

Physical Activity for Disabled Youth: Hidden Parental Labor

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Locating suitable, inclusive community physical activity programs for disabled children can be challenging for parents. The aim of this study was to uncover everyday hidden labor experienced by parents, as they sought inclusive physical activity opportunities for their children. Focus group interviews with eight families of youth aged 13–19 years were completed using an interpretative phenomenological case study research approach. Four themes, interpreted through the framework of relational ethics, captured their experiences: (a) inclusion is immensely effortful; (b) judged by their impairments, not their possibilities; (c) ongoing education needed to open doors and sustain participation; and (d) the guilt of staying home. Reliance on hidden parental labor highlighted an exclusion agenda in community, accentuated by ableist belief systems.

Keywords: developmental delay, inclusion, parents, qualitative inquiry, relational ethics

Physical activity programs for youth extend beyond school-based opportunities (physical education, intramurals, and recess) to encompass family, neighborhood, and community programs (Beets, Wallner, & Beighle, 2010; Kohl & Cook, 2013). Community-based after-school programs, those that are not single activity focused, and target children and youth aged 5–18 years, are integral to healthy child development and daily physical activity requirements (Beets et al., 2010). There are a wide variety of community-based physical activity and fitness programs available, yet disabled people¹ are conspicuously absent due in part to physical, social, architectural, and attitudinal barriers (Kehn & Kroll, 2009; Rimmer, 2005; Wiart, Darrah, Kelly, & Legg, 2015). Structural barriers have been well documented and include physically inaccessible facilities and exercise equipment, poor transportation, membership fee structures, undertrained staff, program procedures and policies, information barriers, and limited resources (French & Hainsworth, 2001; Martin, 2013; Mulligan, Hale, Whitehead, & Baxter, 2012). Further documentation of social and psychological deterrents to

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physical activity include stigma, motivation, self-efficacy, and perceptions of self-worth (Goodwin, Fitzpatrick, Thurmeier, & Hall, 2006; Obrusnikova & Miccinello, 2012; Rimmer & Rowland, 2008; Tsai & Fung, 2009). Beyond documenting barriers and deterrents, there is a social justice need to identify the human cost to people, including parents, who negotiate daily exclusion if actionable change is to occur (Aitchison, 2009; Allison, 2000). The labor disabled people and their families expend to participate in community programs is largely hidden from nondisabled people (Dowling, 2015). The purpose of this study was to explore how parents experience hidden labor as they seek to create physical activity opportunities for their disabled children.

Hidden Labor

Parental support is essential for participation by disabled young people in inclusive community physical activity programs (Pitchford, Siebert, Hamm, & Yun, 2016). Parents manage family resources, so their children can participate in activities similar to that of their peers (Green, 2007; Ryan, 2005). Much of this economically invisible work is the domain of women as primary family care providers (Cancian & O liker, 2000; Home, 2002; Shearn & Todd, 2000). Woodgate, Edwards, and Ripat (2012) spoke about harnessing resources or the work that parents do to obtain the supports required for family life. Harnessing resources includes effortful and planful action to achieve essentials such as transportation, assistive devices, and accessible housing.

Focusing on equipment and other material resources does little, however, to disrupt attitudinal barriers to inclusive participation (Jones, 2003; Nabors, Willoughby, Leff, & McMenamin, 2001). Parents raise their children with devaluing discourses that emphasize the negative and emotional aspects of parenting (e.g., Boerner, Schulz, & Horowitz, 2004; Heiman, 2002). Green (2007) criticized scholars for focusing on the *burden of parenting*, rather than centering negative public attitudes and inadequate support for time-consuming and expensive care. By focusing on “private troubles,” we tend not to seek understanding and alleviation of the sociocultural influences that contribute to the daily labor assumed by families (Oliver, 1996, p. 48).

It is laborful for parents to manage (or pass) the presentation of their children to secure a sense of equal social footing (Goodwin et al., 2006; Scully, 2010; Wiart et al., 2015). The motivations for parents to manage social interactions are fourfold, including soliciting informal and formal supports, maintaining relationships, driving to social change, and maintaining self-respect (Scully, 2010). To bring a shift from individual burden to societal responsibility, information is needed on the nature of the *hidden labor* carried out by parents to manage the presentation of their children in judgmental community programs and the reactions of others to their children.

The efforts of parents include emotional labor. Emotional labor occurs when coping strategies are required to address the dissonance between what is *desired* and what *is* (Blackmore, 1996; Humphrey, Pollack, & Hawver, 2008). First defined by Hochschild (1983), emotional labor is the effort needed to regulate the emotions required to meet or resist organizationally based role expectations. For example, parents may assume the emotional expectation of *gratefulness* for having access to

inclusive community programs, even when they are woefully inadequate for their children's needs (Mitchell & Snyder, 2015). Parents further manage the feelings of disappointment, anger, and fatigue when subsequently asked to become program aides to their children. If the parents refuse to acquiesce to community demands and withdraw their children from the programs, they then assume the labor involved in managing their emotional guilt (King et al., 2009; Knowles, Kirk, & Hughes, 2015).

Ableism

The emotional labor required of parents is often based in ableism or the discriminatory attitudes and behaviors of others that may be conscious (known to the person fully), nonconscious (habitual and unexamined beliefs), or unconscious (beliefs not generally available and which may be actively disavowed; Scully, 2010). Ableism, as a network of beliefs and practices, constructs bodies as impaired and the Other who is different, undesirable, and in need of repair or modification (Campbell, 2001, 2008, 2009; Hodge & Runswick-Cole, 2013). It creates and sustains privilege and preferred status to those who are alike (Lyons, 2013). Othering is a relational process whereby we make, name, and marginalize others as "not one of us" (Johnson et al., 2004). Parents are rightfully apprehensive about social isolation as friendships developed in specialized programs are severed, leaving their children potentially friendless, unwelcome, and ignored (Buttimer & Tierney, 2005; Devine & Parr, 2008; Goodley & Runswick-Cole, 2010; Green, 2007; Knight, Petrie, Zuurmond, & Potts, 2009; Parkyn & Coveney, 2013; Thompson & Emira, 2011). In their desire to include their children in the activities of childhood, parents assume the work of overcoming ableistic Othering (Wiat et al., 2015).

Nonconscious ableism is of ethical concern as change to the ordinary rules and routine of social life, or those "sticky interactions," between disabled and nondisabled people is not possible without awareness (Scully, 2010, p. 28). Uncovering stories and counter-stories (those that counter conventional understanding) of the hidden labor involved in seeking and engaging in community physical activity invite new narratives, interpretations, and conclusions of disability family life where teller and listener can come together to unpack, retell, and relive stories (Goodley & Runswick-Cole, 2011; Nelson, 1995).

Mitchell and Snyder (2015) coined the term *inclusionism* to describe parents' unexamined assumption of needing to decrease demands on existing nonreflective policy makers and service providers regarding the ableism they may be harboring. "Inclusionism requires that disability be tolerated as long as it does not demand an excess degree of change from relatively inflexible institutions, environments, and norms of belonging" (p. 14). Parents may be unwittingly promoting inclusionism to their own disadvantage due to the hidden labor they provide, while alleviating community agencies from their responsibilities. We agree with Updale (2008) that practical problems, such as the unexamined hidden parental labor required to participate in inclusive community programs, are of ethical concern. We examine the labor undertaken by parents of disabled children as they collide with *nonconscious* behaviors of inclusive community physical activity professionals.

Conceptual Framework

Relational ethics was the conceptual framework used to critically look at the actions or inactions that created and sustained sociocultural and historical barriers for the families wishing to engage their children in community physical activity programs (Bergum & Dossetor, 2005; Devine & Parr, 2008; Goodley & Runswick-Cole, 2010; Martin, 2013; Thomas, 2004). Relational ethics was used to examine the meaning behind the labor expended by parents as they navigated depersonalized, dispassionate, inward focused, and inclusive physical activity contexts devoid of relationships (Benner, 2004; Bergum & Dossetor, 2005; Wu & Volker, 2009). Relational ethics places high regard on relationship building to contextually inform actions and bring “a moral language” to issues of “responsibility (justice) and responsiveness (care)” (Bergum & Dossetor, 2005, p. xiv). The traditional understanding of autonomy, or being free from interference, was reconceptualized to reflect the interdependent existence of humans. Broadening our gaze for success from autonomy and independence to the interdependence gained through social relationships clarifies the power structures that restrict or provide genuine opportunities for choice and meaningful self-direction in physical activity contexts (MacDonald, 2002). Ethical moments, or the opportunities to build relationships and nurture ethical understanding, become possible when people connect with one another and create a relational space for trust and authentic receptivity to the everyday existence of shared physical and social worlds (Austin, 2007; Marcellus, 2005). Emotional labor functions to regulate interactions and create interpersonal climates (Ashforth & Humphrey, 1993).

The four tenets of relational ethics are (a) *mutual respect* that reflects the ethical space to explore respect for self and others within an atmosphere of interdependence; (b) *engaged interactions* or the personal responsiveness, true presence, and empathy required for authentic connections and engaged interactions with others; (c) *embodiment* or the interconnectedness of the feeling body and the thinking mind-set in the historical and social contexts of storied lives; and (d) *environment* or the relational space of the individuals who are tied to a network of community, social, and political contexts (Bergum & Dossetor, 2005). Taken together, people come to understand their obligations and responsibilities to themselves (service providers) and users (parents and children) within inclusive community physical activity contexts (Shaw, 2011).

The aim of this study was to learn how parents experience hidden labor as they navigate ableism while pursuing physical activity opportunities within their community. The lens of relational ethics was used to facilitate and interpret the findings.

Methods

The authors’ assumptions are based in a constructivist paradigm, reflecting a relativist ontological, a subjective epistemological, and a hermeneutic methodology. The primary aim of this study was to interpret participants’ meaning of their subjective experiences shared through narrated stories (Guba & Lincoln, 1994; Markula & Silk, 2011). Utilizing an interpretative phenomenological analysis (IPA) research approach provided a systematic way of uncovering

the daily experiences of parents. IPA researchers are interested in the detailed examination of lived experiences or that which we do automatically without prereflective thought (Mayan, 2009; Smith, Flowers, & Larkin, 2009). Parents may expend hidden labor without reflection (Allison, 2000; Scully, 2010). IPA combines phenomenological and hermeneutic insights and connects peoples' everyday and highly personal experiences of the world, their verbal expression of those experiences, and their internal cognitions and emotions through joint meaning representation (Smith et al., 2009). "The participant's meaning-making is first order, while the researcher's sense-making is second-order" (Smith et al., 2009, p. 36). The double hermeneutic involves making sense of the participants making sense of their experiences provides a means for examining and interpreting human predicaments (hidden labor) and what "happen(s) when the everyday flow of lived experience take on a particular significance for people" (Smith et al., 2009, p. 13).

The study was also framed as an instrumental or particularistic case study (Stake, 2006; Yin, 2014). The context of the study was an after-school physical activity and exercise transition program for disabled children from separate (disability only) to community-based inclusive settings in a large urban North American city. In the separate physical activity program, there was no sustained interaction with nondisabled peers. The aim of the program was to develop motor, fitness, and sport skills that enhanced individual confidence and competence toward health and wellness, in an enjoyable social environment under the guidance of adapted physical activity program staff. Program participants ranged in age from 15 to 20 years. There was a ratio of 3:1 participants to staff. Individualized and group programming occurred in the gymnasium, fitness center, or outdoor field. Families paid a minimal fee for the program that was subsidized through grant and government support.

Participants

Consistent with IPA, the participants were a homogeneous group of parents (Smith et al., 2009) who were "thoroughly enculturated" in the process of engagement in inclusive community physical activity programs (Spradley, 1979, p. 47). Program staff e-mailed the study information to 20 parents who met the inclusion criteria. Eight mothers and one father (nine participants) from the separate physical activity program responded to our invitation and volunteered for the study. The sample size was consistent with IPA, enabling in-depth detailed descriptions and perceptions of individual experiences (Smith et al., 2009; Smith & Osborn, 2008). As anticipated, only one father volunteered for the study, as mothers are far more likely to be directly involved in children's routine activities (Green, 2007; Home, 2002). Study participants' age ranged from 41 to 59 years, with a mean age of 50. All but one of the parents was married, and five of the parents had more than one child. All participants but two were White. Family leisure activities ranged from walking and gardening to golf, tennis, and swimming. One mother indicated that she enjoyed baking, skiing, traveling, and theater but had less time and energy to pursue these loved activities. Three of the mothers had given up careers to support their children's development but worked in part-time capacities. Pseudonyms protected the parents' anonymity.

Although not a direct source of information, a description of the children supports the transferability of the findings to other families and contexts (Zitomer & Goodwin, 2014). The children were three girls and five boys, aged 13–19 years (with a mean age of 16). According to the parents, the children had developmental delays that affected their gross motor development and made them eligible for the separate physical activity program. We did not request further diagnostic information to avoid reinforcing ableistic labeling of the children and their families. All children received physical education with the support of educational assistants at school, at the separate program (minimum of 4 years) or both. One child attended a specialized high school, six attended public school, and two were homeschooled. Those who were homeschooled relied solely on the separate after-school physical activity program to fulfill their daily recreation and physical activity requirements.

Data Collection

The University of Alberta issued ethics approval prior to the initiation of the study. The aim of data collection in IPA inquiries is to obtain detailed, rich, and firsthand accounts of experiences, such as those achieved through in-depth interviews (Smith et al., 2009). To elicit stories, thoughts, and feelings about their experiences, the participants took part in audio-taped focus group interviews (one group of four parents, one group of three parents, and one group of two parents) moderated by the second author. The use of focus groups encouraged individual sharing of experiences while simultaneously constructing joint perspectives (Phillips, Montague, & Archer, 2016). Although idiography is a tenet of IPA, we agree that “IPA should be judged on the analysis itself, not the data generation method” (Phillips et al., 2016, p. 290) as information shared by individuals in a group depends on group dynamics and what happens in a group depends upon the individuals in the groups, requiring an interplay between individual and group levels of analysis (Morgan, 1997).

The focus group interview guide promoted in-depth conversations by asking descriptive (e.g., What are you looking for in a community program?), structural (e.g., What is your involvement in setting up, monitoring, or maintaining program participation?), narrative (e.g., Tell me about your experiences of locating a program for your daughter or son?), and evaluative questions (e.g., In what ways does the term hidden labor resonate with you? Smith et al., 2009). Small groupings provided opportunities for self-reflection and elaboration on experiences sparked by interaction with the other parents (Greenbaum, 1998; Krueger & Casey, 2000).

We reflected on relational ethics in the formulation of the focus group probe questions to ensure the relational nature of participation in community physical activity programs was present in the questions asked. Sample probe questions included *engagement* (e.g., What role does relationship development play in creating meaningful opportunities for your daughter or son?), *mutual respect* (e.g., Tell me about the of mutual respect in community program participation?), *embodiment* (e.g., How do you know if a program is right for your daughter or son?), and *environment* (e.g., How did the environment impact the program experience? Bergum & Dossetor, 2005; Briscoe & Arai, 2015). The transcribed focus group interviews were 60–90 min in length. Recorded field notes following

the focus groups included reflections on what was said and preliminary thoughts about themes ideas enabling the researchers to conceptually return to the focus group interview setting during data analysis (Bogdan & Biklen, 2003).

Data Analysis

An inductive thematic analysis completed by the authors identified experiential claims, concerns, and parent understandings. In the case of focus group data for IPA, ideographic analysis means parsing the transcripts twice, line by line, first for idiographic experiences and second for group dynamics and patterns (Smith, 2004). Analysis involved moving between the individual voices on the transcripts to more general experiential categories (Smith et al., 2009). In reading and rereading the transcripts and field notes, descriptive and conceptual comments were compared to determine their separate classification or inclusion in an existing expression or experience. Patterns were further compared with other participants within the group and finally across groups (recurrent themes). Unique idiosyncrasies were respected while seeking meaning for higher order (superordinate themes) experiences of hidden labor. For example, the initial coding of *had to be involved*, developed into *physical and mental energy*, and *problem solving*, toward the emerging theme of *creating a place of comfort*. The ultimate superordinate theme was *inclusion is immensely effortful*. The analysis was completed acknowledging the relational nature of the shared experiences without losing sight of the individual distinctiveness of the stories (Tomkins & Eatough, 2010).

Discussion for common understanding between the authors resolved discrepancies in descriptive noting or placement within a theme. As engagement in community programs occurs in a place of interpersonal relationships, reflection on the tenets of relational ethics—engagement, mutual respect, embodiment, and environment—as a comparative context brought visibility to the phenomenon of hidden labor (van Manen, 1997).

Rigor

Smith et al. (2009) recommend Yardley's (2000) strategy for judging the quality of research using IPA (a) sensitivity to context, (b) commitment to rigor, (c) transparency and coherence, and (d) impact and importance. Sensitivity to context occurred by adhering to idiographic analysis (Smith, 2004). Further, the focus groups provided a context for families to relay detailed personal experiences while also benefiting from shared language and memory triggering stories of other families. The authors adopted a reflective attitude of epistemic humility, as they are not parents of disabled children (Macbeth, 2010; Mackenzie & Scully, 2007; Watson, 2009).

Attaining a commitment to rigor occurred through purposive sampling and careful attention to the depth of the data analysis and interpretation. Also employed were multiple methods (focus group interviews and field notes), multiple data sources (multiple participants), and peer debriefing. The systematic monitoring of transparency and coherence, or the believability and accuracy of the research findings, occurred by maintaining focus on the research question and monitoring the fit of the data and its interpretation against the conceptual framework through

frequent meetings (Wu & Volker, 2009). The importance of participants' voices in identifying gaps and sharing in the interpretation of the findings was encouraged through the conversational nature of the focus group interviews and participant confirmation of transcript accuracy and thematic summaries (member reflections; Smith & McGannon, 2017; Watson, 2009). The transcripts and theme summaries were returned to the participants via e-mail. They confirmed transcript accuracy and returned a form with the statements: (a) *This is me. I see myself in the experiences described in the themes*, (b) *This is me, but I also want to say . . .*, and (c) *This is nothing like me. These themes do not reflect my experiences*. Eight of the nine participants responded to the theme descriptions. Five of the participants checked, *This is me*. Three participants checked, *This is me, but I also want to say . . .* and provided further comments on the theme descriptors. The final themes reflect modifications resultantly made to their descriptions. These modifications included changes to the original theme labels and a more nuanced presentation of the resources that parents found helpful in the community.

Impact and importance of qualitative inquiry rests with the reader. The ideographic nature of IPA was balanced against theoretical transferability, which was aided by providing descriptions of the homogenous sample, the impairment range and ages of their children, the relatedness of the literature to the research question, and the contextualization of the parents' experiences (Pitchford et al., 2016; Reid, Flowers, & Larkin, 2005; Smith et al., 2009; Smith & Osborn, 2008; Zitomer & Goodwin, 2014). The authors are White, have degreed backgrounds in adapted physical activity, are experienced qualitative inquiry researchers (junior and senior researchers) and have professional experience in inclusive recreational, sport, and physical activity contexts. This disciplinary and context knowledge provided a valuable platform for the research, including relationship building during the focus groups, and interpretation of the data. One of the authors shared the lived experiences of parenthood; however, we were outsiders to the parenting of disabled children. Despite the benefits of bringing an objective perspective to the research setting and putting forth our best efforts to be wakeful to hearing, understanding, and presenting family experiences (e.g., two-stage member reflections), we nonetheless acknowledge we may have overlooked important aspects of the parents' experiences. Finally, the experiences presented are from one physical activity program (case) potentially affecting the degree to which the parents' stories may resonate with other families or programs.

Results

Discussions with parents can be described in four themes of hidden labor when creating physical activity opportunities for their children: (a) inclusion is immensely effortful; (b) judged by their impairments, not their possibilities; (c) ongoing education needed to open doors and sustain participation; and (d) the guilt of staying home. It was effortful for parents to locate community physical activity programs where their children would not just be present in the space. Parents researched programs, often doing site visits to ascertain the appropriateness of programs policies, personnel, and facilities. A relational ethic

was not evident in the shared stories. A detailed description of the families' experiences is described below.

Inclusion Is Immensely Effortful

Parents confronted the need to provide an adult to accompany their children, inflexible programs that did not accommodate slower paces of skill acquisitions, and staff who ignored their children or questioned parents' motivations for facility use. Diane recalled, "You have to plan and it's not just [the child] doing the activity, you both have to do the activity, whether it's physically being hands on or you have to stay for it." The ableistic requirement of independent participation removed the obligation of program staff to reflect upon their habitual professional belief systems, eliminating space for exploring avenues for inclusion through *engaged interactions* or the *mutual respect*. When inclusion was not successful, it was when staff members did not feel compelled to work with parents to develop a *relational environment* for understanding family needs. Helen shared, "You do a lot of research and talk to a lot of parents. . . . I always have the assumption that we are not going to be welcome and that we will have to fight our way in there."

Parents were on the outside, looking in, left to determine the fit of a program for their children and how to convince others that their children were deserving of inclusion. There was no relational space or opportunity to use the embodied knowledge held by families and children to facilitate participation.

You have to give up your time to see if he can attend certain things. . . . When you go there you sit and analyze. Are they supportive? Can he do it? Are they treating him well? Are they communicating with him? You have to be really engaged. . . . We've been doing it for so long, I don't even realize it. He's getting older and I'm finding it difficult. It is labor intensive. (Cheryl)

Only when certain parameters were met, often through the labor of the parents (research, advocacy and direct support), was the inclusion of their children possible. It could be argued that parental labor was perpetuating the very ableistic network of beliefs, processes, and practices that initially excluded their families from engagement. The parents endured an ongoing untenable situation of desiring community access, yet submitting themselves and their children to considerable labor to overcome ableistic beliefs that determine who belongs and does not belong. Parents worked to surmount imposed standards of embodiment and who was worthy of involvement (or not), so their children would *fit* within that standard.

As the children became teenagers, parents' roles as helpers, supporters, and workout buddies became less tenable. Without alternate supports, participation opportunities decreased. As Cindy recalled, "She does not want her mother there. She wants her cousins or people her age or people who are more fun, and not so bossy." The labor extended by one family to *relationally engage* with a program manager was successful in securing a *mutually respectful* swimming program environment for their son who was beyond the program cutoff age of 12.

We simply worked with the manager and he will continue to be 12 for as long as it takes to work through the program. . . . It's about finding the people who can . . . just figure out how to move it forward. . . . We are pretty thoughtful

about the kinds of things we engage him in and whether or not he'll feel he's part of that. (Denise)

Gary also recalled the support he received for his son at a golf club. "My son loved golf, but he wasn't really willing to listen to his Dad." We called the golf pro, and he said "Sure, bring him out," so our son had three lessons with him." Even in describing the efforts extended to support their son, Denise and Gary did not feel that they were expending labor that was beyond that of nondisabled families. "You see what some of our friends are doing to get their kids involved and it really isn't any different from that perspective" (Gary). And yet, Denise stated, "We thought we really needed a break" from the energy of planning for and executing family-only centered activities. The parents associated efforts to engage their children in community programs as a matter of course. When asked if the term "hidden labor" resonated with her, Cindy responded, "Until you said this was hidden labor, I didn't even think about it. I know its extra labor, but I did not see it as hidden labor. That's such a good term" (Cindy). When parental labor leads to a program placement, acknowledgment of their research and planning would build the ongoing relational ethic required for sustained participation. Mutual respect, engaged interactions, and sharing of embodied knowledge would decrease *inclusionism* or the assumption of parents that it is their role to decrease demands on service providers in exchange for inclusion of their children in programs. Diane summarized this well when she said, "As a parent to make it all happen - having that acknowledged by saying 'We are so glad you've come to join our program. We will do our best to make it worthwhile for you.'"

Judged by Their Impairments, Not Their Possibilities

The parents expended considerable time and energy (labor) building relationships, educating staff members, and developing armor to overcome nonconscious ableism that labeled their children as disabled. They worked to pass their children as "able enough" in the eyes of others to gain access to the programs, even if passing meant that the parents themselves provided supports where none existed. Diana stated, "People judge our children because of their disability that comes first and foremost." The mutual respect required within community program spaces to encourage engaged interactions was replaced with tolerance of their presence, and program expediency took precedence over "our children's best interests" (Cindy). Kate's counter-story to the policy of inclusion highlights the absence of a professional relational ethic built on an interdependent responsibility to ourselves as professionals and our obligation to others:

They made sure he was safe, but they didn't actually engage him in any way. . . . I hate the word *tolerance*. Tolerance implies that you are putting up with something that you would really rather not have to. It needs to be changed to acceptance . . . believing in their ability and treating them with respect and not putting limitations on them. (Kate)

Hurtful comments from strangers based upon ableistic notions of acceptable bodies Othered their children as different, lesser, or undesirable. The emotional upset required ongoing labor to manage their own emotions and those of others.

Diana and Helen shared the considerable labor involved in managing interactions with others. “What’s wrong with your child?” “Can I pray for him?” “You are such a saint to do this.” “God has made them all so special” and “I’m so sorry.” “You have armor now, but there are still things people say that can be really hurtful.” The labor parents undertook to facilitate their children’s engagement in physical activity programs was invisible to community program personnel, either because of an ableistic staff expectation that it was the parents’ responsibility to provide program supports, or because parents assumed that the role was theirs to carry alone.

We’ve been doing it for so long I don’t even realize it. I’m finding it difficult and it is labor intensive. You have to give up your time to see if he can attend certain things . . . then you go sit there and analyze—are they supportive? Can he do it? Are they treating him well? Are they communicating with him? You have to be really engaged. (Cheryl)

Ongoing Education Needed to Open Doors and Sustain Participation

The parents expressed frustration at the quality of professional and volunteer support for their children. Parents assumed the labor of finding, training, and even paying for people to offset insufficient program supports, reflecting systemic inclusionism that tolerate disability when it does not require resources or change in the institutional or environmental status quo. When seeking a community fitness program for her son, Kate recalled:

Everyone else with a membership has access to a trainer. Why shouldn’t our kids or any other disabled person have access? I can’t really do the community thing by myself. It’s really hard to find the right support or workout buddy. I’m not just going to put this on Kijiji, you know? This is my kid! Finding those people is really labor intensive. If you do find a really good one and they are so good they get another job and they’re gone, so you are constantly on this search. . . . It would be great if we could use our community membership and if they had a staff trained to be a workout buddy for a disabled person.

Ironically, when Cindy and Kate provided qualified personal trainers to work one on one with their children, facility policies restricted their entry because they were not employed by the fitness centers. Ableism prevented community program supports, yet when parents overcame inclusionism and provided the needed supports, they were not permitted. The parents got around the policies by not disclosing the credentials of the trainers and introduced them as volunteer helpers. Cindy recollected:

At the community recreation center where a lot of our community friends go to work out, I was told [my daughter] could not bring in her own personal trainer but on the other hand they don’t have a single soul who is able to work with [my daughter]. (Cindy)

Parents assumed responsibility for successful participation due to the exclusionary nature of community programs due to a lack of relational engagement with

families. The ableistic norm that participation of those with different bodies is not an expectation of physical activity, and that families are to find their own participation solutions is alarming. It is further alarming that the burden of guilt for physical inactivity is placed on parents.

The Guilt of Staying Home

The families were busy from the very early years; they negotiated the schedules of specialized services to develop communication skills, toilet routines, sleeping patterns, dressing, and nutrition. “Going to soccer is not on your list” (Kate). As their children grew older, priorities changed. Previously supportive environments decreased as the children outgrew specialized services or support personnel could no longer be found or afforded. Parents were once again expected to exert the labor needed to create socially inclusive opportunities for their children, but now with fewer resources. Over time, the strain took its toll on family life. Diana stated:

When the kids are younger, you have that energy to be willing to go out and educate. Now that the kids are older, you kinda go “sigh” and you sometimes just tend to just stay home because it is easier.

With age and as physical activity as therapy declined, family life became balancing the multilayered labor required to “make it happen” over other responsibilities. Families were no longer able to do it all. Denise recalled, “Our lives are busy. Having one or two nights a week where he is out doing something is probably a lot for all of us. We need the time to decompress at the end of the day.”

Not being able to do it all, as they had done in the past, added the emotional labor of guilt, a guilt not shared by nondisability families. As children grow older, they take public transportation independently, learn how to drive, and participate on their own or with friends—scenarios that may not occur without supports for disability families. The guilt of not keeping up with neighborhood families was real. Personal failing, not systems failing, framed the parents’ guilt of dropping out of community program opportunities. As Diana explained:

There have been times where I didn’t pursue an activity because I didn’t want to do what it was going to take in order to make it happen. It [recreation] is just one more thing and after all of the care giving you don’t have the energy.

Kate added:

I feel guilty. On the one hand, I think it’s okay we’re just staying home now, or today, or this week. But on the other hand, I feel really guilty. I don’t get him out enough because it’s hard. I should do it more and I feel guilty.

Discussion

Discussion with parents can be described in four themes of hidden labor. The families quietly assumed and equally quietly withdrew their children from physical activity programs when it could not be sustained. The effort of parents in support of their children’s participation exposed the “systemic, pervasive and public nature of

ableism” (Hodge & Runswick-Cole, 2013, p. 316) that existed for these families in community physical activity contexts. The parents highlighted the “institutional unconsciousness” of taken-for-granted ableistic practices of exclusion that has remained hidden from service providers, and in fact, the parents themselves as they quietly labored to provide the same opportunities for their children as other children in their neighborhoods (Goodley & Runswick-Cole, 2011; Hodge & Runswick-Cole, 2013). The parents’ acceptance of hidden labor to benefit their children masked the ableistic behaviors of inclusive service providers and relegated the inclusion of their children as “many private troubles” (Oliver, 1996, p. 48).

Ableism can prevent the development of relationships and the mutual respect needed to breakdown Othering discourses of disability built on enculturated views of vulnerability, dependency, and tragedy (Bergum & Dossetor, 2005; Goodley & Runswick-Cole, 2011). Parents faced the stigma of Othering when they entered community physical activity and recreational sport settings (Green, 2007). They recognized, however, that the “problem” of inclusion did not lie solely within their children or their ability to function in the setting. It also rested with the availability, or lack thereof, of external community supports.

The parents’ stories reinforced the importance of mutually supportive relationship building to enhance service provision for disability families (Bergum & Dossetor, 2005). The families provided examples of how engaged and respectful interdependence can occur when families and community program staff work together (Bergum & Dossetor, 2005; Goodwin, 2008). Unfortunately, as families labored to create welcoming environments for their children, they lost their support as professionally enriched staff members advanced to other positions. The continuous cycle of searching, educating, and losing secure community programs left these families tired and impacted their engagement in physical activity (Green, 2007). “Negative experiences of leisure limit what families can do, expect to do, can be and their imagined future selves” (Hodge & Runswick-Cole, 2013, p. 316). Moreover, to defend physical activity as being inherently valid without addressing support systems raises questions of professional ethical self-reflectiveness (Silva & Howe, 2012). Ethical reflectiveness will bring nonconscious and unconscious ableism to light (Goodwin & Rossow-Kimball, 2012; Scully, 2010).

The parents expended considerable energy to meet cultural and environmental constraints in support of the inclusion of their children. Some reached a point when they could no longer defend the hidden labor involved in maintaining their son or daughter’s participation. When confronted with unstable supports systems and unrealistic expectations, participation was no longer salient for these parents (McLaughlin, Goodley, Clavering, & Fisher, 2008). Rather than off-loading participation responsibilities to parents, an interdependent understanding of inclusion brings a deeper understanding of the complexities of professional service provision obligations. Supporting the findings of McConachie, Colver, Forsyth, Jarvis, and Parkinson (2006), parents withdraw pursuit of inclusive settings if they perceive their children do not have a voice in the activity, do not enjoy the activity, or feel “lesser” than through their participation.

By relying on parental labor, children may not be able to engage in that which they truly value. Denying their children of exposure to health promoting activities, social networks, and skill and social development opportunities was guilt inducing.

The distance between service providers' conceptualization of family needs and resources and the energy needed to engage in the hidden labor to participate were limiting possibilities on both sides. Reliance on hidden parental labor is an ableist practice of inclusive programs that maintain an exclusion agenda in community recreation settings (Hodge & Runswick-Cole, 2013).

In conclusion, the parents of this study, through their stories, ask that we turn our gaze back on ourselves as fitness providers in our everyday relational, systemic, and cultural engagement with disability (Goodley & Runswick-Cole, 2011). The parents reported their efforts at creating a life for their children at the expense of having their own life. Their focus on the construction of disability as the problem shifted the discourse from family burden to how ableism interferes with relationship building. Questions for further consideration include What labor do children and youth expend to engage in inclusive community programs? Should community physical activity programs be reliant upon hidden labor to maximize their inclusive community presence and engagement? and How does relationality, ethics, social connection, and interdependence interface with family and individual agency? Hidden labor is ubiquitous to the disability experience leading to it being nonconscious to those without disabilities (Scully, 2010; Withers, 2012). For the families of this study, there was a disproportionate investment of physical and emotional energy over parents of nondisabled children to engage in the physical activity and recreation sport opportunities of childhood. Bringing a relational ethic to service provision, staff development, and educational programs may have brought a more balanced inclusion experience to the families of this study. Opening dialogue and building relationships with parents may bring wakefulness to, and ethical reflectiveness on, nonconscious and conscious ableistic practices of service providers that exclude families. As Diana said, "It's not always easy for us to make this happen so it would be nice to be told, We are so glad you have come! We will make it our best to make it worthwhile."

Acknowledgments

We would like to thank the Craig H. Neilsen Foundation (provided following peer review) for their generous funding of this research. We thank the Steadward Centre for Personal & Physical Achievement program for their cooperation in the completion of the study. We also extend a warm thanks to the participants who shared their stories and make this study possible.

Note

1. The term *disabled people* reflects that disability is a "set of socially and structurally produced relationships and processes that lead to the categorical impoverishment, isolation, confinement, neglect, and devaluation of an entire social class of people" (Peers, Spencer-Cavaliere, & Eales, 2014, p. 273).

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