

“My Child May Be Ready, but I Am Not”: Parents’ Experiences of Their Children’s Transition to Inclusive Fitness Settings

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Parents play an essential role in the transition from separate physical activity programs to inclusive settings for their children. The purpose of this study was to explore experiences of parents as they anticipate and prepare for their children experiencing disability to transition, understand strategies used to address transition, and gain insights into the supports important to families during transition. Using an interpretative phenomenological analysis research approach, semistructured one-on-one interviews were conducted with 8 parents whose children were undergoing the transition from separate to inclusive community fitness contexts. Four themes described the experiences of parents as they anticipated, prepared for, and supported their child to transition: My child may be ready, but I am not; fear of outside judgment; playing by their rules; and reframing our thinking. Using Schlossberg’s model, the tensions parents faced as they negotiated new roles, relationships, routines, and assumptions as they moved through the transition process were uncovered. The parents experienced transition alongside their children, providing insights for fitness and health-promotion professionals. Without preparation for transition, apprehensions and hesitancy may postpone or prevent their children’s transition to community programs.

Keywords: community transition, disability, phenomenology, qualitative inquiry, youth

Parents play an essential role in influencing and reinforcing physical activity for their children (Trost et al., 2003). For families raising children experiencing disability, this is particularly true (Martin & Choi, 2009; Wiart, Darrah, Kelly, & Legg, 2015). As youth graduate from high school, families seek inclusive¹ community physical activity opportunities (Mulligan, Hale, Whitehead, & Baxter, 2012; Rimmer, 2005; Rimmer & Rowland, 2008; Roth, Pyfer, & Huettig, 2007). With limited resources available in the community, parents are key to ensuring transitions to community programs are successful (Bult, Verschuren, Jongmans,

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Linderman, & Ketelaar, 2011; Martin & Choi, 2009; Pitchford, Siebert, Hamm, & Yun, 2016).

Transition is described as “any event or non-event that results in changed relationships, routines, roles and assumptions” (Schlossberg, Waters, & Goodman, 1995, p. 27). It is a complex and multidimensional psychological process and includes assuming new roles or modify existing ones while reacting, adapting coping, and managing change (Anderson, Goodman, & Schlossberg, 2012; King, Baldwin, Currie, & Evans, 2005; Stewart, Staveness, King, Antle, & Law, 2006). It is thought that parents of children experiencing disability² undergo more role change challenges than parents of children without impairments, which may act as a barrier to transitioning to new settings (Magill-Evans, Wiart, Darrach, & Kratochvil, 2005). Their roles may expand to include that of educator, advocate, and health care provider (Kirk & Glendinning, 2002; McKeever & Miller, 2004). Yet, despite the demands on parents, their perspectives are infrequently represented in transition research (Davies & Beamish, 2009).

Transition can be further regarded as horizontal or vertical (Stoner, Angell, House, & Bock, 2007). Horizontal transitions are defined as unpredictable situations that can take place day-to-day or weekly, 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. In contrast, vertical transitions are defined as predictable and are typically developmental in nature, for example, moving from secondary to postsecondary school or from separate³ fitness to inclusive fitness programs (Stoner et al., 2007). Inclusive fitness programs can involve adaptation to both horizontal and vertical transitions (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 to support the inclusion of their children. They may be asked to stay with their children or find a volunteer to “manage” their behavior, provide physical access support to the facility, or address extended time that may be needed to complete activities (Goodwin & Ebert, 2018). Parents may feel the pressure to reach socially constructed ideals and perceived assumptions of *normalcy*. They may also strive to emulate *normal* standards of behavior 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 (McKeever & Miller, 2004). When *normalcy* is not achieved, parent blaming can be experienced, 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, Columna, Lytle, & Bailey, 2013; Lawrence, Alleckson, & Bjorklund, 2010). This level of *Othering* may create barriers to community sport, recreation and fitness pursuits for their children (Beltran-Carrillo, Devis-Devis, Peiro-Velert, & Brown, 2012; Hodge & Runswick-Cole, 2013; Mulligan et al., 2012).

While there has been considerable research on parental perceptions of barriers and facilitators to participation in community recreation including interpersonal,

intrapersonal, community, institutional, and public policy (see [Obrusnikova & Miccinello, 2012](#)), limited research has been conducted on the lived experiences, supports, and strategies parents use as their children transition from one setting to another. In one such study, Cohen-Podvey, Hinojosa, and Koenig (2010) explored the experiences of six families as their children transitioned vertically from a separate early intervention program to special education preschool services. Although not focused on physical activity, the researchers provided important insights into the lived experiences of parents' transitions. The three themes from the findings were (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 causing anxiety, was best for their children. Comfort levels appeared to be directly related to the quality and types of strategies and supports used by families and professionals.

In a similar school-based vertical transition process, parents of youth transitioning, this time from the structured context of secondary school to adult life, also identified fear to be a major family transition stressor ([Walker, Alfonso, Colquitt, Weeks, & Telfair, 2016](#)). Furthermore, Roth et al. (2007) found that transitioning from school-based recreation activities to either separate programs (e.g., 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. These researchers, along with others ([Goodwin & Ebert, 2018](#); [Schleien, Miller, Walton, & Pruett, 2014](#)) highlighted that although parents valued community contexts, including physical activity and recreation programs, as an important aspect of their children's lives, addressing their anxiety, need for support, and developing strategies for inclusion was labor intensive.

The purpose of this study was to understand how parents of children with impairments experience transition from separate physical activity contexts to community physical activity environments. More specifically, the objectives were 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 change.

Conceptual Framework

Schlossberg's (1981, 2008) conceptual framework provided a way of thinking about the transition literature generally. She identified three stages to transition: (a) moving in, (b) moving out, and (c) moving through ([Anderson et al., 2012](#)). Progressing through the stages requires individuals to learn and become familiar with new roles, responsibilities, routines, and assumptions (moving in); disengage from current roles, relationships, routines, and assumptions (moving out); 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. An end point can occur when children's involvement in a separate fitness program concludes (moving out), and they enter inclusive programs (moving in).

Schlossberg (2008) believed that adults experience a time of disequilibrium as they identify, approach, and proceed through a transition. The disequilibrium varies depending on the type of transition an individual is undergoing (anticipated, unanticipated, or nonevent), their appraisal of the transition (positive, negative, or benign), and its impact on their day-to-day roles, routines, relationships, and assumptions (Anderson et al., 2012). Schlossberg (2008) further 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, and concurrent stress); *self* (personal resources such as socioeconomic status, age, gender, stage in life and psychological resources such as optimism, ego development, commitment, values, spirituality, and resilience); *supports* (types, functions, and options); and *strategies* (coping responses, direct action, and inhibition of action). Each component acts as an asset or liability to transition, varying in importance depending on the individual. The 4 S factors, along with how parents approach, appraise, and anticipate the situation, influence their ability to manage role changes and adaptations required during the transition process.

Method

A research paradigm is an overarching set of beliefs and assumptions that guide “how researchers understand reality and the nature of the truth, how they understand what is knowledge, how they act and the role they undertake, how they understand participants and how they disseminate knowledge” (Markula & Silk, 2011, p. 25). A research paradigm captures what is possible to know about our world, and how it is possible to know it. The research was undertaken under an interpretive paradigm in which researchers and participants bring their own meanings to the social complexities of the world (Markula & Silk, 2011). Proponents of an interpretivist paradigm⁴ assume a relativist ontology, meaning that reality is socially constructed; a subjective epistemology whereby the researcher and researched cocreate knowledge; and a hermeneutic methodology whereby we come to understand ourselves through the interpretation of others’ understandings (Guba & Lincoln, 1994; Markula & Silk, 2011).

Consistent with an interpretive paradigm, an interpretative phenomenological analysis (IPA) study was undertaken. IPA researchers explore people’s relatedness to or involvement in particular day-to-day events in their lives (Smith, 2011; Smith, Flowers, & Larkin, 2009) and provide a “detailed picture of how the families think and feel about the challenges they face” making it a suitable research approach for the study (Brewer et al., 2008, p. 7).

Interpretative phenomenological analysis has its theoretical roots in phenomenology, idiography, and hermeneutics (Smith et al., 2009). To illustrate research coherence and avoid “method slurring,” the tenets of IPA are described (Holloway & Todres, 2003, p. 346). Phenomenologists focus on the rich description of day-to-day lived experiences through individual perspectives and meanings. Participant quotations were used to depict how people made sense of the phenomenon of transition. Idiography is a commitment by researchers to uncover deep and detailed understanding of single participant’s experiences prior to moving across

participants thereby retaining their deep meaning. Analysis of participants' transcripts and preliminary theme development were completed individually and only brought together with others after the full value of individual experiences was understood. The focus of hermeneutics in IPA is interpretation "as there is no such thing as an uninterpreted phenomenon," whereby researchers attend to the dynamic relationship between themselves and their participants in the cocreation of knowledge (Pietkiewicz & Smith, 2012, p. 363). The researchers employed a "double hermeneutic" characteristic of IPA or making sense of the participants making sense of their experiences to provide a "detailed picture of how the families think and feel about the challenges they face" (Brewer et al., 2008, p. 7).

The transition program supported interested individuals experiencing disability to be active in inclusive fitness centers in their own communities, close to home following participation in the facilities separate physical activity program. Using qualified professionals and strong community partnerships, the transition program staff provided community program information, reduced community barriers (e.g., negotiated fee reductions), and offered limited one-on-one support as participants made the transition from separate to inclusive community fitness centers (e.g., individualized tour of facilities, attendance at initial weekly visits). The participants transitioned to public community recreation facilities. The transition program focused on accessing mainstream fitness centers within the facilities.

Participants

Participants were purposively selected using convenience and criterion sampling strategies (Patton, 2002). Convenience sampling was used as the participants were drawn from one program which offered a transition service as part of the offerings. Consistent with IPA, and to ensure that the phenomenon of interest was captured, a homogeneous criterion sample was sought to represent the shared experience of transition (DiCicco-Bloom & Crabtree, 2006; Patton, 2002; Smith et al., 2009). The criteria were (a) parents of a child attending the separate program, (b) child was in the physical activity program within the last 12 months, and (c) the child was 12–21 years of age.

Twenty-five families, who had been or were currently involved in the program, were eligible for the study. Sixteen families expressed interest. Given family activity levels and scheduling challenges, eight families ultimately participated, which was a representative sample size for an IPA study (Smith et al., 2009). An ethics certification was obtained, and participant-signed consent forms were completed prior to initiating the study.

The participants were seven mothers and one father (all mixed gender families) between 43 and 59 years of age, with a mean age of 52 years. The presence of only one father is consistent with previous research, as mothers typically assume the day-to-day care for children experiencing disability, including supporting them in community programs (Home, 2002). We included the one father who volunteered for the study as fathers are underrepresented in child-focused studies and we wanted to honor his willingness to share his experiences and roles in transition (Macfadyen, Swallow, Santacroce, & Lambert, 2011; Phares, Lopez, Fields, Kamboukos, & Duhig, 2005). Education of the parents ranged from high school diplomas to graduate degrees. Household incomes were reported from low to upper

middle-class level. All parents in this study identified as White. Their children, seven boys and two girls ranged in age from 12 to 19 years, with a mean age of 16 years. One participant had two children undergoing the transition together. The parents described their children as having a variety of neuromuscular and developmental impairments that required supports for mobility, communication, and/or social needs. Further diagnostic information was not requested to avoid reinforcing ableistic labeling. The children were enrolled in the separate fitness program for a minimum of 1 year, with the majority involved for over 4 years.

Data Collection

In adherence with IPA research, data collection techniques included semistructured interviews, artifact collection, and a reflexive journal (Smith et al., 2009). In-depth, phenomenological experiences were gathered by the first author during two semistructured face-to-face interviews. Sixty- to 90-min audio-recorded interviews provided candid, detailed, and lengthy detailed first-person accounts (Smith et al., 2009). The interview questions were descriptive, structural, narrative, and evaluative, with a variety of probes to gain clarification and insight (Smith et al., 2009). Sample questions included: What role has physical activity played in your daughter/son's life outside of specialized programming? (structural); Describe the preparation required to consider a community physical activity/fitness program (descriptive); How did you know when you were ready to transition to a community-based fitness program? (structural); and How did you feel about the process of locating a community fitness center for your child?

The first interview covered parents' thoughts, feelings, and understandings about the transition process. At the end of the first interview, parents were invited to bring an artifact to the second interview that would bring additional meaning to their experiences (Sheridan & Chamberlain, 2011). The artifacts presented included program evaluations, crafts, written e-mails to staff, family or friends, and photos and videos taken by participants using a researcher provided camera. They became points of reference for the passage of time in the transition process, brought narrative depth to storytelling than may not have occurred with interviews alone, and were a "way of making life and experiences 'real or more real'" (p. 318). The artifact descriptions were audio taped and became part of the textual data. Notes were recorded in a reflexive journal after each interview to document key thoughts heard and preliminary theme ideas. In addition, they served to record ideas for further probing during the subsequent interview, facilitated data analysis and interpretation by reconnecting the researchers with the participants, and promoted reflexive thoughts about research positionality (Bailey, 2017).

Data Analysis

Data analysis was completed following the six-step IPA process outlined by Smith et al. (2009). Step 1 included the first author reading and re-reading participant one's transcript to be fully immersed into the participant's world. Step 2, comprised of initial note-taking for participant one, including a detailed phenomenological (noninterpretative) exploration and examination of the interview content. For example, notes written in the margins for Lucy's transcript included: needing sense

of safety, abandoned by community programmers, having to start all over again, and not ready. Step 3 consisted of ideographically developing the notes from participant one into themes that reflected participant one's original words and the researcher's interpretation, uncovering hermeneutic meanings not explicitly stated by the participants. The preliminary themes for Lucy were a sense of loss and frustration. Steps 1–3 were completed for the second interview for participant one. Step 4 included searching for connections across the developing subordinate and superordinate themes for participant one, through abstraction and conceptualization using the conceptual framework of Schlossberg's transition model (1981, 2011) as a comparative context for the interpretation of the findings (Sandelowski, 1993; Wu & Volker, 2009).

A superordinate theme for Lucy was formulated as *My Child May Be Ready, but I Am Not* (that was confirmed across participants in the final step of the analysis). Step 5 of the analysis involved repeating Steps 1–4 for all participants. The final step involved looking for patterns (themes) across all participants. Facilitated discussions with the second author led to minor reconfiguration and relabeling of superordinate themes.

Assessing Quality

Yardley's criteria (2000) of sensitivity to context, commitment and rigor, transparency and coherence, and impact and importance are recommended for IPA studies (Smith et al., 2009). Sensitivity to context was achieved through member reflections. Participants were invited via e-mail, to review the accuracy of their transcripts. They were also invited to review a summary of the themes following data analysis and provide reflections on gaps or similarities shared with the researchers on the interpretations of the findings (Smith & McGannon, 2017). All participants indicated that they saw themselves in the theme summaries. Commitment and rigor were demonstrated through appropriate sampling, in-depth interviews, and a commitment to a thorough idiographic and interpretative analysis (Smith et al., 2009). Both transparency and coherence were addressed by keeping a reflexive journal, a detailed filing system, disclosing the research paradigm and coherence with the research approach (method) to the reader, and an in-depth presentation of the research approach and methods. The need for 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 readers. We acknowledge that the participants were from one separate program (case) and that their experiences may be reflective of the dynamics of that program specifically. We were subsequently informed that uptake has already occurred within the transition program, including but not limited to increased access to community programs, enhanced transition preparation time, and the development of parent support groups.

The authors also acknowledge the need for researcher transparency regarding their positionality in the study. They are White middle-class women who do not parent children who experience disability. The authors have professional, teaching, and research backgrounds in adapted physical activity and qualitative inquiry and were not involved with the transition program at the time of the study.

Results

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

My Child May Be Ready, but I Am Not

Moving out of a separate fitness program into a community center involved experiences of disruption, risk, and limited resources. In addition to supporting their children to transition, the parents required time and supports to prepare themselves to leave the stable environment of the separate program and enter less predictable community facilities. They resisted an imposed endpoint to their children's engagement in the separate program, often due to aging beyond the limits of the program, even when this endpoint was an anticipated transition. Holly, the mother of a 19-year-old, remembered her immediate sense of abandonment when asked to leave a support system she depended 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 insecurity and perceived lack of control over the upcoming changes. Holly summed up her apprehension of moving out of the separate program given her past experience with inclusive community programs 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 the separate program provided a level of comfort, supports, ease, and reassurance for parents; a state of equilibrium. It was one of the settings where they could assume the same situational roles as 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 adapted physical activity staff who understood their abilities, and would support them on 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 presence of knowledgeable staff, small ratios, age-appropriate activities, and suitable program expectations meant parents were reluctant to move out of the program, as they were not responsible for providing supports to facilitate their children's participation. 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 inclusive 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 a vertical transition that involved moving into an inclusive environment. 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?'" Parents experienced disequilibrium as they 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 parents during past attempts to transition their children into community fitness environments left them frustrated at the thought of having to do it again. Lucy recalled her reaction when transition to a community fitness facility 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.

Fear of Outside Judgment

Despite strong negative sentiments regarding transition, parents expressed conflicting feelings about what the future held for their children if they did not pursue community transition. 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." And yet, as parents and their children began moving into inclusive community fitness environments, their 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 center 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, parents faced the uncomfortable risk of outside judgment, and an expectation that they were able and available to address all situations that may arise. 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 behavior, 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 strategy to blend in and the fear of being noticed for not conforming to normative behaviors created feelings of failure for parents, who were required to, and yet at times unable to, "control" their children's behaviors. Kara recalled a reaction from an elderly patron when her child was displaying what Kara termed obsessive compulsive behaviors, "Well I would never have allowed my kid to behave like that. . . . They think you're a bad parent and that your kid is misbehaving and that you should be able to control that better." This judgment and expectation from an outsider left Kara generalizing what the public must think. Parents also perceived their role to include managing their children's behavior so they were "invisible" and did not disrupt the program. Nancy talked of the lengths to which she 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 behaviors 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 judgment she and her daughter underwent when they were not "blending in" during their first trip into the community fitness center.

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 behaviors 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 judgment 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 through the transition difficult for all parents but one. Jack, the only father interviewed in the study used another strategy to approach community transition. He took a more laissez-faire approach to his child's behavior and potential judgment from community members. Jack explained:

More and more people have experience because they're not sent to [institutions] anymore. So . . . relax, you know? Manage the most disruptive behavior however you can, but don't sweat the little quirks. . . . 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.

Unlike the others in the study, Jack managed perceived outside judgment 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 the community.

Playing by Their Rules

As parents continued moving into community fitness centers, they were confronted with restrictions imposed by government programs. Parents sought supports that would assist with the transition and independence of their children in physical activity environments. However, due to lack of funding flexibility, funds were 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:

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.

Alternately, parents appreciated when financial support was available for such things as the hiring of 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 required to recruit, screen, interview, and train people who may have no disability backgrounds 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 also spoke of being faced with moments of frustration, having to compromise her own values to acquire the workout buddy required by her son to be successful in a community fitness center as the needed support was not available at the program. Required 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 to her deep regret, hired someone who did not share her aspirations for her son.

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 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 available to assist with community transition, parents were left feeling alone and vulnerable. Moreover, the energy required to take on, yet another role was emotionally and physically draining. Yet somehow their commitment to independence and community engagement for their children gave them the energy to move forward. Dianne recalled, "I don't even know if I have the ability, I just do. Because if I don't, no one else will."

Reframing Our Thinking

Parents accepted early on in their children's lives that in order to qualify for government funding and support, they must succumb to the processes of medical diagnosis, labeling, 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 center] 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 center 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 community fitness centers 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 reevaluation of their own assumptions and roles. Kara looked inward and began to question the level of expectations she held for her child. “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 underestimating her child’s abilities and desire to be in the community. “They are always far more capable and even far more willing [than I understood]. . . . I learn more and more.” As parents began to look at 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 behavior. 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’ judgments toward 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 favorite 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 believing their children *did not* belong, they became convinced of their belonging. “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

The experiences of the parents reflected the disequilibrium that transition can bring (Schlossberg, 1981, 2008). Moving out of a separate program into inclusive community fitness programs was a negatively anticipated event based on past failure experiences. Role changes from being a *typical* program parent with no responsibilities (in the separate program) beyond transportation to and from the program, transitioned to assuming the participatory role of securing fitness buddies or attending the programs themselves. In using Schlossberg’s (2008) 4 S System of transition, it became apparent that the *situation* of transition was triggered by their children’s age and/or encouragement by separate program staff to try inclusive programming due to their children’s success in the program. The *self*, or personal parent resources and their commitment to inclusive opportunities for their children, enabled them to push through their negativity. However, the lack of *supports* necessitated self-reliance as they had few options for supports. *Strategies*

associated with the educational support of the separate program transition staff returned a sense of equilibrium as the perceptions of stereotyping faded with their children's success. The transition was difficult, peppered with experiences with doubts, discomfort, shedding of personal values, and insecurity.

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). Supporting the findings of Stoner et al. (2007), parents⁵ 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 disequilibrium (Schlossberg, 2008). As the transitions began, parents walked the line between preserving available energies by maintaining their old roles, routines, and relationships and digging deep to reevaluate what they knew 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 judgment 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 judgment of others (Ali et al., 2012; Gray, 2002; Schlossberg, 2011). Davey, Imms, and Fossey (2015) found similar findings in their study of 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 achieving "normalcy" was effortful for parents. They, not the community, assumed responsibility for their children's successes and failures. Similar to findings from Nurullah (2013), the parents were living a dual burden—"taking care of their child with a disability while simultaneously facing social stigma for their child's disability" (p. 27). Parents spoke of deep-rooted discomfort with being stigmatized and judged by their own communities (Nurullah, 2013).

Parents acquiesced to a deficit-based model of disability 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 was 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 accepting the

oppression of their children and themselves throughout the transition. Parents' lowered expectations for their community and for their children created a level of *Othering* of their children (Hodge & Runswick-Cole, 2013).

Interestingly, only the mothers in this study shared stories with underpinnings of acquiescence. 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 appears in Schlossberg's 4 S System under the *self*-category, is an asset or a liability depending on the situation at hand (Anderson et al., 2012). We heard 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, behaviors, and actions are viewed as weak, inferior, and of lesser value than that of males (Calhoun et al., 1993). This ingrained way of thinking and being may have influenced the strategies and inhibited actions chosen by the mothers in this study.

There are several limitations to the study. The experiences of only one father were represented, leaving this perspective of transition underrepresented. Future studies on transition that include fathers from multiple sites would add to the experiential knowledge of this study. In addition, the participants were from one specific separate program that offered a well-resourced community transition program, which may not resonate with families enrolled in other programs.

Further investigation is needed on how to bridge the gap to bring professionals and parents together through exploring the understandings of community service providers who work in fitness, recreation, and physical activity on their roles during the transition. Gaining a better understanding of the experiences of those involved in the transition process may 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 conclusion, as parents *moved through* the transition process, they experienced a transformation in their thinking, feelings, and actions. Schlossberg et al. (1995) would argue that parents entered a cycle of renewal. They shared stories of letting go of old ways of thinking and being and adopting new strategies. Confidence and optimism were gained as they observed their children successfully participating, enabling them to regain some semblance of control, balance, and equilibrium in a risky environment. The parents of this study experienced transition alongside their children, providing insights for fitness and health promotion professionals. The development and implementation of transition programs should take not only the person undergoing the transition into consideration, but also their parents or primary care provider. Parents may need encouragement to share their transition concerns while being met with understanding and reassurance by program staff as they create success-oriented environments.

Educational and peer support opportunities before, during, and after transitions may ease parent pressures at times of transition. Transition programs aimed at parents could include educational supports designed to decrease apprehensions and

letting go of old perceptions and utilizing one's strategies (e.g., visiting potential sites), taking on new roles (e.g., requesting support for program aide training, parent to parent support groups), managing new routines (attending the initial sessions until program supports are in place), and addressing new situational challenges such as rules, regulations, norms, and expectations of the new inclusive community context (e.g., fitting in does not take precedence over being engaged in the program) (Anderson et al., 2012; Kralik, Visentin, & Van Loon, 2006). Without preparation for transition, apprehensions and hesitancy may postpone or prevent their children's transition to community programs.

Notes

1. Inclusive programs are defined as contexts where people with and without impairments have the opportunity to interact in all aspects of fitness, sport, and recreation (Wolf Klitzing & Wachter, 2005).
2. "The phrase *person who experiences disability* is designed to acknowledge the wide variety of embodied sensations, social structures, cultural understandings, and identities that may be related to someone's disability experience" (Peers, Spencer-Cavaliere, & Eales, 2014, p. 275).
3. As *segregated* is a term with a history of exclusion, we use the term *separate* to describe physical activity environments that are respectful of the resource needs of people with impairments.
4. An inquiry paradigm defines what falls within and without of legitimate inquiry. The beliefs that define paradigms are in the form of *ontology* which asks what is the form or the nature of reality or what can be known, *epistemology* or what is the nature of the relationship between the knower and what can be known, and *methodology* or how the knower goes about finding out about what can be known (Guba & Lincoln, 1994).
5. We use the term *parents* but acknowledge that the collective experiences are representative of seven mothers and one father.

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