

Transitioning from Separate to Community Physical Activity Contexts for Youth  
with Impairments: The Parental Experience

by

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## Abstract

Moving from separate to inclusive community physical activity for youth with impairments can be a difficult transition for all involved. While research on the barriers for youth undergoing these transitions exists, little attention has been focused on the role and experiences of parents. The purpose of this study is to (a) explore the experiences of parents as they anticipate and prepare for the transition from one setting to another, (b) understand the strategies families use to address transition, and (c) gain insights into the supports that are important as they address the challenges of program changes. Using an interpretative phenomenological analysis and instrumental case study approach, two semi-structured interviews were conducted with each of the eight parents of youth with impairments between the ages of 12 and 19 who were undergoing the transition from separate fitness programs to inclusive community fitness contexts. Using line-by-line thematic analysis, four themes described the experiences of parents as they anticipated, prepared for, and supported their child to transition from one setting to another: (a) my child may be ready, but I am not, (b) fear of outside judgement, (c) playing by their rules, and (d) reframing our thinking. Using Schlossberg's model (1981) the dynamic and powerful interactions between parents' experiences and societal influences were markedly evident throughout the transition. This study provides a deeper understanding of the tensions parents faced as they negotiated new roles, relationships, routines, and assumptions as they moved through the transition process.

## **Preface**

This thesis is an original work by Bobbi-Jo Atchison. The research project, of which this thesis is a part, received research ethics approval from the University of Alberta Research Ethics Board, Project Name “Transitioning from Separate to Community Physical Activity Contexts for Youth with Impairments: The Parental Experience”, No. Pro00039622, August 8, 2013.

## **Acknowledgements**

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## Chapter One: Introduction

*If you've got a special needs kid, at some point, somebody's going to say to you, "You should start thinking about trusteeship, you should start thinking about guardianship, you should start thinking about AISH, you should start thinking about PDD." They should also be saying, "You should start thinking about physical activity." (Jack)*

Everyone experiences change. Some may experience it more than others, but, no matter who you are, change will occur throughout your lifetime. Change is situational, it may include getting married, starting a new job, moving to another city, experiencing a health decline, the death of a loved one, or a divorce (Anderson, Goodman, & Schlossberg, 2012; Bridges, 2010). With change, a transition emerges. Transition is the psychological processes of change, it includes how we react to, adapt to, cope with and manage these adjustments (Anderson et al., 2012; Schlossberg, 1981). In other words, transition is not necessarily an event, but rather the "inner re-orientation and self-redefinition" a person goes through to incorporate this change into her or his life (Bridges, 2004, p. xii).

Families raising children with impairments are thought to go through transition more frequently as they often experience both horizontal and vertical transitions (Stewart et al., 2010; Stoner, Angell, House, & Bock, 2007; Woodgate, Edwards, & Ripat, 2012). Horizontal transitions are defined as unpredictable situations that can take place on a day-to-day or weekly basis, for example, a change in school scheduling (Stoner et al., 2007). In contrast, vertical transitions are defined as predictable and are typically developmental in nature, for example,

moving from secondary school to post-secondary school or from separate<sup>1</sup> physical activity to inclusive<sup>2</sup> physical activity programs (Stoner et al., 2007).

Despite being predictable, vertical transition can be a difficult time for families (Cohen-Podvey, Hinojosa, & Koenig, 2010; Stoner et al., 2007). Specific to physical activity, the considerable efforts required to find suitable programs, environments, supports, and transportation weigh heavily on families (Goodwin & Ebert, 2014; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). Transition teams, including professionals, parents and youth, are often formed to support the movement from one program to another (Roth & Columna, 2013), for example, moving from rehabilitation to community physical activity programs, or moving from school-based adapted physical education to inclusive physical education classes. Once through the transition process, however, families may be left with restricted resources to support participation in inclusive programs.

With limited resources available, parents are vital to the successful transition of their children (Gall, Kingsnorth, & Healy, 2006; Stewart et al., 2010; Stoner et al., 2007). While transitions require adjustment from youth, parents supporting the transition of their children through various life stages also undergo adjustments as they assume multifaceted role changes and expend substantial energy to ensure success (Dellve, Samuelsson, Tallbron, Fasth, & Hallberg, 2006; Goodwin & Ebert, 2014; King, Baldwin, Currie, & Evans, 2005; Rous, Hallam, Harbin, McCormick, & Jung, 2007; Stewart, Staveness, King, Antle, & Law, 2006; Stewart et al., 2010). To begin to understand the complex and multilayered experiences of parents as their

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<sup>1</sup> As 'segregated' is a term with a political history of exclusion, this paper will use the term 'separate' to describe a physical activity environment that is respectful of the resource needs of people with impairments.

<sup>2</sup> For the purpose of this paper, inclusive programs are defined as contexts where people with and without disabilities have the opportunity to interact in all aspects of fitness, sport and recreation (Wolf Klitzing & Wachter, 2005).

children transitioned to community physical activity opportunities, I opened a dialogue with parents whose children were participating in separate programs at The Steadward Centre for Personal & Physical Achievement (TSC)<sup>3</sup>. Their perspectives closely echoed those found throughout the research. They had the perception that, unlike youth without impairment who have a wide range of opportunities to be active within formal and informal physical activity settings as well as structured and unstructured sport, youth with impairments have far fewer opportunities due to negative attitudes, perceptions of ability, and limited program options (Bedini, 2000; Fox & Riddoch, 2000; Jones, 2003; Rimmer & Rowland, 2008). Parents also noted that their child's lack of success, in areas such as motor performance and social interaction, negatively impacted participation (Obrusnikova & Miccinello, 2012).

Surprisingly, I also found parents were hesitant to leave the separate settings on which they had come to rely. They spoke of the comforts separate programs offered them - a 'sanctuary' where they could relax and socialize with other parents, knowing their children were looked after by qualified professionals (Goodwin & Ebert, 2014; Hodge & Runswick-Cole, 2013). My discussion with parents also revealed that much of their free time was consumed with getting through day-to-day routines, planning, scheduling and preparing for what the day would hold. As a result, finding the energy to prepare for a vertical transition to community physical activity programs from a separate context as their children got older became a lower priority. The parents' experiences mirrored the findings of Stoner et al. (2007) who found that parents who are required to focus much of their time on horizontal day-to-day transitions had limited time, ability or desire to begin preparing for larger vertical transitions.

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<sup>3</sup> [www.steadwardcentre.ualberta.ca](http://www.steadwardcentre.ualberta.ca)

These preliminary discussions with parents solidified my suspicions that parents undergo transitions alongside their children. To fully understand how I, and other professionals, could support parents as they prepare for and journey alongside their children during the transition from separate physical activity to community physical activity, I felt I needed to understand how parents experienced the processes of transition. A search of the literature revealed that little attention has been given to the impact of transition on parents, the supports they require and the strategies they use as they transition to community physical activity participation alongside their children (Armstrong, Dedrick, & Greenbaum, 2003; Cooney, 2002; Piskur et al., 2012; Stewart et al., 2010).

The purpose of this study is to understand how parents of children with impairments experience transition from separate physical activity contexts to community physical activity environments. More specifically, this study aims to: (a) explore the experiences of parents as they anticipate and prepare for the transition from one setting to another, (b) understand the strategies the families use to address the transition, and (c) gain insights into the supports that are important as they address the challenges of program changes.

My thesis is presented in paper format. Chapter two is a review of the literature, which will serve as a backdrop for the following chapters. Chapter three is an overview of the methods used to gain insight into parents' transition experiences, chapter four is the research study manuscript including references specific to the manuscript and, finally, chapter five includes my final reflections on the research study.

## Chapter Two: Literature Review

*I'm going to choke him if I try to do this [transition] – my anxiety – and I mean that in the sense of, my anxiety is going to inhibit him truly believing he can. (Laura)*

### Call for Focus on Physical Activity

The Canadian Physical Activity Guidelines<sup>4</sup> produced by the Canadian Society of Exercise Physiology indicate that youth between 5 and 17 years of age should be accumulating a minimum of 60 minutes of moderate to vigorous physical activity daily. However, only nine per cent of children and youth between these ages are actually meeting the physical activity guidelines (ParticipACTION, 2015). While there is limited research on the amount of physical activity and fitness that youth experiencing disability attain on a day-to-day basis in Canada, it is estimated that approximately 56 per cent of all Canadians experiencing disability do not participate in physical activity (Statistics Canada, 2007).

Researchers of a recent study conducted in the United States also found that youth experiencing disability engage in physical activity less than four days per week with a total of 60 minutes of physical activity each week, far less than the recommended guidelines (Pitchford, Siebert, Hamm, & Yun, 2016). Similarly, Steele et al. (2004) found in their study of 319 adolescents experiencing moderate to severe physical disability, between the ages of 11 and 16 that they seldom exercised more than one day per week and were found twice as likely as their peers without impairment to report being engaged in sedentary activity for more than four hours per day.

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<sup>4</sup> <http://www.csep.ca/english/view.asp?x=804>

This tendency towards low physical activity is concerning given that individuals experiencing disability are often at greater risk of secondary health conditions including diabetes; obesity; osteoporosis; heart disease; skin, weight, respiratory, and gastrointestinal problems; as well as emotional difficulties (Antle, Mills, Steele, Kalnins, & Rossen, 2007; Rimmer & Rowland, 2008). It has also been found that as age increases, physical activity participation decreases (Bult, Verschuren, Jongmans, Linderman, & Ketelaar, 2011; Steele et al., 2004). This is particularly concerning as health behaviours and adolescent obesity are carried forward into adulthood, impacting lifelong physical activity and serving as a predictor of secondary health conditions later in life (Bandini et al., 2015; Foxhall, 2006; Rimmer & Rowland, 2008; Yazdani, Yee, & Chung, 2013). Physical activity is arguably one of the most beneficial interventions in the prevention of secondary health conditions (Warburton, Nicol, & Bredin, 2006) and maintaining health and function for individuals living with impairments (Martin & Choi, 2009; Rimmer, Chen, McCubbin, Drum, & Peterson, 2010).

### **Inclusive and Separate Physical Activity Opportunities**

Physical activity opportunities for youth with impairments are typically framed in one of two ways: separate or inclusive. According to Hodge and Runswick-Cole (2013), activities are considered segregated when they are dependent on a diagnosis or label, whereas separate spaces are where individuals experiencing disability find sanctuary or restorative qualities, away from institutionalized oppression, societal assumptions and social stigma (Campbell, 2008; Goodwin & Staples, 2005; Goodwin, Leiberman, Johnston, & Leo, 2011). Separate spaces can be considered therapeutic landscapes and are valued, at least in part, by both youth with impairments and their parents when they offer places of support, healing and empowerment (Goodwin & Staples, 2005; Hodge & Runswick-Cole, 2013). Inclusive physical activity has

varying definitions, however for the purpose of this paper 'inclusive' will be defined as 'contexts where people with and without disabilities have the opportunity to interact in all aspects of fitness, sport and recreation' (Wolf Klitzing & Wachter, 2005).

Although increasing numbers of inclusive opportunities are available, families of youth living with impairments are choosing separate physical activity opportunities over inclusive programs within their communities (Mayer & Anderson, 2014). Researchers have explored the benefit of separate programming for youth and report that they often encourage a sense of belonging amongst peers of similar experience, offer social engagement, skill development, and competition to match youths' age and stage in life, and enhance youths' self-esteem, self-worth and self-acceptance (Bedini & Thomas, 2012; Goodwin & Staples, 2005; Mayer & Anderson, 2014; Ninot, Bilard, & Delignieres, 2005).

Mayer and Anderson (2014) found that although participants themselves appeared to find benefit in both inclusive and separate programs, they often enrolled in separate programs as this was what was encouraged by their support systems. For people living with impairments, support systems can be broad and include various family members, friends, disability organizations and so on. However, for youth, the main support systems tend to be parents, specifically mothers (Peer & Hillman, 2014; Smith, Cheater, & Bekker, 2013; Walker, Alfonso, Colquitt, Weeks, & Telfair, 2016). While choosing separate physical activity options should not be of concern conceptually, pragmatically, the limited number of options available within separate environments and the absence of resources available for these types of programs often results in increased wait times to register and minimal enrollment options for youth and their families (Goodwin & Staples, 2005; Jones, 2003; Shimmel, Gorter, Jackson, Wright, & Galuppi, 2013). In addition, many youth 'age out' of separate programs when they reach adulthood, leaving

fewer options to be active once they graduate from high school (Block, Taliaferro, & Moran, 2013; Rimmer, 2005; Rimmer & Rowland, 2008; Roth, Pyfer, & Huettig, 2007). With limited separate programming possibilities available, youth and young adults are often required to transition to inclusive physical activity programs to remain active.

## **Transition**

The use of the word ‘transition’ is broadly used by a wide range of disciplines and theoretical frameworks to describe “going across, passage over time, stage, subject, or place to another” (Kralik, Visentin, & Van Loon, 2006, p. 322). Levinson (1986) also offered a definition that has been used broadly throughout research stating that it is a “turning point or a period between two periods of stability” (p. 39). For the purpose of this paper, I will be using the definition provided by Schlossberg, Waters and Goodman (1995) who define transition as “any event or non-event that results in changed relationships, routines, roles and assumptions” (p. 27). This definition was chosen as it adequately reflects that community transition from separate programs may introduce new relationships with staff, patrons and children, will disrupt the families’ daily routines, and will present parents with new roles and assumptions.

It is important to note that transition is not simply a change in stability, but also the inner processes involved in letting go, adapting, redefining, redeveloping and reconstructing one’s self-identity within new roles (Anderson et al., 2012; Kralik et al., 2006). This is supported by Kralik et al. (2006), who reviewed 23 articles on transition in the health care literature. All papers framed transition as a passage, movement, transformation, inner reorientation, adaptation and time when mastery was sought to regain control and self-identity.

## Theories of Transition

Several transition theories and frameworks exist within the literature. Four theories are highlighted below: Van Gennepe's Social Transition Model (1960), Meleis Mid-Range Transition Theory (2000), Bridges Transition Theory of Personal Development (2004), and Schlossberg's Transition Framework (1981). These theories were chosen as they have all been used within qualitative research and represent a broad perspective across a range of fields including health sciences, sociology and psychology. In addition, many of these theories build upon one another either through their original or later modified models and frameworks.

**Van Gennepe's social transition model.** Within his three-stage social transition model, Van Gennepe (1960) described three distinct phases: pre-liminal rites, liminal rites and post-liminal rites. A rite of passage can be defined as an important personal life event that requires the movement from one stage or experience to a more advanced one (Barton, 2007; Van Gennepe, 1960). These rites occur under the premise of cultural expectations, social roles, interpersonal relations or developmental and situational changes that may occur (Kralik et al., 2006). Pre-liminal rites can be characterized as the removal of normal social life from an individual; liminal rites are a time of limbo or transition, when an individual may feel isolated or alienated; and, lastly, post-liminal is when an individual is re-incorporated back into society in a new state (Barton, 2007; Kralik et al., 2006). Van Gennepe's transition has been used extensively in research in the area of health sciences, sociology and anthropology. Despite this, critics have argued that Van Gennepe's attempts to be universal have come up short, leading to a more superficial interpretation of individual, cultural, religious, and familial influences on transition (Anttonen, 1992; Barton, 2007). In addition, while Van Gennepe's model outlines role change within the liminal passage, he focuses on the biological and social status impacts of transition.

Little attention is paid to the psychological factors and outside supports associated with transition (Anttonen, 1992; Barton, 2007; Van Gennep, 1960). Because of this, I felt Van Gennep's social transition model would not be the most effective framework for my study.

**Meleis mid-range transition theory.** Unlike Van Gennep's linear approach, Meleis believes that conditions influencing transition vary greatly and are different for individuals, families and organizations (Kralik et al., 2006; Schumacher & Meleis, 1994). Meleis's mid-range transition theory has been used extensively in the nursing profession and has spanned a wide range of transition topics, from immigration, pregnancy, parenting, and menopause, to caregiving and nursing homes (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). Although it is still considered an emerging theory, it has roots in sociology dating back as early as the 1960s (Im, 2011).

The Meleis Transition Theory has four key concepts, each with sub-categories (Im, 2011). The first category, *nature of transitions*, presents the types (developmental, situational, health/illness, and organizational), patterns (single, multiple, sequential, simultaneous, related or unrelated) and properties (awareness, engagement, change/difference, time span, and critical points) occurring at the time of transition. The second category, *transition conditions*, focuses on potential facilitators and inhibitors affecting healthy transitions within three areas: personal, community and society. The third category, *patterns of response*, has two subcategories. The first is *process indicators* (feeling connected, interacting, being situated, and developing confidence and coping) which includes indicators that can lead individuals towards healthy or at risk coping strategies during the unfolding of a transition. The second, *outcome indicators* (mastery and fluid integrative identities) contains the determination of when a transition is complete. According to Meleis et al. (2000), a transition is completed in a healthy way when an

individual demonstrates mastery of the skills and behaviours needed to manage her or his new situation or environment. And lastly, *therapeutics* are used as a way professionals (in this case nurses) can provide interventions to facilitate healthy transitions, decrease unhealthy transitions and effectively use positive process indicators (Schumacher, Jones, & Meleis, 1999).

Therapeutics may include ongoing assessments completed by nurses, role supplementation, ensuring compliance with treatment regimens and providing support preventatively or therapeutically before or after a transition occurs (Chick & Meleis, 1986).

Despite the use of this transition theory in the area of caregiving, parenting and health and illness, the fit for this project was not faultless. While I believe this theory encapsulates many key factors affecting various transitions over a wide range of populations and events, it follows a medical approach influenced by assessments, interventions and treatments as a means to support those in transition. I submit that this does not align well with my personal philosophical assumptions or that of the field of Adapted Physical Activity.

**Bridges transition theory of personal development.** Bridges (2004) claims that transition is a process of development and self-renewal, a “natural process of disorientation and reorientation marking the turning points in the path of growth” (p. 4). Similar to Van Gennep’s framework (1960), Bridges’ transition theory also follows a linear trajectory with three phases of transition: (a) an end, (b) a time in between/neutral zone, and (c) a beginning. Each of these three phases relates to one another and requires adaptation and adjustment as people internalize the psychological impact of new situations and change (Anderson et al., 2012; Bridges, 2010). Despite a transition being perceived as expected, unexpected, positive or negative, and because “we identify ourselves by circumstances in our lives, who we think we are is partly defined by our roles and our relationships” (p. 12), Bridges (2004) believed that a paradox arises at times of

transition: every new beginning starts with an ending. He argued that during a time of transition, the ending is a person's first phase. During an ending phase, people experience disengagement, dis-identification, dismantling, disenchantment and disorientation as they experience letting go during an ending phase. Upon completion of this phase they move into phase two, the neutral zone (Anderson et al., 2012; Bridges, 2004). The neutral zone is characterized by a period of emptiness and absence as a person hangs between the balance of the old and the new. And finally, during the third phase of transition, people finish with a new beginning. According to Bridges (2004), a beginning comes only when the ending and the neutrality are finished. These new beginnings arise when a person can successfully launch into something anew. Bridges reports that these transitions may be untidy, cannot be determined by a checklist, and may not be as obvious as one would like, however, he believes that internal signals alert people to these new beginnings (Bridges, 2004). By understanding the three phases and going against one's intuition to begin at the beginning, and focus on beginning at the end, Bridges feels that people can more smoothly move through a time of transition.

Bridges' personal development theory of transition has been used in the fields of health science, psychology and employee relations. It has also however, been used as a reference point and theoretical backing to many other transition theories, including that of Schlossberg (2008). I was unable to find many critiques of the work done by Bridges, and the three phases of transition appear to fit quite well with the research project at hand. Despite this, I opted to use the Schlossberg (1981) transition framework, as Schlossberg adopted Bridges' process and personal development approach while adding a more in-depth analysis of the roles, relationships, routines and assumptions held by a person during the process of transition.

**Schlossberg transition framework.** Similar to the work done by Van Gennepe (1960) and Bridges (2004), the theory of transition developed by Schlossberg (1981) aligns with a developmental approach and provides a framework to analyze adults in transition. Using this approach, Schlossberg's model (2008) combines various theories, including that of Bridges (2004), to develop an integrative model with three similar phases: *moving out*, *moving in*, and *moving through* (Anderson et al., 2012). Each of these phases requires adaptation and role change. *Moving out* is characterized as a separation, ending or role exit. In this phase, grieving and disengagement of past roles, relationships, routines and assumptions may take place. Transitioning out of a separate program would be considered the moving out phase. Within the *moving in* phase, a person attempts to become familiar with the new system. New roles, relationships, routines and assumptions are developed in this phase. Transitioning into an inclusive program would be considered the moving in phase. And lastly, *moving through* is described as a time of neutrality. Within this phase, a person enters a cycle of renewal, a time where they attempt to find balance between the old and the new. Unlike Bridges (2004), Schlossberg argued that transition is a process with no end point (Anderson et al., 2012).

Anderson et al. (2012), Schlossberg (2008), and Schlossberg et al. (1995) took the framework further by outlining three major parts to the model: (a) approaching transition (transition identification and transition process), (b) taking stock of coping resources (the 4 S system), and (c) taking charge (strengthening resources). In the first part of this model, Schlossberg et al. (1995) outlined various factors influencing adults approaching transition and the ability to cope during anticipated (e.g., graduation, marriage, retirement) and unanticipated (e.g., death, job loss, illness) events. She also argued that a non-event—an event that was expected, but did not occur— can create a time of transition. Irrespective of the type of transition

one is undergoing, individuals find themselves in a state of dis-equilibrium as each transition presents unique challenges and opportunities for growth and transformation (Anderson et al., 2012). Perspective, context, and impact are also seen to be factors influencing those approaching transitions. Everyone experiences transition differently. How one appraises transition and how the transition alters the assumptions, roles, relationships and routines of daily life is key to understanding the effect a transition may have on an individual (Anderson et al., 2012).

In the second part of the model, Schlossberg (2008) focused on four root factors that are thought to influence healthy transitions for adults experiencing change: the 4 S System. Each of the factors can serve as a resource or deficit, depending on the magnitude of the transition, where the individual is at physically, socially, and mentally at the time of transition, and what supports the individual has access to during the transition. The 4 S System is as follows:

*Situation* refers to individuals' personal situations at the time of their transitions (Schlossberg, 2011). Parents' situational factors may include the number of children they have, presence of home care or respite support to assist with day-to-day care of their child, whether the transition is temporary or permanent, past experiences (positive or negative) in inclusive environments, or how much control they have over the transition. Situational factors may have similar impact to both horizontal and vertical transitions for parents.

*Self* refers to both personal characteristics and psychological resources. Personal characteristics may include people's age and stage in life, current health status, socioeconomic status, gender or ethnicity. Psychological resources include a person's values, spirituality, ability to cope with stress, resilience, ego, optimism and level of commitment to the transition (Schlossberg, 2008; Schlossberg, 2011). Factors influencing parents may include their level of

optimism towards the transition; additional stresses they may be experiencing; what stage they are at in their career or in attaining their own goals; their available energy to support their child and family through the transition process; and their level of commitment to the transition itself. Self factors, like situational factors, may have similar impact on both horizontal and vertical transitions.

*Supports* include the types, functions and variety of supports one has available during a time of transition (Schlossberg, 2011). For parents, this may include support from family and friends, disability organizations and/or community organizations, including work, schools or church. Lack of supports available to parents at the time of transition will also affect their transition experience. Further, the type of supports available and utilized may be affected by past transitions (horizontal or vertical) and whether they were perceived as a positive or negative experience.

And lastly, *strategies* refer to people's coping responses during a time of transition. During a transition, strategies may range from taking direct action, inhibiting action, seeking information and supports and/or attempting to change, reframe or reduce the stress of the situation (Schlossberg, 2011). Parents' strategies may range from attempting to do everything on their own with limited supports to pulling in as many resources as possible from their family and the community. The types or number of strategies used may be motivated by past horizontal and vertical transitions and their perceived level of success.

Finally, the last part of the model, *taking charge*, highlights the need for strengthening resources through the use of new strategies. Schlossberg (2011) believes that despite transitions often being out of one's control, we can still control how we manage these transitions and

ultimately work towards a level of mastery through establishing strong resources within self, situation, support and strategies.

While very little research has been noted in the area of disability and parenting youth with impairments, Schlossberg did recognize that transition in its various forms (vertical or horizontal) requires the difficult tasks of changing roles, relationships, routines, and assumptions while new ones are established (Schlossberg, 2011). Schlossberg also acknowledged that transitions are often overwhelming events that require increased energy (Anderson et al., 2012). Parents experiencing the process of transition will also be affected as their children move from a structured, resource rich, separate physical activity environment to less-structured and unpredictable community environments. This form of transition requires parents to change roles and regular routines, while altering relationships and assumptions placed on themselves, their children, and the community. The dis-equilibrium to parents' lives requires parents to use their limited energy stores to secure the supports and strategies that will best assist with the transition (Anderson et al., 2012).

Schlossberg's transition theory (1981) has been used to study transitions in contexts as diverse as marriage, divorce, the military, post-secondary education, careers, and retirement (Anderson et al., 2012). While not directly related to my research, several researchers have successfully used the model as a conceptual framework in disability sport. The first, was completed by Wheeler and colleagues (1996). The researchers of this study sought to understand the experiences of athletes with impairments pre and post retirement and the adaptations and adjustments experienced during this time of transition. The researchers noted that the Schlossberg (1981) model was a natural fit to their research and recommended it as extremely useful for professionals, coaches, and athletes. Secondly, a study conducted by Lenz (2001)

looked at three frameworks that could be used to understand the transition from adolescence to young adulthood. Lenz submitted that although there is no previous work in the area from Schlossberg, this model proved to have many benefits, including the ability to acknowledge factors of successful adaptations and supports, and its applicability to a wide range of professions. Lastly, Constantino (2010) wrote of her own experiences raising two children with impairments. Constantino praised Schlossberg's transition framework as a valuable model for identifying personal strengths as a key factor in how parents of children with impairments cope with unexpected transitions.

### **Impact of Transition on Parents**

For parents, transitioning their children to community physical activity can mean a time of optimism, as it is often associated with their children reaching a milestone or achievement. But it is also a time of uncertainty, vulnerability and insecurity in the resources and supports available (While et al., 2004). For families, "raising a child with a disability is not intuitive and ... many families are unaware of how to best support their child" (Gall et al. 2006, p. 58). In addition to this, children with impairments have fewer informal physical activity opportunities through school, outdoor play or sport, so they are more dependent and reliant on their parents to support, transport, guide and facilitate their engagement in structured physical activity pursuits (Bult et al., 2011; Martin & Choi, 2009).

Goodwin and Ebert (2014) sought to unveil the hidden labour assumed by parents as they continuously attempt to 'find a fit' for their children within community programs. Parents discussed their need to research programs and policies prior to registering for programs, they conducted multiple site visits to analyze facility and staff suitability and they introduced their children to new spaces. They also hired and educated workers to support their children and they

met with management as needed to ensure inclusion for their children—all prior to starting in a new program. The arduous labour required to ensure basic needs are met in community programs can ultimately lead to the avoidance of regular physical activity for families and their children (Goodwin & Ebert, 2014; Obrusnikova & Miccenello, 2012; Roth et al., 2007).

Research on the perceptions and experiences of parents as their youth transition between physical activity settings is limited. However, we do know from research conducted on transitions from youth to adulthood, secondary to post-secondary schooling, and secondary school to vocational settings, that resources (e.g., financial, physical, social, emotional), tools (e.g., education, training workshops, transition plans) and supports (e.g., readiness programs, peer programs, qualified professionals) for parents are inconsistent at best (Folsom-Meek, Nearing, & Bock, 2007; Gall et al., 2006). To reduce stress on parents, researchers indicate that more services, supports, knowledge, training and readiness are required for families, professionals and youth during times of transition (Gall et al., 2006; Roth et al., 2007).

### **Parent-Identified Barriers to Community Programs**

Parents of youth experiencing disability play an essential role in the reinforcement and influence of physical activity for their children (Pitchford et al., 2016). And while they identify the value of having their children exposed to and engaged in community physical activity as a means of achieving life-long self-discipline and self-confidence (Antle et al., 2007; Roth et al., 2007; Thompson & Emira, 2011; Wiart, Darrah, Kelly, & Legg, 2015), they are left to navigate the vast barriers to participation alone. Of particular interest to this study are barriers identified and experienced from the perspective of parents.

In a study conducted by Obrusnikova and Miccenello (2012) on factors influencing after-school physical activity of children with autism spectrum disorder from the perspective of parents, the researchers reported barriers in five domains: intrapersonal, interpersonal, community, institutional, and public policy. Although limited information around public policy was presented by the participants of the study, several barriers were identified within the other four domains.

**Intrapersonal barriers.** Intrapersonal barriers included lack of motivation, time, and attention span experienced by their children. Similar barriers were also reported by Barnett, Dawes & Wilmut (2012) who found motivation and lack of time to be internal factors affecting how often youth living with developmental coordination disorder were active from the perspective of both the parents and the youth. Both research teams also indicated that these obstacles required parents' time and attention to overcome.

**Interpersonal barriers.** Over 80 per cent of interpersonal barriers reported by parents in Obrusnikova and Miccinello's study (2012) focused on parents' lack of time, energy and patience to support their children to engage in physical activity. These barriers stemmed from the level of strategy, planning, and creativity required for parents to get their children active. Parents also reported these barriers often led them to moments of frustration and ultimately an avoidance of physical activity with their children. These findings were echoed by Goodwin and Ebert (2014) and Wiart et al. (2015), who further noted that having to do all the 'heavy lifting' of researching an appropriate fit in the community and preparing their child for this environment required considerable effort, energy and time.

In addition to the interpersonal barriers brought forth by Obrusnikova and Miccinello (2012), Pitchford et al. (2016) found that parents can act as either barriers to or facilitators of physical activity for their children. Parents also identified this in a Roth et al. (2007) study conducted on the impact of parent involvement, or lack thereof, on transitions to physical recreation after high school graduation. In this study, they conducted one-on-one interviews with 17 graduates along with focus groups and questionnaire surveys with 24 parents of graduates with developmental disabilities on their perceptions of physical recreation one to three years post-graduation. The researchers found a significant drop in active participation in recreation activities for most young adults after graduation. Although limited data were reported from the perspectives of the graduates themselves, parents revealed several barriers experienced by their children and their families. In contrast to previous studies, parent participants did not indicate staff training as either a barrier or a facilitator; rather, participants identified lack of parental readiness, education and organization, as well as parental over-protectiveness, as negatively affecting the success of the transition.

Interestingly, the impact of others' attitudes was not identified as a barrier in Obrusnikova and Miccinello's research (2012). Parents noted that the risk of having their children affected by negative attitudes and stigmatizing environments was a barrier to community physical activity environments (Antle et al., 2007; Heah, Case, McGuire, & Law, 2007; Piskur et al., 2012; Piskur et al., 2016). These risky environments required parents to be vigilant and employ management techniques to protect their children from being hurt or affected by the negativity of others (Heah et al., 2007; Segal, Mandich, Polatajko, & Cook, 2002).

**Community barriers.** Obrusnikova and Miccinello (2012) found, in results similar to those of Jones (2003), Piskur et al., (2014), Rimmer and Rowland (2008), and Wiart et al.

(2015), that parents perceived the lack of affordable and developmentally appropriate programs in the community to be a barrier. Piskur et al. (2014) reported that over 50 per cent of their 146 parent participants identified finding suitable recreation activities where support was available was a priority. In addition to these, others reported unknowledgeable, untrained and unprepared community staff as a community barrier. This has also been seen through a wide range of research in the field and has been argued to enhance parents' hesitancy to choose inclusive community programs (Anderson & Heyne, 2000; Goodwin, Atchison, Johnston & Yi, 2013; Jones, 2003; Pitchford et. al., 2016; Thompson & Emira, 2011; Wiart et al., 2015).

**Institutional barriers.** Lastly, the institutional barriers brought forth by participants within the Obrusnikova and Miccinello (2012) study were limited to schools. Parents felt that the lack of suitable physical education in school had a negative impact on their children. This is consistent with findings from systematic reviews conducted by Piskur et al. (2012) and Walker et al. (2016), who found that insufficient system and institutional support within schools, government and the communities can further contribute to social isolation and difficulties for families navigating physical activity for their children. Piskur et al. (2016) also found institutional barriers to be impactful to participation of children in home, school and community by parents. A multitude of institutional barriers were brought forth by the 13 parents participants in this study including structure, flexibility and complexity of the systems, laws and regulations they were working with.

### Chapter Three: Musing the Methods

*You know, sometimes they're building a plane as they're taking off and you have to expect that certain parts just aren't all going to gel together right at the very beginning, right? And so I look at your research and I think, "You're part of putting all those little pieces of that plane together before it takes off", which is really good. (Laura)*

Given the limitations of space within the research paper chapter, I am using this opportunity to provide more detail on my research methods. This chapter provides a more in-depth look at my research decision-making.

For this research study I used qualitative inquiry within an interpretive paradigm. Through this lens my assumptions are based on a relativist ontological and subjective epistemological stance. Relativists hold that there are multiple forms of reality that are socially and experientially based although elements of reality are shared across people and cultures. Subjectivism infers that the investigator and the investigated are interactively linked and that findings are created as part of the research process (Guba & Lincoln, 1994). Under an interpretive paradigm, research is inductive in nature and is undertaken with the aim to understand a person's behaviours, meanings and experiences of a particular phenomenon—in this case, transition (Markula & Silk, 2011). In reading the published literature, many barriers to transition were identified, but my interest was in how they were experienced and negotiated by parents. By assuming an inductive research stance, I was able to use my professional practice observations when working with families undergoing transition to ground the rationale, need and importance of the research study in the experiential lives of families (Mayan, 2009).

I chose to use interpretative phenomenological analysis (IPA), with its theoretical roots in phenomenology, idiography, and hermeneutics as my research approach (Smith, 2011). This

approach assisted me in examining how participants made sense of their life experiences and in exploring participants' involvement in particular day-to-day events in their lives, such as the phenomenon of transition (Smith, Flowers, & Larkin, 2009). Idiography focuses on the particular through a commitment to a detailed understanding of a particular phenomenon (transition) in a particular context (inclusive community physical activity settings) by a particular person (individual parents) (Smith et al., 2009). Lastly, through the use of IPA I was able to operate under a double hermeneutic premise, which involves the researcher making sense of the participants making sense of their own experiences (Pringle, Drummond, McLafferty, & Hendry, 2011; Smith, 2011; Smith et al., 2009).

An IPA researcher seeks to provide a “detailed picture of how the families think and feel about the challenges they face” (Brewer et al., 2008, p. 7). IPA has been used successfully in research studies to gain a better understanding of families' experiences raising youth with impairments. For example, Glasscoe and Smith (2011) used IPA to examine a single case study of a mother's experiences in both parenting and being a health care provider to her child with cystic fibrosis, while Brewer et al. (2008) used IPA to analyze the impact of juvenile Huntington's disease on families and primary caregivers.

An instrumental case study approach was also used for this project. Through this approach I had the opportunity to gain an in-depth understanding of the phenomenon within the real-life context in which it has occurred (Yin, 2009). Parents of youth were recruited from The Steadward Centre for Personal & Physical Achievements (TSC) Community Transition Program<sup>5</sup>. Case study methods provide the opportunity for description of the phenomenon within its natural context and provide a greater opportunity to explore multiple facets of the

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<sup>5</sup> <http://www.steadwardcentre.ualberta.ca/en/Our%20Programs/CommunityTransition.aspx>

phenomenon for better understanding (Baxter & Jack, 2008). While other programs work with youth in either separate or inclusive settings, TSC uses qualified adapted physical activity consultants, trained volunteers and community partners to bridge the gap between each of these settings to ensure youth experiencing disability have options in the types of contexts they choose. This research study was not designed to look specifically at TSC's Community Transition Program; however, without looking at the full context of the program, it would be difficult to gain a true picture of the parents' experiences of this transition process.

Within case studies, boundedness is imperative to ensuring the case is clearly identifiable with clear set boundaries (Stake, 1995). This case study was naturally bound by the already existing program and procedures of TSC's Community Transition Program. It was additionally bound by both time and activity (Stake, 1995), the activity being the transition from separate programs to community physical activity and the time beginning from the start of the community transition program to the present. Bounding the case study ensured the project stayed focused, did not become too broad and was reasonable in scope (Baxter & Jack, 2008).

The ultimate goal of TSC's Community Transition Program is to support interested individuals experiencing disability to be active in fitness centres in their own communities, close to home. Using qualified professionals and strong community partnerships, the program is used to provide education, reduce community barriers and engage in one-on-one support as participants make the transition from separate to inclusive community fitness programs. In 2013/2014, TSC expanded the Community Transition Program to include youth between the ages of 12 and 19. Trigger points for participation in the Community Transition Program were expressed by parents in two different ways, (1) their child had reached an age where they were no longer eligible for TSC youth programs (over the age of 19), and (2) parents wanted to

introduce their child into a community setting to gain more access to physical activity opportunities on a weekly basis.

### **Recruitment**

Permission to conduct the study at TSC was granted by the Director of the Centre. Adapted Physical Activity Consultants within TSC notified families enrolled in the transition program about the study. If parents expressed interest, I sent them a formal invitation via email, which included a brochure and detailed letter with more information on the study. Participation in the study was voluntary and had no impact on participation in TSC programs.

### **Sampling Strategy**

Researchers employing an IPA approach are interested in understanding a particular phenomenon within a particular context, therefore a relatively small sample size of eight was chosen to support in-depth analysis, which may be inhibited by larger sample sizes (Pringle et al., 2011; Smith et al., 2009). A smaller sample size also supports the case study approach and allows researchers to gain insight into the similarities and differences of individuals' experiences in detail, whereas larger samples may decrease the quality of analytical reflection (Smith et al., 2009). Researchers using IPA are encouraged, in addition to choosing a small sample size, to select a homogeneous sample of participants who can provide access to a "particular perspective on the phenomena under study" (Smith et al., 2009, p. 49). Participants who were parents of youth living with impairments between the ages of 12 and 21 who were in transition from separate to inclusive community settings were recruited for this study to better understand parent experiences of transition.

## **Interview Schedule**

An interview schedule was used to encourage participants to talk at length about their transition experiences (see Appendix A). Effectively structured questions enable the interviewer to collect pertinent information while developing rapport and offering a safe and comfortable environment for the participant (DiCicco-Bloom & Crabtree, 2006). Questions were descriptive, structural, narrative, and evaluative, offering a variety of probes to gain more clarification and insight when required (Smith et al., 2009). Descriptive and structural questions, which were broad and non-threatening in nature, were placed at the beginning of the interview to help build rapport (DiCicco-Bloom & Crabtree, 2006). Narrative and evaluative questions were placed toward the middle and end of the interview, providing an opportunity to ask more personal questions once the participants began to feel more comfortable. This enabled participants to tell their stories and reflect on and express feelings, emotions, and concerns at length (Smith et al., 2009).

## **Pilot Interview**

A pilot interview is considered a *practice interview* that researchers conduct to gain more experience and test their interview schedule as a research tool (Markula & Silk, 2011). The interview schedule was piloted with a professional who worked directly with families in TSC. Piloting the interview schedule with a professional working directly in the field gave me the opportunity to gain insight into questions that were missing, ensure questions were relevant to the field and to check the clarity of questions asked. In addition, three pilot interviews were conducted with parents of youth with various impairments and ages. Based on pilot interviews, small revisions to the order of the questions and the addition of some new questions were made to gain the best possible material for future research interviews (Markula & Silk, 2011). Due to

the rich data received in the three pilot interviews conducted with parents, all interviews were used as a part of my research data. Participants were notified of this and agreed to the use of their data.

### **Ethical Concerns and Considerations**

A certificate of ethical approval was obtained from the University of Alberta Research Ethics Board 1 (see Appendix B) prior to conducting the study. There are various principles of ethical research conduct in qualitative research that promote human participants being treated with dignity and respect throughout the research project. According to Markula and Silk (2011), dignity can be respected through the following principles: respect for dignity, free and informed consent, marginalized persons, privacy and confidentiality, and justice and inclusiveness.

**Respect for dignity.** Individual autonomy, and therefore the respect of an individual's autonomy, was upheld throughout the study. Participation in this study was voluntary and participants had the right to refuse answering any interview or demographic questions. They also had the right to withdraw from the study at any point in time, up to one week post final member check.

**Free and informed consent.** Participants were advised about the risks and benefits of participating prior to agreeing to participate. All information was provided in non-academic language at a grade nine level. Participants taking part in the study were asked to sign an informed consent form along with a photo/video consent form.

**Marginalized persons.** This study did not involve participants who would be considered vulnerable, including children, persons experiencing disability, the elderly, or individuals who did not have the means, education or ability to comprehend the research purpose.

**Privacy and confidentiality.** Confidentiality was upheld through anonymity for all participants in this study. Pseudonyms were used for each participant, their child, program staff or school and community organization discussed during the interviews. Research data, including audio recordings, transcripts, personal information, and photographs were stored on an external hard drive and kept in a locked filing cabinet. The external hard drive was password protected and encrypted to ensure confidentiality and privacy. Raw data was seen only by the principle investigator, thesis supervisor and the transcriber. The transcriber signed a confidentiality agreement to ensure confidentiality was upheld.

**Justice and inclusiveness.** Benefits and risks of the research project were explained to participants prior to beginning the study. Benefits of the study are not direct or immediate, although indirect benefits included assisting researchers and professionals to gain a better understanding of the value of parental experiences and development of tools and resources to assist families' transitions to physical activity in their communities. There were no physical risks to being involved in this study, however emotional or mental fatigue may have occurred due to the length of the conversations and the questions posed. I was prepared to book additional interview times. None were required.

## Chapter Four: Research Study

“My child may be ready, but I am not”: Experiences of parents as their children with impairments transition to inclusive fitness environments

*I think some parents will never be ready, and if the child is ready you can't hold them back. You have to let go—as much as ... as icky a feeling as that can be, you've got to do it ... if I was going to wait until I was comfortable with it—well, we'd still be waiting! (Lucy)*

Parents play an essential role in influencing and reinforcing physical activity for their children (Martin & Choi, 2009; Martin, Oliver, & McCaughtry, 2007; Trost et al., 2003). For families raising children living with impairments, this is particularly true. As youth graduate from high school, families seek out inclusive<sup>6</sup> community opportunities to meet physical activity needs (Block, Taliaferro, & Moran, 2013; Rimmer, 2005; Rimmer & Rowland, 2008; Roth, Pyfer, & Huettig, 2007). With limited resources available in the community, parents are key to ensuring transitions to community environments are successful. (Bult, Verschuren, Jongmans, Linderman, & Ketelaar, 2011; Gall, Kingsnorth, & Healy, 2006; Martin & Choi, 2009; Pitchford, Siebert, Hamm, & Yun, 2016; Stewart et al., 2010; Stoner, Angell, House, & Bock, 2007).

Transition is a complex and multi-dimensional phenomenon that involves taking on new roles or modifying existing ones (Dellve, Samuelsson, Tallbron, Fasth, & Hallberg, 2006; King, Baldwin, Currie, & Evans, 2005; Stewart, Staveness, King, Antle, & Law, 2006; Stewart et al., 2010). Parents' roles may expand to include that of educator, advocate, and health care provider (Kirk & Glendinning, 2002; McKeever & Miller, 2004; Nicholl & Begley, 2012). Further, it is thought that parents of children with impairments experience more role change challenges than

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<sup>6</sup> For the purpose of this paper, inclusive programs are defined as contexts where people with and without disabilities have the opportunity to interact in all aspects of fitness, sport and recreation (Wolf Klitzing & Wachter, 2005).

parents of children without impairments, which may act as a barrier to transitioning to new settings (Magill-Evans, Wiart, Darrah, & Kratochvil, 2005; Stewart et al., 2010).

Transition is described as “any event or non-event that results in changed relationships, routines, roles and assumptions” (Schlossberg, Waters & Goodman, 1995, p. 27). Transition can be further broken down into horizontal and vertical transitions (Stoner et al., 2007). Horizontal transitions include day-to-day transitions, such as moving from one task to another, or from home to school or work. For youth experiencing disability, this may entail unpredictable situational changes such as the presence of a substitute teacher, a change in transportation schedule, or a change in community physical activity program staff (Stoner et al., 2007). Vertical transitions are described as predictable life transitions. Movement from elementary to secondary school, secondary education to post-secondary education, or separate<sup>7</sup> to inclusive physical activity programs reflects vertical transitions (Stoner et al., 2007). For youth experiencing disability, inclusive physical activity can involve both horizontal and vertical transition. (Hodge & Runswick-Cole, 2013; Nguyen et al., 2016; Woodgate, Edwards, & Ripat, 2012).

As families transition into unpredictable community environments, they are often burdened by societal pressures and may be required to expend “considerable energy to meet cultural and environmental constraints in support of inclusion of their children” (Goodwin & Ebert, 2014, p. 21). The ongoing perceived and felt dominant cultural assumptions can lead to a form of symbolic violence or “the production and application of classificatory systems and practices that reproduce social inequality ...” (McKeever & Miller, 2004, p. 1179). This can have an impact on families as they enter inclusive settings and feel the pressure to reach socially

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<sup>7</sup> As ‘segregated’ is a term with a political history of exclusion, this paper will use the term ‘separate’ to describe a physical activity environment that is respectful of the resource needs of people with impairments.

constructed ideals and perceived assumptions of *normalcy*. Parents strive to emulate *normal* standards of behaviour and anxiously attempt to *heal, repair, or pass* their children as non-disabled, or are left to deal with the negative effects of societal stigmatization in inclusive community settings (Francis, 2012; McKeever & Miller, 2004). When normalcy isn't achieved, parent-blaming can be seen, from claims of overprotective parenting to shaming parents for bearing a child with impairment (Ali, Hassiotis, Strydom, & King, 2012; Antle, Mills, Steele, Kalnins, & Rossen, 2007; Chaapel, Columa, Lytle, & Bailey, 2013; Francis, 2012; Lawrence, Alleckson, & Bjorklund, 2010; Pascall & Hendey, 2004). This level of 'Othering' may create barriers to sport, recreation and fitness pursuits (Beltran-Carrillo, Devis-Devis, Peiro-Velert, & Brown, 2012; Bruce, 2014).

While there has been research on parental perceptions of barriers and facilitators to participation in community recreation (e.g., interpersonal, intrapersonal, community, institutional, and public policy—see Obrusnikova & Miccinello, 2012), limited research has been conducted on the lived experiences and strategies parents use as their children make the transition to community fitness programs from separate settings. In a related study completed by Cohen-Podvey, Hinojosa, and Koenig (2010), researchers explored the experiences of six families as their children transitioned from a separate early intervention program to special education pre-school services. Although this transition research did not focus on physical activity or youth, it provides important insights into the lived experiences of parents' transitions. Cohen-Podvey et al. (2010) revealed three themes from the data: (a) 'transition is scary', (b) therapy helps children progress but does not assist with transition processes, and (c) communication is key. They also found that families understood that the transition to new environments, despite it causing anxiety, was best for their children. Comfort levels of the family through the transition

process and the success of transition appeared to be directly related to the quality of the transition, including the types of strategies and supports used by families and professionals throughout the transition process.

A similar vertical transition process experienced by parents of youth transitioning from secondary school to adult life provided insight into the life adjustments required from parents as their children move from a structured school environment to a lesser structured community environment. Walker, Alfonso, Colquitt, Weeks, and Telfair (2016) found that parents identified this transition to be a major stressor for their families due to fear, availability of support services, and high demands on the family. Similar findings were reported by Davies and Beamish (2009). They found that moving out of school and into the community, where few program options were available and high levels of supervision were required, left parents to manage the transition. Over half of the 218 parent participants reported that considerable family adjustment was required to meet the demands of the transition.

Roth et al. (2007), conducted a study on the impact of recreation transition programming as perceived by both the parents and their adult children following high school. The researchers found that moving from school-based recreation activities to either separate programs (Special Olympics) or inclusive programs in the community required a significant shift in roles, routines and supports from parents. The shift left parents feeling unprepared to successfully support their children. Similar findings have been found in studies by Schleien, Miller, Walton, and Pruett (2014) and Goodwin and Ebert (2014). Although parents indicated they valued community physical activity and recreation as an important aspect of their children's lives, they were, at times, distraught by having to assume the ongoing and labour-intensive responsibilities of getting

their children active. Yet, despite the demands on parents, their voices are infrequently represented in transition research (Davies & Beamish, 2009).

The purpose of this study is to understand how parents of children with impairments experience transition from separate physical activity contexts to community physical activity environments. More specifically, this study aims to, (a) explore the experiences of parents as they anticipate and prepare for the transition from one setting to another, (b) understand the strategies the families use to address the transition, and (c) gain insights into the supports that are important as they address the challenges of program changes.

### **Conceptual Framework**

Schlossberg's transition model (1981) was used as the guiding conceptual framework for the study. She identified three stages to transition: moving in, moving out, and moving through (Anderson, Goodman, & Schlossberg, 2012). The stages require individuals to disengage from current roles, relationships, routines, and assumptions (moving out), learn and become familiar with new roles, responsibilities, routines, and assumptions (moving in), and reside in a neutral zone where they begin a cycle of renewal and hope for the future (moving through) (Anderson et al., 2012). While *moving in* or beginning something new is often thought of as the first stage in a transition, Bridges (2004) argued that every transition starts with an end point. This can be seen with parents' experiences as their children reach an end point within separate physical activity programs (moving out) and enter into inclusive physical activity (moving in).

Schlossberg (2008) believed that adults experience a time of dis-equilibrium as they identify, approach, and proceed through a transition. The state of dis-equilibrium a person experiences, however, will vary depending on the type of transition an individual is undergoing

(anticipated, unanticipated, or non-event), their appraisal of the transition (positive, negative, or benign), and the impact the transition will have on their day-to-day roles, routines, relationships and assumptions (Anderson et al., 2012). For parents, the event trigger of an anticipated vertical transition amongst the ongoing horizontal transitions, whether viewed as positive or negative, may trigger a state of dis-equilibrium (Anderson et al., 2012; Stoner et al., 2007).

Schlossberg (2008) also argued that the key factors influencing healthy transitions through each transitional stage includes four components, known as the 4 S System: *situation* (event trigger, timing, control, role change, duration, previous experience, concurrent stress), *self* (personal resources: socioeconomic status, age, gender, stage in life; and psychological resources: optimism, ego development, commitment, values, spirituality, resilience), *supports* (types, functions, options), and *strategies* (coping responses, direct action, inhibition of action). Each of these components can act as a potential asset or liability to the transition itself and can vary in importance depending on the individual undergoing the transition. These four key factors, along with how parents approach, appraise and anticipate the situation, may influence their ability to manage role changes and adaptations required during this transition process.

## **Method**

### **Research Approach**

An interpretative phenomenological analysis (IPA) and an instrumental case study approach were used for this study. With its theoretical roots in phenomenology, idiography and hermeneutics, IPA assists researchers to examine how people make sense of their life experiences (Smith, 2011). Through IPA, researchers explore people's relatedness to or involvement in particular day-to-day events in their lives (Smith, Flowers, & Larkin, 2009) and

provide a “detailed picture of how the families think and feel about the challenges they face” (Brewer et al., 2008, p. 7).

Researchers design instrumental case studies to focus on a particular phenomenon, with the ultimate goal of assessing a sample in great detail and depth (Baxter & Jack, 2008; Tobin, 2010). Parents of youth were recruited from a separate physical activity program that uses qualified adapted physical activity consultants, trained volunteers and community partners to bridge the gap between separate and inclusive settings to ensure youth experiencing disability have options in the types of contexts they choose. Within case studies, boundedness is imperative to ensuring the case is clearly identifiable with clear set boundaries (Stake, 1995). This case study was naturally bound by the already existing program and procedures of the separate program. It was additionally bound by both time and activity (Stake, 1995), the activity being the transition from separate programs to community physical activity and the time beginning from the start of the community transition program to the present. Bounding the case study ensured the project stayed focused, did not become too broad and was reasonable in scope (Baxter & Jack, 2008).

### **Participants**

Participants were purposively selected using the strategies of convenience and criterion sampling (Patton, 2002). Convenience sampling was used as participants were drawn from the same program. Consistent with IPA, a homogeneous sample was sought to represent the shared experience of transition (DiCicco-Bloom & Crabtree, 2006; Patton, 2002; Smith et al., 2009). The criterion were (a) parents of a child attending separate program, (b) child was in transition from separate to inclusive community physical activity within the last 12 months, and (c) child was between 12 and 21 years of age.

At the time of data collection, 25 families were participating in or had participated in the transition pilot program within the last 12 months. Sixteen families initially expressed interest and were invited to take part in the study. Eight families ultimately participated in the study. Ethics certification and participant-signed consent were obtained prior to conducting the study.

Participants included seven mothers and one father (from eight families) between 43 and 59 years of age, with a mean age of 52. The presence of only one father is consistent with previous research, as mothers typically assume the role of day-to-day care for children experiencing disability, including supporting them in community programs (Home, 2002). Their children, seven boys and two girls, ranged in age from 12 to 19, with a mean age of 16. One participant had two children undergoing the transition at the same time. The parents described their children as having a variety of neuromuscular and developmental impairments that required supports for mobility, communication, and/or social needs. The children were enrolled in the separate program for a minimum of one year, with the majority of participants having been actively involved in the program for over four years.

The education level of parents ranged from high school diplomas to graduate degrees. Household incomes were reported from low income to upper middle class income, with two participants working full time, three working part time and three participants who identified as full-time caregivers for their families. All families were either single-child or two-child households.

### **Data Collection**

In adherence with IPA research, data collection techniques included semi-structured interviews, artefact collection, and field note documentation (Smith et al., 2009). Participants

were engaged in purposeful conversation about experiences that were directly affected by their child's transition to community physical activity. Two semi-structured interviews, which used open-ended questions to gain in-depth information, enhanced understanding of parents' experiences of transition. Sixty to 90 minute audio-recorded semi-structured interviews provided flexibility for the participants to offer detailed first-person accounts of their experiences and to speak candidly and at length about their experiences (Smith et al., 2009). Face-to-face interviews took place in a pre-determined setting at a pre-determined time, including but not limited to coffee shops, university office space or participant homes.

The aim for both interviews was to “facilitate an interaction which permits participants to tell their own stories, in their own words” (Smith et al., 2009, p. 57). The first interview, following a pilot interview, covered parents' thoughts, feelings and understandings about the transition process. The second interview included the use of artefacts to further stimulate discussion. Artefacts included previous program evaluations (when participant consent was provided), crafts, written e-mails to staff, family or friends, photos and videos taken by participants using a camera provided by the researcher during the transition period, or any additional items chosen by the participants that facilitated meaning and discussion on their experiences. Field notes were recorded by the researcher after each interview to capture initial reflections, which were used during data analysis.

### **Data Analysis**

Data analysis was completed following the four-step IPA process as outlined by Smith et al. (2009). Step one included the reading and re-reading phase, which contained a thorough line-by-line analysis of one transcript, enabling the researcher to be fully immersed into the participant's world. Step two, comprised of initial note-taking, including a detailed exploration

and examination of the interview content and language, including similarities, differences, contraindications and concepts that arose. Step three consisted of developing previous notes and comments into emergent themes that reflected both the participants' original words and the researcher's interpretation. And lastly, step four included searching for connections across emerging themes and evaluating where and if they fit into the research question and objectives. Once themes were incorporated, or not, in each transcript, patterns were sought across all participant transcripts to check superordinate themes. Data analysis software Nvivo was used to assist in the organization of the data. The Schlossberg model (1981) of transition was used to support the interpretation of the findings.

### **Assessing Quality**

Yardley's criteria (2000) was used to assess the quality of this IPA research study, sensitivity to context, commitment and rigour, transparency and coherence, and, lastly, impact and importance. To ensure participants' voices were heard, member checks were conducted with all participants to confirm that interpretations of data accurately reflected their experiences. Commitment and rigour were demonstrated through ensuring an appropriate sample, developing a good interview and sufficient interpretive and idiographic analysis (Smith et al., 2009). Both transparency and coherence were addressed by keeping an audit trail throughout the research process. A detailed filing system of original transcribed interviews, field notes, important data collection information, and evidence of the full coding process was stored and reviewed during the analysis (Wolf, 2003). And finally, Yardley's final principle (2000), impact and importance, acknowledges that one's research must express something interesting, important and useful for the reader (Smith et al., 2009). The usefulness of this study will ultimately lie with the importance of the findings to the readers, however uptake has already occurred within the

transition program used as the case study, including, but not limited to, increased access, education and transition preparation time and parent support groups.

### **Findings**

Four themes captured the experiences of parents as their families *moved out* of a structured, resource rich, separate environment, *moved into* a non-structured, unpredictable community environment and *moved through* the transition process: (a) my child may be ready, but I am not, (b) fear of outside judgement, (c) playing by their rules, and (d) reframing our thinking.

#### **My Child May Be Ready, but I Am Not**

Moving out of a separate program into a community fitness centre involved experiences of disruption, risk, limited resources, and assuming the supporter role. In addition to supporting their children to transition to a community program, the parents recognized that they also required time and supports to prepare themselves. Leaving the stable environment of separate programs and entering a less predictable community environment was not well received by all parents. Holly, the mother of a 19-year-old, remembered her immediate sense of abandonment from a support system she had come to depend on for years, “What do you mean my kid is not going to be here forever ... because I’m comfortable right now ... if you’re taking this away from me, it’s your fault.” Parents’ protests came from a place of fear, insecurity, and perceived lack of control over the upcoming changes. Holly summed up her apprehension this way:

It’s harder for parents to transition than it is for the kids. Because you know what? We just get our kids settled into something that’s safe and fun and good right? And then you have to leave and start all over again.

Remaining in a separate environment provided a level of comfort, ease and reassurance for parents, a state of equilibrium. They assumed the same roles of other parents of children without impairments – registering their children in the program, ensuring they arrived on time, and picking them up at the conclusion of the program - no more, no less. They were secure in knowing their children were in a protected environment, instructed by qualified staff who understood their abilities, and would support them on both their good and bad days. Lucy affirmed, “Everybody understood the disability, everybody had experience and the knowledge and it was safe for me and it was safe for her.” Being assured that their children were *looked after* and *safe* relieved parental pressure, creating an environment that was essentially effortless for them.

The parents were not responsible for providing additional supports and strategies to facilitate their children’s successful participation in the separate setting due to the presence of knowledgeable staff, small ratios, age-appropriate activities, and suitable program expectations. Parents spoke of their delight in not having to assume, yet again, a pseudo professional role to foster inclusion. Laura recalled, “I am almost every assistant title you can imagine ... OT assistant, I’m a PT assistant, I’m an educational assistant. I’m now a tutor, I’m the teacher, and I’m the therapist. You name it, I’m doing it.” The opportunity to *just be a parent* was a gift to families as they did not have this experience in other community environments. Lucy explained:

Sometimes you just want to be a Mom. Like sometimes you don’t want to have to go in there with ... your bin of tricks ... sometimes you just want to be able to just sit back and just watch, right? And there’s not many places that you can go and eventually have that role of just being a parent or just, you know, to sit back with the other Moms and just ... chat about the traffic that day or whatever.

The parents' sense of comfort, safety and control was threatened by the prospect of attempting the vertical transition of moving out into the community. Dianne recalled her feeling at the time, "You're always a little anxious because it's like, 'Oh you've been cut free, the apron strings aren't there anymore' right?" Parents appraised the transition to be a negative change that required additional coping strategies, "I think I was more anxious than [my son] and it was just because I know the history ... it was automatically one more hurdle I had to get over" (Dianne).

Limited resources available to families during their past attempts to integrate their children into community fitness environments left parents frustrated at the thought of having to do it again. Lucy recalled her reaction when the possibility of transition was first discussed with her:

No. She's not going to have a membership to a gym because we've tried it a couple of times and it's not going to work. She's going to be frustrated with the experience and it's going to be frustrating for me.

Yet, despite these strong sentiments, parents had conflicting feelings about what the future held for their children if they did not pursue transition. One mother, Kara, expressed her concern about the separate setting being "not enough for [her son's] physical activity needs." She went on to say, "... he has got to somehow get more comfortable with community settings, right? I'm not going to be here forever and his Dad is not going to be here forever."

### **Fear of Outside Judgement**

As parents and their children began moving into community environments, parents expressed feelings of apprehension, discomfort, and fear. Their concerns of not being able to control the new environment, coupled with recollections of past negative experiences, created

anxiety for parents. For Laura, the anxiety was severe, yet she pushed through it. She described her feelings on her first day going into a community fitness centre with her child, “Pins, needles, nausea, fear, anxiety, felt like passing out—just if you’ve ever gone to a Halloween block or a Halloween house ... that fear, apprehension, the unknown—you didn’t know what was going to pop out.”

In addition to their trepidation at exposing their children to stigmatizing environments, they faced the uncomfortable risk of outside judgement. This apprehension was explained by Lucy, who was expected to manage all contingencies that arose. “Oh my goodness, I’m in my community! ... A lot of people know me and would expect that I would have the answers. And you don’t always have—like you don’t have the answers, right?”

Parents felt ownership for their children’s behaviour, a personal responsibility for how their children reacted to new situations, their personal abilities to cope with those reactions, and how the public reacted to their children. The entrenched need to blend in and the fear of being noticed for not conforming to normative behaviours created feelings of failure for parents, who were required to, and yet at times unable to, ‘control’ their children’s behaviours. Kara recalled a reaction from an elderly patron when her child was displaying what Kara termed “obsessive compulsive behaviours”, “Well I would never have allowed my kid to behave like that.” This judgement and expectation from an outsider left Kara generalizing what the public must think, “They think you’re a bad parent and that your kid is misbehaving and that you should be able to control that better.” Parents perceived their role to be that of ensuring their children were ‘fitting in’, not disrupting the program, and being as invisible as possible. Nancy talked of the lengths to which her family went to ensure that inclusive settings had the sensory and physical adaptations

required for her child “If he didn’t have that, then he becomes a disruption, then it’s not good for anybody.”

The inability to ‘regulate’ their children’s behaviours to suit the expectations of others (and themselves) left parents feeling exposed, devalued, and defenseless. Lucy spoke about her perceptions (real and imagined) of the judgement she and her daughter underwent when they were not ‘blending in’ during their first trip into the community fitness centre.

I know that all eyes weren’t on me and her when she was inappropriate. But I certainly felt like all eyes were on me and her when she was inappropriate. It doesn’t matter how used to behaviours you are, when you’re out in the public and it’s your child and they’re frustrated, you want to fix it. And you feel like you’re on stage.

The repeatedly stated need to maintain a ‘normal’ identity to avoid judgement and rejection within their own communities, along with their inherent need to protect themselves and their children, spoke strongly to the intensity of their transition experiences and the toll it took on their emotional reserves. Lucy reflected on the process of moving into a community facility, “It doesn’t matter how well adjusted you are. It kind of hits you in the face, so it is very emotional ... Like it’s just—I hate transitions. I hate them. It’s very stressful.”

The negative attention parents perceived from the public made moving into the transition difficult for all parents but one. Jack, the only father interviewed in this study, took a more laissez-faire approach to his child’s behaviour and potential judgement from the community. Jack explained, “More and more people have experience because they’re not sent to [institutions] anymore. So ... relax, you know? Manage the most disruptive behaviour however you can, but don’t sweat the little quirks.” Unlike the others in the study, Jack managed perceived outside

judgement not by pointing the finger at himself and viewing himself as a failure, but rather by assuming the role of an educator and using the strategy of developing stronger relationships within their new community. “I mean you have a conversation. Just talk to people—that’s my advice—talk to people. Don’t cut yourself off because your kid has special needs.”

### **Playing by Their Rules**

As parents continued moving into community fitness centres, they were confronted with restrictions imposed by community and government support programs. Parents sought supports that would assist with the transition and independence of their children in physical activity environments, however funding was designated to support activities such as parent respite. Jack explained that parents were encouraged to access public leisure, but to obtain government support he was required to leave his child at home under someone else’s care. Jack explained that one policy does not fit all families:

They sort of take a shotgun approach where they load up with what they figure will hit the most people and blast away ... and if you don’t need that, well tough. If you need something else—sorry. You’ll have to go see a movie and they’ll provide a babysitter.

And yet, parents appreciated the financial support that was available through government agencies for such things as the hiring of respite and instructional aides to support inclusive opportunities. Kara stated, “The money is there for aides and stuff—you can get the funding.” The challenge of finding, hiring, and training aides fell to the families, however. Kara spoke of her experience working with a government agency to find a reputable support person for her child. She was expected to possess the skills to recruit, screen, interview, and train people who may have no background in working with children with impairments in potentially challenging community settings. Kara felt despair as she was advised to hire strangers through an internet

site—a practice she felt was unsafe, potentially placing her child at considerable risk. “The [government] tells you, ‘Well why don’t you just find someone on Kijiji?’ Well I didn’t really want to—like this is ... irresponsible ... it could be anyone out there.”

Laura spoke of being faced with moments of frustration, having to compromise her own values to acquire the workout buddy supports required by her son to be successful in a community fitness centre. With the need to put a workout buddy in place quickly to begin the program, Laura hired the only person who applied for the position. As a parent who worked hard to develop independence for her child, she went against her instincts and hired a workout buddy who did not share her aspirations for her son, something she deeply regretted.

There was no threat to [my son] in any way, but it made me sick to my stomach afterwards that I was going to compromise my family philosophy to bring in a young man that was actually going to treat [my son] more like he was disabled.

When their attempts to find workout buddies failed, parents assumed this role. Being a parent and ‘staff’ was a difficult journey to navigate. Adding on another role of being a workout buddy who is required to instruct, motivate, and ensure the safety of their children was extremely difficult for parents and created frustration for their children. Norma explained:

He doesn’t want me telling him to adjust something or do something. He doesn’t want to hear it from me. And yet, you know, when I’m there with him, I have to make sure he’s safe and make sure he’s using things like they’re meant to be used.

Despite the funding opportunities and supports available to assist with community integration, parents were left feeling alone and vulnerable. Moreover, the energy required to take on yet another role with their children was emotionally and physically draining for parents. Yet

somehow their commitment to independence and community engagement for their children gave them the energy to move forward. “I don’t even know if I have the ability, I just do. Because if I don’t, no one else will” (Dianne).

### **Reframing Our Thinking**

Parents accepted early on in their children’s lives that in order to qualify for government funding, resources, and support, they must succumb to the processes of medical diagnosis, labelling, and an often single-minded focus on what their child could *not* do. The constant requirement to assess children against ‘typical’ developmental norms to achieve government supports only reinforced what their children were not achieving, often overshadowing their children’s accomplishments. “We have everything set for parents to know what their child can’t do,” explained Laura. Expert diagnoses and constant reminders of their children’s deficits, with little focus on what their children could do, quickly became an added stress to parents, creating feelings of uncertainty and lost optimism for the future. Laura added, “We really lost hope in thinking that ... what we saw at home was what he was capable of and that perhaps we were just delusional.”

Over time, parents reluctantly acquiesced, lowering expectations of themselves, their children, and the community. As parents and their children *moved into* community environments, parents automatically assumed that their children would not fit in. Holly questioned: “How is it going to be in you know, some jock sitting in [the community fitness centre] is going to want this kid sitting next to him?” This sentiment was echoed by Laura who stated:

What are the other people in that centre going to think of my son? What are they going to say about my son? Are they going to complain that they're trying to work out and this special needs kid—like what's going to happen?

As parents settled into the new environment and continued to *move through* the transition process, they began to witness the surprising successes of their children in the 'unpredictable' community environment. A transformation of thinking began to take place, shifting parents' previous untrusting, unsettled, and negative viewpoint of their child's presence in the community to a more optimistic dialogue. Laura described the moment she saw her son successfully participating in the community. She observed him confidently moving from one exercise to another, displaying pride and independence that she had not witnessed within a community environment before. Recognizing that there was no one in this environment telling her family what her son couldn't do, she stated, "It was one of the first moments in his life where we could see what he really liked to do and what he was really good at."

As parents experienced success and the enjoyment of their children in new environments, they began to reframe their understanding of their children's abilities, setting into motion a re-evaluation of their own assumptions and roles. Kara looked inward and began to question the level of expectations she held for her child. She reflected, "You have in your own mind what your kid can and can't do. So yeah, you have to check yourself too, to make sure you're not practicing ableism and assuming." Tanya also spoke openly about seeing her children participating successfully in the community after underestimating their abilities and desire to do so. "They are always far more capable and even far more willing [than I understood] ... I learn more and more." As parents began to look deeper into themselves as a potential and unconscious barrier to participation, they acknowledged that they too needed to shift their assumptions and

roles to ensure success in the community. Laura shared the conversation she had with her family therapist, who had spent many years trying to improve her son's behaviour. She concluded that the focus needed to be on the family and not just her son:

Okay we're stopping everything and what you need to do is work on me, and you need to work on my husband and I, and we need to stop doing anything with [my son] and it needs to shift with us.

This powerful shift in thinking through the transition process fostered a broader sense of optimism and hope for the future. The appraisal of the transition was no longer about others' judgements towards themselves or their child fitting into programs, or about parental fears and hesitations, or lack of government support. Rather the transition became about learning what their child *liked* to do and what they were *successful* at. Lucy shared her story of working through feeling uncertain and unsettled and the transformation that took place, "I thought she wasn't fitting in physically ... But no. She—she was able to do it, and then she experienced success and she got stronger and ... wow. She loves it. It's her favourite thing to do."

New opportunities for achievement were found in what had once been appraised by parents as an unsettling risk. Norma spoke of the boost in confidence the transition created for her son, "Independence. It's something he can do. He knows he's safe to do it, and he is confident to do it." Instead of projecting to others that their children *did not* belong, they became convinced their children *did* belong. "I've lost all that garbage dialogue and now it's, 'He's coming, he has every right to be there, get out of his way'" (Laura).

## Discussion

Anderson et al. (2012) stated that “individuals’ appraisal of the transition is key” (p. 63) and how one appraises a transition will “clearly influence how that individual feels and copes with the transition” (p. 63). Regardless of this being an anticipated transition, many parents in this study initially perceived *moving out* of a separate program as a negative transition that would cause added stress to themselves and their children. Supporting the findings of Stoner et al. (2007), parents disclosed the difficulties associated with vertical transitions and their impact on families. Having to assume pseudo professional roles in another context during the onset of a transition set parents’ lives into dis-equilibrium (Schlossberg, 2008). As the transitions began, parents found themselves walking the line between preserving available energies by trying to maintain their old roles, routines, and relationships, and digging deep to re-evaluate what they have known about themselves, their children and the community.

The dynamic and powerful interactions between parents’ experiences and society’s influences were strikingly evident. *Moving into* an inclusive environment increased parents’ risk of being under surveillance by their own communities (Power, 2008). In past experiences, their attempts to ‘pass’ their children as ‘normal’ (Gray, 2002) were unsuccessful, leaving them exposed to stigma, guilt, and shame for putting their children and themselves through such experiences (Nurullah, 2013). This exposure to potential judgement further threatened parents’ sense of self and created a milieu of lost optimism (Schlossberg, 2008). Parents were hesitant to take the risk again. The internalization of these past failed attempts left parents wanting to limit their exposure through strategies of avoidance that would shield and protect them from the perceived outside judgement of others (Ali et al., 2012; Gray, 2002; Schlossberg, 2011). Davey, Imms, and Fossey (2015) found similar findings in their study on social participation. “Parents

drew on past experiences of successful and unsuccessful social participation to weigh up whether they could overcome potential and known barriers, and to decide whether attempting activities was worth their effort” (p. 2268). The defeat from past situational attempts left parents vulnerable as they began the process of *moving out* of a separate program, requiring them to pull on additional supports and strategies to cope (Schlossberg, 2008).

The assumed role of attempting to achieve ‘normalcy’ was not effortless for parents. They, not the community, assumed sole responsibility for their children’s behaviours, successes, and failures. Similar to findings from Nurullah (2013), the parents were living with a dual burden – “taking care of their child with a disability while simultaneously facing social stigma for their child’s disability” (p. 27). Parents’ stories spoke of deep-rooted discomfort with being stigmatized and judged by their own communities (Kediye, Valeo, & Berman, 2009; Nurullah, 2013). Finding the balance between assets and liabilities of the self, supports, situation, and strategies became much more difficult when working against a “parenting deficit model [where] failures are located in parents rather than in support of parents” (Pascall & Hendey, 2004, p. 178; Schlossberg, 2008).

Parents acquiesce to deficit-based models in order to receive necessary supports for their children, leaving parents choosing to “accept their ‘place’ as subordinates” (McKeever & Miller, 2004, p. 1183). The responsibility for gathering additional supports and resources is placed solely on parents, further increasing their stress levels and ability to cope (Schlossberg, 2011), taking all responsibility away from the community and the supports that are supposed to be available (Koro-Ljungberg & Bussing, 2009). This new ‘normal’ was eventually accepted and internalized by parents as being a natural part of raising a child with impairment, which in turn led to parents unconsciously colluding to the oppression of their children and themselves

throughout the transition. Parents' acceptance that anything different is defiant (Ashby, 2010) and their low expectations for their community and for their children created a level of *Othering* of their own children on a subconscious level.

As parents *moved into* the difficult transition of supporting their child to be active in a community setting, symbolic violence was conveyed in forms of reliance of others' acceptance and support, judgement and feeling of belonging (Beltran-Carrillo et al., 2012). Parents' stories expressed the acceptance that their children would not 'fit in' by community standards, and that, in order to 'fit', their children must act and look like other patrons in the community locations. Parents' unconscious strategy to automatically look inward at themselves and their children as an inappropriate fit or the 'failure', rather than looking at the community's structural and environmental deficits, portrays symbolic violence as natural and "a means in which marginalization is accomplished" (Hall, 2004, p. 45).

Interestingly, only mothers in this study shared stories with underpinnings of acquiescence and symbolic violence. Perhaps this was because "gender differentiation continues to exist as a form of domination in modern society" (Calhoun, LiPuma, & Postone, 1993, p. 157). As adults journey through the transition process, they are required to disengage from old roles, routines, and relationships, however, to do this, they must adapt to new roles, routines, and relationships (Schlossberg, 2008). Gender, as seen in Schlossberg's 4 S System under the *self* category, is argued to either be an asset or a liability depending on the situation at hand (Anderson et al., 2012). In this study we saw the father easily push his hesitations aside to take on the role of educator within a new community environment, whereas the mothers used strategies to increase invisibility and decrease impact on those around them. Anderson et al. (2012) have identified that the relationship between gender and transition is one of complexity.

Within an androcentric society, female activities, behaviours, and actions are still seen as weak, inferior, and of less value than that of males (Calhoun et al., 1993). This ingrained way of thinking and being may have very well had influence on the coping strategies used and the direct or inhibited actions chosen by the mothers and father in this study.

As parents *moved through* the transition process, they began to experience a transformation in their thinking, feelings, and actions. At this stage of the transition process, Schlossberg et al. (1995) would argue that parents have entered into a cycle of renewal. This could be seen through parents' experiences as they shared their stories of letting go of old ways of thinking and being, and adapting to new strategies and supports. Confidence and optimism were gained as they observed their children successfully participating, allowing them to regain some semblance of control, balance, and equilibrium in a risky environment.

In summary, the experiences that parents shared indicate that for them, they did indeed experience transition. Throughout their stories, they shared their experiences of approaching transition and their perceptions towards, the context around, and the impact of these experiences. They also shared how they coped and managed as they hesitantly disengaged from the roles, relationships, routines, and assumptions of their current life and became familiar with the rules, regulations, norms, and expectations of the new system (Schlossberg, 2011). In the early stages of transition, parents did their best to seamlessly fit into a new system that has not worked in the past. However as their children began to reach areas of success and achievement, parents navigated the convoluted passage, redefined and re-developed their own norms and expectations, and took charge of life in the new system (Anderson et al., 2012; Kralik, Visentin, & Van Loon, 2006; Schlossberg, 2008).

## **Implications**

Parents are an instrumental piece of the puzzle for youth successfully participating in inclusive physical activity opportunities (Goodwin & Ebert, 2014; Martin & Choi, 2009). The participants of this study were substantially affected by the transition of their children into inclusive community environments and their experiences may provide important insights for health promotion amongst youth with impairment. For participants of this study, the pressure of leading their children through a transition as well as experiencing the transition themselves had substantial impact on their abilities to cope, adapt, and seamlessly provide support for their children to be successful in inclusive environments (Anderson et al., 2012; Pascall & Hendey, 2004; Schlossberg, 2008). Parents, alongside their children, underwent a transition and had expressed the need for support and resources throughout all stages of this process.

Much attention is focused on the needs and readiness of youth as they make the transition to various physical activity contexts throughout their childhood. While we would argue this is still important, the parents were required to employ coping strategies, internal and external supports, and psychological resources as they attempted to support their children and themselves through transition. Understanding parental experiences may mean that community supports and resources are put in place to more effectively assist families undergoing physical activity transitions. Educational and parent–peer opportunities before, during and after transitions, along with tools that can support parents leading up to transitions, may ease apprehensions, thereby preventing undue pressures on parents at times of transition.

**Limitations**

Mothers made up 87 per cent of the participant base, which may not give a true indication of how fathers experience transition. The one father interviewed did not experience the same fear of outside judgement that the mothers experienced and the role adaptation for the father was different than those of the mothers, revealing important information about the potential gender differences. In addition, all participants in this study identified as Caucasian. An examination into how parents with more diverse cultural backgrounds navigate these transitions would be beneficial.

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## Chapter Five: Final Reflections

*Well I guess it shows you that it's possible—that when you have the right support and you have—you've gone through the right training, or your kid has been prepared, you can do it, right? And then when you have people who believe that you can do it, that your kid can do it, then it can be done. (Kara)*

### When Research Meets Practice

Since 2008, I have had the unique role of supporting adults living with impairments and their families in their transition from separate fitness programs to inclusive fitness centres within their own communities. Within this position at TSC, I have had the opportunity to work within the Community Exercise Transition Model (see Appendix C). Expanding on previous models developed by the Rick Hansen Foundation (2007) and Rimmer (2002), this model was developed to tackle the various barriers people living with impairments, their families, and their professional supports face as they transition from separate to inclusive environments. The model encompasses four key components to support with the transition of individuals experiencing disability into community fitness centres, (a) individual readiness, (b) community readiness, (c) physical environment, and (d) community opportunities.

Each of these components provides a unique perspective on diminishing barriers and providing supports to individuals with impairments, community fitness providers, community management and policy makers alike. This model has worked successfully for interested participants in the Greater Edmonton area, with over 300 adults with impairments transitioned into community fitness centres and over 30 strong partnerships established and maintained with fitness and recreation centres (Goodwin et al., 2013).

In 2012, although my experience with youth to that point had been limited, I was confronted with four ethical questions relevant to my professional practice (DePauw, 2009; Goodwin & Howe, 2016; Goodwin & Rossow-Kimball, 2012; Updale, 2008). First, due to a high demand for separate programming at TSC, families were limited to two programs per term, leaving participants receiving only 30 to 90 minutes of physical activity per week—far less than Canada’s recommended physical activity guidelines of 150 minutes per week (ParticipACTION, 2015). Secondly, families were limited in options for organized sport and physical activity outside of school. The third area of concern came from the age restrictions set on TSC programs: the maximum qualifying ages for youth participants at TSC is 19, or when a participant completes high school. Anyone over this age (if they had finished high school) would not be eligible to participate in this program and, depending on their type of impairment, may not have been eligible for adult programs at TSC, which were solely for individuals living with neuromuscular impairments. What did families do once they were no longer eligible for separate resources in their community, and how were they being prepared for this transition once separate programs were no longer an option? And lastly, parents, not youth, appeared to be the driving force as to why children became inactive once they were no longer deemed suitable or ‘aged out’ of TSC programs.

Many factors influenced my decision to focus on transition into inclusive community physical activity. By focusing on transition, I felt that I could further understand why families are choosing to be inactive rather than transitioning to inclusive programs. Furthermore, with the understanding that the resources for TSC programs (and likely other separate programs in our area) were not going to increase and allow for more participation of families within separate

environments, I felt that focusing on transition would have the most impact in getting youth and young adults more active, more often.

### **Research Impact**

I started this research in an attempt to understand the experiences of parents as they anticipated and underwent the transition of their children from a separate context to an inclusive physical activity environment. Results demonstrated that parents in this study experienced transition alongside their children and that this type of transition had an immense impact on parents as they entered and moved along all stages of the transition. Since the completion of this research, a variety of tools have been piloted in an attempt to enhance parent readiness to transition. Parent support groups have been organized and held to provide parents with more opportunities to network, connect and share stories with other parents who are in TSC programs and/or have experienced similar transitions. To help increase the confidence of both parents and youth, a youth readiness strategy has been put into practice. This strategy is designed to ensure that all youth participating in TSC programs will learn skills they can transfer to other areas of interest (community, school, and sport clubs). TSC has also begun offering more programming options with exposure to different community fitness and recreation centres in an effort to increase youth and parent exposure in a supportive and positive way. This strategy has proven to provide a much needed bridge between families and community staff, providing a conduit for developing positive connection between the two (Goodwin et al., 2013).

A necessary revision to the Community Exercise Transition Model has also begun. Assumptions made in the development of the model presumed that only individuals experiencing disability would require readiness and preparation for transition. This model, in its current form, does not take into account the impact on, readiness for and labour assumed by parents during this

time of transition (Goodwin & Ebert, 2014; Roth et al., 2007), nor does it acknowledge that parents also experience transition. With the findings of this study, we are altering the community transition model (see Appendix D) to include not only individual readiness but also family readiness as a key component. This will ensure that family readiness, awareness, education, and tools are kept at the forefront in planning, research and programming.

Perhaps most importantly, the completion of this research prompted me to examine my current professional practice and ableist assumptions. Each day, decisions are made on behalf of individuals experiencing disability in the development, implementation, and preservation of adapted programs (Goodwin & Rossow-Kimball, 2012; Standal & Rugseth, 2016; Updale, 2008). Prior to this research, youth at TSC living with developmental impairment were deemed unsuitable for adult programs. This left families with only two choices, transition to inclusive physical activity or inactivity. This research was a catalyst to starting conversations on how we, as staff, can provide better support to families accessing our programs. The Centre has now opened up suitability criteria, providing opportunities for anyone with expressed need for adapted physical activity to access all programs. Though the Centre still provides transitional support, families now have multiple options for physical activity.

While this research does not generalize, these findings may transfer to other contexts of transition from separate to inclusive environments (Smith et al., 2009). Participants within the Community Transition Program would have been better served by having specific transition resources and a readiness plan as they and their children transitioned to inclusive physical activity. Research on parents' experiences serves as a resource for clinical, separate, and community practice. The development of resources can also be used to further guide professional

practice in efforts to provide choice, bridge the gap, support and empower families, and create more seamless and positive transitions to inclusive community programs.

### **Additional Study Limitations**

Before I conclude this chapter, I think it is also important to expand on the limitations of this study beyond what was provided in chapter four. The transition program that parents participated in is unique and offers substantial resources to support the transition to inclusive environments. These stories may not resonate with parents whose children are transitioning outside of this program and with limited supports. While I do understand that this study is not generalizable, it is my hope that readers will use transferability to connect the findings of this study with their own experiences. Transferability has been enhanced in this project through a detailed description of the methods, the use of thorough field notes, various levels of member checks, the careful selection of salient quotations and staying loyal to parents' information during the analysis phase.

Additionally, it is important to note that due to the limited number of families enrolled in the program, participants were interviewed at different times during the transition process. Some participants were interviewed in the early stages of transition and throughout the transition stages, while others had already completed their transition program and were asked to reflect back on the transition process when they were interviewed. This may have impacted the results, as the stage of transition may have affected the emotions the parent was experiencing at the time and how the questions were answered in the moment (Schlossberg, 2011).

Lastly, I am not a parent raising a child with an impairment, in fact, I am not a parent at all. This left me as an 'outsider' to the research (Macbeth, 2010). Being an outsider is thought to

have both benefits (e.g., gives distance from the familiar) and challenges (e.g., absence of shared experiences, potential for lack of understanding and clarity) (Macbeth, 2010). To help overcome challenges that may arise from being an ‘outsider’, I ensured that all stages of my research were *with* parent participants rather than *on* parent participants (Goodley, 1999). To accomplish this, I chose a research question that was relevant to parents, utilized a qualitative research method that provided parents opportunities to share their stories and experiences in in-depth ways, and I ensured the interview schedule and questions asked were meaningful to parents.

### **Next Steps**

The participants in this study were passionate about having their voices heard. To ensure this happens, these findings will be presented to a wide audience through provincial and national conferences. With that said however, parents are only one piece of the transition puzzle. Further investigation is required on how to bridge the gap to bring professionals and parents together to create greater resources and supports for transition to inclusive community contexts. This can be done through exploring the understandings of community service providers who work in the area of fitness, recreation, and physical activity on their roles during the transition. More research is also needed to hear the voices of youth with impairments to better understand their experiences of transitioning to community contexts. Gaining a full understanding of the experiences of everyone involved in the transition process will provide a clearer understanding of how to best develop tools and strategies to effectively prepare and support all aspects of transition to inclusive community environments. In addition, a look into regional and provincial policies to support families as they undergo physical activity transitions would also be beneficial in gaining a further understanding of the impact these policies have on facilitating or hindering families to be active outside their homes.



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## Appendix A: Interview Schedules

### Parent Interview Schedule # 1

Transition to community physical activity for youth with impairment: The parental experience

**Research Question:** How do parents of youth with impairment approach and experience transition from separate settings to community fitness programs?

**1. Describe your daughter/son's experiences in specialized programming.** *(Descriptive)*

*Probes:* Describe a typical session (who you saw, what you did, what you felt)

What activities were of particular interest/benefit and/or disinterest/disadvantage?

Describe your involvement through this process.

**2. What role did (has) physical activity play(ed) in your daughter/son's rehabilitation process?** *(Structural)*

*Probes:* Describe the activities and why you did them.

Describe your involvement in the activity.

**3. What role has physical activity played in your daughter/son's life outside of specialized programming?** *(Structural)*

*Probes:* Has your child been involved in physical activity in the community?

What type of setting has your child participated in, with who? (Segregated/specialized, integrated, community)

Describe the activities and why you did them.

How has this affected the family?

**4. Describe the preparation required to consider a community physical activity/fitness program for your daughter/son.**

*(Descriptive)*

*Probes:* Describe the importance of independence.

What skill base was required?

Describe your daughter's/son's readiness.

Describe your readiness.

What type of preparation did you have prior?

What type of preparation did your son/daughter have prior?

How did you feel about your preparation – your daughter's/ sons' preparation?

**5. How did you know when you were ready to transition to a community-based fitness program?** *(Structural)*

*Probes:* How did you come to that realization?

What benefits did you perceive?

What triggered this change within your daughter's/son's life and your family life?

*(ENVIRONMENT)*

**6. How did you feel about the process of locating a community fitness centre for your daughter or son?**

*(Evaluative)*

*Probes:* What things were you well prepared for/less well prepared for?  
 What were the perceptions of others about the transition process?  
 Who were the key people and what was the nature of your interactions?

**7. Tell me about what it was like entering the community fitness facility. (Narrative)**

*Probes:* How did you feel at the time?

What thoughts or emotions were you going through?  
 What were you well prepared for? Less prepared for?  
 What has it meant for your daughter's/son's life today?  
 How has this experience impacted your child? Family? You?  
 What did you not do that you wish you would have?

**8. Tell me about the support you received during this process. (Narrative, Environmental)**

*Probes:* What type of professional support did you receive?  
 What type of peer support did you receive?  
 What type of family support did you receive?  
 How does this support differ from the support you received in specialized programming?  
 Who required the most support with the transition? You or your child?

**9. What advice would you give another parent thinking about transitioning to a community exercise program?**

*(Structural)*

*Probes:* What role did mutual respect play in your experiences?  
 How can they be best prepared for transition?  
 At what point should youth and parents begin to prepare for transition? Why?

**10. What advice would you give to staff members of the fitness centre during the transition process?**

*(Structural)*

*Probes:* What in the environment influenced your daughter/son's experience and in what way?  
*(ENVIRONMENT)*

In what ways did you feel there was respect for you, your daughter/son?

*General Probes:*

- Tell me more
- Do you have a story that illustrates that idea
- I am not clear, can you tell me another way
- How would you explain your idea to someone else not familiar with ...
- How did this make you feel?

## Parent Interview Guide # 2

### Photo Elicitation Interview Schedule

Transition to community physical activity for youth with disabilities: The parental experience

**Research Question:** How do parents of youth with disabilities approach and experience transition from separate settings to community fitness programs?

*Ask participant to place the artefacts in order of significance. Then proceed with the interview by asking question one of each of the artefacts presented. Following that, ask questions ...*

**1. Tell me more about this artefact (photo, diary, memorabilia, community pass, etc.).**

*1.1 What does it mean to you?*

*1.2 What do you think it means to your child? Your family?*

*1.3 What story is behind this photo?*

*1.4 How does this photo depict transition?*

*1.5 How does this photo depict your experience of your child's transition?*

**2. What decisions did you encounter as a parent when your child was faced with transition?**

**3. What tools and resources were required from your family to engage in this process?**

**4. How has your understanding and experiences of transition into community recreation evolved since participating in this program/study?**

**5. How has transition to a community facility impacted your family recreation?**

**6. What are your child's (families) future activity goals? How have these goals changed since participating in this program?**

Dependent on situation and if it was not answered in first interview:

**1. Have you continued to access the community facility for physical activity since we last spoke? Why or why not?**

**2. What type of support have you received over the last few weeks?**

*Probes: How have you felt about the support you received?*

- Professional? Peer? Family?
- What were your experiences after specialized staff were no longer attending sessions with your child in community facility?
- How well prepared were you? Explain.

*In addition questions from the first one-on-one interview may be revisited during the artefact interview in order to clarify or add to previously gathered responses.*

## Appendix B: Ethics Approval

### Notification of Approval

Date: August 9, 2013

Study ID: Pro00039622

Principal Investigator: [Bobbi-Jo Atchison](#)

Study Supervisor: [Donna Goodwin](#)

Study Title: Transition to community physical activity for youth with disabilities:  
The parental experience

Approval Expiry Date: August 8, 2014

	Approval Date	Approved Document
Approved Consent Form:	09/08/2013	<a href="#">Parental Experiences - Informed Consent</a>
	09/08/2013	<a href="#">Parental Experiences - Photo &amp; Video Release.pdf</a>

Thank you for submitting the above study to the Research Ethics Board 1. Your application has been reviewed and approved on behalf of the committee.

A renewal report must be submitted next year prior to the expiry of this approval if your study still requires ethics approval. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Approval by the Research Ethics Board does not encompass authorization to access the staff, students, facilities or resources of local institutions for the purposes of the research.

Sincerely,

Dr. William Dunn

Chair, Research Ethics Board 1

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

### Notification of Approval - Amendment

Date: October 17, 2013

Amendment ID: Pro00039622\_AME2

Principal Investigator: [Bobbi-Jo Atchison](#)

Study ID: MS1\_Pro00039622

Study Title: Transition to community physical activity for youth with disabilities: The parental experience

Supervisor: [Donna Goodwin](#)

	Approval Date	Approved Document
Approved Consent Form:	09/08/2013	<a href="#">Parental Experiences - Informed Consent</a>
	09/08/2013	<a href="#">Parental Experiences - Photo &amp; Video Release.pdf</a>

Approval Expiry Date: August 8, 2014

Thank you for submitting an amendment request to the Research Ethics Board 1. This amendment has been reviewed and approved on behalf of the committee. The following has been approved: Change to "Type of Study" to now reflect that this is a graduate student study. The information letter has been amended to indicate that data collected used in this study will be used as part of a graduate thesis.

Sincerely,

Ms. Suzanne Marney

Coordinator, Research Ethics Board 1

*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

### Notification of Approval (Renewal)

Date: July 28, 2015

Amendment ID: Pro00039622\_REN2

Principal Investigator: [Bobbi-Jo Atchison](#)

Study ID: Pro00039622

Study Title: Transition to community physical activity for youth with disabilities:  
The parental experience

Supervisor: [Donna Goodwin](#)

	Approval Date	Approved Document
Approved Consent Form:	8/9/2013	<a href="#">Parental Experiences - Informed Consent</a>
	8/9/2013	<a href="#">Parental Experiences - Photo &amp; Video Release.pdf</a>

Approval Expiry Date: Wednesday, July 27, 2016

Thank you for submitting this renewal application. Your application has been reviewed and approved.

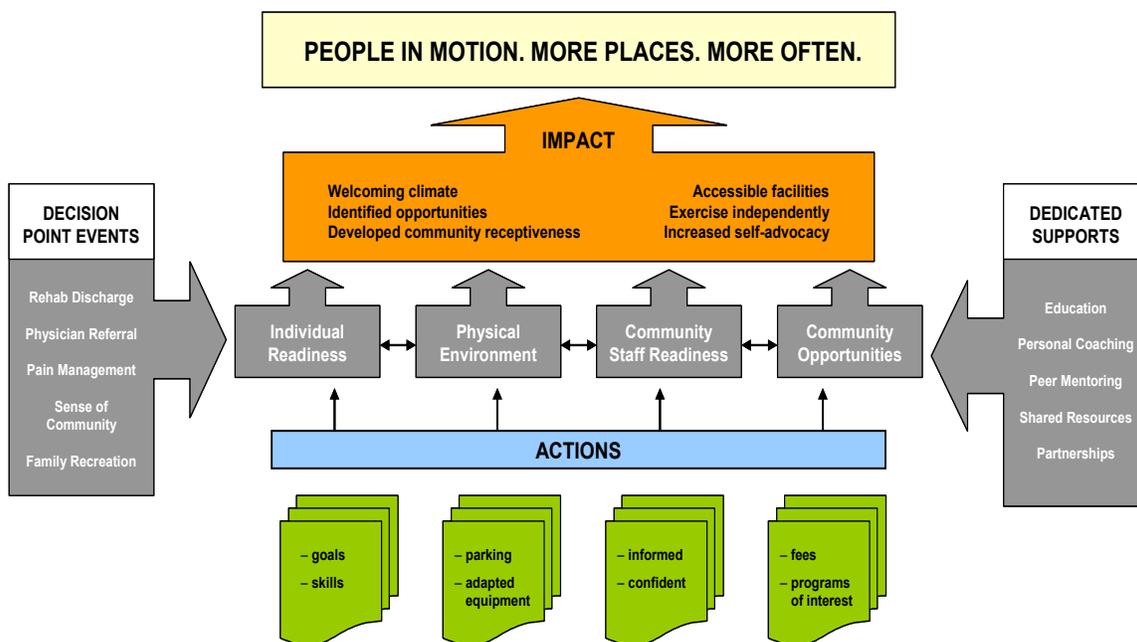
This re-approval is valid for one year. If your study continues past the expiration date as noted above, you will be required to complete another renewal request. Beginning at 30 days prior to the expiration date, you will receive notices that the study is about to expire. If you do not renew on or before the renewal expiry date, you will have to re-submit an ethics application.

Sincerely,

Anne Malena, PhD  
Chair, Research Ethics Board 1

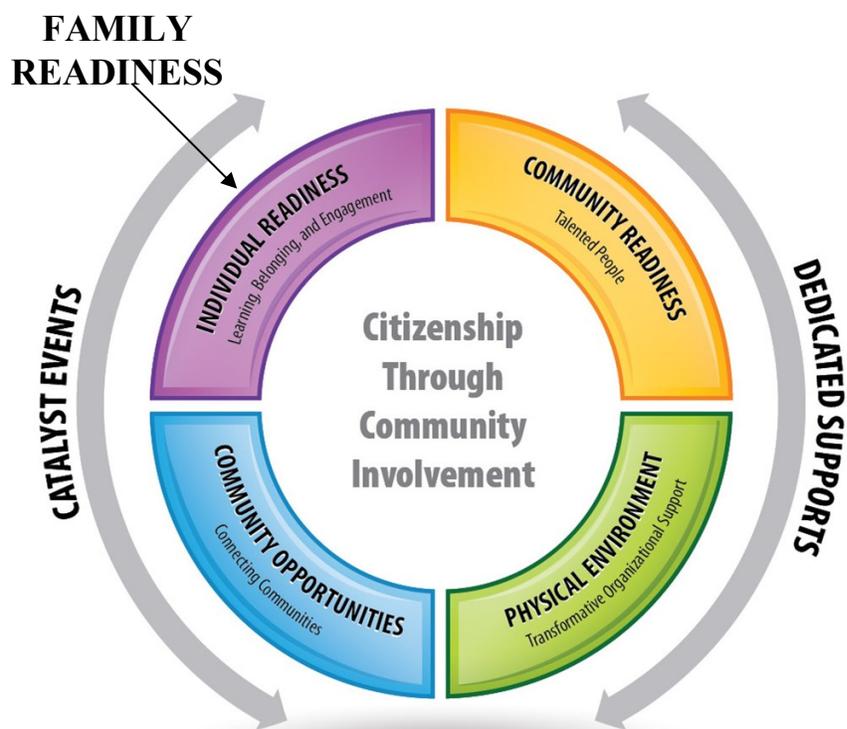
*Note: This correspondence includes an electronic signature (validation and approval via an online system).*

### Appendix C: The Community Exercise Transition Model



**The Community Exercise Transition Model**  
 Goodwin, Atchison, Slater, & Shykoluk (2010)

## Appendix D: Revised Community Exercise Transition Model



**The Community Exercise Transition Model**  
Goodwin, Atchison, Ebert, Slater, & Homes (2016)