

**PARENT EXPERIENCES PROMOTING SAFE AND ACTIVE RECREATION FOR  
CHILDREN LIVING WITH AUTISM SPECTRUM DISORDERS IN  
RURAL SETTINGS**

By

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The following individuals certify that they have read, and recommend to the College of Graduate Studies for acceptance, a thesis/dissertation entitled:

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**Living with Autism Spectrum Disorders in Rural Settings**

submitted by Crystal Ann Shannon in partial fulfillment of the requirements of the degree of Master of Science in Nursing.

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## **Abstract**

Children with autism spectrum disorder (ASD) and their families experience challenges and barriers at multiple levels that influence their activity participation. The purpose of this thesis study was to develop understanding about factors influencing how families can promote safe, active recreation for their children 3 to 12 years living with ASD across rural Okanagan settings and how small centres and rural communities can provide supports for inclusive and safe environments. This qualitative study used an interpretive descriptive approach to explore the views of parents related to safe physical activity needs, barriers and supports for children ages 3 to 12 years living with ASD in rural Okanagan, British Columbia communities. Data collection included in-depth, semi-structured interviews with 12 families, followed by broad-based coding and thematic analysis. Results emerged as four major themes and subsequent subheadings: 1) Barriers to safe, inclusive recreational participation surrounded wide-ranging safety concerns that were linked to child's special interests, complex vulnerabilities, and elopement in rural context. Struggling for inclusive options was another emergent subtheme that hindered child participation and involved a significant lack of community awareness and social exclusion, lack of access to suitable programs, coach/instructor approach, and financial and logistical constraints. 2) Socially supportive rural communities related to parents' experiences of social supports and perceptions of enhanced safety for their children due to familiarity with community members. 3) Parents taking charge for safe participation was facilitated by parent/family involvement, child-centred activity engagement by families, acceptance, and constant supervision and safety planning. 4) Community needs identified included a strong parental desire for safe physical spaces, increasing access to safe, inclusive recreation, and training needs to support their child living with ASD in physical activities and recreational engagement in rural

settings. In conclusion, this study highlights family-centred priority issues such as parental safety concerns related to elopement and risk of injury heightened by environmental and outdoor hazards prominent in rural settings. Autism awareness and recreational training is needed and could incorporate collaborative development of child specific safety plans to foster inclusive opportunities. Program planners can use this information to encourage policy making to aid families' safe activity participation and healthy child development.

## **Lay Summary**

This study's primary goal was to provide a better understanding of the challenges and supports that families with children living with ASD encounter in their day-to-day lives with promoting safe, active recreation across rural Okanagan settings. Additionally, this research sought to identify community needs that could support families in their efforts to engage their children in activity participation. Results emphasized parents' priorities that should be considered for programs and policies to better support inclusive options that are close to home for rural families to aid in activity participation and healthy child development.

## **Preface**

This qualitative study used an interpretive descriptive approach to explore parents' experiences related to safe physical activity needs, barriers and supports for children ages 3 to 12 years living with ASD in rural Okanagan communities. Data collection included in-depth, semi-structured in-person interviews with 12 participants followed by broad-based coding and thematic analysis conducted by Ms. Crystal Shannon under the supervision and mentoring of Dr. Lise Olsen at UBC Okanagan (UBC O). Supervisory committee members, Dr. Rachelle Hole and Dr. Kathy Rush, provided guidance and feedback on the research proposal and write-up of this thesis until completion. Thesis proposal was presented in poster presentations by Crystal Shannon at the Brain-Child-Partners Conference on November 6-9, 2017, Toronto, ON; Thompson Rivers University Graduate Research Symposium, March 22, 2018, Kamloops, BC; and the Qualitative Methods Conference, May 1-3, 2018, Banff, AB. In addition, Ms. Shannon was invited to provide an oral presentation of proposed thesis at a UBC O academic-community symposium event (Get Ready...Get Safe...Go! Symposium) on June 16, 2018 (Autism Okanagan, 2019). Ms. Shannon was profiled in UBC Okanagan's (2018) Nursing Research Report that is also available online. Preliminary findings were presented by Ms. Shannon at the UBC Okanagan Interdisciplinary Student Conference on March 18, 2019, in Kelowna, BC; as well as at an invited panel event (Promoting Safe Active Recreation for Families Living with Autism) June 8, 2019, at the BC Children's Hospital Research Institute in Vancouver, BC. Ms. Crystal Shannon has been accepted to present a poster presentation of her thesis findings at the upcoming World Congress of the International Association for Scientific Study of Intellectual and Developmental Disabilities on August 6-9, 2019, in Glasgow, Scotland, UK. Ethics approval for this study was obtained by the UBC Okanagan Behavioural Research Ethics Board, and was deemed to be

Minimal Risk. Dr. Lise Olsen was listed as the Principal Investigator. The certificate number is H18-00854-A001.

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## **Dedication**

To my fun-loving children, James, Gordon, and Lindsay. Thank you for your inspiration and giving me the strength and drive needed to complete my masters thesis. I could not have accomplished this achievement without your patience, understanding, and continual support at home-base. Most of all, thank you for believing in me, as I believe in each of you.

## **Chapter 1. Introduction**

The number of children diagnosed with Autism Spectrum Disorder (ASD) is on the rise. One in every 66 children has autism (Public Health Agency of Canada, 2018). A 2010 Canadian study found that an ASD diagnosis is nearly five times more common in boys than girls (Health Canada, 2016). Autism is a complex spectrum disorder and can be identified in early childhood, characterized by significant deficits in social communication, social interactions, and behavioural challenges. As a result of their social-emotional, communication, and sensory impairments, children with ASD are at greater risk for inactivity and obesity. As stated by Corvey, Menear, Preskitt, Goldfarb, and Menachemi (2016), young children and adolescents with ASD are less active, engage in more sedentary behaviours and are more likely to be obese than their typically developing peers. In addition, rural youth in general are at an even greater risk than urban youth for obesity and recreational inactivity (Yousefian, Ziller, Swartz, & Hartley, 2009), thus making children living with ASD at particular risk for obesity and inactivity.

Recreational programs and activities have the potential to benefit children with ASD if the social interactions are positive (Ayvazoglu, Kozub, Butera, & Murray, 2015). Caregivers from diverse geographical areas reported that when their children with severe learning disabilities had opportunities to participate in inclusive activities, it increased their child's confidence, interpersonal and social skills; as well as, improved their children's coordination, behaviour, and sleep patterns (Black, McConkey, Roberts, & Ferguson, 2010). However, considering the extent of developmental impairments associated with ASD, parents have complex safety concerns for their children that may impact their children's recreational participation. Caregivers' fears for their child with autism have been found to include emotional harm by peers or physical injury during activity participation (Ayvazoglu et al., 2015).

Participation in activities is the context in which people develop skills and competencies, achieve well-being and health, express creativity and form friendships, and determine meaning and purpose in life (Murphy & Carbone, 2008). Subsequently, this reinforces the importance of inclusive and safe recreational opportunities for all children in varied community settings. There is no previous research to date that has sought to understand caregivers' experiences with safe recreation for their children with autism who live in rural communities. Thus, this research was undertaken in rural communities located in the Okanagan region of British Columbia (BC), Canada with a focus to understand parents' views in relation to safe physical activity needs, and barriers and supports for children 3-12 years with ASD.

### **1.1 Definition of Terms**

**Recreation.** For the purpose of this masters thesis, the Canadian Parks and Recreation Association and Interprovincial Sport and Recreation Council's (2015) renewed definition of recreation was used and defined as, "the experience that results from freely chosen participation in physical, social, intellectual, creative and spiritual pursuits that enhance individual and community wellbeing (p. 4). However, the focus of this study was narrower and pertained more specifically to activities that involved some degree of physical activity. Physical activity, activity participation and recreation were used interchangeably.

**Autism spectrum disorder.** For the purpose of this masters study, ASD, autism, Asperger's syndrome, and Pervasive Developmental Disorder-not otherwise specified (PDD-NOS) were all considered as a diagnosis of ASD despite the classification changes that have occurred to the *Diagnostic and Statistical Manual of Mental Disorders* from the 3<sup>rd</sup> to the 5<sup>th</sup> edition (DSM-5), put forth by the American Psychiatric Association (Johnson, Burkett, Reinhold, & Bultas, 2016). This was necessary in order to include parent participants with

children affected by the spectrum disorder whom may have been diagnosed prior to the broad classification of ASD that went into effect in 2013 with the DSM-5 (American Psychiatric Association, 2013). ASD and autism were used interchangeably in this study.

**Safety.** For the purpose of this study, safety has been defined as “a state in which hazards and conditions leading to physical, psychological or material harm are controlled in order to preserve the health and well-being of individuals and the community” (Maurice, Lavoie, Laflamme, Svanstrom, Romer, & Anderson, 2001, p. 2). This definition includes and relates to parental perceptions and feelings towards their children’s safety and can refer to both physical and psychological aspects of safety.

**Caregivers.** For the purpose of this study, the term ‘caregivers’ was used interchangeably with parents and/or legal guardians and referred to the context of being the primary caregivers raising a child aged 3 to 12 years old living with ASD. The term families will also be used.

**Rural.** For the purpose of this study, the Statistics Canada definition of small population centres and rural areas outside of these centres was used (Statistics Canada, 2016). This means that participants were eligible to take part in the study if they lived in a small population centre of 1,000 – 29,999 or rural area with a population of less than 1,000 (Statistics Canada, 2016). Statistics Canada (2016) states that urban to rural has been described as a continuum with no defined agreement for the cut-off points for rural; therefore, this definition was selected because it best suited my research question and related to the potentially underserved populations that were the focus of this study. My expectation was that those living both in rural areas and in smaller centres might lack recreational services aimed at children with neurodisabilities to a greater extent than those in urban areas. The terms small centre and rural area are included in this definition and were used for this thesis.

## **1.2 Problem and Significance**

It is important that children with ASD participate in recreational physical activities to improve their health, fitness, and quality of life. Physical activity has been found to play an important role in the emotional well-being and development of children (Krauss et al., 2012). Despite these potential benefits, research has shown children with ASD experience higher levels of inactivity and are at greater risk for poorer physical and psychological health-related outcomes (Ayvazoglu et al., 2015). Unfortunately, families with children with autism experience many challenges and barriers at multiple levels that may influence their activity and recreational participation. These levels may include child, family, and community factors. Some of the biggest barriers to recreational participation and connections outside of their home environment for children with ASD may be parental influence and decision-making. For example, parents of children with ASD have significant concerns for safety and injury risks during physical activity due to unique developmental challenges and the lack of adequate supports for their children to successfully participate in community recreational programs (Polfuss, Johnson, Bonis, Hovis, Apollon, & Sawin, 2016; Schleien, Miller, Walton, & Pruett, 2014), and thus may curtail their children's activity participation for these reasons. Barriers to recreational opportunities have also been noted to be greater for families living in rural communities (Moore, Jilcott, Shores, Evenson, Browson, & Novick, 2010), which further justifies the need to explore this topic amongst families living outside larger centres.

## **1.3 Purpose and Objectives**

This masters project took place in British Columbia's Okanagan region. The purpose of this study was to develop understanding about factors influencing how families can promote safe, active recreation for their children 3-12 years old living with ASD across rural Okanagan

settings and how these types of small centres and rural areas can provide support and inclusive environments to assist families. This masters thesis focused on the unique viewpoints of caregivers in rural settings.

There were two main objectives to this qualitative study.

Objective 1: To explore rural caregivers' experiences, perceived barriers and contextual aspects related to promoting safe, active recreation for their children living with ASD.

Objective 2: To identify service needs for families in the rural areas that support caregivers' efforts to promote safe and active recreation.

It is expected that this research will provide a better understanding of the challenges and supports that families with children living with ASD encounter in their day-to-day lives with safe, active recreation across rural Okanagan settings.

#### **1.4 Potential Contributions**

Anticipated contributions of this research were to provide a better understanding of factors influencing how families can promote safe, active recreation for their children living with ASD across rural settings while identifying family-centred priority issues. This research has the potential to inform program planning and decision-making about allocation of resources to support inclusive opportunities. In addition, this thesis study may also encourage research informed decision and policy making to aid families' activity participation and healthy family and child development for the betterment of society as a whole. As stated by Dahan-Oliel, Shikako-Thomas and Majnemer (2011), it is by activity participation that children and adolescents are able to contribute to their community, learn about the expectations of society, and develop the skills they need to transfer success across multiple settings including their home, school, and community. Children with ASD require recreational supports that allow them

inclusive opportunities to learn, grow, and to form meaningful connections with their family, peers, and extended community. Thus, understanding how we can better support parents with aiding their children with ASD to engage in such opportunities, forms an important research purpose.

### **1.5 Overview of Thesis**

This thesis further consists of Chapter 2, Review of Literature, Chapter 3, Methods, Chapter 4, Results, Chapter 5, Discussion, and Chapter 6. Conclusion.

## **Chapter 2. Review of Literature**

The concepts applied to the literature review involved a combination of physical activity, rural, children, and disabilities. An electronic search of the literature was conducted in collaboration with a UBC-O Librarian, using Medline, CINAHL, Embase, ERIC, PsycINFO, Social Work, and SPORTDiscus applying database-specific controlled vocabulary such as MESH terms and field searches surrounding the concepts under study. For physical activity, other terms applied to the search included exercise, sport, walk, cycle, recreation, bike, hike, sport, run, jog, swim, riding, martial, yoga, dance, cardio or aerobic. These recreational terms were used in combination with words such as rural or remote; and the youth component included child, youth, young adult, teenager, kid, school aged, kindergarten, preschool or adolescent. Terms to explore the concept of disabilities were not limited to ASD. Searches included a neurodevelopmental perspective and applied the terms: Fetal Alcohol Spectrum (or Syndrome) Disorder (FASD), behavioral, cognitive, intellectual, social, communication disorder or disability, Cerebral Palsy (CP), Developmental Disorder (DS), Chromosome Disorder, Mental Disorder, Attention Deficit Hyperactivity Disorder (ADHD), Autism, Asperger's and/or ASD to capture all possible relevant articles.

The search strategy combined with the MESH headings and field search terms with the Boolean operators OR and AND were used to obtain the relevant research. Articles included ranged from 2001-2019. Several pertinent articles were located using Google Scholar and were retrieved through UBC databases. Inclusion criteria included English language, empirical studies with abstracts and full text available. Inclusion criteria were: parents (either mothers or fathers) who were raising a child primarily 18 years old or younger with autism or another neurodevelopmental disability. This resulted in 418 abstracts initially found. Following removal

of duplicates and abstracts not meeting criteria (389), there were 29 articles reviewed in full with seven meeting all inclusion criteria that underwent extensive data review. Exclusion criteria were full text articles that could not be found within UBC online databases. Articles were excluded if they were not specific to caregiver's perspectives and if they had no rural component with the exception of one recent Canadian urban study on parents' perspectives of physical activity amongst adolescents with ASD (Gregor et al., 2018). The focus of Gregor et al.'s (2018) study closely relates to this current thesis; however, it differs in that the target age group concentrates on older teenagers whom reside in urban settings. The purpose of this literature review was to examine the existing literature related to rural families' recreational experiences with their children living with ASD and other neurodevelopmental disabilities in order to thoroughly examine the evidence as it relates to this proposed thesis study.

In addition to the articles found during this literature review, a framework known as the Bronfenbrenner's Ecological Model of Human Development illustrates the complexity surrounding childhood development and the factors that may influence their development (Bronfenbrenner, 1979). Bronfenbrenner believed that children's development is influenced by individual characteristics and interpersonal relationships with those around them; along with environmental factors that extend to community-level influences (Bronfenbrenner, 1979). This model addresses key concepts in a comprehensive way that were relevant for the interpretation of the study findings.

## **2.1 Recreation or Participation in Recreation for Children with ASD**

Despite an exhaustive search of multiple databases in collaboration with a UBC O Librarian, no articles were found addressing rural families' perspectives involving their children diagnosed with ASD and the factors affecting recreational participation. This points to the novel

topic of inquiry that this research question reflects. A broader consideration of literature focusing on parental views of barriers and supports for their children living with autism and physical activity in non-rural communities revealed some additional relevant factors. For example, Obrusikova and Miccinello (2012) reported from their online survey and focus group study that parents identified a lack of community activity programs or locations to engage in safe participation, along with the lack of adequately trained staff. Facilitators reported by parents indicated the importance of accessibility and trained staff for inclusive opportunities. In a literature review that included practice applications, authors mentioned there is a lack of meaningful inclusive recreational activities available for children with ASD due to their social, communication and behavioural challenges (Potvin, Prelock, & Snider, 2008), and recommended a collaborative family-centred support strategy to maximize the child's recreational participation. Furthermore, caregivers in another study that used mixed methods, highlighted a lack of awareness and understanding of ASD in community settings, including schools (Ayvazoglu et al., 2015). In addition, these authors argued that unique developmental considerations for each individual child living with ASD must be taken into account when looking at factors affecting recreational participation. In Polfuss et al.,'s (2016) qualitative investigation, parents emphasized ASD-related developmental delays, such as difficulty managing frustration, rigidity, sensory issues, poor coordination, and reduced reaction time as factors related to their children's abilities to engage with physical activities.

Moreover, when we relate this review of data with the literature identified during this study's search that looked at addressing rural caregivers' views of overall services available for their children living with ASD, a theme emerged of parental reports that their rural community, "had less of everything" (Hoogsteen & Woodgate, 2013). This was consistent with Mello,

Goldman, Urbano, and Hodap's (2016) study who found decreased access to services for children with ASD in rural communities when compared to non-rural settings. Therefore, the inference can be made that this may also include recreational programs and services.

## **2.2 Autism Spectrum Disorder and Safety Considerations**

Safety is a significant concern amongst caregivers of children living with ASD with safety issues often linked to the developmental challenges children experience. For example, parents perceived it to be unsafe for their children with autism to engage in outdoor activities due to their children becoming easily distracted or preoccupied (Obrusnikova & Miccinello, 2012). Further, caregivers identified inattention and coordination issues as impacting their child's ability to participate in active play and physical activities safely (Ayvazoglu et al., 2015). Studies confirm children with ASD are more likely to experience a higher incidence of injuries than their typically developing peers (Jain et al., 2014; Lee, Harrington, Chang, & Connors, 2007). Evidence also shows that parents of children with intellectual and related developmental disabilities value community recreation as an important aspect of their children's quality of life; however, they had safety concerns due to underprepared program staff (Schleien et al., 2014). Similarly, other research findings include parent reports of inadequately trained staff appointed to work with their children with ASD in their existing activity programs that then created a community safety and access barrier (Gregor et al., 2018; Obrusnikova & Miccinello, 2012). Additionally, parent participants stated how inappropriate peer behaviour and unsafe neighbourhoods with hazardous biking and playground spaces, reduced their children's activity participation (Obrusnikova & Miccinello, 2012). Parents of youth with ASD worried about their children being vulnerable to bullying, (both physical and verbal), resulting in parents engaging in protective actions that could also lower involvement in activities (Gregor et al., 2018).

Furthermore, caregivers have been reported to not only worry about the safety of their own children with ASD during activity participation but may also have concerns for the safety of others in the case of an emotional outburst or physical aggression, which may also contribute to lower involvement (Ayvazoglu et al., 2015). Thus, this research has identified how safety-related factors at the child, parent, and community levels can influence recreation participation of children with ASD; however, the ways in which these factors are experienced by parents in rural settings specifically has not been studied.

### **2.3 Caregiver Promotion of Activity for Children with ASD**

Some authors argue that caregivers of children with ASD are more stressed than parents of children with any other disability (Hayes & Watson, 2013). This is likely due to the specific challenges and behavioural characteristics of autism. For example, parents may struggle with their children's ongoing difficulty with transition and change associated with going from one situation to another (Ayvazoglu et al., 2015). Furthermore, parents indicated short-term transitional challenges can include going from indoor to outdoor activities; therefore, caregivers may not want to deal with the ongoing struggle and may even avoid outdoor experiences as a result (Ayvazoglu et al., 2015). However, research also shows that caregivers of children with neurodevelopmental disabilities value goals related to activity participation and child ability more than impairment-based, deficit-orientated goals reflected by standardized developmental assessments (Dahan-Oliel et al., 2011). Therefore, in order to remain family-centred and help meet the needs and priorities of this population, it is important for families with children with ASD to have access to opportunities to engage with recreational activities. Physical activity participation may also enhance the behavioural flexibility of children with autism and likewise influence caregivers to promote their children's activity involvement outside the home. This

could include a combination of either unstructured or structured play or activities. Dahan-Oliel et al. (2011) suggest that it is important to acknowledge that there are benefits for both segregated and integrated activity participation and children with neurodevelopmental disabilities should have the chance to engage in both. In terms of services, resources, and everyday parenting requirements, caregivers living rurally, commonly believe that they are on their own and may feel isolated (Hoogsteen & Woodgate, 2013). Therefore, it is through recreational experiences that families and children with ASD may build meaningful friendships and support networks through mutual engagement within their rural communities; thus, potentially combating feelings of isolation and decreasing caregiver's stress.

## **2.4 Rural Issues**

Considering the low population density for rural living, there is a higher likelihood rural youth live further from activity areas (Moore et al., 2010). Therefore, transportation and access to recreational programs and services are additional challenges faced by rural families. Generally, rural caregivers of children with special needs face additional barriers to access available resources due to greater financial difficulties when compared to urban dwellers (Cockrell Skinner & Slifkin, 2007). In terms of general services, parents in a recent study reported that constant advocacy for their children with ASD for inclusive programming is challenging in rural areas due to society's lack of understanding and knowledge about the array of spectrum impairments (Hoogsteen & Woodgate, 2013). In a study of physical inactivity among rural youth (Yousefian et al., 2009), the authors highlighted the importance of creating physical activity programs for rural youth that is affordable, centrally located, family-friendly, and more diverse.

## **2.5 Identified Limitations in the Research**

There was no prior research found during the literature review that specifically related to parents' experiences with promoting recreational activities for their children living with ASD in rural communities. Instead, associated concepts are dispersed across various bodies of literature making it difficult to cohesively bring the topics together. The few articles found to be applicable to this research with a rural component addressed topics such as caregivers' experiences with parenting a child with ASD, studies addressing children with various disabilities and services/delivery, and physical activity for rural youth in general. These seven studies were primarily qualitative with the exception of one survey-based quantitative study. This reflects a very small descriptive body of research with no intervention or evaluation studies. However, the descriptive evidence from the studies obtained on the related concepts, clearly demonstrates the need for this masters thesis project to bring forward the rural factors caregivers face with their children living with autism in relation to recreational participation and how safety issues influence their efforts.

## **Chapter 3. Methods**

### **3.1 Research Question**

According to Agee (2009), qualitative questions should reflect the particularities of the study and explain what it is about. Therefore, the research question for this masters study was as follows: What are the experiences and influencing factors for families living in rural Okanagan communities engaging their children with ASD in safe and active recreation? The question was ethical, purposeful, specific and focused, which made it easily understood for the participants of the qualitative study to discuss and provide their answers.

### **3.2 Study Design**

This study used interpretive description (ID) (Thorne, 2016), which is guided by the naturalistic paradigm characterized by a worldview that acknowledges multiple realities and views truth holistically. Knowledge is produced relationally between the researcher and participant in their natural environment (Weaver & Olson, 2006). The focus of this qualitative study was both subjective and intersubjective. Interpretive research seeks shared meaning and understanding; as such, the current research focused on rural Okanagan caregivers' experiences and factors influencing their ability to engage their children with ASD in safe and active recreation. This naturalistic paradigm is well-suited because it involved a joint investment and partnership between researcher and participants in the undertaking of the research. Utilizing ID methodology allowed myself as the nurse researcher to bring my experiential foreknowledge from working closely with families with children living with disabilities such as ASD, to the forefront to provide a beginning point to orientate this research design. Furthermore, ID as a qualitative approach allowed a rigorous analytic process within and beyond initial theoretical scaffolding to create variation and breadth prior to the interpretation of the data to provide new

insights into the phenomenon under study in a meaningful way (Thorne, Kirkham, & O'Flynn-Magee, 2004).

### **3.3 Participants and Sample**

Caregivers of children ages 3-12 years living with ASD in rural Okanagan settings were initially recruited by convenience sampling, followed by a purposive approach to add diversity to the sample. Thorne (2016) describes a sample formed by “convenience” as appropriate for applied qualitative research in that the participants whom are the closest to the research topic are an excellent source of insight to share their experiences. Convenience sampling worked well initially; however, only mothers were coming forward to participate in the study. Therefore, an additional effort assisted by Autism BC's coordinator via way of social media was made to also purposively recruit fathers to participate in the thesis to include their parental experiences as well.

This sample was recruited from rural areas and small population centres in the Okanagan. According to Statistics Canada (2016), the medium population centres (30,000 – 99,999) to large urban centres (100,000 or more) in the Okanagan are made up of the larger towns of Kelowna, Penticton, Vernon, West Kelowna, and Lake Country. Therefore, the small population centres and rural areas outside of these centres formed the focus for recruitment, such as Armstrong to the north, Peachland to the east, Oliver to south, and Lumby to the west. In this research, the aim was to include a diverse sample of participants; meaning an inclusive definition of caregiver was considered for contemporary childrearing practices. For example, participants included biological parents (mothers and fathers) and adoptive parents, a single parent, and mixed families, as long as the caregivers were, in fact, legal guardians of the children. Thorne (2008) indicates ID can be conducted with almost any sample size; however, the majority of studies

depicting this approach tend to fall within the sample range of 5 to 30 participants. For the purpose of this study, in order to obtain a rich data set that recognized the issues of concern within the rural population, the aim was to interview 10-15 caregivers on one occasion for approximately 45-60 minutes each. The resulting sample size within this target range was 12 parents who were interviewed for the study.

An application that described study procedures including recruitment methods, data collection and analysis procedures, and informed consent was submitted and approved by UBC Okanagan Behavioural Ethics Board prior to the commencement of the thesis study. The certificate number is H18-00854-A001. This application also described how confidential data was to be managed and stored. Consent forms, demographic form, recruitment poster and other messages were also included and approved by UBC Okanagan Behavioural Ethics Board (see Appendix A).

Recruitment of participants included advertising the study in key locations frequented by potential study participants, such as local community and recreation agencies that served families with children in rural Okanagan communities. Avenues that elicited parent participation included advertising with posters and brochures through local community organizations, such as Autism Okanagan Association and children's therapy centres, following approval from associated executive directors and managers. Key community agencies (Autism Okanagan and Autism BC) also posted recruitment messages aimed at caregivers who met the study criteria using social media, such as Facebook. This proved to be an effective way to reach a broader audience who were associated with these key organizations. In addition, the researcher set up an information table about the study at the academic-community symposium event (Get Ready...Get Safe...Go! Symposium) that took place June 16, 2018 (Autism Okanagan, 2019). This provided an

opportunity to connect with potential participants and share information about the study, answer questions from potential participants, and allow those who were interested to sign up for an interview. The procedures to inform those interested and to follow-up with them were described and included as part of the UBC Okanagan ethics application.

### **3.4 Data Collection**

Prior to each participant's interview, the student researcher first reviewed key aspects of consent and allowed participants to ask questions before written consent was obtained.

Following informed consent, the participant was then asked to fill out a demographic information form that asked questions about gender, age, nationality, annual income level, and parent's main activity/job status.

To be least intrusive and ethical, data collection was conducted via a combination of open-ended and semi-structured interview questions using a prepared interview guide (see Appendix B). By maintaining an ID naturalistic inquiry approach, the interviews permitted time and focus dedicated to the study participants outside of work-related spaces to focus on in-depth data collection and qualitative experiences (Thorne, 2008). To enhance the quality of the data retrieved from the interviews, the researcher used an open communication style and introduction to build trust and rapport. Confidentiality was reiterated and options for the interview location were provided. These included meeting with participants in a safe public place, such as a restaurant or café of the family's choice, or at their home in their rural Okanagan community if preferred. It was taken into account that many caregivers may have felt more comfortable to be interviewed at home in order to be more discrete considering that people often know each other in small town settings. It was also easier for some families to be home and available for their

children's needs, as opposed to finding childcare or bringing them out into the community that required them to divide their attention for the interview.

While being mindful not to direct the dialogue, probing questions were sometimes used to encourage and guide the participants' expansion of details within each individual interview. This enhanced clarity of information and helped keep the interview focused close to the caregivers' lived experiences and opinions related to recreation and activities with their children living with ASD. As Thorne (2008) describes, acquiring high-quality data framed with ID as a neutral facilitator, requires a significant dose of humility and reflexivity to ensure a researcher's own passion and personality do not steer the interactions in predictable directions. Upon closing of the interviews that took 45-60 minutes, a \$15 gift card was provided to each of the participants to acknowledge their time and input.

Following interviews, field notes were completed to record general impressions of the interview, reflections on interview questions that worked well, observations about the external environment and/or distractions that may have influenced the interview, and thoughts related to theoretical ideas that resulted from the interview content. I recorded these notes soon after each interview in a field notebook dedicated for this purpose, when I was alone and able to focus on my thoughts. Recording field notes shortly after the details and events occur, ensures that they are not lost from memory; however, the broader patterns may evolve in the longer-term reflection away from the field (Mulhall, 2003).

### **3.5 Data Analysis**

The interviews were audiotaped and later transcribed verbatim. A fourth-year undergraduate nursing student and myself as the graduate student/researcher transcribed the data. Transcripts were double checked by the masters student for accuracy. This was followed by

broad-based coding which resulted in an initial list of codes that reflected parent experiences promoting safe and active recreation for their children living with ASD. Themes were generated by means of inductive and deductive reasoning. Thorne (2016) describes broad-based coding as an ideal way to create a collection of accounts that may reveal a thematic pattern or contextual background to the participants real stories. This coding method was an inductive process that actively evolved over time. Furthermore, to articulate the descriptive and interpretive insights, thematic analysis was applied. The product of ID was a comprehensive description that clearly indicates thematic patterns and commonalities believed to conceptualize the phenomenon that was being studied and also took into account the inevitable individual variations (Thorne et al., 2004). This inductively driven technique was applied to break up significant findings to portray the family caregivers' perspectives and used to formulate concepts discovered. "Thematic analyses seek to unearth the themes salient in a text at different levels" (Attride-Stirling, 2001, p. 387). Braun and Clarke's (2006) approach using six stages of thematic analysis was applied to provide a structured basis to guide this qualitative analytical method. However, it is important to note that this analysis was not a linear process and required engaging with the data in a back and forth manner throughout the interpretive research course as outlined by Braun and Clarke (2006), reflecting both inductive and deductive reasoning processes. With that in mind, the six phases of Braun and Clarke's (2006) thematic analysis that were applied to enhance my qualitative approach and process involved: phase 1) familiarizing yourself with the data, phase 2) generating initial codes, phase 3) searching for themes, phase 4) reviewing themes, phase 5) defining and naming themes, and, phase 6) producing the report.

**Phase 1: familiarizing yourself with your data.** Braun and Clarke (2006) describe how it is vital in the initial stage of thematic analysis to immerse yourself in the data in order to

become familiar with the depth and breadth of the content in an active way that searches for patterns and deeper meanings through “repeated reading.” This was an ongoing stage as I collected data through interactive interviews and took notes thereafter; followed by the data being transcribed into written format. This verbatim transcription of the participants’ perceptions and revisited field notes was time-consuming; however, it was through this process of immersing myself in data and multiple truths and realities of the participants, that interpretation and creation of themes ensued. As stated by Braun and Clarke (2006), time is not wasted during transcription, as it is from this research task that a thorough understanding of the data develops, which, in turn, informs the early stages of analysis.

**Phase 2: generating initial codes.** According to Braun and Clarke (2006), the next stage of thematic analysis begins once the researcher has familiarized themselves with the data, and involves initial coding. The codes were derived manually from the transcribed data by inductively breaking down the entire data set into themes identified by a colour coding scheme. Consistent with Braun and Clarke, this involved a systematic approach that gave full attention to each data item in which the identification of aspects in those data items may produce the repeated patterns and themes across the data set (Braun & Clarke, 2006). In addition, when I analyzed the transcribed interview data, I maintained an openness and curiosity to the data that did not necessarily fit within the dominant codes produced. Braun and Clarke (2006) state, “It is important to retain accounts that depart from the dominant story in the analysis, so do not ignore these in your coding” (p. 89). This statement related well with ID as it reinforced the message of how crucial it is to focus on who the person is and why they were telling you what was being told, as opposed to anticipating powerful stories (Thorne, 2008).

**Phase 3: searching for themes.** Braun and Clarke's (2006) third step to analysis begins after all the data has been coded and involves sorting the individual codes, to broad categories and then into different themes and sub-themes while thinking about the relationship between these codes and themes. Throughout this phase, I created a visual portrayal of my interpretation and analysis alongside some descriptive notes that could be followed in the form of mind-maps that indicated codes that branched off with arrows to different categories and themes. A colour-coded system with highlighters and post-it notes was useful during this stage. This system of tracking and organizing codes and categories was also a part of my reflective ID approach that I maintained throughout my data analysis. Braun and Clarke (2006) explain that some initial codes may produce overarching themes, where as other codes may form sub-themes or be put aside. However, no data or subsequently created codes or themes were disregarded in this stage, rather a category of miscellaneous codes to be revisited at a later stage was created, as deemed acceptable by Braun & Clarke, (2006).

**Phase 4: reviewing themes.** Within the fourth stage of thematic analysis the developed themes and sub-themes were examined in detail to see whether or not they should stay as they were or be refined, combined, separated or put aside (Braun & Clarke, 2006). This involved a two-level process of reviewing themes: one at the level of coded data extracts and the second level in relation to the entire data set (Braun & Clarke, 2006). Therefore, during this stage of analysis, I first re-read the coded parts of each theme and determined whether or not there was a cohesive pattern for the creation of each category to represent level one of Braun and Clarke's (2006) fourth stage of analysis. This involved revamping, adding, recreating, or pushing aside themes. Mind-mapping was useful during this process.

Level two of this phase, not only considered the validity of the entire data set but also

looked at whether or not the thematic map truthfully reflected the meanings of the data set as a whole (Braun & Clarke, 2006). After this two-level review process, I then went back and completed some additional coding and/or re-coding of the data until the thematic map fit with the data set that represented and supported the caregivers' experiences promoting safe recreation for their children with ASD in their rural communities.

**Phase 5: defining and naming themes.** Braun and Clarke (2006) described the fifth stage of thematic analysis as the “defining and refining” stage of what and how each theme or sub-theme fits into the overall story of the data, as it relates to the research question. I immersed myself in this stage with reference to my thematic map by explaining what is of interest about each theme and why my attention was drawn to each one. According to Braun and Clarke (2006), if I was able to describe the scope and content of each theme in a couple of sentences with a clear definition of what each theme was while being mindful of what it was not, then it would be time to move on to the final stage of analysis.

**Phase 6: producing the report.** The final analysis stage involved the write-up of the report when all the themes had been decided on and sufficient evidence was provided to demonstrate the depth within each category (Braun & Clarke, 2006). This entailed scholarly writing that portrayed a valid account of the patterns and themes generated from the experiences of the caregivers as they told their stories to the researcher. Braun and Clarke (2006) indicate the importance during this stage to go beyond describing the data and instead make a coherent, logical argument that relates to the research question. For example, the data extracts captured the essence of the theme and sub-themes as they related to my research question while also addressing concepts of *safety, risks, stigma and inclusion within data collection and analysis with additional consideration of how these concepts may have held heightened salience in rural*

*settings*. Furthermore, the analysis and write-up surrounding the finalized themes was not an isolated process and involved occasional consultation with my UBC Okanagan supervisor and committee members. Checking in with expert researchers with varied backgrounds throughout the data analysis stages was an effective way to enhance the trustworthiness of the study's findings and also allowed opportunities to receive constructive criticism and feedback.

### **3.6 Enhancing Credibility**

The nurse researcher used reflexivity to promote the credibility of the findings through relaying subjective and intersubjective data that were subject to thematic analysis. To enhance the trustworthiness of the qualitative research project, the general principles typically applied to ID and recognized across the “qualitative research spectrum” were pragmatically applied as the evaluative criteria (Thorne, 2016). These criteria introduced by Thorne (2016) included epistemological integrity, representative credibility, analytic logic and interpretive authority.

**Epistemological integrity.** Thorne (2016) states,

[A]ll qualitative research is expected to demonstrate epistemological integrity in the sense that there is a defensible line of reasoning from the assumptions made about the nature of knowledge through to the methodological rules by which decisions about the research process are explained. [p. 233]

In this study, integrity was enhanced through creating a research question that was consistent with the assumptions of the epistemological standpoint that was respectful and upheld the ethical rights of the participants. Moreover, the approach ensured that data collection and analysis strategies used and interpretations made followed logically from the research question (Thorne, 2016). My research question was: What are the experiences and influencing factors for families living in rural Okanagan communities engaging their children with ASD in safe and active recreation? My research question and methods stayed consistent with ID's epistemology due to the efforts instilled to attend to the experiential knowledge of the parents to provide a valued

source of practice input while acknowledging that our interactions were inseparable for the research outcomes (Thorne, 2016). The reflective research practices assisted in ensuring the steps taken in the study were consistent with the foundational approach of ID.

**Representative credibility.** Representative credibility requires prolonged engagement with the phenomenon to produce the study findings (Thorne, 2016). Such engagement entailed a large enough convenience and purposive sample of 12 that generated a rich, in-depth data collection of caregivers' experiences with safe, active recreation for their children living with ASD across varied settings to identify family-centered priorities. Credibility also involved establishing trustworthiness with the participants initially at the time of recruitment, during initial contact via email and/or telephone, by obtaining informed consent in person, and throughout the interview process by sustaining a neutral, holistic way of being. Representative credibility was upheld throughout this study by maintaining the participants' confidence and anonymizing the data. As a naturalistic inquirer engaged with ID, I continually engaged with self and others involved in this thesis and interview process while acknowledging that what may have initially been seen as insignificant may have actually uncovered the hidden realities and truths about the population and phenomena under study.

**Analytic logic.** Analytic logic was monitored by my UBC Okanagan supervisor and committee members throughout the entire research process. Ongoing reflexive notes illustrated an audit trail and the audio taped interviews provided expert researchers the opportunity to examine my reasoning and the product of the data. The researcher's decision-making process used throughout the conduct of interpretive claims of a study must be made available to allow the chance to assess its adequacy (Thorne, 2016). My positioning to uphold the integrity of the interpretive process remained transparent with the use of thick description while grounding the

interpretations I made from the data analysis with verbatim quotes to show support and evidence for these interpretations in order to generate credible findings while remaining flexible and creative with the use of inductive reasoning. As stated by Thorne et al. (2004), excellence in qualitative analysis consistently requires ongoing engagement, conceptual creativity and imagination.

**Interpretive authority.** It is important to keep in mind that no matter how collaborative the research process, it is the researcher who has the potential for “interpretive authority” and how the final conceptualizations of the data will be structured to disseminate the findings (Thorne, et al., 2004). Furthermore, epistemological integrity acknowledges the importance of being able to recognize my recent nursing position as an Infant Development Consultant with Kamloops Infant Development Society throughout the research process. As a practitioner who has worked closely with families with children birth to three years old who may be at risk for or suffer from known developmental delays, including pre and post diagnosed children with ASD, it was critical to be self-aware of my positioning as a researcher within the interpretive research. This included separating my nursing roles of a practitioner and graduate student and acknowledging the difference between the two so not to create any mistrust or potential bias through preconceived ideas from past work experience during this thesis. Thorne (2016) states the importance of being conscious of disciplinary biases that may creep in while setting out to study the phenomenon due to the assumptions we often make about the most appropriate line of reasoning based on our prior knowledge. Decisional strategies I used to maintain epistemological integrity included keeping a reflexive journal and analytical notes as a part of my field notes to track my thoughts following each interview. Additionally, brainstorming with mind mapping drawings and open-ended reflections also aided in the discovery as to what the data meant. These

strategies are consistent with Thorne's (2016) recommendation to go beyond using visual reference points, such as a journal and furthering reflexivity with analytic memos by jotting down written accounts of evolving thoughts and inquiry in a blank notebook. These strategies can help foster critical reflections about ongoing interpretive challenges in ways that respect the nature of my epistemological position. For this reason, I maintained a reflexive stance by applying ongoing ID strategies, such as journaling and brainstorming, that ensured I maintained an accountable and credible research approach. Reflexivity with the concurrent generation of themes aided in the construction of subjective and intersubjective truths that relationally were produced from parental experiences promoting safe recreation for their children with ASD in rural communities. As stated by Thorne et al. (2004), integrity to the interpretative research process will always create more credible findings than a rigid approach to rigor. Therefore, the organization of the research processes coincided with the pragmatic lens of the emergent design of ID.

### **3.7 Ethical Considerations**

Research is a privilege. Therefore, the nurse researcher took steps ensuring the rights and well-being of the participants were preserved, and their vulnerabilities were protected. This was ensured by being accountable and adhering to guiding principles for nursing research ethics (Doody and Noonan, 2016) that include autonomy, beneficence, non-maleficence, justice, veracity, fidelity, and confidentiality.

**Autonomy.** Autonomy involves ensuring participants have the right to self-determination and receive full disclosure of the nature of the study, with the right to withdraw at any time prior to data analysis (Doody & Noonan, 2016). Autonomy included reviewing and obtaining informed consent from the caregivers prior to the interviewees partaking in the study; as well as,

sharing a signed and dated consent form with the participant. Because topics surrounding parenting, children and safety were part of the focus of this thesis, informed consent included mentioning to the interviewees that if abuse of any kind was suspected, the nurse researcher was obligated to report concerns to appropriate authorities.

**Beneficence.** The underlying principle of beneficence was applied to this research as it sought to benefit the participants and society as a whole. The aim of this study was to support inclusive opportunities for families with children with ASD that encourages activity participation and well-being. Having the participants interests in mind, I reflected upon the study participants being provided a \$15 gift card for their time and input and concluded that this incentive was not significant enough to promote feelings of coercion or interfere with caregivers' autonomy.

**Non-maleficence.** Non-maleficence pertains to the researcher seeking to do no harm and involves an assessment of the potential benefits and risks of the research (Doody & Noonan, 2016). Ethical considerations based on potential vulnerabilities on behalf of the families with children living with ASD included the possibility of role strain or caregiver burnout associated with a lack of personal, financial, or community resources. Anticipating that it was plausible that issues of childcare and/or respite may arise during data collection with the participant(s), I was able to be prepared with an understanding of where to refer families for additional supports closest to their area and provided a resource list to the participant of each interview.

**Justice.** According to the principle of justice, the nurse researcher is compelled to treat the potential study participants fairly and equitably throughout the study (Doody & Noonan, 2016). By choosing to represent varied rural population settings, this study included all families interested in participating who met the criteria of living and caring for a child with an ASD diagnosis between the ages of 3 and 12 years old, without prejudice, who resided within the rural

and small population centres of the Okanagan, despite the researcher's potential time and travel challenges with reaching all of these areas.

**Veracity.** In order to maintain respect for the study participants, every effort was made by the researcher to fully inform the caregivers of all aspects of the study in a truthful manner that was easily understood. Moreover, Doody and Noonan (2016) reinforce the veracity must not be dishonoured via way of providing misleading information or deliberately withholding the truth.

**Fidelity.** Fidelity involved a mutual trusting researcher-participant relationship. The researcher trusted in the interviewees that the caregivers met the criteria of the study and in fact had a child diagnosed with ASD and that truthful data were presented. Likewise, the researcher was expected to uphold the participants' autonomy by facilitating informed consent, which included an understanding that they could withdraw from the study, whenever possible, with no consequences. Fidelity also included assurance that the researcher would maintain confidentiality (Doody & Noonan, 2016).

**Confidentiality.** Every effort was taken to safeguard the confidentiality of the research participants. This was crucial when managing sensitive data involving families and children with disabilities. Seeking advice from my thesis supervisor whenever needed, all possible identifiers were removed from transcribed information and the participants were assigned a number prior to the data being coded for analysis. When direct quotes were used for the qualitative study's write-up, special consideration was taken into account to protect participants' geographical identity due to the higher risk that participants could potentially be identified within a small town's population. Therefore, reference to specific locations were not included. Another form of potential confidentiality breach that was important to acknowledge related to sharing caregivers'

perceptions of services or resources across interviews. Therefore, as a researcher, I kept all information shared by participants confidential to that interview. All electronic data were password-protected and kept on a UBC encrypted computer when the researcher was out in the field or was stored on a UBC secured computer drive.

UBC Okanagan research ethics approval was required prior to engaging in the study. As a novice researcher, feedback and advice was sought throughout the entire research process from UBC Okanagan supervisor and committee members, while adhering to the College of Registered Nurses of British Columbia's practice standards. The responsibilities associated with conducting safe, ethical research were not taken lightly and multiple strategies were used to ensure ethical integrity was upheld.

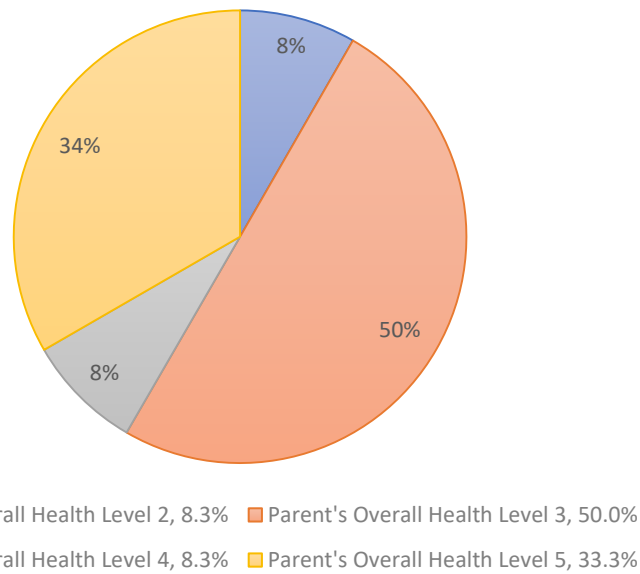
## **Chapter 4. Results**

In this chapter, demographic characteristics of participants and their children living with ASD are presented, followed by the results from this current thesis study. In total, 12 parent participants were recruited into this study. According to Statistics Canada (2016) Census, the population size of the communities where participants resided ranged from 1203 to 11,615. The proximity of the participants' residence to the largest urban centre, Kelowna, BC, ranged from 25 to 135 kilometers. Table 1 illustrates the demographic characteristics of the rural Okanagan parent sample that consisted of 10 mothers (83.3%) and 2 fathers (16.7%) whom were interviewed on an individual basis. None of the parent participants were partners. The parent participants were asked to rate their overall level of health at the point in time of the interview using a scale of 1-5 where 1 is extremely poor and 5 is excellent (see Figure 1).

**Table 1.** Demographic Characteristics of Rural Okanagan Parent Sample

Demographic Characteristic	N	%
<i>Gender</i>		
Male	2	16.7
Female	10	83.3
<i>Age Group</i>		
18-24	1	8.3
25-34	4	33.3
35-44	5	41.7
45-54	2	16.7
<i>Identified Nationality</i>		
Canadian	11	91.7
Other: British Italian French	1	8.3
<i>Education Complete</i>		
Some high school	1	8.3
Some trade school, college or university	1	8.3
Diploma from trade school or college	7	58.3
University degree (Bachelor's or undergraduate degree)	2	16.7
University degree (Master's and/or Doctorate degree)	1	8.3
<i>Marital Status</i>		
Single / never-married	1	8.3
Married	6	50.0
Common-Law	5	41.7
<i>Annual Household Income</i>		
\$30,000-\$59,999	6	50.0
\$60,000-79,999	3	25.0
\$80,000 or greater	3	25.0
<i>Description of Participant's Main Activity/Job Status during the last 12 months</i>		
Stay-at-home parent	6	50.0
Student	1	8.3
Work part-time	2	16.7
Work full-time	3	25.0
<i>Description of child's other Parent's Main Activity/Job Status during the last 12 months</i>		
N/A	1	8.3
Stay-at-home parent	1	8.3
Work part-time	1	8.3
Work full-time	9	75.0

Figure 1.  
Parent Perceptions of their Overall Level of Health (N=12)\*



\*Percentage based on scale of 1-5 with 5 being excellent and 1 being extremely poor.

Most of the parents in the sample were between 25 – 44 years (75%), and nearly all identified as Canadian (92%). The majority had completed post-secondary education (83%), and most were also married or living common-law (92%). Half of the participants had annual household incomes ranging between \$30,000 - \$59,999 (50%), which was similar to the number of participants who reported their main activity/job status within the last 12 months as being stay at home parents (50%).

Table 2 provides an overview of the demographic characteristics of the children of the caregivers interviewed (N=13); 1 parent reported on two children that met the study criteria. Most of the target children with ASD were boys (84.6%). The children living with ASD ranged in age from 3 years old to 12 years old with the mean age of 8.5 years old.

**Table 2.** Characteristics of Rural Okanagan Target Children with ASD

Demographic Characteristic	N	%
<i>Gender</i>		
Male	11	84.6
Female	2	15.4
<i>Ages</i>		
3	1	7.7
4	2	15.4
7	1	7.7
9	3	23.1
10	2	15.4
11	3	23.1
12	1	7.7
<i>Parental Perception of Child's Functional Level on a Scale of 1-5</i>		
2	1	7.7
3	7	53.8
4	1	7.7
5	4	30.8

\* Percentage based on scale of 1-5 with 5 being the highest functioning level and 1 being the lowest.

In this next section, parents' experiences promoting safe and active recreation for their children living with ASD in rural Okanagan settings are presented and explained through the four major themes: barriers to safe, inclusive recreational participation; socially supportive rural communities; parents taking charge for safe participation; and community needs identified. Factors that either hindered or facilitated safe, active participation at child, caregiver, and community levels will be highlighted. Further, how factors were linked to parent experiences specific to the rural context will also be highlighted.

#### **4.1 Barriers to Safe, Inclusive Recreational Participation**

Living in rural communities, parents discussed many barriers to their child's safe participation in recreational activities. These barriers were reflected in the following sub-themes: wide-ranging safety concerns (child special interests, complex vulnerabilities, elopement in rural context) and struggling for inclusive options (lack of community awareness and social exclusion, lack of access to suitable programs, coach/instructor approach, and financial and logistical constraints).

**Wide-ranging safety concerns.** Parents expressed a wide array of parental safety concerns for their children while describing their children's recreation and activity participation. These safety concerns were reflected in sub headings related to the child's special interests, complex vulnerabilities, and elopement in rural context.

***Child's special interests.*** Children with ASD often develop an intense focus or preoccupation with restricted interests. These interests are also known as a child's 'special interests,' because the preferences are unique to the child and can result in compulsive and, at times, dangerous behaviours. Two parents expressed safety concerns linking their child's special interests to impulsive behaviours that could lead them into harms way during activity participation. These caregivers described their child's interests similarly, noting how their children were enticed by particular signs and/or symbols and were also attracted to water. For example, one mother with a 10-year-old son with ASD shared, "He was drawn to signs and he loves water. There's a lot of risk and he would just open the door and go" [Participant 05]. Another mother of two sons ages 9 and 11 with ASD described,

[Child] really liked flags – Canadian flags and he went down the street at my mom's house, to the neighbour's house. They had a little tiny flag in their lawn from Canada Day and he was [found] out there sitting at the bottom of the driveway. If someone would have backed up; they would have driven over him...He used to really like swimming and we used to live by a pond. In the winter, it was freezing but he still wanted to go swimming in it; like, he didn't feel the cold. He would always try to get out to go swimming there, so we had to put locks on the doors. [Participant 11]

Parents explained how these safety concerns affected their sense of burden because as sole primary caregivers familiar with their child's particular interest, only they could predict and decrease the risk of their child's attraction to such unsafe situations. Furthermore, in the rural context there was additional exposure to environmental hazards such as ponds and waterways.

***Complex vulnerabilities.*** Many families expressed concerns for their child's ability to understand and respond appropriately to complex social situations. Therefore, parents felt their children with ASD were at increased risk for emotional, physical and social vulnerabilities during recreational participation. In terms of emotional vulnerabilities, parents expressed concerns about their child being bullied or taken advantage of by peers or others. For example, one mother who had a 9- year-old son explained, "He tends to get picked on. He tends to be almost targeted" [Participant 02]. Another mother reflected on how her 10-year-old son could be easily manipulated, "He wants friends so bad that if someone tells him to do something, he will actually do it; opposed to doing the 'think before you act' ...he wants to belong" [Participant 03]. These parents were reluctant to support their child's activity participation because of concerns for their child's vulnerability to emotional harm. These examples indicated how their children were vulnerable for emotional harm and this concern influenced parents' comfort with supporting their child's activity participation.

Parents also expressed concerns for their child's physical harm and this was at times combined with concerns for emotional safety, reflecting the complexity of these vulnerabilities. For example, caregivers worried about other community members' lack of awareness and understanding of ASD and their child's behaviours, such as not respecting personal boundaries during activity involvement. The potential for others misinterpretation of, and frustration with, their child's behaviours was a concern. In fact, parents thought they might be putting their child's physical and/or emotional safety at risk. For example, a mother who had a 7-year-old son with autism explained,

I have concerns about other people's lack of understanding. I mean, that's basically what I think everything in the world comes down to; is people just don't understand...[Child] will get in personal space; I'm worried that someone will push him out of the way and he'll go falling backwards or something like that. [Participant 07]

A father with an 11-year-old son living with ASD shared that teachers sometimes perceived his son as "...misbehaving because he's not doing what they've asked or able to perform what they've asked." The father further explained, "So, there's big concerns. Especially, emotional safety because he is frequently misunderstood in that kind of area [when instructions are not followed]" [Participant 10]. A mother voiced concerns about public perceptions of her 4-year-old son if he unintentionally hurt another child or became frustrated due to his rigidity with comprehending the social situation. She reflected her concerns for the safety of both her child and other children,

I'm concerned that when we go to the park and people don't understand that he has special needs or struggles...and if he accidentally hurts someone else's child or yells at them because he's frustrated; I'm worried that the other parent isn't understanding. I sometimes get, whether it be nasty looks or glares or them trying to parent him and not understanding that he needs a different style of instructions. Yeah, definitely a concern. [Participant 08]

Parents also expressed fears about a third type of vulnerability, that of children's exposure to dangerous social situations. They described fears related to their child's characteristics potentially predisposing them to danger during recreational events and activities if they encountered someone with malintent. Parents expressed how their children's characteristics related to ASD could increase their risks, such as their child's fearlessness in approaching or being approached by strangers, being over trusting of others, misreading social cues (through not using eye contact or looking at facial expressions), and being nonverbal and unable to call for help when in danger. For example, a mother who had a 4-year-old daughter described, "She is outgoing...her talking to strangers. What if she talks to the wrong stranger one day...and I turn my back or I'm helping [younger sibling] and she's gone. That would be my biggest concern or worry" [Participant 01]. Another mother who had a 10-year-old son disclosed, "I just worry about child predators. [Child] can't talk; if a child predator came...ughhh – I get so worried

because he would easily be identifiable...when you try to talk him, [you can] see that something is wrong” [Participant 05].

In summary, parents had many unsettling concerns related to their child’s spectrum of developmental delays and differences. These concerns often related to their fear of their children being taken advantage of by strangers or child predators whom either live in their rural community or are drawn from elsewhere to local events that take place in some of the smaller Okanagan centres (fairs, festivals, rallies). Parents feared that their children’s characteristics and social challenges could lead them to be physically and psychologically harmed by others but they could also pose a safety risk to other children. These concerns reflected a complicated mixture of potentially vulnerable situations their children could encounter.

***Elopement in rural context.*** Many parents described the burden they carry for their child’s unpredictable elopement or ‘bolting’ behaviour that could occur during recreational activity. This was particularly concerning for parents whose children also had an impaired sense of danger and risk, and thus could find themselves in hazardous circumstances. Parents described this alarming behavioural response often resulting from sensory overload, triggering the child to ‘bolt’ to get away from a situation. Parents described how this bolting behaviour could also result from their child becoming overwhelmed, embarrassed, angry, upset or even bored during recreational activities and could happen instantaneously without warning. For example, a mother with an 11-year-old son described, “His ability to bolt...Fight or flight. [Child] would certainly bolt whether because he misunderstands something or because he thinks somebody laughed at him or he’s just so overwhelmed. If you’re not prepared for it, BANG! That kid’s gone” [Participant 06]. Another mother similarly stated, “[I]f he’s not watched closely and he gets

upset; he does the fight or flight and he will bolt...If something sets him off; gosh knows where we would find him” [Participant 03].

Parents feared if their children did not have sufficient supervision during organized sports and recreational activities they might suddenly run away or wander off and be exposed to danger. These parental concerns influenced their decisions about whether a recreational activity would be a safe experience for their child. Furthermore, in the rural context, these safety concerns were intensified due to environmental hazards such as proximity to major highways and prevalence of nearby bodies of water. For example, one parent of two sons with ASD (9 and 11 years old) expressed concerns that her boys could wander off together and encounter hazards: “[T]hey would leave what they were doing and go find something else to do that maybe wasn’t as safe. Jump in a lake or whatever else. We have a lot of lakes around here” [Participant 11]. Likewise, another mother with a 10-year-old son emphasized her concerns about the risk of injury or death from outdoor hazards due to drowning and/or from traffic,

He would leave. When he learned to open the door, so much opened up in his mind developmentally, it was a huge thing, but it was also like, OH NO we’ve got a swamp down there, we’ve got a major river – not a kilometer away...[and] we’ve got the major highway. [Participant 05]

Two parents voiced a perceived threat from cohabitating wildlife in their rural communities that posed a potential risk to the well-being of their children living with ASD pursuing outdoor recreation. For example, one mother who had a 4-year-old daughter stated, “I can leave them [child with ASD and sibling] in the yard and the only thing I have to worry about is a bear that might randomly come” [Participant 01]. Another mother with a 10-year-old son, stressed her concern for the natural habitation of wildlife in their rural area, “The unpredictability of wildlife!... We have deer in the yard, we have coyotes, there’s bears [and] there’s a lot of literal predators around too” [Participant 05].

Children with ASD are at heightened risk for injury or even death due to a number of psychosocial, emotional, sensory and cognitive impairments. In rural settings, these parental concerns can reflect unique aspects of the environments, such as proximity to outdoor hazards and encounters with wildlife, which when coupled with children's elopement risks may also affect decisions to partake in recreational activities.

**Struggling for inclusive options.** Parents experienced many struggles in attempts to access inclusive recreational opportunities for their children with ASD. The struggles/challenges are reflected in the following subthemes: lack of community awareness and social exclusion, lack of access to suitable programs, coach/instructor approach, and financial and logistical constraints.

***Lack of community awareness and social exclusion.*** Family members perceived a significant lack of public and rural community awareness about autism and children's developmental challenges and special needs. For example, a mother who had a 7-year-old son shared, "I feel that we need more [community autism] awareness ... not so much stigma around what's going on or why [children with ASD] are the way they are" [Participant 07]. There was a sense of rural community members frequently misunderstanding due to their lack of general knowledge about the spectrum disorder and the children's social and behavioural challenges. As the previous parent explained, "... [children with ASD] sometimes look like they're being disobedient or not listening or being aggressive but that [is] sometimes just a release for them."

Along with this lack of understanding of ASD was a strong sense of social exclusion that became evident amongst the family members when they shared their stories. Two parents described their children's longing for inclusion in recreation or play with friends. A mother who had a 9-year-old son expressed, "[Child] wants friends. Wants to do stuff with friends. Badly

wants to do stuff with friends” [Participant 06]. Another parent stressed how kind and genuine his 11-year-old son was and described his child’s desire to be included with his peers. He stated, “... he’s the sweetest thing. He has no ill intention at all. He’d give you anything you wanted. He wants to fit in. He does not want to stick out. He doesn’t want to cause harm to anybody” [Participant 10].

Parents reflected on how exclusion could disrupt feelings of belonging which their children could find confusing while they are learning about the world in which they live. One mother described how others treated her 4-year-old daughter and how this young preschool-aged girl was not able to comprehend the reasons for such segregation as she attempted to learn the social norms of society. The mother reflected,

People kind of see that she’s a little bit different and will kind of be hesitant or standoffish towards her and she’s very outgoing; I can see that she doesn’t really understand why they don’t want to play with her or don’t want to include her in certain things. [Participant 01]

Parents perceived a significant lack of awareness and understanding of ASD in their rural communities. This barrier closely aligns with the parents’ perceptions of social exclusion while trying to promote recreational and physical activities for their children living with ASD. These social barriers cannot be separated from the following concerns related to accessing the programs themselves as these challenges are also problematic at the programming levels.

***Lack of access to suitable programs.*** Repeatedly, participants commented on the lack of programming available to accommodate and support their children living with ASD. Many recreational programs will accept children with neurodevelopmental challenges; however, depending on the functional level and unique needs of the child on the autism spectrum, the activity may not necessarily work out for him or her. As one mother of an 11-year-old son described,

I can sign [child with ASD] up for soccer but he wouldn't be able to participate. They would be more than 'yup, absolutely' they'd take him; but we wouldn't go more than once and it wouldn't work for [him]. So, technically [there's] nothing. [Participant 06]

This mother's frustration was linked to her child being sent home when her efforts to engage him in organized activities were met with providers inability to effectively manage her son's behaviours when he had a 'meltdown.' The assumption that the child needed to be independent for program participation in the family's small towns was frustrating: a mother with a 9-year-old son lamented, "There's nothing here. If your kid can't go to a program by himself then your kid can't go" [Participant 04]. In these situations when there was "nothing" for the child without parental/aide support, it was difficult for some parents to elaborate on recreational opportunities for their children. Parents often expressed the weight resting on them to find these opportunities, such as a father of a 12-year-old girl commented, "None. For activity? I can't think of anything. It's just us as parents" [Participant 12]. Similarly, a mother of a 7-year-old shared, "I haven't found anything for kids with ASD in our area" [Participant 07].

When parents compared their experiences with recreational programming for their neurotypical children, they conveyed a sense of unjustness. For example, one mother with a 9-year-old son living with ASD discussed, "My oldest goes to camp. Well, I can't send [child with ASD] to camp because he doesn't have an aide to go with him and I can't just send him there because nobody understands him. Nobody gets him and it's hard" [Participant 04]. This lack of recreational support for children with disability appeared to be amplified for rural settings. One parent explained, "[T]here is nothing here in [rural community] for any supports for kids with special needs of any type. So, we actually have to travel to [larger centre] and [urban community] for absolutely anything to help him [participate in sport] at all" [Participant 03].

Parents spoke using tones that often sounded disheartened when they described the reality of how there was nothing offered in their smaller communities to promote safe and active play and recreation for their children living with autism that was supportive and inclusive of their children's needs. Without necessary provisions such as a recreational aide or specialized programming with trained individuals facilitating the activity to provide one-one-one support to the autistic children, they were not able to join in on their local physical activity options.

***Coach/instructor approach.*** Parents expressed the negative impact of approaches coaches and recreational leaders used to facilitate participation of their child with ASD in recreational programs and activities. Use of mainstream approaches that failed to attend to the special needs of the child felt exclusive to parents. Parents described several ineffective approaches such as coaches "yelling instructions", "call[ing] out" their child, or failing to break down an activity into its step-by-step components. These approaches discouraged parents from enrolling their children in programs. For example, one parent discussed her discomfort enrolling her 9-year-old son with ASD in a mainstream soccer league due to her perception of the community recreational leaders' lack of awareness and understanding of dealing with her child's specific communication and behaviour challenges. She explained,

If he's on the soccer field, just yelling instructions at him doesn't work. You have to get his attention first and then if you are talking to other kids without saying their names too, [for example], if the coach is giving instructions to other kids on his team and he doesn't use their names, then [child with ASD] will think it's about him and he'll get upset.  
[Participant 02]

Parents detailed their perceptions of effective coaching approaches that would better support their children. These approaches involved providing extra assistance and instruction, and cuing and guidance to help prevent children on the spectrum from experiencing the negative outcomes and emotional defeat from attempting to participate. For example, one mother

discussed how her 11-year-old son with autism required more recreational coaching that focused on individual scaffolding and instruction techniques to help him succeed.

If [recreational leaders] can't show him how to do it and break it down into the steps ahead of time, he can't keep up with the other kids. And, then they're moved on and he's still back at the first step. [Participant 06]

Some parents actively worked with coaches in strategizing best approaches with their children. A father described an ineffective mainstream approach to engage and develop the skills of his 12-year-old daughter and offered a proactive solution to help coaching staff understand how to effectively communicate with his child in a non-threatening manner, conducive to her learning style.

[Instructor's approach] is key 'cuz she'll disengage from the activity and not want to go back if she feels that she doesn't like the way she was treated. She often thinks that if she's being called out that it's personal. When in that type of activity [gymnastics], kids are called out all the time. If they're not working hard enough or doing it in the exact way that they are being instructed, they're called out. Other kids take that as, "The instructor taught me to do better." My daughter takes it very personally. So, we have to usually work with the instructors that are dealing with her to understand that maybe it makes more sense to have a one-on-one with her after class to let her know what their concerns were rather than call her out in class. Try to get them to adjust their style that way. [Participant 12]

These parents perceived that recreational coaches and instructors often lacked experience in facilitating the inclusion of children on the autism spectrum depending on the child's unique presentation of ASD. Therefore, their children's special learning needs were not being met for the performance of the activity or sport creating, another barrier to participation.

***Financial and logistical constraints.*** Families with children living with ASD were found to experience financial and logistical constraints such as time, and travel barriers that contributed to limited physical activity opportunities. When considering their children's special learning needs, parents faced challenges such as paying for qualified personnel's travel costs in addition to their wages in situations where they needed to provide their own aide for their child's

activities. These circumstances significantly increased the financial burden for rural families as professionals were most often recruited from larger centres. For example, a mother who had a 3-year-old son explained, “Everything [therapeutic services] is coming from [larger neighbouring community], so we have to travel there or if I had a support worker come, I would be paying for their mileage to travel” [Participant 09].

Families often had to prioritize their autism funding, which was limited and capped at a certain level. It was not uncommon for parents to use funding for therapeutic supports over recreational supports. Parents described paying for occupational therapists and behavioural interventionists to promote the social-emotional and physiological development of their child over recreational aides to help facilitate recreational activity engagement as one participant elaborates, “[F]unding for an aide or assistant to help your kid with [activity participation] isn’t in the budget.” [Participant 06]. Likewise, another parent simply pointed out that despite the assistance her family received from the government these funds were limited and did not enable her son’s participation in sport. She stated, “[A]utism funding only goes so far” [Participant 03].

Travel to larger populated community centres to access opportunities for their ASD children was a logistical challenge for rural families. Not only was this a cost issue but the opportunities were often during daytime hours when parents were working. For example, a mother described potentially inclusive recreational options for her 3-year-old son that conflicted with her work schedule and made them inaccessible: “I know that there’s some [recreational activities with supports] offered in [larger community centre], but that’s a 45-minute drive and usually during working hours [Participant 09].” Parents described the difficulties of travel for children on the autism spectrum. One father elaborated on the stressful effects that time, travel,

and distance had on his 12-year-old daughter to travel outside of their rural community, which eventually led the family to quit the recreational activity she was excelling in. He stated,

With dance competitions, there's a lot of travel which takes her out of her routines, and long car drives which are two triggers for her. So, while she was still doing dance the past year, we took her out of competition because it was far too stressful. The anticipation leading up to it and then the crash after it coming back became too much. [Participant 12]

Extra expenses, time constraints, travelling distances, and children's needs for routine and predictability all served to further compound the challenges that families experienced in their attempts at accessing health promoting activities in their already busy lives and reflected the reality of living in a rural community. These circumstances appeared to place a greater burden and more demands on parents who were also trying to manage their children's and family's other needs and contributed to the lack of opportunity for recreational participation for their children.

#### **4.2 Socially Supportive Rural Communities**

Caregivers were also asked about what types of factors supported their children with autism in recreational participation in their rural based communities. Although the parents themselves were at the centre of their children's recreational involvement, other key supportive factors were found to be social supports and perceptions of rural safety.

**Social supports.** Social support was an important facilitator of the successful participation of safe play and activity for children living with autism. Parents voiced their perceptions of social support, particularly from family friends and colleagues, peers, and recreational leaders. These supports were valued for the trust they engendered, for offering safe spaces for their children. One parent described her support network as consisting of local friendships that she and her 3-year-old son relied on for playdates and alternate care when needed. She emphasized how being able to trust friends was an important factor that created a

feeling of reassurance that her son would have a safe experience when she was not available. She described,

He has close friends that he's grown up with so he has those bonds; and we do a lot of playdates with them...I work in a [childcare environment], so I have a lot of friends, staff who are somewhat educated in autism. So, they are my friends and I can trust them to watch him. I have a close group of friends that helps meet his needs and helps ensure he's safe when I'm not there. [Participant 09]

Similarly, a father who had an 11-year-old son gave credit to their friends who had access to natural spaces for recreation that was inclusive of his child and their family's lifestyle within their smaller community. He emphasized, "Good neighbourhood connections. We have a lot of family friends who have acreage or pools, or, you know, barbeques, horses...I think what makes recreational activities become more a part of life is that they are not regimented" [Participant 10].

Establishing meaningful friendships was an important factor expressed by parents that helped their children feel valued and included in activity engagement. For example, one father stressed the importance of his 12-year-old daughter having supportive peer relationships as being key to her successful activity participation. He stated how important it was... "That there are friends or people that she feels gets along with" [Participant 12].

Lastly, another parent discussed how her 11-year-old son with ASD received meaningful support and encouragement to participate in recreational activities from familiar group involvement within their "Scouting community." The support she described was not only due to the inclusive leadership style in this group, but also the family experiencing a sense of sameness and acceptance with there being other group members who were also living with special needs.

Within our [Scouts] community because we're part of a smaller group, and even the Scouting groups around know [child]; and there are other kids with challenges. So, when we're out at camp, there is an awful lot of leaders and his peer group, that are like, 'come on, you can do this!'... They'll tell him, 'Wow, you know, two years ago you wouldn't have even tried that and now look at you doing that!' So, our scouting community ... is a smaller community inside of our community. [Participant 06]

Thus, the parental experiences of social support were described as important factors for facilitating activity participation and play opportunities for their children living with autism that were also safe. These facilitators can be summarized as extended and trusted community friendships alongside unstructured or structured recreational supports that were influenced by accepting peers and leadership styles, which allowed them to take advantage of some of the recreational opportunities available within their rural communities.

**Perceptions of rural safety.** While parents identified potential dangers in rural communities, they also highlighted a perception of enhanced safety for their children in their rural communities due to familiarity with community members, which helped promote recreation and physical activity on a daily basis. For example, a mother who had a 9-year-old son expressed, "... it's nice being in a small town, we usually know everybody ... he's very much the kind of kid that needs [to see] the same people every day to recognize and realize that they're a safe person" [Participant 08]. Parents voiced how this familiarity was important to both their child's subjective perception, as well as for their own peace of mind. They expressed feeling comfort in knowing that their neighbours and community members were aware their child had ASD and how he could be easily identified in their small town if supervision was required. As one mother of a 9-year-old son stated, "I think in all honesty, being more rural, being out in nature ... [is] better for his safety because I know where he is. I've got my neighbours; they know he's autistic too. So, they kind of watch out for him" [Participant 02].

The sense of safety that caregivers expressed in regards to their rural communities appeared to relate to their child's characteristics and behaviours. Particularly, parents were at ease knowing that others would recognize their child and possibly be more accepting if an

unregulated behavioural outburst or potential elopement response occurred. As another mother who had a 9-year-old son explained,

[Living rurally] gives people a little more understanding if he's having a meltdown or just a behaviour issue in general and he takes off somewhere or anything. It's good to know that people know who he is and who he belongs to. It makes me feel better that I know he's safe. [Participant 04]

Similarly, a mother with an 11-year-old son stated, "... a lot of people would recognize him ... If for whatever reason he bolted or ran away ... So, there is a lot of positives to living in a small, where 'everybody knows you' kind of place" [Participant 06].

Parental perceptions of trust and safety for their community members and neighbours was evident throughout the family members' accounts for rural living. Rurality was expressed by caregivers as being an important factor for both the child and parent's perceptions of safety to help facilitate positive recreational experiences for their children.

#### **4.3 Parents Taking Charge for Safe Participation**

While parents identified supports that helped facilitate their children's recreational and physical activities, the theme of parents taking charge for safe participation also emerged. Parents engaged their children with autism in family and child-focused strategies that facilitated engagement in recreational activities. The resulting subthemes were parent/family involvement, child-centred activity engagement by families, acceptance, and constant supervision and safety planning.

**Parent/family involvement.** To integrate their children's involvement in sport and recreation more effectively, some parents joined organizations as leaders to facilitate and supervise their children with autism. This strategy allowed them to provide one-on-one support to maximize their child's activity participation and recreational engagement within the team and group environment. For example, one mother (Participant 11) described her husband's

involvement in sport with their son as the attributing factor to their child's successful participation due to his differing abilities and communication challenges. She shared,

[Child]'s dad has been coaching hockey with him, so he's allowed to be out there [on the ice] with him. So, that has taken him a long way to have the one-on-one [support] out there. Definitely, if he didn't have that, it would be a lot different.

Due to the lack of access to specialized programming with one-on-one support, parents described a variety of nature and outdoor activities they did with their children living with autism whether it be at home or in their rural communities. As stated by a mother who had a 3-year-old son, "It's just me ensuring that he's active. Again, there's no programs for him to join as of now, so it's all on myself to ensure he's getting out, going to the park, going for hikes" [Participant 09]. This mother's experience reflected both the lack of activity program options for her child, along with her feelings of being solely responsible to assist him with being active in the outdoors, which may have placed a burden on her that parents of neurotypical children may not experience so intensely.

Families reported how they took advantage of access to many opportunities for outdoor nature activities in their rural communities and perceived it as being key to engaging their children with ASD in physical activity. These activities often took place nears bodies of water and mountains prominent in British Columbia's rural Okanagan settings. One mother with a 9-year-old son summed up the many nature activity options their family did with their child in their rural community, "We do a lot of swimming. Try to go boating, fishing [and] kayaking" [Participant 02]. A father eagerly described his preference for rural living and how he engaged his 11-year-old son with unstructured outdoor and leisure activities available in their smaller community. He shared a fond memory and reflected,

One time when mom went away for the weekend, I took him [child with ASD] and [name of sibling] up the mountains and we pushed rocks over cliffs and tried to knock over

trees. That was great... We've got beach here... You may not have a climbing wall, but there's surely a lot of them on the side of the mountain... There's tons of nature here. A river to go rafting in and that kind of stuff. [Participant 10]

Due to the complex needs of their children with ASD, parents identified active, and at times, intensive involvement as a key strategy they utilized to facilitate safe recreational participation for their children while also promoting healthy child and family development. Activity interests varied across the study participants. Based on the parents' interests and access to nature-based activities, they found ways that worked for them to help their children living with autism stay active while often enjoying what rural living had to offer. Also, by knowing their child's specific needs and capabilities, they were able to foster these activities in a way that met children's safety needs.

**Child-centered activity engagement by families.** Some parents described their experiences of promoting physical activities using therapeutic suggestions from professionals that were aimed at management of the child's autism symptoms and promoting their child's development. These methods of facilitating activity participation were child-centred and unique to each family. For example, one mother explained how her family adapted their home environment to accommodate their 10-year-old son with ASD while incorporating occupational therapy strategies to engage him with physical activities.

[W]e've kind of integrated things around the home; it's hard for him to access sports in the community. He does access Taekwondo with his EA [Educational Assistant], who has been trained by my occupational therapist, and sees him throughout the year; so, he does after school taekwondo one day a week. Around here [family's home], he's got his tricycle, his wagon, we've got a pool in the yard and the river. We go kayaking, he's got the tire swing, balance beams, slip and slides, trampolines. We usually have a yoga ball rolling around but we try to interweave as much activities as we can into stuff. He's got a climbing wall in his room. He wasn't really into that at all; so, what we had to do was, and what we have done often with something that he doesn't quite like is take his little logos [child's special interests] that he likes and put them that he has to engage in this activity to get them... we have built around the occupational therapist's recommendations. [Participant 05]

There was an emphasis on utilizing a child-centred approach where the recreational activities could be initiated on the family's terms to encourage their child's participation and to keep them safe. For example, a father described how mainstream organized sports and activities were not the best fit for his 11-year-old child. The father described, "He needs the freedom, independence, and space to succeed and to fail. You put all his peers around him, throwing balls at him, he can't catch them or throw it as hard; it shuts the whole thing down" [Participant 10]. By applying flexible strategies that were known to engage his child, this father was able to integrate recreational participation and socialization that he felt worked well. While emphasizing his admiration of rural living (Participant 10) further explained, "That's why I'm saying the beauty of a rural community ... is that I can take him out in a field or to the beach with hardly anybody around ... I can choose who will participate ... and that really works."

The previous parents implemented creative child-centred strategies based on their experiences of how to best engage their children with ASD in physical activities by physically or socially adapting their surrounding environment, in order to promote safe, activity participation.

**Acceptance.** Most parents expressed perceptions of their children with ASD that showed an appreciation and acceptance of their child's skills and abilities despite their differences and the stigma they felt from others around them in their rural setting. This acceptance allowed them and their child to feel comfortable participating in activities. For example, a father who had an 11-year-old son declared,

You gotta be able to pick and choose which adaptations you need and when; and you can't be taken to task about it or ashamed of it or ashamed that it's not 'normal.' If your kid has to have an audience, it's pretty much just gotta be you [parents] that he feels is watching. [Participant 10]

Likewise, a mother displayed her unconditional love and acceptance when she reflected on promoting recreational experiences for her 9-year-old child, “He’s different. He doesn’t fit into the ‘normal’ social realms of society. He doesn’t fit in, but that’s okay” [Participant 02]!

Families also displayed a determination to socially integrate and provide recreational options and exposure to their children living with neurodevelopmental disabilities by providing them with essential opportunities as a way to enhance their potential, well-being, and quality of life. The preceding positive interactions reflected parental attitudes of acceptance and highlighted their resilient attitudes while identifying strategies to manage and engage their children in recreational activities. Parents showed confidence to challenge the misconceptions about their children living with ASD while displaying the love and acceptance they felt towards them.

**Constant supervision and safety planning.** A common safety strategy that became evident during discussions with parents of children with ASD as being vital to their child’s participation in recreational activities and programs was their perceived need to be available for their children via way of constant supervision. This was different than parental involvement in their recreational participation insofar as parents expressed the need to be constantly available for their child to provide cues and prompts to promote personal safety. For example, one mother of a 9-year-old boy explained, “I’m always there on the sidelines. I always have to be there to make sure [child is] not playing this way, you know, [child is] not touching this. [Child is] staying in this one spot” [Participant 04]. Similarly, another mother explained the importance of her being present to facilitate her 9-year-old son’s safe play and activity engagement and stated, “I almost have to be constantly watching him because [rules and instructions to safe play] doesn’t sink in almost, like, I have to repeat myself. Especially, when he’s playing with younger kids, he just doesn’t get it” [Participant 02].

Constant parental supervision was not only described as taking place for the protection of the child with ASD but also to protect other children from their child's behaviour during recreational participation. For example, a mother who had a 4-year-old child stated, "I feel like I can't ever really put him in programs without me being there ... I worry about his safety, and I worry about, sometimes, other kids – not because he's a violent person but just because he's not aware" [Participant 08].

Parents perceived constant and intense supervision as an important factor to facilitate their child's activity. It often involved prompting and redirection as needed whether from a lack of understanding or a decreased awareness of their surroundings and those around them. This safety precaution to always be present when their child was partaking in group play or activities meant these parents were just as much tied to their children's activity participation as the child living with ASD themselves.

Another specific strategy that some families used to promote safe, active recreation was the development and rehearsal of proactive family safety plans. This included having a proactive safety plan in place, and rehearsing safe responses with their children in the case unforeseen circumstances happened. The plan also included having an alternate safe person established for supervision with a community member that could be trusted to contact the parents. For example, one mother of a 9-year-old boy shared,

We have set up on main street little cards in the corner of some of the shop windows for a safe point and we've done a couple of tours around town to those stores and he knows if he gets locked out of the house that he can go to those stores and his picture is on the back of the card and it has his name and his phone number.- The community has been pretty good that way. [Participant 04]

Another parent shared their family's safety strategy involving the use of electronic

devices. He explained their safety plan in detail as he would with his 11-year-old child, “All our phones are tracked. So, if you take a phone, I know where you are” [Participant 10]. Further explaining his experience raising his son, he emphasized the importance of having a safety plan in place,

[Children with ASD] get lost easy. They get overwhelmed easily. Disorientated easily. So, you have to think about what the possible outcomes could be...and the default position is, if you get lost or you gotta go to the bathroom, or there's something wrong; go to the pastor's house. [Participant 10]

Despite having individually tailored safety plans for their children, families/parents shared similar strategies for promoting safe activity. They developed concrete safety plans for their autistic children with specific directions to follow if something went wrong within their daily routines and they did not know what to do without supervision. These parents advocated and involved their extended community network in order to prevent the safety risks and hazards associated with living with a neurodevelopmental disorder and trusted in their rural community members to follow the protocol when need be. Thus, the use of safety plans could be put into place when children engaged in recreation activities and they also reflected the sense of familiarity and trust that parents believed were prevalent in their rural communities.

#### **4.4 Community Needs Identified**

Parents provided many suggestions that they believed would help facilitate recreational participation for children living with ASD to meet their diverse needs in their rural communities. These suggestions emerged from discussion and reflections about the barriers that parents experienced in their efforts to promote safe, active recreation as well as the supports they identified and the strategies they used to promote children's participation. Community needs identified by caregivers included the strong desire for safe physical spaces, increasing access to safe, inclusive recreation, and training needs to support child participation.

**Strong desire for safe physical spaces.** Many parents expressed the importance of providing safe physical spaces to promote their children's activity and play. Two parents of children with ASD expressed their desire for fencing in their community's public playgrounds to help reduce the risks to their children living with autism who had unpredictable elopement behaviours. For example, one mother who had a 4-year-old daughter stated her perspective of how to make her rural recreation and play safer for her child and suggested, "Having a gated, fenced off playground" [Participant 01]. Another mother of a 10-year-old boy similarly expressed her small town would, "[p]robably be better [safer] if [rural community] had the playground enclosed" [Participant 03].

Other parents expressed how provision of inclusive playground equipment or "autism friendly" options in their local communities would also increase safe play opportunities and participation for their children. For example, a mother of a 9-year-old son identified this need in her rural area and suggested, "Improving the playground equipment to make it more autism friendly. There's really not much to do in [rural community] for anything" [Participant 02]. Another parent with a 9-year-old boy compared their rural community with others of various population sizes by explaining how improvements could be made. She emphasized, "We don't have the big things or the simple things that the other communities might have or as many. Parks with like, swings that have proper special needs swings or special needs equipment or things like that" [Participant 11].

There was a voiced need for strategies to be implemented to create safe environments and playgrounds to promote inclusive outdoor play opportunities for children with ASD who experience challenges with social, emotional, and physical awareness. As a mother with a 4-year-old son shared, "I just think that the actual environment isn't as set up. Even the

playgrounds here. There's some I can't even take him to because the fall is like an 8 – foot drop” [Participant 08].

As indicated by the parents above, they expressed how creating more secure public spaces by fencing rural recreational areas is needed. Additionally, parents shared how providing a variety of inclusive playground equipment options within these secure public areas, would help promote safe and active outdoor play opportunities for their children with a spectrum of abilities and skills. They further described how such changes would aid them in their supervision efforts.

**Increasing access to inclusive recreation.** Recreational participation provides children with multiple interactive opportunities to enhance their development in multiple domains, whether it be their problem-solving, cognitive, social-emotional, physical, or communication skills. Three parents clearly expressed their perspectives of their smaller communities’ need for inclusive recreational options to provide their children living with autism the chance to participate in recreational and leisure activities. One parent voiced the need for opportunities for her 4-year-old daughter as she specified, “More classes that are designed for ASD children to help them focus and learn” [Participant 01]. Having access to programs specifically tailored to the needs of children with ASD was seen as important by other parents as well. For example, another parent explained this and highlighted how these options were lacking for her 9-year-old son in her small community,

I think that he needs the support and proper group activities where you can be shown properly how to do things. There's nothing here for us to get out to, to be interactive like that. It's a small town and there's lots of families here that we should be able to do that. [Participant 04]

Another parent strongly advocated for equal opportunities, free of discrimination for her 11-year-old son. She firmly stated, “I want everything that's available to all those neurotypical kids; that if my kid wants to try it out, it would be available” [Participant 06]. This parent

described how her son participates well during physical activities when coaches and activity leaders are attuned to his needs and explained, "... if motivated, [child] will try so hard until he physically can't do it [the activity] anymore, but [program leaders] gotta approach it the right way and get him involved in the right way." Another parent of a 9-year-old boy shared how safety challenges can be avoided during her son's recreational participation if his ASD-specific needs are addressed properly, "... if he [child] has someone there watching him and prompting him and cuing him" [Participant 02].

These parents possessed both an optimistic desire and ensuing frustration for the lack of access to inclusive activity options for their family and children living with ASD in their local communities.

**Training needs to support child participation.** Community training and support for recreational coaches and leaders to help facilitate safe and active recreational opportunities for children and youth was seen as another pressing need. Parents described how this included both increasing awareness about autism among recreation leaders and enhancing their qualifications to promote a safe, conducive instruction style for children living with neurodevelopmental disorders in their rural communities. For example, one mother of a 3-year-old son shared her beliefs in how accommodations could be made to improve recreational programming in her small town, "If there was more people educated in the topic or more people that have careers in autism ... there's just really nobody in [rural community]. A lot of people don't even know about autism here. Even the people that do the recreation programs" [Participant 09]. Another parent emphasized how trained support would benefit her boys (ages 9 and 11) to develop their skills and participate safely in sport. She explained,

They'll just turn around, walk the other way and play something different [referring to her children]. And, they won't understand what you're supposed to do. They don't have the instincts to pick up a bat and swing it the proper way and be safe. [Participant 11]

Similarly, another parent emphasized the need for recreational facilitators to be mentally equipped and have the safety awareness when teaching her 11-year-old son with autism, while also being physically prepared to perform the nature activities with him. She exclaimed,

I need somebody that is qualified to handle his behaviours or his reactions, and I need somebody qualified and in shape enough to go hiking or take him stand up paddle boarding or kayaking or any of those things that are readily available [in rural community] but there isn't somebody who is qualified in both autism and the physical part of instructing it. [Participant 06]

Recreational leaders being able to anticipate varied recreational risks and needs of children with ASD was important to parents. For example, a father expressed his safety concern for his 12-year-old daughter's lack of awareness when it comes overexerting herself to the point of sustaining injuries during physical activities. He explained,

She hurts herself quite regularly whether it's doing a back flip and landing. She's had a lot of sprains...She doesn't seem to know a limit. Not so much of endurance, but just how intense of an activity she is doing. [Participant 12]

The above caregivers' perspectives suggest the need for increased training as a possible solution to better prepare their rural communities' recreational staff and volunteers to promote safe opportunities for their children living with ASD.

Parents also expressed how community training for recreation workers and support staff would not only benefit their children with autism to participate in activities and sport but would also benefit parents' by providing a peace of mind that their children would be in safe competent hands. Parents could then feel comfortable to possibly leave their children for the duration of the group activity. For example, one mother of a 7-year-old boy thoughtfully reflected, "... wouldn't it be nice for someone to start something or do something where you could just drop your child

off and know that they are going to be taken care of” [Participant 07]? A second parent with a 9-year-old son echoed this perspective when she suggested,

I would love more support. I would love more opportunities of groups that maybe somebody certified or just somebody that has experience there and say, “Hey, you’ve got a kid that has special needs? Take them and drop them off. We can deal with that.”  
[Participant 04]

Parents expressed a strong desire for qualified recreational leaders who were certified or experienced in interacting and engaging with children living with neurodevelopmental differences. Parents also highlighted the need for such leaders to have the physical skills to engage effectively with children in order to take advantage of the outdoor pursuits available in rural settings and to be adequately prepared to anticipate and meet children’s safety needs. This was clearly indicated by the foregoing parents as a family-centred priority issue to help promote safe physical recreation opportunities needed in their rural communities. Creating such community development initiatives could also provide caregivers with an opportunity for respite knowing their children with ASD were actively engaged and supervised in a health and safety promoting manner.

## **Chapter 5. Discussion**

### **5.1 Key Study Findings**

This research makes an important contribution to the understanding of parents' experiences promoting safe and active recreation for their children living with ASD in rural settings. Results highlighted four main themes that included: family-centred issues surrounding barriers to safe, inclusive recreational participation, socially supportive rural communities, parents taking charge for safe participation, and community needs identified that were intensified for rural contexts. Some of the key findings that were most pertinent to the issues of the rural context will be discussed below.

One major theme in this study was the barriers that parents reported that impeded children's activity participation. Barriers to safe, inclusive recreational participation that were shared included wide-ranging safety concerns (child's special interests, complex vulnerabilities, elopement in rural context), struggling for inclusive options (lack of community awareness and social exclusion, lack of access to suitable programs, coach/instructor approach, and financial and logistical constraints). While these barriers all posed substantial concerns for parents, elopement was of particular concern due to the seriousness of the potential consequences. The findings indicated that parents' safety concerns influenced their child's active recreational participation, especially when it came to their child's elopement behaviours in a rural context. While this is a topic where very little information exists, these findings are consistent with Anderson et al.'s (2012) quantitative study from the U.S. that reported the occurrence of elopement amongst close to half of children with ASD in the study (49%). Elopement concerns were found to increase stress for families and caused many families to give up enjoyable activities outside the home. These findings were echoed by parents in this current study who

feared if their children did not have adequate supervision during organized recreational activities and their child's elopement behaviour was triggered, their safety was in serious jeopardy. In addition, these concerns were found to be heightened for rural caregivers due to the proximity of major highways and abundance of bodies of water, concerns that are justified given the substantial risk to children with ASD for bodily harm from traffic injury, drowning, or even death (Anderson et al., 2012). Findings from a study that explored African American mothers' perspectives on autism and their children's elopement and wandering in Los Angeles County, California, revealed similar parental concerns to this study related to fears associated with their child becoming lost or injured from traffic (Solomon & Lawlor, 2013). However, studies regarding parental experiences with children's autism elopement behaviours associated with recreational participation within rural contexts have not been addressed until this master's thesis. Therefore, this current study provided nuanced information about the rural context and the rich information about the elopement from a parental perspective.

Another important subtheme from among the barriers to safe, active recreation was the significant lack of access to inclusive programs for families with children living with ASD in their rural communities. When facilitated well, inclusive recreational opportunities are important for children with neurodevelopmental disorders because they provide learning opportunities to increase developmental potential, quality of life, and well-being (Dahan-Oliel et al., 2011). Results from this study indicated this lack of access was in part due to independence being a required component to the child participating in the sport or activities that were offered in local communities. Not only do the results expose parental perceptions of little access to programs but also indicate their sense that ASD training for recreational leaders and staff is absent in these rural settings. A recent Canadian qualitative study reinforced this lack of accessibility to physical

activity programs for youth with ASD due to coaches and program staff being unsure of how to adapt their teaching methods to accommodate the children's diverse needs and abilities (Gregor et al., 2018). Results from another study indicated how parents of typically developing children living in rural settings reported that most recreational opportunities for their children were found in urban locations with travelling time identified as a significant barrier to participation (Moore et al., 2010). Likewise, this masters study found travel distances were prohibitive for many families with children with ASD, suggesting that this puts unrealistic demands on limited time these rural families have. For example, findings showed families who have multiple children at various stages that require being dropped off and picked up at different times during the day restrict parents' availability to travel elsewhere for their autistic children to participate. Additionally, thesis results indicated that travelling to larger neighbouring communities was not feasible for parents who worked during the day due to the available recreational options being offered, only during their hours of work.

Lack of community awareness and social exclusion, comprised additional barriers that were highlighted by parents in this study. On the other hand, participants also indicated contrasting views of their rural communities having supports unique to their setting. The conflicting perspectives showed how the family members were 'weighing' the pros and cons of the communities they resided in while contemplating the safety issues and risks posed for their child. Children with ASD often display social interactions and communication difficulties with disruptive behaviours. These results indicated that parents' perceptions of a general societal lack of awareness and understanding of ASD often resulted in their children's autism behaviours being misunderstood. Societal misconceptions and lack of understanding of children with neurodevelopmental challenges can lead to stigmatizing attitudes from others who see them as

being ‘different’ from the social ‘norms’ of society. These findings suggest that families’ experiences include perceptions of being unsupported and excluded by other community members. These parental experiences surrounding a lack of support is consistent with qualitative study findings of challenges faced by parents with children with ASD (Ludlow, Skelly, & Rohleder, 2012). The effects of stigma can have a negative impact on children’s recreational participation as they become excluded by programs and their peers. The current findings showed parental perceptions of their child being socially excluded from peer and community activities in their rural settings. Ludlow et al. (2012) similarly reported parents’ accounts of their child being excluded from birthday parties or other events in their communities. In a United States of America (USA) study, caregivers reported their children with ASD were often rejected by other parents and children when accessing local parks (Li, Larsen, Yang, Zhai, & Sullivan, 2019). The unfortunate result of this pervasive lack of awareness, understanding, and stigmatizing effects on families and children living with ASD may be a lack of empathy and support for the challenges parents face, further exacerbating their withdrawal from community events and recreational opportunities. This may isolate families further from environments and outdoor activities where typical networking and building of friendships can occur to promote healthy family and child development. As stated by Broady et al. (2017), “...perceptions of stigma can profoundly impact the quality of life of these children [with ASD] and their carers alike.” (p. 224). The subsequent effects of children with autism and their families withdrawing from community involvement may lessen awareness of ASD amongst community members and recreational leaders; further compounding the problem of social exclusion.

A core finding from the current study were the strategies and adaptations that parents/families used to take charge and promote their child’s safe participation in activity. These

included parent/family involvement, constant supervision, and safety planning. Findings revealed parents often times joined their children's activities and sports' organizations in order to help integrate their children more effectively in recreational activities while providing them familiar one-to-one support that was otherwise not attainable in their rural settings. Many of the target children in this study were reported to require one-on-one support in order to participate safely and meaningfully in recreational opportunities; these supportive program features were commonly sought out by parents in a similar Canadian study that looked at physical activity participation among adolescents' with ASD living in urban settings (Gregor et al., 2018). Gregor et al. (2018) reported that organized recreational activities required parents to hire private support to integrate their child's participation, which was only possible if families could afford to take such measures. Due to the additional financial and logistic constraints that families faced in this study, activity participation was even less likely for their children in their rural communities. Alternatively, results indicated that parents engaged their children with ASD in outdoor recreation that was nature-based and less restrictive with fewer rules and social expectations. Thesis findings were consistent with Li et al.,'s (2019) who reported physical activity for children living with ASD was promoted in less restrictive environments, such as in parks and 'green spaces' where there were fewer rules and more flexibility with outdoor play. The current results indicate that parental involvement was found to be a crucial component to children's participation and engagement in activities no matter the rural setting. In addition, results from this research showed parents in these rural settings perceived a more extreme need to be involved or present during recreational activities in order to protect and prevent injury or harm to their child or even to other children during recreational activities by way of providing constant supervision. Interestingly, the findings also showed that some parents promoted their child's

outdoor independence through the development and rehearsal of individualized proactive safety plans.

## **5.2 Study Contributions, Strengths, and Limitations**

Autism continues to be on the rise and to-date (Johnson et al., 2016) there is limited research that focuses on parents' perspectives of recreational participation amongst this vulnerable population. This thesis is the first to address this topic in a rural context and provides useful and unique insights into parental perspectives of the barriers and facilitators to safe recreational participation for their children with ASD in rural communities for future recreational program development. Of particular significance were the findings related to caregivers' safety concerns and fears about elopement which appeared to be exacerbated by rurality due to environmental hazards and subsequent increased risks to their children.

Recruitment methods did result in some fathers being recruited to increase the variability across the sample and allowed a dataset that reflected rural families' perspectives and priorities; but did not allow for a gender analysis. In addition, the target sample of children living with ASD included in the study were diverse with ages ranging from 3-12 years and included both boys and girls. This is noteworthy considering the heightened ratio of boys diagnosed with autism when compared with girls (Johnson et al., 2016). Another strength of this study was that the interviews were conducted in person with the individual participants in a location of their choosing, which likely fostered trust and enhanced the researcher-participant relationship contributing to the validity of findings. This family-centred approach was consistent with Thorne's (2016) Interpretive Description methodology in that an effort was made to foster the comfort and trust of the participants to enhance credibility. The sample covered a large

geographical area of both the North and South Okanagan, BC communities that suggests that these findings may be transferrable to other similar rural Canadian settings.

Despite the many strengths of this current study, limitations are important to acknowledge for the focus of future research. Considering topics related to children and safety formed a major focus of the thesis, a potential limitation of this study may have been due to the informed consent process prior to engaging the parents in the interview. The nurse researcher was obligated to mention to the participants that if abuse of any kind was suspected, she was obligated to report concerns to appropriate authorities. As a result, it is important to acknowledge the potential influence on parents' willingness to describe their experiences of significant safety concerns and issues in raising a child with ASD; thus, limiting the information they were willing to disclose and breadth of the findings. Considering the majority of the study participants were Caucasian and born in Canada, future research in diverse cultures that includes Indigenous caregivers' or other diverse perspectives would be valuable to reveal cultural differences and participation needs. Considering only two fathers participated in the study, comparisons of perspectives across genders were not feasible. Furthermore, given the qualitative nature of the study with the small sample size of 12 participants, comparisons across the target children and their diverse spectrum of needs related to ASD were not included. Future research should target the quantifiable functioning levels of children with autism with larger samples as it relates to recreational participation. A mixed methods study that includes parents' experiences promoting safe and active recreation along with objective findings of their children's functional status and individual needs would provide more insight into ASD awareness initiatives and inclusive program development.

### 5.3 Study Implications

**Practice.** Autism prevalence continues to be on the rise. As indicated by Li et al., (2019), ASD is the fastest growing worldwide developmental disorder. For this reason, it is imperative to increase awareness through encouraging curriculum in health and recreation education programs in order to increase the knowledge of professionals and service providers about ASD and safety challenges related to activity participation. Taken together, the findings from this current rural study on parental perspectives about their children with ASD and Gregor et al.'s (2018) urban focused study on youth with autism, point to the significant lack of awareness of recreation staff and service providers in Canada to facilitate recreation program participation for children with ASD across various settings. Enhancing the knowledge of healthcare and recreation providers could lead to more effective family-centred interventions. For example, with an improved understanding of ASD as well as specific barriers to inclusion and participation as identified from this study, health and service providers could work more closely with families to develop child-specific safety plans that promote the child's independence and inclusive recreational participation. Murphy and Carbone (2008) recommended the need to implement strategies that minimize the risk of injury to children with various disabilities and conditions during physical activities prior to participation. Solomon and Lawlor (2013) recommend training for practitioners to recognize parents' discourse of elopement and wandering so advice may be promptly provided. This advice could focus specifically on the importance of safety planning. Autism Speaks (2019), an American leading national organization, currently offers on-line resources on summer recreation safety and creating safety plans. This highly relevant resource could be applied within a Canadian context with rurality as a priority due to the heightened risks associated with hazards and outdoor environments identified in this study. Parents find it helpful

when ideas and strategies to deal with the challenges they face with their children on the autism spectrum are shared by professionals and organizations (Ludlow et al., 2012). Implementation of collaborative safety planning between families and recreational providers to promote activity participation would also enhance the broader rural community's awareness and understanding of ASD with the ultimate goal of acceptance and community development. Having access to trained recreational leaders or aides who could facilitate recreational options in families home towns, is a practical solution that would significantly benefit families and children with autism while allowing safe, inclusive recreational opportunities.

Participants in this study highlighted the need for social supports and family involvement to promote safe, inclusive recreational participation. To further supportive networking, meaningful connections for families and children living with neurodevelopmental disabilities could be encouraged through family networking and community contacts based on a common love for recreation and sport. To address these findings, practitioners and community leaders could help organize social activities to encourage families' socialization. Social networking could be organized by coaches while providing families an opportunity to interact with one another on the sidelines, while the recreational leaders supervise and promote organized activities for their children. Perhaps, the parents could have a coffee session together while their children were occupied in a safe, inclusive environment.

**Policy.** Parents in this study reported a serious lack of access to safe and active recreational opportunities for families with children living with ASD in rural communities. First and foremost, there is a need for policy development and implementation at recreation and municipal levels focused on safe inclusion for children. Family-centred priorities need to be considered to encourage municipal policy making to provide access to safe play spaces to reduce

the barriers for families and their children with autism. Li et al. (2019) recommend outdoor public spaces such as playgrounds and parks should,

... provide enclosed spaces with limited entry points to prevent elopement and allow parents to watch their children, offer private areas to help emotional control, upgrade safety standards to prevent falling and tripping, provide open-ended play options, [and] support a variety of play. [p. 78]

The current findings related to parental concerns about elopement and their child's complex vulnerabilities, reinforce the necessity for Li et al.'s (2019) recommendations to provide safe, inclusive spaces that better meet the needs of families and their children on the autism spectrum.

Recreation policy and resource allocation also needs to address standards such as requirements for leaders working in recreation to have mandatory basic knowledge and training whenever possible. This would enable them to better understand the importance of inclusion, safety needs, and rural issues, in order to tailor programs for children with ASD. Increased funding is also needed for in-person supports when vulnerable populations require one-to-one assistance for safe and active participation. Mandating training for those working in municipal programs would enable recreational leaders to recognize and intervene when additional support or safety plans need to be implemented to promote injury prevention and health promotion. Policy that helps increase the general awareness of ASD is also needed in rural communities and could be promoted by providing 'ASD friendly' activities and events that would not only foster community connections and development but would also help educate the general public's understanding of ASD and the related safety implications of this condition.

**Research.** The recent literature searches did not produce any previous research that sought to understand parents' experiences with safe recreation for their children with ASD who live in rural settings. Clearly, this lack of research, along with this study's findings indicate there is a strong need to continue and further develop research directed at rural parents' experiences of

safe, active recreation and play. Forthcoming knowledge translation activities to share results of the current study are planned. These include conference presentations, publication in peer-reviewed journals, and workshops based on community interests and need.

There are several suggested directions for future research. Studies could compare parenting experiences across gender. Future research could also include perspectives of other community groups living in rural areas, such as including Indigenous perspectives. Considering the seriousness of parental concerns related to risks associated with elopement and wandering behaviours of children with ASD, there is a need for a consistent, concrete definition for the concept of elopement indicating the need for further research and subsequent understanding as it relates to children's safety. As Solomon and Lawlor (2013) suggest, the challenges of understanding elopement and wandering in autism may relate to the ambiguity of the terms and their commonplace usage in everyday language that does not portray any risky behaviour. Future research should also focus on the implementation and evaluation of training for practitioners and enhanced supports for parents to promote access to safe, inclusive recreational opportunities for children living with ASD and the outcome of participation. Studies that focus on training and educational interventions for recreation providers should assess the barriers and facilitators to implementing in-person programs in rural settings for children with ASD. Due to the likely high costs associated with in-person program delivery, it may also be important to develop and evaluate distance-based or on-line strategies that could provide needed resources for both providers and parents. Further exploration of the concept of stigma and how it pertains to parents' experiences promoting safe, recreational participation for their children with ASD is another area of research that should be examined.

## **Chapter 6. Conclusion**

This study highlights how we can better support parents with aiding their children with ASD to engage in safe, inclusive recreational opportunities in rural settings. The findings of this study highlighted key barriers, supportive factors, strategies and adaptations used by parents and the needs they identified as important in helping them to support their children's inclusive and safe participation. There is a clear indication for the need to increase the public's general awareness of autism within rural settings in order to improve the visibility of the challenges these families face. Awareness initiatives that promote community development would allow supportive connections to ensue from within the communities themselves. Policy makers and planners can use the information from this study to increase the knowledge and understanding of priority family-centred parental concerns and issues for health and recreational service providers to promote safe, inclusive activity options for their children. Viable recreation planning for families and their children living with ASD requires a holistic team approach that works directly with the families, professionals, recreational leaders and staff. Effective individual safety plans could then be developed and implemented to foster inclusive access and participation of all children, no matter their setting.

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## Appendix A: Ethics Forms and Poster

### PERMISSION TO CONTACT FORM – PARENTS and/or LEGAL GUARDIANS

Study Title: **How can families living in rural Okanagan communities engage with their children living with autism spectrum disorders in safe and active recreation?**

This is to tell you about a research study that is being carried out by a UBC Okanagan nursing graduate student and graduate research assistant, Crystal Shannon, who is with the School of Nursing. Crystal is asking for your permission to contact you with more information about this study. This study aims to learn about the experiences of parents and/or legal guardians whom live in rural Okanagan or small population centres whose children have challenges associated with Autism Spectrum Disorder (ASD). In particular, we aim to learn about caregivers' views related to challenges, needs and supports for safe physical activity for children. The student researcher would like to talk to you about taking part in an in-person interview. You are receiving this letter because you were identified as a parent or legal guardian who may have an interest in participating in this study.

If you indicate that you would like to be contacted, Crystal will contact you to provide you with more details about the study. If interested, you will receive an Information and Consent form providing further study details including your rights as a study participant. The Information and Consent Form will be signed later on if you agree to participate. Taking part in this study is entirely voluntary. You may refuse to take part or may withdraw at any time. To give your consent to be contacted please sign this form and return to: Crystal Shannon by email @ [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca) or by mail or fax c/o Dr. Lise Olsen, Principal Investigator and Assistant Professor with UBC Okanagan's School of Nursing.

For more information about the study, please contact:

Crystal Shannon

Master of Science in Nursing Student, UBC Okanagan

3333 University Way

Kelowna, BC

Phone: 250-807-8299

Fax: 250-807-9865

Email: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca)

Please indicate your willingness to be contacted to receive more information about the study:

☐ I would like to receive more information about the study

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Name

---

Signature

---

Phone and email



## **PARENT/LEGAL GUARDIAN INFORMATION AND CONSENT FORM - INTERVIEW**

**Study Title: How can families living in rural Okanagan communities engage with their children living with autism spectrum disorders in safe and active recreation?**

**Principal Investigator:** Dr. Lise Olsen, Assistant Professor, School of Nursing  
University of British Columbia Okanagan  
Email: [lise.olsen@ubc.ca](mailto:lise.olsen@ubc.ca) (Phone: 250-807-9180)

**Co-Investigator:** Crystal Shannon, Graduate Student, Graduate Research Assistant  
School of Nursing, University of British Columbia Okanagan  
Email: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca) (Phone: 250-807-8299)

**Sponsor:** Social Sciences and Humanities Research Council of Canada

### **AN INVITATION TO PARTICIPATE**

You are being invited to participate in an interview about your experiences parenting your child and managing issues related to physical activity and safety for your child while living in your rural Okanagan community.

### **WHO IS BEING INVITED TO PARTICIPATE?**

Parents and/or legal guardians who reside in rural Okanagan communities and small population centres who have a medically diagnosed child with ASD between the ages of 3 and 12 years.

### **VOLUNTARY PARTICIPATION**

Your participation in this study is voluntary and you are free to withdraw at any time. You will not be treated any differently by any people who provide care for your child and there will be no negative consequences to you if you choose not to participate in this study. If you wish to withdraw from the study after the interview has taken place you can contact Crystal Shannon, nursing thesis student or Dr. Lise Olsen and all of your information will be deleted from the files.

### **WHAT THE STUDY INVOLVES**

Your participation in the study will involve one interview, approximately 1 hour in length, in which a researcher will ask you questions about your experiences in helping your child engage in physical activity and what things have made these experiences easier or more difficult. Demographic questions will also be asked. The interview will be digitally recorded and transcribed into written format. You will be provided with a \$15.00 gift card to acknowledge your time spent in the study.

### **WHAT ARE THE POSSIBLE RISKS OF PARTICIPATION?**

There are no expected risks to you from participating in the study. However, some parents may feel distress from thinking about or discussing their parenting experiences. A list of resources will be offered to all participants.

### **WHAT ARE THE BENEFITS OF PARTICIPATION?**

By participating in this evaluation, you will have the opportunity to contribute to understanding about how caregivers manage child activity and safety issues and the kinds of supports that they find helpful. By sharing your thoughts, you can contribute to developing a summary of needed supports for parents living in rural Okanagan areas or small population centres.

### **HOW WILL THIS INFORMATION BE USED?**

The results of this study will be compiled into a summary that will be made available at a community presentation. In addition, results may also be published in academic journals, community publications or presented at academic conference. Thesis study documents will be publicly available on the internet. Data from this study may be incorporated into analysis for a later comparison with a larger study of supports and barriers for families of children living with ASD in urban Okanagan communities.

### **WILL THE INFORMATION I PROVIDE BE KEPT CONFIDENTIAL?**

Your identity will be kept strictly confidential. No personal identifiers will be included in project reports, articles or presentations. Research documents will be identified only by a code number. All paper copies and computer files will be stored securely so that no one can have access except the research team members. All data will be stored securely for a minimum of five years following publication. After this time, paper files will be shredded and computer files will be deleted.

### **WHO DO I CONTACT IF I HAVE QUESTIONS ABOUT THE STUDY DURING MY PARTICIPATION?**

If you have any questions or desire further information about this study before or during participation, you can contact Dr. Lise Olsen at 250-807-9180 or email to [lise.olsen@ubc.ca](mailto:lise.olsen@ubc.ca) or contact Crystal Shannon by leaving a message with contact information at 250-807-8299 or email to [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca).

### **WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS ABOUT MY RIGHTS AS A PARTICIPANT DURING THE STUDY?**

If you have any concerns about your rights as a research subject and/or experiences while participating in this study, you may contact the Research Participant Complaint Line in the University of British Columbia Office of Research Services by email at [RSIL@ors.ubc.ca](mailto:RSIL@ors.ubc.ca) or by phone at 250-807-8832 (Toll Free Number 1-877-822-8598). Please reference the study number (H18-00854) when contacting the Complaint Line so the staff can better assist you.

### **CONSENT TO PARTICIPATE**

My participation in this study is entirely voluntary and I may refuse to participate or withdraw from the project at any time without consequences. My signature below indicates that:

- I have read and understood the participant information and consent form
- I have had enough time to think about the information provided and to ask questions if necessary.
- I have read this form and I freely consent to participate in this study.
- I have been told that I will receive a dated and signed copy of this consent form.
- I consent to the interview being recorded. Please indicate your response by initialing in the box beside your answer    YES ☐    or    NO ☐

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Printed Name of Researcher  
obtaining consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

### Demographic Information Form – Parents

1. Are you the child's legal guardian,    ☐ Mother?    ☐ Father? Or ☐ other Caregiver?  
If other please indicate relationship \_\_\_\_\_
2. What is your age? \_\_\_\_\_
3. What are your children's ages and gender? Please place a checkmark beside the child who you are referring to for this study. **Check only one box.**

Child	Age	Male or Female
Child 1		
Child 2		
Child 3		
Child 4		
Child 5		
Child 6		

☐  
☐  
☐  
☐  
☐  
☐  
☐

4. Marital Status: (Please check the most appropriate answer)

- |                                                 |                                    |                                               |
|-------------------------------------------------|------------------------------------|-----------------------------------------------|
| <input type="checkbox"/> Single / never-married | <input type="checkbox"/> Separated | <input type="checkbox"/> Separated Common-law |
| <input type="checkbox"/> Married                | <input type="checkbox"/> Divorced  | <input type="checkbox"/> Widowed Common-law   |
| <input type="checkbox"/> Common-law             | <input type="checkbox"/> Widowed   | <input type="checkbox"/> Prefer not to answer |

5. If you and the child's other parent are not living in the same home, your child lives:

- ☐ Equally with both parents
- ☐ Mostly with the other parent
- ☐ Mostly with me
- ☐ Other living situation; please explain \_\_\_\_\_

6. What is the highest grade or level of education you have attended or completed?

- ☐ Some high school ☐ Graduated high school  
☐ Some - trade school, college or university ☐ Diploma from trade school or college  
☐ University degree (Bachelor's or undergraduate degree)  
☐ University degree (Master's and/or Doctorate degree)

7. Which of the following best describes your main activity during the last 12 months?  
Were you....

- ☐ Working at a job or business?  
If yes, was this work **full time**? ☐ Or **part time**? ☐  
☐ Looking for work? ☐ A student?  
☐ Retired? ☐ Stay-at-home parent?  
☐ Other \_\_\_\_\_

8. Which of the following best describes the child's other parent's main activity during the last 12 months? Was he/she...

- ☐ Working at a job or business?  
If yes, was this work **full time**? ☐ Or **part time**? ☐  
☐ Looking for work? ☐ A student?  
☐ Retired? ☐ Stay-at-home parent?  
☐ Other \_\_\_\_\_ ☐ N/A

9. Were you born in Canada? ☐ Yes ☐ No

If no, how long have you been living in Canada? \_\_\_\_\_

10. How would you best describe your ethnicity/nationality? (e.g., Canadian, African, West Indian):  
\_\_\_\_\_

11. What is your best estimate of the total income of all members of your household from all sources in 2017 before taxes and deductions? Was the total household income....

- ☐ \$14,999 or less ☐ between \$15,000 and \$ 29,999  
☐ between \$ 30,000 and \$ 59,999 ☐ between \$ 60,000 and \$ 79,999  
☐ \$ 80,000 or greater ☐ choose not to respond

12. Name of community in which you reside: \_\_\_\_\_

13. How would you rate your overall level of health at this point in time?

*Please circle the number that most accurately describes your level of health at this time. On a scale of 1–5, where 1 is extremely poor and 5 is excellent.*

<b>Extremely poor</b>				<b>Excellent</b>
1	2	3	4	5

**Message to be posted on Facebook:**

***UBC Study: How can families living in rural Okanagan communities engage with their children living with autism spectrum disorders in safe and active recreation?***

Crystal Shannon, nursing graduate student and graduate research assistant at UBC Okanagan is looking for parents and/or legal guardians with a child 3-12 years with Autism to take part in an interview about their views on promoting physical activity for their child and managing safety concerns in their rural Okanagan community or small population centre in which they reside. If interested, please contact Crystal (Master's of Science in Nursing Student & GRA, UBC Okanagan's School of Nursing) at [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca) or 250-807-8299 or Dr. Lise Olsen (Supervisor) at [lise.olsen@ubc.ca](mailto:lise.olsen@ubc.ca).

#### RECRUITMENT CARD FOR PARENTS and/or LEGAL GUARDIANS



**a place of mind**  
THE UNIVERSITY OF BRITISH COLUMBIA

#### **UBC Study: How can families living in rural Okanagan communities engage with their children living with autism spectrum disorders in safe and active recreation?**

Research participants needed for study on physical activity and safety for children with ASD  
Parents and/or legal guardians of children 3-12 years with ASD who live in rural Okanagan areas or small population centres are invited to take part

- We are looking for parents and/or legal guardians (mothers, fathers, and/or caregivers) who have a child between the ages of 3 and 12 years who has been diagnosed with Autism Spectrum Disorder (ASD).
- The aim is to learn about caregivers' views and experiences related to promoting physical activity for their child and managing safety concerns in their rural community.
- Participation will involve taking part in an interview lasting approximately 1 hour.
- The project is supported by Social Sciences and Humanities Research Council of Canada.

To learn more about the study, please contact Crystal Shannon, Graduate Student,  
School of Nursing, UBC Okanagan

**Contact by email: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca) or by phone: 250-807-8299**

Or Dr. Lise Olsen, Supervisor by email at: [lise.olsen@ubc.ca](mailto:lise.olsen@ubc.ca)

[RECRUITMENT AD FOR PARENTS and/or LEGAL GUARDIANS – WEBSITE/NEWSLETTER POSTING]:

**UBC Study: How can families living in rural Okanagan communities engage with their children living with autism spectrum disorders in safe and active recreation?**

Research participants needed for study on physical activity and safety for children with ASD  
Parents and/or legal guardians of children 3-12 years with ASD who live in rural Okanagan areas or small population centres are invited to take part

Graduate student with the School of Nursing, UBC Okanagan is looking for parents and/or legal guardians who have a child between the ages of 3 and 12 years who has been diagnosed with Autism Spectrum Disorder (ASD). Participation will involve taking part in an interview (approximately 1 hour) about caregivers' experiences views and experiences related to promoting physical activity for their child and managing safety concerns in their rural community in which they reside.

If you or someone you know would like to learn more about the study, please contact:

Crystal Shannon, Graduate Student, School of Nursing, UBC Okanagan

**phone: 250-807-8299 or by email at: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca)**

Or Dr. Lise Olsen, Supervisor by email at: [lise.olsen@ubc.ca](mailto:lise.olsen@ubc.ca)



***How can families living in rural Okanagan communities engage with their children living with autism spectrum disorders in safe and active recreation?***

**STUDY PURPOSE**

To better understand the experiences parents of children living with Autism Spectrum Disorder (ASD) have in helping their children engage in physical activity while staying safe in their rural community. The results of this study will provide valuable information to help children with ASD be physically active. This project is supported by the Social Sciences and Humanities Research Council of Canada.



**ELIGIBILITY**

Parents and/or legal guardians (mothers, fathers and/or caregivers) of children aged **3-12 years old** with ASD who reside in a **rural** Okanagan area or small population centre.

**DETAILS**

Participants will take part in an interview lasting approximately 1 hour. The location of the interview will be scheduled at a time and location convenient for the participant.

**BENEFITS**

- ❖ Contribution to research that will improve physical activity and safety of children with ASD who live in rural communities.
- ❖ Opportunity to share your thoughts and ideas about keeping children active and safe
- ❖ Participants will be provided with a gift card (\$15.00) to acknowledge their time in the study.

**FOR MORE INFO**

Please contact Crystal Shannon (Graduate Student) at UBC Okanagan, School of Nursing: 250-807-8299 or by email: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca) or Dr. Lise Olsen (Supervisor) at [lise.olsen@ubc.ca](mailto:lise.olsen@ubc.ca)

Safe, Active Play/Rural Study  
Call Crystal @ 250-807-8299  
Email: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca)

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Email: [crystal.shannon@ubc.ca](mailto:crystal.shannon@ubc.ca)

## Appendix B: Caregiver Interview Guide

1. Can you tell me a bit about your child?
2. Can you explain some of the ways your child engages in recreational or physical activities?
  - a. What types of indoor or outdoor activities do they enjoy doing?
  - b. What types of play or recreational areas are available for your child to active in your rural community?
  - c. What organized or structured community activities are they involved in?
  - d. What makes it easier for them to do engage in your mentioned activities?
    - i. What makes it easier for you to help them participate in those activities?
  - e. What makes it more difficult?
    - i. What makes it more difficult for you to help them participate?
3. Do you have any concerns about your child's physical or emotional safety when they are being active?
  - a. When you think about your child's safety; what concerns you the most?
    - i. (prompt: *for example, falling when playing, bumping into things, running away from you, other children...etc*)
  - b. What are some things that make it easier for your child to stay safe during recreational or physical activities?  
(prompt: *people around you such as a spouse or support person/friend? Does anything in the physical environment help them stay safe; anything related to being more rural*)
  - c. What are some of the things that make it more difficult for your child to be safe?  
(**prompt:** *child behaviour, social environment e.g. spousal or community members or other children's views or anything in their surroundings/physical environment, anything related to being more rural*)
4. What are some ways that you feel supported in your community to help your child be active?
  - What are some improvements that you feel are needed in your community to help your child be active?
5. What suggestions do you have for ways to improve opportunities for families in rural Okanagan communities to help their children with ASD experience safe and active recreation and play on a regular basis?
  - a. What kinds of services are needed?
  - b. What kinds of recreational or activity options would you like to see?