THE DEVELOPMENT OF PEER SOCIAL SUPPORT NETWORKS AMONG FAMILIES OF CHILDREN WITH NEURODEVELOPMENTAL AND INTELLECTUAL DISABILITIES ATTENDING PHYSICAL ACTIVITY PROGRAMS

by

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Abstract

According to the World Health Organization, "family" is an important contextual factor for childcare and development of children with neurodevelopmental and intellectual disabilities (NDID). However, caregiving-related stressors result in multiple challenges, contributing towards the families' social isolation and distress. This further affects families' quality of life, mental health and ultimately childcare.

Peer support networks represent established strategies for social integration; however, families are often unable to attend these networks due to unavailable time and childcare resources. Therefore, ways to socially integrate families, while simultaneously supporting the child are warranted. Community-based adapted physical activity programs (PA programs) represent a promising approach.

This thesis investigated the potential of peer support network development at PA programs, their impact on the families' quality of life, resilience and empowerment and relative importance compared to other peer support networks. A mixed-methods approach was implemented where quantitative information for the cross-sectional study was collected using standardized scales on perceived social support, family quality of life, resilience, and self-efficacy and qualitative information was collected using semi-structured interviews and ethnographic observation.

Fifty families having a child with NDID participated from twenty-two programs across British Columbia. Interviews demonstrated network formation was facilitated by the presence of families at the PA program that provided them with valuable time to interact with other parents. The regularity of the programs' schedule, and its duration were important factors. Moreover, the presence of children with similar abilities facilitated the child's friendship development, which appeared to be a motivation for parents to form networks. Parental networks developed in two ways, through their child's friendship's resulting in parental interactions and through direct parent-parent engagement on site.

Emergent themes illustrated networks promoted families' sense of community, offered emotional and informational support, helped families developing resiliency and empowered them. However, all these elements were not well-captured by the standard scales. Finally, seventy percent families ranked these PA-related networks as 'important' compared to other peer networks, as simultaneously, parents benefit from socialising while their child from activities.

Overall, evidence demonstrated the unique benefit of these programs that potentially strengthen both families and children simultaneously. Ultimately, strengthened families deliver better childcare.

Lay Summary

'Family' is an important contextual factor for childcare and development of children with neurodevelopmental and intellectual disabilities (NDID). However, caregiving-related stressors often result in challenges, contributing towards families' social isolation and distress, affecting parental quality of life and childcare.

Peer support networks represent strategies for social integration; however, parents are often unable to join networks due to unavailable time and resources. Therefore, ways to strengthen families while simultaneously supporting children are warranted.

Community-based adapted physical activity programs represent a solution. Using a mixed-methods approach, this thesis investigated parental peer support network development at these programs and their impact on families'. Fifty families having a child with NDID participated across twenty-two programs. Interviews illustrated network development among families. Emergent themes demonstrated these networks provided emotional and informational support, promoting sense of community, resiliency and empowerment. These programs represent a promising platform for simultaneously strengthening families and supporting child care and development.

Preface

This statement is to confirm that the work presented in this dissertation was conducted, analyzed, and written by Michelle Chakraborti. Michelle designed the research, established the research objectives, collected data, conducted the data analyses, and wrote each chapter of this dissertation. This work has been conducted under the guidance of Michelle's thesis committee— Supervisor: Dr. Jean-Paul Collet; Co-Supervisor: Dr. William McKellin and Committee member: Dr. Anton Miller. This project was reviewed and approved by the University of British Columbia Behavioural Research Ethics Board, certificate number: H16-01237.

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I conceptualized the study in collaboration with Dr. Collet. I took the lead on study design, analysis, synthesis, and manuscript writing. Dr. Gitimoghaddam helped to screen the articles obtained. Dr. McKellin and Dr. Miller edited sections of the manuscript. All authors contributed to the final version of the manuscript.

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List of Abbreviations

ANOVA	Analysis of Variance
ASD	Autism Spectrum Disorder
CDC	Centers for Disease Control and Prevention
CP	Cerebral Palsy
FES	Family Empowerment Scale
FRAS	Family Resilience Assessment Scale
FQOL	Family Quality of Life
ID	Intellectual disability
NDID	Neurodevelopmental and Intellectual Disabilities
PSS	Perception of Social Support
PSS-PA Program friends	Perception of Social Support from Physical Activity Program friends
PSS-non PA Program friends	Perception of Social Support from Non Physical Activity Program friends
PA program	Physical Activity program
PA program-related social networks	Physical Activity program--related social networks
WHO	World Health Organization

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Dedication

To My Family ——Mom, Dad and Bhai

Chapter 1: Introduction

The World Health Organization's International Classification of Functioning, Disability and Health–Child and Youth version (ICF-CY) highlights the "family" as an essential contextual factor for child-care and development (1). For children and youth with neurodevelopmental and intellectual disabilities (NDID), families are the primary caregivers responsible for providing continuity of care across their lifespan. While caregiving for a child with NDID, families are often faced with multifaceted psychological, social, and economic challenges affecting both the child and the family. For example, due to the child's behavioral challenges, parents often restrict themselves to places where they can and cannot go in public (2). These challenges contribute towards the families' social isolation, further affecting their mental health, social well-being and the child's development (3,4). Family caregiving is therefore, an emerging public health concern (5) and strengthening families through social integration is critical for their own well-being, in addition to the child's well-being.

Social integration of families through informal social support systems such as parental peer-to peer social support groups or networks, are well-established 'protective' buffers against distress (6,7). They modify the way in which stressors are perceived, by strengthening the family, which positively effects the child's development (4). However, attendance at these groups is not always feasible for families due to a variety of reasons such as their involvement in the daily caregiver routine leaving no time for other activities, or unavailable childcare and respite services, or limited availability of financial resources for child care and respite services while parents attend these groups (7,8).

Therefore, ways to simultaneously support the family, while the child is supported are warranted. Community-based adapted physical activity programs (here onwards, referred to as PA programs) organized for children with NDID may be a potential approach. These are inclusive community-based adapted sports programs that support the child with NDID's physical, motor and social skill development. Research illustrates that while these children participate in physical activities, families are often present at the program site (9,10).

Therefore, the aim of the thesis is two-fold: 1) conduct a scoping review to understand the existing peer-reviewed literature on peer-to-peer support networks for families of children with NDID, specifically documenting the characteristics and impact of peer-to-peer support networks for families of children with NDID and 2) using a mixed-methods approach, determine whether PA programs for children with NDID represent a potential avenue for peer-to-peer support network development, and their impact on the family's quality of life, resilience and empowerment.

1.1 Rationale

Parents or family caregivers accompany their child with NDID to weekly scheduled PA programs. Depending on the program requirements and parents' personal needs, parents' either remain at the program site, waiting for their child to finish physical activities or leave and pick the child up after the program. For parents gathered at these programs, PA programs have the potential to provide a natural platform for mutual engagement with other parents that may include the exchange or sharing of information, resources and emotional support aimed towards a mutual goal of helping their child with NDID. This naturally resulting 'community of practice' or peer-to-peer support network has the potential to further support parents, ultimately positively affecting some family outcomes such as quality of life, self-efficacy feelings and resilience.

1.2 Objectives

The study objectives are two-fold:

A. To understand, explore and review literature on peer-to-peer support groups for families of children with NDID, mapping i) the characteristics of peer-to-peer networks and their development process; ii) characteristics and needs of families participating in peer-to-peer networks; iii) impact of peer-to-peer networks on families; iv) factors affecting participation of families

B. To conduct a prospective study to explore the physical activity programs as an avenue for peer support development for families of children with NDID

1.3   Dissertation Structure

Chapter 2 of this thesis provides a review of the literature on families of children with NDID, including information about children with NDIDs' diagnosis, the family's role as a primary caregiver and social support as a strategy for supporting families of children with NDID. Chapter 3 introduces the concept of peer-to-peer social support networks or groups and theories associated with the development and positive effect of peer-to-peer social support networks. This is followed by a scoping review critically appraising the existing literature on peer-to-peer social support networks. This review maps the characteristics of peer to-peer social networks and their development process, characteristics and needs of families attending peer networks, the perceived impacts of peer to-peer social support networks on families and the factors affecting participation of families. This review highlights the gap in literature, specifically, the need for research on programs that simultaneously support both families and their children with NDID. Chapter 4 builds on the work of chapter 3; here the author introduces and discusses the rationale and objectives for a community-based study to investigate family attendance at PA programs for children with NDID and the potential for peer support network development at these programs. Specifically, this mixed-methods study seeks to understand what parents do at these programs, the extent to which these programs that are already supporting the child's development, can also provide a beneficial avenue for parents to develop organically driven peer social support networks. In Chapter 5, the research design of the community study is discussed. Chapter 6 describes the results of the community-based study and Chapter 7discusses the results. Finally, Chapter 8, the conclusions chapter, highlights the significance of this thesis, discusses the limitations and proposes new directions for future research.

Chapter 2: Review of Literature on Families of Children with Neurodevelopmental and Intellectual Disabilities

Families are the primary caregivers for children with NDID; they are responsible for providing continuity in care across the lifespan of the child, advocating for the child's needs, and navigating services. Although families report a profound sense of meaning and purpose caring for children with NDID, at the same time, they are often faced with multifaceted psychological, social, and economic challenges that affect both the child and family.

In this chapter, I review literature on the role of family as the primary caregiver for children with NDID. This chapter begins by defining NDID and documenting its prevalence. This is followed by a description of the family's role in caregiving and the adjustment and adaptation families experience while caring for their child. Finally, I discuss strategies for supporting families, highlighting the importance of social support, and specifically peer support networks for supporting families of children with NDID.

2.1   Neurodevelopmental and Intellectual Disabilities (NDID)

2.1.1 Definition

Neurodevelopmental disabilities, also known as neurodevelopmental disorders or brain-based developmental disabilities, refers to a group of severe conditions caused by "impairment of the brain and/or neuromuscular system, resulting in long-term functional limitations" (11). Functional limitations may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behavior. These different expressions will likely affect the child's overall learning and developmental abilities, with subsequent limitations on social and psychological developments. These conditions may be congenital or acquired in nature and are permanent; they include a broad range of severity and complexity and may occur alone or as a comorbidity. Consequently, individuals require continuous support across their lifespan.

Intellectual disabilities are neurodevelopmental disabilities characterized by significant cognitive deficits (with an IQ score of below 70) and limitations in functional and adaptive skills. Examples of conditions under NDID include: pervasive developmental disorders such as Autism

Spectrum Disorder (ASD), intellectual disability, cerebral palsy and genetic conditions such as trisomy 21 (Down syndrome) (11,12).

2.1.2   Prevalence

According to the Centers for Disease Control and Prevention (CDC), up to 1 in 6 children have a developmental disability (13). For NDIDs such as autism, the CDC reported that 1 in 88 children in the United States are diagnosed with autism (14,15). In Canada, the 2018 National Autism Spectrum Disorder Surveillance System report estimated autism's prevalence in 5- to 17-year-olds as 1 in 66 children (16).

There has been a rapid increase in the prevalence of NDIDs such as autism over the past decade (14,15). Some researchers attribute it to the way children are identified, diagnosed and served in their communities, although exactly how much is due to these factors is unknown (14,15,17). However, as a consequence of this rapid increase, there is an enormous burden on the healthcare system in terms of the availability of formal resources for supporting the children and their families.

In order to identify resources required for the optimal functioning of children with NDID, understanding different aspects of child functioning, together with the environmental aspects, is key to providing a holistic perspective of the child's functioning. Moreover, this also helps to better understand barriers and facilitators for the learning and development of children with NDID. In section, 2.1.3, I describe the International Classification of Functioning, Disability and Health -Child and Youth framework (ICF-CY), a classification system that addresses each individual's functional status in a holistic framework, thereby, moving beyond understanding disability as a merely biologic or medical phenomenon, and instead, looking at the impact of disability on a person's functioning and across their life experience.

2.1.3   Learning and development in Children with NDID: The International Classification of Functioning, Disability and Health -Child and Youth framework (ICF-CY)

Diagnosis of health conditions and the assessment of individual functioning are at the core of clinical practice. For more than a century, health professionals relied on the International Classification of Disease (ICD) to provide information about the etiology and pathology of

diseases. However the ICD classification does not capture the impact of disease on an individual's functional abilities, either at the individual's activity level or in their social interactions (18,19). Moreover, evidence indicates that diagnoses alone do not predict the quality of care and patient functional outcomes (18). In other words, the information necessary for optimal healthcare planning and management may be overlooked by using the medical classification of diagnoses as an isolated instrument (20).

Taking this gap into consideration, the World Health Organization created the International Classification of Functioning, Disability and Health (ICF) framework in 2001. The goal of the ICF was to provide a structure defining health and well-being, by incorporating both the medical and functional social model. In other words, this model described the individuals' health by their functional outcomes rather than only by their clinical diagnosis as the individuals' body functions ultimately impact their ability to perform and participate in activities. In 2007, the World Health Organization established the International Classification of Functioning, Disability and Health-Child and Youth version (ICF – CY) to meet the specific needs for assessing disability and health-related conditions pertaining to children with disabilities. It addresses differences in the nature, impact and intensity of pediatric conditions compared to adults with special healthcare needs as observed in the ICF (20). The multiple ICF – CY dimensions include biological, psychological, social and environmental aspects of child functioning (21). As illustrated in Figure 2.1, for any given health condition, the ICF – CY identifies three health outcomes, namely: body function and structure, activities, and participation. Each of these three health outcomes could be affected by disease, disorder or injury, resulting in each component being described as an impairment, activity limitation and participation restriction. The relationship between the three components is influenced by contextual factors, which have two components: environmental and personal (20).

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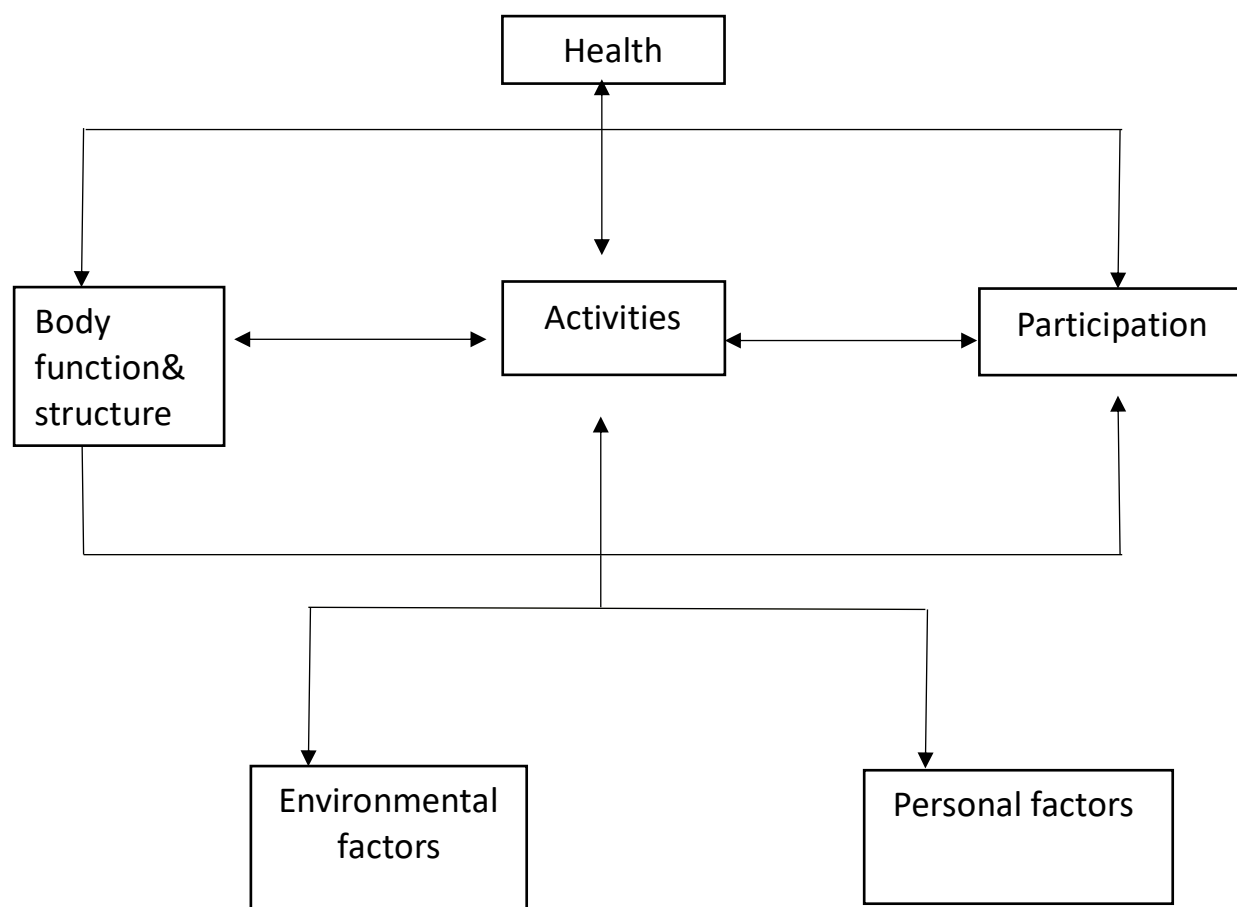
Figure 2.1 The ICF – CY Framework.

The "body" domain (body function and body structure) concentrates on physical and mental functions, sensory responses, structure and function of the multi-organ system, movement capabilities and reproductive ability. The "activities and participation" domain assesses the child's ability to learn and apply knowledge, follow general tasks, communicate and care for him/herself. The ICF-CY also describes two types of contextual factors, namely environmental and personal factors. The domain of "environmental factors" identifies products and technologies available to assist the patient, community services that are available to the patient as well as relationships such as family members, support and care offered outside the clinical setting. Personal factors, refer to attributes including age, sex, educational background, social class, culture, past experiences, personal character traits, lifestyle, coping style and occupation (21). Thus, the conceptual framework of the ICF-CY identifies contextual factors as having important influences on outcomes.

In this thesis, the ICF-CY framework forms the basis for our understanding about families as an important contextual factor for children with NDID's development as it empowers us to think about the 'context' of a child's life, emphasizing that a child's essential context is their family. Moreover, the family, especially parents are responsible for providing continuity in care across the life span of the child (22). Consequently, a child's well-being will be powerfully influenced by the well-being of their parents and families (21). And therefore, improving the parents' well-being ,for example through peer support networks will also benefit the child's well-being.

2.2   Families: Primary Caregivers for Children with NDID

The United Nations recognizes family as the "basic unit of society" (23). For children with NDID, family is the primary caregiver responsible for providing care and navigating services across their lifespan. Two major social shifts in care have made the consideration of the family caregiver particularly relevant. First, the principles of family-centered care have been implanted in health policy and embraced by health and social service organizations (24) that provide services to children with disabilities and their families. Family-centered service according to the *CanChild* Centre for Childhood Disability Research "is a philosophy and method of service delivery that (a) recognizes parents as the experts on their child's needs, (b) promotes partnership between parents and service providers, and (c) supports the family's role in decision-making about services for their child." (24). As a consequence, family caregivers are instrumental partners actively influencing the nature and direction of the care their child receives (24,25). Second, with the progression towards community-based rehabilitation of children with disabilities, community-based rehabilitation acknowledges family caregivers as partners in the provision of care. Thus, these social shifts have placed greater emphasis on the family caregiver voice and involvement, simultaneously representing extraordinary parental responsibility (26). Therefore, understanding the role of the family caregiver is critical in order to provide optimal levels of care for the child with NDID. Below, I discuss the dual role of the family caregiver and the impact of caregiving on the family.

2.2.1 Dual Role of the Family Caregiver

The family caregiver plays the dual role of the parent/guardian and the caregiver, providing at-home care to their child with NDID. The family caregiver is considered as one of the most vulnerable caregivers due to the lack of distinction between the parental and caregiver roles. The caregivers are responsible for providing continuity in care across their child's lifespan (22). Thus, caregiver parents are expected to absorb their caregiver duties into the parental role and subsequent lifetime responsibilities (27).

Although caregiving is a normal part of parenting, the intensive level of care required by a child with NDID is often burdensome and varies depending on the child's abilities and challenges, as well as the families' abilities to handle the challenges (28). Research illustrates that families of children with NDID compared to typical families, are at higher risk of being emotionally vulnerable, have higher levels of anxiety, stress, depression and lower levels of self-efficacy feelings and health-related quality of life due to the continued uncertainty surrounding their child's challenges (22,29-32). This impact on caregiving is further discussed in the next section.

2.2.2 Impact of Caregiving on the Family: Caregiver-related Stressors

All parents, irrespective of their child's abilities, experience stressors related to parenting, and parents differ in their abilities and opportunities to adapt to these challenges (33). Specifically, families of children with NDID encounter numerous challenges following the diagnosis of their child with NDID. The challenges faced by families are often described as "stressors". These stressors may be due to numerous reasons such as child-related characteristics, for example, the child's behavior, the parents' adaptation to the behavioral challenge and the child-parent relationship. Stressors on the family represent undesirable conditions that disrupt one's usual activities acutely or chronically and is perceived as a threat to well-being (34). The effect of stressors cannot be meaningfully understood without considering each family individually, as each family is unique and therefore, heterogeneous in the way they approach stressors. For example, some families can be overwhelmed by a child whose disorder seems relatively mild, whereas other families with much more seriously affected children can cope in a healthy manner and describe positive benefits such as experiencing considerable personal growth from their

experience (35). Thus, there are reports in literature of both positive and negative effects on parental caregivers.

As families play a key role in the lives of their children, their own well-being is inextricably linked to that of their children (26).With the onset of the child's diagnosis, families reassess their life priorities and relationship demands in order to meet the caregiving demands of their child with NDID (36). For example, to care for their child with NDID, many family caregivers reduce their work hours while facing high out-of-pocket costs needed for medical specialists, respite care, speech pathologists, and behavior therapists (23). These additional financial stressors add to the emotional stress which parents are already feeling around the diagnosis, leading to significant concerns for parental mental health. In fact, research indicates parents of children with autism experience more negative psychological outcomes such as elevated stress levels and depressive symptoms when compared to parents of typically developing children (29,37-39) and to parents of children with other developmental disabilities or healthcare needs. Moreover, this may be due to the child with NDID's often challenging behavior requiring ongoing monitoring (3). In turn, this limits families' abilities to participate in social activities such as meetings with friends or even feeling unable to be in public due to their child's behavior (2,3). The common reduction of income, coupled with increased costs of care and the social disruption with the demands on their time to care for their child and the need to adapt to their child's behaviours ultimately contribute to their stress and sense of social isolation (23,27,40)

As child-related stressors effect the families' functioning, similarly, the effect of stressors on the family, has a reciprocal effect on the child as well. This creates an ongoing bi-directional relationship between the child and parents (or family) where the child influences his or her environment (in this case, the parents) while the environment simultaneously influences the child; this bidirectional relationship is referred to as the transactional relationship between the parent and the child (41,42). For example, Lecavalier *et al*. (43) examined a sample of children with autism and their families. They found child problem behavior exacerbated maternal parenting stress, and maternal parenting stress exacerbated child problem behavior where each model, coincidentally, accounted for 72% of the variance within their respective outcomes, indicating a transactional relation. In another study, Baker *et al*. (44) found that family adaptability to the situation influenced both maternal depression and child behavior problems in

autism and noted that their findings supported the idea that "children with autism…likely respond to their family environment in addition to acting upon it" (44). Thus, this transactional relationship will play an important role in all kinds of interventions that target the stressors related to children with NDID or their families. For example, the child's behavior is one important stressor for families, that leads to more isolation and increased stress; any intervention that can help developing the child's self-control will then have a positive impact on the family. This is one reason that explains the search for physical activity programs by families, to help support their child with NDID's learning and development. Similarly, reducing the effect of the stressors on the families, for example, through participation in peer support networks, can have a positive effect on the child. The theoretical representation of this transactional relationship is further illustrated through the family systems theory, discussed in the next section.

2.2.3   Family Systems Theory to Understand the Transactional Relationship between Families and their Children with NDID

The fundamental basis of the family systems theory is that families are a collective whole made up of interconnected individuals, and therefore, changes in one family member or in a family member's relationship with each other can affect the functioning of the whole family (45-47). In addition, the stressors that affect the system (or family) affect the individual, and vice versa. Thus, the family systems theory approach is bidirectional in nature such that a change in one person affects the functioning of all family members, which in turn has an effect on the person who caused the change. The family systems theory highlights the connectedness and interdependence of all the individual members who make up a family (48).

Family systems theory is not directly evaluated in the present study, but it is an important theory to consider as (i) it provides the link or rationale between supporting one parent to improving the whole family, and also (ii) the link between supporting families in order to improve the child with NDID's condition. Furthermore, it encourages researchers to consider the family as a system or a whole unit rather than focusing solely on one individual. Thus, according to this theory, if parents are positively adapting to the stressor situation through external mechanisms such as social support from peers, for instance, this will also affect the whole family outcomes, and also the child. Finally, based on family systems, addressing the needs of a parent

will promote positive change within the family and positive interactions among family members, including the child with NDID.

2.3 Overcoming Caregiving-related Stressors: Social Support as a Way to Support Family Caregivers

In section 2.2, I described the role of parents as caregivers and the relationship between the child with NDID and family members, in the context of a family system. Parents or families face numerous challenges while raising a child with NDID, including greater parenting demands and consequently higher stress and poorer psychological health compared to parents of typical children (23,26). The degree to which these stressors impact the daily lives of parents is unique for each family and depends upon how individuals perceive and adapt to their situation. One way to help support and strengthen parents to reduce the impact of stressors, is through social support. Social support is a well-established buffer against stressors. In section 2.3, I will define social support and describe formal and informal social support.

2.3.1 Definition of Social Support

Social support, according to Cobb is defined as "information leading the subject to believe that he is cared for and loved, esteemed, and is a member of a network of mutual obligations." It is "a multidimensional construct that includes physical and instrumental assistance, attitude transmission, resource and information sharing, and emotional and psychological support" (6)(p. 403). Social support is an important factor that safeguards families against distress (35,49). According to Fischer *et al.* (50)(p. 413), social support "has been found in a number of studies to be an important buffer against family crisis factors, and to be a factor in family resiliency promoting family recovery, and as a mediator of family distress." Previous research has acknowledged social support as an important resource that families can utilize to learn coping strategies, possibly reducing the negative psychological impact that is often associated with bringing up a child with an NDID (51) Examples of social support include spousal support, the extended family, friends, professional help, and services and programs that are accessible to families who have a child with NDID such as respite services, home health care, family education and training, family counseling and support groups (52). These examples encompass the different types of social support, formal and informal. Taken together, both formal and

informal social supports help in the reduction and management of stress levels and provide multiple ways for families to reassess and reframe their stressors, thereby learning to cope with adversity and becoming more resilient.

2.3.2 Types of Social Support

2.3.2.1 Formal Social Support

Formal social support is defined as "assistance that is social, psychological, physical, or financial and is provided either for free or in exchange for a fee through an organized group or agency" (53). Formal social support includes services from professionals such as psychologists, counsellors and structured organizations such as social clubs or churches (53).

Commonly cited formal support interventions include caregivers' training workshops, and psychosocial strategies such as counselling, church support groups, cognitive behavioral techniques, and respite care services. Formal interventions, for example, counseling or behavior strategy sessions, provide parents with opportunities to connect with professionals such as counselors, psychologists and social workers and learn different techniques from them that may help parents cope with their present challenges by positively reflecting and reframing their situation, helping them to reduce their stress, develop resiliency and feel more empowered. For example, in a review on parent training studies by Schultz *et al*. (54), researchers found that benefits of parent training included a reduction in stress and a decrease in depressive symptoms experienced by the parents (54,55).

2.3.2.2 Informal Social Support

Informal social support is defined as "a network that may include the immediate and extended family, friends, neighbors, and other parents of children with disabilities" (53). Other examples of informal social supports include other individuals close to the family who provide help and assistance (53). Similar to the contributions of formal social supports, informal social supports play an important role helping caregivers reduce their feelings of isolation and helplessness often associated with raising a child with NDID (56). Boyd (53) found that support from a partner/spouse was an important source of support, as they provide respite support and are able to assume many household responsibilities. Additionally, research has identified support groups or peer-to-peer support for parents of children with NDID as particularly helpful, offering the

opportunity for caregivers to engage with similar parents, thereby reducing social isolation, sharing information and resources, and perhaps increase access to other services or formal supports (53,57,58). For example, Clifford et *al*. (53) organized an online peer support group that lasted over four months for twenty-five families of children with autism. Although the difference in the scores on the scales for anxiety, mood and positive perception levels were elevated but not significantly different from the control group, the parents reported that the group was useful, specifically highlighting the opportunity to connect with other parents and share information about resources. Although these groups are beneficial, parents of children with NDID often juggle multiple and competing caregiving demands, and as a result parents face difficulties in carving out time in their routine to socialize with peers or seek out peer support. Therefore, groups that can support parents while providing support to the child may be beneficial. Having said that, the need to engage in support is dependent on the parent and their circumstances. The presence of support, although beneficial, does not in any way mean the parent will always spontaneously engage in the support available.

These informal parental peer-to-peer social support networks are further described in Chapter 3 as it is the main focus of the thesis.

2.4   Attending Physical Activity Programs as a Venue for the Development of Peer Support Networks for Families of Children with NDID

This thesis focuses on exploring, in the context of attending PA programs for their child, whether families develop peer support networks with other parents at PA programs. Therefore, here, I review the types of PA programs for children with NDID, and their possible impacts on children and families.

2.4.1   Physical Activity Programs for Children with NDID

Children with developmental disabilities have a physical fitness level that is inferior to their typical peers and thus, reflect a population that exhibits a sedentary lifestyle (59). Several challenges, including documented motor impairments, social and behavioral deficits and psychological limitations make it difficult for children with NDID to participate in physical activities (60). Jasmin *et al.* (61) illustrated that physical activity and exercise becomes a critical

tool in improving the motor performance and health status of children with NDID. Physical activity helps in improving the way these children move and explore their environments, which positively effects their socio-cognitive developments (61).

In this regard, community-based adapted physical activity programs that provide specific teaching/training approaches tailored to children with NDID have been documented to be beneficial. (10,60,62). Research studies illustrate that PA programs for children with NDID such as swimming and horseback riding may lead to a decrease in behavioral issues, an increase in levels of physical fitness, improvement in motor co-ordination and social skills as well as greater enjoyment of physical and recreational activity times (63). Furthermore, involvement in these programs like the Special Olympics has been "positively associated with improvements in a person's self-worth and perceived physical competence" (62). For example, Weiss (62) states: "[a] majority of parents of Special Olympics athletes believe that the organization is beneficial in promoting life satisfaction and social adjustment of their child and that it enhances levels of family support, involvement, and cohesiveness". Thus, these programs have also been recognized to provide participants with a sense of purpose and belonging and enhanced social connectivity to the community. Having mentioned that these activity programs are beneficial for children with NDID, it is critical to note that not all children with NDID can participate in these programs. In particular, children participating in these programs have specific ability levels and independence necessary for their participation in these programs.

2.4.2   Physical Activity Programs for Children with NDID: Impact on Families

Research findings suggest that participation in adapted physical activity programs, such as the Special Olympics, is in addition to being beneficial for the participants, also beneficial for their families (9). For example Bowers *et al.* (10) in interviews conducted with parents at the PA program found that a child's participation positively reinforces families by highlighting the abilities of their family members. Programs raise family expectations of their child with NDID, by providing opportunities for enhancing the child's skills and increasing their social networks and community participation. Furthermore, researchers reported an increased community/family involvement as volunteers and coaches (64). Families also felt that these organizations provided opportunities to strengthen relationships between all family members and allowed family members to socialize with new individuals within the community. Weiss *et al.* (62) in their study

indicated these programs were a mediator between stressors and maternal role restriction. The authors cited potential reasons this involvement may buffer the effect of stressors on parent functioning such as the availability of parent support, availability of informal service supports that help supporting children with NDID, and watching children perform activities provides respite to the parents.

So far, there is limited research on the potential benefits of parental attendance at the physical activity programs (10,64). Therefore, this dissertation is a detailed exploration to determine the possible effects of aspects of these PA programs on families, provided parents or family members are present at the PA program site and waiting for their child to complete the physical activities. Furthermore, this thesis will examine the barriers and facilitators for the parents attending these programs to join or develop social networks.

Also, little research has been conducted on the potential benefits of parental attendance at the physical activity programs (10,64). In fact, most of the research has focussed on understanding the impact of these programs on the child with NDID's development. Therefore, this dissertation is a detailed exploration to determine the possible effects of aspects of these PA programs on families provided parents or family members are present the PA program site, waiting for their child to complete the physical activities. Furthermore, this thesis will examine the barriers and facilitators for the parents attending these programs to join or develop social networks.

Chapter 3: Review of Literature on Peer Support Networks

In Chapter I reviewed the literature on the role of families as a caregiver for children with NDID, and discussed social support as a well-established buffer against stressors. In this chapter I specifically review literature on a type of informal social support known as peer-to-peer social support networks or peer support networks or peer support groups. I begin by defining parental peer-to-peer social support networks, followed by a description of theories that explain the supporting role of peer-to-peer social support networks.

In the second part of this chapter (3.2), I describe the scoping review elaborating on (a) characteristics of peer support groups and their development process (b) characteristics and needs of families attending peer support networks; (c) impact of peer support networks on families of children with NDID, and (d) factors affecting the participation of families in peer support networks. This review was conducted to provide an in-depth understanding of the importance of peer support (groups or networks or spontaneous interaction) for parents of children with NDID. It was specifically designed to understand what parents receive from these interactions with 'similar other parents'. This review builds our knowledge about potential outcomes when parents interact with each other. The review informed our examination of physical activity programs described in chapter 4.

3.1   Peer-to-Peer Social Support Networks

3.1.1   Definition

Peer-to-peer social support groups or networks, which will be referred to as "peer support networks", are a form of informal social support focused on mutual support provided by parents who share similar experiences (7,82). In these networks, parents are the experts. These networks range from informal interactions between members by members, to those that are professionally-facilitated, with a facilitator whose role is to manage a group's interpersonal processes only (65). These networks do not train parents to act as therapists for their children (66). The benefits of peer support networks for families have been previously identified in other caregiving populations such as families of children with juvenile arthritis and obesity as enabling members to share their feelings, providing a sense of belonging to the community, and enlarging their social networks to include other families who can lend a hand during difficult times (65).

3.1.2   Importance of Peer -to-Peer Social Support Networks

Peer support networks are important in promoting the well-being in parents of children with NDID (7). For example, peer support provides families with emotional and informational support that helps parents to cope with their stressors by positively reframing their current stressful situations (67,68). Furthermore, parents are responsible for ensuring continuity of care for children with NDID and other disabilities across their child's lifespan. Miller *et al*. (69) in their study, interviewed forty-seven parents of children with complex conditions in order to understand their perceptions on the continuity of care. They found that because these children require a plethora of services that go beyond medical and nursing services, extending to rehabilitation, education, social, and family support services, parents experience frustration as they try to weave through a complex and fragmented array of services that are difficult to manage (69). Research illustrates that peer support from similar families assists others in navigating the systems of care (68,70). For example, Baumbusch *et al* (68) interviewed 15 parents of children with a rare disease about their experience navigating the healthcare system; parents highlighted the peer support as a key resource for informational and emotional support.

The need for peer support networks by families is dependent on the specific families' situation, such as the existing resources available for support, and the particular kinds of support needed. Support networks are frequently aimed at providing assistance during acute periods of stress and change – such as following birth, diagnosis or injury to a child. For example, Kingsnorth et al, designed and evaluated a peer support group for parents whose children were transitioning into adulthood. This group was designed based on a needs assessment conducted among parents. The need for a Transition Peer Support Group was identified as a priority as transition to adulthood was identified as a time of stress and change for families . They determined that parents could benefit from the informational, emotional and affirmational support afforded by parent-to-parent support (8).

Several factors contribute to families' participation in peer support groups. According to a survey by Mandell and Salzar in the United States, (57), peer support groups were more likely attended by parents of older children than parents with younger children due to the additional time it takes to establish routines and identify resources. They also found these groups appealed

to middle- and upper-income, more educated, married, suburban whites. Some of the reasons include that individuals with these characteristics may have greater comfort in discussing private feelings and experiences with others, possibly due to educational and cultural factors. They may also have greater resources and time to find or initiate such groups in their communities, thereby increasing access. It may also be that poor, less educated, urban and rural residents, as well as African American parents or those from other cultures, think that these groups will not address their specific needs.

However, parents from culturally and linguistically diverse communities may bear the effects of numerous stressors, such as economic instability, language barriers, limited access to disability-related information, and lack of social support (71). Unfortunately, when these families reach out for support, the support they receive may not be culturally sensitive or culturally appropriate (72). For example, Dodds *et al.* in their evaluation of a one to one peer-to-peer support program in Virginia, reported that there were not enough diversity trained parents participating in the program who may be able to better engage with the needs of culturally and linguistically diverse communities.

Overall, a study by Clifford *et al* (73), illustrated that peer support groups help parents to positively reframe their situation by gaining emotional and informational support, thereby encouraging the development of the individuals adaptive coping style. In addition, there is extensive research regarding how members of families use social or peer support as a coping strategy. Glidden *et al.* (74) examined the individual differences in the ways mothers and fathers cope with having a child with a developmental disability. They collected data using narratives from the mothers and fathers in addition to completing a questionnaire. Mothers reported more use of social support than fathers. Additionally, Dabrowska and Pisula (75) examined the profiles of stress in mothers and fathers of children with autism, Down syndrome, and typically developing children. Mothers were found to use more emotion-oriented coping strategies and social diversion than fathers. Mothers used social support as a means of exchange of emotional support, that helped them in reframing their stressor/situation. This illustrates that the value of peer support is also dependent on the specific gender of the parent and more specifically, the coping style of the individual.

3.1.3   Theories

The foundation of peer support networks is based on several sociological theories, of which the Social Learning Theory, Communities of Practice Theory and Social Comparison Theory will be discussed in brief. These theoretical frameworks are important as they guide researchers in understanding the process of peer-to-peer interaction among family members of children with NDID, which is key to understanding peer support network development among families at PA programs described in Chapter 4.

3.1.3.1   Social Learning Theory

Social Learning Theory, following Vygotsky (76), contends that learning is a social rather than purely individual process. Communities are the setting where individuals   learning through observation and interaction with experts and through discussion with colleagues.

Two important components of social learning theory are that people's views of their capabilities "influence[s] their behavior, thinking, and emotional reactions in stressful situations" and most behaviors develop through modeling by others (77). Thus, as Stewart (77) noted, self-efficacy and modeling are important in understanding how change occurs as a consequence of social support. Moreover, Bandura emphasized that observing other people's behaviour and engaging with them in activities provides a safer and more efficient way of acquiring complex behaviours or skills, compared to learning through trial and error (78). Applied to parental peer support networks or communities, parents who interact with each other enhance each parents' adjustment to stressors by "modeling coping and health-enhancing behaviors" and "enhancing self-efficacy that one can change behavior" (79) (p. 360).

3.1.3.2   Communities of Practice Theory

The main idea behind Communities of Practice is that communities are social learning systems. Engagement in social contexts involves a dual process of meaning making- social engagement and means of socially representing knowledge. On the one hand, "we engage directly in activities, conversations, reflections, and other forms of personal participation in social life. On the other hand, we produce physical and conceptual artefacts – words, tools, concepts, methods, stories, documents, links to resources– that reflect our shared experience and around which we

organise our participation." (80) Moreover, these groups of individuals or 'communities' with similar goals can benefit from their commonality in purpose and can grow from mutual interaction because of their shared interests. Communities of Practice are formed around all sorts of hobbies, infrastructure, and even forced situations (81).

The communities of practice theory has the same source as social learning theory, in that they both propose learning is a social activity occurring through the exchange of knowledge at a social rather than an individual level. Learning does not solely come about from the transfer of knowledge from a teacher to a student, but rather is constructed as the new members of a group learn from the more experienced members. Communities of practice places less emphasis on the teacher and student roles but more on group interaction and negotiating meaning and future goals and practices collectively.

According to Wenger (81), there are three essential components that identify Communities of Practice: mutual engagement, joint enterprise, and shared repertoire. The term mutual engagement represents why the group can be termed a community in the first place. Mutual engagement requires a community of participants usually in relation to a common purpose. The community of individuals must be engaged and focused on similarly minded goals. Despite the commonality of purpose, the community does not need to be homogeneous. . Wenger assumes that there are different levels of expertise in a Community of Practice. Also, agreement and disagreement, differences and similarities, and construction and deconstruction of ideas can all exist within and create mutual engagement as long as the individuals share relationships and interest in a similar focus.

Joint enterprise refers to the theoretical and realistic efforts that are made through the pursuit of mutual engagement. Joint enterprise is created through the community negotiation of response in relation to the goals they have. According to Wenger, "Becoming good at something involves developing specialized sensitivities, an aesthetic sense, and refined perceptions that are brought to bear on making judgments about the qualities of a product or an action. That these become shared in a community of practice is what allows participants to negotiate the appropriateness of what they'll do" (81) (p. 81). Joint enterprise does not imply a set of rules of standards but a continually molded process of determining the best course of action to reach the goal of mutual engagement.

Shared repertoire is related to the similar shared experiences or expectations that community members have. Shared repertoire can manifest itself in many ways, including stories, tools, historical events, actions, routines and styles. These common occurrences are normally recognizable among community members, and are often even used to generate new meanings or put new issues into perspective.

Wenger (81) illustrated that individuals participating in communities of practice are better able to define and solve problems, develop new skills, learn best practices, gain confidence, save time, improve innate abilities, avoid mistakes, and jointly create new knowledge.

The concept of Community of Practice can be applied to peer support networks for families of children with NDID. In fact, peer support networks are 'communities of practice'; peer parents through observation of and conversations with the other parents can be helped to find meaning and purpose in their children's disabilities and even some benefits. Parents with more experience and knowledge can offer support and information to new parents. For example, parents of children with NDID over time, find positive ways in which having a child with autism impacts them and their families (82). Much of this cognitive adaptation is facilitated by narrative exchange (83). In peer-to-peer support, parents exchange narratives about their experiences. Parents of children with disabilities have found such exchanges to be "healing, cathartic, validating of their emotions and concerns, and to promote their adjustment through the process of cognitive adaptation" (83).

Thus, communities of practice focus on the formation of relationships, engagement in learning, developing practice, carrying out tasks and projects, and creating new knowledge. These purposes align very closely to those reported by parents of children with NDID in peer support networks (7,84). Moreover, Communities of Practice provide a structure for parents of children with NDID to explore relevant topics and knowledge, discuss this knowledge gained with other parents, and implement it into practice related to their current needs. In addition, the peer interaction offers a platform for parents to form relationships, to gain emotional and social support, and to construct new knowledge that may impact other parents in their situation.

3.1.3.3 The Social Comparison Theory

Developed by Leon Festinger, this theory illustrates that under threatening, uncertain, or stressful circumstances, individuals conduct social comparisons with similar others for self- enhancement (i.e., to feel better about themselves), to evaluate their skill-related abilities, to gauge the appropriateness and strength of their emotional reactions and opinions, and for guidance and/or modeling (34,85). Thus, social comparison processes appear central to coping with stressful circumstances and to the use of social support towards this end. In peer-to-peer support, parents may derive benefits from parents whose children have similar conditions as their comparison models (86). These benefits accrue from downward comparisons (comparing themselves to worse-off parents) and upward comparisons (comparing themselves to better off parents). Upward comparisons reinforce hope, motivation, and inspiration and models of coping and problem-solving (79,85). Downward comparisons can lead to ego enhancement and positive affect by "providing examples of how bad things could be" (79) (p.360).

Within the context of peer support networks, people experiencing the same difficulties come together in the hope to gain support from their peers due to their shared understanding and empathy, which seems to promote a positive sense of self for members as role-players in someone else's healing process (57,87,88)

3.1.3.4 Theories on Peer Support Impact on Family

Studies investigating mechanisms or pathways linking social support for families identify several possible ways in which parental support has a positive impact on the child. One hypothesis is that parental social support has a direct effect on parenting behaviours and child well-being. Social support may also influence parenting practicesby increasing parent exposure to informal and incidental learning opportunities and/or by reinforcing and 'policing' parenting norms (i.e. social pressure to conform to generalized expectations of parenting behaviour). Similarly, when parents have a strong support network their children are more likely to be exposed to many and varied 'competence promoting' social interactions (6).

Another hypothesis is that parental social support has a positive effect on parenting behaviour and child development by reducing and/or ameliorating the effects of parenting stress. This is referred to as the stress-buffering hypothesis (46). Social support may buffer parental stress by moderating the relationship between parent stressors (such as financial hardship and

child problem behaviours) and parent stress, and/or between parent stress and parenting behaviours (89). Therefore, parental social support may enhance parent and family resilience in the face of difficult life circumstances and events (90).

3.2   Scoping Review on Peer Support Networks

We conducted a scoping review on peer support networks in this population to substantiate knowledge and understanding of various aspects of peer support networks. The main themes emerging from the review include (i) characteristics of peer support networks and their development process (ii) characteristics and needs of families attending peer support networks; (iii) impact of peer support networks on families of children with NDID, and (iv) factors affecting the participation of families in peer support networks

3.2.1   Search Strategy

This scoping review was conducted using the scoping review methodological framework by Arksey and O'Malley (91). This scoping review maps out existing research on peer support networks for families of children with NDID. In order to identify relevant studies, a comprehensive search for articles was conducted using multiple databases: Academic Search Complete, CINAHL Complete; CINAHL with Full Text, Education Source, ERIC, MEDLINE with Full Text, PsycARTICLES, PsycEXTRA, PsycINFO, Social Work Abstracts and SPORTDiscus. The publication year was not restricted. We restricted our search to peer-reviewed literature and included the snowballing approach to scan references of the final list of selected papers. All searches included a combination of the terms (i) *'peer support networks',* (ii) *'children with* neurodevelopmental and intellectual disabilities' *and* (iii) 'family *caregiver outcomes'*. We defined (i) Peer support networks as the presence of a community of similar interests where parents of children with NDID come together (in person or virtually by computer or telephone) to share their experiences, provide emotional, informational and instrumental support as well as find answers to their questions. This is consistent with definitions used in published Cochrane reviews, with the additional specification that the knowledge possessed by the peer support networks is concrete, practical, and obtained from personal experience rather than formal training (92,93). We also defined (ii) children and youth with neurodevelopmental and intellectual disabilities as children having impairments in the cognitive, behavioural, motor,

and/or language functioning, resulting in a variety of challenges associated with ambulation, information processing, self-regulation (e.g. self-injury and unpredictable behaviour) and communication (11,94).We selected the highly prevalent NDID's, including Autism Spectrum Disorder (ASD), Down Syndrome, Cerebral Palsy (CP), Learning disability, intellectual disability, fetal alcohol syndrome (FASD) and attention deficit hyperactivity disorder (ADHD). *(iii) 'Family caregiver outcomes* were defined as the well-being of caregivers who were the immediate family members that included parents and/or mother and/or father of children with neurodevelopmental and intellectual disabilities. Studies that reported on outcomes related to caregiver well-being were included. The concept of caregiver well-being, the primary intervention outcome, is slightly nebulous in nature. Therefore, we anticipated that included studies will evaluate a broad range of measures related to one or more of the following: psychological health, family functioning, family resilience, family quality of life. The relevant keywords used in each individual search is provided in Table 3.1. Two separate searches using a combination of the different keywords were conducted. Search 1 involved key terms (i), (ii) and (iii) while in search 2, a fourth term, i.e. 'family member caregiver term', parents and/or mother and/or father were added to ensure networks for specific family caregivers of children with NDID are included. The search terms were truncated when appropriate to ensure relevant papers were captured by the search.

Table 3.1 Key Terms Applied to Conduct the Search

Key Term Combination 1

PEER SUPPORT NETWORK TERMS	FAMILY CARE-GIVER OUTCOME TERMS	CHILDREN WITH NDID TERMS
("FAMILY SUPPORT GROUPS" OR "SOCIAL SUPPORT NETWORK" OR "SOCIAL NETWORK" OR "SUPPORT GROUPS" OR "GROUP PARTICIPATION" OR "PEER SUPPORT GROUP" OR "PEER SUPPORT" OR "PEER NETWORK")	("FAMILY OUTCOMES" OR "FAMILY FUNCTIONING" OR "QUALITY OF LIFE" OR "WELL BEING" OR "RESILIENCE")	("FAMILIES OF CHILDREN WITH AUTISM" OR "FAMILIES OF CHILDREN WITH DOWN SYNDROME" OR "FAMILIES OF CHILDREN WITH CEREBRAL PALSY" OR "FAMILIES OF CHILDREN WITH FETAL ALCOHOL SPECTRUM DISORDER" OR "FAMILIES OF CHILDREN WITH INTELLECTUAL DISABILITY" OR "FAMILIES OF CHILDREN WITH LEARNING DISABILITY" OR "FAMILIES OF CHILDREN WITH AUTISM SPECTRUM DISORDER"OR "FAMILIES OF CHILDREN WITH ASPERGERS" OR "FAMILIES OF CHILDREN WITH NEURODEVELOPMENTAL DISABILITY")

Key Term Combination 2

PEER SUPPORT NETWORK TERMS	FAMILY CARE-GIVER OUTCOME TERMS	NDID TERMS*	FAMILY CARE-GIVER TERMS
("FAMILY SUPPORT GROUPS" OR "SOCIAL SUPPORT NETWORK" OR "SOCIAL NETWORK" OR "SUPPORT GROUPS" OR "GROUP PARTICIPATION" OR "PEER SUPPORT GROUP")	("FAMILY OUTCOMES" OR "FAMILY FUNCTIONING" OR "QUALITY OF LIFE" OR "WELL BEING" OR "RESILIENCE")	("AUTISM" OR "CEREBRAL PALSY" OR "DOWN SYNDROME" OR "INTELLECTUAL DISABILITY" OR "LEARNING DISABILITY" OR "NEURODEVELOPMENTAL DISABILITY" OR "AUTISM SPECTRUM DISORDER" OR "ASPERGERS")	"PARENTS" OR "MOTHER" OR "FATHER"

3.2.2 Selection Process

For study selection, a step-by-step selection procedure was implemented to obtain the relevant articles. Studies presenting original research published in peer-reviewed journals in English were included. The purpose of the scoping review was to explore and understand the existing literature on peer support networks for family caregivers (i.e. parents and/or mother and/or father) of children with NDID. Interventions which utilized a formal or professional facilitator were included, provided the facilitator's role was to facilitate discussion rather than providing didactic instruction, active counselling or psycho-education. We included studies that focused on families of children and youth as the support requirements as the families of adults with NDID may be different considering the different health and support services and resources available compared to families of children and youth.

We excluded papers focused on: (a) informal support networks between friends (who do not have a child with a NDID) and/or family and/or colleagues; (b) measurement of perceived social support between friends (who do not have a child with NDID) or family or colleagues [e.g., Benson *et al.* (95)]; (c) facilitated groups that involved training by professional facilitators [e.g., Hudson *et al.*(96)]; (d) studies pertaining to siblings and grandparents as we were interested in understanding the impact on the immediate parental caregiver, and (e) letters to the editor, commentaries, conference abstracts, plenary lectures, magazines and news articles.

Once all articles were retrieved, the duplicate articles were first removed. Then the remaining article titles and abstracts were screened and irrelevant articles removed. Titles and abstracts retrieved by the electronic searches were screened by two reviewers (MC and MG) using

the inclusion/exclusion criteria. Disagreements were resolved by discussion with a third reviewer where necessary. The papers that did not meet the inclusion criteria were rejected. Next, full text copies of potentially relevant studies were obtained and assessed for inclusion using the criteria specified. Finally, the snowballing approach was implemented, in which the reference list of the selected articles were screened to ensure that all relevant studies were captured by the search. Any additional article found was further assessed for eligibility. The search details are provided in Figure 3.1
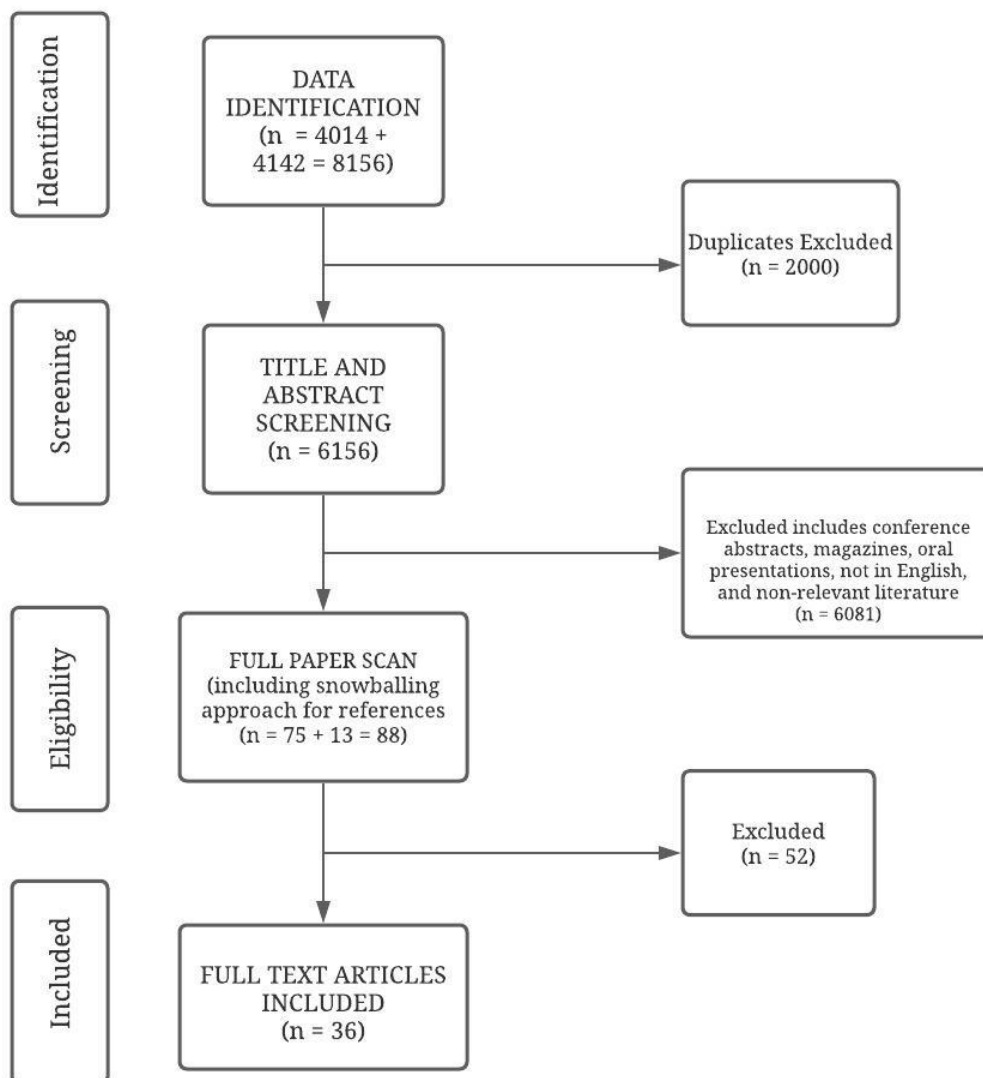
Figure 3.1 The Search Strategy

3.2.3   Results

3.2.3.1   Search Results

Figure 3.1 outlines the procedure for article selection. The electronic search resulted in 8156 articles. Subsequently, duplicate articles were removed (n=2000) resulting in 6156 articles. These articles were screened on the basis of title and abstracts. Letters to the editor, commentaries, conference abstracts, plenary lectures, magazines, articles not in English and newspaper articles were excluded, resulting in the exclusion of 6081 articles. Following this exclusion, a total of 75 articles were obtained. These articles were fully read including references to ensure all relevant articles were included. Additionally, 13 articles were obtained while screening their references. Each of these 88 articles were read in detail by two coders in order to verify relevance with regard to the objectives of the review. This resulted in the rejection of 52 articles and final inclusion of 36 articles. All articles were accessed electronically. Included articles were summarized in relation to their objective, methods, sample characteristics, and relevant results and presented in Table A.1 (see Appendix A.1).

Most of the peer support network research studies were conducted in North America (Table 3.2); studies included perspectives of both parents' (N=30), only mother (N=4) or father (N=2) (Table 3.3). Also, a majority of studies included parents of children with a wide range of NDID, rather than focusing on a single NDID (Table 3.4), thus adopting a non-categorical approach.

Table 3.2 Division of Papers Based on Country where Research was Conducted

Country	Number of studies
Europe (Greece and Italy and UK)	8
Canada	8
USA	15
Australia	1
Asia (China and Taiwan)	3
Africa	1

Table 3.3 Family Members Participating in the Study

Family Member	Number of Studies
Parents (mother and fathers)	30
Only mothers	4
Only fathers	2

Table 3.4 Child Disabilities Represented in the Studies

Neurodevelopmental and Intellectual Disabilities	Number of Studies
Mixed (e.g., ASD,ADHD, CP, Severe learning difficulties, Spina bifida Complex, additional needs with sensory issues, Developmental delay, Down syndrome, Dyslexia, Partial trisomy)	16
Autism spectrum disorder	14
Intellectual disability	3
ADHD	1
Learning disability	1
Down syndrome	1

3.2.3.2 Literature Review Results

This is the final step of the Arksey and O'Malley framework where the information obtained is summarized and reported. The relevant information extracted from the different studies was mapped into the following categories: (i) characteristics of peer support networks and their development process (ii) characteristics and needs of families attending peer support networks; (iii) impact of peer support networks on families of children with NDID, and (iv) factors affecting the participation of families in peer support networks

3.2.3.2.1 Characteristics of Peer Support Networks and their Development Process

Our study found that the peer support networks identified were either set-up by organizations (N=22) or peer support networks designed by researchers (N=14). No study described the spontaneous formation of networks formulated under the parents' leadership. The researcher-designed networks were implemented on the basis of community needs. For example, in the study by Kingsnorth *et al*., a parents' needs assessment was conducted, which guided the design for the peer support intervention for parents whose children had transitioned or were in the process of transitioning from youth to adults (8). The peer support networks under study either included parents only (N=30) or networks that also provided child-care support while the parents attended the peer support network (N=6). These peer networks involving child-care givers e.g. (97) engaged

the children in numerous activities such as arts and crafts. Their ability to engage children in different activities was the main focus of these networks as they allowed parents to focus on the group interactions.

The network size varied from a minimum of two individuals to a maximum of 150 individuals (84,98). Interaction between parents at peer support networks involved either one on one interaction (n=5), in which the trained parent volunteers, who were also parents of children with NDID, offered one-to-one support to their peers or support to groups of individuals (n=31). These groups were led either by a parent peer leader or a professional facilitator whose role was limited to ensuring the efficient functioning of the group. Peer support networks were either conducted with face to face encounters (N=31) or interacting virtually (N=5) using email (N=1) (99) or online encounters (N=4) (73,100). The duration and number of sessions parents met varied across studies. Some interventions only lasted 6-weeks with weekly sessions of two-three hours each week (101);while others were conducted once a month with each session of one- two hours per month (8,97) or even three times a week during the school year from September to April (102). The group's dynamics or the peer support development process were characterized by echoing, resonance, and mirroring patterns that not only favored the integration and cohesion of the group and promoted mutual identification but also de-individualized and normalized the experiences of the parents by invoking commonality between their situations to demonstrate that the parents had done nothing wrong (103).

3.2.3.2.2 Characteristics and Needs of Parents Attending Peer Support Networks

The characteristics of parents attending peer support networks was the primary focus of two articles. On the basis of a survey administered to parents of children with ASD (n =1005), Mandell and Salzer (57) identified two-thirds of their sample to have participated in peer support networks in their lifetime. Parents involved in peer support networks had higher household incomes, educational attainments and were more likely to be in two-parent families.

Also, Mandell and Salzer (57) found participation was influenced by ethnicity, e.g., in studies in the US they are less likely to be African-American compared to Euro-American. They also found that network participants were more likely to have older children and children with self-injurious behaviour, sleep problems, and severe language deficits and were more likely to attend the peer support network if referred by a physician. In another study on parent characteristics,

Clifford *et al*. (58) discovered that parents of children with ASD (n =149) attending a peer support network used more adaptive coping strategies such as seeking emotional and instrumental support than parents who never attended them.

Furthermore, parents participating in peer support networks reported stronger belief in their benefits, greater support from important others to participate in peer support networks, and fewer difficulties with participation than parents not presently participating. The authors identified two distinct groups of parents not presently participating in support groups: (i) parents who despite believing them to be beneficial, never tried them, because of difficulties associated with attendance such as the location, meeting time, and lack of child care, and (ii) parents who attended them in the past, but found them not to be beneficial. Additionally, these latter participants reported less support from important others in choosing to participate.

We found only one paper that focused on the needs of parental participation in peer support networks. Papageorgiou *et al* (104) administered an open-ended questionnaire to families of children with ASD (N=299); they identified four main reasons parents participated in support groups: (a) to be informed about the disorder (64.5%), (b) to receive practical help to develop their child's autonomy (19.5%), and (c) to meet and talk with other parents (8%), or (d) to benefit from counselling (3%). These needs reported by parents were influenced by their level of education. Parents with secondary school education wanted more practical support, as opposed to university educated parents who wanted more psychological support). Occupation was not correlated with the needs of the parents.

3.2.3.2.3   The Impact of Peer Support Groups on Families of Children with NDID

From the articles obtained in our search, we identified 25 articles with 4 quantitative studies, 17 qualitative studies and 4 mixed-method studies that measured and explored the impact of peer support networks. Quantitative studies reported various designs such as randomized controlled trials, quasi-experimental studies (pre- and post-test with follow-up), cross-sectional studies, and prospective cohort studies to understand the impact of peer support networks. The qualitative studies (including the qualitative part of the mixed-methods studies) used various techniques such as interviews, focus groups, and ethnographic observation. The interviews allowed the authors to capture the diverse experiences of individuals in these networks, while focus groups captured the dynamic interaction between group members and facilitators.

Numerous methodologies were adopted for the analysis of data; the constant comparative or grounded theory approach, ethnographic discursive approach and observation, interpretive descriptive thematic and content analysis, and case study and the framework method of analysis. (For study details, please refer to Table A1) The impact of peer support networks on the families of children with NDID, are categorized into 7 themes. The process followed was similar to a thematic analysis. Two researchers read each article in detail and listed any attributes related to the impact of peer support networks. Then, each author compared the attributes they listed for each paper. Any disagreements were resolved by discussion with a third reviewer where necessary. Once the list of attributes were finalized, in subsequent meetings, through an iterative process, themes were proposed and discussed by the researchers until consensus regarding the theme structure was reached. The following themes were finalized and are discussed below: (i) creating a shared experience (ii) promoting optimism and empowerment (iii) learning (iv) developing social opportunities (v) enhancing a sense of belonging (vi) developing emotional and psychological well-being (vii) developing advocacy skills and knowledge.

(i) Creating a shared experience: Creating a shared experience was the most common theme observed where both the individuals providing and receiving support understand each other as a result of having children with the same condition. This provided parents with the feeling of equality in their relationships with other parents (105) and positively reinforced them about their child (106), allowing them to speak honestly, to share and understand one another in a non-judgmental way (87). Parents found this as key to the successful functioning of a peer support network (84,105). Moreover, sharing with others provided parents with hope (107), the ability to make meaning of their child's disability and validate their concerns (8,77,87,91,92).

In addition, cultural similarity or belonging to the same ethnic groups, e.g., Chinese and Latina groups (97,108) allowed parents to communicate comfortably in their own language, creating a comfortable bond among parents and making it easier for them to understand one another and overcome cultural problems such as stigmatization or shame in their own culture (109).

(ii) Promoting optimism and empowerment: Peer support networks positively reinforced parents as demonstrated through participants' interviews (84,105). Through networks, parents developed

feelings of normalcy, received tips on how to manage day-to-day challenges, found security in having an available support, and benefited from helping others. Interviews with network participants also reported that participant parents felt empowered to handle problems (103,105). Furthermore, parents reported that network participation allowed them to re-evaluate their parenting skills and their expectations of their children (110). The authors suggested that this could result from their increased sense of competence and self-efficacy after belonging to a peer support network (110). Furthermore, in a study by Kingsnorth *et al*. participation in a transition peer support network helped parents to envision a future for their child (8,99). The repeated exposure to new ideas played a role in changing parents attitudes and generating hope for the future (110). However, in the multi-site mixed method RCT study by Singer *et al* (111), the changes of scores on the empowerment scale were not statistically significant, which is contrary to the qualitative data collected by the researchers. The authors indicated that the lack of robustness of the scale and therefore, the requirement of further psychometric evaluation of the scale.

(iii) Learning: Discussions among parents within networks focused on knowledge about funding, caregiving, training opportunities and skills in navigating relevant social and healthcare systems (8,84). Through interviews with parents of children with different NDID such as cerebral palsy and developmental delay, Ainbinder *et al.,* reported that parental interactions initiated 'new' learning among parents (105). Furthermore parents viewed this as an opportunity to learn from each other's mistakes resulting in the growth of parental adaptive coping skills (109). This experiential knowledge gained through interactions with other parents promoted awareness, hope, and an active plan for their child's future, especially during critical periods such as transitioning from adolescence to adulthood (8,97,101,112).

(iv) Developing social opportunities: The peer support networks allowed parents to interact and connect with one another (101,113). These meaningful interactions were responsible for reducing social isolation, promoting social reinforcement and cognitive adaptation to emerging situations (103,110,114). Lo *et al.* in their study found that participants also reported that their gatherings not only strengthened their friendships with each other, but also provided their children with opportunities to develop friendships outside of school (103,110,114).

(v) Enhancing a sense of belonging: The relaxed non-judgmental interaction among parents was instrumental in creating a sense of belonging to their community (98). Consequently, parents cultivated friendly 'family-like' connections with each other (97,98,109). Moreover parents in the studies described parent support meetings as an accepting and encouraging place where they felt welcome (87). For example, if a child had a behavior issue or meltdown at one of the Family Fun Day events, the parents felt that everyone understood because they had similar experiences with their own children (101).

(vi) Developing emotional support and psychological well-being: The studies reported that seeking other parents of children with NDID for emotional support is often one of the main reasons parents participated in the networks (7,97,99,115). These studies employed a number of different outcome measures. These included measures for psychological well-being and mental health [e.g. (114)]; quality of life [e.g., (106)]; depression and marital satisfaction [e.g. (114,116)], coping [e.g., (117)], and stress, mood, anxiety, optimism [e.g.,(73)]. Shapiro *et al.* (117) in their study on mothers of children with NDID found that mothers who participated in a support group were less depressed than the mothers who did not ($p < .01$); perceived themselves as less burdened by their child than did nonparticipants ($p = .05$); and also tended to engage in more problem- solving coping strategies with their child than did nonparticipants ($p = .04$). However, there were no significant differences between participants and non-participants and other stress or coping scales.

Similarly, the quantitative results obtained for other outcomes such as psychological well-being were not statistically significant in most of the cases. For example, the study by Shu *et al.* (114) evaluating the effect of groups on psychological well-being (n= 27), found that despite the differences in the means of the psychological well-being scores between the intervention and control groups at the end of the program, the results were not statistically significant.

In the multi-site mixed method RCT study by Singer *et al.* (111), a statistical significant difference was observed between the intervention and control group on family strength and closeness. Minimum coping scores suggested that parents attending the peer network supported their family strength and coping. In fact parents have also mentioned that groups became an

important reference point in their lives by providing reassurance by merely knowing of the groups' existence (118).

(vii) Developing advocacy skills: Researchers in several studies observed that parents became experts in providing solutions for their child with NDID, especially regarding community integration (97,99,112). However, parents also recognized the difficulty of influencing community changes without an organization behind them. Thus, being part of the group encouraged participants to advocate for the needs of their children and discouraged ineffective practices (87,119,120).

3.2.3.2.4   Factors Affecting the Participation of Families in Peer Support Networks

Although 7 papers discussed factors affecting participation in peer support networks, this was the primary research theme of only three articles (121). Participation of families in peer support networks was affected by the nature of the facilitators, parents and support organizations. A committed and motivated facilitator was critical for the optimal functioning of a group. In the study by Shilling *et al.* (121), interviews with parents participating in one peer support network identified that the facilitator's training (i.e. a peer parent) was essential to ensure they had updated knowledge in the area, a protocol for maintaining confidentiality and good listening skills.

Characteristics of the parents also influenced the group's functioning. As individuals differ in the amount and way they cope and share, the timing of support was an important factor. In their study, Shilling *et al*. (121) identified that peer support networks were beneficial for parents who were open and prepared to share with the other parent, while maintaining a degree of professionalism. Parental values or beliefs affected their suitability in the match of parents to groups [e.g.(99,105,111)]. For instance, there were divergent views on the matching of parents according to the cause of the child's disability, where some parents preferred to interact with families of children with the same disability [e.g., (105)], while in another study [e.g., (122)] the families felt the diversity allowed them to learn more and implement similarities. Hammarberg *et al*. (122) observed that the child's disability severity did not affect parents in the study, instead they appreciated the diversity and being understood by peers.

The organization of child care is also important to facilitate family networking, especially when caregiving for the child is offered during the networking time (97,102,118,123). Hammarberg *et al*. (122) showed that the presence of playful helpers who provided childcare, while the parents attended the support groups, allowed parents to focus on their networking activities Barriers to network participation were also identified. These included the unavailability of child care, transport issues, various competing families responsibilities, employment commitments and fatigue that prevented parents from participating in every session (102). Some parents expressed additional challenges to attending peer support networks including the overload of information and the emotional nature of the discussions which were overwhelming at times (8). Online networks, although convenient and flexible in terms of execution and attendance, raised concerns among some parents about confidentiality and the exchange of unreliable information (113). Another major point of concern identified by parents participating in research-based group support studies was that the support did not expand beyond the end of study (8,84,97).

3.3   Discussion

Research evidence suggests these families of children with NDID experience more negative psychological outcomes than families of children with other disabilities or those having a child with normal development (124). Furthermore, high levels of parenting stress are often associated with poor outcomes in behavioral interventions for their children (125). Thus, it has been well recognized that supporting the family is essential not only for the caregiver, but for the child's well-being as well (126,127).

Numerous interventions have been proposed to support families of children with NDID. Support strengthens parents, provides them with emotional and information support and helps families to socially integrate within the community, thereby reducing feelings of social isolation and providing a sense of belonging. In this review we focused on peer support networks formed by parents of children with NDID. We excluded professional led networks that provides didactic instruction or training such as psychoeducational or counselling or therapy groups, as the group's dynamic is different compared to peer support networks (66). To our knowledge, this is the first review of the literature that focuses specifically on parents of children with NDID. Our review

led to the inclusion of 36 articles that represented research in 6 countries suggesting that peer support groups or networks are used worldwide by families of children with NDID.

Regarding characteristics of peer groups, Our results show that most network meetings were designed for face-to-face settings (31/36) compared to online (5/36). However online group meetings have been studied more recently and are becoming more popular, especially with the growth of secure online platforms. These online networks have the ability to overcome some disadvantages of traditional face to face networks such as convenient times or distance, thereby allowing more people to participate from home. However, as this medium becomes popular due to its convenience, more studies are needed to understand the impact in further detail.

In addition to the medium of the networks, we also observed the duration of the network experience varied across studies, from once per week for 6 weeks to thrice per week for nine months. It is interesting that, irrespective of duration, the families found the peer support networks helpful, but some parents worried about the support termination in context of a study. More studies are needed to understand what parents receive from peer support networks over different times and the parents' change in needs over time. This may help to develop networks that can support different parental needs over different time periods. Similarly, the density of exposure requires more in-depth study. If we assume that parents interact with their peers to the extent that they perceive it useful, it would be interesting to understand the specific needs that lead parents to meet three times a week vs only once a month. Perceived need is certainly what leads most parents to participate in studies; for instance Ireys *et al*. (86) illustrated that compared to the mothers that were randomized, the mothers who self-selected themselves to not be randomized to access the group support, documented as having fewer psychological symptoms and a higher perception of their available social support.

Regarding peer support networks' organization, we found that those networks that offer child care were the most beneficial for the parents to overcome attendance barriers for parents. Although only six studies were designed in this context, (87,97,101,102,118,122,123) they all had a positive impact on the family outcomes. Taking care of the child may be a favorable way to facilitate peer support networks and may improve parental attendance at the activity sites. For example, in one case it was compulsory for the parents to bring their child to the summer camp for activities [e.g. (101)] or at the group meeting location [e.g. (122)]. Parents perceive child-care as a helpful idea that could benefit the child as well. Additionally, these groups foster the

development of friendship among children within the playgroups. Research studies in this direction, where peer support networks develop organically when the child is supported for various activities are warranted.

Regarding parents' characteristics, we found that parents involved in peer support networks had higher household incomes and educational attainments, were more likely to be in two-parent families, and more likely to be Euro-American. In fact, the latter finding is consistent with the literature on support group use in other populations such as parents of children with type 1 diabetes [e.g.,(128)] where the majority participants were Euro-American. This may be related to the cultural homogeneity that is required for good communication of personal worries (57). This is confirmed by studies on ethnic groups such as Chinese parent support groups that show parents' preference for 'ethnic groups' for better communication. Mandell and Salzer (57) showed that participants in most studies were more likely to have elder children with higher severity such as self-injurious behaviour, sleep problems, and severe language deficits; which may represent the special needs of parents with severe conditions or at critical time (puberty or transition to adulthood). This illustrates that parents may be reaching out to meet the needs of their family, and moreover, research illustrates that higher the needs satisfaction levels are linked to lower stress and better parent child outcomes (129).

Although, the studies in our search included both parents of children and youth, further studies are needed to examine the benefits of peer support for families with children in different age groups and functional levels. This will help to understand the needs of parents having children in different age groups, which are critical periods of development, adaptation and adjustment for the child and the parents. Furthermore, comparative analyses between peer support networks and formal instruction support like psycho-education for different developmental and age levels, may help to understand which groups may benefit most from the different types of support.

Regarding the network impact, while analyzing the information, we found that shared experience among families was key to network formation, providing them with an avenue for learning, social integration, optimism and empowerment. The studies carried out were either quantitative, qualitative or mixed-methods in design. Interviews suggested that peer support networks were effective when participants perceived sameness among each other, fostering a shared identity. Consequently, this provided positive reinforcement in families such as reduced

isolation, emotional and informational support, feeling of belonging to a new community, hence reduced stress and improved skills to better adapt to the situation groups [e.g. (84,87,105)]. These themes are consistent with the literature on self-help (34) and social comparison theory. Thoit proposed that self-help programs work via the perceived sameness of experience that members share. The social support offered by self-help groups serves as an extension of individual coping efforts. According to Thoit's theory, individuals' efforts to cope with challenging circumstances are enhanced and promoted through the modeling and practical advice offered by other group members (99,111).

Although, encouraging, it is critical to keep in mind these study results report the parents' experience of those who attended the groups from the beginning to the end and therefore, were more likely satisfied than those who left earlier. This 'prevalence bias' is a general concern of all these studies whereby those involved actively in a support service are likely to have an optimistic view for it; this places restrictions on the inferences that can be drawn from the review. Thus, in order to overcome this, future studies, should include a prospective follow up of each individual with careful recording of the reasons for leaving the peer support network.

Quantitative studies were mainly exploratory with small sample size. These studies showed similar benefits as qualitative studies regarding psychological well-being, coping and empowerment; however, because of small sample size, most differences were not statistically significant. Although encouraging, these results deserve cautious interpretation because of possible biases such as self-selection bias or the Hawthorne effect. Causal inference is another issue as association between variables, even if statistically significant, does not establish causation. For instance, people who have good psychological and mental health may be those that are attending the support group until the end. Therefore, in order to better understand the efficacy of the peer support networks, we need more robust study designs, such as randomized pragmatic trials with larger sample sizes and careful follow-up of each participant. The 4 mixed method studies provided a broader and deeper understanding of the outcomes and enhanced the results' validity (e.g., (106)). Mixed-method designed studies are certainly worth considering in future studies; even the design of randomized trials will better evaluate the effectiveness of support groups for the families (130).

Another limitation of the published studies is the possible contamination by co-interventions, e.g., other family supports, organizational support obtained by parents on their

own. The impact of these co-interventions is difficult to assess and represent a serious threat to the results' validity as we do not know precisely which factor leads parents to perceive a benefit. Thus, future studies need to better assess the concomitant interventions to better understand the specific benefits of the peer support network.

3.4 Conclusions

In conclusion, providing optimal care for the child is a family affair and therefore, supporting the well-being of the family caregivers is essential as it directly impacts the well-being of the child. Peer support networks represent a way to strengthen families, building resilience and developing social interactions. Family members who share similar experience can support one another and provide critical information to each member. Future studies incorporating the recommendations mentioned above will help developing more adapted peer networks to support families in meeting their specific needs, and to better evaluate their effectiveness for the parents, the family and the child with NDID.

Chapter 4: Rationale and Objectives

In Chapter 3, I reviewed literature on the development of peer support networks, including characteristics and needs of families participating in these networks, the impact of these networks on families of children with NDID and features that facilitate or create barriers for the development of peer support networks. Results from this review highlighted that attendance at peer support networks positively reinforced families of children with NDID through social integration in the community.

4.1 Rationale

Peer support provides families with benefits including a sense of belonging to the community, improved psychological well-being and an opportunity for social learning. A critical gap observed in literature is that majority of the programs only provide parental support and do not extend support for the child while the parent engages in peer support. This is a key barrier to regular parental attendance at these peer support programs. This highlights the need for programs that can simultaneously support the child while parents are involved in the peer support network. In this context, we explored community-based adapted PA programs for children with NDID. As parents bring their children with NDID to PA programs for participation in physical activities, they are mostly present at the PA program site. Therefore, we hypothesized that while children participate in PA programs, this may be an opportunity for parents to obtain and provide peer support.

4.2 Study Goals

The goals of this study were to examine PA programs as a potential avenue for the spontaneous development of peer support networks among parents, and to assess their effect on families' quality of life, resilience, and self-efficacy at baseline and quarterly over a 12-month period. The study also examined the mechanisms behind network development and identified the factors that facilitate and create barriers for network development. Finally, this study examined the respective importance parents give to these PA program-related social networks compared to other peer support networks or support groups.

4.3   Research Questions

The research questions identified to lead this work include:

(1) What do parents do at the PA programs while their child is engaged in physical activities?

(2) If PA program-related social networks of parents develop,
-   How do they develop?
-   What are the processes involved?
-   What are the factors associated with PA program-related social network development?

(3) What are the effects of PA program-related social networks on family resilience, family quality of life, self-efficacy, stress, and coping? Are there any measurable changes over time (i.e. over 12 months)?

(4) How do families compare PA program-related social networks to other peer support networks?

4.4   Objectives:

The objectives identified for this work include:

Primary objective:

(1) To explore what parents do at the PA programs while their child is engaged in activities. If PA program-related networks develop, to understand the development process of PA program-related social networks and identify barriers and facilitators for the development of these networks

Secondary objectives:

(2) To determine the "support" effects of these peer networks by assessing (i) the impact of PA programs-related social networks on families, measured by changes over time in family quality of life, family resilience, empowerment, stress and coping (ii) how these changes in families impact the perception of self-efficacy for child care and (iii) any potential effect on child behavior

(3) To understand the importance of PA program -related social networks compared to other

peer support networks

Chapter 5: Research Design & Methods for the Community Study

In this chapter, I describe the study design and methods for a community study. This study explores the development of peer support networks between parents of children with NDID at adapted community-based PA program sites, while parents are waiting for their children to finish their activities.

5.1   Study Design

This mixed method prospective cohort study was designed as a descriptive study because to our knowledge no previous studies have explored in-depth, family attendance and the spontaneous development of peer support networks among parents attending community-based PA programs. The 12 months study was designed to examine the development of PA program-related social networks among families to understand and measure the impact of support networks on the families at 3 month intervals over 12 months.

A mixed research design was employed to 1) examine whether peer support networks develop among parents at the adapted PA programs, 2) describe the characteristics of these networks, 3) identify the underlying mechanisms for network formation, and 4) understand their impact on the families.

The quantitative aspect of the mixed-methods study included the administration of standardised scales at baseline and quarterly over a 12-month period. The qualitative design of the study complemented the information gathered from standard scales to understand the PA programs-related social network development process and its impact as perceived by parents. It also included an ethnographic approach where data were collected through interviews and ethnographic observations of the parents/family caregivers at the PA program site at baseline and quarterly intervals over 12 months.

5.2   Mixed-Methods Approach

5.2.1   Epistemology

Researchers' acknowledge the mixed-methods approach as a distinct research methodology (131). This section describes the epistemological implications of combining the two methodologies, namely, quantitative and qualitative methodologies I have employed in my

research. The paradigms connected with the research methodologies are described and the difficulties in combining quantitative and qualitative methods are recognised. Pragmatism is the paradigm presented for the methodological justification of mixed methods research, thereby unifying the ontological and epistemological barriers. The positivist and interpretivist paradigms discussed below are most strongly associated with quantitative and qualitative research respectively. Quantitative research is connected with a positivist paradigm (132,133). It acknowledges that the object of study is an objective and measurable reality. Epistemological assumptions arising from this approach acknowledge that knowledge can be obtained through the objective, reductionist, and deductive methodologies (134). These methodologies highlight that the observer is impersonal, passive and separate from research (135). Positivist methods are closed-ended techniques, for example, the questionnaires used in the study which produced numerical data.

On the other hand, qualitative research is associated with an interpretivist or constructivist paradigm (136). It acknowledges the multiple socially constructed realities of meaning, thus rejecting the positivist's single reality (137). Epistemological assumptions arising from this approach acknowledge that knowledge can be obtained subjectively and inductively. "The researcher is recognized as part of data generation and multiple interpretations of phenomena are accepted (136). Interpretivist or constructivist methods include interviews, focus groups, and ethnography.(136).

Some researchers report that the two methods, qualitative and quantitative methods are distinct from each other due to their opposing epistemological and ontological standpoints, and therefore, cannot and should not be mixed (130,135,138). Therefore, in order to move forward with the approach of mixed-methods, a philosophical union of the two methods was required. Pragmatism (132) is the solution to this issue (139).

A Pragmatic approach that employs the compatibility thesis, brings these two methodologies together by seeking the similarities between quantitative and qualitative research which are combined for effective research. Pragmatists emphasise similarities between positivist and interpretivist paradigms and consequently value both qualitative and quantitative research (139). This epistemological justification permits the application of the most appropriate method for each research question. In this thesis, the pragmatic ontological perspective, is warranted for the different research questions regarding peer support network development, the mechanisms

behind the network development, and the impact of the PA program network on parents. Neither quantitative nor qualitative methods alone could adequately investigate these. Thus, pragmaticism allows the combination of these methods within a single study with the purpose of producing results which are more than the sum of their parts (140).

5.2.2   Purpose of Mixed-Methods

In this study, quantitative and qualitative methodologies were designed to complement each other. Complementarity was achieved by using different methods of data collection to address different dimensions of the study. As Greene and colleagues state, "complementarity can be achieved using methods which examine *different facets of a single phenomenon"* (131) (p. 266). The quantitative standardized questionnaires and network questions, complemented the qualitative semi-structured interviews and ethnographic observation).

In my study, the single phenomenon examined was peer support networks for families of children at PA programs. The different "facets" of this phenomenon that I examined included: what parents did at the networks, the mechanisms of network formation (as measured via interviews and observation), parents' perceptions of support, family outcomes and the impact of the networks (as measured via standardized scales and described in interviews), and barriers to PA program networks (described in interviews and observation). Complementarity is accomplished by examination of these different facets using both quantitative and qualitative methods.

5.2.3   Our specific mixed-methods approach: Convergent Parallel Design

I applied a convergent parallel design. This involved concurrent collection of data, that is, the data was analyzed during the same phase of the research process. Consequently, both the methods are allocated equal weight. The results of each individual method was described independently, and then interpreted together (132).

I employed a convergent parallel design for several reasons. This design allows the researcher to provide equal weight to both the quantitative and qualitative data collected. The assignment of equal weight to both methods guaranteed that no method was given priority over the other. Furthermore a convergent parallel design allows the researcher to analyze and report the results from each method independently from the other method applied. The separate

analyses of data collected from each method helps the researcher to focus on capturing the strengths of both approaches, and then, bringing them together in the final stages of interpretation, thereby providing an in-depth examination of the research questions. Besides, this design further allows the researcher to detect similarities and dissimilarities in the quantitative and qualitative data collected, providing the researcher with a comprehensive understanding of the phenomenon under study (132).

5.3 Sampling and Recruitment

A three-stage sampling procedure was implemented that first recruited PA program sites, next, the coaches involved in these programs, and finally, once our relationships with the programs and coaches were established, we recruited parents of children with NDID who attended these PA programs.

5.3.1 Physical Activity Program Sites' Recruitment

Adapted PA programs were defined as programs that provide children with NDID the opportunity to engage in structured physical activity or sports programs. These included team building sports such as soccer and basketball and singular activity programs such as skating. Information on the different PA program sites was obtained from the parents' advisory committee for the ongoing project in the lab and by searching through the Jooay app (app containing information about activity programs for children with disabilities) and Google Search. The PA program sites across Vancouver, Burnaby, Richmond, Coquitlam and Surrey were emailed requesting to meet with the researchers to explain the study and verify that children with NDID met the inclusion criteria. The programs that did not involve physical activity (e.g., art activities) or children without NDID (e.g., children with physical disabilities) were not contacted.
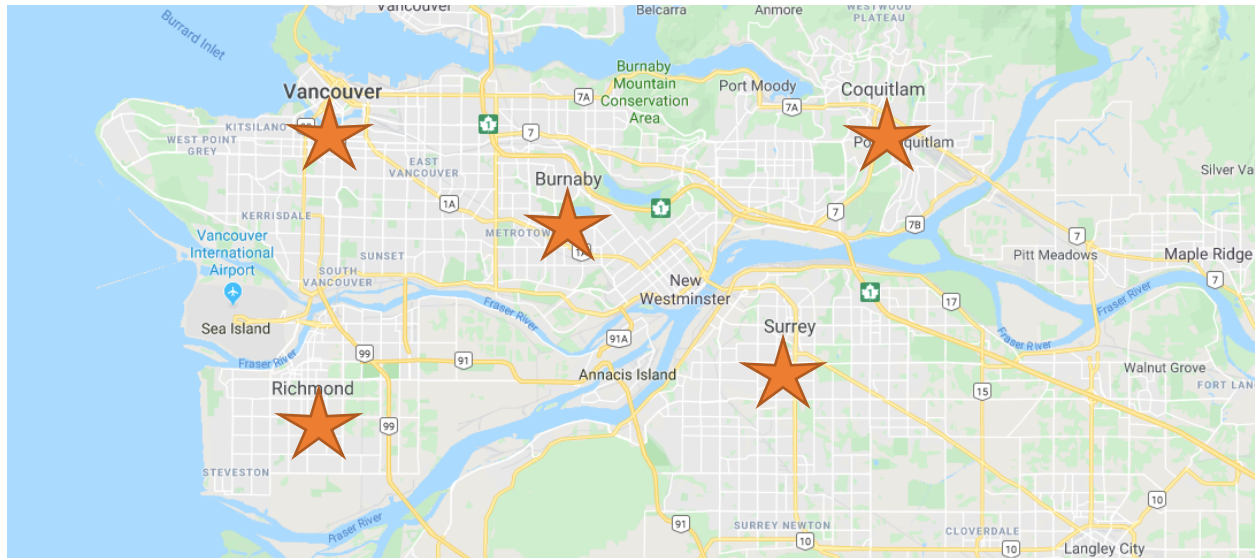
Figure 5.1 Representation of the Sites for Physical Activity Programs Recruitment

5.3.2   Participants' Recruitment

After each PA program site was recruited and coaches at each site agreed to introduce researchers to their program's participants, we invited families to join the study. In every participating PA program, each family whose child met the inclusion criteria was invited to participate, except for participants already involved in a concurrent study in our lab. These families were excluded from the invitation to avoid over-burdening the participants.

The inclusion criteria included families having a child with NDID aged 6 to 19 years, who was attending the participating PA programs. Two groups of participants were included: families who had already been in the program for >3 months at the time of first contact, and those that joined the program in the last 3 months or were going to join the program during the follow-up. Participating families were required to speak English, live in the lower mainland and be a family member who regularly accompanied the child to the PA program site, even if the parent left the site for personal reasons.

5.4   Sample Size

In this study the sample size was not formally defined because of the descriptive nature of the study and the lack of evidence regarding the possible effects of attending PA program-related social networks on the families. There were no previous studies using quantitative data assessing the relationships between peer support at adapted PA programs and quality of life, family resilience, and empowerment.

We decided to recruit 50 participants based on the following consideration: this sample size provides >80% power to find significant (alpha≤0.05) a medium correlation (≥0.4) between perceived social support and family quality of life, if it really exists (power ≥80%).

5.5 Recruitment and Data Collection Procedure

Meetings were organized with the executive team and coaches of PA program sites. In these meetings, the researchers described the study concept and logistics, and each program was invited to participate in the research.

Once the program site agreed to participate, the coaches, who were in direct contact with the families, informed the families about the project. Next, the coaches introduced the researchers to the families over email and in person at the PA program site. At the site, the researchers discussed the background and goals of the study with prospective participant families. They also provided families with an information letter outlining the study purpose and participation requirements. Information related to confidentiality and data storage was also reviewed and potential participants were reminded that they could withdraw from the study at any time, without penalty.

Once the parents agreed to participate in the study, the informed consent document was provided so participants could review and sign it. Next, they completed the demographic questionnaire which took approximately 10 minutes and participants were asked to also complete a baseline questionnaire with standardized scales on paper or online. For participants opting for the paper format, the questionnaire booklet was provided to them at the program. For participants opting for the online questionnaire containing the standardized scales, an email invitation containing a hyperlink for access to the online questionnaire was sent via the REDCap system. Participants were instructed to fill out the forms independently without consulting other family members. Also, at the end of the questionnaire, a text box was available for participants' comments about the study and related procedures. The total time commitment for the online portion of the study was approximately 90-120 minutes. Three waves of emails were sent to remind non-responders, as recommended for online studies (141). Surveys were sent to participants within one day of completing the informed consent and demographic questionnaire. Simultaneously, a phone or in-person interview was scheduled for participants at a mutually agreed upon time. At the interviews, participants were informed that the purpose was to provide

families an opportunity to share their experiences and perceptions regarding the PA programs, their attendance at these programs, information about other families they meet at the programs, how often do they meet the other families at the PA program, the nature of the interaction between the families and whether they meet outside the PA program. They were also asked about the place of these programs in their family daily functioning. The same procedure was implemented quarterly over the 12-month period.

At the start of each interview, the researcher reviewed study aims and answered any questions regarding the goals and informed consent. These initial conversations provided an opportunity to establish rapport, as the researcher and participants often talked briefly about their daily activities and participation of their children in the activities (132). Furthermore, the interviewers explained that although questions had been prepared, participants were encouraged to go outside of those specific topics, and share whatever they felt was relevant. The format was semi-structured and open. As the primary researcher, I employed active listening, and often recapitulated central points from participants' discussions to clarify that statements were interpreted correctly. Follow-up questions were subsequently posed. I also took reflective fieldnotes, as this helped to keep track of follow-up points. Each interview was audio recorded and transcribed verbatim (for details on the interview guide refer to section 5.8.1).

5.6 Outcomes

The following points were the outcomes described for the study:

(1) Description of the families' experience to become involved in PA program-related social networks (as reported by family caregivers)

(2) Identification of the perceived impact of being involved in PA program-related social networks on families (as reported by caregivers)

(3) Description of the relation between the change overtime in perceived social support score from PA program-related social networks and family quality of life, family resilience, self-efficacy, coping and stress scores (all standard scales)

(4) Description of the perceived barriers and facilitators for development of PA program-related social networks (as reported by family caregivers)

(5)   Description of the perception of the relative importance of PA program-related social networks for families, compared to other types of supporting networks (as reported by family caregivers)

Below, I describe the quantitative (section 5.7) and the qualitative (section 5.8) approaches to assess the different outcomes.

5.7   Mixed Methods: Quantitative Assessment

5.7.1 Measurement Tools

Here I describe the measurement tools that were finalized for use in the study. The Family Demographics questionnaire was used to collect information on participant demographics. The Family Quality of Life, Family Resilience, Perceived Self-Efficacy and Perceived Social Support Scales were used to measure the family quality of life, resilience, self-efficacy and perception of social support variables.

5.7.1.1   Family Demographics Questionnaire

The Family Demographics Questionnaire was adapted from Gardiner *et al.* (142). The questionnaire included basic questions about the respondent's family and child with NDID (see Appendix B). The measure also included questions about family income and disability severity as reported by parents. The question regarding disability severity included four levels: mild, moderate, severe, and very severe. This questionnaire took approximately 10 minutes to complete.

5.7.1.2   Beach Centre Family Quality of Life scale (FQOL)

The Beach Centre FQOL Scale (143) measures FQOL satisfaction across five domains. These domains are Family Interaction, Parenting, Emotional Well-Being, Physical/Material Well-Being, and Disability-Related Support. This scale contained 25 questions with responses based on a 5-point Likert scale ranging from 'Very Dissatisfied' (1) to 'Very Satisfied' (5). Domain scores were obtained by calculating the mean score of the domain-relevant items (ranging from 1- 5). An overall score was obtained by calculating the average of all item ratings (computed overall FQOL). This scale is internally consistent, and has illustrated concurrent validity with

other family scales such as the Family APGAR and Family Resources Scale (143). Cronbach's alpha in the current study was 0.95

5.7.1.3   Family Resilience Assessment Scale (FRAS)

The Family Resilience Assessment Scale (144) was developed based on Walsh's family resilience model. Family resilience is measured across six subscales: Family Communication and Problem Solving, Utilizing Social and Economic Resources, Maintaining a Positive Outlook, Family Connectedness, Family Spirituality, and Ability to Make Meaning of Adversity. The scale includes 54-items with responses based on a 4-point Likert-type scale ranging from 'strongly disagree' (1) to 'strongly agree' (4). Responses were summed; higher scores indicated greater resilience. The instrument demonstrated good internal consistency across the total and subscales scores. Alpha values in this study were 0.95. Subscales on the FRAS have illustrated convergent validity with other family measures, including the Family Assessment Device and the Personal Meaning Index (144)

5.7.1.4   Family Empowerment Scale (Perceived Self-Efficacy; FES)

Perceived self-efficacy was measured using the Family subscale of the Family Empowerment Scale (145). It is a 12-item subscale, used to assess a parent's feeling of personal control and self-efficacy in relation to raising a child with a disability. Each item is measured on a 5-point scale (1 = Very Untrue; 5 = Very True). A mean score is reported, with higher scores indicating a greater sense of empowerment. Strong internal reliability and test-retest reliability (alpha coefficient = .88 and r = .83, respectively) have been reported (146). Cronbach's alpha in the current study was .94. This sub-scale has been used in previous studies to measure perceived self-efficacy as well [e.g., (147)].

5.7.1.5   Multidimensional Scale of Perceived Social Support (PSS)

The perception of social support was assessed using the Multidimensional Scale of Perceived Social Support (148). This measure had 12-items that included measuring perceived support from family, friends and significant other (spouses). In this study, perceived support from friends was measured separately twice, first as a variable to measure perceived social support from friends at physical activity programs (PSS PA program friends) and second, as a variable to

measure perceived social support from friends at places other than physical activity programs (non-physical activity programs) (PSS NPA Program friends). Higher scores on the scale and sub-scales indicated greater perceived social support. The reliability of the scale in the current study is 0.94.

5.7.2 Quantitative Analysis

Prior to the analysis, the data were first examined for missing values in excel. Missing data was unexpected as responses for items on the questionnaire were set as 'required', and thus the survey could not be submitted until entirely complete. For parents, who completed the paper version of the questionnaires, the researcher ensured that all the questions were responded to, before the researcher manually entered the data into the online REDCap tool. Assumptions were tested for a multiple regression analysis, which included absence of outliers, verification of normality, linearity, homoscedasticity of errors, absence of multicollinearity, independence of observations (149).

Bivariate analyses were first conducted to determine the relationship among independent variables and outcome variables. Pearson product moment and point-biserial correlations were used to examine the relationships among different continuous and dichotomous demographic variables (child age, family income, years in the PA program). A multivariate hierarchical model with repeated measures was planned to test the relative contributions of each set of predictors with perceived social support from PA program friends. Statistical analyses were performed with SPSS Statistics, Version 20.

5.8 Mixed Methods: Qualitative Assessment

Along with quantitative methods, a qualitative approach is useful in further exploration of participant perceptions and the meaning behind their actions and decisions, enabling the researcher to go beyond statistical interference in interpreting the relationship between variables (150). In this study, interviews were conducted with the parent who was present at the PA program site and/or responsible for bringing their child with NDID to the PA program, and who also responded to the questionnaires described above in the quantitative section.

5.8.1 Interview Guide

The interview protocol was informed by the research questions, that is, an a priori theoretical orientation was adopted (151). The interview guide including sample questions were developed by the researcher based on a review of relevant literature and discussion with field experts and families. However, the semi-structured nature of the interview questions encouraged further exploration as this allowed interviewees to share their perceptions regarding attendance at PA programs and the place of these programs in their lives. The interview guide explored areas including (i) personal support from friends and family members (ii) detailed description about the PA program attended by the child and families (topics included program characteristics, program participation outcomes and social participation for families (iii) information about social networks including names of people families interacted with both within and outside of the program, (iv) in-depth descriptions about the interaction, and (v) comparisons made by the interviewee between PA program social network support and other peer support networks. Interviews were conducted quarterly interview over 12 months) and lasted approximately 45-60 minutes. For further details, see Appendix C.

5.8.2 Qualitative Analysis

Generally, I employed an ethnographic approach that make use of two forms of qualitative methods - participant observation and interviews.

5.8.2.1 Participant Observation

An ethnographic approach aims to describe and explain in detail the lived experiences of a particular group of people. According to DeWalt and DeWalt (152)(p. 92) "the goal for research using participant observation as a method is to develop a holistic understanding of the phenomena under study as observations may help the researcher have a better understanding of the context and phenomenon under study." This includes taking part with people while they are participating in the activities understudy. This enables the researcher to understand the implicit, often kinaesthetic aspects of the roles of participants. The researcher becomes both a participant in, and an observer of the activity.

In this study, using participant observation, the aim involved understanding what families of children do at the PA programs while their children are participating in the activities.

I specifically focussed on whether and in what way parents interact with each other. This involved in actively participating along with the parents in the PA program activities. In the various programs I skated, played basketball and soccer, and assisted with gymnastics along with the parent-volunteers. Like many parents, I also helped out as a volunteer at the organization activities. I also spent time doing what many parents did- talking with parents on the sidelines while the children played.

As a researcher, this active engagement enabled me to immerse myself in the field, to observe and understand the program operations, the families that participate in the program, and the interactions among the different families while their children engaged in activities. This information added depth and texture to the interviews I conducted. I reflected on the process of observation and journaled my experiences after each observation session

5.8.2.2   Semi-structured Interviews

I also conducted semi-structured interviews with parents of children with neurodevelopmental and intellectual disabilities. The interviews are described under section 5.5.

The interviews were transcribed and then analyzed using NVivo16 software for Mac. The qualitative methodology used to analyze the interviews was discourse analysis. Discourse analysis is the study of speech in context, in contrast to phrases examined in isolation. Specifically, discourse analysis examines the complex relationships between "language, action, knowledge, and situation. (153)." Examining the organization of information in an utterance helped to identify the themes. In particular I examined the way the individual organized information across the whole interview, in conversational turns, structured their sentence while speaking, and used stress and intonation to indicate information that speakers emphasized. These patterns of information while speaking helped to identify participants themes in their responses to my interview questions. The recognition of the importance of contextualized language makes discourse analysis the most suitable methodology for this study.

In this thesis, the implementation of the discourse analysis methodology was based on an approach described by Gee (2011) (153). Within the interview data, two tools of inquiry were used. Tools of inquiry included the discourses (the combination of language and non-language elements to enact a particular identity), and intertextuality (how words relate to the words of others). As the discourse analysis revealed portions of utterances that were thematized or treated

as important information by the speakers. From this thematized information codes were created and applied to the interview transcripts inductively. By using an utterance-based approach to identifying themes, codes arose out of the data rather than depending on the researcher's intuition or preconceived theories and opinions.

Once initial inductive codes were created, these codes were refined to be "discrete and mutually exclusive (153)". The final codes obtained were organized into a codebook. The codebook included the codes definitions, inclusion/exclusion criteria and illustrative examples. Codes were then grouped into analytical themes and the relationships among themes were developed. This frequently made it necessary to return to the original transcripts to verify the analysis.

The utterance-based discourse analysis approach was used because the way that people whose first language is not English organize information when they speak is often different from native speakers and therefore what is grammatically importantly may not be thematically important. This study included individuals speaking 7 different languages and therefore, the discourse analysis was a necessary approach to ensure the identification of speakers' themes was not simply based on the researcher's intuitive understanding of the interview answers.

5.9   Mixed-Methods Analyses

The successful integration of mixed methods data is possible if the analysis of individual datasets is high quality and the integration of the data is also high (132,154). This section discusses integration at three levels, that is, design, method, and interpretation (155). Integration at the design level was accomplished through the application of a convergent, parallel design (132). Integration at the method level was accomplished through "merging, in which the data was brought together for analysis and compared side by side, once the independent quantitative and qualitative analysis was performed (155). For example, participant observation notes for each interview participant contributed towards data collection during interviews and constituted within-participant integration (155). Finally, at the interpretation and reporting levels, matrices, joint display, and narratives using the contiguous approach were applied for analyses and presentation of results (132,155).This involved the presentation of findings where the qualitative and quantitative findings are reported in different sections.

5.10 Ensuring Trustworthiness of Data Collected and Interpreted

Trustworthiness in qualitative research mirrors the process of ensuring rigour in quantitative research. The standardized questionnaires were useful in accessing participants' information through their responses to five scales (completed using the online or paper-based questionnaire version). Face to face or over the phone semi-structured interviews were conducted to explore the parents' constructs of interest. This method where data collected through one source (e.g, standard scale) was verified through another source (e.g., interviews and observation) helped to reduce bias by providing a more rich and contextualized understanding of these constructs. Peer debriefing was also implemented. Here, the researcher and a peer familiar with qualitative methods met throughout the data analysis process to discuss the coding approach implemented, credibility, dependability, and emerging themes. The researcher also had meetings with her supervisor and committee members, during which they discussed the identified themes and reviewed representative quotes. Furthermore, portions of the results were presented at two conferences, attended by families, professionals, and researchers; these have been additional opportunities to elicit feedback and gain insight, as audience members speculated about possible reasons underlying the findings. Finally, transferability or the extent to which findings are generalizable to other contexts was addressed through a comprehensive description of the research context in the introduction about the inclusion and exclusion criteria, details of physical activity recruitment and details pertaining to research design. Furthermore, fieldnotes used during data collection were consulted and interviews were transcribed verbatim (156). Participants' demographic characteristics were also encorporated so readers were aware of key sample characteristics and thereby, determine comparability to other studies or personal settings. Finally, strategies for ensuring confirmability were addressed as well. This included keeping an audit trail, peer debriefing, and reflexive journaling. These methods helped in reducing the influence of the researcher's assumptions and biases on the interpretation of results. Furthermore, the interview was conducted in an open and non-judgmental conversational tone, in which participants were not aware of the researcher beliefs or biases, and they were encouraged to share their perceptions.

5.11 Study Modifications

Several study modifications were implemented in order to overcome the challenges in the recruitment process, and establishing contact with families for the follow-up. We present these changes in a special section of the Methods because they affected the study objectives, design and the types of analyses.

5.11.1 Modification in Participant Recruitment at Baseline

Recruitment within the first three months for this group proved difficult with only 10 individuals recruited. As a result, the participant recruitment criteria were modified to include family participants who had children with NDID within the age range of 4-24 years (instead of 6-19 years indicated previously) participating at these PA programs.

5.11.2 Modification in Quantitative Measurement Tools Used in the Study

The initial plan in the study involved measuring six quantitative measures (child behavior, stress, perceived social support, self-efficacy, FQOL and family resilience). The administration of these scales would take approximately 90-120 minutes. However, in discussion with families at the program site, they reported that the tasks were too long and inconvenient. Furthermore, an ongoing study in the lab received similar feedback from parents regarding the length of time taken to fill in the questionnaires. Taking into consideration these issues, and in order to lessen the burden on the families, the research team decided to reduce the number of questionnaires to 4, which took approximately 30-45 minutes to complete. The questionnaires deleted included questionnaires on stress, coping and child behavior. The questionnaires retained were those that assessed perceived social support, self-efficacy, family quality of life (FQOL), and family resilience.

5.11.3 Modification of the Quarterly Follow- Up

Due to a low percentage of participants in the first quarterly follow-up, this portion of the study was also changed.

The procedure for establishing contact with participants at baseline was implemented in the quarterly follow-up. All the participants were contacted first through email. Repeated emails were sent as follow up reminders. Also, the researchers contacted the program coaches for

reaching out to the parent participants; the coaches also sent email blasts as a follow-up to the email sent out by the researcher. In addition, the researcher attended the PA programs in order to re-establish contact with the families for the follow-up part of the study. Despite an intense follow-up procedure, from the 50 participants contacted, only 8 responded to the email and participated in the first quarterly follow-up. As the researcher visited the PA program regularly, 4 more participants (who did not respond to the email sent out but were located on site) completed the follow-up. However, for the remaining participants, the researcher did not find them at the PA program site. Also, they did not respond to the email reminder sent out by the researcher and the coach. Due to this low percentage of participants in the first quarterly follow-up (12/50), a meeting was scheduled with my doctoral committee members, brainstorming on ways to proceed forward.

The committee decided to not continue with the follow-up part of the study because the limited data would not provide precise and accurate understanding of the changes in the measurement parameters overtime. An additional reason was the introduction of a selection bias as a result of the limited follow-up participation, which would affect the study validity. Therefore, it was decided to continue and analyze the study as a cross-sectional study, instead of the previously described prospective cohort design.

5.11.4   Modification in Objectives and Hypothesis for the Study

As a consequence of the problems faced at the follow-up stage related to the participants' participation, the research questions and objectives were tailored to a cross-sectional study (see below). Thus, the study included the administration of 4 quantitative measures, followed by interviews and observations to determine the existence of a peer social network at each PA site and to understand the impact as perceived by families attending these programs.

5.11.5   Modified Set of Research Questions

The research questions were modified to adapt to the initial problems of participation and consequently, the need for a revised study design. The research question removed included the measurement of the changes in the PA program-related social networks over time, including the change of effects on families' quality of life, resilience and self-efficacy over time.

The new research questions were as follows:

(1) What do parents do at the PA programs while their child is engaged in physical activities?

(2) If PA program-related social networks of parents do develop,

- How do they develop?

- What are the processes involved?

- What are the factors associated with PA program-related network development?

(3) What are the effects of PA program-related social networks on family resilience, family quality of life and self-efficacy?

(4) How do families compare PA program-related social network to other peer support networks?

5.11.6 Modified Objectives

Similar to the research questions, the specific objectives were also modified to adapt in line with a revised study design. The correlations between changes in quantitative scales and changes in parents' perception regarding PA program-related networks and impact (i.e. the dynamic aspect of the changes) could not be studied. Therefore, primarily, the research objectives removed included the measurement of the changes in the PA program-related social networks, including their effect on families quality of life, resilience and self-efficacy, quarterly, over 12 months. The new research objectives were as follows

Primary objective:

(1) To explore what parents do at the PA programs while their child is engaged in activities.

(2) If PA program-related networks do develop, to understand the development process of PA program-related social networks and

(3) To understand what families obtain from PA program-related networks

(4) To identify barriers and facilitators for the development of these network

Secondary objectives:

(5) To assess the association of PA program-related social networks on families, measured by FQOL, family resilience, self-efficacy

(6) To understand the importance of PA program-related social networks compared to other peer support networks

5.11.7 Outcomes

Similarly, the outcomes for the study were changed to reflect the modifications in the study design. Specifically, the outcome on measurement of changes over time between the dependent and independent variables were removed.

The modified outcomes described for the study included:

(1) Description of activities families are involved in at PA programs while children engaged in activities

(2) Description of the families' experience to get involved in PA program-related social networks (as reported by family caregivers)

(3) Identification of the impact of being involved in PA program-related social networks on families (as reported by family caregivers)

(4) Correlation between perceived social support score from PA program-related social networks and family quality of life, family resilience, self-efficacy scores (all standard scales)

(5) Perceived barriers and facilitators for development of PA program-related social networks (as reported by family caregivers)

(6) Perception of the relative importance of PA program-related social networks for families, compared to other types of supporting networks (as reported by family caregivers)

5.11.8 Modification in Quantitative Analysis Method

As the study transitioned from the prospective cohort design to the cross-sectional design, there was only one time point of data collection and therefore we could not look into changes and correlations between different changes over time. A hierarchical multiple regression model was implemented in order to understand the relation between perceived social support at the physical activity program and family quality of life, family resilience, and perceived self-efficacy.

5.11.9 Modification in Qualitative Analysis Method

As the study transitioned from the prospective cohort design to the cross-sectional design, we could not look into quarterly changes over a 12-month time period. Therefore, interviews were only conducted at one time point (i.e. baseline).

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Chapter 6: Results from the Community-Based Study

This chapter provides a detailed presentation of the study results, beginning with information on the recruited PA programs and participant families, with a description of their demographic characteristics and compilation of scores on the three measurement scales regarding quality of life, resilience and self-efficacy. This is followed by the description of the study results according to each study objective presented in Chapter 5.

6.1 Results on Recruitment of PA program Sites and Participants

6.1.1 Recruitment of Programs

We contacted 28 sites that offered PA programs for children with NDID. Of the 28 programs contacted, 26 agreed to participate. Table 5.1 below provides details about the participating sites. Two programs declined participation in the study explaining that they did not want to overburden families who were already participating in other research studies. Of the remaining 26 programs, we recruited families from 22 programs. The logistics of 4 programs prevented us from recruiting families because either (i) the program was cancelled as there were not enough participants; or (ii) there were no available families with children within the specific age range at our time of recruitment. Table 6.1 contains details of the participating PA Program sites.

Table 6.1 Details about Participating Physical Activity Program Sites

PA programs contacted to participate in the study	Number of invitations handed out or emailed	Number of participants recruited	Number of participant Dropouts (signed consent)	Number of participants finally participated	Reason for no recruitment
PA program 1 Vancouver (10 programs*)	33	22	4	18	
PA program 2 Richmond (5 programs*)	32	22	2	20	
PA program 3 Coquitlam (4 programs*)	10	7	1	6	
PA program 4 Richmond	5	3	-	3	
PA program 5 Vancouver	2	2	1	1	
PA program 6 Surrey	3	2	-	2	

PA program 7 Richmond	2	0		0 (ultimately program cancelled)	The program cancelled as not enough participants for the program to continue
PA program 8 Vancouver	8 (contacted by program)	0	0	0	The program coaches relayed that no participant contacted the program coaches for participation in the study
PA program 9 Burnaby	8 (contacted by program)	0	0	0 (ultimately program cancelled)	The program cancelled as not enough participants for the program to continue
PA program 10 Burnaby	4 (contacted by program)	0	0	0	No participant in the specific age range criteria

* PA program 1-4 represent physical activity organizations that have different sports programs such as skating, basketball, gymnastics under them. The number of programs participants were recruited from that PA program organization are indicated in the brackets

6.1.2   Recruitment of Participants

Participants who had a child in the age range of 4-24 years were recruited as it includes both children and youth according to the World Health Organization's definition of child and youth (17). However, two participants had children within the age range of 24 when recruited, but were 25 years of age when the study was initiated. Therefore, we expanded the age range to 25 years. We emailed and handed out 107 invitations to families, and recruited 58 participants in the study. However, eight families dropped out from the study before completing the standard scales and undergoing the interview, citing personal reasons or other conditions not related to the study. Ultimately, 50 families participated in the study. The recruitment rate was 55%.

6.1.3   Participants Demographics

Fifty participants were finally included in the study. They included 39 mothers and 11 fathers. The participants ranged in age from 30 to 64 years (mean = 49.4, SD = 6.6; median = 49.5). 78%

families were married, 18% were divorced and 4% were common law (4%). Families represented a range of ethnicities and most (66%) families indicated English was their family's primary language. Considering employment of the participating families, 68% mothers and 76% fathers were employed. The median family income was $50,000-$79,999. Of the participating families, 80% had one child diagnosed and 20% had two children with NDID. The most common diagnosis for the child was ASD (62%), 14% of these children were diagnosed with a comorbidity. Other diagnoses included intellectual disability, cerebral palsy, attention deficit hyperactivity disorder, and Down Syndrome. Parents' reported severity of their child's disability ranged from mild (14%), moderate (74%), severe (10%) and very severe (2%). See Table 6.2 for family demographic characteristics.

Table 6.2 Participant Demographics

Demographic Information (Parents)	n (%)
Participants relationship to the child with NDID	
Mother	39 (78)
Father	11 (22)
Primary caregivers age (M= 49.43, SD=6.57; R=32-64)	
30-39	4 (8)
40-49	21 (42)
50-59	23 (46)
60-69	2 (4)
Marital status	
Married	39 (78)
Common-law	2 (4)
Separated or Divorced	9 (18)
Ethnicity	
Canadian	8 (16)
Asian	26 (52)
European	3 (6)
Mixed	11 (22)
Mexican	1 (2)
Latin	1 (2)
Language	
English	33 (66)
Chinese (Mandarin and Cantonese)	8 (16)
English and Chinese	4 (8)
Spanish	2 (4)

Other (Russian, Punjabi and Tagalog)	3 (6)
Mother's educational level	
Not applicable	1 (2)
Elementary School	1 (2)
High School	8 (16)
Professional Diploma	11 (22)
Undergraduate	17 (34)
Graduate	11 (22)
Other	1 (2)
Mother's employment status	
Not applicable	1 (2)
Unemployed	2 (4)
Employed (Part-time)	10 (20)
Employed (Full-time)	24 (48)
Homemaker	13 (26)
Father's educational level	
Not applicable	7 (14)
High School	5 (10)
Professional Diploma	15 (30)
Undergraduate	14(28)
Graduate	8 (16)
Other	1 (2)
Father's employment status	
Not applicable/not disclosed	8 (16)
Unemployed	1 (2)
Retired	1 (2)
Employed (Part-time)	6 (12)
Employed (Full-time; includes self-employed)	33 (66)
Homemaker	1 (2)
Annual family income	
< $20,000	3 (6)
$21,000-$49,000	5 (10)
$50,000-$79,999	14 (28)
$80,000-$109,999	8 (16)
$110,000-$139,999	5 (10)
$140,000-$169,999	6 (12)
>$170,000	5 (10)
Not disclosed	4 (8)

Demographic Information (Child)	n (%)
Number of children in family with NDID	
One	40 (80)
Two	10 (20)
Gender	
Male	36 (72)
Female	14 (28)
Age of child with NDID (M= 14.03, SD=6.20; R=4-25)	
4-12	19 (40)
13-18	16 (32)
19-25	15 (28)
Primary diagnosis	
Autism Spectrum Disorder (ASD)	24 (48)
ASD and IDD	5 (10)
ASD and ADHD	2 (4)
Cerebral Palsy	1 (2)
Down Syndrome	9 (18)
Intellectual developmental disorder (IDD)	7 (14)
Other (PWS and cleft palate)	2 (4)
Parent reported classification of child's disability level	
Mild	7 (14)
Moderate	37 (74)
Severe	5 (10)
Very severe	1 (2)

ASD: Autism Spectrum Disorder
IDD: Intellectual Developmental Disability
ADHD: Attention Deficit Hyperactivity Disorder
PWS: Prader-Willi Syndrome

6.2 Scores of Perceived Social Support, Family Quality of Life, Family Resilience and Perception of Self-efficacy

6.2.1 Data Checking for Outlier and Normal Distribution

Before compilation of the standardized scale values, the data collected was checked for outliers and normal distribution. For outlier detection, the visual inspection of histograms and boxplots were assessed for each scale. Then, the data were converted to z-scores and screened for

significant outliers using a critical value of +/- 3.29 (which corresponds to an alpha level 0.05) (157). Although 4 points did not meet the leverage value cut offs (leverage value is the measure of how far an observation of perceived social support from PA program friends is from the mean observations), data from these four participants were not removed from further analyses. These four participants reported higher scores on each of the independent and dependent variables (perceived social support from PA program friends, family quality of life, family resilience and self-efficacy). These observations were not removed in context of the exploratory study, considering the aim was to investigate all the families attending these PA programs to understand the diversity in the participant's profile and perspectives.

Also, the data were normally distributed as determined by visual inspection of the histograms. The Kolmogorov-Smirnov value for the dependent variables (p>0.05) indicated that the observed distribution was not significantly different from a normal distribution. In addition, the skewness and kurtosis values were examined. Although there was a slight deviation (value greater than zero in the values for the independent and dependent variables (highest=0.6), no data transformations were implemented to maintain interpretability of the findings. For the assessment of linearity and homoscedasticity of errors, the scatterplot of the residuals between predictor variables and errors of predictions were examined. Based on visual inspection, this assumption appears to be met. Multicollinearity was assessed by examining bivariate correlations between the dependent and independent variables being used in the models. No correlations were identified as being excessively high (i.e., above .80) (157).The variance inflation factor (VIF) was also examined, and all values were lower than 10, which is cut-off value (157). Also, the tolerance values were higher than 0.2, which also indicates no multicollinearity. Therefore, this assumption was met. The data compilation and quantitative analyses were performed on the complete set of data (n=50).

6.2.2   Scores on Standardized Scales

As described in chapter 4, we used four standardized scales in this study. The Multidimensional Scale of Perceived Social Support (PSS) was used to measure perceived social support from family, significant others and friends. We computed two total PSS scores: one for the perceived support from family, significant others and "PA program friends" and one for the perceived support from family, significant others and "non-PA program friends". The Family Quality of

Life instrument measured the FQOL satisfaction. The Family Resilience Assessment scale measured family resilience and Perceived Self-Efficacy scale measured the Perception of Self-efficacy in relation to raising a child with NDID.

Descriptive statistics for each measure is provided in Table 5.3. The total PSS scores (PA program friends) were 5.01 (range = 1.6 to 7.0), that is in the 'upper moderate to high' range of total PSS score. The total PSS scores (non-PA program friends) were 4.93 (range = 1.5 to 6.5), that is also in the 'upper moderate' range of total PSS score. In both PSS scores (for PA and non-PA), the "friends" component showed the lowest score, compared to "family" and "significant other" components. The total FQOL score was 3.8 (range from 2.4 to 5.0), indicating family quality of life satisfaction was on the higher side of FQOL profile. The observed FRAS mean score was 156.1 (normal range from 116 to 195), which shows moderate resilience among the participating families. Finally, the mean perceived self-efficacy score reported in the study was 46.1 (normal range from 33 to 59), which is on the higher side of the perceived self-efficacy scale.

Table 6.3 Family Well-Being: Descriptive Statistics

Scale	Mean (SD)	Observed Range	Theoretical Range
Multidimensional Scale of Perceived Social Support (PSS)			
Model-1: Total PSS (with PA program friends)	**5.01 (1.14)**	**1.58-7**	**1-7**
Significant other (spouse)	5.23 (1.46)	1.25-7	1-7
Family	5.3 (1.26)	1.5-7	1-7
Friends (PA Programs)	4.50 (1.29)	1-7	1-7
Model-2: Total PSS (with non-PA program friends)	**4.93 (1.12)**	**1.5-6.50**	**1-7**
Significant other	5.23 (1.46)	1.25-7	1-7
Family	5.3 (1.26)	1.5-7	1-7
Friends (non-PA program friends)	4.28 (1.24)	1.25-6.75	1-7
Family Quality of Life (FQOL)			
Total	**3.8 (0.6)**	**2.4-5**	**1-5**
- Family Interaction	3.9 (0.7)	2.5-5	1-5
- Parenting	3.9 (0.8)	1.8-5	1-5
- Emotional Well-Being	3.3(0.9)	1-5	1-5
- Physical / Material Well-Being	4.1 (0.70)	2.4-5	1-5
- Disability-Related Support	3.9 (0.8)	1.8-5	1-5
Family Resilience (FRAS)			

Total	**156.1 (17.7)**	**116-195**	**54-216**
- Family Communication and Problem Solving	81.5 (12.1)	53-108	27-108
- Utilizing Social and Economic Resources	22.3 (2.7)	15-30	8-32
- Maintaining a Positive Outlook	17.9 (3.09)	10-24	6-24
- Family Connectedness	15.7 (1.3)	13-19	6-24
- Family Spirituality	9.1 (3.0)	4-16	4-16
- Ability to Make Meaning of Adversity	9.6 (1.5)	5-12	3-12
Perceived self-efficacy scale (FES)	**46.1 (5.7)**	**33-59**	**12-60**

6.3 Presentation of the Results by Study Objectives

The quantitative measurements represent data from 50 participant families and the qualitative data includes the perspectives of 44 participant families. Although a total of 50 interviews were conducted, 6 interviews were not recorded due to technical errors. Objectives 2 and 4 represent data collected only from the interviews while objective 3 involves the use of data from standard scales. The remaining objectives 1, 5 and 6 benefit from both qualitative and quantitative data analyses.

6.3.1 Results for Objective 1: Parents Activities During Attendance at PA programs

During the interviews, participants were asked to reflect on what parents do once their child is engaged in the program's physical activity training, and to specify the primary activity in which they are involved in. All parents reported they were involved in socialising with other parents to varying degrees; also, a few parents took advantage of the PA program time to do other activities including watching their child, using this period as respite time, and leaving the site to perform errands while the child is at the activity.

Watching their child: Nine families mentioned they watched their child's performance and/or helped them out with the activity when needed. For example, parent S4, has a 13-year-old son diagnosed with intellectual disability. The father brought his son to the program every week, and watched his son, while he participated in the program activities.

> "Interviewer: So, when your child is attending the program, what do you
> generally do?
> Participant: I just sit over there and watch."S4

Socializing: Thirty-one families reported socializing as one important activity while waiting for their child. For 7 families, socializing with and talking to other parents seemed to be the most important activity. For example, parent S10 has a 13-year-old son diagnosed with ASD and is part of the PA programs for the past 5 years. From my participant observation notes and during interactions with the parent, I found that her child was able to participate independently in the PA programs and therefore, the parent did not have to worry about taking care of the child during the program activities. In the quote below, the parent revealed that this is the time when she catches up with other families at the program, discussing their child with NDID and the ongoing week.

> "Interviewer: So when T is participating in these programs, what do you typically do?
> Participant: Talk to the parents. That's how we socialize and catch up how the week was, what's going well or is there any concerns with their kids, is there any health issues that occurred."S10

Twenty-four families mentioned they do both, watched their child and helped when needed, as well as were involved in socializing and talking to other parents. For example, parent S5 has a 5-year-old son diagnosed with ASD 2 years ago. The child has been attending the PA program for the past one and half year. The quote below demonstrates that at the program, parent S5 keeps a watch on her child, helping when needed but otherwise is talking to other parents at the program site. Additionally, the parent indicates the presence of trained volunteers on site who help out the child, allowing the parents to interact with each other.

> "Sometimes have to work with them to get him engaged in the activity and to focus, but I usually try and let the volunteers do that because I find that they do better with him, R is better with them and, so I'm often trying to be just on the side you know chatting with a parent. Just watching and chatting with a parent."S5

Respite: Two participants conveyed that this was respite time for them. The participant parents demonstrated that they used this time to do other activities for themselves or volunteered and if there was time remaining, once they were back, they watched their child or socialized with other parents. For example, we observed that participant S51's daughter was 19 years old and could

independently participate in the sports activities. As their child could independently take care of herself, the parent used this time for themselves by engaging in running activities.

> "… for softball, we volunteer for softball. Sometimes, I just try to… I run, I usually just try to run, just exercise basically while I'm waiting for her. If I finish early, I'll just sit there and watch her."S51

Errands: Also, two families mentioned that they watched the child and sometimes dropped off the child and left the site to finish other chores or self-respite time. For example, from the participant observation notes and interactions with parent S25, the parent indicated that her son is capable of taking care of themselves. As a result, the son did not require much assistance and therefore, in the quote below, the parent initially attended a few programs to ensure his son's smooth transition into the activity and then on a regular basis, dropped his son off and picked them up at the end of the program.

> "Interviewer: Like what do you generally do while he's attending the program??
> Participant: At all programs that is new to him I always stay for the first one or two sessions. And then, once he's comfortable, I tend to just do a drop off and a pick up later." S25

These responses illustrated that at the PA program site, parents are involved in different activities that include volunteering, helping the coach, talking with other families, watching and self-respite time. The majority of parents are involved in watching their child at the program and socializing with other parents. In total, 31 parents (of the 44 parent interviews recorded) (70.45%) reported being involved in socialising with other parents as their primary activity at the PA program.

6.3.2   Results for Objective 2: Perceived Gain by Families from PA Program-related social networks

To understand the perceived impact of the PA program-related social networks on participant families, the participants were asked to reflect on the nature of their interactions with other families at the PA programs. On the basis of their responses in the interviews, the following themes emerged: gain in social support, sense of belonging to the community, gain in self-

efficacy, building resilience and mentorship. These themes were generated through an inductive approach

Gaining Social Support

The inductive category of 'Gaining support' corresponded to concepts used in other research. For example, social support as described by Uchino *et al.* (158), refers to "the comfort, care or help" available to a family of a child with NDID at the PA program, which is provided by another family at the program. Social support has been further categorized into two sub-themes: informational support and emotional support.

Informational Support

All participants reported that interaction with other parents at the PA programs provided them with informational support for their children with NDID. This included information about educational resources, events and program information and information related to child care and government services for their children with NDID. This peer-to-peer informational support is well illustrated in the quote below where the participant mentioned that interacting with parents at the programs who also have children with the same diagnosis provided specific information that was useful for the child.

> "Although I had gone to the BC Center for Ability, for some of the ongoing questions and stuff, but my son has aged out, it only goes to a certain age. So, I used to go there to get some information, but of course everybody's disabilities are different, they are not all autistic kids, and they all have different disabilities that they have a concern with. **That's why when I found fundamentals that involve mostly autistic kids, I kind of meet up with people here and receive information here that way**."S10.

Parents also shared useful information about programs, their experiences and other support resources with one another as mentioned in the quote below:

> "Well I think the significant help I get is that we exchange information, whether we got a good experience or a bad experience, and we provide support to each other. **So if we have any question, we send an email to the group and we make…people**

will share their experience or provide comments so I think that is very important…as parents we need to know depending…I mean, all kinds of information…any new treatment, or any new social skill group, or even we have a consultant…if you have a new behaviour consultant you ask if anyone has experience with this consultant…**all those information**."S11

Emotional Support

The inductive category of 'Emotional Support' also corresponded to concepts used in other research. For example, researchers described emotional support as the care, empathy, concern or positive regard provided towards the family by another family at the program (159). Only sixteen families mentioned their emotional exchange with other families at the programs, with the key factor for emotional support being the mutual understanding that families have for each other, because they live the same situation. Of the 16 families who escribed exchange of emotional support, none of the participants were fathers; all participants were mothers of children with NDID. For example, parent S39 has a 13-year-old, diagnosed with ASD and intellectual disability. Her son has been attending the PA programs for the past three and half years. While her son was engaged in the PA programs activities, she stayed at the site, keeping herself occupied in different ways, for instance, engaging with other parents. From participant observation notes and my interactions with the parent, the parent revealed she had recently separated. And therefore, being at the PA program provides her with an outlet to speak with other similar families. In the quote below, the parent explained having understanding people to talk to and express and share their feelings about what's going on, related to the child on a daily basis was comforting.

> "Um… yeah, I think that **just being able to sort of express what we're feeling**…or just what's going on a day to day basis at home. **So, it's kind of nice to get those feelings out. Nice to have people to talk to, because they understand**."S39

Another parent S43 has a 7 year-old son diagnosed with ASD and intellectual disability. Her son has been attending the program for the past two years. She mentioned that being busy with house work and caregiving, she did not get a chance to speak with other people. Therefore, attending the physical activity programs was a good chance for her to interact with other parents in a similar situation, which was good for her mental health and was a way to release parental stress.

"…I think maybe it's **better for my mental, or because I have chance to talk to people who has a similar situation with their family**. I'm a housewife. I am not working so, I take care of him and do housework all the time. **And if you don't have a social network, you don't have the chance to speak with people. That's not healthy for your mental health, it's not very good. So I think that's the one way to release my stress**." S43

Having mentioned the type of support received, when families were asked about the directionality of support, a majority of families reported a mutuality or reciprocity of support. Unidirectional support was specific only in cases where families were mentors for the families who had children younger than their own children. In such cases, families shared their experiences with each other but may not have learned new information as they may already be aware of such information (the mentorship theme is further discussed below).

Thus, socialising or interaction between families of children with NDID at these programs provided both *informational* and *emotional support* to families. The support was primarily multidirectional in nature.

Gaining Mentorship Abilities

Fourteen families discussed mentorship abilities; families stated they were either a mentor for a family, or were mentored by another family at the PA program. Interestingly, 10 of the 11 fathers who participated reported being a mentor for other families, by sharing their knowledge with other families and thereby paying it forward. The inductive category of 'Gaining Mentorship Abilities' also corresponded to concepts used by other researchers. For example the act of providing support such as sharing the information one has learned through their experience with another family (160)

Mentorship is an important component in the development of a Community of Practice. The 'mentor' parents felt that interacting with other parents and providing them with support was a way of paying it forward and helping the younger children and their families.
For example, participant S26 has a 24-year-old son diagnosed with ASD. He has been attending the PA programs for the past 5 years. The parent mentioned that when his son was diagnosed twenty years ago, there weren't many families to talk to about the diagnosis. However, now, being one of the families who have experience in dealing with their child with ASD, they try to help the community of similar others.

"Generally speaking, because we're one of the first cohorts. because P is in one of the groups that received therapy early on. So, we're sort of the front end, so there weren't a lot of folks that were ahead of us, doing the therapy in an intensive way in British Columbia, so for us, it was difficult because there wasn't a whole lot of references right. **We couldn't sort of refer to parents with older children, so one of the things that I'm trying to do with the community is I'm trying to see if I can be of any use to people with youngsters that are coming up now**."S26

Along with providing mentorship, this quote also illustrates the parents feeling of belonging to the community and therefore, the need to help out families who are part of the community as the family themselves did not have a lot of families to look up to support their child 20 years ago.

Gaining a Sense of Community or Belonging to the Community

Fifteen parents mentioned that the interaction with other families at the PA programs provided them with a deep sense of belonging to the community. The interaction provided them an avenue to communicate comfortably with other parents who can understand them, without feeling isolated.

For example, in the quote below, the participant parent mentioned the presence of a community feeling with these parents at the program allowed her to be open and ask for help when needed, compared to parents who are not part of the PA program or do not have a child with special needs.

"**It is just having that comfort zone,** it's nice, cause it is different, even, **let's say, at school there are parents that are understanding and so forth, but at the same time I don't try to impose on them,** right? Like I socialize with them, talk with them but I'm not imposing them, like can you watch my kid for a second, **I don't impose on them as I would with the other parents that I met through this group of activities that are specially for autism or kids with special needs**."S10

Similarly, as illustrated in the quote below, another parent mentioned that parents were interested to be involved in these networks as it helped them understand how to handle child-related issues,

"… you have a lot of parents that are there because they want to be involved and it is an important network for us. I think **without it we'd, a lot of us would be very stressed out and unsure about how to handle things** with our kids."S39

In another quote below, a parent mentioned how the families are not much different from one another as they all face similar challenges, and therefore, were part of a community of families who could share valuable experiences with each other.

> "Yeah, I guess I learned that **I'm not the only one. There's a lot of parents out there that support their children and they've made their lives revolve around their kids, so we're not much different from them and we know some of their challenges and sometimes they talk about it and trade experiences. It's sort of a community thing because over the years, you always see the same group of parents that are supporting their kids**…." S28

All these quotes support the common theme of feeling a sense of belonging to the community; the participants noted that they understood each other due to similarity in their children and situation. Moreover, this community provided both emotional and informational support and a feeling of empowerment and resilience. In the long run, they developed a sense of comfort and could openly share and discuss how to handle specific issues on the basis of their similar situation. Both the development of mentorship and a sense of belonging are important components to the on-going development of a Community of Practice.

Gain in Perceived Self-Efficacy or Empowerment

The participation of children in the programs and parent's interaction with their peers was perceived to be empowering by parents. This inductive category also corresponded to concepts used by other researchers, for example, Coleman and Karraker (161) referred to the parents' perception of their "own competency to meet the demands of providing and obtaining care for their child".

Eight parents mentioned perceived self-efficacy or the feeling of empowerment when they interacted with families at the program site. For example, parent S3 was a single parent with two children, a son and daughter 9 and 8 years old, diagnosed with ASD. She has been accompanying her children to the programs over the past three and half years. In the quote, parent S3 mentioned that interacting with other parents, provided her with more information, which helped her to help her children

"I think the most significant benefit for myself is able to connect with other parents and getting information from other parents .... so I get to learn more information on helping my children." S3

Similarly, in the quote below, parent S8, has a 9 year-old daughter diagnosed with ASD and Down Syndrome. She mentioned talking to other parents at PA programs was hugely beneficial as parents who have been through the situation provided informational support. Moreover, they understood the situation compared to parents who did not have a child with special needs.

"yeah, absolutely talking to other parents is something you just don't really get from parents in general who don't have a child with special needs; there is just no way they could really understand either the medical stuff or the development you know, without feeling deficient somehow so yeah **it's hugely beneficial just to have a few words with somebody and tell them either yeah we've been through that, you'll get through it or either get some tips and support yourself. So yeah, hugely beneficial.**" S8

Both of these quotes illustrate the dynamic interaction between different themes; it provides an understanding of how this parent is empowered by the informational support obtained from other parents at the program by learning new information which she can use to help her children or support oneself.

Gaining Resilience

Participant families also mentioned that by interacting with other parents at the program and seeing their children, it comforted them and promoted their coping skills and resiliency. This inductive category also corresponded to concepts used by other researchers, such as Walsh who defined it as "the ability to withstand hardship and rebound from adversity, becoming more strengthened and resourceful" (160)

Parent S16 has a 6-year-old daughter diagnosed with ASD a year ago. She has been attending the PA program with her daughter since the diagnosis. Participant observation and conversations with parent S16 revealed that the parent has learned about the child's diagnosis but was uncertain about her future. In the quote below, the parent mentioned that by talking to families at the programs and observing the other children, it has helped her to learn from other

parents, think positively and also comforted the family, to see the future possibilities for the child.

> "Because the program is for special kids, we talk about other special kids, like so **it has kind of increased my knowledge and ..every special kids face different challenge, so I also learn from other parents what their challenge are.** Yeah, just by casual talk it is comfortable just to talk about dinner and it can be a comfort too, so life is not just about the kids when with like other people, with friends and with work. And then like it is really comforting just focusing on daily life and focus on the problems and they special too, we just don't have struggle we also have enjoyment, we don't have to struggle all the time, **I try to think positively because I have all these great parents around me, because my husband and we are sometimes so blessed. By talking to other parents and seeing other kids, it is a great comfort to us, so we are not the worst,** yeah."S16

Overall, from these physical activity programs, the subthemes and supporting quotes illustrated that parental interaction at the program sites provided families with emotional and informational support, enabled them to support other families through mentorship, provided a feeling of sense of belonging to the community, a sense of being competent/self-efficacious. These are all characteristics that contribute to making these families more resilient and help them to improve their quality of life satisfaction.

6.3.3   Results for Objective 3: Association between Perceived PA program-related Social Networks and Family Quality of Life, Family Resilience and Self-Efficacy

This objective was chosen to illustrate the relationship between PA program-related friends perceived social support and different outcomes assessed at family level (FQOL, resilience and self-efficacy). The objective is studied by assessing the correlation between PSS from PA program-related friends scores and the score obtained on each of the three standardized scales for family quality of life (FQOL), family resilience (FRAS) and self-efficacy (FES).

We did not find any significant association between the perception of social support from PA program-related friends and the scores from standard scales on FQOL, resilience and self-efficacy, after controlling for demographic factors and other support networks. These results are presented under sections 6.3.3.1, 6.3.3.2 and 6.3.3.3, with more details in Appendix D. The demographic variables controlled for in the model included the child age, family income and years in the program. These variables were incorporated in the model as previous research has illustrated relations between the outcome variable, FQOL and child age and family income. Also,

a significant correlation existed between years in the program and the outcome variable and therefore, it was incorporated in the model, considering that years in the program may affect the perception of social support from PA program friends and also the FQOL variable. On the basis of literature available, other demographic variables looked at included ethnicity, gender, marital status, mother's education and father's education. However, as there were no significant correlations and considering the limited sample size, to prevent overfitting the model, these variables were not included in the model.

6.3.3.1   Association between Perceived Social Support from PA program Friends (PSS-PA program friends) and Family Quality of Life Satisfaction (FQOL) after Controlling for Demographic Variables and other Predictors.

We hypothesized that the score of PSS-PA program friends would be positively associated with FQOL satisfaction after controlling for child age, family income, years in the program, family perceived social support and non-PA program friends perceived social support.

The matrix of correlation illustrated that all variables were positively associated with FQOL and many of the variables were also associated with each other (refer to Appendix D, Table D.1). We then computed a multivariate Hierarchical Regression Model that included the different predictors and FQOL. We found that PSS-family (perceived social support from family members) was the only variable significantly associated with FQOL (p = 0.0001); the perception of social support from PA program friends or from other friends (non-PA program) were not associated with family quality of life (Table 6.4 below). For further details of the model refer to Appendix D.

Table 6.4 Hierarchical Multiple Regression Analysis of the Association between FQOL and PSS-PA Program Friends

Predictor Variable (OUTCOME=FQOL)	R	R^2	Adjusted R^2	b	SEb	Standardized Coefficient β	p
Step3	.753	.567	.506				
Constant				3.871	.068		.000
Child Age				.023	.013	.227	.097
Family Income				2.44e-6	.000	.185	.118
Year in Program				-0.015	.023	-.096	.507
PSS-Family				2.67	.064	.538	.000
PSS-non PA program friends				.078	.065	.184	.158
PSS-PA program friends				-.032	.063	-.066	.614

PSS-family refers to perceived social support from family members

PSS- non PA program friends refers to perceived social support from friends who are not part of the PA Programs

PSS- PA program friends refers to perceived social support from the PA Program friends

We also conducted an analysis of variance (ANOVA) to compare the FQOL scores across different categories of PSS-PA program friends' levels (low, moderate or high). We found that participants under the 'low' PSS- PA program friends' group (n= 6 families) had a statistically significant lower mean FQOL than those in the 'moderate' and 'high range' of PSS-PA program related friends. The difference of FQOL between the two categories of 'high' and 'moderate' PSS- PA program related friends was not significant (for further details about the analysis, refer to Appendix D)

6.3.3.2 Association between Perceived Social Support from PA program Friends (PSS-PA program friends) and Family Resilience (FRAS) after Controlling for the Demographic Variables and other Predictors

We hypothesized that the score on the standardized scale PSS- PA program friends would be positively associated with FRAS after controlling for child age, family income, years in the program, family perceived social support and non- PA program perceived social support.

The matrix of correlation illustrated that all variables were positively associated with FRAS and many of the variables were also associated with each other (Refer to Appendix D). We then computed a multivariate Hierarchical Regression Model that included the different predictors and FRAS. We found that PSS-family (perceived social support from family members) was the only variable significantly associated with family resilience (p = 0.019); the perception of social support from PA program friends or from other friends (non-PA program) were not associated with family resilience (Table 6.5; for further details of the model refer to Appendix D).

Table 6.5 Hierarchical Multiple Regression Analysis Predicting Family Resilience (FRAS) by Perceived Social Support from Physical Activity Program Friends (PSS-PA Program friends)

Predictor Variable- (OUTCOME=FRAS)	R	R^2	Adjusted R^2	b	SEb	Standardized Coefficient β	p
Step3	.54	.29	.19				
Constant				157.54	2.44		.000
Child Age				.47	.48	0.17	.337
Family Income				.8.57e-5	.00	0.23	.129
Year in Program				-1.64	.83	-.36	.054
PSS-Family				5.61	2.30	.40	.019
PSS-non PA program friends				1.11	2.33	.08	.636
PSS-PA program friends				-.21	2.27	-.02	.926

PSS-family refers to perceived social support from family members

PSS- non PA program friends refers to perceived social support from friends who are not part of the PA Programs

PSS- PA program friends refers to perceived social support from the PA Program friends

We also conducted an analysis of variance (ANOVA) to compare the mean FRAS score across different categories of PSS-PA program friends' levels. We found that although, difference in mean FRAS score across the different levels of PSS- PA program friends was not statistically significant, the FRAS scores were lowest for the low PSS- PA program friends compared to the moderate and high PSS- PA program friends (for further details about the analysis, refer to Appendix D).

6.3.3.3 Association between Perceived Social Support from PA Program Friends (PSS-PA Program friends) and Self-efficacy (FES) after Controlling for the Demographic Variables and other Predictors.

We hypothesized that the score of PSS-PA Program friends would be associated with FES after controlling for child age, family income, years in the program, family perceived social support and non-PA Program friends perceived social support

The matrix of correlation illustrated that all variables were positively associated with FES and many of the variables were also associated with each other (Refer to Appendix D). We then computed a multivariate Hierarchical Regression Model that included the different predictors and FES. We found that none of the perceived social support from family, PA program friends or from other friends (non-PA program) were associated with family self-efficacy (Table 6.6; for further details of the model refer to Appendix D).

Table 6.6 Hierarchical Multiple Regression Analysis Predicting Self-efficacy (FES) by Perceived Social Support from Physical Activity Program Friends (PSS-PA Program friends)

Predictor Variable- (OUTCOME=FES)	R	R^2	Adjusted R^2	b	SEb	Standardized Coefficient β	p
Step3	.488	.239	.132				
Constant				46.21	.817		.000
Child Age				.283	.162	0.309	.089
Family Income				7.69 e-6	.000	.064	.681
Year in Program				-0.118	.279	0.081	.674
PSS-Family				1.233	.773	-.272	.118
PSS-non PA program friends				-.104	.782	.023	.895
PSS-PA program friends				.468	.762	.106	.542

FES refers to perceived self-efficacy or empowerment

PSS-family refers to perceived social support from family members

PSS- non PA program friends refers to perceived social support from friends who are not part of the PA Programs

PSS- PA program friends refers to perceived social support from the PA Program friends

We also conducted an ANOVA to compare the mean FES score across different categories of PSS-PA program friends levels. We found that the FES scores were lowest for the low PSS PA Program-related friends compared to the moderate and high PSS- PA program friends, but the difference was not significant. (for further details about the analysis, refer to Appendix D).

Overall, results from the ANOVA analyses identified 6 families that had the lowest levels of perceived social support from PA program friends. These individuals (in most cases except for the participants highlighted in Table 6.7) have lower family quality of life satisfaction, family resilience and self-efficacy scores compared to families with moderate and high level of perceived social support from PA program friends. In the section below, we provide more information regarding these 6 families to describe their characteristics and identify possible reasons for low levels of perceived social support from PA program friends. These characteristics have been documented through participant observation notes and interactions with the participants:

- Participant 4 had a 13-year-old son diagnosed with intellectual disability. The parent's quality of life and perception of social support from family members were in the moderate category. The program we recruited the participant from only had two families

(S4 and another family). Moreover, participant S4 mentioned the other family was not always at the program site. Not being present at the program site resulted in decreased frequency of contact which ultimately hampered network formation.

- Participant 22 had two children diagnosed with ASD and intellectual disability. Their child participating in the study was 8 years old. The family quality of life scores was in the moderate range. However, the perception of social support from PA program friends was low, although perception of support from other friends was in the moderate range. When the participant was asked what they do during the time their child attends the activities, they mentioned that they dropped them off to gain respite time (S22).
"I just drop them off and, I'll usually try and go for a walk, get my own bit of exercise and pick them up at the end." S22

This illustrates the parent was not present at site, due to personal reasons. In conversations with the parent, he mentioned that this was his only free time from office work and child-related caregiver activities, so he uses this time as his own respite time by doing some exercise while the children are independent enough to be at the PA program activities on their own. The absence of the parent during the PA program time, therefore, limits the development of the PA program-related social network.

- Participant 37 had a 12-year-old child diagnosed with Down Syndrome. This parent had the lowest scores on all the scales, including perception of support from PA program, family quality of life, resilience and self-efficacy. The parent reported the child's disability as moderate. The parental interview indicated this parent was attending the program with the child after a gap of few months. At the program, the participant supported their child during the activity as mentioned in the quote
"You know, for the activity there's enough volunteers one for one, but J don't. J want me to help him." S37

This highlights that the child's needs prevented the parent from being involved in other activities such as interacting with other parents during the program. The parent reported

the child's disability as moderate. We also found the parent reported that irrespective of volunteers present on site, the child wanted the parent to help them in the activity. Although, we did not measure other factors such as parental mental health and depression, conversations with the parent revealed the parent had separated from the child's mother and at present he was the only caregiver for the child. Moreover, being mentally unavailable also may limit the interaction of the parent with other parents, in addition to attending to the child's needs.

- Participant 40, unfortunately the interview was not recorded. This participant had a 17-year-old son diagnosed with autism. The parent revealed their child had a mild level of disability. Although low levels of perception of support from PA program as well as non-PA program friends (other friends), the parent perceived moderate level of family and spousal support. Additionally, being on site at the PA program, the researcher observed that the family dropped off their child, went for a walk with their family and came back to pick up their child from this program. This observation indicated that the child was independent to handle themselves at the activities and consequently, the family did not stay on site. They interacted with other members of their family but their absence from the site hampered their PA program-related social network development.

- Participant 44 had a 20-year-old son diagnosed with autism. The parent reported their child's disability level as severe. The parent also reported a high-level of family social support in contrast to a low perception of PA program friend support. The parent mentioned they were new to the PA program and their child was older than other children in the program. This hampered the formation of parental social connections as illustrated in the quote below.

> "Okay, say when you're at the program, do you have interactions with other families?
> Participant: Maybe just a couple of them…most of them have younger children than my son…..… I think the problem there is there's a huge age gap. Like I said, there's only a few I know. Those few that I know, they have young adults, right. But then, it depends on age. The younger one tends to stay with their own group, because they have younger kids." S40

- Participant 45 had a 4-year-old son diagnosed with Down Syndrome. The child recently started the program and the parent recently started learning about the program for her child, which explains the low perception of support from PA program friends. The parent did mention that in future, she believes the PA program-related social networks will be an important network for her. The family's scores on the perception of social support from the family and spouse and family quality of life was on the moderate side. The parent's perceived self-efficacy was the lowest of all parents participating in the study. A key reason (considering the child being the youngest in the study) may be that the parent has slowly started learning about the disability and ways to support the child including the programs available for the child.

Table 6.7 Details of the Six Participants with Low Perception of Social Support from Physical Activity Program Friends

Participant ID	Language	Family Income	Number of children with NDID	Child Age	Parent Reported Disability	Parent Reported Disability Severity	PSS_ SigOther Mean 5.23 Range (1.25-7)	PSS_ Family Mean 5.3 Range (1.5-7)	PSS PA Program friends Mean 4.5 Range (1-7)	PSS_Non PA Program friends Mean 4.28 Range (1.25-6.75)	FQOL Mean 3.8 Range (2.4-5)	FRAS Mean 156.1 Range (116-195)	FES Mean 46.1 Range (33-59)
4	Chinese	$50K-$79,999	1	13	Intellectual disability	Moderate	3	3.25	2.75	2.75	2.9	143	43
22	English	$80K-$109,999	2	8	Autism and ID	Moderate	2.75	2.25	2.5	3.5	3.3	127	39
37	English with Son, Mandarin with Wife	$21K-$49K	1	12	Down syndrome	Moderate	1.25	1.5	2	1.75	2.7	126	48
40	English	$80K-$109,999	1	17	Autism	Mild	3.75	5	1	1.25	**3.9**	**170**	**46**
44	English and Chinese	$140K-$169,999	1	20	Autism	Severe	4.5	**6.25**	2.75	2	3.7	135	**47**
45	English	$50K-$79,999	1	4	Down syndrome	Moderate	3.25	5	2	3	3	126	35

PSS=Perception of Social Support
PSS=SigOther= Perception of Social Support from Significant Other
PSS=Family= Perception of Social Support from Family
PSS=PA Program friends= Perception of Social Support from PA Program friends
PSS=Non PA Program friends= Perception of Social Support from non-PA Program friends
FQOL= Family Quality of Life satisfaction
FRAS= Family Resilience
FES=Self-Efficacy

Apart from the perception of social support from PA program friends measured by the PSS-PA Program friends scale, we also documented the "received support" from all participants. This was assessed by identifying the actual number of individuals the participants socialize with at the PA program. The parents were asked to name individuals from the PA programs who provide them with support related to their daily functioning, caregiving related to the child etc. The number of friends they named ranged from 0 to 8. One participant mentioned no friends as this family was new to the program, having attended only one class so far. Nine families named at least one family they have met at the program and is important to them. Eleven families mentioned 2 friends, thirteen families mentioned 3 friends, five families mentioned four friends, two families mentioned 5 friends, two families mentioned 6 friends, one family each mentioned seven and eight friends.

We also found that the number of PA program friends for the families (received support) was significantly moderately correlated with the perception of social support from PA program friends (measured by PSS-PA program friends scale): r=0.47, p<0.001. To some extent this suggests that parents' perception of their availability of support from their PA program friends mirrors the actual support they receive from those friends.

Overall, findings related to this objective illustrate that the perception of social support from PA program friends, after controlling for the predictors, was not strongly associated with any of the three family outcome variables regarding quality of life, resilience and self-efficacy. However, we found that the perception of social support from the family was strongly associated with Family quality of life and Family Resilience. Additionally, we also found that individuals with lower perception support from PA program friends had lower levels of family quality of life, resilience and self-efficacy scores. And the number of PA program friends (received support) was directly correlated with the perceived support from PSS-PA program friends score.

6.3.4   Results for objective 4: Development process of PA Program-Related Social Networks

To understand the process underlying the development of PA program-related social networks, during the interviews, participants were asked to reflect on their interaction with other families at the programs and name friends (if any) whom they met at the program site. Also, families were asked to provide details of how they met these PA program friends. On the basis of their

responses, we observed two major themes that described the developmental process of PA program-related social networks: through the children and through the families.

6.3.4.1 Parents Network Development through the Children's Friendships

Several families revealed that their children developed friendships through the PA program activities. Importantly, they reported that these friendships between their children, translated into parents' friendships. For example, parent S6 had a 6-year-old son diagnosed with ASD. She has accompanied her child to the program for the past three years. Participant observation and conversations with the parent revealed that it was not easy for her child to form friendships; however, in the quote below, the parent explained that their child developed a meaningful friendship with another child at the PA program camp, and this resulted in the parents meeting each other based on this child's connection.

> "We met one of our good friends actually out of all these families, at a PA program camp. We went to camp and **the boys met each other which was interesting, you know they're playing together, you know, which doesn't happen a lot with autistic people, they just sort of had a connection and then we got to know them, the parents** and they're wonderful….." S6

In the quote below, parent S27 has a 20-year old daughter diagnosed with ASD. She has attended PA programs for the past 17 years and revealed that because her child developed friendships with a selected group of children at a program, the families also became friends, and then together, all the families joined another physical activity program. While the girls enjoyed their friendship and activities together, at the same time, the families had the time to interact, shared resources and know each other.

> "There is a group of girls, all with similar diagnoses. We found each other when the kids were, I guess, about thirteen or fourteen years ago. We approached a speech-language pathologist and asked her to create a social skills group for them because we felt that girls socialize very differently from boys and we felt that it was important to have a group that was just female only, that would be a benefit. **They met together, the families became friends and we outgrew the social skills group and we approached a dance instructor and asked her to create a dance group for these girls and so that continues, so we still see each other on a weekly basis, when the girls go to dance and so that's a time for the parents to sit and just kind of share the woes of the world.** We are resources for each other and that's

kind of nice and the girls consider the girls friends, although they're all quite different and interactions are quite challenging."S27

In both cases, we can see that development of the children's social interaction/friendship was an important aspect for the parents, significant enough that it drove the family-friendship development, hence contributing to the peer-support social network development. Children socialising appeared as one key factor, or expectation, that lead parents attending the PA programs to form networks. Of the 44 parents, 14 parents (32%) talked about the formation of their child's friendship and more specifically, one of the reasons they attended and got to know families further as a result of their child's friendship.

6.3.4.2   Parents Network Development through Interaction with other Parents

This theme highlighted the social network development between families at PA programs, developed through direct parental interaction already described in sections 6.3.1 and 6.3.2. However, parents described two different ways related to whether the parents knew each other (or not) before attending the PA program:

In this example, the parents met or got to know each other at the PA program. Due to the PA program structure, parents were at the program waiting for an hour; this context gave them an opportunity to interact with one another informally every week. For example, parent S50 has a 6-year-old son diagnosed with ASD. Her son has been attending the program over the past two years. In the quote below, the parent confirmed that consistent meeting with other parents every week and also attending the same program over time fostered the development of friendships.

> "Yes absolutely, because even with the C program, like the parents do have that chance, you know, because they're on the sideline. So, you know, majority of the time you see parents on their phones, which is their brain break, and I understand it, but it **does give that chance to, for parents to kind of talk and you know share information and just kind of get to know each other, you know. And you know, if you continue with a program, say C program, then you see like familiar faces, so you know, it does take time, but you know, eventually, you know, things do happen, and you start meeting friends that way**"S50

In the second instance, families already knew each other outside the PA Programs. Families mentioned they met other families outside of the PA program, through other activities,

e.g., at schools or other support or therapy groups, and as a result of knowing each other, they brought their friends to the same PA program, expanding their own network of 'known' parents at the program. For example, parent S3 is a single parent with two children, a son and daughter 9 and 8 years old diagnosed with ASD. She has been accompanying her children to the programs over the past three and half years. Apart from attending the PA programs, she is also part of support groups, WeChat groups for Chinese parents of children with ASD and other specific Autism related groups. The parent mentioned she has formed friends with families in these other groups that she attends. In the quote below, parent S3 describes introducing other families whom she already knows and interacts with at another support group, to the PA program (which indirectly helps in developing the network).

> "I introduced other parents to join the skating program. So that night when you met me at the skating program um a lot of Chinese parents, they all know me because I'm the one that brought them into the skating program." S3

Having described the PA program connections through their child's friendships and parent friendship's, families were asked to reflect on the extension of the network, that is, whether the network was only limited to the PA program site or whether families met outside the PA program as well. 75% families mentioned their network was restricted to the PA programs. Some of the reasons include that parents were busy in daily caregiving duties for their child and do not have time for interaction outside PA programs. For example, parent S9 has two children aged 15 and 18 diagnosed with ASD, and the parents have been accompanying their children to the programs since the past six and half years. Conversations with the family revealed that both parents are invested in the daily caregiving for their children and are not left with a lot of time to interact with parents outside of the PA program. In the quote below, the parent indicates the short interactions that occur within the program with other parents, but limited to the PA program.

> "And these sessions are like very, very short and **we get to talk to parents and we get to share information about where our kids are going, what they're doing and stuff but I've not really had an opportunity to connect and see those other families on an outside… when we see each other, when we have the program,** kind of thing."S9

In another quote, parent S10, illustrated that it is easier for parents to socialize at the program site, considering that outside the PA program, parents are busy, invested in the daily caregiving routine and thus it's hard to find a time that works for everyone.

> " I think for the **majority of time just socializing at the activities. It makes it easier because it is also a challenging thing to have when you have a special need kid and always arrange schedule that fits everybody because all of us have different activities or therapies**, so it is always hard to find a time that is suitable for everybody. S10

Significantly, it was valuable to find that 11 parents out of 44 interviews recorded (25%) continued to meet with families outside the PA program. One of the reasons included the similarity in the children, leading to playdates for the children. For example, parent S12 revealed they (families and children) met the other similar PA program families outside PA program for playdates.

> "Yeah, sometimes **we get together for playdates and things like that, and that goes with most,** and I would I say we get playdates with V's family and J's family, and we don't really do much with others because the kids are oldish."S12

To summarize the main findings, the interaction between families or the development of PA program social networks between families was driven by either the child's friendships or the parent-to-parent interactions or both. When driven by the child's-friendship, it was related to the child's social interaction and when it was driven by friendship between families, there was also the child's perspective to develop friendship with families that have a child with similar abilities. Thus, the development of the social abilities of the child seems to be priority for the families.

Of the families, 75% indicated that their PA program friendships were limited to the PA program site while 25% families mentioned they also met outside the PA program. We found the depth of the connections depends on numerous factors such as the similarity in the ability of their children, and/or the need to find friends for their children or the amount of time the parents have after finishing their caregiver duties.

6.3.5 Results for Objective 5: Barriers and Facilitators for the Development of PA program-related Social Networks

To understand the facilitators and barriers for the formation of these PA program-related social networks, the participant families were asked to reflect on the PA program, their structure, the families with whom they connected, how they met and the interactions they developed with the different families. On the basis of their responses in the interviews, several themes and sub-themes came up that described factors responsible for strengthening the network among parents. For instance, we already found that the development of children's friendship was a strong motivation and facilitator for parents to interact with another family, and likely the PA program-related social network. Also, parents described what prevented or hampered their interactions with the parents at the PA program. The emerging themes are described below (Table 6.8) and are categorized under PA program structure and participants' characteristics.

Table 6.8 Themes Illustrating the Barriers and Facilitators for the Formation of Physical Activity Program-related Social Networks at Physical Activity Programs

Facilitators	
1. PA program structure	1. Regularity in the program schedule 2. Requirement to be present on site during the program 3. Activities organized by program 4. Having PA helpers to help the coach
2. Similarity in children's needs	
Barriers	
1. PA program structure	1. Length of sessions at the program 2. Duration of the program is too short
2. Participant family characteristics	1. Lack of time for interacting 2. Communication abilities (language, isolation, depression) 3. Lack of reasons and incentives (child is too old or too different)

6.3.5.1 Facilitators to PA program-related Social Network Formation

Families, while reflecting on their experience with PA program-related social networks discussed similarity in their child's needs, program structure, and language as facilitators for the peer-to-peer interaction among families.

6.3.5.1.1 PA program-related Program Structure

The regularity in program schedule ensured parents see each other regularly, which facilitated the interaction between families. It is an important point, as illustrated in the quote by parent S5:

> "… often you **start to see the same people you know,** like there's one mom I've gotten to know; **we met at skating and then they were in the same swimming this past fall**, so we've we haven't connected outside that activity, but I've got to know her a little bit. **You might see from time to time the same people, so yeah we share information, we just vent a bit about you know how things are going and share challenges**." S5

Certain PA programs make it mandatory for parents to be present at the program at all times, which creates more opportunities for the families to interact with each other. These programs provide seating space and coffee for the parents, reinforcing the importance for parents to socialize with each other, relax and enjoy the coffee while the volunteers support their child on the field, as demonstrated in the quote below:

> "….so the soccer is a big one it's probably I would have to say that's number one because when we did the active start we were very hands-on with them, we often have to be in there help redirecting them, so there was very little time to sort of stand back; and kind of we did chat with each other but there was very little of that. So that's a **big thing that they emphasize when they send the emails out about the soccer; we want you to come and you need to be on the field but you need to stand there and relax there. That's very big for them and they realize that that's important for the parents, so they do emphasize that as well: have your coffee, sit down relax, chat.** You know, they really put that out there." S8

Also, some PA programs organized activities that helped families to socialize and interact with one another which was highly valued by some parents that considered their child's social development as priority; as demonstrated in the quote below:

"They have a couple events this season of just getting the team and the families just get together, have pizza you know that kind of thing. Just sort of a loose social gathering." S19

Some parents mentioned the variation in the length of PA programs affected interaction between the families. For example, in the quote below, the family mentioned that in programs of longer length (a nine-month program vs a six-week program), the potential of meeting a family on a regular basis every week was longer in length, and consequently, helpful for friendship formation as explained in the quote below.

".. you see a lot of people but you might have a fleeting conversation and it's helpful, but you don't see them the next session like they're not in the same activity right? When at 'A' PA program, **it's the same group so over time I expect to get to know that group better, it's very small and it's the same people every week**; with 'C' PA program it's different parents every session that you attend, right."S5

The presence of volunteers on site to help out the children was a facilitator for parents network development as it allowed parents some respite time, and therefore time to socialize with other parents as describe in the quote below

"Yeah, well they're generally all part of the same event. I mean, they talk, the parents, while the kids, the nice thing is at S program is they provide one on one assist for the kids. They're volunteers so young people, teenagers or adults provide one on one support for the kids so you can just, you don't have to parent while you're there. You know, so you get a break for an hour and that's what makes it easier to socialize with other parents, you know." S22

6.3.5.1.2 Family characteristics: Similarity in Children's Needs

As mentioned previously in sections , similarity in the child's needs served as facilitator to the formation of PA program-related social networks. For example, in the quote below, participant S12 explains that she is able to understand and align herself with other parents who are in the similar situation, facing similar challenges as her.

"….I think **the people that I've ended up aligning myself with**, like those ladies, those five ladies that I talked about, **we're all kind of in the same boat a little bit more, so we tend to understand each other's challenges a bit more, because we're facing very similar challenges**."S12

As corollary, parents that have children outside of the age range (i.e. like 24 years old) or beyond the expected interaction possibility, due to condition's severity, had less possibility to interact with other families that face similar challenges.

6.3.5.2   Barriers to PA Program-Related Social Network Formation

Several characteristics of families and features of programs that had an impact on parents' opportunity to connect with other parents are discussed below.

6.3.5.2.1   Participant family characteristics

As seen under the facilitators for networks, family-child characteristics can be a facilitator for PA program- related social network formation when children have the same needs or ability levels. It becomes a barrier to network formation when the child/family needs differ from other families. Some families mentioned that they helped out their child in the activities and as a result were busy during the program time. Consequently, this implies they were not available for interacting with other families at the program.

The quote from parent S37, who has a 12-year-old son diagnosed with Down Syndrome illustrates this. Although, he has been at the program for the past three and half years, the child prefers his father's support while performing PA program activities as illustrated in the quote below:

> "Do you think activities might be helpful for parents interaction? Maybe just informational activities?
> Participant: You know, **for the activity there's enough volunteers one to one, but J don't. J want me to help him**."S37

Similarly, besides lack of available time to interact with other families, one important limitation for families' interaction was the lack of common interest because the children are too different in age or developmental skills. In the quote below, the parent S14 emphasized the difference in the child's ability levels as a barrier to supporting and interacting with other families

"…**their kids also vary in different levels, in terms of ability**, so it sound like some of them have more challenges. Some of them in fact don't even have language, it's not verbal and I don't understand that, because obviously my two are verbal, and so I don't have the same challenge and I empathize, **I empathize with them a lot because I know it's challenging. So I don't think I can completely support them in the same way as I do with other similar families,**

because I'm not able to give them my opinion you know because I don't understand their situation as much" S14

Another important barrier was the presence of a communication barrier due to the participants fluency in a specific language. Communication was an issue for parents who did not speak fluent English to interact with other families and to join the PA program-related social network. Two families specifically emphasized the importance of speaking the same language to interact and help each other. In the quote below, the participant S11 connects and helps out another family as they speak the same language, as the other family is not fluent English, having recently immigrated to Vancouver.

> "English is not her first language. Yeah, right now the other mom, of the younger child, E, she asks me for information so I give her a lot of information. Because English is not her first language, so it's challenging for her to find resources, like where to go."S11

Therefore, being able to communicate or establishing good communication between parents is a critical step for joining the social network and contributing to it. It is certainly one challenge that deserves special consideration given the high number of immigrants in our community.

6.3.5.2.2   PA Program Structure

Families mentioned the importance of having enough time to interact with other families. Both the length of the program sessions influenced the scope of interaction among the parents. The physical activity sessions were of different durations varied for different programs.

For example, when the programs offered shorter sessions, the consequence on social network development was described by parents. For instance, 9 families mentioned that they remained at the PA program site after the regular session and as a result, interacted with one another; while in programs that offered longer sessions, some families only dropped off their child and picked them up. In this case having sessions of short duration enhanced the opportunity for parental interaction while longer duration sessions encouraged parents to use the time for other activities which hampered interactions or networking among parents as demonstrated in the quote below.

> **"Soccer is one and a half hours. So that's why parents cannot stay there. Some parents go shopping. But for the ice skating, only forty-five minutes. That's why a lot of parents stay over** there and wait for kids. So very different. Both programs are very different and based on the time and everything"S30

Overall, facilitators to the network formation included the consistent schedule of the specific programs, organization of a social gathering, presence of volunteers, similarity in child's needs and participants similarity in the spoken language. In contrast, the unavailability of the family during the program time due to the need to support their child during the activity was described as a key barrier for peer-to-peer social development.

6.3.6 Results for Objective 6: Comparisons between PA program-related Social Networks and other Peer Support Networks

The aim of the objective was to understand the specific importance of the PA program-related social networks, compared to other peer support networks. Specifically, parents were asked to reflect on 1) ranking these PA program-related networks compared to other peer networks, 2) identifying differences between PA program-related social networks and other peer social networks attended by parents/families and 3) providing any recommendation for PA programs related to the development of these spontaneous networks. During the interviews, families were asked to reflect on the interactions between families at PA program-related social networks, their relevance for their family and comparison in interaction with other peer support networks attended by parents.

1) Of forty-four parents, thirty-one parents (70.5%) ranked these spontaneously developed PA program-related social networks as important for their families, relative to other peer support networks they've attended. Nine families (20.5%) indicated they were equal in position, compared to peer support networks. The families that ranked the PA programs as important for their families revealed the reason as the dual benefit of PA programs, as a venue for providing physical activity classes for the child and an avenue for parents to interact with each other as the primary reason for their importance. Other networks do not provide the same convenience. For example, Parent S12 has two children 8 and 12-year-old diagnosed with ASD. She has been accompanying her children to the PAPs for the past four and half years. In the quote below, she demonstrates that being at the PA programs is beneficial to both her children and herself.

" I think **it's very important just because you know the physical activity is a big challenge,** because our kids are different, they are not going to be as simple as signing them up for any program, it's harder for them to find a good fit. So that part is tough**, but I think in the meantime, as we're learning and meeting other families at various programs, it has also been very helpful for us to become a soundboard for each other,** because we do talk about what works for your child and what does not work, try this strategy, try this professional; it's been very helpful and also just I think for a family trying to deal with a diagnosis, you know, our family we've had 2 diagnosis for both our kids just trying to find people that understand the challenges, because you know I think it is very hard for families, especially if you don't a child, you know, I think every family has their difficulties and they have their challenges, but I find that the child on the spectrum just think differently and they think differently from me, and sometimes it's hard for me to completely… I mean at the end of the day I'm always trying to help them through their day, sometimes I feel awful that I don't understand them, but they are you know, they are good kids and it's a huge learning curve; **but I think having those families there really help, because they understand that learning curve and they also understand it is not as easy as it may seem. I would say that is the biggest thing, at least for me**." S12

In contrast to the above quote, only 4 parents (9%) did not rank the PA program-related social networks as important. Considering their child was older, the phase of their child's development and their own needs, they described the PA programs as a place that is only important for the child's development.

For example, parent S28 has a 25-year-old son diagnoses with ASD; he has been accompanying his son to the program over the past 11 years. In the quote below, the parent explained that being a parent to an older child, the peer-to-peer support is not critical at this time for their family, they only go to the PA Program for their child; however, it may be beneficial for younger families.

"I think most people are like us, **I don't think we go there for support. It's just that our kids are at the program and we just happen to be there.** This is my opinion, that the individuals don't really have close knit support with each other. **These programs are good for our kids, it's not necessarily something the parents, you know, getting the benefit out of. That's not to say some parents don't because there's a lot of young parents that through their friends that's how they then found out about Special Olympics because it's through word of mouth and through friendship. I guess we're more mature, not on the lookout for new support or they're new to this.** Like our kids, for twenty years so we've

gone through the hard times, and we know what we want. So, for older families, I don't think it's necessarily as important as for newer families that are just starting out and that don't know what's out there." S28

2) *Compared to other peer-support-networks*: Parents mentioned that compared to other peer-support-networks, the PA program-related social networks provide a common ground for parents to talk and connect with each other, considering the children are also at the program attending the same activity as mentioned by parent S44 below, who has a 20-year-old son diagnosed with ASD. Her son has been attending the PAPs for the past fifteen years:

" See the parents support group, like I only gone once, I mean not once, a few times. **It's just parent support groups are just parents, and we don't really; the kids are not really with you. You can't get together right, so I think since the kids are already there doing the same kind of sport, so it's kind of good idea. You can share something, some common thing.** You could talking about skating."S44

Compared to typical PA programs: Similarly, families also compared their PA program-related social network interaction at adapted programs with families at typical PA programs. Family S14 explained the feeling of a difference in the level of connection development in the quote below:

"Well with adaptive ones, yeah, we're always chatting about stuff and you know always sharing our experiences, whether it be experiences or just sharing. I just feel that **with the regular parents, a lot of times, once in a while they may ask me how J is doing but otherwise we're just chatting you know, general**, or we could be chatting about what camps we're going to put our kids in and things like that, **so I guess it's just the same, but a different level.**"S14

Compared to parent networks at the child's school: Also, as demonstrated in the quote below, families revealed that meeting other parents having children with similar conditions in the PA program was comforting and they felt these parents understand them better, compared to their interaction with parents at the child's school.

"It is just having that comfort zone, it's nice, cause it is different, even, let's say, at school there are parents that are understanding and so forth, but at the same time I don't try to impose on them, right? Like I socialize with them, talk with them but I'm not imposing them, like can you watch my kid for a second. **I don't**

impose on them as I would with the other parents that I met through this group of activities that are specially for autism or kids with special needs."S10

Compared to online peer support groups: Families preferred the PA program-related social networks to online peer support groups because they have met each participant in person (quote below).

Interviewer: Do you mean to say the physical activity networks are more personal?
Speaker: Oh, with the parents, yeah, because **I know them in person, whereas the google group it is more online, that is what I meant, and there is like about seventy families in the google group, a lot of them I have never even met, for me I wouldn't even you know write up something very personal…"**S14

Three parents, being new to the program, did not comment on the program comparisons because they were still getting acquainted with the programs and facilities. However, one of the families mentioned, that in future, the group of families at the PA Programs would be a critical support network for all the reasons mentioned above.

"I would see it as very important, especially as we outgrow the playgroup. Because we have found that is very beneficial having a group of parents, even if we don't see each other in between. Just having someone in a similar boat is very useful and as moving forward, I don't know if we're going to have as much opportunity to like, to keep up with those parents in the same way, so I can see you know, it's a small group of kids in this program, it's easier to get to know everyone. I could see it being beneficial, but yes, I do imagine it will be, I just can't say it is at this point. ...And this is a small group so I can see you know, **it's the same kids every week it's only four or five kids. Um, once I have been there for a while, I think we'll start to get to know the other parents and people can be quite friendly, so we're all in a similar boat here**. And also, I don't see as many opportunities just to meet systematically with parents. Like I think, I do think, these physical activity programs will be the main way going forward. I don't really know what else there is."S45

3) Because these PA program-related networks developed spontaneously, compared to other peer support groups, the families were asked if they were interested and would like to have activities for parents at the program. Of the 44 parents, 33 parents (75%) mentioned they would like more activities for parents to socialize and interact with each other, whereas 8 parents mentioned that more activities were not needed for the parents, as the main focus of the programs were for the

child's development, and 3 parents did not comment. Parent S44's quote demonstrates the importance of activities during at the PA programs for connecting with other parents:

> "Yeah like I said, **if you get to talk about once a month, or even once every two months, you know, while they're skating if you have something you want to you know not just talk about skating or maybe just a social gathering or something, and family who's there have the time to talk or something**. Even if you share my son is L or others say that oh my son wants to be…, maybe my son and your son can get together during the skating or maybe you can have coffee afterwards or whatever. I think just so that you would have, even during time they have during skating, have a special time for just the parents. Like coffee time I don't know" S44

In contrast to the quote above, the quote from parent S22 here demonstrates the absence of needs for more activities; moreover, the parent indicates if individuals require support, they can seek it out from support groups.

> "..I don't really think (need activities at PA programs to connect with parents), unless the kids are involved it wouldn't really be realistic. *You know,* ***I think because there's all sorts of support groups and those are by choice and people can join them***." S22

Summarizing the data for this objective, 33 (70%) family participants ranked these PA program-related social networks as important for them and their families, compared to other peer support networks. These families described the dual benefits of the PA programs which are positive for both families' interactions and child participation, in comparison to other networks. Furthermore, the comfort of knowing each other in person with face-to-face meetings and having a child with similar conditions separated the PA program-related social networks from the other peer support networks. Parents who were new to the program, anticipated the PA program social network to become an important support for them in future. Furthermore, 75% families were in favor of having activities for parents organized at the program to socialize and interact with each other in future.

Chapter 7: Discussion

Families of children with NDID experience increased amounts of stress, depression, and anxiety (39,162). A key factor contributing to these negative outcomes is the social isolation created by the families decrease in community involvement due to their child's behavior, loss of friends, being treated badly by strangers (2). In addition, prioritizing child care, they are often left with no time for socialising, adding to their feelings of social isolation. Peer networks or groups help support and promote social integration of these families in the community (chapter 3). However, families often cannot attend peer support programs as they do not have resources or respite caregivers to look after their child, while they attend the program. Therefore, ways to support families, while the child is simultaneously supported are warranted.

In this thesis, we approach this problem by exploring the role of adapted PA programs for children with NDID as a venue for peer support network development in families. These inclusive sports programs stimulate the child with NDID's motor and social skill development. The objectives of this study attempt to understand what parents do at the program, whether they interact with other families, forming peer support networks at the program, and if they form networks, how these networks affect the parents and family as a whole.

Our study revealed that the PA program-related social networks develop spontaneously when parents attend the program, but there are important factors that foster this development and others that can prevent parents from socialising. In this section we will review the factors that make PA program-related networks unique and we will discuss some key factors that would be worth promoting or better controlling for optimal development of the peer-to-peer support. Overall, results from this study shed light on the importance of PA programs peer support networks for families of children with NDID.

Our first aim involved to understand whether there were parents at the program site and any activities they are involved in onsite. We found most parents were present at the PA program, and predominantly involved themselves in socialising with other parents through PA program-related social networks at the program. This spontaneous social network development highlights PA programs are a positive environment that helps in bringing families together for their child's activities, and while waiting for their child, on the side, parents spontaneously gain social networks. Having said that, it is critical to highlight that along with socialising, parents were involved in numerous activities such as watching their child, running errands, and using

their child's engagement in the activity as respite time for themselves. Therefore, this indicates that PA programs are a platform for providing space for parents to socialize as well as to fulfil other needs or demands. Specifically, parents socialising is contingent on the child's ability to engage in the activity independent from the parent and other competing demands on the parent during this time. Furthermore, parents' engagement in PA-based social networks is dependent on the parent remaining at the program site.

Previous studies have reported parents' involvement in socializing at recreational programs (10,62,64). For example, Bowers *et al.* (10) interviewed families of youth and adults with intellectual disability and reported that attendance at the program site provided families with opportunities to meet and socialize with other families. However, social network development of parents was not the prime focus of these studies, and therefore, they did not provide further in-depth knowledge on the reasons for socializing, how socializing occurs and the impact of the interaction on families. Our study is the first one to our knowledge that focuses primarily on the aspects of parental network development at PA programs, providing an in-depth analysis of the network formation process and their importance for families.

Socializing with other parents is valuable to parents while attending the PA program because they recognize the similarity of the other parents' needs when caring for their children with NDID, and parents have the desire to promote their children's social development and social interaction. The need to care for their children who have similar needs provided them with a common ground to interact with each other. This similarity most likely reinforces the feeling of normalization among parents, which is comforting for parents, motivating them to socially connect with other parents at the program (85,87).

Considering that children with NDID differ from typically developing children in the extent of their social and behavioral abilities and the amount of care required from family caregivers, the presence of children with similar ability levels is important in these adapted-PA programs. This similarity in children's abilities is indicative of the PA programs structure, where the child's participation in these programs is contingent upon a certain level of ability irrespective of their diagnosis. In comparison, parents attending conventional peer support groups do not necessarily have children with the same abilities (7,105). Although the views in literature on the importance of being able to communicate with families having children with similar abilities to improve personal abilities is mixed and most likely dependent on each

parent's preference or situation, research studies illustrating appreciation of similar ability levels indicate parents find it as a key factor to experiencing positive impacts of peer support networks (7,84,88,105). Drawing on the social comparison theory, this suggests that being able to interact with families that face similar challenges due to the similar ability levels and therefore similar needs, helps parents to gauge the appropriateness and strength of their own emotional reactions and opinions, and for guidance and/or modeling (34,85,87).

Apart from parents being in the similar situations, spontaneous socializing is facilitated by the context created by the PA program while children practice activities; it is therefore a convenient time that enables parental interaction. This suggests that the parents could interact without having to take time away from their caregiver roles for their children. Moreover, the simultaneous presence of volunteers on site help parents to not worry for their child related duties, thereby providing them with some 'free time' as indicated by S22

> "..There are volunteers so young people, teenagers or adults provide one on one support for the kids so you can just, you don't have to parent while you're there. You know, so you get a break for an hour and that's what makes it easier to socialize with other parents.."

Their child's physical activity program time offers parents an opportunity to socialize, as previous research has found that parents have limited time and often have no alternate caregivers that would free them to enable them to attend social support groups (7,8). In other words, often, parents find themselves in a position of having to choose between prioritizing caregiving and their coping resources. This dual benefit of the PA program - providing care for the child and simultaneously providing support for the parents , was the major reason PA program-related social networks were considered as 'important' for their families compared to other support networks.

Finally, the spontaneous development of these networks around PA programs is an unexpected benefit for parents as their primary motivation is to bring their child to the programs for physical activity and psycho-social development. This perceived benefit for parents to socialize with other families and gain support was recognized by many families. They recommended that more program activities should be provided for parents to socialize and interact with each other during the PA program time. This speaks to the parental interest in

further development of these networks, indicating in the future that PA programs can help developing these networks by setting up parental activities. This may also be helpful in engaging parents who otherwise would not stay at the program site or are too shy to interact with other parents.

Having understood the reasons behind parents forming networks at the PA programs, next, we investigated the process behind the network formation. We found, that PA programs represent a good place for children with NDID to develop friendships with other children. Formation of friendships is a primary motivation for most families when they decide to attend a PA program. Interviews identified two ways to promote "family socializing". One approach involved parents forming social connections with other parents whom their children befriended at the PA (section 6.3.4.1), in order to nurture and encourage their child's friendship; as illustrated by participant S5 "*the boys met each other which was interesting you know they're playing together you know which doesn't happen a lot with autistic people you know they just sort of had a connection and then we got to know them*".

In the second approach, parents directly initiated the relationship between children by interacting with other parents, thus expanding this interaction to their children (section 6.3.4.2). Some of the families also knew each other through their child's school or common social groups or having seen each other at other PA program sites, as demonstrated by the quote S10

> "…making connections ..or making play dates, realizing kids are similar enough….Because finding kids are at similar levels, I think that's why I am connected with these parents better, in a sense their kids are more at E's level so they would be able to understand." S10

Interestingly, an important motivation for the parents, seems to be the development of their children's networks, which often leads to an expansion of parents' own networks. Social interaction among parents to develop their child's friendship is not surprising, given the importance of that parents place on friendship formation for child's learning and development (161,162), the difficulties that children with NDID have in socializing and developing friendship, and the subsequent social isolation and loneliness which children experience due to limited social interaction (163,164).

Their child's social limitations and loneliness are the source of immense parental stress, substantially affecting parental well-being (165,166). Therefore, parents' being able to foster friendships for their children is of utmost importance for their own psycho-social health (167,168). This illustrates the uniqueness of the PA program platform in contrast to conventional parental support groups.

Not surprisingly, the interview revealed that PA program-related networks extended outside of the PA venue for 25 percent of the families (11 families) in the form of play dates or family get-togethers, thus further promoting and nurturing their child's friendship. However, this is not always possible for every family as illustrated by S10

> "..**Majority of time just socializing at the activities. It makes it easier because it is also a challenging thing to have when you have a special need kid and always arrange schedule that fits everybody because all of us have different activities or therapies**, so it is always hard to find a time that is suitable for everybody."

This illustrates the importance of using the PA program time for socializing because parents are available to interact. In summary, the patterns of interaction and the amounts of interaction families find meaningful is multifactorial in nature and a complex balance between needs and possible availabilities of each participant family.

Having understood the mechanism of peer-to-peer network formation, next, we explored key factors that may facilitate or prevent the development of these PA program-related social networks. For successful social interaction at PA programs, the presence of parents at the program site is critical. Although, some programs do indicate it is mandatory for parents to be present on site and not be involved in other activities, it is not the rule everywhere. Consequently, 2 out of 6 parents who reported the least perception of support at PA programs were not present at the site during their child's activity. Again, not all parents require new network support, especially families who have older children, as they may have already adapted to the stressor and have developed their support circle, compared to younger parents who are searching for new friends and networks. Therefore, it may not be of benefit to make it mandatory for parents to stay at the program site as parents are free to use the time however they prefer.

Thus programs that organize activities such as coffee and tables for eating, as observed in one of the programs, may be a helpful respite time for parents who are looking for ways to socialize with one another. Moreover, having more social activities for parents was also requested by several families.

Regular attendance at the PA program on a weekly basis was considered favorable because it translated into consistent face-to-face parental social interaction over the entire duration of the program. This continuity in interaction was demonstrated in previous studies to further reinforce and strengthen peer support relationships between parents. For example, in a study by Coatsworth *et al.* (169), participants attending a mental health peer support network found that a greater frequency and consistency of contact influenced the formation of their relationship, specifically contributing to the development and maintenance of trust.

Barriers to social network formation included the inability to communicate with parents due to language differences. Moreover, parents whose social interaction may be limited by language might also be parents who are new to the country and probably require more support. Parents did overcome these challenges by finding parents who speak the similar language at the PA program site. However, some parents may not be comfortable to reach out to other parents. In this case, another way may be for the program to reach out to such parents and help them by pairing them with parents who may speak the same language. As studies such as Mueller *et al.*, have demonstrated, programs can help families speaking the same language connect with each other on the basis of shared cultural experiences, providing families with a 'feeling like home', which helps them to develop trust and emotional support with each other, thereby strengthening these parents (97).

Other barriers to peer support network development occurred when parents were either absent from the program sites, were new to the PA program, had to help their child in the physical activity, consequently unavailable for parental interaction. Our quantitative data illustrated that these families indicated a low perception of support from PA program friends. The need for one parent to assist their child during the activity was further explored through participant observation and an interview. During participant observation and detailed conversations with the parent, they reported that his child was attending the program after a gap of attendance and therefore, the child was still adjusting to the program and required their parent's assistance. In a situation like this, the child may adapt to the program and may not

require further close parental support. In addition, this parent was overcoming personal challenges at the time of the interview and may therefore, be mentally unavailable to interact with other parents onsite at that specific time.

This data about the experience of social support though parents' interaction illustrates the benefits of utilising both quantitative and qualitative methods. They facilitate an enriched understanding of why the participant indicated low perception of support from peer support networks. These insights would not have been obtained had a single method been used.

Thus, for these families, considering adjustment and adaptation of families to stressors varies and changes over time depending on factors such as the nature of stressors, the parents' resilience, and other child-related factors. In future studies, analysis of these parents' network development over time would be helpful to further understand what any changes to the parents' situation affect the dynamic process of developing networks for support.

Finally, we explored the particular benefits of these PA program-related networks as perceived by families. The emerging patterns from our interview data revealed that parents valued the meaningful conversations with peers, empathy from other parents, informational support in the form of learning from other parents about programs or child-related issues. In fact, all parents indicated they received informational support from one another and only 16 parents discussed emotional support. This is not surprising, considering that research studies indicate parents of children with disabilities are the most frequent source of informational support (170) because they are in a similar situation. Parents' recognition of the informational support that they received from other parents demonstrates that these networks serve as Communities of Practice for social learning.

Furthermore, the giving and receiving of emotional support depends on numerous factors such as comfort and trust between families, emotional availability of families and openness to one another (105,121). All these factors such as trust develop over time and this may be a reason that the 16 families that indicated emotional support have known each other for at least over a year. Having said that, it is important to note that none of the 16 parents who indicated emotional support were fathers. This may be related to the gender difference in coping styles of mothers verses fathers. As other researchers have observed, mothers adapt an avoidant and emotional coping style with peers, compared to fathers who display higher emotional inhibition (171).

Parents also reported that interactions with other parents empowered them, providing them with hope and resilience and a feeling of belonging to the community. This was as expressed by parent S16

> "we just don't have struggle we also have enjoyment…I try to think positively because I have all these great parents around me, because my husband and we are sometimes so blessed. By talking to other parents and seeing other kids, it is a great comfort to us, so we are not the worst, yeah."S16

We found these benefits are inter-related with each other. For example, as families gained emotional and informational support, this improved their resilience, self-efficacy and feelings of community belonging, which affected their overall well-being, FQOL and mental wellness (Figure 7.1). Moreover, quality of life satisfaction improves when families have opportunities to pursue important possibilities and achieve goals within their present life settings (172,173,177)
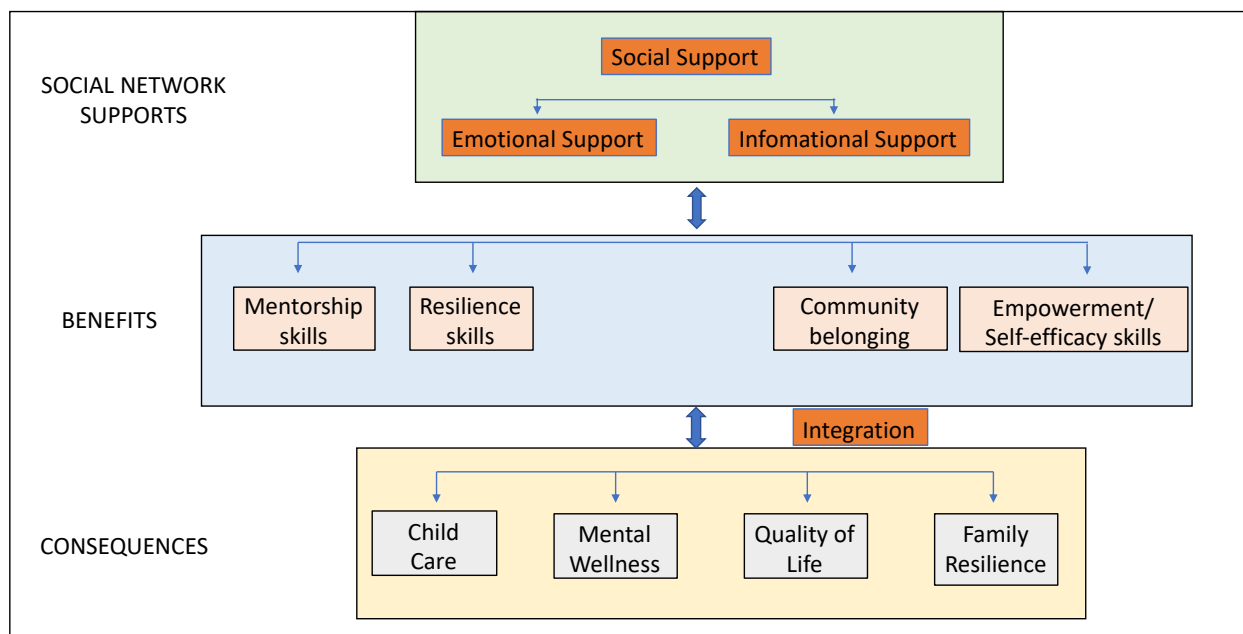
Figure 7.1 Illustrates the Three Levels of Dynamic Interaction between the Emerging Themes on the Impact of Physical Activity Program-Related Networks on Families

Therefore, drawing on the family systems theory, where the family is considered a system, with each person affecting one another and the family as a whole, this implies that the benefit of strengthening one family member through the PA program-related social network, also

positively reinforces other family members, helping in their adjustment and adaptation to the many daily stressors. Furthermore, considering the transactional relation between the parent and child with NDID, a resilient and strengthened family will likely be better equipped to cope with their complex child's needs and this will positively impact the child as well. The benefits of these spontaneously developed PA program-related support networks are consistent with other qualitative studies that focused on the impact of facilitated peer-to-peer support networks (7,87,98,105,111). For example, in a previous study Ainbinder *et al.* (105) interviewed 24 parents of children with NDID between the age of 1 to 16 at organized parent to parent support programs and found that parents of children with similar abilities in the peer support networks were a reliable ally for each other, promoting mutual sharing, learning from each other and empowered parents. This illustrates that the creation of a sense of shared experience between 'similar others' is the crux of community feelings that make peer support possible, in whatever context it may occur. This developing community of similar others at PA programs mirrors a community of practice or many small communities of practice where parents with similar needs and goals "develop relationships, engage in learning and developing practice, carrying out tasks and projects, and creating new knowledge by interacting regularly during the PA program" (80,174). The uniqueness of this community is that social learning from parental experience is further strengthened by the presence of the child on site, thereby initiating new patterns of behavior development through observation and direct experience of interacting with others such that learning the practice of caring for a child with NDID is learning "*how to 'live' knowledge, not just acquiring it in the abstract*" (81,175). This experiential knowledge provides families with competency to manage child-related stressors, which promotes coping and positive psychological reinforcement.

Our study also revealed a sharp contrast between the interviews that demonstrated the positive perceived benefits of attending PA program-related peer-to-peer support networks on family quality of life, satisfaction, resilience and perceived self-efficacy, and the absence of significant association between the perception of social support from PA program-related friends and the scores from standard scales on FQOL, resilience and self-efficacy (sections 6.3.3). In these analyses, the only strong association was with the family-related network. Several reasons may explain this apparent contradiction between qualitative and quantitative results. First it is not surprising that family-related networks are perceived as strongest to support families; these

networks comprise the most enduring and natural sources of support for children with NDID and the whole family. Moreover, the family's support is permanent in nature and preceded all other networks, especially the PA program-related network that will likely be transient. This may explain why family support is perceived as more meaningful and more reliable compared to the perception of social support from the PA program friends.

Second, PA program-friends seems to be mostly useful to gain information regarding NDID or to provide information to other parents, to share ideas regarding NDID, and to build child's friendship to help developing social skills. All these elements are not captured well with FQOL, FRAS and FES measurement scales. Therefore, it is possible that parents may find the PSS-PA program friends extremely important for these aspects in their daily life, while they do not translate well into a score of FQOL, resilience and self-efficacy. From a scientific view, the limited capacity of the standard scales (FQOL, FES and FRAS) to capture what counts for each individual is really possible. Standard scales are developed from different populations that may not represent well the situation of families with a child affected by NDID; therefore, the domains that appears in the standard FQOL, as example, may not represent well what counts for that specific individual family. Therefore, the standard scales' scores represent the average value when parents answer a set of questions while the interviews record the perception of the network's impact in many aspects of daily life; this means that both assessments are useful, but they are not measuring the same thing, with possible divergence when assessing their correlations. Along the same line of possible measurement errors, we used the PSS-PA program-friends in two ways: as a score of perception to captures the 'feeling of being supported', and also by counting the number of friends one family has. Certainly, the validity of "feeling of being supported" requires more work to understand the reasons parents give different scores. We realize that some families may feel extremely well supported for some aspects (for instance getting good response to important child related questions), but this support may not be enough to improve their FQOL. These different reasons may explain the difference between the positive perception of being supported by friends at the PA program and the absence of correlation with FQOL, resilience or self-efficacy feelings.

Finally, although research indicates friends comprise important support systems (176), the limited duration of the relationships of the families in this study may have only captured the beginnings of friendship relationships rather than the more fully developed and supportive

relationships. Twoy (176) reported that the majority of support parents received when they faced difficulties in their family came from people close to them (other relatives and friends). However, PA program-related friends support may be hard to account for in this category, considering these friendships are new and may not be comparable to existing friendships; which may explain a marginal effect on the quality of life, resilience and self-efficacy scales. Having said this, for parents who have been at the PA program for a longer time, the friendship with the parents may have grown and stabilized such that friends are like family members and consequently, these friends have been captured under perceived family support at PA program.

Study Limitations and Challenges

To our knowledge, this is the first study to explore the potential of family attendance at physical activity programs as an avenue for developing PA program-related social networks. Our study met several important challenges, the main ones for recruiting programs and families, and to engage these families in a prospective follow-up with quarterly encounters to assess changes overtime. These challenges led us to change the study design after 6 months, transforming the prospective cohort study into a cross sectional study.

In total, fifty participants from twenty-two programs were recruited for the study. The initial plan was to recruit from ten programs across Vancouver. These programs were involved in the initial planning of our study. However, of the 10 programs, by the time we started recruitment, one was already over for the season (Program 2) and another one got cancelled as there were not enough participants (Programs 9). Finally, in Program 8, the coach informed us within the first month of starting their class that no family was interested to participate in the study. As a result, we expanded to contact twenty-two programs in order to meet our recruitment objectives. A major point we noted that hampered program recruitment and therefore participants' recruitment was the variability in the program duration over the year. For example, some programs were only active for two months each semester and consequently, by the time we began recruitment, it was the end of their program. The short duration of these programs is also a barrier to the development of social networks.

We also increased the age-range of children with NDID to recruit more participants in several programs. An increase in the number of young adults may be that these youth are transitioning from high school and these programs helps them stay involved in the community,

and likewise for their parents: it provides them with an opportunity to interact with other families and learn about the resources available on transitioning from high school (8). Regarding our study, this group provides an interesting perspective as parents have a long experience of PA Program-related networks.

Although, we successfully recruited fifty participants in our study over the first year, we faced difficulty in retaining them for the follow up studies. Only 12/50 (24%) participants completed both the questionnaire and interview at the first quarterly follow-up. As a consequence, the study was transformed into a cross-sectional study. Some of the reasons we noticed were that (i) the families' stopped frequently attending the programs due to the child's related issues; (ii) as relayed by the program coaches, some children switched to different programs which were more suitable for the child's capability, and as a result we were not able to connect with the family in-person as they did not respond to the emails sent out by the research team; (iii) some families informed the research team that they had urgent matters to resolve or were moving away from the city and did not have time to complete the study; (iv) families were away on holidays especially during summer and may not have joined back to the program after and as a result were untraceable. Loss to follow up is not uncommon in longitudinal clinical research studies. This difficulty to recruit sites that offer long-term programs associated with the difficulty to follow participants over time makes the study of children with NDID in this community context very difficult. This may explain why most studies analysed in chapter 3 (review of literature) are of short duration and do not include large sample size. For future purposes, engaging the participants frequently with the study team may help us to better interact and keep in touch with our participants. We may also consider organizing telephone or skype communication with families, that offers more flexibility to discuss diverse perspectives with parents at a time convenient to them.

Another challenge was the amount of data to collect, using standard scales. Parents found the number of scales too large and taking too much time, we had to reduce the number of scales from 7 initially to 4. Therefore, we missed the opportunity to study child behavior, parental coping, parental stress, and parental mental health/depression. Overburdening participants by asking them too much information is a classic problem when working with families that are already stretched and facing more important priorities. One possible solution for future studies could be the recruitment of a large sample size and to use different scales by different sub-groups

selected randomly. This shared burden to answer the questions decrease the pressure on each family and can generate a more accurate and richer description of this population. Ideally, this assessment could be done routinely, as part of the PA program usual process.

As a consequence of the loss to follow up, the cross-sectional study design was implemented in place of the prospective cohort study. This is a significant limitation to our study as it limited our understanding of the changes over time in the spontaneous development of the peer support network on the family (measured by FQOL, FRAS, FES). With the implementation of the cross-sectional study, it was hard to differentiate the cause and effect from association, i.e., does increase in PSS-PA Program friends increase FQOL or the other way around? (177). Therefore, the study's ultimate analysis was descriptive, providing a snapshot of family attendance and generating hypotheses around the potential peer network formation at PA programs.

Finally, future studies in the PA program for children with NDID would benefit from having organized data collection regarding important outcomes in a structural way. This information is important for each site to evaluate the coaching performance and understand the benefits/limitations of the PA program interventions. Research projects, with appropriate ethics permission, may then have access to these data already collected. The qualitative aspect may then be conducted as a second focus to gather more precise data regarding the How? What? or the Why? perspectives of the study. To overcome these particular challenges in this area, developing 'collaborative projects' that involve parents and children, coaches and organizations as well as researchers would be important.

Chapter 8: Conclusion

Families providing care for a child with NDID are often faced with numerous challenges due to the child's specific physical needs, difficulties integrating the child into social interactions, and their occasionally unpredictable behavior. As a result, these families experience high levels of distress, which ultimately affects families' well-being which ultimately rebound on the child with NDID. Considering the ICF-CY framework, strengthening the family is critical because it is an essential context influencing the health and development for all children, including those with NDID. Support in the form of social networks are well established 'protective' buffers against distress.

In this thesis I investigated social support networks in the form of peer support networks. Evidence from the literature on peer support networks (Chapter 3) indicate that these networks positively reinforce and strengthen families. However, two major systemic gaps that restrict parents' regular participation in social support networks: the need to caring for their child, and the difficulty finding alternative care to enable parents to attend support group meetings. Considering this gap, this thesis explored the social networks of parents at community-based adapted PA programs that are regularly attended by children with NDID for their physical activities and development. A mixed-methods study design was implemented to investigate whether peer support networks develop between parents at the program site, while their child is involved in the PA program.

Overall, we found that the PA program community-based services, which are universally accessible, have the potential to simultaneously support the child's social development and the development of peer support networks for the children's families. These PA programs enhance interaction among parents as well as facilitate child related peer network development. PA program sites therefore, represent a unique platform that provides dual benefits, for the family as shown by the parent to parent, peer-to-peer support development and for the child to participate in physical activities and improve motor functions and possibly engage in friendship development. Therefore, the PA programs complement the healthcare system in a favorable way by providing social support to families, while at the same time supporting the child's development; this is not often seen in existing programs, and therefore, these programs have a role to overcome this system gap. In addition to PA programs supporting parents by facilitating

the development of social networks, we discovered that these programs also support parents by provide opportunities of respite and care for their child while they engage in other tasks.

By employing a mixed methods research design, it was possible to go beyond the findings using standardized quantitative measures. The interviews with families determined that interaction with PA program-related peers provided parents with informational and emotional support and a sense of belonging to the community. Moreover, the interviews revealed that PA program-related friends seemed to be mostly useful to gain information regarding NDID or to provide information to other parents, to share ideas regarding NDID, and to build the child's friendship to help develop their social skills. All of these elements were not well captured with family quality of life, resilience and self-efficacy measurement scales. While the quantitative results did not find a meaningful correlation between the PA-related social network and family quality of life, resilience and self-efficacy, the observations of parent interaction and the interviews with parents helped to explain the apparent contradictions among the different scales. The mixed method approach provided a more accurate picture of what each family means by experiencing informational or emotional "peer-support".

8.1   Implications

The implications for the study are discussed below:

First, the PA program is a unique model for peer-to-peer support network development that has the potential to reinforce and socially integrate families while the child is engaged in recreational activities. Considering families are at the PA program site, they benefit from seeing their child participate in the program activities, interact with friends and learn new skills as well as they benefit from the networks they develop with the peer parents. Together this strengthens the family members present on site by enhancing their resilience, learning new information, empowering them to understand their child better.

Within the family systems model, this positive reinforcement for the parent on site would be expected to positively affect all family members in their adjustment and adaptation to daily stressors (not measured in this work). Furthermore, given the transactional assumptions of the family systems model, a positive adaptation in the family will likely positively affect the child's development. In return, this beneficial effect on the child (associated to the benefit of attending the PA program and developing social skills), will positively reinforce the parents,

resulting in a continuous cycle of positive reinforcement between the family and the child, in context of attending the program together (Figure 8.1). This model of positive adaptation with mutual reinforcement in a continuous-reciprocal way opens up new possible applications in a broader range of activities, where children and parents are present at the same site. For example, this model may also fit situations like child art activity programs or school programs.
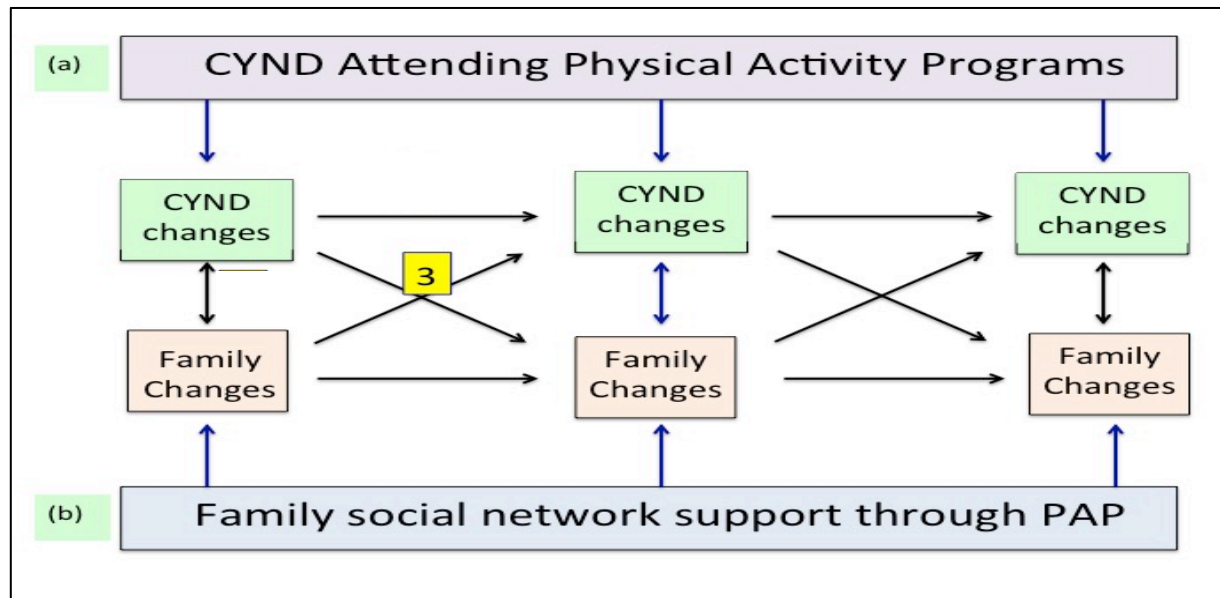
Figure 8.1 Model Illustrating the Effect of the Physical Activity Program on Families and Children

(a) represents the effects on children. (b) represents the effects on family. The effect on families is either direct (though social networking) or indirect (through child participation in activities). The effect on children is either direct (through physical activity participation) or indirect (through family reinforcement) (For detailed description, refer to point 1 under implications.[CYND refers to children and youth with neurodevelopmental disorders or disabilities and PAP refers to Physical Activity Program in the figure]

2) Given the PA program accessibility and characteristics, the networks formed at the program have a huge potential to help families who are awaiting services including families with a child waitlist before receiving a diagnosis, those who have yet to receive services, immigrant and refugee families new to the country, as well as families of children transitioning from youth to adult stages. These families all suffer from gaps in the health system that make their life difficult and certainly affect negatively the child's learning and development.

On the other hand our study shows the importance of language as key component for integrating a peer-to-peer support networks. For families who do not speak English as their first language, the environment needs to be adapted to facilitate integration. In the same way, new families or families with a new diagnosis may need some direct support to navigate the service system and overcome systemic barriers (178). We believe the peer-to-peer support from PA program social networks is just being discovered as a unique, financially accessible setting, to support families that have children with NDID. More research is needed to better understand the process of network development and the different ways to promote interactions among parents to and support families and to help them to understand and navigate the complex care system with their child.

8.2   Limitations

Several limitations are worth noting. One important lesson from this study is the difficulty of conducting prospective studies of families having a child with NDID. We were forced to limit the study to a cross-sectional design that could not capture the impact of physical activity program attendance and network formation in a dynamic way. More studies are needed to understand the changes in parents' networks and what they receive from peer support networks overtime. Although the physical activity programs were involved in planning the study, while implementing the study we realized numerous factors that we would take into consideration while planning the study in future. For example, the physical activity programs operate from September to June with various schedules and durations. Therefore, we need to ensure that our recruitment plan and the follow up process are flexible and adapted to the specific time period of each site to prevent losing out families. Also, a continuous update about the study every month and more involvement of the families in a 'collaborative project' (through different channels such as social media platforms) may help to retain participants in the study time period.

We observed that a majority of participants were mothers. This is consistent with most research assessing parental and family outcomes among children with NDID, and is also likely reflective of the distribution of parental responsibility in many families. This speaks to a larger issue present in the current study as well as more broadly in the field, associated with having only one member speaking on behalf of the collective family unit. The researcher attempted to

mitigate this concern in the qualitative component by allowing the study participants partners (if also present at the physical activity program sites) to participate.

Also, the data are limited by the fact that all surveys were available only in English, and therefore required participants to be reasonably proficient in this language. Although a range of ethnicities was represented in the sample, and approximately one third of participants indicated that a language other than English was spoken in the home, this study excluded families who were not comfortable enough with English to participate. This may be a particularly isolated and at-risk group of families, and the findings cannot generalize to this circumstance. It is important that in future research, a special effort to seek out and involve such individuals is performed, as they may require very specific supports.

Data are also limited by the fact that only those families of children able to attend the physical activity program can participate. Participants whose child's functional ability and severity may be different compared to those that participate in the study were not accounted for. This may be a particularly isolated and at-risk group of families, and the findings cannot generalize to this circumstance. It is important that future research make special effort to seek out these families. This may be challenging considering that children with higher severity of disability may not be able to attend these programs or they may require very specific supports and busy attending other therapeutic programs, which may not be group based.

In our study there is no control group, which is another limitation. Although children with NDID that do not attend PA program activities are quite different in many ways that makes the comparison less valid. For instance, those children not attending the programs most likely have increased functional severity and do not benefit from multiple exposure in daily life activities; therefore, the parents' needs are quite different compared to families attending PA programs and thus, would not be comparable. Therefore, having a control group made of children that do not attend PA programs would be highly biased, with considerable challenges to interpret the meaning of possible differences. However, for future studies, comparing these spontaneous peer-to peer support networks with organized peer support groups would help in understanding the comparative benefits and limitations of the PA program-related supports. It may also be possible to compare sites that offer social gathering to facilitate the peer-to-peer network development to other sites that do not offer any special support.

Selection biases is another issue, as our results reflect the parents' experience of those who were attending/ at physical activity programs and accepted to participate in the study, and therefore, were more likely satisfied than those who did not attend PA program. This "prevalence bias" is a general concern of all these studies whereby those involved actively in a support service are likely to have an optimistic view for it. This places restrictions on the inferences that can be drawn from the results. Thus, in order to overcome this, future studies, should include a prospective follow up of each individual with careful recording of the reasons for leaving the peer support network. Additionally, we also were not able to get in touch with parents who did not stay at the program sites as parental attendance was not mandatory. Only 3 parents over 50 stated that they preferred to leave instead of staying at the site; it is difficult to interpret this behavior that may be related to various factors the need to rest, some excess pressure they feel or different priorities. Finally, the cross-sectional nature of the study prevents drawing conclusion regarding this behavior, for instance to know whether it is a permanent trait or a simple 'need for respite' that happened at the time of interviewing families.

Finally, we implemented a mixed method study. Reflecting back on the experience, the interviews provided an in-depth understanding of the network. However, they were limited in certain aspects. For example, we did not explore the specific needs of the families and the families' mental health. Also, we did not measure the effect of PA program attendance on parents' mental health, which may have been helpful to further understand the families' interactions and emotional support at peer-to-peer support networks.

8.3 Future Directions

The thesis presented the exploratory phase of research to describe the spontaneous development of peer-to-peer support networks at physical activity programs and to assess its values and the determinants. Future directions include:

1) The comparison of effectiveness of PA program-related peer-to-peer support networks and other types of family peer-support networks. This involves interviewing families and measuring changes in mental health, family quality of life and resilience over time. This will help in understanding the difference and similarities between these two types of support networks on families.

2)   In our study, 75% families indicated they would like more structured family peer-to-peer support activities at the PA program. Therefore, implementing and evaluating the specific supports PA programs can provide to facilitate the development of peer-to-peer support groups will be an important study. Moreover, the implementation of a peer-to-peer support program as part of the PA program may assist in overcoming the issue of participants' recruitment, we faced in our study of spontaneous development of peer support networks. Also, this may help overcome the issue of participants' retention in the study as a timely follow-up may be more feasible as the PA program -related network will be one objective of the PA program.

3)   In addition to point 2 above, it may be worth considering the implementation of an online community of practice in collaboration with the physical activity programs. This online site will help parents share and exchange information as well as contact each other in times of needs. Also, parents not present at the PA program site, will be able to avail this support. Evaluation of this online site through interviews and a quarterly online survey will help in understanding the impact on families, the barriers and facilitators to attending the community of practice and the online knowledge uptake.

4)   Following this, implementation and evaluation of a pan-Canadian study (providing greater sample size and population diversity) will allow in the better understanding of the impact of the peer-to-peer physical activity program-networks on families and whether they are capable of providing adjunct support in different geographical and demographic areas. For instance, in rural BC, catering to the diverse rural and Indigenous populations.

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Appendices

Appendix A Summary of Peer-Reviewed Articles on Peer Support Networks

Table A.1 Summary of Peer-Reviewed Articles on Peer Support Networks for Families of Children with NDID

First Author; Year; Country where study conducted	Study Objectives	Parent Population; Child's characteristics	N= (parent, control, intervention group)	Methodology; duration	Features of support groups	Measured Outcome	Important results
Shu, B. 2005, Taiwan	To investigate the effect of peer support groups on the mental health and quality of life for mothers of children with autism	- mothers of children with autism (age between 30-51 years) - children diagnosed with autism	27, 19,8	-quasi-experimental; pre and post test -1 month follow up; 14 weeks	- face to face -facilitated by psychiatric nurse who helped facilitate interaction among members	- Chinese health questionnaire (for psychological well-being) - WHO quality of life questionnaire	- mental health did not significantly improve in the intervention compared to the control at the end of the first month and at follow up. However, employment status and subjective well-being affected mental health. Also, subjective well-being impacted quality of life. - support group participation provided emotional support to the mothers. Moreover the presence of a support group served as a buffer to stress. - the group leaders required continuous training in order to better support the caregivers
Santelli, B. 1995 USA	To explore the importance of the parent to parent support program as part of comprehensive family services	- parents participating in existing support groups; - children with different disorders: developmental delay, down syndrome, mental retardation, autism, learning disability, visual impairment, CP , multiple disabilities, chronic illness, prematurity, chronic	200 referred and 330 veteran parents	Two survey administered: one for referred parent and the other for serving parents	- face to face; - pre-existing group 1:1 peer to peer -referred parent matched with a veteran parent.		-the support groups provide referred parents with informational, emotional and other program supports (e.g. 24 h lines, family social events, group meetings for education etc. -Similarly veteran parents were benefitted from the training they received

		illness, prematurity, hearing impairment, and technology supported					
Elfert,M. 2015 Canada	To examine the impact of a support group for fathers of children with ASD	fathers of children with ASD (not be receiving psychotherapy or taking medication for mental health issues at the time of the study; Participants age range was 34–56 yrs - children with autism (3-15 years)	12 (Two groups of 6 fathers each)	-quasi-experimental; pre and post test, - 8 weeks 2h sessions; with a 4-month follow-up - Participants were assigned to one of the two groups based on their availability and geographic location (not random) - During the eight weeks that Group 1 was active, Group 2 engaged in no formal activities related to the study. The day after Group 1 completed its final session, Group 2 commenced and ran for eight weeks. During these eight	- face to face -facilitated by the researcher but no didactic instruction provided	five standardized instruments: - depression (Beck Depression Inventory-II) - parenting stress (Parenting Stress Index – 4th Edition Short Form) - marital satisfaction (Dyadic Adjustment Scale) - optimism (Life Orientation Test – Revised) - coping strategies (Ways of Coping Questionnaire)	-Results indicated no significant changes ; however, participants strongly supported the importance of the support group experience

				weeks that Group 2 was underway, Group 1 did not partake in any formal activities related to the study. Follow- up data was collected only from Group 1, four months after the conclusion of their group.			
Clifford,T. 2013 Canada	To evaluate whether participation in an online parent support group affects parent reported perceived stress, symptoms of anxiety, depression, and positive perceptions of their child.	- Parents of children with ASD (33 to 53 years), control group (26 to 65 years) - children diagnosed with autism (2 to 22 years); control group (3 to 17 years)	Finally (based on all test conducted, 25 parents (control) and 20 (intervention group)	-pre and post); - 8-session support group,	- online parent support group designed by the researcher as a discussion group for parents - facilitation from a counselling professional - topics of discussion were based on parent suggestions	-parenting stress, -positive perceptions, -anxiety and depression symptoms -participants completed a pre and post-group survey,	-No changes in parental well-being; however, the parents who participated in this online group reported being satisfied with the group and with the support received.

First Author; Year; Country where study conducted	Study Objectives	Parent Population; Child's characteristics	n= Parents	Methodology; duration	Features of support groups	Important results
Kingsnorth, S. 2011 Canada	To explore the benefits, limitations and outcomes of a parent -led peer support group for families of children with special needs during the phase of service transition.	- parents of transition-age youth who are receiving augmentative communication support (7 mothers and 1 father) - children with developmental and/or physical disabilities with a varied functional and communicative ability between 12-18 years	8	- Qualitative descriptive methods, focus groups were conducted in order to better understand the group dynamics; and observation -11 Transition peer support group sessions over 1 year. Each session is 2 h	- face to face - facilitated by experienced parent, experienced parent facilitated the interaction among families; 2-14 members in a group - pilot program created for research purposes,	- emerging themes suggest the peer group experience benefited parents by providing them with awareness, active planning methods and knowledge based on parental experience about the transition process into adulthood
Law,M. 2002 Canada	To examine the effects of parent led support groups on parents of children with disabilities	-parents of children with disabilities (ages:20-49 years) -children diagnosed with developmental problems: cerebral palsy, communication disorder syndrome, acquired brain injury Duchenne muscular dystrophy , global delay, autism, lupus, seizures, developmental problem behavior, developmental delay, seizures, hearing impairment, learning disorder, visual impairment ;	20 (from the nine parent led support groups were selected)	- open-ended interviews, observation of group meetings, and a review of support group documents	- face to face - facilitated by an experienced parent -pre-existing support program	-The interviews apprise the importance of parent led support groups: increasing skills, provide a sense of power and belonging. Moreover, participants interacted with each other and provided support and skills to deal with daily issues related to their child.

		ages: 0-17.9 years				
Shilling,V. 2015 UK	To explore the perceived outcomes for a one to one peer group for families of children with disabilities and the service providers	- parents and trained parent volunteers who were in contact with the Face2Face one-to-one befriending service during a 12-month period, and -10 professionals in health, social care and education services who are responsible for providing referrals to families and are responsible for providing funding to organizations	12 parents and 23 trained parent volunteers	-interviews and focus groups	- pre-existing program, parent is matched with a trained parent - individualized support provided face to face -facilitated by an experienced parent	-Shared experience was valued by all participant groups as a vital component of peer support. - Key outcomes include reduced social isolation and emotional stability and personal growth. -Likewise, by sharing information, the trained parents experienced positive outcomes by training, support being reciprocated and the feeling that they can help others.

		-children of help seeking parents were diagnosed with: ASD, ADHD, CP, Auditory processing disorder,, Congenital heart disease, Currarino triad, Severe learning difficulties, Spina bifida (age range: 3.5–14) years WHILE expert parents had children diagnosed with CP, Complex additional needs with sensory issues, Developmental delay, Down syndrome, Dyslexia, Partial trisomy and Semantic pragmatic disorder (age range: 4–22)				-The negative outcomes included the emotional drain they felt by befriending the support receiving parents
Linder,R 1979 USA	To explore the benefits of a weekly support group	-parents of children with disabilities (ages:20-49 years) -children with CP, muscle dystrophy or congenital cardiac anomaly	5 mothers	-observation by researcher -weekly meeting over 6 months	-face to face -peer to peer support groups initiated by researcher	-Mothers expressed the feeling of reassurance knowing that there was the group (a reference point) for them. -The groups allow them to interact with each other. Also, the kids

					played with each other while the mothers participate in the group, and they look forward to the playdates
Mueller, T.G. 2009 USA	To explore the experiences of mothers in the support group for Latina mothers of children with disabilities	-Spanish speaking parents of children with disabilities CP, Down syndrome, Multiple disabilities(heart condition, cleft pallet, speech and language needs deaf, mobility issues, seizure disorder, Multiple physical and cognitive disabilities (visual impairment, cognitive delay, motor problems) -The age of the children ranged from 4-16 years	8 mothers	-semi-structured interviews were conducted -monthly meeting throughout the year, with vacation during summer times	-face to face group -expert led group (local community board member in order to facilitate the group peer to peer interaction -informational seminars were also provided by experts; -during the meeting time, child care for the children with disabilities and their nondisabled siblings were provided	-Emerging themes suggest the support group experience provided the Spanish speaking parents with a feeling of family among the members allowing them to discuss their concerns in their own language creating an environment of trust -The group also contributed towards exchanging and receiving informational and emotional support -The child-care provision was viewed as positive among the parents
Troester, J.D 2000 USA	To explore the experience of parents in a support group facilitated by researchers from a special education class	-parents of children with disabilities such as autism, learning disability, multiple and severe disabilities, hearing and emotional disabilities (children were between 6-24 years)	17 parents in group; 8 parents participated in the evaluation	Qualitative analysis included observation, content analysis and evaluation by a form -30 sessions in total; session offerings of one and a half hours, arranged on a biweekly basis and adjusted	- face to face - peer to peer support provided - researcher initiated group group facilitated by the school social worker -babysitters took care of children while the parents attended the group;	-Evaluation of the group based on a survey at the end of the group sessions suggest parents found the group beneficial as it helped them to become more vigilant and have their views corrected, informative, and they enjoyed the group experience. -The content analysis illustrated

				to the school year calenda		that the main areas of discussion were about relationships, the emotional and physical needs of the children, community resources. -the parents felt they identified with each other.
Stallard,J 1993 UK	To explore the development and effects of a support group for parents of children with special needs	-mothers referred by professionals, these mothers have been experiencing difficulty in adapting to their child with special needs -children were diagnosed with, learning disorder, SLD and mobility problems (15-30 months)	22 parents; 5-8 in each group with 4 groups in total	- Qualitative analysis included observation, and evaluation by a form -one session per week; 10-15 sessions in total	-face to face facilitated peer support group - researcher designed group; facilitated by an expert psychologist and occupational therapist -nurseries with trained nurses to babysit the children whose parents participate in the support group	-Group evaluation suggested the mothers found the group useful, they could discuss feelings, education and other benefits. -The mothers group led to the formation of a fathers group. The fathers suggested it provided them with an opportunity such as to share their feelings, share problems with individuals in a similar position - at the end of the groups, even though the parents suggested they would like more sessions in future, there were none after the group ended
McCabe, H 2013 China	To examine the benefits of two support groups: a) group for parents of young children verses b) parent with elder children with special needs	-group A: parents of children with autism and group B: parents with children with intellectual disability or mental health disabilities	group A+B initial attendance was 42; number of total interviews from both groups=10 interviews	-semi-structured interviews were conducted one year after the support group was initiated, -also, open ended questionnaires were	- face to face - expert parent/researcher led, facilitated peer support group -group organised by two chinese parents and researchers; -for group A, parents left kids	-Results from both groups suggest that the parents benefitted from the groups in terms of sharing of information, learning from others experience. -Interestingly, Group A parents requested more

		-group A children were mostly 10 and under, except 5 families being 11 and above; group B children were between the age of 20-33		administered during month 5 and 11 monthly sessions over the year qualitative	at home while for group B, parents brought children along	information to handle their children while -group B parents were interested to know about more opportunities available for their children.
McCabe, H. 2008 China	To explore the experiences of participants before, during and after a short term support group program	-group A: parents of children with autism, attending the Autism Institute support group and group B: parents with children with autism attending the government run mental health centre -children with autism (group A: 3-14,B: 4-7 years)	43 parents in total from both groups	-semi-structured interviews -group A: four, 11 week sessions per year (families are served in four small groups) while group B are individualized sessions	-group A is a facilitated expert led group while groupB is a one to one individualized peer support group -face to face -pre-existing groups;	-Emerging themes focus on the importance of these groups for parents (in two ways): as a means for sharing and learning from each other and, supporting and accepting each other
Lock,R.H. 2010 USA	To examine the family fun days experience as a venue for providing opportunities for parent's support in addition to the children leisure activities	-parents of children with autism attending the family fun days (age range: 20-59 years) -children with autism (age range:5 to 18 ears)	25 families (23 mothers, 1 father and 1 grandmother) for the open end surveys; 11 participated in the interviews	-semistructured interviews, evaluative surveys and observation -Family days expanded over 6 weeks in summer	-face to face -peer to peer support provided; - initiated by the organization, based on parental requests; family days was initiated to bring the parents together	-Family fun days provided parents with the opportunity for interacting with each other and connect with on issues relating to their child. - regarding parents time, parents felt more in control in the amount of time they spent in interacting and participating in fun activities with their children. Moreover, they did not feel pressured and looked forward to interacting with other parents. -With an increase in the number of

						participants over the conventional support groups, these activities have the potential to attract families that avoid formal support groups to participate and interact with parents
Lo,L. 2010 USA	To explore the purpose and perceived benefits of Chinese families attending support groups	-Chinese parents with a child with disability who has participated in a support group -children with autism, learning disability, cerebral palsy, hunter's syndrome and hard of hearing	15 families	Semi-structured interviews	-families were recruited from two support groups hosted by a community organisation and a parent. -The groups were parent led by a parent having a child with a learning disability -face to face interaction -families were recruited from the 'same culture' support group	- the Chinese families participated in the Chinese support groups as they wanted to meet families who had the same cultural background and were experiencing the same 'cultural' pressures. - participation in the group made them feel supported, provided the families with a sense of belonging, empowerment and informational support. Also, it helped to generate hope for the future
Huws,J.C. 2001 UK	To investigate the experiences of parents in an email discussion list	-parents in an email group concerning children with autism	374 email addresses of parents were examined	symbolic interactionism methodology is used as as it recognizes the impact of interpretive processes such as the email discussions and social	-face to face -online email group where pre-existing email group messages were analyzed	-the group provided an active social network for the parents. - the email list allowed parents to reappraise their situation, make meaning and understand autism which supported

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				contexts such as the parents'daily life functioning in which meanings and actions are negotiated		them to adjust to changes, share experiences and understand and provide support
Frigerio,A 2016 Italy	To examine the dynamics of the interactions that occur within a self-help group for parents of children with ADHD	parents of children with ADHD attending a ADHD mutual support group	Over a 6-month period, the authors observed the meetings of a self-help group of parents of children diagnosed with ADHD.	- an ethnographic-discursive approach to observe the forms of interaction and collaboration exhibited among parents over 6 months - the meetings were monthly, and each meeting lasted approximately 3 hours	-peer to peer support group -face to face -pre-existing groups; -facilitator moderates the group	- Observation of the interactions among group members suggest that the production of a "homogeneous space" and a shared experience within the group allows parents to cope with issues and appraise themselves as good parents
Fine,M. 1983 Canada	To explore support groups for parents of children with downs syndrome and other disabilities	-from parents attending the Peel Infant Stimulation program, the parents were chosen by the program coordinators assessment, based on family functioning children 2 years and under with down syndrome and multiple handicaps	6 families per group (group size kept small to ensure all members get a chance for engaging with the group)	-observation over 6 weeks of a group created for research purposes	-expert facilitated (social worker and psychologist) peer support group -face to face -not a pre-existing group; the group created as a part of an infant program. It provides problem solving strategies for the parents to deal with their child	- feedback from the co-ordinators and the questionnaires filled by parents at the end of the program suggested the parent support program was beneficial for the parents as it allowed the parents to share information and emotions with each other

Carter,I 2009 Canada	To explore the experiences of parents of children with autism in an online self-help group	-parents with children with autism living in the Greater Toronto Areachildren with autism	22 parents (17 mothers, 3 mother and father dyads, 1 mother and grandmother dyad, and 1 divorced father)	semi-structured interviews; thematic analysis	-Online pre-existing online peer support group	The emerging themes suggest, the online groups support families by providing them with information, opportunities to interact with each other and a tool for promoting advocacy among the members. -The list of challenges included accessibility issues, lists of unknown and costly treatments, confidentiality issues.
Ainbinder, J. G. 1998 USA	To explore qualitatively the experiences of parents in the parent to parent support programs	-parents of children with special needs -children with special needs (age=1-16 years) special needs (non-categorical approach)= children with any developmental disabilities, learning disabilities, emotional needs or special health care needs- mild to severe diagnosis of CP, epilepsy, developmental delay, mental retardation. learning, hearing/vision deficits	24 parents recruited were biological parents (23 mothers, 1 father)	-semi-structured telephone interview -one on one, matched with trained parent; parents were randomly assigned into two groups: either they were directly matched or waited for 8 weeks before matched	- peer to peer (one is to one match) - pre-existing support program evaluated -face to face -support group matched	-Parental attendance in the peer support networks resulted in favorable interaction and learning among parents -successful match depends on a reliable supportive parent consisting: 1) similarity in condition 2) availability of individual 3) comparable conditions, allowing learning and growth 4) mutuality of support -barriers to group formation : Parents busy schedule long distance between the parents involved negligent follow up by other parents

Aldersey,H.M. 2016 Congo,Africa	To explore the experience of parents in a self-help group	-parents of children with intellectual disability	14 members (mothers, fathers, sister, grandmother)	-observation and semi-structured interviews peer support for eight weeks	-face to face support - pre-existing support program evaluated peer to peer support -group leader is a experienced parent	-Through observation by the group members parents illuminated upon the importance of support provided by peers in the group- emotional, informational, material, instrumental and physical support
West,A 1998 UK	To pilot and explore a group for fathers of children with down syndrome	-parents of children with down syndrome -children were aged from 14 weeks to 4.5 years	4 fathers	-observation (4 sessions, with each session for 1h)	-face to face support - program developed by researcher to evaluate the importance of peer networks	-The researcher observed that the fathers gave and received emotional and informational support. Anger and anxiety were the predominant emotions expressed -the researcher noticed the powerful group dynamics and the mentorship provided by the 'senior' fathers to the 'junior' fathers -the fathers reported a positive experience for attending the group and would like to attend in future
Swanke,J 2013 USA	To explore the interest of mothers to participate in social networks through blogging	-parents of children with ASD	25 mother bloggers	-observation by researcher (reading the blogs)	-online network	-the blogs demonstrated the emotional support blogger mothers provide to each other in their online world -it provided them the ability to express themselves freely and separate from the physical world -through blogs, the mothers provided each

						other with instrumental support as well such as feedback on parenting experiences, advocacy -they referred to blogging as a therapeutic experience as it allowed mothers to communicate freely

First Author; Year; Country where study conducted	Study Objectives	Parent Population; Child's characteristics	N (Parents) N (Control) N(intervention)	Methodology; duration	Features of support groups	Measured Outcomes	Important results
Singer, George HS 1999 USA; conducted in five states: Kansas, New Hampshire, North Carolina, South Carolina, and Vermont	The study evaluated the effect of the multisite 'Parent to Parent' support programs for parents	-Parents, foster parents, or grand parents of children with a disability or chronic health conditions not presently participating in the 'parent to parent' support programs, majority sample consisted of mothers and one father -mean age of the children were 6.9 (intervention) and 7.7 (wait-list group)	128 (Quantitative); 24 (Qualitative, randomly selected from the pool of participants categorized as those who found the group helpful verses those who did not in the quantitative part)72 (waiting list control; these participants were provided with Parent to Parent support after the post-test)	-Mixed-methods: RCT, 2 months ; pre and post test comparison between intervention and control group; -Qualitative: semi-structured interviews (emerging themes were identified using the constant-comparative method)	-peer to peer. Parents matched with a suitable trained mentor parentthe parent interacted with the mentor through 4 phone calls over 2 monthsPRE-EXISTING support program, 1:1 match with a mentor	-Cognitive adaptation (Kansas Inventory of Parental Perceptions scale); -Empowerment (Family Empowerment Scale), Coping (Parent Coping Efficacy Scale), progress made on a problem and helpfulness of the group	-parents using Parent to Parent for "non- urgent" help benefit from engaging with other parents by (a) coping better with their child and family's situation, (b) view their condition with greater positivity and (c) able to progress on goals that are important and make a difference iin their lives -Parents did not feel empowered by only a brief involvement with the program
Solomon, M. 2001 UK	The study examined the positive effect of support groups on parents of children with special needs	-six support groups were recruited for the study. -Parents from these groups were recruited (the mean length of time for parents in these groups was 3.9 years). The sample constituted 52 mothers and 4 fathers	-56 (Quantitative); - 43 (Qualitative;	Mixed-methods: Quantitative: crosssectional study; Qualitative: focus group sessions (emerging themes were identified using the constant-comparative method)	-facilitated by a trained parent, -the group interacted face to face -meeting continued for 2 h -pre-existing support program	-Overall helpfulness (session impacts scale), -satisfaction (client satisfaction questionnaire), -group social climate (group environment scale)	-From the quantitative data: parents significantly benefitted from their groups rating them high on helpfulness and satisfaction, cohesion and task orientation. -From the qualitative

		-mean age of the children was 9 years (range=1 to 26 years); the children's condition included specific learning difficulty, dyspraxia, attention deficit disorder, or speech delay, a severe or profound mental or physical disability or both, autism spectrum disorder and moderate learning disabilities					data, parents' described an increased sense of control, sense of belonging to their community, and their experience of self change towards the situation
Bray,L. 2017 UK	To explore the impact of peer to peer support groups on the well - being of parents of children with special needs.	-parents of children attending the face to face support group -children were diagnosed with ASD, Down's syndrome, Cerebral palsy, Attention Deficit Hyperactivity Disorder, Microcephaly, Fragile X , Foetal alcohol syndrome, Genetic disorders	-70 interviews (qualitative) were conducted and -68 sets of questionnaires (quantitative)	-Mixed-methods -prospective concurrent mixed method study design with baseline and follow-up data to map out any changes. -Qualitative interview data and quantitative questionnaire data provided different but complementary sources of evidence and were afforded equal priority in the collection and analysis process	-peer to peer; one is to one match of befriender with befriendee -face to face -pre-existing support program	-General Health Questionnaire -12 (GHQ-12)(examines psychological distress and parental mental wellbeing), -Pediatric Inventory for Parents (PIP) (Assesses parental stress related), -Peds QLTM -Family Impact Module (Health Related Quality of Life and Family Functioning)	-The peer-to-peer parenting support created meaningful relationships for 'befriendees' for opportunities to thrive - the Befrienders also thrived as a result of their interaction; through training, engaging with others and seeing possibilities for the near future -The quantitative

							evidence is supported by the qualitative evidence; demonstrating improvements in emotional and psychosocial well-being. -The befriendees transversed from a position of" 'feeling lost' and 'struggling day by day' towards a 'better place.'"
Shapiro, J 1989 USA	To explore the relation between support group participation and meaning attribution to stress and depression levels in mothers	-mothers of children suffering from developmental delays, children with down syndrome, cerebral palsy, William syndrome, spina bifida, and developmental delay	-56 (34 already participated in a support group, 22 did not before)	-Mixed methods: Quantitative: questionnaires and semi-structured interviews -All groups met approximately once a week for 1-1.5 hours	-face to face -facilitated by a licensed psychologist -pre-existing groups,	-The Center for Epidemiological Studies Depression Scale, -The Coping with Stress Inventory, -The Questionnaire on Resources and Stress	-mothers participating in support groups were less depressed than those who didn't; perceived as less burdened due to their child than those who did not take part and engaged in greater problem solving coping strategies with their child. -no significant relation between participation and other stress or coping scales. -Mothers rated high on the meaning scale, were

							positively correlated with decreased depression and stress (in terms of daily aspects of care). meaning was positively correlated with emotional coping and problem solving coping. However it is unclear whether support groups resulted in greater meaning or vice versa, higher meaning mothers received higher benefits in support groups

First Author; Year; Country where study conducted	Study Objectives	Parent Population; Child's characteristics	N= (parent, control, intervention group)	Methodology; duration	Features of support groups	Important results
Shilling,V 2014 UK	To explore the factors (both facilitators and barriers) that contribute towards the development of a participants shared experience in a support group	-parents and trained parent volunteers who were in contact with the Face2Face one-to-one befriending service during a 12-month period, and 10 professionals in health, social care and education services who provide referrals to families and funding to organizations -children of these parents were diagnosed with: ASD, ADHD, CP, Auditory processing disorder,, Congenital heart disease, Currarino triad,Severe learning difficulties, Spina bifida (age range: 3.5–14) years WHILE expert parents had children diagnosed with CP, Complex additional needs with sensory issues, Developmental delay, Down syndrome, Dyslexia, Partial trisomy and Semantic pragmatic	12 parents and 23 trained parent volunteers	interviews	-face to face -peer to peer match -pre-existing support group	-Results suggest formal structures such as proper training of the matched parents, ongoing supervison and the rightful matching of the support receiving parent and befriender are important for the successful operation of a mutual support group

		disorder (age range: 4–22)				
King,G. 2000 Canada	To explore the organizational characteristics and factors affecting the longevity of the self-help support groups	-parents of children with special needs were recruited from these nine groups (20 to 49 years) -children CP, communication problems, various syndromes, and acquired brain injury (5%). Secondary development problems included developmental delay (70%), learning disorder, seizures, behavior problems, hearing impairments, and visual impairments.	20 (10 mothers and 10 fathers)	-Qualitative (semi-structured interviews and observation of group meetings)	-face to face -most groups held meetings once a month or less	-Emerging themes about important organizational characteristics determining the group longevity are effective leadership strategies, community connections providing funds and the inclination of group members to change the activities to meet the shifting group needs. This allows the effective functioning of the groups over time.
Hammarberg,K 2014 Australia	To investigate the barriers and promoters for participation in peer support group programs	-parents/caregivers attending the group during the school year (25 to 45 years) -children with special needs	20 parents	Qualitative (semi-structured interviews)	-Meetings of groups of 4–12 carers are facilitated by a trained group leader and assisted by a play helper. -Group facilitators are workers qualified in disability, parenting or family support. Play helpers keep children, including under school-aged	-Good group facilitation, presence of play helpers, access to information and expertise, and the mutual support among members emerged as the most important promoters of group participation. -Barriers included insufficient funding to run the program throughout the year, diversity in group members' socio-economic position and severity of their childs disability.

					siblings, occupied with a range of activities while the parents engage in the group activities .	
					- In addition to reciprocal peer support, group members are offered information to help them navigate the disability funding and service systems and manage the daily functioning with a child with high and complex needs. -Groups also have a modest budget to occasionally invite external speakers or people who offer services such as art therapy	

First Author; Year; Country where study conducted	Study Objectives	Parent Population; Child's characteristics	N (PARENTS)N (Control)N (INTERVENTION)	Methodology; duration	Features of support groups	Outcome measures	Important results
Papageriou,V. 2010 Greece	To investigate the reason why parents attend support groups	parents of children with ASD attending support groups	299 parents(72 fathers and 227 mothers; age ranging from 27 to 60 years)	Quantitative (open end questionnaire)	-face to face		-Most parents state that they participated in the groups as that they wanted to be informed about developments in the area of ASD, such as new therapies, wanted to receive support, engage with parents of children with similar disabilities, Also, the parents felt they needed pome informal psychological support that the group could provide -They found that the types of needs reported by parents were influenced by their level of education, and gender and age of their children, but that there were no differences in the type of

							occupation of the parents.
Clifford,T. 2013 Canada	To examine the influence of beliefs about support groups, beliefs about significant others' opinions about support groups, mood, coping style, and social support between individuals currently attending, previously attended and never attended support groups.	-parents of children with ASD (age range: 24 to 65 years)	149 parents [based on their support group use: never used support groups (n = 36), past support group use (n = 37), and current support group use (n = 76)]	Quantitative (questionnaires)		-State Trait Anxiety Inventory, -State-Trait Depression Scales, -Kansas Inventory of Parental Perceptions, -Types of Support Questionnaire, -Brief COPE, -Views About Parent Support Groups Questionnaire	- the three groups differed significantly in their beliefs and attitudes about support groups and in their use of adaptive coping strategies; however, no significant differences in availability of peer support, anxiety or depression signs, or beliefs about control of ASD was observed. - current support group users reported using more adaptive coping strategies than the other two groups.

							Past group users mentioned they did not find the groups as beneficial as current users, and those who never participated in peer groups reported difficulties with accessibility.
Mandell,D.S 2007 USA	To examine the factors associated with support group participation	-family members (mothers, fathers and legal guardians) of children with autism (age range:23-70 years) -children with autism (age range: 2-53 years)	1005 participants	Quantitative (survey)			-Adjusted analyses suggest participation in a support group is associated with demographic characteristics such as child age, child sex, ethnicity, parent education and income. -the surveys suggest parents of children who are self-injurious, have sleep and language problems are more likely to attend these groups, as well as parents who are referred by their consulting physician.

Appendix B Demographics Questionnaire

- **<u>Demographics</u>**

➢ Relationship to child:

➢ Please check which form of contact is most preferred: Telephone   E-mail

➢ Age: _____

➢ Gender: _____

➢ Marital Status: Married   Common Law   Divorced

                   Separated   Widowed   Never Married

➢ How many members are there in your family (who reside with you in your home)? Who are they? (e.g. grandparents, other children etc.)

_____

➢ Primary Language spoken at home:

_____

➢ Other languages spoken:

_____

➢ What is your family's cultural or ethnic background? (e.g. Italian, Metis, Cantonese, English, Canadian)

_____

_____

➢ What is the primary employment status of each of the child's parents:

Mother: Unemployed Retired   Employed part-time   Employed full-time

              Homemaker Student   Other

Father: Unemployed Retired   Employed part-time   Employed full-time

              Homemaker Student   Other

➢ Occupation of parents (if employed):

Mother: _____   Father: _____

➢ Highest education level of parents (please check one):

Mother: Elementary School   High School   Professional Diploma

| | Undergraduate | Graduate | Other |

Father: Elementary School   High School   Professional Diploma

            Undergraduate   Graduate   Other

➢ Annual Family Income:

< $20,000 $21,000-$49,999 $50,000- $79,999 $80,000-$109,999

$110,000-$139,999 $140,000-$169,999   >$170,000

➢ Which family member(s) is/are involved in the day-to-day functioning of the family members?_____

➢ How much responsibility do you personally have in the day to day functioning of your family?

Much more responsibility than I would like

More responsibility than I would like

About the responsibility I like

Less responsibility than I would like

Much less responsibility than I would like

- How much responsibility related to your family member with developmental disorder, do you personally have?

Much more responsibility than I would like

More responsibility than I would like

About the responsibility I like

Less responsibility than I would like

Much less responsibility than I would like

- **Child's information:**
  - How many children do you have: _____
  - What are their ages: _____
  - Do you have more than one child with a developmental disability? YES   NO
  - If YES, how many children do you have with a developmental disability, in total___
  - What are their diagnoses: _____
  - Ages: _____

- Child's primary diagnosis:_____

- If your child is diagnosed with autism ☐ YES ☐ NO

  Child primary autism diagnosis:

➢ What kind of professional diagnosed the child?

  Pediatrician   Family doctor   Psychologist   Psychiatrist

  Diagnosis through BC Autism Assessment Network (BCAAN)

➢ At which age was your child diagnosed:_____

➢ Current professional services received:_____

  _____

➢ Does your child take medication regularly: YES   NO

  If YES, please specify: _____

➢ Which agency provides your family with funding services:

  BC Ministry of Children and Family Development (Autism Funding Program)

  Community Living BC   None   Other

  If other, please specify: _____

➢ How satisfied are you with the resources and funds available?

  Very Dissatisfied   Dissatisfied   Neither   Satisfied   Very Satisfied

  Please explain: _____

  _____

➢ Please estimate your child's level of intellectual functioning in comparison to peers:

  Low   Low Average   Average   High Average Superior

➢ Please estimate your child's level of social functioning in comparison to peers:

  Low   Low Average   Average   High Average Superior

➢ Often children with developmental disabilities have more than one condition. Please check all than apply to your child:

Intellectual disability

Behavioral problems

Mood/expression/anxiety problems

Severe psychiatric disturbances (schizophrenia or other psychoses)

General problem with motor control/ co-ordination

Seizures

Alzheimers disease or other types of dementia

Major vision impairment

Major hearing impairment

Sensory integration impairment

Speech or language difficulties

Feeding or eating difficulties (feed tubes, major allergies)

Heart problems

Asthma or respiratory disease

Gastrointestinal/digestive problems

Other

If other, please describe _____

➢ Would you classify your child's disability as:

Mild   Moderate   Severe   Very Severe

➢ Does any other family member (other than the children) have a developmental disability?

☐ YES   ☐ NO

If yes, what are their diagnoses _____

➢ Do they have any other conditions. Please check all that apply.

Intellectual disability

Behavioral problems

Mood/expression/anxiety problems

Severe psychiatric disturbances (schizophrenia or other psychoses)

General problem with motor control/ co-ordination Seizures

Alzheimers disease or other types of dementia

Major vision impairment

Major hearing impairment

Sensory integration impairment

Speech or language difficulties

Feeding or eating difficulties (feed tubes, major allergies)

Heart problems

Asthma or respiratory disease

Gastrointestinal/digestive problems

Other

If other, please describe _____

Appendix C Interview Guide

Note:

1. The transcript is a guideline for the questions to be asked; the questions are not necessarily asked in the same way and order as documented in the transcript)

2. The baseline questionnaire contains information on the immediate family members/those who stay with you.

Interview Transcript:

Hello,

Thank you for participating in our study and in completing the questionnaires. Today we will conduct the next part, that is the interview about the type of supports you received and still receive from other families, friends or family members. All the information we collect will remain confidential. Any names provided in the process will remain confidential and will be de-identified in case of public use eg. for publication purposes.

1. <u>Family and friends</u>

Me: You mentioned you have x family members in your house. Can you name them?

Participant: 4, son, daughter, husband and wife…………………………

a) The personal support (individuals)

Me: Could you name some people who are important for you in relation to your child's condition; they are not necessarily friends and family members. For instance because they have experience and can share resources, because they provide good and trustful support for you, because they are important for your child, or because they facilitate social participation

Participant: _____   _____

_____   _____

_____   _____

_____   _____

Me: Now For each participant listed I would like to know some information. We will start by the persons you feel the most important for you:

Important Participant #1: _____

1. Relationship to respondent _____
2. What kind of support do they provide to you/child and family? _____
3. How do you know each other? (e.g. same club, church…)_____
4. How long have you known him/her

   _____

5. How often do you see him/her? How often are you in touch by phone or internet
6. Do you provide them with support?   _____
7. Are they other people that are part of the same "group"? how many (only provide #s)?
8. What activities do you do together?

Participant #2: _____

b) The personal support (from group/organizations)

Me: From the list, we can see that you have connections with people in different organizations (list….) Could you rank these organizations in order of their importance for your/ family). If other organizations also help you, you may identify them.

Organizations:

_____   _____
_____   _____
_____   _____
_____   _____

2. Physical activity programs

2.1 History (PA Programs that are not attended anymore)

Me: What Community-based programs has your child attended (exclusion of PT, OT ST)? Can you provide a brief historical account from past to <u>present</u>.

Participant:………..

First one:

a. What was the age of your child? Which program?

b. What was the program like?

c. What were your expectations? Did it meet your expectations for you and your child? Can you elaborate

(Prompts: Overall, was it a good experience for your child? (what was good; any friendship?); any difficulties? Why did you stop attending? Was it a good experience for you? Do you still have connections with this PA Program?)

d. Did you meet other parents there that you are still in contact with now?

Second one: etc…

2.2 Present PA Program – and other concomitant attendance of other PA Programs:

2.2.1 Your child is in the _____program (the one where recruitment happened and others) Which of these programs is most important with regard to the personal support you gain?" If the parent name a different program, I would use the same set of questions you use for the reference one (where interview is conducted)

(if two children, focus can be on both or parent dependent; they can mention ALL programs they attend, ask which is more important for support)

1. Program characteristics
   a. Your child is
   b. How did you hear about the program? What were you told about the program before your started?
   c. What were your expectations about the program?
   d. Why did you decide to have your child participate in this program?
2. Program Participation
   a. How long has your child been attending this program?

     b. How do you think your child benefits from the program?

     c. What are the challenges in having your child attend the program?

     d. How do you pay for the program?

3. Social participation

     a. When your child is attending, what do you do?

          .(example, on site watch, talk to others….)

     b. Do you or other members of the family benefit from your child's participation?

     c. What interaction do you have with other families?

     d. Have you learned anything from other parents at the program?

     e. Is the program organizing social activities for families? Do you attend? Are you involved in activities in the PA Program

     f. In your opinion, should activities for child/families be organized more systematically by the PA Program?

2.2.1 Your child is also in _____program (#2)

    1. Program characteristics

       a. Your child is etc…. etc….

Me: <u>In the xxx programs you are presently attending:</u>

Me: Now, I would like you to name a few friends that <u>are (or were) part of the physical activity programs you have attended </u>who you think are important to you/ your Child/ family

Participant: _____   _____

_____   _____

_____   _____

_____   _____

_____   _____

Me: Now for each participant listed I would like to know some information. We will start by the persons you feel the most important for you:

Important person #1

    a. For how long have you known this persons? At which PA Program?

    b. Did you know them prior to the program_____

    c. What support do they provide to you/child/family

        _____?

    d. Do you provide them with support_____?

    e. How often do you see/contact each other?

    f. Do you have activities together (social, leisure…..)?

    g. Are there other people that are part of the same "group"? how many (only #)?

FINALLY:

Me: Previously, you've mentioned the systems that are important for your family (list from above). How do you see the importance of the PA Programs networks for you and your family? Please describe

How do you compare them to other networks you described at the beginning of the interview

Participant: _____   _____

_____   _____

_____   _____

_____   _____

_____   _____

Recap ……

Closing:

    a. Are there other things that you feel would be important for us to know, which we haven't covered in our interview?

b. Do you have any specific questions for me?

Thank you very much for your participation.

Appendix D Details of the Quantitative Section

D.1   Results for objective 3: Association between PA Program-related Social Networks and FQOL, Family Resilience and Self-Efficacy

This objective is studied by assessing the correlation between the perceived social support from PAP friends (PSS-PAP friends) scores measured using the perceived social support from PA Program friends scale and the score obtains at each of the 3 scales FQOL, FRAS and FES. We present them in three different sections.

D.2   Association between Perceived Social Support from PAP friends (PSS-PAP friends) and Family Quality of Life Satisfaction (FQOL) after Controlling for Demographic Variables and other Predictors.

Hypothesis: the score of PSS-PA Program friends is positively associated with FQOL satisfaction after controlling for child age, family income, years in the program, family perceived social support and non-PA Program friends perception of social support

Bivariate analysis examined this relationship between FQOL and continuous predictors such as age, family income, years in the PAP program, perception of social support from family (PSS-family), perception of social support from non-PAP friends (PSS-NPAP friends) and perception of social support from PAP friends (PSS-PAP friends). Table D.1 shows the correlations matrix; all variables were positively associated with FQOL, which means that the higher the value for each variable, the higher the FQOL. Highest correlations were found for PSS-family, PSS-NPAP friends and family income. Many of the variables were also associated with each other (Table D.1); for instance years in the program was positively associated with child age.

Table D.1. Correlations Among FQOL, Demographic Variables, PSS-Family, non-PAP friends and PAP friends

Predictor Variables	1	2	3	4	5	6	7
1. FQOL	-	0.38^{**}	0.43^{**}	0.31^{*}	0.695^{**}	0.44^{**}	0.35^{*}
2. Child age	-	-	0.22	0.65^{**}	0.31^{*}	0.055	0.07

		1	2	3	4	5	6	7
3.	Family income	-	-	-	0.38**	0.39**	0.24	0.32*
4.	Years in program	-	-	-	-	0.37**	-0.00	0.15
5.	PSS-family[1]	-	-	-	-	-	0.43**	0.47**
6.	PSS-non PA Program[2] friends	-	-	-	-	-	-	0.56**
7.	PSS- PA Program friends[3]	-	-	-	-	-	-	-

$^*p < .05,\ ^{**}p < .01$

[1]PSS-family refers to perceived social support from family members
[2]PSS-non-PA Program friends refers to perceived social support from friends who are not part of the PA Programs
[3]PSS-PA Program friends refers to perceived social support from the PA Program friends

We then computed a multivariate Hierarchical Regression Model

From Table D.1. we can see that Family income, child age and years in program were significantly correlated with the outcome and/or other predictors while other variables such as ethnicity and marital status (not included here) were not strongly correlated with the variables and therefore not included into the model. The variables were added in a stepwise way into the model as illustrated in Table D.2

Table D.2: Hierarchical Multiple Regression Analysis of the Association between FQOL and PSS-PA Program friends

Predictor Variable (OUTCOME=FQOL)	R	R^2	Adjusted R^2	b	SEb	Standardized Coefficient β	p
Step 1	.522	.272	.225				
Constant				3.91	.084		.000
Child Age				.033	.017	0.327	.054
Family Income				5.003e-6	.000	0.377	.008
Year in Program				-0.007	.028	-.047	.790
Step 2	.751	.564	.515				
Constant				3.87	.067		.000
Child Age				.023	.013	.234	.083
Family Income				2.35e-6	.000	.177	.127
Year in Program				-0.016	.023	-.102	.474
PSS-family				2.60	.062	.523	.000
PSS-non PA Program[2] friends				.078	.057	.155	.179
Step3	.753	.567	.506				

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Constant				3.871	.068		.000
Child Age				.023	.013	.227	.097
Family Income				2.44e-6	.000	.185	.118
Year in Program				-0.015	.023	-.096	.507
PSS-Family				2.67	.064	.538	.000
PSS-non PA Program friends[2]				.078	.065	.184	.158
PSS-PA Program friends				-.032	.063	-.066	.614

[1]PSS-family refers to perceived social support from family members
[2]PSS-non-PA Program friends refers to perceived social support from friends who are not part of the PA Programs
[3]PSS-PA Program friends refers to perceived social support from the PA Program friends

From Table D.2, we see that in Step 1, only family income approached significance (p =.01), accounting for 14.4% of the variance in the outcome. In Step 2, the predictor PSS-Family ($p < .001$) was significant, and accounted for 28.8 % of the variance in the model above and beyond child age, income, years in the program and PSS-non PA program friends. In Step 3, the final predictor PSS- PA program -related friends was added to the model. Here, only the predictor PSS-Family was significantly associated with FQOL ($p < .001$) and was the only predictor to make a significant contribution in the final model.

Thus, the regression coefficient value indicated that a one standard deviation unit increase in PSS-Family was associated with a .53 standard deviation unit increase in FQOL satisfaction, if the effects of all other predictors were held constant. This indicates the strong association between perceived social support from family and family quality of life above and beyond other predictors in the model.

After each step 1, 2 and 3, the models were checked for interaction terms. Interaction terms were not significant and therefore they are not part of the final model

How does FQOL score vary across different PSS PA Program-related friend levels?

Hypothesis: Individuals with high level of perceived social support from PA program friends (PSS- PA program friends) will have a higher FQOL score.

PSS- PA program friends scale was categorized into high (score>5), medium (score 3-5.0) and low (score =<3) perception of social support, based on the scale raw scores.

ANOVA

A one-way ANOVA was conducted to compare the mean FQOL in different categories of PSS PA program -related friends (low, moderate and high) entered as a fixed factor. Normality was

assumed due to the presence of univariate normality. The assumption of homogeneity of variances was met for the FQOL domain as demonstrated by Levene's test ($p > .05$). Because the sample sizes were unequal in the three groups, the Welch's F test ANOVA was used. The F test was $F(2, 14.49) = 4.37$, $p < .05$, indicating that there was a significant effect of the level of PSS PA Program-related friends on FQOL. This was followed by Gabriel's post-hoc procedure which revealed that participants in the 'low' PSS- PA program friends group had a statistically significant lower mean FQOL satisfaction than those in the 'moderate' and 'high range' of PSS-PA program related friends. The difference of FQOL between 'high' and 'moderate' PSS- PA program related friends was not significant. For details refer to Table D.3 and Figure D.1

Table D.3 Descriptive Statistics of FQOL Across Levels of PSS-PA Program-related friends

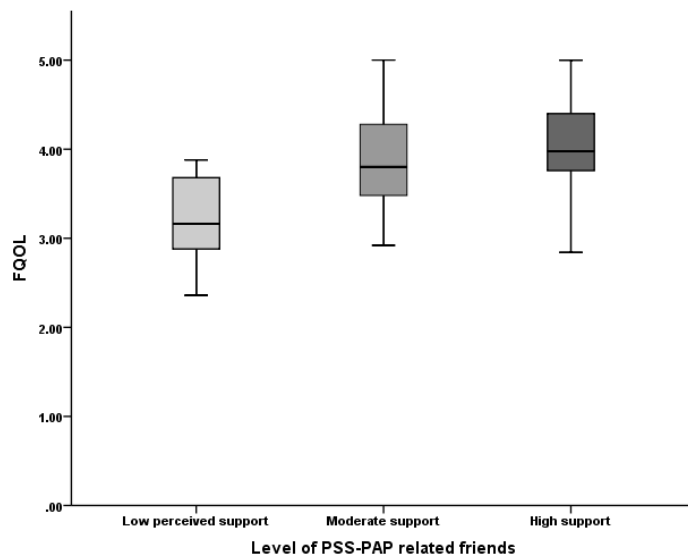| Level of Perceived Social Support from PA Program-related friends (PSS-PA Program related friends)	FQOL (Mean, S. D)	N
Low level of perception of social support from PA program -friends	3.19 (0.56)	6
Moderate level of perception of social support from PA program -friends	3.88 (0.59)	26
High level of perception of social support from PA PA program -friends	3.97 (0.59)	18

Figure D.1 FQOL Satisfaction Across Different Levels of PSS-PA Program friends

D.3 Association between Perceived Social Support from PAP Friends (PSS-PA Program friends) and Family Resilience (FRAS) after Controlling for the Demographic Variables and other Predictors

Hypothesis: the score of PSS-PA Program friends is positively associated with FRAS after controlling for child age, family income, years in the program, family perceived social support and non- PA program perceived social support.

Bi-variate analysis was used to examine this relationship between FRAS and continuous predictors such as age, family income, years in the PAP program, perception of social support from family (PSS-family), perception of social support from non- PA program friends (PSS-non-PA program friends) and perception of social support from PA program friends (PSS- PA program friends). Table D.4 shows the correlations matrix; all variables were positively associated with FRAS, which means that the higher the value for each variable, the higher the FRAS. Highest correlations were found for PSS-family, PSS-non PA program friends and family income. Many of the variables were also associated with each other; for instance years in the program was positively associated with child age.

Table D.4 Correlations Among FRAS, Demographic Variables, PSS from family, non-PA Program friends and PA Program friends

Predictor Variables	1	2	3	4	5	6	7
1. FRAS	-	0.11	0.30^*	-0.03	0.44^{**}	0.31^*	0.25
2. Child age	-	-	0.22	0.65^{**}	0.31^*	0.05	0.07
3. Family income	-	-	-	0.38^{**}	0.39^{**}	0.24	0.32^*
4. Years in program	-	-	-	-	0.37^{**}	-0.002	0.15
5. PSS-family[1]	-	-	-	-	-	0.43^{**}	0.47^{**}
6. PSS-non PA Program friends[2]	-	-	-	-	-	-	0.56^{**}

7. **PSS-PA Program friends**[3]	-	-	-	-	-	-	-

We then computed a multivariate Hierarchical Regression Model

The stepwise procedure followed is the same as mentioned previously. From Table D.5, we see that in Step 1, only family income approached significance ($p > .05$), accounting for 11.9% of the variance in the outcome. In Step 2, the predictor PSS-Family ($p < .05$) was significant, and accounted for 12.5 % of the variance in the model above and beyond child age, income, years in the program and PSS-non PA Program friends. In Step 3, the final predictor PSS-PA Program-related friends was added to the model. Here, only the predictor PSS-Family was significant ($p < .05$). This was the only predictor to make a significant contribution to the model above and beyond the other predictors in the final model. The regression coefficient value indicated that a one standard deviation unit increase in PSS-Family is associated with a .401 standard deviation unit increase in FRAS, if the effects of all other predictors are held constant. See Table D.5 for a summary of the model at each step.

Interaction terms: After each step 1, 2 and 3, the models were checked for interaction terms. Interaction terms were not significant and therefore they are not part of the final model

Table D.5: Hierarchical Multiple Regression Analysis Predicting Family Resilience (FRAS) by Perceived Social Support from PA Program friends (PSS-PA Program friends)

Predictor Variable- (OUTCOME=FRAS)	R	R^2	Adjusted R^2	b	SEb	Standardized Coefficient β	p
Step 1	.38	.14	.09				
Constant				158.41	2.56		.000
Child Age				.66	.50	0.23	.200
Family Income				.00	.00	0.37	.016
Year in Program				-1.42	.86	-.31	.103
Step 2	.54	.29	.21				

				B	SE	β	p
Constant				157.53	2.41		.000
Child Age				.48	.47	0.17	.323
Family Income				.8.52e-5	.00	0.29	.124
Year in Program				-1.65	.82	-.37	.050
PSS-Family				5.56	2.21	.340	.016
PSS-non PA Program friends				1.01	2.06	.07	.625
Step3	.54	.29	.19				
Constant				157.54	2.44		.000
Child Age				.47	.48	0.17	.337
Family Income				.8.57e-5	.00	0.23	.129
Year in Program				-1.64	.83	-.36	.054
PSS-Family				5.61	2.30	.40	.019
PSS-non PA Program friends				1.11	2.33	.08	.636
PSS-PA Program friends				-.21	2.27	-.02	.926

[1]PSS-family refers to perceived social support from family members
[2]PSS-non-PA Program friends refers to perceived social support from friends who are not part of the PA Programs
[3]PSS-PA Program friends refers to perceived social support from the PA Program friends

How does FRAS score vary across different PSS PA Program-related friend levels?

Hypothesis: Individuals with high level of perceived social support from PA Program friends (PSS-PA Program) will have a higher family resilience score (FRAS)

PSS-PA Program friends scale was categorized into high (score>5), medium (score 3-5.0) and low (score =<3) perception of social support, based on the scale raw scores.

Analysis of Variance

For the purposes of exploring the relationship between FRAS and PSS-PA Program friends, a one-way ANOVA was conducted with PSS-PA Program friends (low, moderate and high) entered as a fixed factor and FRAS domain as the dependent variable. The same steps were used as described above under the ANOVA description. Here, as the sample sizes were unequal in the three groups, Welch's F test ANOVA was interpreted. The Welch's F test was interpreted as $F_{(2, 14.031)} = 3.757$, $p = .05$, indicating that there is not a significant difference in the FRAS across the different level of PSS-PA Program -related friends. Although, difference in mean FRAS score across the different levels of PSS-PA Program friends was not statistically significant, the FRAS scores were lowest for the low PSS-PA Program friends compared to the moderate and high PSS-PA Program friends. Table D.6 illustrates the descriptive statistics for the FRAS across different PSS-PA Program friends levels.

Table D.6 Descriptive Statistics of FRAS Across Levels of PSS-PA Program related friends

Level of Perceived Social Support from PA Program-related friends (PSS-PA Program related friends)	FRAS (Mean, S. D)	N
Low level of perception of social support from PA Program-friends	137.8 (17.1)	6
Moderate level of perception of social support from PA Program -friends	159.2 (16.7)	26
High level of perception of social support from PA Program -friends	157.7 (16.5)	18

D.4 Association between Perceived Social Support from PA Program Friends (PSS-PA Program friends) and Self-efficacy (FES) after Controlling for the Demographic Variables and other Predictors.

Hypothesis: the score of PSS-PA Program friends predict FES after controlling for child age, family income, years in the program, family perceived social support and non- PA Program friends perceived social support

Bi-variate analysis was used to examine this relationship between FES and continuous predictors such as age, family income, years in the PA program, perception of social support from family (PSS-family), perception of social support from non- PA Program friends (PSS- non PA Program friends) and perception of social support from PA Program friends (PSS-PA Program friends). Table B.7 shows the correlations matrix; all variables were positively associated with FES, which means that the higher the value for each variable, the higher the FRAS. Highest correlations were found for PSS-family and child age. Many of the variables were also associated with each other (Table D.7); for instance PSS-family.

Table D.7 Correlations Among FES, Demographic Variables, PSS from family, non-PA Program friends and PA Program friends

Predictor Variables	1	2	3	4	5	6	7
1. FES[1]	-	0.36^{**}	0.24	0.26	0.40^{**}	0.19	0.25
2. Child age	-	-	0.22	0.65^{**}	0.31^{*}	0.05	0.73
3. Family income	-	-	-	0.38^{**}	0.39^{**}	0.24	0.32^{*}
4. Years in program	-	-	-	-	0.37^{**}	-0.002	0.15

5.	**PSS-family[2]**	-	-	-	-	-	0.43**	0.47**
6.	**PSS-non PA Program friends[3]**	-	-	-	-	-	-	0.56**
7.	**PSS-PA Program friends[4]**	-	-	-	-	-	-	-

*$p < .05$, **$p < .01$

[1]PSS-family refers to perceived social support from family members
[2]PSS-non-PA Program friends refers to perceived social support from friends who are not part of the PA Programs
[3]PSS-PA Program friends refers to perceived social support from the PA Program friends

We then computed a multivariate Hierarchical Regression Model

The stepwise procedure followed is the same as mentioned above. From Table D.8 we see that in Step 1, family income was statistically significant ($p < 0.05$), accounting for 2.9% of the variance in the outcome above and beyond child age and years in program. Although the model was significant ($p<.001$), the other predictors did not account for a statistically significant proportion of the variance in FQOL satisfaction. In Step 2, the predictors did not account for a statistically significant proportion of the variance in FES. In Step 3, the final predictor PSS-PA Program-related friends was added to the model. none of the predictors contribution was significant ($p >.05$) as revealed by the t-tests of the regression coefficients. For details refer to Table D.8. Interaction terms: After each of the steps 1, 2 and 3, the models were checked for interaction terms. Interaction terms were not significant, therefore they are not part of the final model.

Table D.8: Hierarchical Multiple Regression Analysis Predicting Self-efficacy (FES) by Perceived Social Support from PA Program friends (PSS-PA Program friends)

Predictor Variable- (OUTCOME=FES)	R	R^2	Adjusted R^2	b	SEb	Standardized Coefficient β	p
Step 1	.397	.158	.103				
Constant				46.43	.823		.000
Child Age				.313	.163	0.343	.060
Family Income				2.08 e-5	.000	0.172	.246
Year in Program				-.040	.274	-.027	.885
Step 2	.482	.232	.145				
Constant				46.24	.810		.000
Child Age				.272	.160	0.297	.097
Family Income				9.18 e-6	.000	.076	.618

				B	SE	Beta	p
Year in Program				-0.103	.276	0.070	.710
PSS-Family				1.345	.745	-.297	.078
PSS-non PA Program friends				.110	.695	.024	.875
Step3	.488	.239	.132				
Constant				46.21	.817		.000
Child Age				.283	.162	0.309	.089
Family Income				7.69 e-6	.000	.064	.681
Year in Program				-0.118	.279	0.081	.674
PSS-Family				1.233	.773	-.272	.118
PSSNPA Program friends				-.104	.782	.023	.895
PSS-PA Program friends				.468	.762	.106	.542

FES refers to perceived self-efficacy or empowerment
[1]PSS-family refers to perceived social support from family members
[2]PSS-non-PA Program friends refers to perceived social support from friends who are not part of the PA Programs
[3]PSS-PA Program friends refers to perceived social support from the PA Program friends

How does FES score vary across different PSS PA Program-related friend levels?

Hypothesis: Individuals with high level of perceived social support from PA Program friends (PSS-PA Program) will have a higher perceived self-efficacy score (FES)

PSS-PA Program friends scale was categorized into high (score>5), medium (score 3-5.0) and low (score =< 3) perception of social support, based on the scale raw scores.

Analysis of Variance

For the purposes of initially exploring the relationship between FES and PSS PA Program - related friends, a one-way ANOVA was conducted with PSS PA Program-related friends (low, moderate and high) entered as a fixed factor and FES domain as the dependent variable. The same process was used as described in previous sections. As the sample sizes were unequal in the three groups, Welch's F test ANOVA was interpreted. The Welch's F test was interpreted as $F(2, 14.64) = 1.92$, $p >.05$, indicating that there is not a significant effect of the level of PSS PA Program-related friends on FES. Although, FES was not statistically significant across the different levels of PSS- PA Program -related friends, the FES scores were lowest for the low PSS- PA Program -related friends compared to the moderate and high PSS PA Program -related friends. Table D.9 illustrates the descriptive statistics for FES across different PSS- PA Program friends levels.

Table D.9 Descriptive Statistics of FES Across Levels of PSS-PA Program related friends

Level of Perceived Social Support from PA Program friends (PSS-PA Program related friends)	FES (Self-effiacy) (Mean, S.D)	N
Low level of perception of social support from PA Program -friends	43.0 (5.1)	6
Moderate level of perception of social support from PA Program -friends	45.8 (6.5)	26
High level of perception of social support from PA Program -friends	47.5 (4.4)	18

The results from Tables D.3, D.6 and D.9 indicate 6 families that have low level of perceived social support from PA program friends. Also these individuals (in most cases except for the participants highlighted in Table 5.7) have lower family quality of life satisfaction, family resilience and self-efficacy scores compared to families with moderate and high level of perception of social support from PA Program friends.