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"STANDING TALL": AN ANALYSIS OF PARENTS' EVALUATIONS OF A WALKER FOR CHILDREN WITH CEREBRAL PALSY

by

Jane-Anne Bradbury

A thesis submitted in conformity with the requirements for the degree of Master of Science Graduate Department of Nursing Science University of Toronto

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Abstract

This thesis is derived from a larger study which evaluated the effectiveness of a new walking aid for children with cerebral palsy and other disabilities (Wright, Belbin, Jutai, Bortolussi & McKeever, 1997). Qualitative data were collected through interviews with 19 parents of children who had been using the aid for one year. These data were analyzed in two stages. First, the interviews were summarized and major themes were identified. Although improvements in walking were not dramatic, findings indicated that the children had benefitted physically, psychologically and socially from the aid. Second, a theoretical analysis was conducted using Bourdieu’s concept of “habitus” or social position. Parents’ descriptions of the esthetic qualities of the walker, and changes in physical comportment and behaviour, revealed their perception that the children’s habitus had been altered positively as a result of using the aid. Implications for professional practice and future research are reviewed.
Dedication

This thesis is dedicated to children and youth with disabilities, and their families.

who are our greatest teachers.
Acknowledgments

Thanks to the principal investigators of the overall study, Ms. Virginia Wright and Mr. Greg Belbin, and to the other investigators, Mr. Mendal Slack, Dr. Jeffrey Jutai, Mr. Joe Bortolussi and Dr. Patricia McKeever. They were responsible for the development of the methodology and data collection, and their results are summarized in the background to this thesis. Thanks to the Easter Seal Society and to the Windsor Rotary Foundation for their funding of the overall study, and to Bloorview MacMillan Centre for their financial support of my graduate studies. Many thanks to my thesis advisor, Dr. Patricia McKeever, whose expertise in social science provided the foundation for this thesis. She patiently supported me through my learning, and has been a constant source of support and mentorship over several years. Many thanks as well to the members of my thesis committee, Ms. Jan Angus, Dr. Mickey Milner and Ms. Virginia Wright, who reviewed countless drafts, and continually challenged my thinking. Dr. Milner’s advice about how to make two plus two equal five has served me well. Thanks to Mr. Mendal Slack, who, as the coordinator of the overall study, provided me with invaluable assistance, to Ms. Denise Guerreire as the interviewer of the parents, and to Dr. Bonnie Stevens, as my fourth reader. Thanks to my colleagues who have so strongly supported research and ongoing education, including Ms. Sheila Jarvis, Mr. Bill Innis, Ms. Joan Ferguson, Mr. Ben Sybring, and Ms. Therese Fioravanti. Thanks to my family and friends, and especially to Mr. Glen Campbell. Finally, thanks to the therapists and orthotists who made this thesis possible, and most of all to the children and parents from whom I have learned so much.
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Chapter 1: Introduction and Background

The Hart Walker Orthosis is an aid developed in the United Kingdom in the late 1980s that encourages children with cerebral palsy (CP) and other disabilities who would normally use wheelchairs to stand and walk. The Hart Walker Orthosis (hereafter known as the walking aid or walker) differs from other walkers in that it suspends the child with a bracing mechanism around the pelvis to relieve the legs of most of the child’s weight, and allow the child to use his/her arms freely. A pilot study to evaluate the effectiveness of the walker using quantitative and qualitative measures was conducted by Wright, Belbin, Slack, Jutai, Bortolussi and McKeever (1997) in a large Canadian city. The qualitative data included interviews with parents of 19 children who had been using the walker for a year. Under McKeever’s supervision, I analysed the interview data from the study for this thesis.

I conducted the analysis in two stages. In the first stage, I summarized the answers to the interview questions and identified major themes. While quantitative data from the larger study indicated that children made modest measurable progress in their ability to take steps with the walking aid, analysis of the qualitative data revealed that parents evaluated the walker very positively. They identified many physical benefits of the walker. More surprisingly, they stressed non-physical benefits, including positive emotional effects, gains in development, and improved interactions with others. Enabling the children to stand and walk was of great importance to the parents. As well, it appeared that putting the children in a standing position and enabling some to walk functionally had a positive influence on the children’s social relationships. These findings are very important because people with disabilities are often viewed negatively by others and hold devalued positions in society.
With these findings in mind, we reviewed the literature to identify a suitable theoretical perspective to conduct a second stage analysis of the qualitative data. The work of the French social theorist Pierre Bourdieu was selected because it focuses on how people acquire social position or "habitus". Based on the hypothesis that use of the walker elevates the habitus of the children, I formulated questions focusing on how parents perceived that the walker had affected the children's behavior, self-image and social position.

In the remainder of this chapter, I will summarize the background to the thesis and summarizes the original study upon which this thesis is built. In Chapter 2, the theoretical framework and relevant literature are reviewed. Chapter 3 includes the method and findings. In Chapter 4, implications of the research for practice and further study are explored.

**Background**

The upright posture distinguishes humans from other living creatures (Straus, 1966). The shape and function of the human body are determined in almost every detail by and for this posture. The significance of upright posture is not confined to the technical problems of locomotion because it contains a psychological element. According to Straus (1966), uprightness "is pregnant with a meaning not exhausted by the physiological tasks of meeting the forces of gravity and maintaining equilibrium" (p. 137). He adds that uprightness leads to "a definite attitude toward the world; it is a specific mode of being-in-the-world" (p. 139).

Hence there is a correspondence between the human physique and the basic traits of human experience and behavior. Vision, hearing and language, for example, are all related to our orientation in the world as upright creatures (Straus, 1966). The ability to walk is highly valued universally and symbolizes health, vigour, independence, and autonomy. This is clearly reflected in metaphoric North American language. An "upright" person is one who is
considered righteous, honourable and honest. According to Straus (1966), "there are good reasons to assume that the term "upright" in its moral connotation is more than a mere allegory" (p. 137).

The upright posture is an indispensable condition of man's self-preservation. Yet for most people, walking from place to place is a taken-for-granted ability and a feature of everyday experience (Ryave & Schenkein, 1974). Although healthy people do not reflect on their ability to see or walk, disabilities of breath, sight, or gait "startle" them (Straus, 1966). Because upright posture is the lietmotiv in the formation of the human organism, individuals who lose or are deprived of the capacity to get up and keep themselves upright are seen to depend for survival on the aid of others. The inability to walk and other visible disabilities serve as cues which can negatively influence impressions that others form. These impressions can extend to include negative evaluations of personality and social characteristics that have no actual relationship with the disability (Gething, 1992). Hence, being unable to stand and walk after infancy can be profoundly stigmatizing.

Given the significance of walking, it is understandable why health professionals and parents seek to enable children and youth with disabilities to walk. For some people with disabilities and their families, this goal tends to persist indefinitely, regardless of the extent of the person's physical disability and psychological characteristics (Vogel and Lubicky, 1985). Walking aids have been shown to have both physiological and psychological benefits for people with disabilities. Potential physical benefits include promotion of bone growth, cardiovascular and musculoskeletal fitness, and prevention of disuse osteoporosis, contractures, pressure sores, and urinary tract stones and infections (Natvig & McAdam, 1978; Stuberg, 1992; Jaeger, Yarkony & Roth, 1989).
Walking and standing through the use of assistive devices may have important psychological advantages for children with disabilities. Anecdotally, walking aides have been shown to enhance children's ability to explore their environments and to interact with peers (Allison, 1980; Coghlan, Robinson, Newmarch & Jackson, 1980; Greiner, Czerniecki & Deitz, 1993; Myles, 1983; Natvig & McAdam, 1978). Children and their families tend to feel positively about having had the opportunity to try walkers, even when the children have very limited ability to move themselves around in them. As a result of trying to use aids, individuals and families often develop realistic goals related to walking (Vogel & Lubicky, 1995). The potential psychological benefits of walkers and other assistive devices must be weighed against the costs of the orthotics and training, and the limited ambulation that many clients are able to achieve (Vogel & Lubicky, 1995). Clinical anecdotal evidence suggests that although some children with disabilities mimic walking, they may have no intent or desire to walk. Other children may find it too exhausting to use the walker. The wishes of the children as well as those of the parents must be considered, and these may not always coincide.

Based on the modest measurable progress that children with severe disabilities made using this new walker for 12 months (Wright et al., 1997), many people have questioned the motivations of professionals and parents who continue to advocate wide dissemination of the walker. They have expressed the concern that professionals and parents may actually be meeting their own needs rather than acting in the children's best interests. As well, they may be capitulating to societal expectations that children with disabilities be "fixed" or normalized. It has been asserted increasingly in the literature of the past 25 years that the challenges of disability are more related to societal attitudes of non-acceptance rather than the disability itself. For example, Roush (1976) argues that the challenge of rehabilitation is not the
development of new technology and miracle drugs, but to overcome attitudinal barriers to social acceptance and barrier free environments. Similarly, Williams (1984) believes that successful rehabilitation is not just about restoration of lost function as the medical model suggests. Rather, "it should represent the intensification of the struggle of the person 'to become what he is'....To be midwife to this struggle, then, should be the central concern of rehabilitation." (p. 101). Arguably, focusing on the goals of standing and walking with use of the walker could be seen as hindering other areas of the children's development because of the time and energy involved. As well, it may prevent rehabilitation professionals and others in society from appreciating people who cannot stand or walk as they are, for the qualities they have. Added to this dilemma is the trend to allocate resources based on cost-benefit analyses. With increasing constraints on health budgets, many professionals, funding bodies and members of the public are asking for assurance that such devices are indeed benefitting the children.

Considering the above issues, the absence of research evaluating this or similar types of walkers, and strong consumer pressure to increase availability of the walker in Canada, it was very important that the walker be carefully evaluated. The need to assess physical, psychological and social effects requiring both qualitative and quantitative evaluation methods was recognized by Wright and her colleagues (1997), the designers of the overall study. Methodologists such as Bourdieu (1990) would support this approach because they highlight the limitations of measures and surveys in eliciting information about psychological and social effects that are not amenable to measurement, and advocate the use of qualitative as well as quantitative methods in developing an understanding of people and social life. The semi-structured interviews with parents of the children using the walker provided a means of
facilitating “authentic”, rather than predetermined responses (Fowler. 1996). This combined approach led to a more comprehensive understanding of the effectiveness of the walker.

The Walker

Information in this section is derived from the original study proposal (Belbin. Wright, Jutai, Bortolussi & McKeever. 1995). and the final report to the funding agency (Wright et al., 1997). The walker consists of a custom built orthosis that fits around the child’s pelvis/lower limbs and a wheeled frame. The child is placed in the brace which is secured in the wheeled frame using a posterior spring-loaded attachment. The brace optimizes lower extremity alignment, providing support and directional control. The support mechanism gives regulated weightbearing support and gait guidance. If the child gains strength and coordination and becomes more able to support his/her own weight, the support may be adjusted gradually to reduce the help being given.

The walker has significant advantages over wheelchairs and other types of walkers. It potentially enables many children with severe disabilities to stand upright and move independently who would not otherwise have this opportunity. It does not require the upper extremity strength or control required for use of other types of walkers. The weight relieving mechanism, directional control, and freedom of the child’s hands are significant advances in design. The walker is stable and tip resistant. It is also esthetically attractive, and available in brightly coloured frames. Finally, the shoes used while in the walker are fashionably designed and also brightly coloured.

The walker also has disadvantages. It is expensive and resource intensive in terms of therapist and orthotist involvement. It does not enable most users to walk independently. The walker can be difficult to use in the home because of its large size and the restrictions of
domestic rooms and doorways. As well, most children cannot move the walker over carpeted floors, which further restricts its use. The user must also be carefully supervised for safety as the walking aid is only stable on flat, smooth surfaces and children are at risk of falling over curbs and down stairs. Finally, although it is available in three sizes, the walker is not available in large sizes for older youths and adults because of the difficulty in providing stability.

The walker has been used for some time in the United Kingdom, but has not been used widely in other parts of the world. Prior to the investigation by Wright et al. (1997), its utility and effectiveness had not been evaluated systematically. The walker has received considerable attention in Canada from parents of children with special needs, rehabilitation professionals, and the media. There are over one hundred children on a waiting list for the walker, most of whom live in the province where the study was located.

The Original Study

In order to contextualize the research that will be presented in this thesis, the objectives, methods, and findings of the overall study will be described in this section. Most of this information was extracted from the final report by Wright et al. (1997). Comprehensive demographic information was not systematically collected for each child during the study. Some of the information in the section on description of the participants was obtained from the coordinator of the study who had direct knowledge of the participants, and from the health records of the clients.

Objectives and selection of participants. The objectives of the study were to evaluate the effectiveness of the walker in facilitating walking in previously non-ambulatory children with severe CP and to assess its clinical utility. Aspects of fine motor function, activities of daily living, and social function were also evaluated. The proposal for the study successfully
underwent scientific and ethical review. Using selection criteria listed in Appendix A, twenty children with cerebral palsy were selected from a list of 61 applicants on a waiting list for the walker. Of the 61 applicants, 13 did not meet the criteria. The remaining 46 children were assigned numbers using a random numbers table. They were then grouped in one of four geographic regions of the province/country (central, western, eastern and northern), and in one of two age groups (4 to 7 years, and 8 years and over. Applicants were selected using a random numbers table, ensuring the same representation by geographic region and age group as existed on the list of 46 qualifying children. The sample size was small due to the high costs associated with manufacturing the walking aids, as well as the time required for orthotists and therapists to monitor the children's progress and to adjust the aids frequently. The study was explained to the parents by a member of the research team. Parents were told that they could withdraw their children from the research at any time without penalty, and that they could keep the walker at the end of the study. Parents gave informed consent for participation in the study.

Design. A single group pre- and post-test prospective design was used. Children were fitted for the walker by an orthotist at a children's rehabilitation centre. The walker was to be used for 12 months in home, school, and therapy settings. Children attended a special clinic every 3 weeks for monitoring. Baseline assessment included evaluation of range of motion, upper and lower extremity tone, gross motor function, sitting, and developmental level. Evaluations were conducted at baseline, 2, 6, and 12 months. These included gait assessment, fine motor and functional assessment, adverse effects, documentation of the walker's use in the home, community and during therapy, parents' and therapists' satisfaction ratings, and tracking of orthotic adjustments required. Twelve of the parents completed the Paediatric Evaluation of Disability Inventory (PEDI) (Haley, Coster, Ludlow, Haltwanger & Andrellos, 1992), a
questionnaire that focused on the child's abilities in self-care, mobility, and social function domains, one month after beginning to use the walker and at the end of the year. The amount of time required for all of the initial assessments precluded the PEDI from being completed for the first eight families at the beginning of the study, although five of these families did complete the PEDI at the end of the study. Specific evaluations were made of functional skills and caregiver assistance needed. Details of the assessment measures, including reliability, can be reviewed in the study report by Wright et al. (1997). The interviews were conducted after the children had been using the walker for one year.

**Description of participants.** The baseline mean age of the children was 7.9 years, with a range from 4 to almost 13 years. Thirteen of the children were boys and 6 were girls. All of the children had quadriplegic cerebral palsy, with 17 having spastic CP and 2 the athetoid form. Seventeen of the children had had CP since birth. The children had varying levels of cognitive disability, and 13 were nonverbal. When the study began, 13 of the children were using, or had used in the past, some type of stander. Eleven children had had previous experience with the use of a conventional or hands-free walker, generally with little success. Seven children used electric wheelchairs, while the rest used manual wheelchairs or strollers. Three children had experience with adapted tricycles.

Most of the children had been born in the province where the study was conducted. Two had been born in other provinces, and 1 in the United States. All but 1 of the families were living in the province at the time of the study. Four of the families were living in the same city as the rehabilitation centre, and 3 others were living in other large cities. The other 11 families were living in small cities or rural areas. Nine lived 2 or more hours away by car. Of these, 2 lived more than 10 hours away, with 1 needing to fly in for appointments. Three
families were living in apartments, and the rest were living in houses. Most if not all of the houses were owned by the families.

The families all appeared to be of Anglo-Saxon or southern European descent. While they were not ethnорacially representative of families with children with disabilities in the city where the study was conducted, they were probably representative of such families with in the province. Two of the parents interviewed did not speak English fluently. According to the research coordinator and health record information, about 10 appeared to have middle incomes, 6 lower incomes, and 3 higher incomes. All but 1 of the families had 2 parents living at home, with only 1 family being a single parent family. All of the fathers were employed at the time of the study, but it is not known whether they were employed full time or part time. Eleven of the mothers were full time homemakers at the time of the study, with the other 8 employed full time or part time outside the home. Fourteen of the 19 families clearly identified other siblings in the interviews or other study data.

**Results.** The walking abilities of the children significantly improved over the 12 months. At 12 months, 11 of 20 children were able to use the walker to walk at least 30 metres. Eight of these children walked independently, while 3 needed some assistance to steer the walker. However, all required more than 120 seconds to complete 30 metres (compared to 20 to 30 seconds for children without disabilities). The other nine children walked less than 30 metres, although all of them could initiate steps in non-test situations. Nine children increased their weightbearing abilities by more than 10 percent during the study, but all still needed the support of the full orthosis at 12 months. Muscle tone remained unchanged, and no adverse incidents involving the walker were reported. Fine motor abilities were not different when performed in the walker than when performed in a wheelchair. Social Function Domain scores
on the PEDI improved, but this improvement was not statistically significant. The scores were consistent with parental reports of increased communication, participation and social interaction.

Parents' and teachers' weekly logs described walker use in terms of gross and fine motor, educational and social activities in various environments. Self-report satisfaction data were collected, but the results were not statistically significant. On satisfaction questionnaires with 10 cm linear rating scales ranging from "of no use" to "extremely useful". and rating scales ranging from 1 (poor) to 5 (excellent). parents gave the walker high ratings for overall utility (mean ≥8/10). On rating scales ranging from 1 (poor) to 5 (excellent) for specific items. the walking aid was given lower ratings for the ease of getting the child in and out of the brace and frame (5.9 and 5.5/10 respectively) and the children's ability to control the walker's direction and the associated impact on independence (7.4 and 5.4/10 respectively). Community therapists' comments (n=15) were generally positive: 80 percent rated the device as "definitely useful". Their specific concerns included problems with fit and pressure areas, gait deviations, upper extremity reactions, slow rate of progress, and challenges with functional use. The extensive time required to teach children to transfer weight and initiate steps without excessive trunk/upper extremity contribution, and the difficulties in learning directional control were noted for all children. All children completed the study and their parents planned to keep using the walkers.

Conclusions. Given the promising results from this pilot study, the researchers recommended manufacture and distribution of the walker to children with quadriplegic CP. They also suggested that the eligibility criteria that had been set for the pilot study could be used in the initial screening of the suitability of the walker for particular children. The most
important eligibility criteria for the walker appeared to be: 1) the child's ability to initiate 3 or 4 sequential steps on command when supported under the arms; 2) the presence of adequate hip and knee extension to permit fit of the brace (less than 20 degree contractures); 3) determination that the child's size was within the height and weight restrictions of the walker; and 4) confirmation by the community therapist(s) of the child's ability to follow along with the walker's therapy training program. The researchers recommended that additional research should include a randomized controlled trial, perhaps comparing the walker with other hands-free walkers and a cost-benefit analysis.
Chapter 2: Theoretical Perspective and Review of the Literature

Theoretical Perspective

For the past 20 years, one stream of disability literature has emphasized that the challenges of disability lie in societal attitudes, and has encouraged the use of sociological perspectives for related empirical research. According to this perspective, the evaluation of assistive devices such as walking aids requires an examination of how people with disabilities interact with others and are able to participate in society. People with disabilities have struggled to gain social status in society. They are a minority group, but differ from other minority groups such as ethno-racial groups in that they tend not to be raised by others with the same minority status (Zola, 1993). Pierre Bourdieu’s theoretical writings are consistent with this perspective. It was considered particularly well suited to the evaluation of the walker because it is impossible to separate the physical benefits of the walker from its psychological and social benefits. Furthermore, as discussed earlier, the upright posture is highly valued and metaphorically significant.

The work of Pierre Bourdieu was selected to guide the secondary analysis of the open-ended interview data. Pierre Bourdieu is a social theorist whose concept of “habitus”, or social status, builds on the work of Marx and Weber. Bourdieu’s theory positions people in social space according to their economic, social, and cultural characteristics, which he considers forms of capital. It is more elaborate than the work of Marx, whose concepts of capital and class were restricted to a system of economic ownership (Anheier, Gerhards & Romo, 1995). Weber introduced the concepts of symbolic capital and status honour. Although status honour and economic capital usually go hand in hand, this is not always the case. For example, priests usually have little economic status but high status honour. In contrast to the work of Marx and
Weber, which are both macrosociological. Bourdieu focuses more on microsocial relations, and the competition between individuals for hierarchical positions within particular strata or “fields” of society (Anheier et al., 1995).

I considered other perspectives and approaches. Fine and Asch (1988) indicate that notions of disability are often used to advance social theories rather than to advance knowledge of the experience of disability. Phenomenological approaches would be appropriate to increase understanding of the experience of using a walker from the perspective of the user. The parents were interviewed in the study, however, and a phenomenological approach would not have provided an analysis of the social dynamics believed to be highly relevant to the study. As well, the interviews had been conducted in a more structured format than a phenomenological approach would suggest. Among other social theories, Goffman’s (1968) work on stigma could have been chosen but was seen to be more limiting than that of Bourdieu. Goffman tends to lead the researcher to focus on the negative aspects of the interactions and relationships between people with disabilities and others. Increasingly, however, these interactions and relationships have been found to be complex and to encompass both positive and negative qualities. Cahill and Eggleston (1995) explain that “however natural it may be, referring to people with disabilities as stigmatized persons invites neglect of the situated complexity and variability of construction, preservation, spoilage, and restoration” (p. 682) of identity.

Bourdieu’s central concepts of field, habitus, capital and esthetics outlined in Logic of Practice (1990), and An Invitation to Reflexive Sociology (Bourdieu & Wacquant, 1992) were seen to be particularly relevant to the analysis of the interview data. Although these are intertwined and have reciprocal effects, each will be discussed in turn.
Field and habitus. According to Bourdieu, in highly differentiated societies the social cosmos is made up of a number of relatively autonomous microcosms, called “fields”. Each field has its own logic, or “rules of the game”, and demands specific behaviours from the people who occupy it. Within fields, people compete for social positions, and this competition gives rise to social structure by positioning people according to the amount of economic and other forms of capital (e.g. appearance, talent) that they possess. Children may inhabit several fields - peer group, school, family, community, etc., and may be strongly socialized into them. Indeed, one enters a particular field by birth, or by “a slow process of co-option and initiation which is equivalent to a second birth” (Bourdieu, 1990, p. 68), as would be the case, for example, in the process of becoming a gymnast, musician, or health professional.

Habitus refers to the conditionings associated with a particular position within a field. These conditionings are internalized, deeply rooted and unconscious, reflecting the influence of the collective past. A person’s habitus leads him/her to form hypotheses or predictions about future events based on past experiences and events. Present experience and events further contribute to the structure of the habitus. While all experiences have an impact on the habitus, the experiences of childhood contribute heavily to the adult habitus. A person’s habitus will lead him or her to seek out experiences, information, and things that are consistent and comfortable with his or her habitus, rather than those that are different and challenging. In other words, people come to “know their place”, and to feel comfortable with others of the same rank. This seeking out and finding one’s place, as well as choosing things and behaviours, reflect the unconscious drives of the habitus. People come to want what they are expected to want within a particular habitus. One’s goals tend to reflect and be consistent with
an accurate reading of one's "life chances". This allows the social order to run smoothly.

Bourdieu (1990) explains:

[The habitus] ensures the active presence of past experiences, which, deposited in each organism in the form of schemes of perception, thought and action, tend to guarantee the 'correctness' of practices and their constancy over time, more reliably than all formal rules and explicit norms. (p. 54)

Because groups of people who share a habitus make similar choices in regards to such things as where they live and what they wear, the habitus is remarkably stable, resistant to change and self-perpetuating. Children learn their social "place" or habitus at an early age and come to want what is expected of them in relation to their social standing. The social mechanisms that ensure the production of a particular habitus are an integral part of the conditions of reproduction of the social order (Bourdieu, 1990). While there are individual differences within a habitus, these tend to be differences on a common structural scheme, reflected as variations in personal style within a particular habitus, as opposed to a different habitus altogether.

Bourdieu would agree that in most parts of the Western world, people with disabilities incorporate a habitus that reflects their low status in the social hierarchy. Disabilities often have visible distinguishing features that signify little symbolic capital and ultimately lead to the lowly positioning in various fields. Wheelchairs are particularly potent icons that signify negative differences and dependence (McKeever & Angus, 1995). According to Bourdieu (1989), such icons signify social distinction and shape how their bearers are perceived and treated, and how they see themselves. "Wheelchair users are literally and figuratively unable to stand up for themselves and hence are the antithesis of the culturally ideal of the 'upright, autonomous, independent, self-sufficient citizen'(McKeever & Angus, 1995, p. 4)." Unless
compensated for by extensive capital in other realms (e.g. economic wealth), most children with disabilities acquire a habitus that reflects the low societal positioning of people with disabilities. They experience a “present past that perpetuates itself into the future by reactivation in similarly structured practices” (Bourdieu, 1990, p. 54), meaning that the way they define themselves is affected by their early experiences as people with disabilities, as well as other social factors such as the importance of being upright and mobile.

**Capital.** Bourdieu argues that various forms of capital confer power and status, and hence determine habitus. He describes three different types of “capital” that individuals can have in society. Economic capital is the first of these, and is related to an individual’s material resources or assets. Higher economic power is generally equated with higher habitus. The second is cultural capital, which exists in several forms. It includes long-standing dispositions and tastes acquired through the socialization process such as formal educational qualifications and training, and the accumulation of valued cultural objects (Anheier et al., 1995). For example, university professors would be seen to have a considerable cultural power in the western world. A distinction is also made between “incorporated” cultural capital that takes the form of education and knowledge, and “symbolic” cultural capital, possessed by celebrity figures, which refers to the capacity to define and legitimize values, standards and styles (Anheier et al., 1995). Finally, social capital is the sum of the actual and potential resources that can be mobilized through physical attractiveness and membership in social networks and organizations (Anheier et al., 1995). Christopher Reeves is a good example of a person who has used the social capital that he acquired as a movie star to positively affect the status of people with quadriplegia and to stimulate investment in spinal cord research.
Bourdieu emphasizes the importance of personal taste or sense of esthetics in defining membership in a social class or habitus. Group and individual tastes or esthetics are seen as important in expressing and defining both cultural and economic power, and set a stage for negotiation and jockeying for position in social fields. People "read" and "place" each other according to outward appearance and accoutrements. Taste is represented in the things that people choose, such as first names for children, types of food, clothes, cars, and hairstyles. Bourdieu believes that taste reflects or is based on collective norms within a particular social group or shared habitus. Thus "good" taste, rather than being universal as some sociologists have theorized, is very much defined by the particular group into which a person has been socialized. What is considered "appropriate" will differ significantly between various social groups. Reflections of taste are thus observable indicators of class and habitus. Regardless of the social position of the observer, however, there is a common notion of what constitutes "good" taste in many areas, usually related to the tastes of the dominant economic social class. Things considered tasteful or of "good taste" reflect forms of symbolic capital as do things of "bad taste", because they locate people and open or close up possibilities for interaction.

Appearance is thus an important indicator of social standing or habitus, according to Bourdieu. How one appears (e.g. in relation to clothes, hairstyle, etc.) and sounds (e.g. in use of language, dialect, presence of accent, etc.) influence how one's social status is perceived. As has been discussed, people with severe disabilities occupy a low "standing" or habitus in society. Wheelchairs and crutches are highly visible icons that have historically been associated with dependence, often evoking pity. Cumbersome wheelchairs, crutches, walkers and leg braces, clunky dark shoes, and items such as bibs, hearing aids, and thick lensed glasses are items that imply and contribute to definition of membership in a marginalized or
stigmatized group and reinforce a lowly habitus. These assistive devices have tended to focus on function and have not consistently been updated in terms of style. They are not generally considered "tasteful" aids in comparison to, for example, something like designer eyewear.

Bourdieu would argue that low habitus can be elevated through accumulating things representing higher standings. Things that are esthetically pleasing and reflecting "good" taste i.e. higher status. Fashionable looking wheelchairs, walkers, splints and shoes in popular shades of colour and black, as well as the European styling that is highly valued by North Americans, convey that the user was obviously "worth" the expenditure on such esthetically pleasing items. In our society, "high" tech gadgets such as electric wheelchairs and computerized equipment are forms of valued symbolic capital and may also elevate the habitus of the person with the disability by improving the person's appearance in social terms.

Esthetics and taste link the macro and micro aspects of Bourdieu's theory through the body by its adornment. The body provides individuals with a way of presenting the self and relating to the social world, and announces one's place or habitus. The body bears the physical attributes or "distinctions" that we are born with or that we adorn ourselves with for functional or esthetic reasons. Therefore, the body and social habitus are linked and are mutually constituting.

**Body comportment.** Body comportment in this study refers to bearing or carriage in the physical sense. People's relation to their bodies is a fundamental dimension of the habitus and is inseparable from a relation to language and to time. Bourdieu (1990) explains that habitus cannot be reduced to a "body image" or even "body concept" which are subjective representations of one's own body reinforced by the feedback of others. The process of acquisition and reproduction of habitus tend to take place below the level of consciousness.
“The body *enacts* the past, bringing it back to life.” (Bourdieu, 1990, p. 73). The body is not something that one has, but something that one is. The physical body is therefore central to the concept of habitus. With our bodies, we unconsciously act on our historically developed perceptions of our place among social relations and structures.

Bourdieu extends the phenomenological work of Straus regarding uprightness and helps us to understand the meaning of standing and walking in social terms of a dominant (high) or submissive (low) habitus. He states that “the opposition between the straight and the bent...is central to most of the marks of respect or contempt...in many societies to symbolize relations of domination.” (Bourdieu, 1990, p. 72). Men who are taller often enjoy higher social status or elevated habitus. For example, most American presidents have been tall men. Many words that refer to bodily postures evoke virtues and states of mind (Bourdieu, 1990, p. 70). For example, the expressions “standing up and looking someone in the eye”, “standing tall”, “standing up to someone”, “taking a stand”, “standing on your own two feet”, and “holding your head up high” are metaphors that associate standing with the qualities of assertiveness and the ability to defend oneself and one’s interests (i.e. dominance).

Common cultural phrases such as “standing on your own two feet”, besides conveying assertiveness, convey achievement of adulthood and maturity. The saying “back on your feet” refers to overcoming a major obstacle. These are things that, in the literal sense, are impossible for many children with disabilities to achieve. Metaphorically, one’s standing also refers to status and reputation e.g. “someone’s standing in the community” or “upstanding citizen”, conveying honesty and determination. Use of the term “standing” can also convey ranking, as in the case of the expression “standing in one’s class”. The adjective “good” is often used to describe academic standing. If one is not in “good standing”, one is presumed to be failing, or
to have some type of probationary status. The term “upright” also has huge symbolic meaning referring to honesty and good character. While “standing” is used more in the contexts of assertiveness and ranking, “upright” conveys honesty and morality as in the expression “upright citizen”. Finally the word “straight” has additional meanings of wholesomeness and heterosexuality.

In contrast to the above, “not having a leg to stand on” conveys a position that is not well supported by evidence. “Taking it lying down” conveys weakness, lack of assertiveness, submissiveness and dependence, while “laying low” refers to avoidance and “low” alone may imply despicable behaviour. Terms such as “crooked”, “bent”, “twisted”, and “screwed up” have literal meanings related to lack of straightness, but also have metaphorical meanings conveying lack of honesty or mental stability when they refer to character. “Falling”, besides its literal meaning, also has symbolic meanings related to loss of social status, as in “falling from grace”. Language is thus fundamental to the process of constituting things and defining positions (Fowler, 1996). Bourdieu argues that symbolic meanings are used to perpetuate habitus structures. Hence, “socialization instils a sense of equivalence between physical space and social space and between movements (rising, falling, etc.) in the two spaces and thereby roots the most fundamental structures of the group in the primary experience of the body” (Bourdieu, 1990, p. 71).

Positions and movements of the body are socially qualified and influence a person’s habitus (Bourdieu, 1990). People with severe physical disabilities tend to occupy low positions in physical space when in wheelchairs, crawling on the floor, lying in a bed or on the floor. People with severe disabilities often appear stooped, with head down and eyes downcast. They are often bent over in their wheelchairs, or hunched over in traditional walkers due to poor
muscular control and/or poor seating. They have to “look up” to others, both literally and metaphorically. This physical positioning reflects the social position or habitus people with disabilities have in contemporary society. As a group, they occupy an inferior social status that is consistent with their low physical status. The low physical status of individuals thus continues to reinforce their lowly social status, as part of their habitus. Wheelchairs are often positioned away from others, out of the way or in separate sections that may be wheelchair accessible, but are physically separate. Thus, wheelchairs can act as barriers to both physical entry and social inclusion.

Critique of Bourdieu. Critiques of Bourdieu’s work focus on the lack of empirical support for his theories. (Anheimer, Gerhards & Romo, 1995). In one of the only studies attempting to test Bourdieu’s theories, Anheimer, Gerhards and Romo (1994) tested the assumption that people are positioned in a “topography” of social relationships according to their endowments of economic, social, and cultural capital. Data about German writers were analyzed to identify a social structure in which positions vary according to the types and amounts of capital each had accumulated. The researchers found that Bourdieu’s theory was helpful in understanding the social positioning of German writers. A strong split between elite and marginal writers was found to dominate the social structure, with significant differences in both cultural and social capital distinguishing elite from non-elite positions. Within this bipartition, pronounced differences were found to separate high and low culture.

Bourdieu has been criticized for creating a perception that people are restricted to their social circumstances. In other words, people’s positionings are determined to a high degree by structured factors which “locate” people and in which people tend to feel they belong. Bourdieu posits that through socialization processes, people come to expect their “lot in life”
and hence social positioning is resistant to change. However, he also argues that it is possible to move up or down in the social hierarchy, and that understanding of these dynamics makes social change more likely to take place.

In summary, uprightness and independent mobility are forms of capital that able-bodied people take for granted. Considering the importance of being upright and the negative association with using a wheelchair, enabling children to stand and thereby increase their distance from the ground, as well as facilitating autonomous movement, may elevate their habitus. I hypothesized that the standing, walking and social benefits of the walker, together with its esthetic qualities, may increase the habitus of children with disabilities.

Research questions. The following questions were used to guide the analysis of the interview data:

• How did the parents and others describe and respond to the walker?
• How did the walker affect perceptions of the body comportment of the children?
• How did the walker appear to influence the child's behaviour and sense of self?
• How did the walker affect the habitus of the child?

Review of the Literature

No research was found on the social and psychological significance of walker use in children with disabilities. Other areas of study considered pertinent included research related to the onset of walking in infants, the benefits of standing and walking for people with disabilities, the benefits and drawbacks of powered mobility, and attitudes toward people with disabilities. The literature pertaining to each of these areas will be reviewed in turn.
Onset of walking and its effects in infants without disabilities. The literature on general infant development was reviewed to understand what happens when children stand and walk for the first time. Cognitive psychologists and therapists such as Acredolo (1988), Gibson (1988), Hay (1986), Gustafson (1984), Lewis and Feiring (1981), Piaget and Inhelder (1956) and Piaget (1978) cite independent mobility as a key to exploration and cognitive and social growth. According to Gibson (1988):

A kind of cognitive revolution must result when an infant’s horizons are expanded by acquisition of self-initiated, self-controlled locomotion... A new kind of activity that is both exploratory and performatory becomes available for learning about the larger world.” (p. 27)

Clinicians have anecdotally reported that the onset of walking engenders an enhancement of emotional expression in infants (Acredolo, 1988: Biringen, Emde, Campos & Appelbaum, 1995), but little empirical evidence exists on the subject. In a naturalistic home study by Biringen et al. (1995) involving 46 mother and infant dyads, “earlier” and “later” walking groups were delineated on the basis of when this developmental transition occurred. Age-held constant analyses indicated that earlier walkers and their mothers generally showed a rise in positive exchanges as well as “testing of wills” across the transition to walking. Although these changes were less clear for the later walkers, differences in interactions had been observed between the two groups even prior to walking, making the actual impact of walking difficult to ascertain.

An older set of studies relevant to this issue by Gustafson (1984) documented precisely how the ability to locomote changes the way children interact with the environment. In these studies three groups of six and a half to ten month old infants were compared as they explored a
laboratory space containing toys and their mother. The results showed quite clearly that the capacity for self-movement altered infants' experiences in dramatic ways. Mobile infants covered more distance, played with more toys, and attended to a wider variety of environmental stimuli than their non-mobile peers. Thus, the assumption that mobility widens children's experience of spatial features and perspectives was upheld. In addition, the mobile infants spent more time approaching, looking at, smiling at, and vocalizing to the people in the room. In fact, Gustafson concluded that a major impact of self-produced locomotion on infants lies in the more active role it allows them in patterning their social interaction.

It appears that children learn new words and new usages as their repertoire of spatial concepts expands (Johnston, 1988). According to Johnston (1988), at least three studies (Halpern, Corrigan & Aviezer, 1988; Levine & Carey, 1988; and Johnston, 1979) have compared children's performance on related nonverbal and verbal tasks and have found that success on the nonverbal problem preceded verbal proficiency. Since these studies relate to normal child development, they have questionable relevance to children who have disabilities. No literature was found that addressed the impact on spatial orientation or language skills when children do not begin to walk at the expected developmental age.

Benefits of standing and mobility for people with disabilities. Although many researchers and authors have hypothesized that standing and walking benefit people with disabilities, little research on the physical, psychological or social benefits exists. In a review of the scientific basis for standing programs, Stuberg (1992) concluded that daily periods (i.e. at least 60 minutes per day) of standing may have a positive effect on bone development and reduce the incidence and extent of soft tissue contractures in children with developmental disabilities. Active participation from the child was recommended to increase strain on the
bone through muscle activity. Greiner, Czerniecki and Deitz (1993) compared the effects of posterior and anterior walkers on the gait parameters of five children with spastic diplegia. The posterior walker was found to have a more positive effect on upright posture and walking velocity than the anterior walker. Both children and parents preferred the posterior walker, and parents reported that children walked more normally in the posterior than in the anterior walker. There are anecdotal reports that the use of walkers positively influences the ability of children with spastic diplegia to explore their environment and to interact with peers (Allison, 1980; Myles, 1983), but these effects have not been measured. A number of studies were found that researched predictors of ambulation in specific client populations (Hoffer, Feiwell, Perry, Perry & Bonnett, 1973; Hussey & Stauffer, 1973; Vogel & Lubicky, 1995; Natvig & McAdam, 1978; Yarkony & Roth, 1989). While reference was often made to psychological and social benefits of ambulation, these benefits were not measured.

The electric wheelchair is an assistive device that enables many children with moderate and severe disabilities to move themselves through the environment. It is used by a growing number of children, and research on its use is increasing. Pope, Bowes & Booth (1994) monitored the patterns of use of powered mobility in nine children with spastic cerebral palsy. In each of the three years of the study, the children were observed and parents were interviewed about the chairs. The children spent from 0.3 to 12 hours per day in their chairs depending on the children's health, the need for repairs, and problems with transporting the chair. Three children used the chair in school only, one used it in the home, and five used their chairs in both home and school.

Berry, McLaurin & Sparling (1996) examined the use of power wheelchairs by children with developmental disabilities who were otherwise completely dependent on their caregivers
for mobility. Thirty-six caregivers of children were interviewed to determine frequency of use and caregiver perception regarding power chairs. The chairs were used by 57\% of the children both at school and home, and by another 35\% primarily at school, whereas 9\% seldom used their power chair. Environmental limitations and barriers may have resulted in decreased use of the chairs.

In research involving adults, Miles-Tapping and MacDonald (1994) interviewed 11 users of power chairs and scooters aged 35 to 85 about their experiences. The participants reported problems with restricted environments which made use of the chairs difficult in many homes, but generally they felt the power chairs enhanced their leisure time and increased their productivity. Kohn, LeBlanc & Mortola (1994) documented user satisfaction and follow up data for 103 adults using electric wheelchairs and scooters. After seven months, 93\% were still using their power chairs for at least nine hours per day. However, 57\% reported their chair had needed repairs within that time span. Dudley and McMahon (1993) examined use of power chairs intended only for outdoor use among 34 subjects ages 25 to 89 years. Use of the chairs ranged from three times a week by some to not at all by others. Reasons for not using the chairs included the weight of the chair and difficulty negotiating curbs and steps. Phillips and Zhao (1993) surveyed 227 participants to determine why electric wheelchair and scooter users decided to use or not use their devices. Factors found to be significantly related to not using the device included lack of consideration of user opinion in selection, and poor device performance.

Charlene Butler conducted several studies on use of motorized wheelchairs by young children with disabilities. In two studies (Butler, 1983; Butler, 1984) involving between nine and 13 children each, she reported that children with physical disabilities as young as 24
months could learn to drive motorized wheelchairs (Butler, 1984). In these studies, parents
anecdotally reported that the independent mobility stimulated the children’s social, emotional
and intellectual behaviour. In a later study, Butler (1986) measured the effects of powered
mobility on self-initiated behaviours of six children between 23 and 38 months of age. Two-
hour observation periods were videorecorded before and after they achieved independent
mobility. Frequency of self-initiated interaction with objects, spatial exploration and
communication with care-givers were analyzed. Three children increased all three types of
behaviour: one increased in spatial exploration and communication, but decreased in interaction
with objects; and two increased in spatial exploration only. This was the only study found that
attempted to document changes in behaviour as a result of use of powered mobility. Verburg
(1996) reported on an informal study done in 1987 which demonstrated potential gains in
developmental level for some individuals with significant cognitive disabilities who began to
use electric wheelchairs operated with switches and stimulus lights.

**Attitudes toward people with disabilities.** While no research was identified about public
attitudes toward particular therapeutic devices, research about attitudes toward people with
disabilities was considered pertinent to this study. In a field project on oral narratives, Phillips
(1990) documented personal experience stories from 33 persons with visible, physical
disabilities. Three cultural notions about disability dominated the narratives: (1) that society
perceives people with disabilities to be damaged, defective, and less socially “marketable” than
people without disabilities; (2) that society believes people with disabilities must try harder to
overcome obstacles in culture and should strive to achieve normality; and (3) that society
attributes to people with disabilities a preference to be with their own kind (Phillips, 1990).
A secondary analysis was conducted on these data related to the notion of people with disabilities as "damaged goods". The narratives illustrated the prevalence in the popular media of language and images which perpetuate the notion of defectiveness of persons with disabilities. Secondly, they note the underlying message, imbedded in both the medical and rehabilitation models, of the essential "wrongness" of their bodies. Thirdly, they affirm the transformational and liberating effects on their self-images of those philosophies which demonstrated not their deviance, but their social minority status, and which strongly disavow the status-quo notion of disabled-as-damaged-goods. Phillips (1990) concluded that popular American notions about disability frame social interactions between people with and without disabilities, that these interactions affect the self-images of people with disabilities, and that the predictability of such interactions constitutes an experience of people with disabilities that may be uniform across American culture.

Cahill and Eggleston (1995) used ethnographic methods to study the public experiences of 13 wheelchair users. Their analysis focused on the encounters in which wheelchair users requested and received various forms of assistance. Findings indicated that wheelchair users regularly had experiences that were at the same time positive and negative, accepting and rejecting. Accepting and helpful behaviours were often demonstrated, but wheelchair users are still "made to feel like visitors who are dependent on the graciousness of their walking hosts" (Cahill & Eggleston, 1995, p. 694). They make use of Candace Clark's (1990) notion of "place", which is similar to Bourdieu's habitus, and hypothesized that "every time wheelchair users request assistance, they mark their place as subordinately dependent petitioners. Every time walkers offer or grant a wheelchair user assistance, they mark their place as superordinately capable and gracious benefactors" (Cahill & Eggleson, 1995, p. 694). The
authors concluded that the wheelchair user’s place in public life is “uncertain and unsettled” and less predictable than concepts of deviance and stigma would suggest.

Gething (1992) studied the attitudes of health professionals toward people with disabilities. A sample of 636 trainee and practising health professionals made semantic differential ratings of a job applicant observed in a videotaped interview. Twelve parallel videos were produced in which disability (use of a wheelchair), gender, and manner of behaviour (shy-neutral-brash) of the applicant were varied. Analyses of variance revealed significant main effects for each independent variable. Interaction effects were limited. Further analyses of the ratings indicated that respondents devalued applicants with disabilities because presence of the wheelchair negatively influenced judgements about social and psychological adjustment and about general competence and capability. Gething’s (1992) review of the literature indicated that two variables have crucial effects on attitudes: amount of accurate information about and level of prior contact a person has had with people with disabilities (Wright, 1983; Casey, 1978; Evans, 1979; Crisp, 1987). While this study’s results would appear to contradict previous findings, Gething also notes that previous research suggests that certain types of contact are more effective in promoting positive attitudes. Effective interaction tends to be on an equal-status level where the people with and without disabilities are of approximately the same age, social, education and vocational status. It is perceived as voluntary and mutually rewarding from the perspectives of the people with and without disabilities, and enables the people with disabilities to present themselves as capable, multifaceted, and having aspirations as well as limitations (Goffman, 1968; Crisp, 1987). Gething (1993) indicated that such features rarely characterize the relationships between rehabilitation
professionals, who are placed in helper roles, with the focus on the problems of the person with the disability.

In summary, the review of the literature revealed that little research has been conducted that addresses the benefits of walking aids and other assistive devices, especially the psychological and social effects. Research suggests that walking stimulates the social and psychological development of infants without disabilities. Other research demonstrated that walking with assistive devices has physical benefits for people with disabilities, and that use of powered mobility may enhance the psychosocial development of young children. It was found that attitudes towards people with disabilities are often negative, and that public encounters between people using wheelchairs and others tend to reinforce differences in social status. The available empirical evidence is consistent with Bourdieu's theory, supporting the interdependence of physical, social and psychological elements of the self. It also illustrates the complex issues related to social status that affect the relationships and encounters between people with disabilities and others.
Chapter 3: Method and Findings of the Qualitative Analysis

Method

As part of the original study, a semi-structured interview was developed by McKeever and Angus to elicit descriptions in parents' own words about physical, psychological, developmental and social changes in children's abilities since the introduction of the walker. The schedule of questions had been developed after two field trips to the centre to observe children using the walkers, review videotaped assessments, and interview therapists involved in the program. The interview questions focused on the parents' expectations of the walker and whether these expectation had been met, children's use of the walker, and the outcomes of using the walker, including changes, benefits and drawbacks. (The schedule of questions is included as Appendix B.)

The interviews were conducted by a nurse graduate student who had not been otherwise involved in the study, or in providing services to the children. They occurred approximately 12 months after the children had begun to use the walkers. An information sheet about this aspect of the study was presented to parents at the beginning of the interview and a separate informed consent was obtained. The interviewer followed a schedule of open ended questions and prompts. She also explored spontaneous comments raised by the parents during the interview.

Data collection. In total, 19 interviews were completed. Twenty families were enrolled in the original study, but arrangements could not be made to interview one family. The interviews took place in a private room at the rehabilitation centre in 1996, and were audiotaped. Most were held while the child was in a clinic at the centre and lasted about one hour. Some were completed in as little as 30 minutes because of time constraints of the parents. Thirteen of the interviews were conducted with mothers and five with fathers. One
interview involved both parents and a child user of the walker participated to a very limited extent in another. The audiorecorded interviews were transcribed verbatim by an independent typist. One interview was marred through poor audio recording, making many words and sentences inaudible. Another interview tape had been misplaced, forcing me to rely on the transcribed text of the interview. Field notes taken by the interviewer included descriptive information about the participants, the length and location of the interview, and other observations. Device rating forms completed by the parents, and activity/device use log books filled out by parents, teachers and therapists were other sources of data that I reviewed.

Data analysis. I used an iterative method involving first and second stages to analyze the interview data. The first stage involved a content analysis answering the research questions, while the second stage was a theoretically oriented analysis. I used an approach described by Crabtree and Miller (1992) that involves the systematic arrangement and coding of data from narratives in a series of progressively more abstract and interpretive steps. First, I summarized each interview transcript in order to obtain a general sense of each case as a whole and to identify tentative themes. I organized transcripts and document files for each participant. I listened to each tape, and then read and coded the transcription. I then compiled a summary of each interview based on the list of interview questions. Each summary included direct quotations to illustrate main points. As participants had often changed topics in their answers to the interviewer’s questions, I regrouped the data to correspond to the interview questions. I determined the numbers of particular types of responses and identified major themes arising from the data. I made every effort to highlight divergent responses because of the small sample size.
After major themes had been identified, I reviewed the Device Rating Forms that had been filled in by the parents. This review confirmed that the information given by parents during the interviews was consistent with that filled out on the Rating Forms. Excerpts from the log books were also reviewed. These had been filled out by parents, physiotherapists, and teachers. Again, it was found that information related by parents during the interviews was consistent with that documented in the logs books. The information conveyed during the interviews was richer, more detailed and focused more on the non-physical aspects of using the walker.

The next step of analysis described by Crabtree and Miller (1992) consists of the identification or ‘coding’ of specific phrases in each narrative. The arrangement of topics in the interview schedule was used to guide the development of a system of codes and subsequent identification of noteworthy statements within each transcript. All of the responses to each interview question were then analyzed for major themes. In conjunction with identification of phrases, I recorded my observations about these phrases. At this point, the notations were related to the specific narrative in question and not to its relationship with other narratives, but they served as memos which were subsequently compared across interviews at the next stage of analysis.

The second stage was a theoretical analysis involving the search for organizing relationships, contradictions, and similarities (Hammersley & Atkinson, 1983). The summaries and full texts of the interviews were reviewed again, with an orientation based on the work of Bourdieu as discussed in Chapter 2.

Methodological rigour. Plummer (1983) outlines factors that affect the validity and quality of qualitative research arising from the interview process. These are related to the
participant, the interviewer, and the interviewer-researcher interaction. The parents in this study had been assured that as part of their agreement to participate in the study, they could keep the walker upon its completion or if they withdrew. This may have reduced the potential for bias toward positive responses if parents had feared that the walkers might be taken away if they evaluated the effects of the walker negatively, or if the children did not demonstrate sufficient progress according to the quantitative measures. Responses may have also been positively biased, however, if study parents feared that other children would not have access to the walker in future if the results were negative. In relation to the interviewer, prejudices, assumptions, theoretical perspectives, demographic characteristics and mood may reduce validity. If the interviewer had a previously established positive view of the benefits of the walker, she may have influenced the responses of participants in a positive direction. In this study such bias is unlikely as the interviewer had no vested interest in, or prior involvement with the walker or the study.

In the interaction between researcher and participant, the physical setting, prior interaction, and communication patterns may be sources of bias. Conducting the interviews at the rehabilitation centre may have increased the tendency of participants to give positive responses for fear of negative repercussions. Despite reassurances to the contrary, they may have feared negative effects on accessibility or quality of services at the rehabilitation centre. The potential for this was reduced by conducting the interviews in a private room, and by the assurances of the researcher and interviewer prior to the participant’s agreement to participate that they could withdraw at any time with no negative effects on services, and that confidentiality and anonymity would be maintained. As well, the interviewer was independent and not involved in service provision to the clients. Finally, the semi-structured framework of
the interview ensured consistency in the interviewer's approach between participants. Location of the interviews at the centre at the time of the clinic may have elicited more negative responses in some areas, especially related to the challenges associated with travelling to the centre from out of town to participate in the study.

Plummer (1983) recommends the review of findings by participants, study of pertinent records, and comparison between informants as appropriate validity checks. In this study, log books were reviewed to assess consistency of client responses in two different mediums at two points in time. Discussions had also taken place between the interviewer and the principal investigator throughout the qualitative data collection to share impressions of the interviews and the continuing data analysis. It was not possible to do informant checks due to the time and financial constraints of the study. To enhance validity, triangulation is also recommended. Triangulation involves use of multiple data sources, methods, and theoretical schemes to identify counterpatterns as well as convergences in the data (Lather, 1986). In this study, a number of sources of data were reviewed and compared. These included all of the Device Rating Forms completed by the parents, as well as parent, teacher and therapist log books entries for six of the children. The qualitative data were also compared to the functional measures.

Regarding the question of internal generalizability of findings, an account may miss aspects of the person's perspectives that were not expressed in the interview. This can easily lead to false inferences about his or her actions outside the interview situation (Maxwell, 1992). While only one interview was held with each of the 19 participants, and some of these interviews were slightly rushed because of the parent's need to pick the child up after his/her clinic visit, completion of the Device Rating Form helped to assess the consistency of views
over time. As well, the final unstructured interview question asking for other comments was helpful in ensuring that the participant had the opportunity to share all of his/her views.

External generalizability refers to the extent to which findings are applicable to children beyond those involved in the study. Because the children in the study were on a waiting list for the walker, their parents initially may have had more positive views about the walker than parents who did not know about the walker, or those who knew about the walker, but had not chosen to put their children on the waiting list. As the interviews were held after one year of use, however, one can presume that any initial positive feelings would have worn off if actual experience with the walker had been negative.

Limitations of approach. The fact that I had not been involved in the interviewing was a limitation that was reduced to some extent by the fact that I listened to each of the audiotapes. Furthermore, the analysis of data by an individual who had not been involved in the interviews allowed for different insights and potentially reduced bias. Like the interviewer, I had no vested interest in a particular result of the study. Other limitations included the small sample size and the fact that sampling involved a random selection of children whose parents had expressed positive interest in the walker and had put their children on a waiting list. As well, due to budget constraints, the children were neither observed using the walker in natural settings nor interviewed. In almost all cases only one parent was interviewed, and the siblings were not involved. Finally, only one fairly short (one hour) interview was conducted with each family, and the interviews were sometimes rushed.

Findings of First Stage of Analysis

This section contains a summary of the findings of the first stage, or content analysis. (For a detailed report, please see Appendix C.)
Expectations. Most parents recalled having fairly modest expectations going into the study. Most parents wanted their children to experience standing, and to have the opportunity to try to take steps. Two thirds of the parents indicated that their expectations had been met, and in four of these cases they had been exceeded. Three parents indicated that their expectations had not been met, and three reported mixed feelings. While the physical benefits had been anticipated, many parents were surprised at how much their children had benefited from the walkers in other ways. Particularly significant were the positive effects of the walker on independence, self-confidence, self-esteem and interaction with others.

Patterns of usage. Most children used the walker at school and at home. Indoors in the home, use of the walker tended to be restricted to areas with smooth flooring and more open space, including the kitchen, halls, and basement. Almost all children found the walker very difficult or impossible to use on carpeting, and most had difficulty negotiating corners. Many children used the walker outside on the driveway, in the street, or on the deck, and as a result, found that they were able to use it more in the nice weather. Parents took their children places with paved surfaces, such as parks. Several families had taken the walkers on vacation with them.

Most parents reported that their children used the walker daily, or almost daily, for about one hour at a time. Reasons for not using the walker included the child being too tired or not feeling well, and the child and/or family being too busy.

Practical considerations. Ten parents indicated that their families had made specific changes to their homes to enable their children to better use the walkers. In most cases, these were minor changes such as moving furniture to create pathways, and ensuring availability of
an appropriate table for the child's use. Four families had made significant changes such as installing hardwood floors, or were planning to do so.

Ten parents described the walker as portable. Many indicated that it was easier to transport than a wheelchair. Most of the parents who found the walker easy to transport had vans. Nine parents found the walker difficult to transport because of its large size and awkwardness. It was difficult to get the walker into a car, or even into a van if other children and equipment also needed to be transported. Parents also found it difficult to carry the walker, especially through doorways.

Twelve (60%) of parents found that support services such as physiotherapy were accessible and available. These parents had a great deal of praise for community and school therapists, as well as centre staff. Five parents had mixed feelings, usually because they felt their children were not receiving enough therapy. Two parents indicated that therapists had not been supportive.

**Benefits of the walker.** Parents cited many benefits of the walker. The major benefits mentioned most often included physical benefits (n=13), increased independence (n=11), increased interaction with others (n=8), increased self-confidence and self-esteem (n=8), and improved communication (n=7). The improved interaction with others was seen to result from the increased self esteem and the ability to get involved in activities with peers. As well, several parents indicated that other children reacted to the child using the walker differently than when the same child was using a wheelchair. The walker was seen to be less of a physical barrier, and in enabling the child to stand, encouraged an image of the child that was less dependent. This was seen to increase potential for integration.
Drawbacks/challenges. The top drawback of the walker was seen to be the difficulty in getting the children in and out of the walker, mentioned by 11 parents. Other significant drawbacks included the lack of portability of the walker, the limitations of the walker in terms of maneuverability and the terrain on which it could be used, the time required for use of the walker, and the numerous trips to the rehabilitation centre during the study. Six parents related physical problems, such as skin lesions, pressure areas and soreness, as being major challenges. Six discussed the need for frequent adjustments, and 5 related technical difficulties. Teaching the children to use the walker was also identified as a significant challenge by several parents.

In terms of safety issues, almost all parents indicated the need for constant supervision of the child in the walker. One child had tipped, and several others had almost tipped. Other safety concerns included negative physical effects on the children, such as skin lesions. Parents themselves had pinched their fingers in the joints of the brace, and experienced difficulty with the lifting.

Physical effects. Fourteen of the parents cited positive physical effects of the walker on their children. These included increased muscle mass and strength (n=12), increased or improved use of upper extremities (n=5), increase in height (n=4), improved use of lower extremities (n=3), reduced chest congestion (n=3), and fewer problems with constipation (n=3). Improved balance, posture, sitting, flexibility, range of movement, head control and general health were each cited by two parents. Negative effects were cited by 6 parents. These included muscle and joint tightness (n=4), crossing of legs (n=2), and reduced ability to stand with support (n=2). One child’s hip dislocation worsened during the course of the study according to the parent, although the deterioration could not be detected by the child’s orthopedic surgeon and no action was required.
In terms of comfort, 10 of the parents felt that their children were comfortable or very comfortable when using the walker. Five felt that their children were fairly comfortable most of the time. Four children were believed to experience discomfort frequently, usually as a result of muscle soreness and/or stiffness, pressure areas, or foot pain.

**Emotional effects.** Twelve of the children were happy or very happy to go in the walker. Six children were not consistently happy to go in or be in, and one child regularly resisted going in the walker. Although the parents were not always sure, the most common reasons for ambivalent or negative feelings were thought to be discomfort and the effort required for the child to use the walker.

Fifteen parents cited positive emotional effects, and no parents indicated that the walker had had a negative impact on their children emotionally. The emotional benefits described most often were increased self confidence and self esteem (n=6), increased and improved interactions with others (n=5), and increased independence (n=5). Other benefits included increase in general happiness even when out of the walker (n=2), increase in interest and activity levels (n=2), and improved concentration (n=2).

**Developmental effects.** Fourteen parents indicated that their children had made significant developmental gains during the study. Increased use of arms was mentioned by 10 parents. Children tended to reach more, and to take and hold objects. Two parents described how their children got into much more mischief as a result of this. Seven parents felt that their children communicated better as a result of the walker. The most common differences noted were increased frequency of vocalization and increased voice volume. Parents were often surprised at how their children had become much louder. Increased awareness of self and others, improved attention, greater responsiveness or improved concentration were noted by
several parents (n=7), as was increased eye contact (n=6), although several parents were uncertain how much the walker had contributed to this improvement. Developments were also cited in the areas of interest in doing things and learning (n=3), spatial concepts (n=2), improved coordination (n=1), and improved head control (n=1).

In terms of use of hands when in the walker, children often used their hands for stationary activities, such as playing, reading and colouring. Most children had difficulty walking and doing things with their hands at the same time. Other common activities involving use of hands when in the walker included kitchen activities such as cooking and washing, and playing ball games of various kinds.

**Perspectives of others.** Parents had generally heard very positive comments about the walker from family members, friends, school staff, therapists, and the general public. Negative comments were few and far between. Most parents liked the appearance of the walker, believing it to be less obtrusive than a wheelchair. The parents said that they would encourage other parents to try the walker, indicating that the benefits extended far beyond walking. They would also advise other parents to be realistic in their expectations, patient, and willing to put in the time and effort required. They would warn parents about the drawbacks, but tell them that the benefits outweighed the hardships. Several parents indicated that all children should have the opportunity to use the walker.

**Summary and implications.** The nineteen interviews with parents provided a great deal of information supporting the use of the walker by the children in the study. The walkers met or exceeded the expectations of most parents. Most of the children were able to take at least a few functional steps with the walker, and some were able to use the walker for many activities for periods of three hours or more at a time. Most parents noted physical benefits such as
improved strength and positive effects on development, especially increased use of arms. More than one third of parents felt that their children communicated better since beginning to use the walker. Almost all parents noted positive emotional effects, including increased independence, increased self-confidence and self-esteem, and improved interaction with others. Of special note was the perception by parents that others reacted to the children more positively when the children used the walkers compared to when they used wheelchairs. While almost all the parents saw the benefits of the walker outweighing the drawbacks, the drawbacks were notable. Getting the child in and out of the walker was the biggest difficulty reported.

Implications for practice arising from the primary analysis include the need to further develop the design of the walking aid to enable it to fold for easier transport. As well, the terrain limitations of the walker would suggest the need to improve the design of the wheels to facilitate use on carpets, grass, snow and sand. Consideration must also be given to the difficulties of family members in lifting children who are often well over 40 pounds into the frame, especially when needing to do so without the assistance of another person. Some type of lifting device may be helpful. Considering the positive physical, emotional and psychological effects of the aid noted by the parents, it is important to ensure that the practical issues of transportability and lifting the children do not prevent some families, especially single parent families, from using the walker.

Other implications arising from the primary analysis include the need to carefully consider the perspective of parents when evaluating therapeutic devices. The interviews yielded a wealth of information about the effects of the walker that were not fully captured in the quantitative data. The importance of incorporating qualitative measures into the design of studies evaluating outcomes of therapeutic devices was highlighted. Finally, this analysis
confirmed the importance of standing and walking to the parents of the children in the study. Beyond this, the analysis suggested that others react differently to the children when they are using the walker. This reflects the complex sociological context in which children with disabilities interact with others. Health professionals must carefully consider this context in all clinical practice and research related to clients with disabilities, including the development of therapeutic devices and recommendations for their use.

Findings of Second Stage of Analysis

To illustrate the findings of the second stage theoretical analysis, parent interviews have been directly quoted whenever possible. The letters at the end of the quotes refer to particular participants, but bear no relationship to their actual names. They are randomized (A to S) from the study numbers assigned to the participants in order to maintain anonymity. The numbers refer to page numbers of the interview transcripts. Where the specific name of the type of walker was used by the participants, it has been replaced with the words "another walker" in brackets. In a few other situations, the participants' words were replaced with others in brackets to assure anonymity. No editorial changes have been made to the quotes, hence they appear with the hesitancies and other characteristics of natural speech.

Descriptions of and responses to the walker. Most parents commented on the appearance of the walker at some point during the interview. Five parents commented positively, and 12 indicated that they had "no concerns", or were indifferent to the appearance of the walker. Of the parents who seemed indifferent, one made the following comment, in response to the interviewer's question about whether she had any concerns about the appearance of the walker:
No. (Laughing) Appearance doesn’t bother me too much.... You’re so used to the way people look at you nothing fazes you. Least of my concerns. (parent F. p. 18)

Another parent similarly responded “no. we don’t care about stuff like that” (parent S. p. 12).

From the perspective of Bourdieu, the habitus of these children and parents may have been reduced over time. The parents may have come to expect the stares of others, and the new walking aid did not worsen this situation.

Positive comments indicated that the walker represented a significant improvement over the appearance of previous walkers that the children had used. One parent described the walker that her child had been previously using as a “huge cumbersome thing” (parent L. p. 4). Another parent described traditional walkers as being “atrocious looking” (parent C. p. 10). In contrast, parents indicated that other children didn’t seem to notice the new walker as much as other devices, and that it did not frighten away other children as much. The negative views of the parents and others of other therapeutic devices that the children had used in the past confirms that such devices are highly visible icons with negative associations that reflect and further contribute to the habitus of the users. In comparison, the new walker was described by parents and others as being both less visible and more attractive than other devices. It was seen to be “sleeker” and “a lot less cumbersome” (parent L. p. 9) than other walkers, and many comments focused on the compact and unobtrusive nature of the device. Bourdieu would argue that these characteristics of the new walker would not only avoid further contributing to a negative habitus, but could potentially elevate the habitus of the children. The following interview excerpts are of spontaneous positive comments made about the appearance of the walker:
If anything, I think the look is better [than a wheelchair]. because you don't really--you don't see--it's not the first thing you see: whereas if you look at him sitting in the wheelchair, the wheelchair is the first thing you see: in the walker the first thing you see is him and then. you now. because it's so narrow and you know. the straps co-ordinate with his clothes (laughs) there's a lot of red. then no. you don't really--it's not that noticeable. It doesn't look like a disability type thing as much as the wheelchair or some of the other walkers.... And it's nice that it's not chrome. Chrome has a definite hospital-type look to it. (parent S. p. 13)

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...in the wheelchair his tray around him. he can't--doesn't have to be part of the world: he has his own little space. and he's got a buffer all around him. In the [walker] there's no buffer... (parent S. p. 3)

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That's one of the things that we liked about it is it's very compact, it doesn't have a lot of extra parts. and it's quite unobtrusive when the children are in it. and ah. I think for us. that's probably one of its. ahm. its main benefits. You know, other types of walkers that we've seen and he did try [another walker], he did have one for a couple of years. and it was so big, and it just looked so medieval almost. you know, it looked like some torture contraption. that ahm. we found that the kids stayed away from him when he was in it. you know. We were really pleased that. ah. the [walker] was designed the way it was, in that. ahm. the kids didn't seem to notice it. (parent C. pp. 7-8)

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[The walker is], as I said, certainly a lot less cumbersome and a lot smaller than the other walker that he was in. So it actually even looks sleeker, so I don't know.

Sometimes when they're big and huge the kids are kind of afraid to, you know, kind of approach it or touch it or something. But the kids don't seem to have any problem with this at all. (parent L. p. 9)

One parent who worked in the field of design felt the appearance could be improved and made the following comments:

And you know, it is--when I say cumbersome, it's. I mean you--I think it's a pretty good device, it looks very funny: I tell people it's a strange collection of bicycle parts and dog leashes and horse tackle, you know, it's the most unlikely looking thing, I must say.

Today I'm here because I'm looking at the next generation and it's a much more, ah. being [of a particular profession] I sort of keep an eye on how things are designed. And this generation seems to be, you know, sort of modern era... (parent Q. p. 6)

These comments further reinforce the awareness that parents have of how others react to the appearance of devices, and the importance of continually improving designs.

In summary, the appearance of the walker was only perceived negatively by one of the nineteen parents involved in the interviews. In this parent's comments, the importance of the appearance of therapeutic devices came through clearly. Four of the parents who indicated that appearance made no difference to them clearly indicated that they were accustomed to unattractive equipment, and to the stares of others consistent with the view that the children were of lower social standing and habitus. The parents who made positive comments about the walker indicated that its appearance was an improvement over walkers they had used in the past, and over wheelchairs. The sleekness of the walker was the characteristic most often
emphasized by the parents themselves. The improved appearance of the walker can be seen to have had a positive impact on the habitus of the children.

In terms of the comments that others made about the walker, one parent called it “a very friendly device” (parent R. p. 11). Several parents indicated that other children found the new walking aid less frightening than wheelchairs and other types of walkers. Its appearance was perceived by the parents to increase the level of comfort of others in approaching the children, and in even touching the walker and the children themselves. All parents related that almost everyone had made very positive comments about the walker. There tended to be great interest in the walker among people familiar with the child, parents of children with disabilities, and the general public. Many people had seen the walker on television or had heard about it. Several parents had been approached or telephoned by people trying to get more information about the walker.

Many of the comments that the parents had received from others were very enthusiastic. Parents indicated that others were “thrilled”, “impressed”, “intrigued”, “amazed”, and “excited” when they saw the children using the walkers. Several used the words “wow” and “curiosity” in their descriptions. Excerpts from four different interviews describe the comments typical of others:

Kids and adults alike seem to be very intrigued with it, are amazed at how wonderful, like wow! Imagine, he’s able to walk in this and what a great piece of equipment! Like it’s always been a very, very positive thing” (parent L, p. 26).

* * *

They just thought it was a very interesting piece of equipment. Like they thought it was designed…nicely. They felt this was such a neat little piece of equipment, you know.
they hadn’t seen it: what a good idea to make something like that. Outside people at the new school, just look at them you know. they say, you know. ‘Wow! This looks--this is really interesting’. And they think it is an amazing little piece of work. (parent B, p. 14)

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I think I waited a long time before taking her to the mall. Because kids stare. people stare, but actually once I got there the stares weren’t stares. they were curiosity and ‘wow!’. Like a sense of ‘Isn’t this a neat thing?’. And it was a very friendly device and the people, it brought a lot of really neat things out of people. Maybe they knew. had relatives or family with disabilities and said ‘Wow, how can we get a hold of one of these?’ So it induced a lot of conversation. (parent R, p. 11)

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I think kids approach him better in the walker than in the wheelchair because they can see more of him. I think it’s from a child’s point of view. well he’s upright and there’s not a lot of stuff around him like the tray and all those things. It doesn’t look as -- in the wheelchair he looks very dependent: in the walker he looks like he has some independence so I think regular children approach him more in that. (parent M, pp. 3-4)

According to the parents. others tended to perceive the walker as an interesting and innovative piece of equipment. The reactions of surprise and awe indicate that the walker was somehow different from other equipment that they had associated with children with disabilities in the past. The unobtrusiveness of the walker reduced the tendency to focus on the child’s equipment, thereby increasing the visibility of the child him or herself. Parents felt that the lack of bulky equipment around the child led to greater accessibility of others to the child,
promoting more physical contact, and affectionate exchanges such as hugging and hand holding. As well, parents perceived that the walker reduced the fear that their children often engendered in others. The walker drew others to the child, rather than acting as an aversive stimulus.

In summary, the esthetic qualities of the walker, and the relative absence of negative characteristics, were important to parents. From the perspective of Bourdieu, the pleasing qualities of the walker, especially its sleek, “high tech” design, serve to increase the habitus of the child with the disability by increasing his/her visibility and interactions with others. The surprised reaction of others indicates that the child with the disability is not in keeping with what they normally expect of children with severe disabilities, but is seen anew. The children are using equipment that is literally awe inspiring, and the children are more accessible to others because they are eliciting more interest than fear. In these ways, the child’s habitus can be seen to be elevated in the eyes of others.

These two important and desirable elements from the perspective of the parents, the “invisibility” of the walker, and the “awe-inspired” reaction of others, are somewhat paradoxical. The invisibility is actually what most children without disabilities and their parents would normally experience on a day to day basis in life, and would thus be a positive thing for these parents and their children. The awe-inspired reaction is not “normal”, and may be seen to reinforce the “unusual” aspects of these children, as well as the “hero” perception that is often perceived negatively by people with disabilities. On the other hand, the awe-inspired reaction is probably much more desirable to most of these parents than a very negative and aversive reaction. Even if the parents are not entirely positive about the awe-inspired reactions and curiosity of strangers, these reactions provide opportunities for public education
and positive interaction. As well, it is important for all children to have opportunities to receive positive feedback for the skills and abilities that they have. and most children would receive feedback of this type from strangers on occasion.

**Perceptions of children’s stature and body comportment.** Four parents perceived that their children had grown between one and five inches in height during the course of the study. While there is evidence from the quantitative data that many of the children had indeed grown several centimetres during the 12 months of the study, it is probable that some of the parents perceived a dramatic increase in height because the children were standing upright, rather than sitting in a wheelchair, and were straight up due to the bracing apparatus, rather than bent over. Several parents also indicated that others had commented on the height of the children, as in “Look how tall you are!” (parent P. p. 1). One mother made the following comments when asked whether the walker had met her expectations:

She really, ah. is able to be a little bit more active and participate in school activities, walking from class to class and gym. be right in there with the other kids and with some limitation, but without the [walker] she`d be wouldn’t have had any chance of walking independently. So I think it’s been good for her self-esteem also and it’s built her up. you know, the other kids who well. “Look how tall you are!” and you know. “You’re actually walking!” and they take an interest in her and what she’s doing, you know. not just somebody who’s sitting in a wheelchair all the time. And that’s been nice. (parent P. p. 1)

Note the use of the phrase “built her up” by this mother. While used figuratively, it illustrates that the walker literally had this effect on the daughter. Another parent emphasized how siblings had noticed the height of their brother when he was standing in his walker. This height
emphasized for them. for the first time, his ordinal position and role as the big brother in the family:

Psychologically, it’s been amazing, really amazing. The whole family dynamic is really changed. He has two younger brothers and they always pretty well disregarded him.... But they wouldn’t normally play with him or if he was in his wheelchair they would just walk by. In the walker they can’t do that. In the walker they go over, they hug him and they... ah. you know. we’ve taken pictures with them all together and they’re all standing there, and they realize that he’s bigger than they, and that he’s older than they are and that he is indeed the big brother. Which is something that they never really realized before. So the whole interaction between the children has changed, which is interesting. And now if they want to play with his computer or do something with one of this toys, they don’t ask me. they ask him directly. So that’s really a big step. (parent S. p. 2)

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...his brothers come up and play with him; the dog comes up and plays with him. they know he’s the big brother ‘cause they’re smaller than he is. (parent S. p. 7)

This example demonstrates how use of the walker enhanced the child’s ability to “stand up for himself” and actualize his ordinal position in the family. Note the use of the phrase “a really big step” as another interesting metaphor signifying the child’s progress in assertive interactions with others. As well, with free arms, the child was more able to give and receive physical affection appropriate for his role in the family. Several parents made similar comments about the ability of their children to hug, hold hands, and to affectionately interact in other ways with family members and friends when in the walker. This very positive exchange
further served to increase the habitus of the children. Another parent gave a similar example of a boy being better able to realize his role amongst family and friends when in the walker:

And we could also probably talk a little bit about, you know, how he socializes with other kids because, you know, a lot of the time when friends come over, his friends come over, they step over him to play with his toys, you know. And when he’s vertical they interact face to face. I mean, X is pretty good: he can bark commands from a prone position, but he doesn’t. He’s much better when he’s vertical, and you can just see the interaction, you know, you can see his cousins who, my wife comes from a large family and so he’s got lots of cousins and so similar age, so you can see the way they react to him when he’s vertical.... yeah, he’s there, he’s a real person, he’s not just something. just a boulder on the floor. (parent Q, p. 9)

This parent’s observations illustrate that increased interaction and assertiveness was associated with increased recognition of the “humanness” of these children. This is very consistent with Bourdieu’s association of more dominant behaviour with higher habitus in particular fields. Another parent commented on how her child was less intimidated by others when in her walker:

Socially she’s done...she’s always been a social child, but now she’s even more social. like before, you know, if somebody was really tall they would upset her. There was a man with a beard or a dark person or, ahm, even animals, she was afraid of them. But now, with her being in the walker, she’s at standing level but she’s able to not feel as...I guess intimidated by them. (parent C, p. 6)

Finally, in reviewing findings related to body comportment, it is important to note that physical benefits were described most often when parents were asked about the major benefits
of the walking aid. Fourteen, or three quarters of the parents cited positive physical effects of
the walker, including increased muscle mass and strength, increased or improved use of upper
and lower extremities, reduced chest congestion, and fewer problems with constipation. These
physical benefits probably contributed to a greater sense of well-being that had a positive effect
on the children’s behaviour, interactions with others, and hence their habitus. It is also
important to note the value that society places on health and vigour. Toned muscles are
associated with upright posture. “Being in shape” is a focus of many in contemporary society.
and is associated with attractiveness and higher social status. In its benefits to the children in
these areas, the walker is not only providing the actual physical benefits described, but is also
potentially enhancing the children’s habitus by increasing their social capital.

In summary, many parents focused on the increase in their children’s height or vertical
stature during the study. They noted the number of inches that their children had grown, and
they focused on how others, especially siblings and peers, had remarked on the height of the
children when standing. The children were seen to have a greater presence in the home among
family members and were more likely to be recognized as a big brother or sister if older. In
other words, they seemed to have assumed their rightful “place” or ordinal position in the
family. In and out of the home, the children using the walkers were more likely to elicit
attention and respect from others. They were also more likely to be able to give and take
affectionate behaviour with family and friends consistent with their roles. Bourdieu
emphasizes the importance of physical positioning in relationships of submission and
dominance. The upright, more dominant position assumed by the children in the walkers gave
them stronger presence and increased symbolic stature, which in turn commanded more
respectful behaviors from others. The social mechanisms that ensure the production of a
particular habitus are an integral part of the conditions of reproduction of the social order (Bourdieu. 1990). The parents clearly described how being upright altered the usual social mechanisms at work in the interaction between their children and others. In at least two thirds of the interviews, the children were clearly seen to have higher social standing as a result of using the walker. The physical benefits of the walker may have also had a positive effect on the children’s habitus through an enhanced sense of wellbeing, and the involvement in socially sanctioned physical exercise.

Effects on children’s behaviour and sense of self. Parents perceived positive effects on the children’s behaviour and sense of self as a result of using the walker. While these benefits were mentioned almost as often as physical benefits, they had surprised many parents. Furthermore, the beneficial effects persisted beyond the times when the children were using the walkers. Parents emphasized that while the changes might have seemed subtle to a person who did not know the child well, they were often dramatic to the parents and school staff. One parent described the change in her child’s behaviour and sense of self as follows:

He has to concentrate in order to walk in the walker, he has to work through his spasticity. There is a certain threshold that he has to cross in order to be able to walk. He just can’t take a step; he actually has to physically get through his disability in order to take that step....It’s all part and parcel of not living with his disability, but learning to get through his disability to live. And that’s what he’s doing, and the response is remarkable... I can’t say enough about him. There’s a HUGE difference. (parent S, pp. 7-8)

Parents’ perceptions of changes in behaviours were captured mainly in response to the interviewer’s question about developmental benefits related to the walker. Fourteen, or three
quarters. of the parents indicated that their children had made significant gains during the study. with increased use of arms (n=10) and improved communication (n=7) cited most often. Three parents with children between 11 and 14 years of age described the changes in her behaviour as follows:

[Her] speech changed in the walker. She was MUCH more verbal in the walker. And MUCH more aware of her surroundings, aware of the ground and her feet. The second day, she was just smiling and looking out the windows and stretching her hand to see - like seeing things that she hadn’t seen before. So, it’s really opened up her world for her. (parent F. p. 11)

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She was always silent before. Like she would laugh and now like, you know. she’ll scream if she wants something or... she wouldn’t do that before. She’s. you know. like her “yes” and “nos” are getting good and she’s starting to say names and, you know, like getting--you know when she wants something, you know what she wants. Like there’s no way you can miss that because... just the way she, you know, even her gestures have changed. (parent C. p. 7)

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She listens, like, you know. if you’re looking at her and talking to her, she’s -- instead of just, you know, having her head down and just listening, she’s actually looking at you and listening at the same time, so yeah, there’s a lot of benefit from that. (parent C. pp. 7-8)

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He’s really been ahm. quite happy to be in [the walker]. He’s become a little more vocal, a lot more vocal, ahm, left him with more confidence than we’ve seen in him.....

He has this tiny little voice. So he got...he got more volume. He also got more inflection. you know, it’s... went more sing-songy. more like he was thinking he was speaking, ahm. that kind of thing. (parent C. pp. 11-12)

A person with a louder voice is more likely to be able to assert him or herself, and to be less submissive and more dominant in interactions with others. Having a louder voice is a social gain, both literally and metaphorically. This increased interest in the environment and vocalization has also been observed in infants without disabilities when the capacity for self-movement was attained (Gufstason. 1984).

The perceived effects on sense of self were mainly captured in the parents’ responses to the question about the emotional benefits of the walker. The majority of parents noted positive emotional effects, and no parents noted negative emotional effects. This was a major finding. The emotional benefits described most often were increased self confidence and self esteem (n=6). increased and improved interactions with others (n=5). and increased independence (n=5). Seven parents spoke of how happy their children were when using the walkers, but the positive emotional effects were seen by several parents to have had an impact on the children in a more general way. According to one mother, being upright had “changed her (daughter’s) whole perspective”. She began to interact with her environment. According to this mother, the beneficial effects “had a lot to do with motivation. and her environment reacting to what she did. She was empowered by this increased mobility” (parent R. p. 4). Two parents described the major emotional benefits of the walker as follows:
The best benefits is his self-confidence and his way of dealing with life, you know. And his motivation and his curiosity around him. You know that makes him, he feels more that, not that he feels indefinite, he feels that he can be. He rely on his own capacity. and get through. and get independent that way. I think that’s the most important thing with the walker, much more than just walking around. The feeling that has--that comes from standing and be by yourself is the major difference that’s worth any other hard part that can be deal with. (parent J. p. 11)

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Just for him to get motivated and to be in control of his own environment. I think it’s given him a lot of self-esteem.... And that’s all I wanted, because he was a very frustrated child who wants to walk. I don’t know whether he knows where he’s going but wants to, but couldn’t. I tried every walker out there he just, he was frightened. And the minute I put him in this thing, it was “Let’s go!”. I mean he’s not going far, but he’s going far enough to make him feel better about himself. As for me whatever makes him happy I’ll go for. I’ll walk a million miles just to see him smile. (parent M. p. 11)

In some cases, children using the walkers were perceived to be able to experience a more “normal” childhood. One mother explained her child’s new-found independence:

She knows she can do more when she’s standing than when she’s sitting and she can. like it’s funny, it’s almost like a game when you’re doing something and she knows she’s not supposed to touch something, she will walk and touch it and then she laughs because she knows she’s not to do it. That’s great! It’s so normal! You know, like it’s just great! So, I know she’s enjoying that, you know, and having that independence. (parent F. p. 14)
Several other parents made similar observations about their children getting into mischief for the first time in their lives. The increase in self confidence and self esteem in the children perceived by the parents is associated with an increase in habitus.

Of great interest is the fact that parents were enthusiastic about the walker despite the practical challenges. Many drawbacks were identified, most often the difficulty in getting the children in and out of the walker, which was mentioned by 11 parents. Other drawbacks, each cited by 4 or 5 parents, included the lack of portability of the walker, the limitations of the walker in terms of manoeuverability and the terrain on which it could be used, the time required for use of the walker, and the numerous trips to the rehabilitation centre required for appointments with orthotists and therapists. Despite these drawbacks, even the least satisfied parents said that they would tell other parents to try the walker. As one father said: “We see it as a real advance, not as something that has problems” (parent Q, p. 10). Another mother outlined the challenges that she would tell other parents about, the “hard going” during the first six months, then at other times as well. She then went on to relate:

I mean it’s work well rewarded in the end. So just stick with it... Because even if he don’t walk I’m quite sure there are benefits. There really are benefits to the child themselves. (parent M, p. 14)

Effects on habitus of children and parents. Several parents indicated that the experience of seeing their children upright and walking had been very meaningful to them. The following comments describe these feelings:

Actually, ahm. yes. it is kind of a miracle. Like they see--if you see Y., I mean you can see him how he is. He can’t sit on his own, he can’t do anything. To think that a kid like that can walk is really amazing, it really is. (parent S, p. 12)
So there's been so many -- the benefits are kind of subtle, but they've been big to me. They've been big. Anybody else -- like I can see if someone else too was to watch what X's done and really hasn't had any experience in this area or been with a kid like X, they would say well, she's not walking very much. No! She isn't! You know. Twenty-five, thirty feet, fifty feet is really, (laughing) really good day for X. But wow! That's amazing, you know. That's amazing! So, I guess they're a little bit, they're big to me.

This same mother poignantly talked about how she and her daughter had finally "been given a chance" when her daughter was entered into the walker study:

It put X in an upright position and given her mobility, that's really the major. For me, a major benefit is. and maybe it doesn't really - it kind of has to do with the walker but not totally - I knew X could do more. I believed in X. I know in this walker she could do something. .... For someone else to have the same, like to believe in her like I believe in her. that was really important to me. That was REALLY important to me. .... all she needed was a chance and I knew that. and they gave her that chance. (parent F. pp. 14-15)

The parents attempted to describe how being upright had affected the children themselves. One mother said the following:

I think the walker is much better [than the wheelchair], I think. Yeah. I think it's much better. Because he can go around by himself sometimes when he wants. I can stand him in it. forget about him and be doing something and he'll go right off to do something else. And I don't know, the straight position I don't know. something
happens when you are straight. in the straight position. I don’t know. For us that takes
that for granted, it’s a different thing. I don’t know how--what to say to you but I can
see when he’s straight, up straight and for him something change inside. (parent J. p. 8)

Several parents discussed the meaning of walking to siblings. One parent said:

“He’ll walk beside him and things like that. He thinks it’s great. And as I said, the fact that
he’s standing up like he used to, it’s good for them.” (parent L. p 16)

Parents clearly indicated that they felt that the children’s standing and walking had
affected the dynamic in the children’s relationships with others. One parent explained as
follows:

I think it boosts his confidence level in himself that he’s walking, so he is better able to
socialize. It’s not that the kids are interacting better with him but maybe he’s
interacting better with them, because he’s feeling good. (parent A. p. 21)

Another parent talked about how friends at school saw her child “in a different light” when she
began to use the walker:

I think it’s been good, it was interesting because it was good for her friends at
school to see her that way too. Because it’s almost like, ahm. you always see X
in a chair. I remember when they put her in the walker, well the kids were -- the
kids really accept X the way she is: but it almost made her like, oh! You know
look, she’s as tall as me. you know. It was really they saw her in a different
light, and that was kind of good too, and not so much like she’s a baby to be
pushed around on a stroller. Not that they--I don’t mean that in a nasty way
because kids are great with her at school, but I think they saw her differently too.
So there’s been so many -- benefits are kind of subtle, but they’ve been big to
me, they’ve been big. (parent F. p. 15)

Parents often spoke of the strong emotional reactions that seeing their children walking
elicted in others, even complete strangers: “Just cheering and for the walker and...some was
very emotional and almost cry seeing him walking.” (parent J. p. 14) Another parent described
the reactions of others as follows:

They all--everybody thinks it’s wonderful because it lets, you know again I think
people think the wheelchair is, you know, they want all kids to walk. I think it
sort of gives everybody else some hope. I don’t know. (parent H. p. 10)

Parents spoke of how others remarked on the progress that their children had made in the
walkers. One mother commented that “after one year they didn’t believe that is the same girl”
(parent G. p. 3).

The importance of standing and walking to parents and others was described very
clearly, and was consistent with Straus’ (1966) description of the upright posture as the
leitmotif of humanness. In many cases, walking was seen to be miraculous and hope inspiring.
Descriptions of the children using phrases such as “like a boulder on the floor”, and “not just
somebody who’s sitting in a wheelchair all the time” clearly conveyed the negative light in
which parents believed that their children with disabilities were generally viewed. Phrases such
as “children like that” also conveyed the low societal expectations and shared habitus of
children with disabilities as a group. When the children used the new walkers, they had a
greater tendency to be recognized by others as individuals. The habitus associated with being
an upright, standing and walking child is afforded higher value in society, and is thus more
powerful. The walker helped to elevate the habitus of the children with the disabilities
While parents tended to focus during the interviews on their perceptions of how the interactions between their children and others had changed, it was very obvious that the interactions between the parents and others had also changed. Several commented on how they had become accustomed, as parents of children with disabilities, to stares from others. The stares were interpreted as conveying sympathy, revulsion, or even fright. Others tended to avoid the child with the disability and his/her family.

The parents described a huge difference in the way others looked at their family when the child was in the walker. Parents perceived that the children were more “invisible” in the walkers than when they used other devices. This was seen positively as more “normal” experience. Paradoxically, parents also described in positive terms how others tended to be drawn to the children in the walkers. Many people were “awe inspired” seeing the children in the walkers. These reactions may be seen to focus on the “unusual” characteristics of the children, encouraging intrusive behaviour from strangers, and promoting the perception of the children as heroes. On the other hand, these reactions were obviously preferred by parents to avoidant or negative reactions. The usual looks of sympathy and revulsion were replaced with awe and curiosity, and the tendency to avoid the family was replaced with a tendency to approach the family. Rather than being avoided, the parents were asked questions by complete strangers, providing opportunities for public education. According to one mother, people “ask me zillions and zillions of questions and they want to watch Y” (parent N, p. 11). Parents also received welcomed praise and encouragement from strangers. One mother’s reference to the walker as a “friendly device” clearly symbolizes the ability of the walker to elicit the friendly overtures of others. It is important to note that many of these parents would not have received many compliments about their children from the public, compliments that could be affirming of
their roles as successful parents. Many of these parents may also have become more socially isolated since having a child with a disability because of the time taken with the care needs of the child, and because of the loss of friends that they had before having the child with the disability. Not only did others in the community tend to be more receptive, the children and parents had also received media attention as a result of their use of the innovative walker. This seemed to reinforce their “worthiness” of the interest and attention of the public. Several parents commented positively about this media attention.

Several parents explicitly stated that their children were more highly thought of as a result of using the walker. The comments from parents about the relationship between the child with the disability and siblings and other family members demonstrated that the child was assigned a higher status as a result of being upright. Beyond the family, the enthusiastic support from others indicated that the children had become “worthy” of the attention of others, as a result of being upright, and as a result of using a device that was seen in other fields to be an innovative and high-tech form of capital.

While the increase in the social position of the child from the perspective of the parents is an obvious conclusion emanating from the data, the increase in the social position of the parents is also significant. As a result of their children being seen as being more capable and worthy of the interest of others, the parents themselves received more friendly overtures and positive feedback from others. In having a child who could stand and walk, the habitus of the parents was also elevated.

Summary. In summary, parents of children using the walker clearly articulated the following benefits to using the walker:
- physical benefits
- increased and more positive interaction between the child and others
- increased independence
- increased self esteem
- developmental gains, especially improved communication

The benefits of the walker were very much related to an increase in social status or habitus achieved by the child as a result of using the walker. The following characteristics of the walker contributed to its ability to increase the social status of the children:

1) the pleasing, innovative appearance of the walker, which does not cause negative reactions in others or create distance between the walker and others. Indeed, the walker elicited the awe and curiosity of others as a result of its sleek and innovative appearance.

2) literally straightening and raising the children up, as this increase in stature changes the dynamic between the child and others through the actual increase in height, and through the symbolic significance of increased height the ability to "stand on their own two feet". The change in stature of the children clearly affected their relationships with others, often resulting in a position of greater power among other children in the family, and eliciting greater respect from others in the community.

3) enabling the children to participate in more activities, including walking in some cases, but also other functional activities, especially communicating. These activities are highly valued in society.
Thus, in many situations the walker literally and metaphorically "puts the child in position" to be more successful in interacting with the world, in keeping with the self-fulfilling nature of the habitus.
Chapter 4: Discussion

Development of Therapeutic Approaches and Devices

This study provides some interesting findings about the benefits of walking aids and other therapeutic devices. While direct improvement in walking was very important to the parents in this study, it is only one of the ways that the walker benefitted the children. Other improvements in function are very much related to factors that increase the child’s social positioning in the world. While this walker in particular may not be appropriate for all children with severe cerebral palsy, characteristics of the walker that are related to its perceived benefits in improving the child’s habitus may be applied to the development of other devices. The three most important characteristics include 1) the ability of the walker to stand the children upright, 2) the ability of the walker to raise the children much higher than they would be in a wheelchair, and 3) the design and appearance of the walker. Each of these will be discussed in turn.

Standing children upright. While the literature supports self-propelled mobility in assisting the development of children with disabilities, much of this literature has focused on powered wheelchair mobility. The literature on walkers has tended to examine factors associated with whether or not children will be able to use walkers, and issues related to cessation of walker use, and the transition to full-time wheelchair use. The present study supports the value of positioning people with disabilities upright whenever possible. While the invention of the wheelchair must have had a huge impact in enabling the mobility of people who would have previously been in bed or in a chair, the sitting position makes eye to eye contact difficult. As well, stooping down is patronizing, according to Bourdieu because going down to the child’s level sustains barriers and the existing habitus of both people involved in
the interaction. People tend to naturally seek to be in the same position as those with whom they are talking, whether this is standing or sitting. It would be ideal if therapeutic devices of the future could enable the user to be in a standing or a sitting position. According to Bourdieu, early experiences are especially influential in development of the habitus, which tends to be relatively stable throughout life. It is thus important for children who are born with disabilities to have the experience of being positioned upright, and the opportunity to try to walk as early as possible, in order to be socially visible. Parents in this study clearly explained how uprightness opened up the world to their children with disabilities.

**Raising the height of people with disabilities.** This study reinforces the importance of improving positioning as much as possible to enable people to have their heads up, rather than being hunched over. Developments in communication were one of the most important benefits identified by parents, and may have been related to the improved physical positioning. As well, "holding one's head up high" (versus "hanging one's head") has important symbolic significance.

Although some people could never be supported upright, it would appear to be advantageous to increase the height of wheelchairs. This is a difficult issue, as manual wheelchairs have optimal function in lower positions for people who can propel themselves, transfer themselves in and out of the wheelchair, and often need to position themselves under table tops. While they cannot be self propelled, standers may be just as beneficial as walkers for some clients who cannot take steps by facilitating eye contact, communication, and participation in stationary activities.

**Improving the design and appearance of therapeutic devices.** Some implications for the design of walking and standing aids were reviewed in the primary analysis. These included the
need to improve portability of the walker, perhaps through a fold-up design. Large wheels and tires need to be developed to enable the walker to be used on a variety of terrain including carpet, grass, sand, and snow. Finally, the difficulties that family members have in getting the children into the device need to be addressed. A lifting device could potentially be used to assist the child into the frame. The benefits of the walker make it especially important to address these design issues to prevent practical considerations from becoming barriers to use.

This study reinforced the importance of creating orthotic devices that are sleek, rather than “clunky”. and use fashionable colours rather than institutional looking colours like silver. Huge strides have been made in this area over the past few years. The benefit of having people with disabilities, including children, “test” designs of therapeutic devices to determine what kind of reactions they elicit is an important implication of this study. Significant work in this area has already begun. Batavia and Hammer (1990) used small focus groups and a consensus building approach to determine what a select group of consumers believed to be the most important factors for evaluation of assistive devices. Jacques, Ryan, Naumann, Milner and Cleghorn (1994) used a novel design strategy called Quality Function Deployment (QFD) for the development of improved assistive technologies. Following the QFD technique, developers create a design matrix that illustrates the interrelationship between the technical or design parameters and consumer requirements. Ryan, Rigby and From (1996) describe different strategies based on collaborative approaches to involve consumers in the development of assistive devices. These include consumer advisory panels, self-report questionnaires, focus groups, and family trials. The authors describe how they used these strategies in the development of a wheelchair seating system for children.
Outcome Based Practice

While this walking aid is believed by parents to have important benefits for their children, the age of "outcome based practice" requires us to test the value of therapeutic devices in objective terms. In rehabilitation, these are usually associated with functional improvement. With the walker, some children became functional walkers using the device. Those who had the highest baseline gross motor function scores achieved the highest ambulatory function. There was also evidence that the younger the child when the walker was introduced, the greater the ambulatory potential. The researchers did not find a relationship between cognitive abilities and ambulatory outcome, which was surprising to them considering the complexities of learning to use the walker (Wright et al., 1997). However, the sample may have been too small and variable to test for this. Many children, however, were perceived to greatly benefit from the walker despite being unable to walk in it by the end of the study. It is difficult to measure the effects of changes in a child’s social positioning, but this study challenges us to think carefully about how we measure outcomes. Qualitative methods are often needed to elicit this information.

Ethical Issues

With a device as expensive and resource intensive as the walker, we are challenged to think carefully about who the device will be offered to, and at what cost to the child, family and society. The fact that the benefits of the walker extend to children who may never become functional walkers in this or any device makes the question of which children should receive walkers more complex. In confronting this question, it is important to note two issues.

First, we know from this and other studies that the motivation for many parents to have their children with disabilities stand and walk is very strong and may be a predominant goal.
There is the potential that some children will be expected to focus on the goal of walking to the
detriment of their development in other areas and/or to endure significant discomfort in
attempting to use the walker. A few children in this study did not always enjoy being in the
walkers. These children tended to have athetoid cerebral palsy. While their parents believed
that the children benefitted from the walkers, the children did not enjoy the experience and
occasionally endured major discomfort. It is important to work with parents in assisting them
to make decisions in this area. Other devices such as standers may be more comfortable for
some children and may achieve some of the same goals.

Secondly, it will be important to recognize that there may be other ways that children
can experience the benefits of the walker without using this walker in particular. In focusing on
what we can do to increase the social positioning of children with disabilities, a variety of
therapeutic devices and approaches, such as use of standers, may be beneficial. Although the
parents in this study had all tried other devices and were dissatisfied with the options, they
expect continued technological improvements through research and development.

Implications for Future Research

According to Bourdieu, the work of the researcher requires clarity about the
philosophical underpinnings of empirical enquiry and a reappraisal of this in light of the tools
to be used to understand people (Fowler, 1996). Surveys and structured interviews are often
limited when they are used to “measure” meaning because they only elicit presentations of the
self and of everyday experience which correspond to prevailing orthodoxies (Fowler, 1996).
This study demonstrated the value of qualitative research techniques in eliciting data to
evaluate a therapeutic device. The quantitative measures alone did not provide a complete
picture of the benefits and complexities around use of the walker. It is very important for
qualitative techniques to be built into measurement of outcomes in rehabilitation and habilitation, and integrated into the interpretation of results.

This study also demonstrated the value of examining disability issues from a sociological perspective. Many of the problems that people with disabilities face lie within society. It is obvious that research into attitudes towards people with disabilities can be very beneficial in developing approaches to change those attitudes, and, as was shown in this study, in developing therapeutic devices and approaches that can help to improve the social positioning of people with disabilities.

Future research should focus on the perceptions of the child users of the walker. Because many children with disabilities have communication challenges, their perceptions are more difficult to obtain. The perceptions of the children may differ significantly from those of the parents, however, and are an essential missing piece of the research on the walker to date. Ryan et al. (1996) indicate that published literature provides little guidance on how to solicit opinions about products from children. Use of a two-step survey method based upon materials from marketing research, and the experiences of psychologists, educators and occupational therapists has been reported (Ryan, Rigby, From & Kofman, 1993; Ryan, Rigby, From, Walczak & Jutai, 1994). The survey, conducted in two schools, involved a session of hands-on experiences with components of seating systems, followed the next day with a structured discussion in the classroom. Consistent with the experiences of consumer marketing research with children, it was found that school-aged children could make discriminating choices and provide a rationale for their choices.

Actual observations of the children in the community are also lacking. Further study of the interactions between parents and children related to use and non-use of the walker using
ethnographic methods would be very valuable in learning about social relations of use. Finally, the study of ethno-cultural issues related to use of assistive devices such as walking aids is important in Canada with its diverse population.

Implications for Nursing Practice

Nurses are important members of the interdisciplinary team for rehabilitation and habilitation. Nurses currently provide many services to children with disabilities in the community, and may be the only health professional going into some children's homes. In all settings, nurses should promote the positioning of infants with disabilities upright as early as possible. As nurses move increasingly to serving clients in the community with current trends in delivery of health services, they will be in an increasingly important position to be working with families to examine how children with disabilities are interacting with other members of the family and community. As this study has clearly shown, use of assistive devices has implications far beyond the client's ability to perform tasks. With their holistic focus on all aspects of wellness, nurses are in an excellent position to assess a child's and family's overall functioning and wellbeing, to make referrals to interdisciplinary colleagues for assistive devices that may increase the habitus of the child, and to play important roles as members of the walking aid rehabilitation team.

Summary

This study focused on the analysis of qualitative interview data of parents' perceptions of a new walker after one year of use by their children with cerebral palsy. Two levels of analyses were completed. The primary or content analysis revealed that the walkers met or exceeded the expectations of most parents. The major themes identified included the important physical benefits, and the important and often unexpected emotional and developmental
benefits. These benefits were definitely seen to outweigh the challenges. Finally, the meaning of standing and walking was very important to most of the parents.

The work of Bourdieu was used to develop questions for the secondary theoretical analysis of the data. This analysis revealed that enabling the children to stand and walk using the walker had a positive impact on the habitus of most of the children involved in the study, as well as on the habitus of their parents. Three attributes of the walker were found to contribute to the beneficial effects: 1) the pleasing, innovative appearance of the walker, which does not cause negative reactions in others or create distance between the walker and others; 2) its ability to straighten and raise the children up, as this increase in stature changes the dynamic between the child and others through the actual increase in height, and through the symbolic significance of “standing on their own two feet”; and 3) enabling the children to walk and/or perform other valuable functional activities, as well as facilitating communication.

Implications for practice and research were discussed. While this walker may only be appropriate for a small percentage of children with physical disabilities, the lessons learned from “standing tall” can benefit children more widely by encouraging us to consider how we can physically position children in walkers, wheelchairs and other assistive devices to enhance their social positioning and well-being. The study also demonstrated the value of qualitative methods in eliciting meaningful data. They should be used with quantitative methods as part of comprehensive programs evaluating the effectiveness of therapeutic techniques and devices.
References


Appendix A: Participant Selection Criteria (Wright et al. 1997)

The pilot study's eligibility criteria were as follows:

1. confirmed diagnosis of CP (any type).
2. ages 5 to 13 years at time of eligibility screening (hip to floor measurements between 42 cm and 76 cm to ensure height is within limits of the frame).
3. non-ambulatory because of insufficient upper extremity control to stand and walk with traditional walker/rollator.
4. hip and knee range of motion adequate to permit fitting of brace. i.e. flexion contractures less than 30 degrees.
5. attempts steps when held in supported standing and encouraged by parent/therapist.
6. may currently use (or have used) a standing frame.
7. must attend school (minimum of half days), and have support of child's classroom teacher for use of the walker in school.
8. must currently be enrolled in a physiotherapy program for active treatment. i.e. at least one session per week.
9. able to commit to attend the rehabilitation centre for assessment/fitting appointments. and every three weeks for monitoring and adjustments of the walker.
10. meets criteria for funding by charitable organization funding the study.
Appendix B: Schedule of Interview Questions (Belbin et al. 1995)

1. **Expectations**

   a) When you first learned your child would receive a walker, what were your expectations?

   b) (Child’s name) has used the walker for about a year now. Were your expectations met? Why or why not?

2. **Use of the Walker**

   a) Describe what happens when your child uses the walker.

      • Where is the walker used?

      • Who is with the child and what does that person do?

      • Where does the child go with the walker?

      • How does the child respond emotionally to using the walker? (e.g. eager to use the walker, has to be persuaded, refuses)

      • What does the child do with his/her hands while in the walker?

   b) How do you decide how often and how long your child uses the walker?

   c) What changes (if any) have you made to your home to enable your child to use the walker? (e.g. doorways widened, safety issues)

   d) What problems or challenges did you and/or your child encounter while he or she was learning to use the walker?

      • What concerns arose about the safe use of the walker?

      • How comfortable was the walker for the child to use?

      • How portable is the walker?

      • How accessible were support services such as physiotherapy?
3. Outcomes

a) What have been the major benefits of using the walker?

b) What have been the major drawbacks of using the walker?

c) What changes have you noticed in your child since he or she began using the walker?
   - What physical changes have you noticed in your child? (e.g. changes in muscle girth or strength)
   - What emotional changes have you noticed in your child? (e.g. confidence, frustration)
   - What developmental changes have you noticed in your child? (e.g. use of eye contact, use of arms and hands, changes in speech and communication)
   - What comments have others made about the walker? (e.g. siblings and other family members, teachers, peers)

4. Debriefing Questions

a) What would you tell another parent whose child is about to begin using the walker?

b) Is there anything else you would like to add about the experiences you and your child have had with the walker?
Appendix C: Detailed Findings of Content Analysis

1. Expectations

a) When you first learned your child would receive a walker, what were your expectations? Most parents indicated that they wanted their children to experience being upright, and to have a chance to try to take some steps. Many parents indicated that they wanted their children to experience being upright without the support from other people that they would normally require. Parents also said that they wished their children to experience more independence, and to be able to do more. Most parents felt that they had been very conservative and realistic in their expectations of their children. Parents involved in the study had been very eager for their children to participate, and conveyed having been very excited about the prospect of beginning the study.

b) (Child’s name) has used the walker for about a year now. Were your expectations met? Why or why not? Thirteen parents indicated that their expectations had been met, and of these, four said that they had been exceeded. Three parents indicated that their expectations had not been met, and three had mixed feelings. While some parents related the success of the study in terms of their children’s walking, most parents focused as well on the other benefits that their children had gained. These benefits were often unexpected for the parents. The areas most often focused on were increased independence, increase in self esteem, greater happiness, improved speech, greater awareness and attention, and improved use of hands and arms, as well as physical benefits such as stronger and larger leg muscles and greater trunk control for sitting. As well, many parents talked about the differences in how others, especially children, related to the child using the walker. Parents detected a significant difference in how other children regarded and related to the child in the walker as opposed to when the child was in a
wheelchair. Peers commented on the height of the child, expressed great interest in the walking, and interacted more frequently and more significantly with the child in the walker. The child was often included more in activities at school and in the home. Some parents hypothesized that the wheelchair presents a barrier, and sets expectations of dependence which the walker removes. Peers then relate more to the child as a capable person.

Three of the parents did not have their expectations met during the study. One of these parents found that his child needed a great deal of motivation to walk, and tended not to want to be in the walker. Two other mothers felt that their children had not made the progress that they had anticipated. Of the three parents with mixed feelings, one parent found that the child was not able to use the walker for mobility. Another thought that the child would be walking better, and found that her son needed a lot of motivation to get going in the walker. The third felt that her child's progress had been limited initially by her tendency to hyperextend in the walker, and once this had been corrected, by repeated illness.

2. Use of Walker

a) Describe what happens when your child uses the walker? Several parents related that their children “take off” when put in the walker. About half of the parents interviewed indicated that their children initiated their own activities, and go where they want to within the limits of their environment and abilities. The other half of the parents described needing to actively motivate their children and provide stimulating activities for them in order to initiate walking and/or ensure their contentment in the walker. Some parents found that considerable energy was required to find things that would motivate, stimulate, and entertain the children.

Most parents indicated that their children moved towards things, people and activities that motivated them. Six of the children walked considerable distances with the walker, and
used it for many activities. Six others used it for more limited walking for short distances and tended to spend shorter lengths of time in it. Seven others used the walker mainly for standing and exercise, taking occasional steps with supervision.

(i) Where is the walker used? The walker was used mainly at home and at school by these families. Four of the families did not use the walker at school because of difficulties incorporating the walker into the school routine, concerns about the lifting required or the unavailability of two people for lifting, concerns about safety, and, in one case, the child’s inability to walk at school because of excitement induced spasticity. At school, the walker tended to be used in the classroom for stationary activities, for moving between classrooms, and for gym. Most also used the walker outside, although for at least one child this was not possible because of concerns about safety and lack of available supervision.

In the home, children usually used the walkers in the kitchen, hallways, basement, and family room. Many parents indicated that their homes lacked space for walking. Rooms were often not big enough to allow much freedom, and corners were difficult for children to negotiate. Most of the children were described as having difficulty negotiating corners, and often getting “stuck”. Almost all parents experienced difficulties with doorways being too narrow to allow the child the space to negotiate their way through. Carpets were also described as a problem by most parents. Very few children could use the walker on plush carpets. Hardwood floors, ceramic tile and linoleum were cited as desirable floor materials for using the walker.

Outside, driveways and decks were the most common places for the children to use their walkers. Most children could not use the walkers on grass, although parents of two children specifically indicated that their children could. Most parents emphasized that flat, smooth
surfaces were needed. Many children used the walker on the street and around the
neighbourhood, particularly when they lived on quiet streets.

Beyond the home, children used the walkers at rehabilitation and recreation centres.
Some also used them in parks and malls. Many visited the homes of relatives. Several families
indicated that they had taken the walkers on vacation with them e.g. to a southern resort and up
to the cottage. These parents related that it was very difficult to use the walkers on the beach.
Other interesting places the walkers were used included churches, Cubs, an in-line skating ring,
the science centre, camps, and social functions such as dances. One parent had even taken her
son skating, by putting old fashioned strap-on skates on his shoes!

(ii) Who is with the child and what does that person do? Parents and school staff were
with the children most frequently. Other people included siblings and other relatives, peers,
friends, special support workers, and therapists. Parents supervised the children, walked along
side them when outside, helped them with their walking, helped them get around corners,
assisted them when they became stuck, encouraged them and provided activities for them.

Siblings and peers played with the children. Activities commonly included gross motor ball
games, such as soccer, baseball and water games, as well as stationary activities such board and
card games, painting and drawing, and playing with toys and puzzles.

(iii) Where does the child go with the walker? Parents all described that their children
walked towards things that interested them and motivated them. Many children actively
explored their environments, touching things, and sometimes getting into mischief pulling
things out of drawers and cupboards. Parents were delighted by this normal behaviour. Some
children could use things like computers, phones and remote controls for stereo and VCR.
They would often head for these, as they could control them. Many parents said that their
children were very inclined to walk towards other people, especially children, and pets. Likewise, when there was little in their environments that interested them, they were much less inclined to walk, and indeed, were less inclined to enjoy being in the walker. Parents described their frustration when their children would not “perform” their walking for an audience, e.g. at the rehabilitation centre when they were being assessed. In these situations, there was often little in the environment to motivate them.

(iv) How does the child respond emotionally to using the walker? (e.g. eager to use the walker, has to be persuaded, refuses) Twelve of the children were happy or very happy to be in the walker. About half of these children tended to be very enthusiastic, often smiling, laughing and otherwise demonstrating their excitement at the prospect of going in. These children wanted to be in the walker the majority of the time when asked. One of the children pointed to the walker when she wanted to go in, while another asked to go in unprompted. Only occasionally did these children not want to go into their walkers. The most common reasons for not wanting to go in it were tiredness or illness.

Six of the children had mixed emotional reactions to the walker. These children were sometimes reluctant. One child apparently enjoyed the walker about half of the time. Another one was usually reluctant to go in the walker, but his father believed that he was comfortable and happy once in it. Yet another child did not seem to care whether she was in the walker or not. Two of the parents indicated that the mixed reactions were attributable to discomfort and pain. Another parent pointed out the long procedure of buckling the child in.

The last child resisted the walker. He really did not want to go in it. His father suspected that he found it tiring and difficult to use. The child did seem to enjoy the walker
more during the summer because he got involved in activities that he would not normally have been able to participate in.

v) What does the child do with his/her hands while in the walker? It was often unclear from the parents’ descriptions what the children were doing with their hands independently, and what they were doing with assistance. Many parents indicated that their children had difficulty walking and using their hands at the same time. Many activities involving hands were stationary activities. Most parents had a table that their children could stand at to do activities such as painting, colouring, drawing, reading, writing, playing with toys, doing puzzles, etc... Some of these tables had been specially constructed or modified for the children. They were often in the kitchen, where the children went about their activities when their mothers were busy in the kitchen.

Many children ate and drank while in their walkers. Others helped with washing in the sink, laundry, cooking, baking and other household activities involving use of their hands. As mentioned earlier, some children used remote controls, computers and Nintendo. Others turned stereos and lights on and off. Several parents pointed out that their children would pick up objects while they stood, and get into drawers and cupboards. The children had never been able to do these things before. Gross motor activities included throwing balls, bean bags and darts.

Many parents indicated that their children used their hands more since beginning to use the Walker. These findings will be reviewed in the section on outcomes. 3 (c) (iii).

b) How do you decide how often and how long your child uses the walker? Most of the parents ensured that their children used the walkers daily, or almost daily. Three children used it less than this. While some children used the walkers at school during the day and then at home in the evening, most did not. The reasons most commonly cited for not putting children
in the walkers in the evening were that the children were too tired. there wasn’t enough time.
and the family was busy doing other things. Most of the parents put their children in the
walkers on a semi-structured routine, or when it was convenient and appropriate activities were
available for the children. Two of the parents had highly structured routines for use of the
walkers. Another asked the child whether she wanted to go in, and left the decision up to her.

The length of time spent in the walker ranged from about five minutes to three and a
half hours at a time. Most of the parents seemed to aim for their children to spend about an
hour in the walker, while four of the children regularly spent much longer in the walker, and
four generally spent less than an hour. Parents usually took their children out of the walkers
when the children asked to come out, or became uncomfortable or irritable. With the non-
verbal children, parents described how they knew when their children needed to come out.
Some children would stop moving and “sag” down in the walkers, while many would become
“whiney” or begin to cry. A small number of children would develop reddened pressure areas
if they had been in the walkers for too long. For the children who tended to be very
enthusiastic about using the walkers, tiredness and illness were the most common reasons for
occasionally not wanting to go in.

Several parents discussed the challenges of fitting the walker into the child’s schedule,
as well as the family’s schedule. Three parents related that their own energy levels were a
significant factor impacting walker use by their children. Finally, weather was another factor
that was seen to affect walker use. Most parents who commented on this had found that their
children used the walkers more in the nice weather because of the ease of use on pavement, and
the greater number of available activities.
c) What changes (if any) have you made to your home to enable your child to use the walker? Ten of the parents indicated that they had made specific changes to their homes to accommodate the walker. In most cases, these were fairly minor changes. Furniture was often moved to create pathways for the children. In at least 4 cases, families had arranged to have a table at a convenient height for the child. Sometimes these tables had been made, modified or bought. One parent described the need to move objects that were not previously within the reach of the child. Four families had made significant changes or were planning to do so. One family had ripped up carpets and installed hardwood floors. Another family was about to do the same. A third family had taken up the carpet that was becoming worn anyway. A fourth family was looking for a larger home to better accommodate the child with the walker. Several other families had already made changes to their homes over the past few years in order to better accommodate children using wheelchairs. They indicated that the changes required for wheelchairs and walkers were similar. Two parents had specific plans for the future. One had decided not to replace a carpet once it had worn out. Another had more extensive renovations in mind, including enlarging the kitchen and installing a wide ramp up to the front of the house. These changes would also be appropriate for wheelchair use. A few other parents also mentioned that they were prepared to make further changes in future, if their children began to use the walkers more.

d) What problems or challenges did you and/or your child encounter while he or she was learning to use the walker? The problem or challenge mentioned by parents most often was getting the children in and out of the walkers. Eight parents related this concern. The weight of the children, the need for two people to lift the children in, the tendency for children to become spastic when being put it, and the difficulties (especially during the first few weeks
of the program) in properly positioning the children and adjusting all the straps were the most common reasons parents gave for finding it difficult to get the children in and out of the walkers. Some parents also specifically mentioned problems with their backs or arthritis.

Six parents related that their children had experienced physical problems resulting from use of the walker, especially during the first few weeks. These included skin lesions and pressure areas, tender areas, sore muscles, and leaning on feet improperly. Six parents (generally the same ones who related physical problems) also discussed the challenge of needing frequent adjustments to the walker, especially during the first few weeks, but also on an ongoing basis as a result of the child's growth.

Five parents experienced difficulty with the walker from a technical perspective. Two had difficulty doing up the straps correctly. One of these parents tended to get the straps mixed up, and one found the straps difficult to do up, and hard on one's fingers. Another parent had difficulty with the latching mechanism, which became bent and rusty. Two parents had difficulty with loose or dislodged screws, and one found that the foam padding kept breaking.

Two parents related the challenges of teaching the child to use the walker. This was very time consuming, and one of the parents had found it very frustrating trying to help her child learn to turn corners. One parent described the numerous trips to the rehabilitation centre as being a significant challenge.

(i) What concerns arose about the safe use of the walker? Eight of the parents expressed concerns about tipping. While only one child had ever actually tipped, two or three other parents indicated that the walker had almost tipped, with two of the wheels coming off the ground. Seven of the parents emphasized the need for supervision of the children at all times. Other safety concerns expressed included potential detrimental effects on one child's foot
because of it being bent over while the child used the walker. concern expressed by two mothers about potential harm to children who sustained pinches and bruises (especially in the case of one child who did not tend to react to pain). and concern expressed by another parent about the back support of the walker potentially breaking off.

In terms of parental safety, two mothers related having had their fingers pinched, and one mother expressed concern about her back. This parent had had back surgery two years previously.

(iii) How comfortable was the walker for the child to use? Ten of the parents related that their children were comfortable in the walkers. Of the others, five indicated that the children were fairly comfortable. Two of these parents indicated that their children were much more comfortable at the time of the interview than they had been earlier on. Two parents indicated that it was difficult to tell, as their children were non-verbal. One parent related the tendency of the child to develop pressure areas. Four of the parents indicated that their children frequently experienced discomfort. Discomfort was seen to be related to muscles soreness and stiffness in two cases. pressure areas in one case, and foot pain in one case.

(iii) How portable is the walker? Ten of the parents told the interviewer that they found the walker portable. Many of these parents indicated that the walker was lighter and less cumbersome than a wheelchair. Almost all of them, however, had vans. Nine of the parents found the walker awkward and cumbersome. Five of these parents indicated that it was difficult to transport the walker because of its size. It was difficult to fit the walker into a car. Some parents had also experienced difficulty finding enough room for the walker in a van, especially when room was required for other equipment and family members. In one case, the school bus could not fit the walker, requiring the parents to transport the walker to school. Five
parents also related difficulties carrying the walker, especially through doorways. Other concerns about portability included difficulties getting the children in and out of the walker, especially when two people were required. Concerns about whether there would be appropriate places to use the walker at the other end of a journey, and problems with storing such a large item.

Many of the parents had taken the walker apart for easier transport. Some turned it upside down. Of interest is the wide range of opinion on this question. Parents with vans and small families did not tend to experience difficulty, while those without vans and/or with large families did.

(iv) How accessible were support services such as physiotherapy? Twelve parents indicated that support services such as physiotherapy were accessible. They were pleased with the support they had received from school therapists, community therapists, and staff at the rehabilitation centre. Parents were very impressed by the commitment of community therapists and centre staff. They described numerous instances when both community therapists and centre staff had gone out of their way to help the children and their families.

Five parents had mixed feelings. The most common concern was that their children were not receiving enough therapy, mainly PT and OT. These parents felt that their children needed more stretching, more attention from the school or community therapist, and more of the therapist's involvement with the walker.

Of the remaining two parents, one indicated that the community physiotherapist was not supportive of the walker because it did not allow the child to bend at the hips, which the therapist believed was necessary for development of walking. The other parent was not satisfied with the support received in the community or at the rehabilitation centre. This parent
was unhappy with the level of therapy at school, and felt that the walker should have been used at school more than the two days a week allotted in the schedule. The school therapist was not as interested in the walker as the mother would have liked, and the mother needed to transport the walker to school because it wouldn’t fit in the bus. In terms of the support received from study staff, the mother felt that the physiotherapist should have come to clinic appointments. She felt that there should have been more open dialogue with the therapist, especially as she had specific concerns. (The interviewer strongly encouraged this parent to discuss her concerns with clinic staff the same day.)

3. Outcomes

   a) Major benefits. Physical benefits were listed by 13 of the parents. These included exercise, increased endurance, increased muscle size and strength, and better bodily functions such as bowel movements. Increased independence was the benefit indicated second most often, by 11 parents. Third came increased interaction with others, increased socialization and improved integration. This benefit was cited by eight parents. Increased self confidence and/or self esteem was deemed a major benefit by eight parents as well. Improved speech was identified by seven parents. While several parents indicated that they did not know whether improved speech could be entirely attributable to the walker, they had often noted that their children spoke louder, and more often. Some children had also developed their vocabularies, and/or their ability to speak in sentences. Parents recognized that other factors, such as beginning school, had probably also played a significant role in language development.

   Five parents related the differences in the ways other children and people perceived the children using the walkers as a major benefit. Friends and family were seen to react differently to the children. One father stated: “He’s there, he’s a real person, he’s not just something, just
a boulder on the floor". Two mothers indicated that others were less likely to treat the children like infants. "It was really they saw her in a different light, and that was kind of good too, and not so much like she's a baby to be pushed around on a stroller." Siblings and other children realized how tall the children were when they were in their walkers. They took a greater interest in them, and interacted more with them. The appearance of the walker was seen to be conducive to this. It was seen to be less obtrusive than a wheelchair, and created less of a barrier.

Four parents indicated that their children had increased awareness of their environments since beginning to use the walker. The same number of parents cited increase motivation as a significant benefit. Standing in itself was described as a benefit by three parents, as was mobility by three others. These parents believed that the children saw themselves in a more positive way as a result of standing and/or walking. Two parents specifically said that they believed their children to be happier as a result of the walker. Other benefits noted by parents included increased activity levels, improved balance, increased trunk control, improved posture, improved sitting, increased and improved use of arms, reduced response time, increased range of motion, and increased eye contact.

b) Major drawbacks. The most common drawback cited by parents was the difficulty in getting the child in and out of the walker. This was found to be awkward, time consuming, and most importantly, difficult because of all the lifting involved. This drawback was mentioned by 11 parents. Portability was seen to be a major drawback by five parents. The limitations of the walker in terms of maneuverability and terrain it could be used on was seen to be a drawback by five parents as well. The difficulties of including use of the walker in the family's schedule and the time involved were cited by four parents. One of these parents
indicated that "it's a real high maintenance thing". The number of trips to the rehabilitation centre (i.e. 23), and the time required for traveling were seen to be major issues by four parents. These parents often needed to take vacation time off work, and needed to find someone else to accompany them on the trip. Parents traveling long distances often had to arrive the day before their appointment to ensure that the child was not too tired for his or her assessment. One of these parents also emphasized the costs involved in making the trips.

Other drawbacks identified by parents included anticipated problems with availability of the walker as children got bigger and older, and physical problems that children had developed as a result of the walker. The physical problems, identified by two parents, included tightness, increased spasticity, reduced ability to stand with support, and a foot turning over. Other drawbacks included the need for the child to be motivated to use the walker and safety issues. One parent felt that specific technical improvements could be made to improve the walker, and he had discussed these with the staff.

c) What changes have you noticed in your child since he or she began using the walker?

(i) What physical changes have you noticed in your child? (e.g. changes in muscle girth or strength) Sixteen of the parents identified changes, while three parents identified very little or no physical change that they could attribute to the walker. Of the 16 parents who identified changes, 10 identified positive changes only, 4 identified positive and negative changes, and 2 identified negative changes only.

Of the positive changes, 12 parents indicated that their children had gained size and strength in their muscles. One additional parent related that tone was more balanced, with a desirable reduction in tone in one leg. While calves and hamstrings were mentioned most often, abdominal muscles were also seen to have been positively affected. Improved use of
upper extremities was cited by 5 parents. Interestingly, 4 parents attributed an increase in their children's height during the study to use of the walker.

Improved use of lower extremities was mentioned by 3 parents, as were reduced chest congestion and fewer problems with constipation. Improved balance, posture, sitting, flexibility, range of movement, head control and general health were each cited by 2 parents. Improved cardiovascular health and fitness was mentioned by 1 parent, as were better sleep, fewer colds, and greater warmth in the feet.

Six parents had noted physical changes since their children had begun to use the walker that they saw as negative. Tightness was the most common one, noted by 4 parents. This tightness was most common in the legs, hamstrings, knees and hips. Two parents found that their children's legs tended to cross more as a result of walker use. Two found that their children didn't stand as well without the walker. One noted increased shaking, and 1 increased clonus. One child's hip became more dislocated during the study. Two parents noted negative physical changes without identifying any positive physical changes. These parents did, however, identify positive emotional and developmental changes.

(ii) What emotional changes have you noticed in your child? Of the 17 parents asked the question, 15 had noted positive emotional changes since their children had begun to use the walker. Two parents had not identified any emotional changes that they could attribute to the walker. Two parents were not asked the question. Of these, one parent conveyed positive emotional benefits, the other made no comments. None of the parents indicated that their children had experienced negative emotional changes.

Six parents indicated that their children had experienced increased self confidence and/or self-esteem since beginning to use the walker. Five indicated that their children enjoyed
increased independence. Five also indicated that their children interacted more with other children, and often tended to play longer with them. Seven parents indicated that their children were very happy when using the walkers. Two of these parents emphasized that they believed their children to be generally happier since beginning to use the walker. Two parents noted increased interest and activity level, 2 noted improved concentration, and 1 noted increased creativity.

(iii) What developmental changes have you noticed in your child? (e.g. use of eye contact, use of arms and hands, changes in speech and communication) Fourteen of the 19 parents indicated that they had noted positive developmental changes as a result of the walker. Of the other 5 parents, 2 had noted changes, but did not feel that these were attributable to the walker. The other 2 said that they had not noted any changes in this area. None of the parents identified negative developmental changes.

Ten parents said that their children used one or both hands and/or arms more. If the child had a hand that was less functional than the other, this was the hand that tended to show the most improvement. The children reached for objects more, grasped and held objects more, and tended to get into more trouble as a result of this! Another parent indicated that self feeding skills had improved, but was unsure whether this was related to use of the walker.

Nine of the parents conveyed that their children’s communication had improved. Two of the parents felt unsure how much the walker had been a factor in this. The parents indicated that their children vocalized or verbalized more often, and more loudly. In several children, significant gains in language development were noted.

Seven parents related improvements in awareness of self and/or the environment, improved attention, greater responsiveness or improved concentration. In many cases, parents
believed that these changes were dramatic. In 1 case, parents believed that the improved
congestion had led to a reduction in drooling. Six parents noted improved eye contact, but
some of these parents were unsure how much the walker had contributed to the improvement.
Three parents said that their children were more interested in doing things, and in learning.
Two parents felt that their children had developed spacial concepts since beginning to use the
walker. Other cited improvements included improved coordination and improved head
position.

While these changes may have seemed dramatic to the parents, 1 parent emphasized
their subtle nature. She doubted that people who did not know her child well would recognize
these benefits.

(iv) What comments have others made about the walker? All of the parents related that
almost everyone had made very positive comments about the walker. One mother said that her
husband disliked the walker, because of its size and the difficulty in getting the child in. One
parent conveyed that a therapist had not been positive about the walker. A couple of parents
indicated that school staff could have been more supportive. One mother indicated that while
her family was very supportive of the walker, they were concerned about potential injury and
stress to the mother because of the work and lifting involved. One father disliked the
appearance of the walker, but most parents were either indifferent or positive about the walker’s
appearance.

Many of the comments that the parents had received from others were very enthusiastic.
Parents indicated that others were “thrilled”, “impressed”, “intrigued”, “amazed”, and
“excited”. There tended to be great interest in the walker among people familiar with the child,
as well as parents of children with disabilities, and the general public as well. Many people had
seen the walker on television or heard about it. Several parents had been approached or called by people trying to get more information about the walker.

Family members, friends, and school staff were usually extremely supportive, encouraging, and very pleased with the progress of the children. They often recognized and pointed out the children’s accomplishments to the parents.

4. Debriefing questions

a) What would you tell another parent whose child is about to begin using the walker?

Most parents indicated that they would tell other families the benefits and the drawbacks. They emphasized the need to have realistic expectations, and to recognize that there are benefits to use of the walker beyond the walking. They emphasized the importance of taking things slowly, of not becoming frustrated, and of needing to put the time and energy into helping their children to use the walker. Almost all the families related that the program had been a very positive experience for them overall, and that it had been worth the hard work, time and effort. Even the parents who had the least positive experiences indicated that families should try the walker. Two parents expressed concern about how other families would obtain the walker once the study was over. They pointed out the high cost of the walkers, and the fact that parents in another province still had no access to the walkers despite having become interested in them before the parents in the province where the study was located.

b) Is there anything else you would like to add about the experiences you and your child have had with the walker? Many parents took the opportunity to thank people for the opportunity to have been involved. In many cases, they recounted the benefits to the child. Several parents expressed their belief that all children should have the opportunity to try the walker.
Four parents emphasized the difficulty with the number of trips to the rehabilitation centre, and recommended that services be developed closer to home to make the needed adjustments to the walkers. Two other parents expressed concern about the ongoing costs of using the walker once the study was over. One parent emphasized the problem with lack of portability.