., 2020), which was apparent in how mothers discussed feeling that their family members were
becoming more impatient with each other. Parents felt isolated and worried about possible long-term implications it may have on their child living with a disability. The lack of PA opportunities during COVID-19 has placed greater responsibility on families to facilitate PA for children living with a disability on their own (Yarimkaya & Esenturk, 2020). Parents often worry that they are unable to plan developmentally enhancing PA for their child (Yarimkaya & Esenturk, 2020). Social engagement through PA can also enhance the self-esteem and self-confidence among individuals living with a disability (Martin, 2013). Not having this opportunity to participate in PA programs may impede building that confidence that families have previously noticed with camp participation.

5.2 Limitations

Limitations of this study include that because of program suspension due to COVID-19, the focus groups with the families took place over a year after camp participation. Family members may not remember some events that occurred at the camp. However, this delay provided an opportunity for families to comment on their experiences of longer-term implications that camp may have had on family relationships. It was necessary to conduct all focus groups via Zoom rather than in-person, and this online format made it more challenging to establish rapport. Families who volunteered to participate in this study may have been more likely to have a positive experience with participating in the camp than those who did not volunteer. Therefore, the findings may not represent the full range of families’ experiences. My position as a camp coordinator for the Rocky Mountain Adaptive Family Camp meant that families might have a sense of what I wanted to hear. However, this relationship is a strength of that study because it enhanced rapport during the focus groups. For the study with the University of Calgary camp, the fact that I was unable to spend time at the camp and meet the children and
adolescents who participated and their families in person may have limited our rapport during the focus groups.

5.3 Theoretical Implications

The use of the social relational model of disability (Reindal, 2008) and Bowen’s family systems theory (Brown, 1999) provided a framework for examining adapted PA in this research. The social relational model of disability provided a framework to understand barriers families including a child living with a disability may experience, and how adapted PA may help address some of those barriers. The application of Bowen’s family systems theory was novel in the adapted PA literature, and helps provide new insights into family process that are relevant to and could be affected by participation in adapted recreation camps. For example, the use of these two theories helped to identify how adapted PA may decrease anxiety in families who have a child living with a disability. This work could serve to guide future methodologies and research examining family relationships as they relate to adapted PA.

5.4 Practical Implications

The findings from this research can be used to enhance adapted PA programming to consider the experiences of families and draw attention to how those experiences may be relevant to family relationships. For example, programs that incorporate the entire family in recreation opportunities can tailor their activities to allow for time for familial bonding which may affect communication and support within families. In both types of programs, the findings also draw attention to the value of creating opportunities for the child living with a disability to demonstrate and experience independence, as those experiences may have positive implications for family relationships. Program practitioners should also be aware of the role they play in alleviating family stress and reducing structural barriers to PA for families with a child living
with a disability. Designing programs that attend to these potential benefits may alleviate some of the stress and barriers faced by families and have positive implications for family relationships.

5.5 Future Directions

There is limited research examining how adapted PA for children and adolescents living with a disability impacts family relationships. Future research should examine family relationships over time throughout participation in adapted PA programs to examine how family relationships change over time. Further work examining practitioner perspectives on how programs may enhance family relationships may also provide insight into ways that programs could assist families and provide a positive context for family interactions.

5.6 Conclusions

The findings of this study suggest that there may be positive implications for family interactions and relationships associated with participation in adapted PA camps. Family members experienced changes in their perspectives regarding what their child living with a disability is able to achieve, conversations surrounding disability, supported for managing daily stressors, an understanding of one another, shared experiences and memories, sibling bonding, and pride in the child with a disability. Families also noticed that the confidence and independence experienced by the child living with a disability was meaningful for interactions within their families. These findings can be used to inform future programs by providing a basis of knowledge regarding family relationships as they relate to adapted PA, which can be used to foster more positive experiences in both PA and family life for children and adolescents living with a disability.
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Appendix A: Child Assent Form, Rocky Mountain Adaptive Camp

UNIVERSITY OF CALGARY

GENERAL ASSENT TO PARTICIPATE IN RESEARCH

Family Focus Groups – Rocky Mountain Adaptive Friends and Family Camp

TITLE: Adapted physical Activity Camps: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:

Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

A research study is a way to find out new information about something. People don’t need to participate in a research study if they don’t want to participate.

You can talk this over with your parents/guardians before you decide whether or not to participate. We will also ask your parents/guardians to give their permission for you to take part in this study. But even if your parents/guardians say “yes” you can still decide not to do this.

WHY IS THIS STUDY BEING DONE?
You are being asked to take part in this research study because we want to find out more about what you think of physical activity and your relationships with other people in your family. We also want to know what you think about how physical activity may have an impact on those relationships. We are asking you to be in the study because you participated in the Rocky Mountain Adaptive Friends and Family Camp. About 10 families will be in this study.

**WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?**

If you decide to take part in this study, here are some things that will happen:

You and your family members will take part in a focus group (45-60 minutes). A focus group is a group interview. The focus group will be done online over Skype, Zoom, or Microsoft Teams. In the focus group the researcher will ask you and your family questions about your relationships after participating in the adapted summer camp, and not being able to go to the adapted summer camp because of COVID 19.

**ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?**

There are minimal risks connected with being in this study. It is possible that you may not feel comfortable answering some of the questions. You may choose not to answer any questions you do not feel comfortable with.

**WILL THE STUDY HELP OTHERS?**

If you agree to be in the study, it may or may not help you. But the information we learn about you will help make future programs better and help us learn more about adapted programming and family relationships.

**WHO WILL SEE THE INFORMATION COLLECTED ABOUT ME?**

The information collected about you during this study will be kept safely locked up. Nobody will read it except the people doing the research. The study information about you will be given to your parents/guardians. The researchers won’t tell your friends or anyone else that you are in this study, or share any information about you.
DO I HAVE TO BE IN THE STUDY?

You don’t have to be in the study. It is up to you. No one will be upset if you don’t want to do this study. You can say yes, or you can say no. You can also take more time to think about being in the study.

If you want to stop, then all you have to do is tell us you want to stop. No one will be mad at you if you don’t want to be in the study, or if you say yes now then want to stop later.

WHAT DO I GET FOR BEING IN THE STUDY?

We cannot pay you for being in the study, but you will not have to pay for anything to do any part of the research study.

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You can ask any questions that you may have about the study. If you have a question later that you didn’t think of now, either you can call or have your parents. You can also take more time to think about being in the study and also talk some more with your parents about being in the study.

WOULD YOU LIKE TO BE IN THIS RESEARCH STUDY?

If you decide to be in the study, then please write your name below. You can change your mind and stop being part of the study at any time. All you have to do is tell us. It’s okay. The researchers and your parents won’t be upset with you

☑ Yes, I want to be in this study. ☐ No, I don’t want to do this.

________________________________________
Name of Participant

________________________________________  _________________________
Signature of Participant                        Date
SIGNATURE OF PERSON OBTAINING ASSENT

_________________________________________________
Name of Person who received assent

_________________________________________________  ________________
Signature of Person who received assent                        Date

You will be given an online copy to keep.
Appendix B: Child Assent Form, University of Calgary Camp

UNIVERSITY OF CALGARY
GENERAL ASSENT TO PARTICIPATE IN RESEARCH

Family Focus Groups – Adapted Sport and Recreation Camp

TITLE: Adapted physical Activity Camps: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

A research study is a way to find out new information about something. People don’t need to participate in a research study if they don’t want to participate.

You can talk this over with your parents/guardians before you decide whether or not to participate. We will also ask your parents/guardians to give their permission for you to take part in this study. But even if your parents/guardians say “yes” you can still decide not to do this.

WHY IS THIS STUDY BEING DONE?

You are being asked to take part in this research study because we want to find out more about what you think of physical activity and your relationships with other people in your family. We also want to know what you think about how physical activity may have an impact on those relationships. We are asking you to be in the study because you participated in the Adapted Sport and Recreation Camp at the University of Calgary. About 20 families will be in this study.
WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you decide to take part in this study, here are some things that will happen:

You and your family members will take part in a focus group (45-60 minutes). A focus group is a group interview. The focus group will be done online over Skype, Zoom, or Microsoft Teams. In the focus group the researcher will ask you and your family questions about your relationships after participating in the adapted summer camp, and not being able to go to the adapted summer camp because of COVID 19.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

There are minimal risks connected with being in this study. It is possible that you may not feel comfortable answering some of the questions. You may choose not to answer any questions you do not feel comfortable with.

WILL THE STUDY HELP OTHERS?

If you agree to be in the study, it may or may not help you. But the information we learn about you will help make future programs better and help us learn more about adapted programming and family relationships.

WHO WILL SEE THE INFORMATION COLLECTED ABOUT ME?

The information collected about you during this study will be kept safely locked up. Nobody will read it except the people doing the research. The study information about you will be given to your parents/guardians. The researchers won’t tell your friends or anyone else that you are in this study, or share any information about you.

DO I HAVE TO BE IN THE STUDY?

You don’t have to be in the study. It is up to you. No one will be upset if you don’t want to do this study. You can say yes, or you can say no. You can also take more time to think about being in the study.

If you want to stop, then all you have to do is tell us you want to stop. No one will be mad at you if you don’t want to be in the study, or if you say yes now then want to stop later.

WHAT DO I GET FOR BEING IN THE STUDY?

We cannot pay you for being in the study, but you will not have to pay for anything to do any part of the research study.

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?
The Research Team:
You can ask any questions that you may have about the study. If you have a question later that you didn’t think of now, either you can call or have your parents call the research team. You can also take more time to think about being in the study and also talk some more with your parents about being in the study.

WOULD YOU LIKE TO BE IN THIS RESEARCH STUDY?

If you decide to be in the study, then please write your name below. You can change your mind and stop being part of the study at any time. All you have to do is tell us. It’s okay. The researchers and your parents won’t be upset with you.

☑ Yes, I want to be in this study.    ☐ No, I don’t want to do this.

________________________________________________________
Name of Participant

________________________________________________________
Signature of Participant                      Date

SIGNATURE OF PERSON OBTAINING ASSENT

________________________________________________________
Name of Person who received assent

________________________________________________________
Signature of Person who received assent                      Date

You will be given an online copy to keep.
Appendix C: Child Assent Form, Sibling Participants

UNIVERSITY OF CALGARY
GENERAL ASSENT TO PARTICIPATE IN RESEARCH

Family Focus Groups – Adapted Sport and Recreation Camp

TITLE: Adapted physical Activity Camps: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

A research study is a way to find out new information about something. People don’t need to participate in a research study if they don’t want to participate.

You can talk this over with your parents/guardians before you decide whether or not to participate. We will also ask your parents/guardians to give their permission for you to take part in this study. But even if your parents/guardians say “yes” you can still decide not to do this.

WHY IS THIS STUDY BEING DONE?

You are being asked to take part in this research study because we want to find out more about what you think of physical activity and your relationships with other people in your family. We also want to know what you think about how physical activity may have an impact on those relationships. We are asking you to be in the study because you participated in the Adapted Sport and Recreation Camp at the University of Calgary. About 20 families will be in this study.
WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you decide to take part in this study, here are some things that will happen:

You and your family members will take part in a focus group (45-60 minutes). A focus group is a group interview. The focus group will be done online over Skype, Zoom, or Microsoft Teams. In the focus group the researcher will ask you and your family questions about your relationships after participating in the adapted summer camp, and not being able to go to the adapted summer camp because of COVID 19.

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

There are minimal risks connected with being in this study. It is possible that you may not feel comfortable answering some of the questions. You may choose not to answer any questions you do not feel comfortable with.

WILL THE STUDY HELP OTHERS?

If you agree to be in the study, it may or may not help you. But the information we learn about you will help make future programs better and help us learn more about adapted programming and family relationships.

WHO WILL SEE THE INFORMATION COLLECTED ABOUT ME?

The information collected about you during this study will be kept safely locked up. Nobody will read it except the people doing the research. The study information about you will be given to your parents/guardians. The researchers won't tell your friends or anyone else that you are in this study, or share any information about you.

DO I HAVE TO BE IN THE STUDY?

You don’t have to be in the study. It is up to you. No one will be upset if you don’t want to do this study. You can say yes, or you can say no. You can also take more time to think about being in the study.

If you want to stop, then all you have to do is tell us you want to stop. No one will be mad at you if you don’t want to be in the study, or if you say yes now then want to stop later.

WHAT DO I GET FOR BEING IN THE STUDY?

We cannot pay you for being in the study, but you will not have to pay for anything to do any part of the research study.

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?
The Research Team:
You can ask any questions that you may have about the study. If you have a question later that you didn’t think of now, either you can call or have your parents call. You can also take more time to think about being in the study and also talk some more with your parents about being in the study.

WOULD YOU LIKE TO BE IN THIS RESEARCH STUDY?

If you decide to be in the study, then please write your name below. You can change your mind and stop being part of the study at any time. All you have to do is tell us. It’s okay. The researchers and your parents won’t be upset with you

☐ Yes, I want to be in this study. ☐ No, I don’t want to do this.

__________________________________________
Name of Participant

__________________________________________    __________________________
Signature of Participant    Date

SIGNATURE OF PERSON OBTAINING ASSENT

__________________________________________
Name of Person who received assent

__________________________________________    __________________________
Signature of Person who received assent    Date

You will be given an online copy to keep.
UNIVERSITY OF CALGARY
PARENT CONSENT FOR CHILD TO PARTICIPATE IN RESEARCH

Parent/Guardian Consent for Child Participants (Under 14 Years)
Family Focus Groups – Rocky Mountain Adaptive Friends and Family Camp

TITLE: Adapted Physical Activity Summer Camps: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about, and what your child’s participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

Your child was identified as a possible participant in this study because they participated in the Rocky Mountain Adaptive Friends and Family Camp. Your child’s participation in this research study is voluntary.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 6-10 families you participated in the Rocky Mountain Adaptive Friends and Family Camp.

WHAT WILL HAPPEN IF MY CHILD TAKES PART IN THIS RESEARCH STUDY?

If you agree to allow your child to participate in this study, we would ask them to:

- Participate in a focus group with you and your other family members (approximately 45-60 minutes)
- The focus group will take place online over Skype, Zoom or Microsoft Teams
- In the focus group the researcher will ask you and your family questions regarding their experiences with your family in the 2019 Rocky Mountain Adaptive Friends and Family Camp, your relationships, and the loss of recreation due to the COVID19 pandemic.
- The focus group will be audio-recorded

HOW LONG WILL MY CHILD BE IN THE RESEARCH STUDY?

Your child will take part in one online focus group with you and your other family members. Participation will take a total of about 45-60 minutes

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT MY CHILD CAN EXPECT FROM THIS STUDY?

There are minimal risks associated with participating in this study. It is possible that your child may not be comfortable with certain questions. They may refuse to answer any question they do not feel comfortable with.
ARE THERE ANY POTENTIAL BENEFITS TO MY CHILD IF THEY PARTICIPATE?

There will be no direct benefits to your child from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

WHAT OTHER CHOICES DOES MY CHILD HAVE IF THEY DO NOT PARTICIPATE?

No, your child does not have to participate. Participation is completely voluntary. If you decide not to have your child take part in this study, there will be no penalty to your child.

CAN MY CHILD STOP BEING IN THE STUDY?

Yes. You can decide to stop your child’s participation at any time. Tell the researchers if you are thinking about stopping or decide to stop your child’s participation.

CAN THE RESEARCHERS REMOVE MY CHILD FROM THIS STUDY?

The researchers may end your child’s participation in this study if they miss scheduled focus group. The researchers or the study sponsor might also decide to stop the study at any time.

WITHDRAWAL OF STUDY DATA

You are free to withdraw your child from the study at any time by contacting the researcher. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your child’s participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw your child from the study you may also request that their data be withdrawn up until one month after the focus group.
WILL MY CHILD BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.

WILL INFORMATION ABOUT MY CHILD’S PARTICIPATION BE KEPT CONFIDENTIAL?

All of the information collected will remain strictly confidential. Your child’s privacy will be assured. Only the investigators responsible for this study, the research assistants who will be doing the assessments and data analysis, and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure, either locked, or password protected location, for five years after completion of the study. Confidentiality will be protected by using a study identification number in the database. Any results reported from the study will in no way identify study participants.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

The researchers intend to keep the research data and records for approximately 5 years.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask for my child to take part in other research studies.

☐ YES
☐ NO

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:
You may contact the research team with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):
If you have any questions concerning your child’s rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Study results will be available upon participants request

WHAT ARE MY CHILD’S RIGHTS IF THEY TAKE PART IN THIS STUDY?

Your child’s participation in this study is a choice. You can choose whether or not you want your child to participate. Whatever decision you make, there will be no penalty to you or your child.

• You have a right to have all of your questions answered before deciding whether your child will take part.
• If you decide for your child to take part, they can leave the study at any time.
• Your child may refuse to answer any questions that they do not want to answer and still remain in the study.

HOW DO I INDICATE AGREEMENT FOR MY CHILD TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child’s participation in the research project and agree for them to participate as a participant. In no way does this waive your or your child’s legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

______________________________
Name of Child

SIGNATURE OF PARENT OR LEGAL GUARDIAN

______________________________
Name of Parent or Legal Guardian

______________________________  _________________________
Signature of Parent or Legal Guardian  Date

SIGNATURE OF PERSON OBTAINING CONSENT
A signed online copy of this consent form has been given to you to keep for your records and reference.
Appendix E: Parent/Guardian Consent Form for Children Under 14, University of Calgary Camp

UNIVERSITY OF CALGARY
PARENT CONSENT FOR CHILD TO PARTICIPATE IN RESEARCH

Parent/Guardian Consent for Child Participants (Under 14 Years)
Family Focus Groups – Adapted Sport and Recreation Camp

TITLE: Adapted Physical Activity Summer Camps: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about, and what your child’s participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

Your child was identified as a possible participant in this study because they participated in the Adapted Sport and Recreation Camp at the University of Calgary. Your child’s participation in this research study is voluntary.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 15-20 families who have a child who participated in the Adapted Sport and Recreation Camp will take part in this study.

WHAT WILL HAPPEN IF MY CHILD TAKES PART IN THIS RESEARCH STUDY?

If you agree to allow your child to participate in this study, we would ask them to:

- Participate in a focus group with you and your other family members (approximately 45-60 minutes)
- The focus group will take place online over Skype, Zoom or Microsoft Teams
- In the focus group the researcher will ask your child questions regarding their experiences with family relationships after participating in the adapted sport camp, their experiences after participating in the camp, and the loss of recreation due to the COVID19 pandemic.
- The focus group will be audio-recorded

HOW LONG WILL MY CHILD BE IN THE RESEARCH STUDY?

Your child will take part in one online focus group with you and your other family members. Participation will take a total of about 45-60 minutes

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT MY CHILD CAN EXPECT FROM THIS STUDY?
There are minimal risks associated with participating in this study. It is possible that your child may not be comfortable with certain questions. They may refuse to answer any question they do not feel comfortable with.

ARE THERE ANY POTENTIAL BENEFITS TO MY CHILD IF THEY PARTICIPATE?

There will be no direct benefits to your child from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

WHAT OTHER CHOICES DOES MY CHILD HAVE IF THEY DO NOT PARTICIPATE?

No, your child does not have to participate. Participation is completely voluntary. If you decide not to have your child take part in this study, there will be no penalty to your child.

CAN MY CHILD STOP BEING IN THE STUDY?

Yes. You can decide to stop your child’s participation at any time. Tell the researchers if you are thinking about stopping or decide to stop your child’s participation.

CAN THE RESEARCHERS REMOVE MY CHILD FROM THIS STUDY?

The researchers may end your child’s participation in this study if they miss scheduled focus group. The researchers or the study sponsor might also decide to stop the study at any time.

WITHDRAWAL OF STUDY DATA

You are free to withdraw your child from the study at any time by contacting the researcher. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your child’s participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw your child from the study you may also request that their data be withdrawn for up to one month after the focus group.
WILL MY CHILD BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.

WILL INFORMATION ABOUT MY CHILD’S PARTICIPATION BE KEPT CONFIDENTIAL?

All of the information collected will remain strictly confidential. Your child’s privacy will be assured. Only the investigators responsible for this study, the research assistants who will be doing the assessments and data analysis, and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure, either locked, or password protected location, for five years after completion of the study. Confidentiality will be protected by using a study identification number in the database. Any results reported from the study will in no way identify study participants.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

The researchers intend to keep the research data and records for approximately 5 years.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask for my child to take part in other research studies.

☐ YES
☐ NO

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:
You may contact the research team with any questions or concerns about the research or your participation in this study.
Conjoint Health Research Ethics Board (CHREB):
If you have any questions concerning your child’s rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Study results will be available upon participants request

WHAT ARE MY CHILD’S RIGHTS IF THEY TAKE PART IN THIS STUDY?

Your child’s participation in this study is a choice. You can choose whether or not you want your child to participate. Whatever decision you make, there will be no penalty to you or your child.

- You have a right to have all of your questions answered before deciding whether your child will take part.
- If you decide for your child to take part, they can leave the study at any time.
- Your child may refuse to answer any questions that they do not want to answer and still remain in the study.

HOW DO I INDICATE AGREEMENT FOR MY CHILD TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child’s participation in the research project and agree for them to participate as a participant. In no way does this waive your or your child’s legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

________________________________________
Name of Child

SIGNATURE OF PARENT OR LEGAL GUARDIAN

________________________________________
Name of Parent or Legal Guardian

________________________________________  ______________________
Signature of Parent or Legal Guardian          Date
SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent

Signature of Person Obtaining Consent

Contact Number

Date

SIGNATURE OF THE WITNESS

Name of Witness

Signature of Witness

Date

A signed online copy of this consent form has been given to you to keep for your records and reference.
Appendix F: Parent/Guardian Consent Form for Children Under 14, Sibling Participants

UNIVERSITY OF CALGARY
PARENT CONSENT FOR CHILD TO PARTICIPATE IN RESEARCH

Parent/Guardian Consent for Sibling Participants (Under 14 Years)
Family Focus Groups – Adapted Sport and Recreation Camp

TITLE: Adapted Physical Activity Summer Camps: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about, and what your child’s participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information.

Your child was identified as a possible participant in this study because their sibling participated in the Adapted Sport and Recreation Camp at the University of Calgary. Your child’s participation in this research study is voluntary.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 15-20 families who have a child who participated in the Adapted Sport and Recreation Camp will take part in this study.

WHAT WILL HAPPEN IF MY CHILD TAKES PART IN THIS RESEARCH STUDY?

If you agree to allow your child to participate in this study, we would ask them to:

- Participate in a focus group with you and your other family members (approximately 45-60 minutes)
- The focus group will take place online over Skype, Zoom or Microsoft Teams
- In the focus group the researcher will ask your child questions regarding their experiences with family relationships after their sibling participated in the adapted sport camp, their experiences after their sibling participated in the camp, and the loss of recreation due to the COVID19 pandemic.
- The focus group will be audio-recorded

HOW LONG WILL MY CHILD BE IN THE RESEARCH STUDY?

Your child will take part in one online focus group with you and your other family members. Participation will take a total of about 45-60 minutes

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT MY CHILD CAN EXPECT FROM THIS STUDY?
There are minimal risks associated with participating in this study. It is possible that your child may not be comfortable with certain questions. They may refuse to answer any question they do not feel comfortable with.

ARE THERE ANY POTENTIAL BENEFITS TO MY CHILD IF THEY PARTICIPATE?

There will be no direct benefits to your child from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

WHAT OTHER CHOICES DOES MY CHILD HAVE IF THEY DO NOT PARTICIPATE?

No, your child does not have to participate. Participation is completely voluntary. If you decide not to have your child take part in this study, there will be no penalty to your child.

CAN MY CHILD STOP BEING IN THE STUDY?

Yes. You can decide to stop your child’s participation at any time. Tell the researchers if you are thinking about stopping or decide to stop your child’s participation.

CAN THE RESEARCHERS REMOVE MY CHILD FROM THIS STUDY?

The researchers may end your child’s participation in this study if they miss scheduled focus group. The researchers or the study sponsor might also decide to stop the study at any time.

WITHDRAWAL OF STUDY DATA

You are free to withdraw your child from the study at any time by contacting the research team. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your child’s participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw your child from the study you may also request that their data be withdrawn up until one month after the focus group.
WILL MY CHILD BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.

WILL INFORMATION ABOUT MY CHILD’S PARTICIPATION BE KEPT CONFIDENTIAL?

All of the information collected will remain strictly confidential. Your child’s privacy will be assured. Only the investigators responsible for this study, the research assistants who will be doing the assessments and data analysis, and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure, either locked, or password protected location, for five years after completion of the study. Confidentiality will be protected by using a study identification number in the database. Any results reported from the study will in no way identify study participants.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

The researchers intend to keep the research data and records for approximately 5 years.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask for my child to take part in other research studies.

☐ YES
☐ NO

WHO CAN I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:
You may contact the research team with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):
If you have any questions concerning your child’s rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Study results will be available upon participants request

WHAT ARE MY CHILD’S RIGHTS IF THEY TAKE PART IN THIS STUDY?

Your child’s participation in this study is a choice. You can choose whether or not you want your child to participate. Whatever decision you make, there will be no penalty to you or your child.

- You have a right to have all of your questions answered before deciding whether your child will take part.
- If you decide for your child to take part, they can leave the study at any time.
- Your child may refuse to answer any questions that they do not want to answer and still remain in the study.

HOW DO I INDICATE AGREEMENT FOR MY CHILD TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your child’s participation in the research project and agree for them to participate as a participant. In no way does this waive your or your child’s legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

Name of Child

SIGNATURE OF PARENT OR LEGAL GUARDIAN

Name of Parent or Legal Guardian

Signature of Parent or Legal Guardian  Date
SIGNATURE OF PERSON OBTAINING CONSENT

Name of Person Obtaining Consent   Contact Number

Signature of Person Obtaining Consent   Date

SIGNATURE OF THE WITNESS

Name of Witness

Signature of Witness   Date

A signed online copy of this consent form has been given to you to keep for your records and reference.
Appendix G: Informed Consent Form for Youth Participants, Rocky Mountain Adaptive Camp

UNIVERSITY OF CALGARY
CONSENT TO PARTICIPATE IN RESEARCH

Consent Form for Adolescent Sibling Participants (Youth 14 and over)
Family Focus Groups with Participants in the Rocky Mountain Adaptive Friends and Family Camp

TITLE: Adapted Physical Activity Summer Camp: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because you participated in the Rocky Mountain Adaptive Friends and Family Camp.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 6-10 families who participated in the Rocky Mountain Adapted Friends and Family Camp will take part in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Participate in a focus group with your family members (approximately 45-60 minutes)
- The focus group will take place online over Skype, Zoom or Microsoft Teams
- The researcher will ask you and your family questions about your experience participating with your family in the 2019 Rocky Mountain Adaptive Friends and Family Camp, your family relationships after participating in the camp, and the loss of recreation due to the COVID19 Pandemic.
- The focus group will be audio-recorded

HOW LONG WILL I BE IN THIS STUDY?

You will take part in one online focus group with your family members. Participation will take a total of about 45-60 minutes

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?
There are minimal risks associated with answering these questions. It is possible that you may not be comfortable with certain questions. You may refuse to answer any question you do not feel comfortable with.

**ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?**

There will be no direct benefits to you from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

**WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?**

You are free to choose not to participate in the study. Participation is completely voluntary. If you decide not to take part in this study, there will be no penalty to you.

**CAN I STOP BEING IN THE STUDY?**

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

**WITHDRAWAL OF STUDY DATA**

You are free to withdraw from the study at any time by contacting the research team. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw from the study you may also request that your data be withdrawn for up to one month after the focus group.

**WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.
WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

All of the information collected will remain strictly confidential. We will assure your privacy. Only the scientists and students doing this study and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure password protected server, for 5 years after completion of the study. Confidentiality will be protected by using a study ID number in the database. Any results reported from the study will in no way identify study participants.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

The researchers intend to keep the research data and records for approximately 5 years.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

☐ YES
☐ NO

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You may contact the research team with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Study results will be available upon participants request.
WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

- You have a right to have all of your questions answered before deciding whether to take part.
- If you decide to take part, you may leave the study at any time

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

__________________________
Name of Participant

__________________________  ______________
Signature of Participant     Date

SIGNATURE OF PERSON OBTAINING CONSENT

__________________________
Name of Person Obtaining Consent

__________________________  __________________
Signature of Person Obtaining Consent     Contact Number

__________________________  ______________
Signature of Person Obtaining Consent     Date

SIGNATURE OF THE WITNESS

__________________________
Name of Witness

________________________________

_____________________

Signature of Witness Date

A signed online copy of this consent form has been given to you to keep for your records and reference.
Appendix H: Informed Consent Form for Youth Participants, University of Calgary

Camp

UNIVERSITY OF CALGARY
CONSENT TO PARTICIPATE IN RESEARCH
Consent Form for Adolescent Participants (Youth 14 and over)
Family Focus Groups with Family Members of Participants in the Adapted Sport and Recreation Camp

TITLE: Adapted Physical Activity Summer Camp: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because you participated in the Adapted Sport and Recreation Camp at the University of Calgary. Your participation in this research study is voluntary.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 15-20 families who had a child who participated in the Adapted Sport and Recreation Camp will take part in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Participate in a focus group with your family members (approximately 45-60 minutes)
- The focus group will take place online over Skype, Zoom or Microsoft Teams
- The researcher will ask you and your family questions about your relationships after you participated in the Adapted Sport and Recreation Summer camp, your experience after participating in the camp, and the loss of recreation due to the COVID19 pandemic
- The focus group will be audio-recorded

HOW LONG WILL I BE IN THIS STUDY?

You will take part in one online focus group with your family members. Participation will take a total of about 45-60 minutes

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?
There are minimal risks associated with answering these questions. It is possible that you may not be comfortable with certain questions. You may refuse to answer any question you do not feel comfortable with.

**ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?**

There will be no direct benefits to you from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

**WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?**

You are free to choose not to participate in the study. Participation is completely voluntary. If you decide not to take part in this study, there will be no penalty to you.

**CAN I STOP BEING IN THE STUDY?**

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

**WITHDRAWAL OF STUDY DATA**

You are free to withdraw from the study at any time by contacting the researcher. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw from the study you may also request that your data be withdrawn for up to one month after the focus group.

**WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.
WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

All of the information collected will remain strictly confidential. We will assure your privacy. Only the scientists and students doing this study and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure password protected server, for 5 years after completion of the study. Confidentiality will be protected by using a study ID number in the database. Any results reported from the study will in no way identify study participants.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

The researchers intend to keep the research data and records for approximately 5 years.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

☐ YES
☐ NO

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You may contact the research team with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?
Study results will be available upon participants request

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.
- You have a right to have all of your questions answered before deciding whether to take part.
- If you decide to take part, you may leave the study at any time

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

__________________________________________
Name of Participant

__________________________________________    ______________
Signature of Participant    Date

SIGNATURE OF PERSON OBTAINING CONSENT

__________________________________________    ______________________
Name of Person Obtaining Consent    Contact Number

__________________________________________    ______________________
Signature of Person Obtaining Consent    Date

SIGNATURE OF THE WITNESS
A signed online copy of this consent form has been given to you to keep for your records and reference.
Appendix I: Informed Consent Form for Youth Participants, Sibling Participants

UNIVERSITY OF CALGARY
CONSENT TO PARTICIPATE IN RESEARCH

Consent Form for Adolescent Sibling Participants (Youth 14 and over)
Family Focus Groups with Family Members of Participants in the Adapted Sport and Recreation Camp

TITLE: Adapted Physical Activity Summer Camp: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because your sibling participated in the Adapted Sport and Recreation Camp at the University of Calgary. Your participation in this research study is voluntary.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 15-20 families who have a child who participated in the Adapted Sport and Recreation Camp will take part in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Participate in a focus group with your family members (approximately 45-60 minutes)
- The focus group will take place online over Skype, Zoom or Microsoft Teams
- The researcher will ask you and your family questions about your relationships after your sibling participated in the Adapted Sport and Recreation Summer camp, your experience after your sibling’s participation in the camp, and the loss of recreation due to the COVID19 pandemic
- The focus group will be audio-recorded

HOW LONG WILL I BE IN THIS STUDY?

You will take part in one online focus group with your family members. Participation will take a total of about 45-60 minutes

ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?
There are minimal risks associated with answering these questions. It is possible that you may not be comfortable with certain questions. You may refuse to answer any question you do not feel comfortable with.

**ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?**

There will be no direct benefits to you from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

**WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?**

You are free to choose not to participate in the study. Participation is completely voluntary. If you decide not to take part in this study, there will be no penalty to you.

**CAN I STOP BEING IN THE STUDY?**

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

**WITHDRAWAL OF STUDY DATA**

You are free to withdraw from the study at any time by contacting the researcher. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw from the study you may request that your data be withdrawn for up to one month after the focus group.

**WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.

**WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?**

All of the information collected will remain strictly confidential. We will assure your privacy. Only the scientists and students doing this study and the University of Calgary Conjoint Health
Research Ethics Board will have access to this information. Data will be kept in a secure password protected server, for 5 years after completion of the study. Confidentiality will be protected by using a study ID number in the database. Any results reported from the study will in no way identify study participants.

**HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?**

The researchers intend to keep the research data and records for approximately 5 years.

**CONTACT FOR FUTURE RESEARCH**

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

☐ YES
☐ NO

**WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?**

The Research Team:

You may contact the research team with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

**HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?**

Study results will be available upon participants request

**WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?**
Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

- You have a right to have all of your questions answered before deciding whether to take part.
- If you decide to take part, you may leave the study at any time

**HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

**SIGNATURE OF STUDY PARTICIPANT**

Name of Participant

________________________________

Signature of Participant  Date

**SIGNATURE OF PERSON OBTAINING CONSENT**

Name of Person Obtaining Consent  Contact Number

________________________________

Signature of Person Obtaining Consent  Date

**SIGNATURE OF THE WITNESS**

Name of Witness

________________________________
Signature of Witness                  Date

A signed online copy of this consent form has been given to you to keep for your records and reference.
INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because you participated in the Rocky Mountain Adaptive Friends and Family Camp.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 6-10 families who participated in the Rocky Mountain Adaptive Friends and Family Camp will participate in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Participate in a brief 10-15 minute phone interview with a member of our research team. In this interview the researcher will ask you various questions regarding your family demographics.
- Participate in a focus group with your family members (approximately 45-60 minutes). The focus group will take place online over Skype, Zoom or Microsoft Teams. The researcher will ask you and your family questions about your experience participating with your family in the 2019 Rocky Mountain Adaptive Friends and Family Camp, your family relationships after participating in the camp, and the loss of recreation due to the COVID19 Pandemic. The focus group will be audio-recorded.

HOW LONG WILL I BE IN THIS STUDY?

First you will take part in a brief 10-15 minute phone interview. You will also take part in one online focus group with your family members, lasting approximately 45-60 minutes. Participation in this study will take a total of 55-75 minutes.
ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

There are minimal risks associated with answering these questions. It is possible that you may not be comfortable with certain questions. You may refuse to answer any question you do not feel comfortable with.

ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?

There will be no direct benefits to you from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?

You are free to choose not to participate in the study. Participation is completely voluntary. If you decide not to take part in this study, there will be no penalty to you.

CAN I STOP BEING IN THE STUDY?

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

WITHDRAWAL OF STUDY DATA

You are free to withdraw from the study at any time by contacting the researcher. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw from the study you may also request that your data be withdrawn for upto a month after the focus group.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?

You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.
WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?

All of the information collected will remain strictly confidential. We will assure your privacy. Only the scientists and students doing this study and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure password protected server, for 5 years after completion of the study. Confidentiality will be protected by using a study ID number in the database. Any results reported from the study will in no way identify study participants.

HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?

The researchers intend to keep the research data and records for approximately 5 years.

CONTACT FOR FUTURE RESEARCH

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

☐ YES
☐ NO

WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?

The Research Team:

You may contact the research team with any questions or concerns about the research or your participation in this study.

Conjoint Health Research Ethics Board (CHREB):

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.

HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Study results will be available upon participants request
WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

- You have a right to have all of your questions answered before deciding whether to take part.
- If you decide to take part, you may leave the study at any time

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

________________________________________
Name of Participant

________________________________________
Signature of Participant

________________________________________
Date

SIGNATURE OF PERSON OBTAINING CONSENT

________________________________________
Name of Person Obtaining Consent

________________________________________
Contact Number

________________________________________
Signature of Person Obtaining Consent

________________________________________
Date

SIGNATURE OF THE WITNESS

________________________________________
Name of Witness

_________________________________________  __________________________
Signature of Witness                      Date

A signed online copy of this consent form has been given to you to keep for your records and reference.
CONSENT TO PARTICIPATE IN RESEARCH

Consent Form for Parent Participants
Family Focus Groups with Families who have a Child who Participated in the
Adapted Sport and Recreation Summer Camp

TITLE: Adapted Physical Activity Summer Camp: Family Experiences and Implications for Family Relationships

SPONSOR: University of Calgary

FUNDER: Alberta Children’s Hospital Research Institute, Vi Riddell Pediatric Rehabilitation Research Program

INVESTIGATORS:
Principal Investigator: Carolyn Emery
Co-Investigators: Dr. Meghan McDonough, Dr. Elizabeth Condliffe, Dr. David Legg, Elysa Sandron, Leticia Janzen, Jessica Youngblood, Catherine Tremblay

INTRODUCTION

Carolyn Emery, and associates from the Department of Kinesiology at the University of Calgary are conducting a research study.

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form for your records.

You were identified as a possible participant in this study because your child participated in the Adapted Sport and Recreation Camp at the University of Calgary. Your participation in this research study is voluntary.
WHY IS THIS STUDY BEING DONE?

Physical activity is important in maintaining a healthy lifestyle. There are not enough options for people with disabilities. We want to learn more about families who have a child who participated in a physical activity program for children and adolescents with disabilities. Understanding those experiences and how they may affect your family relationships can help better support families with a child with a disability.

The purpose of this research study is to examine family members’ perspectives on the ways in which participation in an adapted summer camp for children and adolescents with disabilities impacts family relationships.

HOW MANY PEOPLE WILL TAKE PART IN THIS STUDY?

About 15-20 families who have a child who participated in the Adapted Sport and Recreation Camp will take part in this study.

WHAT WILL HAPPEN IF I TAKE PART IN THIS STUDY?

If you volunteer to participate in this study, the researcher will ask you to do the following:

- Participate in a brief 10-15 minute phone interview with a member of our research team. In this interview the researcher will ask you various questions regarding your family demographics.
- Participate in a focus group with your family members (approximately 45-60 minutes). The focus group will take place online over Skype, Zoom or Microsoft Teams. The researcher will ask you and your family questions about your relationships after your child participated in the Adapted Sport and Recreation Summer camp, your experience after your child’s participation in the camp, and the loss of recreation due to the COVID19 pandemic. The focus group will be audio-recorded.

HOW LONG WILL I BE IN THIS STUDY?

First you will take part in a brief 10-15 minute phone interview. You will also take part in one online focus group with your family members, lasting approximately 45-60 minutes. Participation in this study will take a total of 55-75 minutes.
ARE THERE ANY POTENTIAL RISKS OR DISCOMFORTS THAT I CAN EXPECT FROM THIS STUDY?

There are minimal risks associated with answering these questions. It is possible that you may not be comfortable with certain questions. You may refuse to answer any question you do not feel comfortable with.

ARE THERE ANY POTENTIAL BENEFITS IF I PARTICIPATE?

There will be no direct benefits to you from participating in this study. However, this study may help the researchers learn more about how participation in an adapted physical activity summer camp for youth and adolescence with disabilities may impact family relationships.

WHAT OTHER CHOICES DO I HAVE IF I CHOOSE NOT TO PARTICIPATE?

You are free to choose not to participate in the study. Participation is completely voluntary. If you decide not to take part in this study, there will be no penalty to you.

CAN I STOP BEING IN THE STUDY?

Yes. You can decide to stop at any time. Tell the researchers if you are thinking about stopping or decide to stop.

WITHDRAWAL OF STUDY DATA

You are free to withdraw from the study at any time by contacting the researcher. Continued participation should be as informed as your initial consent. Feel free to ask questions throughout your participation in the study. If there is new information available throughout this study period, you will be informed as soon as possible. If you decide to withdraw from the study you may also request that your data be withdrawn for up to one month after the focus group.

WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?
You will not be paid for your participation in this research study. There will be no cost associated with participating in the study.

**WILL INFORMATION ABOUT ME AND MY PARTICIPATION BE KEPT CONFIDENTIAL?**

All of the information collected will remain strictly confidential. We will assure your privacy. Only the scientists and students doing this study and the University of Calgary Conjoint Health Research Ethics Board will have access to this information. Data will be kept in a secure password protected server, for 5 years after completion of the study. Confidentiality will be protected by using a study ID number in the database. Any results reported from the study will in no way identify study participants.

**HOW LONG WILL INFORMATION FROM THE STUDY BE KEPT?**

The researchers intend to keep the research data and records for approximately 5 years.

**CONTACT FOR FUTURE RESEARCH**

University of Calgary researchers may contact me in the future to ask me to take part in other research studies.

☐ YES
☐ NO

**WHOM MAY I CONTACT IF I HAVE QUESTIONS ABOUT THIS STUDY?**

**The Research Team:**

You may contact the research team with any questions or concerns about the research or your participation in this study.

**Conjoint Health Research Ethics Board (CHREB):**

If you have any questions concerning your rights as a possible participant in this research, please contact the Chair, Conjoint Health Research Ethics Board, University of Calgary at 403-220-7990.
HOW CAN I FIND OUT ABOUT THE STUDY RESULTS?

Study results will be available upon participants request

WHAT ARE MY RIGHTS IF I TAKE PART IN THIS STUDY?

Taking part in this study is your choice. You can choose whether or not you want to participate. Whatever decision you make, there will be no penalty to you.

• You have a right to have all of your questions answered before deciding whether to take part.
• If you decide to take part, you may leave the study at any time

HOW DO I INDICATE MY AGREEMENT TO PARTICIPATE?

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and agree to take part in the study. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities.

SIGNATURE OF STUDY PARTICIPANT

________________________________
Name of Participant

________________________________
Signature of Participant                  Date

SIGNATURE OF PERSON OBTAINING CONSENT

________________________________
Name of Person Obtaining Consent                  Contact Number

________________________________
Signature of Person Obtaining Consent  Date

SIGNATURE OF THE WITNESS

________________________________
Name of Witness

________________________________
Signature of Witness  Date

A signed online copy of this consent form has been given to you to keep for your records and reference.
Appendix L: Demographics Interview Guide

Introduction:
- [Welcome, introduce ourselves and thank parent]
- Today we are going to go through a few questions that will give me information regarding your family demographics. This will take approximately 10-15 minutes
- I will be audio-recording this phone call
- Would you like to ask me anything before we start?
- [start the audio recorder]

First could you please identify who you consider to be the members of your immediate family? Please tell me their names, and their relationship to you.

Which members of your family have a disability?
- What is the diagnosis?
- Could you please describe the disability to me?
- How does this disability impact your daily life?

Next I will ask you questions about each of your family members

First, I am going to ask you a few questions about yourself (person answering the questions):
- What is your age?
- What gender do you identify with?
- What is your first language?
- What ethnic group or groups do you identify with?
- What is your marital status?

Next I am going to ask you a few questions about (child’s name) (repeat for each child):
- What is their age?
- What gender do they identify with?
- What is their first language?
- What ethnic group or groups does your child identify with?

Now I am going to ask you questions about your other family members. Let’s start with (person’s name) (repeat for each member):
- What is their age?
- What is the gender they identify with?
- What is their first language?
- What is the ethnic group or groups do they identify with?

Could you please describe for me the physical activity patterns of your family before COVID-19?
• How active was each family member?
• How much activity did you do as a family?

Could you please describe the physical activity patterns of your family now, during COVID-19?
• How active is each family member?
• How much activity do you do as a family?

Thank you so much for participating in this quick interview [stop recording]. If you have any questions about the focus group your family will participate in please feel free to ask me now. I would now like to schedule a time for that online focus group to occur. Could you please tell me a date and time that work for you and your family?
Appendix M: Focus Group Guide, Rocky Mountain Adaptive Camp

Introduction:
- [Welcome, introduce ourselves, and thank the participants as they sign in to the meeting]
- I am a master’s student at the University of Calgary
- I am going to audio record our discussion. All information gathered during this interview is confidential, which means that when we talk about the results we will not tell people who you are, and if we quote you, will not use your name.
- We are interested in understanding your family’s experience with the Rocky Mountain Adaptive Friends and Family Camp, and if it had any effects on your family.
- You are the experts on what it is like to be a family at the camp. I have some questions I will ask, but there are no right or wrong answers. I am here to learn from you, and want to understand your thoughts.
- If there is a question you do not want to answer, you don’t have to answer it. If you want to stop at any point you can do that too, just let me know.
- Is there anything you would like to ask me before we start?
- [start the audio recorder]

1. Tell me about what it was like to participate in the Friends and Family Camp.
   - What was going to the camp like for you as a family?
   - Were there any activities at the camp that were new for you? What was it like to try new activities together?
   - What was it like to help each other in the activities?
   - Were there parts of the camp that you liked? Please describe.
   - Were there any challenges you faced? Any challenges you needed to get through as a family?
   - Questions for Children and Adolescents
     - Can you tell me more about what it was like for you to go to the camp with your parents?
     - Can you tell me more about what it was like for you to go to the camp with your brother/sister?
     - How did being at the camp make you feel?
     - Can you tell me what it was like to see your older/younger brother/sister do new activities?
     - Did this camp change your thoughts on what (child’s name) is able to do?
     - Did going to this camp change your thoughts on what you are able to do?
     - How did going to the camp make you feel?
   - Questions for Adults
     - Can you tell me more about what it was like participating in the camp with your children?
     - What was it like seeing (child’s name) participate in new activities?
1. Did this camp change your perspective on what (child’s name) is able to do?
   - How did this experience make you feel?

2. Have you noticed any changes in your relationships with anyone else in your family by participating in the camp? If yes, please describe.
   - Have you noticed any changes in relationships between family members?
     - What about relationships with your brother(s) and/or sister(s)?
     - What about your relationship with your parents?
     - What about your relationship with your child?
   - Did going to the camp affect your relationship with any of your family members?

3. (Name of child with a disability) have you noticed anything new that you can do now after going to the camp?
   - Tell me more about that
   - Ask other family members
     - As a family have you noticed anything new (child’s name) does after participating in the camp?

4. Did you notice any changes in how you talk or listen to anyone else in your family? If so, who? How did it change?
   - Have you observed any changes in the ways you talk or listen to your family members after the camp?
   - Ask each family member → have you experienced any changes in how you communicate with anyone in your family?

5. Did you notice a change in the amount of activity you do as a family?
   - How has your activity as a family changed?

The next questions are about the loss of opportunities like this camp, because of COVID-19

6. Did the camp not running this year affect your family? How?
   - How has it impacted your family?
   - How does this make you feel?
   - What does the loss of this camp mean to your family?

7. Did your family face any challenges because you weren’t able to go to the camp?
   - Please tell me about those challenges.
   - How did these challenges impact your family?
   - Did the challenges you faced impact family relationships in anyway?
   - How do these challenges make you feel?

Is there something else you would like to share about your experience participating in the camp?
Thank you for your participation [stop audio recording]. This has been very helpful; we really appreciate you being a part of this study. If you have any questions feel free to contact me. Thank you again for participating.
Appendix N: Focus Group Guide, University of Calgary Camp

Introduction:
- [Welcome, introduce ourselves, and thank the participants as they sign in to the meeting]
- I am a master’s student at the University of Calgary
- I am going to audio record our discussion. All information gathered during this interview is confidential, which means that when we talk about the results we will not tell people who you are, and if we quote you, will not use your name.
- We are interested in understanding your family’s experience with the University of Calgary Adapted Sport and Recreation Camp, and if it had any effects on your family.
- You are the experts on what it is like to be a family at the camp. I have some questions I will ask, but there are no right or wrong answers. I am here to learn from you, and want to understand your thoughts.
- If there is a question you do not want to answer, you don’t have to answer it. If you want to stop or pause at any point you can do that too, just let me know.
- Is there anything you would like to ask me before we start?
- [start the audio recorder]

1. Tell me about what the adapted sport camp was like for you
   - Questions for child who participated
     - Tell me more about what it was like meeting other children with disabilities
     - Where there any new activities you tried at the camp?
       - What was it like to participate in new activities?
     - Is there any part of the camp that you really liked? Please describe
     - Were there challenges you faced? Anything you needed to overcome?
   - Questions for parents/other adults
     - Tell me more about what is was like to see your child participate in new activities
     - Is there any aspect of the camp you noticed that impacted your child?
     - Did you notice any differences in your child after participating in the camp?
   - Questions for siblings
     - Tell me about what it was like seeing your brother/sister try new activities
     - How did you feel about your older/younger brother/sister being in the camp?
     - Did you notice anything different in your brother/sister after participating in the camp?

2. Did you have a chance to see the video at the end of the week? (if yes continue on to questions related to video)
   - Questions for parents/other adults
     - What was it like to see the activities your child was participating in?
     - Did it change your perspective on what your child can do?
Did this experience impact how you interact with your child?

- Questions for sibling
  - Did you have a chance to see the video? *(if yes continue on with questions related to video)*
  - How did you feel seeing your older/younger brother/sister participate in the camp?
  - Did seeing the video change your view on what your brother/sister can do?
  - Did this camp affect how you talk to your brother/sister?

- Questions for child who participated
  - What was it like for you to show your family the activities you were doing at the camp?
  - Did this experience impact (change) how you talk with your family?

3. Have you noticed any changes in your relationships with anyone else in your family after *(child’s name)* went to the camp? If yes, please describe.
   - Have you noticed any changes in relationships between family members?
     - What about relationships with your brother(s) and/or sister(s)?
     - What about your relationship with your parents?
     - What about your relationship with your child?
   - Have you noticed changes in how you talk or listen to your family members? If yes, please describe.
   - How do these changes make you feel?

4. *(Child name)* is there anything new you are able to do after the camp?
   - What kind of things can you do now that you maybe couldn’t do before?
   - As family members, have you noticed anything new *(child’s name)* is able to do after participating in the camp?
   - Are there things at home *(child’s name)* does that they didn’t used to do before participating in the camp?

5. After the camp did you *(child who participated in camp)* continue to do activities you tried at the camp? *(if yes continue on with related questions)*
   - How does doing to these activities make you feel?
   - Did you want to try these activities before the camp?
   - Has the fact that you are doing more activities changed how you interact as a family?
   - Questions for parents?
     - What is it like for you to see your child participate in more activities than they did before?
     - How does this increase in participation make you feel?
   - Questions for sibling?
     - What is it like for you to see your brother/sister do these activities?
     - How does seeing them do activities make you feel?

6. Are there any other changes you have noticed after going to the camp?
• (child’s name) have you noticed anything you can do by yourself that you couldn’t do before?
• Any other changes at home?

The next questions are about the loss of opportunities, like this camp because of COVID-19

7. Did the camp not running this year affect your family? How?
   • How has not being able to go to the camp affected your family?
   • How does not being able to go to the camp make you feel?
   • What does the loss of this camp mean to your family?

8. What were some challenges you faced as a family because (child’s name) wasn’t able to go to the camp?
   • Please tell me more about those challenges
   • How did these challenges impact your family?
   • Did the challenges you faced impact family relationships in any way?
   • How do these challenges make you feel?

Is there something else you would like to share about your experience within the camp?

Thank you for your participation [stop audio recording]. This has been very helpful; we really appreciate you being a part of this study. If you have any questions feel free to contact me. Thank you again for participating.