Physical Education for Students With Spina Bifida: Mothers’ Perspectives

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This study described the meaning 7 mothers of children with spina bifida ascribed to their children’s physical education, the mothers’ roles in the schools, and the importance of the IEP in home and school communication. The stories of 4 mothers of elementary and 3 mothers of secondary aged children were gathered using the phenomenological methods of semistructured interviews, artifacts, and field notes. The thematic analysis revealed three themes: a good thing but . . . , connection to sports, and beyond the curriculum. The mothers valued their children’s participation in physical education and provided instrumental support to teachers and teaching associates. They also valued sport as an avenue for developing sport specific skills, which in turn enriched the school experience. The findings are discussed within the context of Peters’ (1996) model of disablement.

Parents have been identified as fundamental partners in the development of educational programs for children with disabilities for some time (Folsom-Meek, 1984; Lytle & Bordin, 2001) and yet their voices have been relatively absent from the discourse on inclusive physical education (Erwin & Sooddak, 1995). In one of the few studies investigating the factors parents deemed essential for the placement of their children with physical disabilities into inclusive physical education programs, 100 parents from six elementary schools completed a 21 question survey (Downing & Rebollo, 1999). The parents reported the most important factors to successful inclusion in physical education to be (a) class size and the motivation to implement an integrated physical education program; (b) teacher, parent, and administrative support and interest; and (c) physical health. This study, in combination with others (Kozub, 2001; Melograno & Loovis, 1991; LaMaster, Gall, Kinchin, & Seidentop, 1998; Lieberman, Houston-Wilson, & Kozub, 2002; Ryndak, Downing, Jacqueline, & Morrison, 1995), suggests that parents understand many of the determinants of success in inclusive physical education and have a knowledge base that may be of considerable value to school personnel.

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Parents take on multiple roles in the education process of their children (Kozub, 2001) and have confirmed the social benefits (Castaneda & Sherrill, 1999), health benefits (Kristen, Patriksson, & Fridlund; 2003), and motor skill development (Hamilton, Goodway, & Haubenstricker, 1999) that result from participation in physical education and community based physical activity. Parents in North America have traditionally been involved in special education planning for their children through the individual education program (IEP) process, a practice that continued as special education teachers continued to support students with disabilities as they moved into inclusive education settings (Sherrill, 2004). The IEP requires written goals for the upcoming school year and the resources and services required to support success. It acts as a planning document, a management tool, and an evaluation device for monitoring student progress (Block, 2000; Edmiaston, Dolezal, Doolittle, Erickson, & Merritt, 2000). The IEP is designed to assist students, but it also serves as a vehicle for communication among teachers, parents, and other educationally focused professionals (Lytle & Bordin, 2001; Yun, Shapiro, & Kennedy, 2000).

The role of parents in the development of the IEP has been open to numerous interpretations. Although parents are encouraged to play active roles and be equal partners with educators in decisions related to their children’s educational programming, parents are often allocated to a passive role (Fiorini, Stanton, & Reid, 1996). Garriott, Wandry, and Snyder (2000) conducted a study on parental involvement and satisfaction in the IEP planning conference. They were interested in parents’ attendance at the conference, their role as a team member, and their involvement in decision making. Eighty-nine percent of the parents stated that they always attended their children’s IEP conferences, but few were attended with their spouses or partners because of scheduling problems due to work, marital status, and/or mothers assuming the major responsibility for the child. Generally, parents were encouraged to actively participate; however, they were recipients of information rather than providers. Giangreco, Dennis, Edelman, and Cloninger (1994) found that for 46 students who transferred from segregated to inclusive educational environments, the IEP was broad, inconsistent, inadequately referenced to the general education context, and often listed goals for staff rather than those for students. These findings raise questions about the overall effectiveness of the IEP process in its present form within inclusive educational settings, its overall place in the education of students with disabilities, and its role in physical education in particular.

Similarly, Salembier and Furney (1997) explored parents’ perceptions of their involvement and level of satisfaction with their children’s IEP meetings. Two-thirds of the 36 parents interviewed expressed satisfaction. They stated that they were given the opportunity to talk, to listen, and to ask and answer questions. However, 30% of the respondents expressed dissatisfaction with the process, indicating that they had poor relationships with professionals, lacked information about the planning process, and believed that professionals exerted excessive control over the process.

Given teacher and parent dissatisfaction with the use of the IEPs, there are many unanswered questions surrounding the role parents play in their child’s educational planning in inclusive physical education settings. The purpose of this study was to gain an understanding of parents’ perspectives of their children’s experiences in inclusive physical education. More specifically, this study described (a) the importance of the IEP process in home and school communication, (b) the meaning
parents gave to physical education for their children, and (c) the roles they assumed in support of their children’s physical education experiences.

Many models illustrating disablement have been introduced in the literature (e.g., Nagi, 1965; Verbrugge & Jette, 1994). Peters’ (1996) model of disablement emphasizes both the objective (disability observed) and subjective (disability experienced) features of impairment and the impact of not only the biological manifestations of impairment on function, but the role that society can play in the production of disability. This framework is organized around three perspectives: the outsider, the interventionist, and the insider.

The outsider perspective is characterized by objective descriptions of disablement, such as those found in research journals, textbooks, diagnostic reports, and classification systems (including sport). Policy makers, researchers, and physicians are considered to be outsiders. The interventionist perspective goes beyond the abstract objective knowledge that characterizes the outsider perspective. In this instance, the knowledge is applied in concrete ways with the goal of enhancing the individual’s quality of life. Teachers, teacher associates (also referred to as teaching assistants, paraprofessionals, teacher aides), and rehabilitation therapists act as interventionists when the structure and function of the individual is viewed within a social support context. The insider perspective represents that of the person with the disability and integrates the subjective experience of disablement with environmental and social contexts. People living the reality of disability reveal their personal meanings of disablement. The social context determines the constraints and affordances that emerge from physical environments, attitudes, cultural norms, and policy.

Peters’ (1996) disablement model provides a valuable heuristic framework from which to interpret the data of this study. Parents, according to his model, are considered to be interventionists as they continually work to provide the best opportunities and experiences for their children. Parents also communicate frequently with other interventionists through the school systems. Parents of children with disabilities also become experts at interpreting the knowledge of outsiders as they traverse the medical system and interpret information about their children for others, including teachers and teacher associates. Outside of the children themselves, the parents come as close to the insider perspective as is possible. Parents are often asked to represent their children’s interests as in the case of the IEP process.

**Method**

A phenomenological approach was utilized as it offers a descriptive, reflective, interpretive, and engaged mode of inquiry for understanding parents’ perspectives of their children’s experiences in inclusive physical education. Through phenomenology, an understanding and description of the essence of experiences, the underlying structures (themes), and commonalities in meanings are sought (Moustakas, 1994; van Manen, 1997). The phenomenological approach was also inherently hermeneutic in nature. Parents spoke about their experiences and those of their children as expressed through subjective, non-neutral, and relational use of words. Understanding the commonality of meaning behind the language used to describe their experiences requires interpretation on the part of the reader (van Manen, 1997).
Participants

A homogeneous sampling strategy was utilized (single disability, all women, parents of school aged children, middle class families), thereby facilitating the transferability of the results to other parents who share similar life situations (Meadows & Morse, 2001; Patton, 2001). The focus on mothers does not suggest that fathers do not play active roles in the education of their children; however, mothers tend to play a more active role in the day-to-day school activities of their children (Garriott et al., 2000) and take the lead role in the IEP process (Salembier & Furney, 1997).

The participants were recruited through the Spina Bifida Association of a mid sized city in western Canada. A letter describing the study was sent to the president of the Association and shared among the membership. Seven women of children with spina bifida ultimately participated in the study, six Caucasian mothers and one Caucasian grandmother, who was the child’s primary caregiver and thereby designated as her mother for this study. Four mothers had children of elementary school age (one boy and three girls with an average age of 9.5 years, range 8 to 12 years) and three mothers had high school aged children (two boys and one girl with an average age of 14.3 years, range 14 to 15 years). The children used wheelchairs for mobility and all had at least one sibling. Four of the mothers were employed outside the home (2 part-time and 2 full-time). Three mothers completed high school, two had a college degree, one obtained a nursing diploma, and one completed grade 9 (see Table 1). With approval from the supporting institution, informed consent was obtained from all participants.

The schools were located in the same mid sized city. The elementary schools held the physical education classes of approximately 30 students for 45 min, 2 or 3 days per week with the exception of one school that had daily physical education. The high school physical education programs ran single classes of approximately 30 students for one hour, 5 days per week for one semester. Classroom teachers, with one exception, taught the elementary physical education programs. Physical education specialists taught the high school programs. None of the teachers had taken any classes in adapted physical education as part of their teacher preparation. Elementary students received the support of a full time teacher associate (TA) in physical education. Although the high school students had part time teacher associate support, the TAs did not attend physical education. All gymnasium facilities were wheelchair accessible. All of the children were involved in physical activity programs outside of school at the time of study. Their average years of participation was 5.4 years (range 3 to 10 years). Four of the children participated in sport programs for individuals with disabilities exclusively, while the remaining 3 participated in both sport and community physical activity programs.

The IEP meetings were held at the beginning and the end of school year, except for one IEP team that met four times per year. The members of the IEP meeting team consisted of the principal, classroom teacher, special education teacher, teacher associate, and parents. Three students participated in the IEP meetings. The high school physical education specialists were not involved in the IEP process. Depending upon the needs of the student, other professionals may have attended the IEP meeting (e.g., nurse, speech pathologist).
<table>
<thead>
<tr>
<th>Name</th>
<th>Occupation</th>
<th>Education</th>
<th>Martial status</th>
<th>Name</th>
<th>Age</th>
<th>Grade</th>
<th>Sport</th>
<th>Community sport</th>
<th>Years involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Helen</td>
<td>Retail manager FT</td>
<td>Grade 12</td>
<td>Married</td>
<td>Lisa</td>
<td>9</td>
<td>2</td>
<td>Dance, swimming</td>
<td>No</td>
<td>3</td>
</tr>
<tr>
<td>Erin</td>
<td>N/A</td>
<td>College</td>
<td>Married</td>
<td>Rebecca</td>
<td>8</td>
<td>3</td>
<td>Dance, basketball, swimming</td>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Bonnie</td>
<td>Nurse PT</td>
<td>College</td>
<td>Married</td>
<td>Andy</td>
<td>9</td>
<td>3</td>
<td>Dance, tennis, basketball, swimming</td>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Andrea</td>
<td>Executive director FT</td>
<td>College</td>
<td>Partner</td>
<td>Julie</td>
<td>12</td>
<td>6</td>
<td>Dance, skiing, swimming</td>
<td>Swimming, dancing</td>
<td>7</td>
</tr>
<tr>
<td>Kim</td>
<td>N/A</td>
<td>Grade 9</td>
<td>Divorced</td>
<td>Megan</td>
<td>14</td>
<td>9</td>
<td>Track, basketball, skiing, swimming, tennis</td>
<td>No</td>
<td>5</td>
</tr>
<tr>
<td>Margie</td>
<td>School bus driver PT</td>
<td>Grade 12</td>
<td>Married</td>
<td>Dustin</td>
<td>14</td>
<td>10</td>
<td>Basketball, skiing, swimming</td>
<td>Basketball, wrestling</td>
<td>10</td>
</tr>
<tr>
<td>Jeanette</td>
<td>N/A</td>
<td>Grade 12</td>
<td>Married</td>
<td>John</td>
<td>15</td>
<td>10</td>
<td>Basketball, rugby, swimming</td>
<td>Bowling, soccer</td>
<td>3</td>
</tr>
</tbody>
</table>

*Note. FT = Full Time; PT = Part Time*
Data Collection

A combination of data sources were used to gather the parents’ perspectives, including interviews, visual artifacts, documents, and field notes. The multiple perspectives resulting from combination of data sources aids in understanding the essence of the experiences encountered.

Interviews. The primary sources of data were semistructured, audio-taped, face-to-face interviews completed by the first author and subsequently transcribed verbatim. Predetermined but open-ended questions, with an expectation of a broad range of responses were completed (Fontana & Frey, 1994; van Manen, 1997). Sample interview questions included the following: How would you describe your child’s participation in physical education? What role does physical education play in your child’s overall school experience? How meaningful are the opportunities you have to discuss your child’s physical education with school personnel?

All but one of the mothers took part in two interviews, lasting approximately 45 to 60 min. One mother did not complete the second interview due to time constraints. The focus of the initial interview was on understanding parents’ perspectives of their children’s experiences in inclusive physical education. The second interview focused on understanding the means of communication parents used to share their thoughts about their children’s participation in physical education. During the second interview, the participants also explained the significance of artifacts and documents they provided (e.g., photographs and IEP documents). Asking the mothers to describe their experiences with the aide of documents and photographs added depth to the information and decreased the potential for researcher bias in their interpretation (Patton, 2001).

Artifacts. The artifacts took two forms, photographs and written school documents. Photographs provided “a sense of the physical environment” (Patton, 2001) and context to the interview transcripts (Bogdan & Biklen, 2003). Five of the participants provided completed IEPs, four provided report cards, and one mother provided a daily communication book she used to communicate with the teaching associate. As with photographs, documents supplement interview data and add to the trustworthiness of the findings (Bogdan & Biklen, 2003).

Field Notes. Field notes were recorded after each interview and contained reflections about what was said that day, ideas for further probing with subsequent participants, and preliminary thoughts about themes that were emerging from the data. These notes permitted the investigators to conceptually return to the interview setting during data analysis (Bogdan & Biklen, 2003).

Data Analysis

To analyze the meaning, structure, and essence of the participants’ experiences, a thematic line-by-line analysis of the interview data was completed. Thematic analysis identifies common structures of the particular experiences under study and is the primary mechanism by which understanding was achieved (van Manen, 1997). It entailed reading the interview transcripts and field notes numerous times. Particularly revealing phrases were highlighted and coded with meaningful labels.
Codes that are conceptually similar were gathered together into thematic statements, giving fundamental meaning to the experiences (Patton, 2001). The photographs and document data were used to verify the thematic statements.

The data were analyzed separately by school grouping of the children (elementary and high school). The essential themes that emerged from the data were similar for both groups, although some distinctions were evident between the two groups given the high school emphasis on skill development and application. These distinctions will be highlighted in the results and discussion. The analysis was completed with gender sensitivity, meaning that the transcripts were read carefully for differences that may have been expressed by caregivers of sons or daughters. No thematic differences were noted.

**Trustworthiness**

Credibility, which refers to the truth value of the findings (Meadows & Morse, 2001), was enhanced by reaching data saturation. Repetition occurred in the narratives of the mothers as the stories shared by later interviews began to confirm earlier ones. Different data sources or data triangulation (i.e., parents of elementary and secondary school aged children) were purposefully and systematically incorporated into the design of the study. Method triangulation was also undertaken as interview and artifact information was gathered. Finally, a two-phase member check was completed whereby the participants verified the transcripts and the results of the thematic analysis reflected their experiences (Meadows & Morse, 2001). All participants reviewed their transcripts for accuracy and returned signed transcript release forms. A summary description of the themes was subsequently mailed to the mothers with a short form asking them to confirm that their experiences were reflected in the themes and to provide feedback. All participants returned the forms indicating their experiences were reflected in the thematic summaries.

To bring dependability or soundness to the findings, multiple data sources were utilized (i.e., interview transcripts, visual artifacts, documents, field notes). Confirmability, which refers to the neutrality of the data (Creswell, 1998), was established through investigator triangulation (i.e., first and second author peer debriefing). The authors coded the data separately and collaboratively determined the themes (Brantlinger, Jimenez, Klingner, Pugach, & Richardson, 2005).

Naturalistic transferability was enhanced by providing descriptions of the participants (Denzin & Lincoln, 2000) and utilizing a homogeneous sampling strategy (Patton, 2001), thereby providing a foundation for recognizable congruence between these parents and other parents of children with spina bifida.

**Results**

Three themes emerged from the thematic analysis of mothers’ perceptions: (a) a good thing but . . . , (b) connection to sports, and (c) beyond the curriculum. The themes are supported by subthemes illustrated with the words of the mothers. Pseudonyms have been used throughout.
A Good Thing But . . .

The mothers believed that the physical education program supported the development of their children in numerous ways. They recognized the important role physical education plays in social development, including making friends, having fun, and developing a sense of belonging. The health benefits of physical activity as an intervention against obesity brought about by sedentary lifestyles were also recognized. Although the mothers recognized these benefits, they also expressed concern over environmental, instructional, and curriculum barriers to their children’s participation.

Feeling Connected. The mothers placed a high value on the social benefit of physical education at both the elementary and secondary level, even if their children were not active participants in all activities. Repeatedly, the mothers identified interaction with peers during physical education as important to their children’s school experience. Erin, mother of 8-year-old Rebecca, recalled,

She gets enjoyment out of it. I don’t know how much physical activity she actually gets. I just want her to have fun. . . . The day that she has gym she comes out from school and has a big smile on her face and she says, “I had gym today” and she’ll tell me what she did.

Jeanette also commented on the importance of connecting with friends for her high school aged son: “I think it’s a sociable thing for him. I mean he can make friends there. . . . If there were no physical education in school, he would feel set apart from them [classmates].”

Health Benefits. All of the mothers perceived health benefits as an important outcome of physical education. Mothers recognized that their children experienced less physical movement than other children because they spend much of their day in their wheelchairs. Obesity, as a health risk, was clearly on the minds of mothers of even the youngest of the participants. Erin mentioned that physical education helped 8-year-old Rebecca avoid obesity as a secondary impairment to her spina bifida. Erin stated, “I think, because of using a wheelchair you are at risk for secondary type things like the obesity. I think physical education lends a big part to a healthy lifestyle.” Andrea, mother of 12-year-old Julie further stated,

Julie has grown this year . . . but she is always been kind of on the heavier side because of her height. Her stature is short so we want her to maintain a good level of physical activity and to keep her weight down, you know, to have a good heart, build up her heart, and build up her upper body muscle.

Participation Barriers. Along with the positive views of their children’s participation in physical education, the mothers also expressed several concerns. Barriers to participation included safety concerns, equipment and wheelchair accessibility, and instructional support.

Safety was of prime concern to the mothers. The mothers used their outsider knowledge of spina bifida (i.e., understanding the condition from a medical perspective) to recognize contraindications to participation in physical education due
to health and safety risks. Margie was concerned about Dustin (age 14) wrestling due to the presence of a shunt to control his hydrocephalus: “The wrestling bothers me. I didn’t like to see pulling on his head. He’s got the shunt. I didn’t like what they were doing to his head.”

The mothers also spoke of the risk of serious injury to their children’s lower limbs. Erin recalled an outdoor game that her daughter Rebecca’s (age 8) physical education class played on the hard surface adjacent to the school. The exterior wall of the school was considered a safe zone. She stated,

I think the only time that physical education is not appropriate would be [if] it is unsafe. When you touched the wall, you were considered safe or free. She would run or wheel and her legs would constantly slap into the cement or concrete wall. She can’t feel that hurt. Her bones are not as strong as her mind. She can end up with broken bones. When it’s not a safe environment, it would be the only time that I would hesitate.

Jeanette, mother of 15-year-old John, also discussed the safety risks of using the small gymnasium that potentially increased the risk of contacting the wall thereby risking injury. The teacher in this instance restricted John’s participation:

The smaller gym was dangerous for him because he was always hitting the wall.
I remember certain games that the teachers never let him play. He thought he should, but I think they were really worried about the safety, his safety.

The mothers explained that their concerns for safety were often at odds with what their children desired. Although scooter board activities had the potential to equalize the abilities of all students, Bonnie felt that they were unsafe for her son. Andy (age 9) had poor sitting balance and without the support of his wheelchair was at risk of falling. Andy in contrast enjoyed the activity. Bonnie recalled,

Scooter boards were one that I wasn’t very happy about because I didn’t feel that a lot of thought went into it. It was very unsafe. They are a lot of fun for the kids and Andy, of course, thought [it was] a lot of fun as well, but it was so unsafe because he doesn’t have any upper body stability right now. They actually let him sit on one and it was so unsafe for him.

For their children to be actively and safely involved in physical education, the mothers acknowledged that they required modified or specialized equipment. Jeanette, mother of 15-year-old John, explained, “I think a lot of things are not appropriate because they don’t have the equipment that he would need. If they are doing hockey, he needs a shorter stick.” Sport days and special school outings were especially challenging, as the students found it difficult to negotiate natural surfaces or keep up with classmates when activities are taken off the school site. In some instances, mothers intervened by providing specialized sports equipment to enhance participation opportunities. In doing so, the mothers brought together their knowledge of adapted equipment (e.g., sit skis, hand crank cycles) with their understanding of the children’s abilities. School staff members were reported to be appreciative of the expertise the mothers brought to the instructional setting. Andrea, mother of 12-year-old Julie, recollected,
If the program didn’t include the equipment that she needed, we worked with the teacher or the resource room teacher to get the equipment for her. We had to rent [a sit ski] for the year and had to make sure that we got the equipment to the school.

Erin also indicated that she borrowed a hand-crank cycle from her friend who had a spinal cord injury so Rebecca (age 8) could participate in biking with her peers. The positive social impact of her being able to participate is relayed below:

Last week there was a bike safety clinic at school. We borrowed a hand-crank cycle. . . . There’s a huge hill in a playground where she went. I think everyone was in a shock. They didn’t think that she is being able to climb the hill but she certainly did.

In other instances, mothers were unable to secure the needed equipment that ultimately resulted in exclusion from the class activity as the school did not investigate the availability of specialized equipment. Bonnie, mother of 9-year-old Andy, stated, “Today is sport day and they’re having bikes. They will be biking which is wonderful but of course not at all good for him because we would have to provide the bike and we don’t have that, you know.”

Use of wheelchair friendly or accessible spaces was also identified as one of the environmental barriers to participation in physical education. All gymnasiums were accessible, but other learning environments may not have been. Jeanette was unhappy that John (age 15) was not able to use the weight room facility. She explained, “I know several high schools that have weight rooms. He can’t get there because they’re upstairs, no lifts, and no anything.”

Barriers were evident outside of the schools as well. Grass playing fields posed an environmental barrier. Grass increased the resistance to wheeling. Andrea provided a photograph of Julie at her grade 5 track meet. Although she participated with her classmates, the tremendous physical challenge created by the wheelchair unfriendly grass left her far behind her classmates, alone with little social contact.

A third perceived participation barrier identified by the mothers was related to the implementation of the program. The mothers discussed shortcomings in curriculum adaptations and the lack of instructional support. The mothers recognized that full participation in physical education at all times was not realistic. Andrea, remarked, “High jump, she’ll never be able to do. Some [activities] are not appropriate because physically she’s not capable of doing that no matter how many adaptations we made for it.” The mothers felt, however, that curriculum adaptations in some areas could enhance their children’s participation. Andrea recognized the teacher was not deliberately excluding her daughter, but her lack of preparation resulted in her daughter’s (Julie, age 12) exclusion in some activities: Andrea recalled,

The teacher made her wheel around the gym. By the time she was done doing that three times, like every other child, she was exhausted and frustrated. She had usually missed most of the class instruction that took place after the warm-ups. . . . The teacher didn’t have an idea of how Julie fits into the physical
education program. . . . Sometimes there is exclusion because teachers haven’t put enough full thought or thought ahead about activity. I don’t think the intent is to leave the child out but I think sometimes it’s an error of omission.

The mothers discussed the important role of teaching associates in physical education given the lack of individualized instruction time available to teachers. They recognized the important role TAs played in translating the biological manifestations of spina bifida to the instructional setting. Andrea explained,

I think the TA is necessary. She has a really good understanding of Julie’s disability, what her limitations are, and what she is capable of. . . . Having a TA is very valuable because she has the time to pay attention to things that her teacher might not.

When a TA did not possess the skills required to implement the instructional program, however, mothers were required to stand in such as during swimming. Mothers had to stand in creating a social context unique to their child. Erin recalled Rebecca’s swimming experience: “When her school goes swimming, her TA actually doesn’t swim. My husband or I go with her, but I feel like she’s starting to notice her mom is the only one with her in class.”

TA support at the high school was used to provide specialized programming for some students. When the teacher felt the activity expectations were beyond John’s abilities (age 15), the TA who did not attend the physical education program was called up to complete an exercise therapy program. Although the completion of the exercise therapy program removed John from his classmates, his mother was pleased that he had the support of a teaching associate during these times and was not totally excluded from an exercise context. Jeanette recalled,

When the children climbed or kicked anything, he couldn’t do that at all. He just can’t. The teacher associate last year would actually do therapy with John. He came to the hospital and learned some therapy exercises. When the class was doing something he couldn’t do very much then John would do special exercise with his TA. That was very good. I was very happy because if he can’t do what the class is doing, he should be doing something.

In contrast, the presence of a TA also created concerns for mothers. Helen wanted Lisa (age 9) involved in class activities and not engaging in special programs. Helen recalled instances when the presence of the disability alone determined whether Lisa would be involved, reflecting an outsider perspective to Lisa’s abilities. The interaction between the functional ability of her daughter, the instructional environment, and the importance of the social context were not taken into consideration. Helen called for an interventionist approach that maximized her daughter’s abilities to function within a physical education context. Helen recalled,

I’d like them to find more activities that she could be involved in. If she couldn’t play basketball or floor hockey, she went to the OT room (occupation therapy). I don’t know that she needs her own program. I think modification is a huge thing. There’s got to be ways you can modify things that she can do
it. I would like to see them find some modifications and areas where Lisa can participate a little more.

Some mothers’ messages appear to be contradictory, but upon closer reflection may indicate the importance that mothers of younger children place on friendships, a sense of belonging, and social contact. Mothers of older children may recognize that a constant adult companion throughout the school day may not be desirable, but that occasional support is.

Margie discussed that dependency on one person can be created over time. Margie recognized the need for TA support for Dustin (age 14) for an activity such as skiing, although she intervened when she perceived the support had the potential to negatively impact his independence, individual identity, and need to experience self-realization. She was concerned that full time adult attention would diminish expectations her son held for himself as well as others. Margie remembered,

I was getting worried in elementary school. He had the same lady from kindergarten to grade 6. She was like his mother. Dustin got so used to her. She did everything for him and that’s not good, so I switched to a male in Grade 7 and that was a lot better. . . . I think he has grown up so he doesn’t need it. He’s capable of working on his own.

**Connection to Sports**

The mothers discussed how their children’s school physical education experiences helped prepare them for more specialized sports experiences in the community. In turn, the community sport experiences resulted in more active participation in selected components of the school physical education program. The link between the school and community sport was a mutually beneficial one.

**Enhanced School Participation.** The mothers felt that physical activity experiences outside of school gave their children the confidence and knowledge required to be more secure in their participation at school. Andrea explained,

She was involved with [wheelchair basketball] for couple of years. When they started learning basketball in the physical education class at school, she was able to tell the teacher about the rules. They had a wheelchair there so that they have someone participating with her, and she was very confident and very involved in the physical education class. . . . She [also] did sit-skiing with a group of kids who were in wheelchairs. It’s a more even playing field for her. She developed her skill level in a group of children with disabilities and now she’s moved onto skiing with her peers, able-bodied kids.

Erin stated that Rebecca (age 8) had been involved in sports since she was five years old. It provided contact with others of similar ability where she could come to understand her strengths and how her body moved. Erin recalled,

The activities that she does outside of school are segregated. I think it gave her a sense of competence. In school, she is the only one in a wheelchair so I
think she needs to figure out how she is going to be involved. It helped her to figure out how she’s going to participate in physical education.

Kim also discussed the importance of sport in developing confidence as she shared photographs of Megan participating in sport activities. Kim became Megan’s (age 14) full-time caregiver when she was 9 years old. She recalled,

When she was younger, I walked by the school and she was sitting in the corner. When I got her, she didn’t have friends coming over. I just thought she can’t go through life this way. She’s got to meet people and that’s why I got her into the sports. She gets to know people and have fun with them. . . . She loves [physical education] now. She gets out there to join in and do whatever and she doesn’t hesitate to participate in it.

Similar sentiments were heard from other mothers of the high school-aged children. The experiences gained in sports for individuals with disabilities (e.g., wheelchair basketball, wheelchair racing, and sit-skiing) provided motivation for their children to be involved in physical education. Margie said, “. . . in high school now he joins the wrestling team.”

**Developing Sports Skills.** Participation in school physical education was also perceived to provide an impetus for their children to participate in community sport. Andrea said of Julie (age 12): “Physical education has played a big role in her ability to participate in her physical activities outside of school. If she had no physical activity at school, her dancing and her swimming would be harder.”

The link between school physical education and sport participation was reflected on Lisa’s school progress report. It stated, “Lisa increased her confidence and enjoyment in the water . . . supporting the limbs and limiting the impact on the joints . . . it would be beneficial and fun for her to swim more regularly.”

Following the IEP meeting, Helen enrolled Lisa in swimming and wheelchair dance. Although one of the program goals outlined on the IEP forms was “motor development,” only two of the 5 IEP documents included information specific to physical education. The information included under the goal of motor development was “To improve and maintain strengths and stamina.” “To participate in the cross-country skiing for the class” (Julie, age 12). “Adapt gym activities so that Andy can participate as much as possible (e.g., floor hockey & basketball)” (Andy, age 9).

Jeanette wanted her son, John (age 15), to have the same experience as other children but recognized that a high level of play would have to occur outside of physical education and within the context of wheelchair sports.

When he got bigger, he couldn’t compete in basketball and soccer [at school]. He did all those when he was really small, but there is a point and certain sports where people who can’t run, just can’t participate. . . . Certain things have to go into the wheelchair side of things so then he’s equal with his peers in that sport.

**Beyond the Curriculum**

The theme, beyond the curriculum, reflects the role the mothers played in helping others understand their children beyond what they did or did not do in class. They worked to demystify the wheelchair and explain to teachers, teaching
associates, and classmates what spina bifida was, highlighting how similar their children’s interests and abilities were to that of other students. They were also involved in the IEP process and used this opportunity to share information about their children.

**Bringing a Different Frame of Reference.** The mothers indicated that they wanted others to see their children as children first and children with a disability second. To do this, the mothers facilitated disability awareness sessions at school. At times they spoke directly to school personnel and at other times they enlisted the support of others. Helen shared photographs taken of a disability awareness session presented by a physical therapist to Lisa’s classmates (age 9). In viewing the photographs, she remarked,

> We set up the meeting for her to explain some of her situation to her class. A physical therapist from the rehabilitation center came out and basically tried to explain to her classmates why she’s in a wheelchair and what it means to her. They brought out Petti [a doll], she’s got spina bifida as well and is in a little wheelchair. It was a good because it seems they understand a little bit better why Lisa is in a wheelchair.

The mothers were also instrumental in arranging wheelchair sports demonstrations (e.g., wheelchair basketball, wheelchair rugby) for the school. Andrea, Julia’s mother, explained the enhanced understanding, empathy, and support resulting from a member of the disability community leading sports awareness sessions in physical education classes. Andrea explained,

> All of her class got to try wheelchairs. It gives a different mind frame. They had a better understanding of some of Julie’s struggles . . . . I would say that Nick’s involvement in Julie’s physical education class has really helped the kids have different perceptions of Julie because seeing an adult who has all these skills and abilities in a wheelchair produces a lot of admiration, you know. It gives them a different view of the person.

**Keeping the Balance.** The mothers used numerous forms of communication to share insights on their children’s abilities and help others see their children beyond outsider perceptions of the disability and wheelchair that can prevail. Their expectations for their children’s educational programs where made apparent through the formal IEP process and by ongoing informal personal communication.

Andrea, mother of 12-year-old Julie, indicated that she perceived her role as a member of the IEP team was to help other members of the team understand her daughter strengths both in and out of school. She highlighted the need for sincere participation on the part of the mothers if the process is to be meaningful. She expressed frustration when the IEP was regarded as paper work and there was no implementation of identified goals or objectives. Andrea explained,

> Sometimes I think Julie’s abilities and skills are not recognized. There is always a role for us to play at home. If people are not taking their role seriously, it completely defeats the purpose of the IEP. . . . If you really want something for your child as a parent, you have to be the one to initiate. . . . I find that some
teachers treat the IEP as a nuisance. . . . I feel that as a parent, I put a lot of energy into trying to explain to them where Julie is at, where the family is at, what our goals and expectations are. If it doesn’t go from the paper to practice then you get really frustrated.

The mothers of high school aged children expressed less concerns with their role in the IEP process. They indicated the high school structure was one that encouraged and required more student independence. In essence, the significance of the IEP changed. Margie, mother of 14-year-old Dustin, stated that the IEP process was not utilized as extensively in planning Dustin’s educational program as in elementary school. She felt this was appropriate as it increased his self-accountability although it decreased structured opportunities for the mothers to meet with school personnel. Margie recalled,

In elementary school Dustin was followed more closely, but I think that’s only proper because he’s younger, but in high school they expect him to do lots more on his own. He’s growing up now and he’s got to be more responsible than in elementary school.

The second form of communication described by the mothers was personal communication. They took advantage of teacher-parent interview sessions with the teachers. They also utilized informal contact through the telephone, e-mail, and communication booklets. The mothers also felt they were welcome to drop by the school and meet individually with teachers and others as needed. Erin, mother of 8-year-old Rebecca, said that she could talk to the physical education specialist if she had ideas for programs or concerns for Rebecca. “Rebecca’s physical education teacher is very approachable. I wouldn’t hesitate. If I had a concern or something, I would just ask her for a minute or raise concerns,” she said. Bonnie, mother of 9-year-old Andy, also recalled that she was welcomed to approach school personnel:

At any time I can go into the class to ask the teacher about the program or go to the TA. I actually come to the school every Thursday. I mean I can ask at any time Andy’s teacher, “How he’s doing?” It’s very open and it’s very informal.

Some mothers felt that the teacher-parent interview sessions were too short and they should be given more time given the needs of their children exceeded those of children without disabilities. Andrea, mother of 12-year-old Julie, stated, “If the educational system wants parents to play a stronger role in the education of children, I think the parents need to be given a stronger line of communication at the school.” Due to the brevity of teacher-parent interviews and the limited flexibility of teachers to meet, the mothers communicated more frequently with the TA than with the teachers. Andrea, mother of 12-year-old Julie, relayed, “I’m very happy with my communication with the TA because she is continually updating me on what Julie’s progress is.”

Jeanette, mother of 15-year-old John, highlighted the individual nature of the relationship between mothers and school personnel. She felt better about the communication she had with John’s high school TA than with his elementary school TA. In high school she could discuss John’s programs and his participation with his
teachers and TA at any time and received prompt feedback from them. She also felt that the TA was very supportive: “It’s so much better. They phoned me. It’s wonderful. The TA is very good in high school. The most important thing was that he reads all the information [spina bifida and sports involvement] that I gave him.”

Erin, Rebecca’s mother, used a booklet to communicate with her teachers and TA in early elementary school. She recorded notes about how Rebecca was feeling and her needs of the day: “We have a little booklet they sent back and forth . . . it worked really well in earlier grades. This year it’s been used very minimally. I’m still keeping it in her backpack and I tried to mention anything.” In a similar way, Helen maintained a communication book. Helen recalled, “I actually keep fairly good contact with her [TA]. We keep a daily communication log. Every day we write. There is a little something in there. They tell me what they did. We do have very good communication.”

**Discussion**

The mothers of this study demonstrated a strong interest in and understanding of their children’s physical education experiences. They articulated the physical and social benefits of physical education and were extremely insightful as to the barriers to their children’s participation. Physical education was recognized by the mothers as a contributing factor to the maintenance of a healthy body weight and the long term prevention of obesity through engagement in a physically active lifestyle. The mothers also viewed physical education as beneficial to the development of social skills including friendship, a sense of belonging, and self-confidence.

The findings of this study were very much in accordance with the views expressed by others and give credence to the value of parent involvement in inclusive educational programming. The voice of these mothers adds to earlier voices of children with disabilities, teachers, and adapted physical activity professionals and scholars (e.g., Blinde & McCallister, 1998; Goodwin & Watkinson, 2000; Sherrill, 2004). The mothers also highlighted barriers to their children’s participation. The “participation barriers” of environment, safety, and instruction add to previously reported literature of barriers to participation expressed by students and teachers (Blinde & McCallister, 1998; Goodwin, 2001; Lieberman et al., 2002). The concern of dependency imposed through over reliance on an instructional assistance or the perception that their children required special programming through the implementation of the IEP process echoes what Goodwin (2001) referred to as self-threatening interactions, in a study focusing on the experiences of children with disabilities in physical education. The mothers of this study concurred with the experiences reported by children that help resulting in lost independence or was interfering was undesirable.

To counteract perceived limitations to school opportunities, the mothers created opportunities for their children to participate in sports outside of school and brought awareness of sports for individuals with disabilities to the schools. It is very unlikely the mothers of this study were familiar with Peters’ (1996) model of disablement and the important interventionist role they played by taking the knowledge they possessed about their children and applying it in concrete ways to support the implementation of their children’s physical education programs.
The mothers understood the importance of the knowledge they possessed and how it could be used to positively influence the educational programming of their children. They recognized the outsider’s perspective, which objectifies disability and classifies function through a medical model, did not tell the whole story of their children. They assumed an interventionist role to help school personnel and classmates see their children as more like than unlike other children.

The role of interventionist is often associated with rehabilitation practitioners, teachers, or teaching associates within the educational context. The experiences of these mothers suggest that mothers have a strong interventionist role to play as they complement the efforts of school personnel. The mothers provided disability information and instrumental support by locating sports equipment to enhance participation. The mothers most able to do this were those who had their children involved in community-based sport and hence possessed the requisite knowledge.

The mothers felt that participation in physical education could place their children in harm’s ways on occasion. More specifically, the mothers described lack of understanding of the disability and class size as contributing to unsafe environments. These findings were previously reported by Block and Horton (1996) and Downing and Rebollo (1999). Information on the impact of paralysis on circulation, bone strength, skin care, balance, strength, and physical sensation are all of direct relevance to participation in physical education and left mothers frustrated when their efforts to share this information were not acknowledged.

The need to establish links between disability observed (e.g., physicians), disability intervened upon (e.g., mothers, teachers, and teacher associates), and disability experienced (e.g., students) becomes very apparent. The need for open, respectful, and ongoing communication would appear to be fundamental to a positive educational experience for teachers, mothers, and students alike.

The mothers spoke of limited curriculum adaptations and knowledge of disability. Similar barriers have been reported for students with visual impairments (Lieberman et al., 2002). The mothers in this study felt that the adaptations were not always implemented although the importance of curriculum adaptation and modification to achieve success in inclusive physical education is well documented (Block, 2000).

The present study lends empirical support for the need for collaboration between home, school, and the sport community for individuals with disabilities. The mothers generously gave of their time and expertise to help others understand their children. In turn, the school personnel respected and listened to the mothers’ voices, thereby making their interventionist role within the school possible. The mothers indicated that the IEP process, although not specific to physical education, provided an opportunity to be heard. The mothers’ reports were similar to the findings of Melograno and Loovis (1991) who twenty years ago suggested the IEP did not assist teachers in day-to-day instruction or qualitatively affect the education of students with disabilities.

It is worthy of mention that the IEP of the children studied seldom addressed physical education. In fact, the form used has the heading “motor development” (i.e., fine or gross). The terminology reflects an outsider perspective that is situated within a medical model, not an educational framework. This may help explain why the importance of physical education may be overlooked by members of the IEP team.
The mothers recognized the value of physical education, but it would take a tremendously informed parent to make the link between the goals and objectives of physical education and the IEP heading of “motor development” (i.e., fine or gross). An outdated form could be reinforcing a medical model of disablement that encourages rehabilitation over a model that recognizes the interaction of impairment or disability with the environmental, social, and cognitive parameters of the educational setting.

In addition, the mothers recognized that teachers’ preparation received in teaching physical education to students with disabilities was in all likelihood minimal. This insightful observation has been reported previously (Goodwin, 2001; LaMaster et al., 1998; Lieberman et al., 2002; Suomi, Collier, & Brown, 2003). In response, some mothers took the initiative to support the teachers, and ultimately their children, by bringing knowledge of sport to the school. This was accomplished by arranging for in school sport demonstrations, locating and loaning special equipment (e.g., sit ski), and providing contact numbers for community program, and volunteering to accompany classes on outings. The mothers took on an interventionist perspective (Peters, 1996) that was founded on the similarities between children with and without disabilities, and not their differences. These mothers recognized the importance of physical education as a means by which to send this message.

The importance of tapping into the knowledge and support of mothers on the educational experience of teachers and children alike may have been under-recognized previously. The mothers in this study chose to be directly or indirectly involved in their children’s physical education programs. Not all mothers, however, have the prerequisite knowledge of physical activity or sport to be effective in this regard, and hence internal school resources may need to be utilized to locate needed resources and expertise.

It is clear that for an interventionist perspective to be welcomed in a school setting and not be seen as meddling or interfering with the educational process, a strong partnership between home and school is needed. Much of the literature on parents’ roles in the education of their children with disabilities suggests that although presumed to be equal partners, parents are often passive partners and primarily the recipients of school based planning and decision making (Salembier & Furney, 1997). This again, was not the case with the mothers of this study. The IEP was recognized to be the major source of communication between home and school. Consistent with the findings of Garriott et al. (2000) and Salembier et al. (1997), the mothers used the IEP process to explain their children’s disability, their children’s strengths and weaknesses, and their expectations for educational goals. The mothers also received information regarding their children’s performances.

The IEP process appeared to provide a structured mechanism that provided opportunities for mothers to have voice in their children’s education. The mothers also indicated, however, that the process was only meaningful if they chose to make it so and take advantage of the opportunity to not only receive information, but bring concerns and issues forward. Living with and raising a child with a disability meant the mothers had unique information and insights they felt were important to share with school personnel. They also used the IEP forum to bring a holistic view of their children forward to balance the perspective of disability as observed (i.e., outsider perspective; Peters, 1996), which can be deficit based. The mothers
of this study brought a strong interventionist perspective to the education of their children. Fortunately, there was a strong partnership between the homes and schools of the participants. This was fostered by open communication and the sharing of responsibilities toward a quality educational experience for their children.

The education of the students was not assumed to be the sole responsibility of the school. The mothers took responsibility for becoming involved and fostered collaboration among the school, the home, and the community. Implications from this study suggest that the IEP forms used need to be updated to reflect an educational model (e.g., physical education) and not a medical model (e.g., rehabilitation). The IEP should more closely reflect the physical education curriculum goals and objectives of physical education.

Disability awareness for school personnel and classmates is an ongoing need, and parents may be able to play an important role in identifying community resources (e.g., health district experts). Parents may also possess important information on specialized sports equipment for use by their children and have contacts with specialized sports organizations (e.g., Canadian Paraplegic Association, Wheelchair Sports Canada) for the purposes of class demonstrations. Teachers and instructional assistants are in need of support with curriculum adaptations. Parents who have had their children involved in sport may be able to bring a knowledge base to the instructional program that school personnel do not possess.

Families of children with disabilities have many priorities and are often stretched for time and energy. The families of this study demonstrated their willingness to be involved in their children’s educational programs, and this willingness was welcomed by the staff members of the respective schools. The IEP process, although much maligned, provided a structure for mothers to have input into the educational programming of their children. The forms that school districts use to guide the IEP process need to be modified, however, to reflect physical education curricular goals rather than therapy and/or rehabilitation goals. In doing so, the knowledge mothers possess about community programs, adapted equipment, and their child’s sport and community physical activity interests may be brought more closely into alignment.

References


