INFORMATION TO USERS

This manuscript has been reproduced from the microfilm master. UMI films the text directly from the original or copy submitted. Thus, some thesis and dissertation copies are in typewriter face, while others may be from any type of computer printer.

The quality of this reproduction is dependent upon the quality of the copy submitted. Broken or indistinct print, colored or poor quality illustrations and photographs, print bleedthrough, substandard margins, and improper alignment can adversely affect reproduction.

In the unlikely event that the author did not send UMI a complete manuscript and there are missing pages, these will be noted. Also, if unauthorized copyright material had to be removed, a note will indicate the deletion.

Oversize materials (e.g., maps, drawings, charts) are reproduced by sectioning the original, beginning at the upper left-hand corner and continuing from left to right in equal sections with small overlaps.

Photographs included in the original manuscript have been reproduced xerographically in this copy. Higher quality 6" x 9" black and white photographic prints are available for any photographs or illustrations appearing in this copy for an additional charge. Contact UMI directly to order.

ProQuest Information and Learning
300 North Zeeb Road, Ann Arbor, MI 48106-1346 USA
800-521-0600

UMI®

University of Alberta

Evaluation of Powered Mobility Use by Children and Adolescents with Physical Disabilities in Alberta

by

Lesley Elizabeth Wiart ©

A thesis submitted to the Faculty of Graduate Studies and Research in partial fulfillment of the requirements for the degree of Master of Science

Department of Physical Therapy

Edmonton, Alberta

Spring 2002

0-612-69775-4

University of Alberta

Library Release Form

Name of Author:	Lesley Elizabeth Wiart
Title of Thesis:	Evaluation of Powered Mobility Use by Children and Adolescents with Physical Disabilities in Alberta
Degree:	Master of Science
Year this Degree Granted:	2002

Lesley Wiart

1 - 2nd Avenue
Ardrossan, Alberta T8E 2A2

March 1, 2002

University of Alberta

Faculty of Graduate Studies and Research

The undersigned certify that they have read, and recommend to the Faculty of Graduate Studies and Research for acceptance, a thesis entitled Evaluation of Powered Mobility Use by Children and Adolescents with Physical Disabilities in Alberta submitted by Lesley Elizabeth Wiart in partial fulfillment of the requirements for the degree of Master of Science.

Johanna Darrah

Johanna Darrah PhD

Al Cook PhD

Vivien Hollis PhD

Laura May PhD

January 28, 2002

To Johanna Darrah, my supervisor and mentor, whose support, confidence in my abilities, and dedication to teaching took me farther than I ever could have imagined. To Denis and Josh – without their patience, encouragement, and understanding I would have not been able to complete this project.

ABSTRACT

This study evaluated the use of powered mobility by individuals who received powered wheelchairs as children or adolescents. Structured telephone interviews were used to gather information on their use of powered mobility. A subset of five mothers completed additional interviews that were analyzed using a phenomenological approach.

Young children are successful long-term users of powered mobility. Powered mobility is introduced at young ages as 51.5% of the participants received powered mobility at 5 years of age or younger. Despite changing attitudes about the use of powered mobility, only children with the most severe physical disabilities are receiving powered wheelchairs.

Qualitative results revealed that mothers had both negative and positive initial reactions to powered mobility for their children. However, all mothers eventually considered powered mobility as a profoundly positive influence because of the independence and personal control it afforded their children.

The results of this study reinforce the need for clinicians to introduce the concept of an array of mobility options early in the management of children with physical disabilities.

ACKNOWLEDGEMENTS

I would like to express my appreciation to the many individuals who contributed to this thesis. First, I would like to acknowledge the Physiotherapy Foundation of Canada and the Alberta Physiotherapy Association for financially supporting this project. My appreciation to the staff at Alberta Aids to Daily Living (AADL), particularly Muriel Rogensack, for their assistance with the recruitment of participants for the study. To my friend and colleague, Lynda Schmidt for her encouragement and valuable suggestions throughout the preparation of this thesis. To my committee members, Dr. Johanna Darrah, Dr. Al Cook, Dr. Vivien Hollis and Dr. Laura May for their guidance and support and for making my experience as a graduate student so positive. Finally, I would like to extend a special thank you to the participants in the study, particularly the mothers who participated in the qualitative portion, for giving of their time so freely.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

Introduction to the Thesis

Over the past twenty years, there has been a shift in the philosophical framework used to guide intervention strategies in paediatric rehabilitation. This shift is characterized by less emphasis on the achievement of normal movement patterns and more emphasis on the attainment of effective and efficient methods of functional movement. In addition, with the emergence of family centered models of service provision, families are more involved in decision making regarding rehabilitation intervention strategies for their children. As applied to clinical practice in occupational and physical therapy, this shift is characterized by increased consideration of the use of augmentative mobility methods by younger children with physical disabilities. Traditionally only children with the most severe motor impairments were considered candidates for powered mobility, but now children with less severe physical disabilities can be offered powered mobility as one of an array of movement options. Families can consider powered mobility as an option when their children are very young which allows them to establish the best fit between mobility options and the movement and environmental demands of their lifestyles.

Statement of the Problem

Despite the recent shift in approaches to intervention with children with physical disabilities, there is a paucity of information in the literature describing the characteristics of children who receive powered mobility. Are children successful long-term users of powered mobility and what factors affect their success with powered mobility? Specifically in Alberta, Canada, there have been no evaluative studies to address these issues. Descriptive information about the use of powered mobility by children as well as the barriers and facilitators to powered mobility use experienced by these children would assist clinicians who work with children with physical disabilities and their families. Information about the actual use of powered mobility is also important to funding agencies as it may influence criteria used to guide funding for paediatric powered wheelchairs. Further understanding of perceptions and experiences of parents of children who have received powered mobility would also assist clinicians in their collaborations with families.

Aim of the Study

The aim of this study was to explore the use of powered mobility by individuals who received powered mobility at eighteen years of age or younger in the province of Alberta, Canada. The specific objectives of the study were to:

1) determine the proportion of individuals who continued to use powered mobility
2) describe the children and adolescents who receive powered wheelchairs and the extent to which they use them
3) identify barriers and facilitators to successful powered mobility use, and
4) explore, with a subset of participants, their experiences with their children's receipt and use of powered mobility.

Overview of the Thesis

A combination of quantitative and qualitative methodologies was used to address the four objectives of the study. A quantitative approach was used to address the first three objectives. A qualitative approach, phenomenology, was used to explore the experiences of mothers whose children had received powered wheelchairs.

The thesis follows a non–traditional format and consists of three distinct papers. The first paper, presented as Chapter 2, is a description of the factors that have contributed to the recent philosophical shift in paediatric rehabilitation and the influence of this change on the provision of powered mobility to children. In Chapter 3, the results of the quantitative portion of the study are reported. Chapter 4 is a summary of the qualitative results of the study. Chapter 5 consists of a synopsis of the results of both the quantitative and qualitative portions of the study. Clinical implications, plans for dissemination of the results and implications for future research are also addressed in Chapter 5.

CHAPTER 2

CHANGING PHILOSOPHICAL PERSPECTIVES ON THE MANAGEMENT OF CHILDREN WITH PHYSICAL DISABILITIES: THEIR EFFECT ON THE USE OF POWERED MOBILITY

Introduction

In paediatric rehabilitation, some researchers and clinicians believe the traditional paradigm based on the acquisition of "normal" movements has failed to adequately address important issues in the management of children with physical disabilities. Therefore, a new philosophical framework has emerged which suggests that successful movement may be achieved by modification of factors external to the child. As a result, traditional and contemporary paradigms exist concurrently in the rehabilitation management of children with physical disabilities.

Traditionally, children with physical disabilities were encouraged to attain the highest level of independent movement possible without the use of assistive devices (Furumasu, Guerette & Tefft, 1996). Motor skills were viewed as hierarchical, and therefore more value was placed on walking independently as the most "normal" method of mobility. Children were expected to walk as much as possible although ambulation may not have been the most functional method of mobility in all environments. The dominant model of motor development, the neuromaturational theory, encouraged intervention strategies that aspired to normalize movement patterns by changing the child. Modification of factors external to the child for the purpose of achieving successful movement was not valued as much as changing factors within the child (Valvano & Long, 1991). As a result, powered mobility was considered as a movement option for children with physical disabilities only when other methods of mobility were tried and deemed ineffective.

In the last decade, a new philosophy in paediatric rehabilitation has encouraged therapists to consider alternative methods of movement for children with physical disabilities. This philosophy is characterized by two concepts new to the management of children with physical disabilities. First, "normal" movement patterns and strategies may not always be the most efficient movement patterns for children with physical disabilities (Burton & Davis, 1992; Latash & Anson, 1996). Second, children with physical disabilities and their families may choose different mobility solutions depending on the environment and the context of the movement (York, 1989).

The purpose of this paper is to discuss the effect of the new paradigm on the exploration of mobility options, specifically, powered mobility by children with physical disabilities. Factors that have contributed to the emergence of the new paradigm are discussed individually and include: the disability movement, the evolution of models of disablement, the shift from a medical model to a family-centered model of health care service provision, the emergence of a new theory to explain motor development and increased availability of assistive technology. Finally, a collaborative approach to working with families throughout the process of selecting mobility options for their children is discussed.

The Disability Movement

Over the past fifty years individuals with disabilities have formed themselves into a socio-political movement fueled by their determination to attain equality and to eliminate longstanding oppression and exclusion (Johstone, 1998; Oliver, 1990). They have demanded the right to be proud of individual differences and not to conform to standards of normalcy determined by individuals without disabilities. The assumption that individuals with disabilities aspire to normalcy has been described as a highly oppressive experience (Morris, 1993; Richardson, 1972). In rehabilitation, some programs remain immersed in the traditional restorative model and therefore many service providers strive to "fix" or eliminate disability (Finkelstein, 2000; Kendall, Buys & Larner, 2000). The contribution of restorative approaches to rehabilitation to individuals with physical disabilities has been compared to the effect of the dieting industry on women due to our society's idolization of "a full and completely artificial conception of bodily perfection" (Giangreco, 1996 p.6). Intervention strategies in rehabilitation that encourage a focus on the achievement of "normal" movement assume that individuals with disabilities are dissatisfied with their bodies. This assumption contributes to the marginalization of individuals with physical disabilities (Middleton, 1999). Furthermore, the consideration of disability as a problem or deficit within the individual, with little consideration of society's role in the construction of disability, discounts the influence of social and legal barriers (Condeluci, 1995; Finkelstein & Stuart, 1996; Rioux, 1994a, 1994b). The "problem" of disability can be redefined as inadequacies within the community that limit participation in society (Condeluci, 1995). Therefore, the fact that a wheelchair user cannot access a bus can be attributed to a lack of accessible public transportation as opposed to inadequacies or deficits within the individual. Individuals with disabilities have facilitated the emergence of this conceptual shift in rehabilitation by contributing to models of disablement used to guide practice.

Models of Disablement

Prior to 1980, the medical model of disease was frequently used to describe the disease process. This model described the disease process in a hierarchical fashion from etiology to pathology to manifestation of disease (Wood, 1980). The medical model failed to address functioning and the possibility that restoration to a "normal" state may be neither possible nor desired by the individual with the disability. In response to the need to include functioning in a model of disablement, the World Health Organization (WHO) produced the International Classification of Impairments, Disabilities and Handicaps (ICIDH) in 1980 (Wood, 1980). The ICIDH was intended to enhance the medical model by categorizing abnormalities at the organ level (impairment), functional abilities (disability) and the "disadvantages experienced...as a result of impairments and disabilities" (handicap) (Wood, 1980, p.14). This model, although hierarchical in its conception, encouraged consideration that the presence of one level of the hierarchy did not necessarily lead to the next level. For example, an individual with significantly decreased range of motion of the hip joints (impairment) may still move around independently with a wheelchair (no disability). The ICIDH did not address, however, the significance of barriers external to the individual (Pfeiffer, 1998) and was seen by individuals with disabilities to be "grounded firmly in the principles of normalization" (Johnstone, 1998, p. 17). The underlying assumption of a model that focuses solely on deficiencies of functioning as a result of impairment is that the return to a "normal state" is ideal and achievable.

As a result of these concerns, the WHO incorporated contemporary philosophy into the most recent version of the ICIDH, the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). This model describes functioning using two components: 1) body functions and structures, and 2) activities and participation. Human function is depicted as the result of interaction between health conditions and various environmental or personal contextual factors. The addition of environmental contextual factors encourages consideration of facilitators and barriers to participation in society that exist external to the individual. This new framework reflects the conceptual shift towards acknowledging that aspects of disability are socially constructed and away from the assumption that barriers to functioning always exist within the individual. In addition, it encourages a shift in emphasis away from the basic level of impairment to issues that are more meaningful in the lives of all individuals such as community living, employment and educational opportunities. Concurrent with the shift in conceptual framework of models of disablement, came the challenge for health care professionals to evaluate philosophies of health care service provision for children with physical disabilities and their families.

Models of Health Care Service Provision

Models of health care service provision shifted dramatically during the later part of the twentieth century with the emergence of client-centered models of service (Leviton, Mueller & Kauffman, 1992). Traditionally, health care professionals employed a prescriptive, expert driven model of service provision with limited input from the family or the individual receiving service (Viscardis, 1998). In paediatric rehabilitation, recognition of the role of the family in the rehabilitation process has emerged within the past twenty years with the introduction of family centered service.

Family centered service is a philosophy of health care service provision based on the idea of family empowerment (Pearl, 1993). Under the philosophical framework of family centered service, it is assumed that parents know their children best (Rosenbaum, King, Law, King, & Evans, 1998) and that all families can function well with adequate social support and resources (Pearl, 1993). The family is recognized as the constant in their child's life, not the health care professional (Bailey, Buysse, Edmondson & Smith, 1992; Pearl, 1993; Shelton & Stepanek, 1994; Viscardis, 1998). Service providers collaborate with families to identify the needs and abilities of the child

(Brinker, Seifer, & Sameroff, 1994; Dunst, Trivette, Boyd, & Brookfield, 1994; Hanft & Pilkington, 2000; Lewis, Scott, Pantell & Wolf, 1986) provide information to families on options available to them (Galvin et al., 2000; Simeonson & Bailey, 1990) and work in partnership with families to implement intervention strategies (Simeonson, 1990). The intervention is defined by the unique needs of each family and not the constraints or framework of existing programs or services (Rosenbaum et al., 1998).

While the emergence of family centered philosophy in paediatric rehabilitation has directly influenced the extent of families' involvement in defining and implementing rehabilitation services for their children, a new theory to explain motor development challenged the assumption that the goal of intervention with children with physical disabilities should always be the attainment of typical movement patterns.

Models of Motor Development

The neuromaturational model, the traditional model of motor development, was widely advocated in the mid-1900's by McGraw (1945), Shirley (1931) and Gesell and Amatruda (1947). Although the role of the environment is not ignored in this model, development is seen as primarily the result of central nervous system maturation and accompanying inhibition of lower centers of the brain.

Neurodevelopmental treatment strategies that arose from this model emphasized changing the child through the attainment of "normal" movement patterns, with little regard for altering the task or the environment (Bobath, 1967; Bobath, 1971). Movement patterns deemed "abnormal" were discouraged as it was assumed that they contributed to permanent muscle contractures and subsequent lack of movement (Bobath, 1967). Independent ambulation with "normal" movement patterns was often the goal of therapy despite the fact that walking may have neither been the primary goal of the individual with the disability nor the most efficient way to move (Kibele, 1989; Latash & Anson, 1996; Richardson, 1972). Some clinicians and researchers are beginning to challenge the assumption that movement patterns used by persons without physical disabilities are more efficient than compensatory movement patterns for individuals with physical disabilities (Holt, Obusek & Fonseca, 1996; Jeng, Holt, Fetters & Certo, 1996; Latash & Anson, 1996). As Latash and Anson (1996) point out, the traditional perspective was based on assumptions including:

> 1) Patterns of voluntary movements seen in the general population are the only correct ones.
>
> 2) Deviations from "normal" patterns reflect a failure of the central nervous system to behave "correctly". (p.55)

A contemporary model of motor behavior, Dynamic Systems Theory (DST), considers the effect of interactions between person, task and environment on motor development (Darrah & Bartlett, 1995; Kelso & Tuller, 1984; Thelen, 1995). DST is a non-linear, non-hierarchical model that states that function drives behaviour, not preprogrammed instructions. Spontaneous self-organization results in the use of different movements strategies in different environments and with different tasks in response to constraints imposed on the system (Newell, 1986). Changes in movement patterns are due to changes in constraints on the system and are not exclusively the result of central nervous system maturation (Newell, 1986). Constraints may be environmental, task oriented or may come from within the child. DST, as applied to the management of children with physical disabilities, dictates that elements in the system, other than the child, can be altered to achieve success at a task.

Clinical applications of DST include Ecological Task Analysis (ETA) (Davis & Burton, 1991), the Person Environment Occupation (PEO) model (Law et al., 1996), Family-Centered Functional Therapy (Law et al., 1998) and the Human Activity Assistive Technology model (HAAT) (Cook & Hussey, 2002). In the ETA model, Davis and Burton suggest that aspects of motor behavior are a result of three sets of constraints: performer, environment and task. Using this model, optimal motor performance may be achieved by movement patterns that may not be considered "normal". Professionals who work with children with physical disabilities can assist children to discover their most functional movement patterns (Burton & Davis, 1992). The PEO model describes the ongoing dynamic relationships between the person, the environment and the occupation. Congruency between the three dimensions is indicative of the quality of a person's experience, which is defined as the level of satisfaction and functioning (Strong et al., 1999). Family-Centered Functional Therapy emphasizes the identification of constraints within the child, environment or task. Meaningful functional goals are identified collaboratively by the child, their family and the health care professional. The HAAT model emphasizes the importance of the interaction between human skills, the activity, the context of the activity and the assistive technology.

These four models share similar qualities that embrace contemporary beliefs regarding intervention. They encourage an array of movement options that depend upon the interaction of the task, the environment and the attributes of the child. They suggest that there is no one right way to move. Rather, there may be a variety of ways to achieve successful completion of a functional and meaningful task. Finally, they include the use of compensatory movements and assistive devices for the purpose of achieving a task as an acceptable movement solution. This conceptual shift was facilitated, in part, by the explosion of assistive technology knowledge and product availability.

Increased Availability of Assistive Technology

The availability and quality of assistive technology has increased dramatically over the past 20 years. Assistive devices such as augmentative communication systems, specialized computer access and powered wheelchairs have enabled children with physical disabilities to participate in age appropriate activities (Butler, 1988). Young children use sophisticated voice output systems as complicated communication software originally produced for adults has been adapted for children under the age of three (Hutinger, 1987). A multitude of alternatives for computer access for individuals with physical disabilities is now available including alternative keyboards, mouse emulators, mouse driven keyboards, software with word prediction capabilities, screen enlargers, touch screens, voice recognition software and eye-controlled input (Anson, 1997). Robotic arms have been used successfully by children with physical disabilities to engage in successful play experiences (Cook, Howery, Gu & Meng, 2000). Powered wheelchairs can now be customized to meet the needs of children as joysticks and switches can be mounted in various locations to allow easy access to controls. In addition, some paediatric powered wheelchairs can accommodate for the growth of a child and uneven terrain during play. These technological advances have enhanced the ability of children with physical disabilities to interact with and explore their environment.

Changing Perspectives on the Use of Powered Mobility

Under the assumptions of traditional philosophy in paediatric rehabilitation, young children may not have been encouraged to use a variety of movement options because it was assumed that the use of assistive devices would impede or prevent the attainment of higher level motor skills. For example, the introduction of a manual or powered wheelchair as a mobility option to a child who can walk short distances may be perceived as a deterrent to the child's ability to improve his or her walking abilities. The assumption that the child's most "normal" motor skill must be used to the greatest extent possible perpetuated a reticence by rehabilitation professionals to explore the early use of assistive devices.

As a result of this widespread belief, children with physical disabilities were encouraged to walk as much as possible despite the significant amount of energy that is required for them to walk (Kramer & MacPhail, 1994; Rose, Gamble, Medeiros, Burgos & Haskell, 1989). This attitude was also evident in the management of children with other medical diagnoses. For example, children with severe cognitive impairments received speech and language therapy to encourage the exclusive development of verbal communication instead of exploring a variety of nonverbal options, which may have resulted in the emergence of other communication strategies at younger ages (Coleman, 1979).

Contemporary philosophy encourages therapists to consider strategies that involve altering the task and environment rather than those that focus exclusively on changing the child (Butler, 1991). For example, success may be defined as the child's ability to keep up with his or her peers at school, regardless of how this task is accomplished. In addition, children with physical disabilities are now provided with an array of movement options as they may use different motor solutions in different environments to be successful with movement and to enable participation in meaningful activities (Butler, 1991). For example, a student with a diagnosis of spastic diplegic cerebral palsy who attends a large high school may walk for short distances in the classroom and use a powered wheelchair to move between classes. With powered mobility, he is able to keep up with his friends, arrive at classes on time and conserve his energy for learning.

This philosophy is also evident in intervention approaches associated with other developmental domains. For example, children with delays in communication skills are now encouraged to explore a variety of communication options that facilitate age appropriate expression to augment verbal communication skills (Dowden, 1999). Picture communication systems, sign language, and assistive technology devices are used for this purpose.

Recognition of the breadth of learning experiences gained from independent movement has also facilitated the shift towards the early use of powered mobility by some children with physical disabilities. Cognitive and psychosocial development are affected by the child's ability to move independently to explore his or her environment (Yarrow & Pedersen, 1976). Lack of opportunities for independent movement experiences may result in decreased motivation to move and feelings of incompetence, even in typically developing children (Rosenbloom, 1975; Zubek, Aftanas, Kovach, Wilgosh & Winocur, 1963). For example, learned helplessness, when a child gives up attempting to manipulate and explore their environment, has been identified in children with physical disabilities as young as three months of age (Brinker & Lewis, 1982). Many children with physical disabilities lack experience with independent movement as they must consistently rely on others for assistance. Use of a powered wheelchair or motorized cart has been advocated for children as young as 18 months for the purpose of affording the child the opportunity to learn through self-initiated exploration of their environment (Butler, 1988).

Research with children with physical disabilities supports the use of powered mobility by very young children (Butler, 1986; Butler, Okamoto & McKay, 1983). In addition, Butler (1986) reported positive effects on self-initiated behaviors including interaction with objects, communication and changes in location for children with physical disabilities between 23 and 38 months of age. These studies confirmed that very young children could learn how to drive powered wheelchairs successfully.

As the non-hierarchical model of provision of mobility options filters into clinical practice, many parents hesitate to explore wheelchairs, particularly powered wheelchairs, as a mobility option for their young children. The reasons for their hesitancy are unclear. They may perceive the introduction of powered mobility as "giving up" on their child's potential for walking; the powered wheelchair may signify a loss of hope. A socio-historical perspective suggests that parents may respond to intervention using the social perspective dominant when they first experienced the effect of their child's disability, even though philosophies change (MacKinnon & Marlett, 1984). Thus, parents who were initially introduced to traditional philosophies in rehabilitation may regard the use of powered mobility as a failure. Parents who experience an ongoing grieving process may also hesitate to explore powered mobility. Contemporary views on grieving the loss of the "perfect child" suggest that sadness recurs and is exacerbated at critical periods in the child's development, including the typical age of independent walking, puberty and graduation from high school (Teel, 1991). The introduction of a powered wheelchair at a young age may serve as a powerful reminder of their child's limitations and the possibility of stigmatization.

Parents may also be fearful that a powered wheelchair will emphasize their child's physical disability. Reasons for families' hesitation to explore powered mobility are complex and require further exploration and understanding.

Selection of Mobility Options: A Collaborative Approach

Families are more likely to experience successful community living when they are empowered to make their own life-defining decisions with the support of appropriate resources in their community (Kendall, 2000). Rehabilitation professionals can facilitate self-determination and community inclusion by introducing families to an array of early movement options and by supporting the family as the child implements the use of these mobility options in their community. Throughout the decision making process, families and clinicians can collaboratively explore the possibilities. They may identify solutions that would not have been identified by either party acting alone (Kendall, 2000). This approach encourages each family to determine which movement options are most appropriate for their child in a variety of environments and situations. An early awareness of all options available to them enables families to prepare their own supports for the future, including the purchase of a wheelchair accessible home or a van that may accommodate a hydraulic lift.

Given the evidence of the positive effects of independent meaningful movement experiences on childhood development, clinicians can convey to parents the potential benefits of powered mobility for their children. Parents also need to be informed of potential challenges with powered mobility such as specialized transportation needs and difficulty with accessibility in some environments, including their home. Only with all of the information can parents make informed decisions regarding mobility options for their children. Professionals can assist families by sharing information on the availability of resources to support the use of a powered wheelchair such as funding sources for a van lift or home modifications. Clinicians can play a role in increasing the appeal of powered mobility. Young children and families may prefer to use a small, motorized vehicle in a preschool environment prior to committing to a powered wheelchair.

The past decade has been an exciting time of change as perspectives in paediatric rehabilitation shift to meet the needs of children with physical disabilities and their families. The explosion of assistive technology has facilitated the philosophical shift, as powered wheelchairs are now available as a feasible and flexible mobility option for children with physical disabilities. Additional insight into how parents experience the introduction of powered mobility and the values that service providers place on it will enable professionals to assist parents in discovering the exciting possibilities that powered mobility has to offer as an early movement option for their children.

References

Anson, D. (1997). Alternative computer access: A guide to selection. Philadelphia: F.A. Davis Company.

Bailey, D.B., Buysse, V., Edmondson, R., & Smith, T.M. (1992). Creating family-centered services in early intervention: Perceptions of professionals in four states. Exceptional Children, 58, 298-309.

Bobath, B. (1967). The very early treatment of cerebral palsy. Developmental Medicine and Child Neurology, 9, 373-390.

Bobath, B. (1971). Motor development, its effects on general development, and application to the treatment of cerebral palsy. Physiotherapy, 57, 526-532.

Brinker, R., & Lewis, M. (1982). Making the world work with microcomputers: A learning prosthesis for handicapped infants. Exceptional Children, 49, 163-170.

Brinker, R.P., Seifer, R., & Sameroff, A.J. (1994). Relations among maternal stress, cognitive development, and early intervention in middle- and low-SES infants with developmental disabilities. American Journal of Mental Retardation, 98, 463-480.

Burton, A.W., & Davis, W.E. (1992). Optimizing the involvement and performance of children with physical impairments in movement activities. Pediatric Exercise Science, 4, 236-248.

Butler, C. (1986). Effects of powered mobility on self-initiated behaviors of very young children with locomotor disability. Developmental Medicine and Child Neurology, 28, 325-332.

Butler, C. (1988). High tech tots: Technology for mobility, manipulation, communication, and learning in early childhood. Infants and Young Children, 1, 66-73.

Butler, C. (1991). Augmentative mobility: Why do it? Physical Medicine and Rehabilitation Clinics of North America, 2, 147-159.

Butler, C., Okamoto, G., & McKay, T.M. (1983). Powered mobility for very young disabled children. Developmental Medicine and Child Neurology, 25, 472-474.

Coleman, C.L. (1979). Delayed Language. In M.V. Jones (Ed.), Speech and language problems: An overview. (pp. 49-67). Springfield, Ill: Charles C. Thomas.

Condeluci, A. (1995). Interdependence: The route to community. Winter Park, FL: GR Press Inc.

Cook, A., Howery, K., Gu, J., & Meng, M. (2000). Robot enhanced interaction and learning for children with profound physical disabilities. Technology and Disability, 13, 1-8.

Cook, A.M., & Hussey, S.M. (2002). Assistive technologies: Principles and practice (2nded). St Louis: Mosby Yearbook Publishing.

Darrah, J., & Bartlett, D. (1995). Dynamic systems theory and management of children with cerebral palsy: Unresolved issues. Infants and Young Children, 8, 52-59.

Davis, W.E., & Burton, A.W. (1991). Ecological task analysis: Translating movement theory into practice. Adapted Physical Activity Quarterly, 8, 154-177.

Dowden, P. (1999). Augmentative and alternative communication for children with motor speech disorders. In A.J. Caruso, & E.A. Strand (Eds.), Clinical management of motor speech disorders in children. (pp. 345-383). New York: Thieme.

Dunst, C.J., Trivette, C.M., Boyd, K., & Brookfield, J. (1994). Helpgiving practices and the self-efficacy appraisals of parents. In: C.J. Dunst, C.M. Trivette, & A.G. Deal (Eds.) Supporting and strengthening families: methods, strategies and practices (pp. 212-220). Cambridge, MA: Brookline Books.

Finkelstein, V. (2000). No ot's, you can't make me 'able'. Therapy Weekly, 26, 12.

Finkelstein, V., & Stuart, O. (1996). Developing new services. In: G. Hales (Ed.), Beyond disability: towards an enabling society (pp. 170-187). London: Sage.

Furumasu, J., Guerette, P., & Tefft, D. (1996). The development of a powered wheelchair mobility program for young children. Technology and Disability, 5, 41-48.

Galvin, E., Boyers, L., Schwartz, P.K., Jones, M.W., Mooney, P., Warwick, J., & Davis, J. (2000). Challenging the precepts of family-centered care: Testing a philosophy. Pediatric Nursing, 26, 625-632.

Gesell, A., & Amatruda, C. (1947). Developmental diagnosis: Normal and abnormal child development, clinical methods and pediatric applications. New York: Hoeber.

Giangreco, M.F. (1996). "The stairs didn't go anywhere!" A self-advocates reflections on specialized services and their impact on people with disabilities. Physical Disabilities: Education and Related Services, 14, 1-12.

Hanft, B.E., & Pilkington, K.O. (2000). Therapy in natural environments: The means or end goal for early intervention? Infants and Young Children, 12, 1-13.

Holt, K.G., Obusek, J.P., & Fonseca S.T. (1996). Constraints on disordered locomotion: A dynamical systems perspective on spastic cerebral palsy. Human Movement Science, 15, 177-202.

Hutinger, P. (1987). Computers, communication and young handicapped children: a winning combination. Closing the Gap, 9, 12.

Jeng, S.F., Holt, K.G., Fetters, L., & Certo, C. (1996). Self-optimization of walking in non-disabled children and children with spastic hemiplegic cerebral palsy. Journal of Motor Behaviour, 28, 15-27.

Johnstone, D. (1998). An Introduction to Disability Studies. London: David Fulton Publishers Ltd.

Kelso, J.A., & Tuller, B. (1984). A dynamical basis for action systems. In: M. Gazzaniga (Ed.), Handbook of Neuroscience. New York: Plenum.

Kendall, E., Buys, N., & Larner, J. (2000). Community-based service delivery in rehabilitation: The promise and the paradox. Disability and Rehabilitation, 22, 435-445.

Kibele A. (1989). Occupational therapy's role in improving the quality of life for persons with cerebral palsy. The American Journal of Occupational Therapy, 43, 371-377.

Kramer J.F., & MacPhail, H.E. (1994). Relationships among measures of walking efficiency, gross motor ability and isokinetic strength in adolescents with cerebral palsy. Pediatric Physical Therapy, 6, 3-8.

Latash, M.L., & Anson, G. (1996). What are "normal movements" in atypical populations? Behavioral and Brain Sciences, 19, 55-106.

Law, M., Darrah, J., Rosenbaum, P., Pollock, N., King, G., Russell, D., Palisano, R., Harris, S., Walter, S., Armstrong, R., & Watt, J. (1998). Family-centered functional therapy for children with cerebral palsy: An emerging practice model. Physical and Occupational Therapy in Pediatrics, 18, 83-102.

Law, M., Cooper, B., Strong, S., Stewart, D., Rigby, P., & Letts, L. (1996). The person-environment-occupation model: A transactive approach to occupational performance. Canadian Journal of Occupational Therapy, 63, 9-23.

Leviton, A., Mueller, M., & Kauffman, C. (1992). The family-centered consultation model: Practical applications for professionals. Infants and Young Children, 4, 1-8.

Lewis, C.C., Scott, D.E., Pantell, R.H., & Wolf, M.H. (1986). Parent satisfaction with children's medical care: Development, field test, and validation of a questionnaire. Medical Care, 24, 209-215.

MacKinnon, L., & Marlett, N. (1984). A social action perspective: The disabled and their families in context. In: J.C. Hansen, & E.I. Coppersmith (Eds.) Families with handicapped members. Rockville MD: Aspen Systems Corp.

McGraw, M.B. (1945). The neuromuscular maturation of the human infant. New York: Hafner Publishing Co.

Middleton, L. (1999). Building disadvantage. In: O. Stevenson (Ed.), Disabled children: challenging social exclusion (pp. 31-70). Oxford: Blackwell Science.

Morris, J. (1993). Independent Lives: Community Care and Disabled People. Basingstoke: Macmillan.

Newell, K.M. (1986). Constraints on the development of coordination. In: M.G. Wade & H.T.A. Whiting (Eds.), Motor development in children: Aspects of co-ordination and control (pp. 341-359). Boston: Martiners Nijhoff Publishers.

Oliver, M. (1990). The Politics of Disablement. London: Macmillan.

Pearl, L.F. (1993). Providing family-centered early intervention. In: W.Brown, S.K. Thurman, & L.F. Pearl (Eds.), Family-centered early intervention with infants & toddlers: Innovative cross-disciplinary approaches. Baltimore Maryland: Paul H. Brookes.

Pfeiffer, D. (1998). The ICIDH and the need for its revision. Disability & Society, 13, 503-523.

Richardson, S.A. (1972). People with cerebral palsy talk for themselves. Developmental Medicine and Child Neurology,14, 524-535.

Rioux, M.H. (1994a). New research directions and paradigms: Disability is not measles. In: M.H. Rioux & M. Bach (Eds.), Disability is not measles: New research paradigms in disability (pp.1-7). North York, ON: Roeher Institute.

Rioux, M.H. (1994b). Towards a concept of equality of well-being: overcoming the social and legal construction of inequality. In: M.H. Rioux & M. Bach (Eds.), Disability is not measles: New research paradigms in disability (pp. 67-108). North York, ON: Roeher Institute.

Rose, J., Gamble, J.G., Medeiros, J.M., Burgos, A., & Haskell, W.L. (1989). Energy cost of walking in normal children and in those with cerebral palsy: Comparison of heart rate and oxygen uptake. Journal of Pediatric Orthopedics, 9, 276-279.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: a conceptual framework and research review. Physical and Occupational Therapy in Pediatrics, 18, 1-20.

Rosenbloom L. (1975). The consequences of impaired movement - A hypothesis and review. In: K. Holt (Ed.), Movement and Child Development Clinics in Developmental Medicine. Philadelphia: Lippincott.

Shelton, T.L. & Stepanek, J.S. (1994). Family-centered care for children needing specialized health and developmental services (3rd ed.). Bethesda, Maryland: Association for the Care of Children's Health.

Shirley, M.M. (1931). The first two years: A study of twenty-five babies. Minneapolis: University of Minnesota Press.

Simeonson, R.J. & Bailey, D.B. (1990). Family dimensions in early intervention. In: S.J. Meisels & J.P. Shonkoff (Eds.), Handbook of Early Childhood Intervention New York, Cambridge University Press.

Strong, S., Rigby, P., Stewart, D., Law, M., Letts, L., & Cooper, B. (1999). Application of the person-environment-occupation model: A practical tool. Canadian Journal of Occupational Therapy 1999, 66, 122-133.

Teel, C.S. (1991). Chronic sorrow: Analysis of the concept. Journal of Advanced Nursing, 16, 1311-1319.

Thelen, E. (1995). Motor development: A new synthesis. American Psychologist, 50, 79-95.

Valvano, J. & Long, T. (1991). Neurodevelopmental treatment: A review of the writings of the Bobaths. Pediatric Physical Therapy, 3, 125-129.

Viscardis, L. (1998). Family-centred approach to providing services: a parent perspective. Physical & Occupational Therapy in Pediatrics, 18, 41-53.

Wood, P. (1980). ICIDH - International classification of impairments, disabilities and handicaps. Geneva: World Health Organization.

World Health Organization (2001). (ICF) International classification of functioning, disability and health. Geneva: World Health Organization.

Yarrow, L.J., & Pedersen, F.A. (1976). The interplay between cognition and motivation in infancy. In: M. Lewis (Ed.) Origins of intelligence. New York: Plenum Press.

York, J. (1989). Mobility methods selected for use in home and community environments. Physical Therapy, 69, 736-747.

Zubek, J.P., Aftanas, M., Kovach, K., Wilgosh, L., & Winocur, G. (1963). Effect of severe immobilization of the body on intellectual and perceptual processes. Canadian Journal of Psychology, 17, 118-133.

CHAPTER 3

Introduction

As a result of recent socio-political changes, more individuals with disabilities are integrated into society and are recognized as part of a diverse community. Children with disabilities attend community schools and participate in community recreation programs (Darrah, Wessel, Nearingburg & O'Connor, 1999; Schleien, Germ & McAvoy, 1996). To participate in these pursuits independently, many children require the use of augmentative mobility devices such as powered wheelchairs.

Prior to the early 1980's, powered mobility was considered as a mobility option only for older children with severe physical disabilities. Traditional rehabilitation approaches emphasized the achievement of "normal" movement through the attainment of a hierarchical set of motor skills. Working within this framework, many rehabilitation professionals were hesitant to explore assistive device alternatives with young children (Bottos et al., 1999; Wiart & Darrah, 2002) because of the assumption that the use of powered mobility interfered with attainment of higher level motor skills (Paulsson & Christoffersen, 1984). Only older children who could not walk or propel a manual wheelchair received powered mobility (Breed & Ibler, 1982).

Contemporary management approaches in pediatric rehabilitation such as Ecological Task Analysis (Davis & Burton, 1991), Family Centered Functional Therapy (Law et al., 1998) and the Human Activity Assistive Technology model (HAAT) (Cook &, Hussey, 2002) suggest that children can use different mobility choices in different environments. Children are encouraged to discover their most effective and efficient movement strategies to enable participation in meaningful activities (Burton & Davis, 1992). This perspective suggests that even children who can walk short distances or who are independent with manual wheelchair propulsion may use powered mobility in some environments.

Children as young as 17 months of age can learn to drive powered mobility devices successfully (Butler, Okamoto & McKay, 1983; Zazula & Foulds, 1983). Additional work by Butler (1986) suggests that use of powered mobility by young children may improve their social and cognitive development by enabling them to independently and spontaneously explore their environments. Lack of opportunities for environmental exploration by young children may interfere with social, cognitive and communication development (Becker, 1975; Brinker & Lewis, 1982).

Recent advances in the quality and versatility of assistive technology have made powered mobility a feasible and flexible mobility option for young children (Butler, 1988). These advances in assistive technology allow customization of the powered wheelchair and access system to meet the individual needs of children with physical disabilities.

Most research about paediatric powered mobility has focussed on the performance of particular brands and styles of powered wheelchairs (Deitz, Jaffe, Wolf, Massagli, & Anson, 1991; Wolf, Massagli, Jaffe, & Deitz, 1991) and clinical aspects of powered mobility such as predictors of successful powered mobility control (Tefft, Guerette & Furumasu, 1999; Verburg, 1987), driver readiness (Furumasu, Guerette & Tefft, 1996) and the effectiveness of a specific seating system in a powered wheelchair base (Pope, Bowes & Booth, 1994). Only one study (Berry, McLaurin & Sparling, 1996) explored lifestyle issues of children who use powered mobility and their families. They reported frequency and location of powered mobility use as well as concerns and needs of parents and caregivers of 36 children who used powered mobility. Difficulty with transporting the powered wheelchair and environmental accessibility were the most common barriers to powered mobility use expressed by the participants and caregivers in this study.

Despite the trend towards increased use of powered mobility by children with physical disabilities, information regarding families satisfaction with powered mobility and the actual use of powered mobility by children is lacking. This information is important for both families and therapists making decisions about powered mobility for children. With increased emphasis on cost effectiveness in health care, funding agencies also need information about the actual use of powered wheelchairs by children. A clear understanding of who uses powered mobility and the barriers and facilitators to continued use is needed to guide decision making by all parties.

The objectives of this study were to:

1) describe the characteristics of children and adolescents who receive powered wheelchairs
2) evaluate the longitudinal use or disuse of powered mobility by children and adolescents who were prescribed powered wheelchairs at eighteen years of age or younger
3) describe the extent and locations of use of powered wheelchairs by these participants
4) explore environmental (i.e. physical, social and attitudinal) barriers and facilitators to successful powered mobility use with the participants and their families

Method

The ethics review board provided ethical approval prior to initiation of the study.

Subjects

Potential participants were identified from the database of Alberta Aids to Daily Living (AADL), a government funding agency in the province of Alberta, Canada, by an employee of AADL. Eligible individuals had received a powered wheelchair at or before the age of 18 years. Individuals with degenerative medical conditions were excluded from the study as their medical conditions, rather than the factors described in the objectives, may have contributed to discontinuation of powered mobility use. Limitations in the government database precluded access to files of individuals who had received powered wheelchairs before 1991.

One hundred and ninety-seven letters were mailed to potential participants on two occasions, two weeks apart. The researchers received responses from 81 families expressing an interest in participating in the study. As the families responded directly to the researchers, AADL is unaware of the families who participated in the study. The response rate was 41.1%, a good response rate for a mail survey (Portney & Watkins, 1993). Of the 81 potential participants, 15 individuals were excluded either because of time demands or because they did not meet the inclusion criteria. Sixty-six individuals (40 male, 26 female) participated in the study.

Procedure

A structured telephone interview was used to gather information from the participants. Participants received a copy of the interview questions in the mail at least one week prior to the telephone interview. As some of the participants in the study were either very young or had difficulty talking on the telephone, many parents and caregivers completed the telephone interview (n=52). The participants who used powered mobility had the opportunity to share their responses with the family member or caregiver who completed the telephone interview prior to the interview.

At the beginning of the telephone interview, participants or caregivers provided verbal informed consent to participate. A physical therapist (LW) experienced working with children who use powered mobility conducted and tape-recorded all interviews. If the participant had discontinued using powered mobility at the time of the interview, the interviewer collected information on prior use of the powered wheelchair.

Interview Questions

The draft version of the International Classification of Functioning and Disability (ICIDH-2) was used as the conceptual framework for the development of the interview questions (World Health Organization [WHO], 1999). The ICIDH-2 draft version used three dimensions to describe human functioning: 1) body functions and structures, 2) activities at the individual level, and 3) participation in society. Human functioning is influenced by various positive or negative contextual factors, which may be environmental or personal. The final version of the ICIDH-2 has recently been released as the International Classification of Functioning, Disability and Health (ICF) (WHO, 2001). Although the title and organization of the final version has changed since the 1999 draft, the basic conceptual framework remained the same, although contextual factors, both environmental and personal, receive more recognition in the most recent version.

The interview consisted of 22 closed-ended questions and 4 open-ended questions (Appendix A). Participants provided the following descriptive information: medical diagnosis, age of receipt of their first powered wheelchair, methods used to transport the powered wheelchair, methods of mobility used at the time of the interview, frequency and location of powered wheelchair use and locations and nature of environmental barriers and facilitators to powered mobility use. The interviewer used the open-ended questions to probe for additional information regarding barriers or facilitators to powered mobility use. The interviews varied in length from 20 to 90 minutes. Participants had the opportunity to provide specific examples of their experiences and to elaborate on their responses.

A senior physical therapy student listened to and re-scored fifteen percent of the tape-recorded interviews to ensure reliability of response recording by the interviewer.

Data Analysis

Descriptive statistics were used to summarize information regarding the participants, their use of powered mobility and factors that hinder or facilitate successful use of powered mobility.

Results

Participants ranged in age from 4.5 to 27.5 years (mean=15.2 years, SD=6.2). Fifty-one of the participants had a medical diagnosis of cerebral palsy. The remaining participants had medical diagnoses of bilateral, above knee amputations (n=1), arthrogryposis (n=3), juvenile rheumatoid arthritis (n=1), osteogenesis imperfecta (n=1), spina bifida (n=3), tetraplegia due to spinal cord injury (n=2), traumatic brain injury (n=2), and non-progressive syndromes (n=2). Of the sixty-six participants in the study, 56 (84.8 %) used their powered wheelchairs at the time of the telephone interview. Mean age of receipt of the first powered wheelchair was 7.0 years (SD=4.3 years). Thirty-four participants (51.5%) reported receipt of their first powered wheelchair at five years of age or younger. Additional information regarding the participants is presented in Table 3-1.

Participants used their powered wheelchairs an average of 8.1 hours daily (SD= 4.1 hours), ranging from 5 to 16 hours per day. Mean weekly frequency of use was 5.5 days (SD=1.4 days). Locations of powered wheelchair use by the participants are presented in Figure 3-1. Individuals who had discontinued using their powered wheelchairs reported various reasons for their decisions including: concerns regarding safety (n=1), a poor fit between the specific type of powered wheelchair or access system and the user (n=4), a change in medical condition or functional abilities (n=2), and lack of success with using the powered wheelchair effectively (n=3). Participants reported alternate methods of mobility used at the time of the interview including: floor mobility (e.g. creeping, rolling or bottom shuffling) (48.5%), independent manual wheelchair propulsion (37.9%), manual wheelchair with assistance (95.5%), walking with canes (3.0%), walking with walkers (37.9%) and walking without assistive devices

Table 3-1 Participant Information

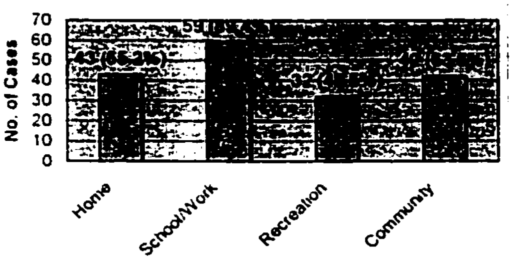
Medical Diagnosis (n)	Mean Age (SD)	Mean age P w/c received (SD)	Methods of Mobility Used					
			W– no AD	W – c/ w	M w/c – assist	M w/c no assist	FM	P w/c
Amputee (1)	7	6.5	0	0	1	0	1	1
Arthrogryposis (3)	16.6 (3.4)	5.0 (2.8)	0	0	2	1	2	3
CP – athetosis (4)	16.7 (6.9)	9.25(6.1)	0	1	4	1	2	1
CP – hypotonia (1)	14	8.0	0	0	1	0	0	1
CP–spastic diplegia (4)	11.7 (5.6)	7.3 (3.8)	0	4	4	3	3	4
CP–spastic quadriplegia (40)	14.2(6.0)	5.6(3.0)	0	17	38	13	21	35
CP–spastic triplegia (2)	14.5 (4.5)	4.5 (2.1)	0	2	2	0	2	2
Juvenile rheumatoid arthritis (1)	27.5	17.0	0	1	1	1	0	1
Osteogenesis imperfecta (1)	18.3	7.5	0	0	1	0	0	1
Spina bifida (3)	18.5 (2.4)	8.8 (4.5)	0	0	3	2	1	3
Spinal cord injury (2)	22.1 (6.2)	16.5 (0.7)	0	0	2	0	0	1
Traumatic brain injury (2)	25.8 (1.4)	14.0 (2.8)	0	1	1	2	0	1
Non progressive syndrome (2)	12.1 (7.1)	10.5 (7.8)	1	1	1	2	1	2
Total (66)	15.2 (6.2)	7.0 (4.3)	1	27	61	25	33	56

Legend

P w/c= Powered wheelchair
W-no AD = Walking - no assistive devices
W-c/w = Walking - canes or walkers
M w/c – assist = Manual wheelchair with assistance
M w/c no assist = Manual wheelchair without assistance
FM = Floor mobility
CP = Cerebral Palsy

(1.5%). Most of the participants (92.4%) required assistance with transfers into their powered wheelchairs, manual wheelchairs or walkers. Five participants reported the use of walking or independent manual wheelchair propulsion as functional methods of mobility for short distances in some environments while one participant reported walking and manual wheelchair propulsion as functional for him in many environments. The other participants who used canes or walkers reported walking as a form of exercise and change of position as opposed to a functional method of mobility. Many adolescents and adults (i.e. 40.6% of the participants aged 13 years of age or older) reported using floor mobility within their homes as a method of functional, independent mobility in this environment.

Figure 3-1 Locations of Powered Mobility Use



Forty-one participants (62.1%) reported that physical barriers at school and/or work adversely affected powered mobility use. Thirty-seven (56.1%) of the participants experienced physical barriers in community buildings, while 33 (50%) experienced barriers in the home. Nineteen participants (28.8%) reported the presence of physical barriers in community recreational facilities. Forty-seven of the participants (71.2%) reported difficulty with transporting the powered wheelchair. Many of the participants (n=39) used a personal van to transport their powered wheelchair. Two-thirds of the participants (n=44) utilized public transportation, primarily in the form of a local wheelchair accessible transportation service. Seven (10.61%) families lifted the powered wheelchair in and out of the back of their pickup truck, van or sports utility vehicle without using a lift or ramp. One family reported they had no way of transporting the powered wheelchair.

Discussion

The results of this study reveal some interesting findings about the current use of powered mobility by young individuals with physical disabilities. The discussion is organized by the four study objectives. Clinical implications of the results are discussed.

Who Receives Powered Mobility and Who Continues to Use It?

It is encouraging that many participants received their powered wheelchairs at young ages. This finding suggests that intervention strategies in rehabilitation have shifted away from traditional approaches that discouraged the use of alternative movement strategies with young children. Therapists and families now recognize that young children with physical disabilities need to independently explore and learn from their environment. Interestingly, parents voiced varying opinions about early introduction of powered mobility to their children. Two parents of children who received powered wheelchairs at 3 years of age felt that their children were too young to receive powered wheelchairs. Other parents expressed regret that their children did not have the opportunity to explore powered mobility at younger ages and reported trying to convince professionals of their children's readiness for powered mobility.

Physical and occupational therapists can facilitate children's success with powered mobility by ensuring that the introduction of powered mobility is guided by family centered principles. Powered mobility can be discussed as an option with parents of young children to ensure that each family makes the best decision for their unique circumstances. Phillips and Zhao (1993) reported that consumer involvement in the selection of assistive devices contributes significantly to successful long-term use of assistive technology.

The finding that most participants reported powered mobility as their only method of functional, independent mobility in the community suggests that powered mobility is still reserved for children with the most severe physical disabilities. Many children with less severe physical disabilities can walk by utilizing a large amount of energy (Rose, Gamble, Medeiros, Burgos, & Haskell, 1989). Some contemporary approaches to intervention with children with physical disabilities suggest that different mobility options may be needed in different environments and that therapists need to consider an array of movement options rather than generalizing the "most normal"' movement option to all situations (Burton & Davis, 1992; Darrah, Law & Pollock, 2001). Therapists need to consider the best fit between human skills, the activity, the context of the activity and the assistive technology (Cook & Hussey, 2002) when considering mobility options for children with less severe physical impairments. This perspective suggests that children who can walk short distances can use powered mobility to move for longer distances or to keep up with their peers. York (1989) observed that adults with physical disabilities who used wheeled mobility in the community were able to travel longer distances and participate to a greater extent than individuals with less severe physical impairments who walked in the community.

Clinicians can work closely with families of children who experience difficulty with walking or manual wheelchair propulsion for long distances to facilitate their understanding of the change in philosophy regarding the use of powered mobility. Changes in philosophy may be confusing and threatening to both therapists and families, and the use of powered mobility by less severely involved children needs to be evaluated closely. The following statement by one of the participants suggests that we need to re-consider the criteria for prescribing powered mobility: "I wish I would have had the power wheelchair when I was in school because I had to rely on other students to push me around and school was not fun because of that."

Where and to What Extent is Powered Mobility Used?

Many participants in the study used their powered wheelchairs in a variety of different locations. Although 65% reported using powered mobility in their homes, many participants considered the home environment impractical for powered mobility use. Reasons for not using the powered wheelchair in the home included: the existence of physical barriers, difficulties with transporting the powered wheelchair between school or work and home, access to other, more convenient mobility methods such as floor mobility or a manual wheelchair, the requirement for change of position out of the powered wheelchair, and the inability to afford financially extensive home modifications. Even older participants used different floor mobility methods such as creeping, crawling, rolling and bottom shuffling in their homes rather than a wheelchair. These movement choices have also been reported by York (1989) and they suggest that persons with physical disabilities are already independently choosing the best fit between individual abilities, mobility requirements and the environment. Given the physical constraints of using powered wheelchairs in the home, and the short distances required to move in that environment, it is not surprising that many individuals with physical disabilities choose floor mobility in their homes.

Participants repeatedly commented on the freedom that powered mobility allowed. Parents reported the joy of watching their child move freely to play with other children for the first time. Some participants described their powered wheelchair as their legs and experienced sadness or depression when their powered wheelchair was inoperable due to the need for repairs or maintenance. The consideration of the powered wheelchair as an integral part of the person has also been described by other researchers (Berry et al., 1996; Miles-Tapping, 1997).

The value participants placed on powered mobility was not directly related to the amount of time or number of locations they used their powered wheelchairs. A high school student, the only participant in the study who was proficient with independent manual wheelchair propulsion indoors at school and walking without assistive devices at home, experienced one of the most profound effects of powered mobility. Difficulty with effective manual wheelchair propulsion on the rough outdoor terrain of the school football field interfered with socialization with his friends. Although he initially feared potential stigmatization from his peers as a result of using a powered wheelchair, he discovered that the ability to move around outside with his friends made a tremendous positive contribution to his confidence and self-esteem. The importance of focussing on the value of participating in meaningful movement experiences instead of focussing on how movement is performed is clearly outlined by his experience and has been articulated by others (Kibele, 1989; Richardson, 1972).

What are the Barriers and Facilitators to Successful Powered Mobility Use?

Despite the recent changes toward universal accessibility in public buildings and transportation systems, significant barriers to successful use of powered mobility continue to exist. Almost all of the environmental barriers reported were physical in nature. Public buildings considered wheelchair accessible are not always easily accessible to individuals who use powered wheelchairs. Many participants shared their frustration with the inability of public washrooms to accommodate a powered wheelchair and a caregiver within the space designated as wheelchair accessible. As a result, families described returning to their homes to use their washrooms or changing their children on the floor in public washrooms. Some participants reported encountering automatic doors that were not easily accessible due to the awkward location or size of activation switches.

Some parents attributed lack of accessibility to societal attitudes toward individuals with disabilities. For example, a father of one of the participants attributed the prevalence of physical barriers in his community to the "inability of society to see the powered wheelchair as an integral part of the person who uses it". Another parent stated that anyone who builds an inaccessible building intended for public use "may as well put up a handicapped sticker with a line through it....They are making a bigger statement by not allowing access than by saying it." Other participants attributed inaccessible public buildings to a lack of knowledge in the community regarding the requirements for universal accessibility.

Transportation was one of the most significant barriers to successful powered wheelchair use for many of the families in this study. This finding supports the results of previous studies (Berry et al., 1996; Pope et al., 1994). The large size and weight of a powered wheelchair coupled with the rigidity of the frame, necessitates specialty adaptations to personal vans such as tie down systems, increased headspace and a ramp or mechanical lift system. The amount of effort required by the families who lifted the powered wheelchairs in and out of their vehicles made it challenging or impossible to incorporate powered mobility into their daily routines. The particular models used by these participants weighed between 70 and 120 pounds with the batteries removed.

Another difficulty reported by some of the families was the predominance of poorly planned wheelchair accessible parking in many public parking lots. Lack of space made it difficult to use a side mounted, mechanical van lift or ramp. Others reported having to walk a long distance on the street to access a cut out curb or ultimately lifting the powered wheelchair up onto the sidewalk.

Although families had more difficulty identifying the facilitators of powered mobility use, the most commonly cited environmental facilitators were the presence of well maintained, accessible sidewalks and curbs and accessible automatic doors. It should be noted that none of the individuals in this study discontinued use of powered mobility strictly because of barriers in the environment and therefore it becomes apparent that, for many individuals, the benefits of powered mobility outweigh the disadvantages.

Physical and occupational therapists who work with individuals who use wheeled mobility devices need to be aware of environmental barriers in their communities. Individuals with disabilities should be encouraged and welcomed to share their experiences with physical accessibility to increase public awareness of issues surrounding societal induced barriers to functioning. Educating community members as to the value and meaning of universal accessibility may facilitate change at the community level. Physical and occupational therapists can consult with government agencies in collaboration with individuals and families who have experienced limitations with physical accessibility to facilitate political change regarding these issues. In addition, therapists may continue to advocate for increased availability of funding for powered wheelchairs as well as the equipment required to support them such as van lifts or portable ramps. Continued advances in assistive technology, such as folding powered wheelchairs, and increased public awareness of the need for universal accessibility will likely address some of the issues shared by the participants in this study.

Conclusion

Young children with physical disabilities who have received powered wheelchairs at young ages can be successful long-term users of powered mobility. Despite this finding, parents and therapists may not always consider powered mobility as an early movement option for children who have other less efficient but more socially acceptable means of independent mobility. It appears as though the prescription of powered mobility continues to be primarily limited to children with the most severe physical disabilities.

Early introduction of the possibility of using powered mobility as a movement option allows families to prepare for modifications and adaptations to their lifestyle and may influence their choices of vehicles and housing. Powered mobility can be presented to families of young children as one of an array of mobility options. Some families may choose not to explore powered mobility because the perceived disadvantages of powered mobility outweigh the benefits in their particular situation. As with all mobility options, ongoing support and problem solving by therapists with families will facilitate long-term success with powered mobility use.

Limitations and Implications for Future Research

The convenience method of subject selection used to recruit the participants was a limitation in this study. It is possible that the actual proportion of current users and non-users differed from the proportions presented. It is also possible that the severity of impairment of the participants in this study was not representative of the range of severity levels in the population of powered mobility users.

Future research in this area could explore the perceptions and experiences of professionals who prescribe powered wheelchairs and powered mobility training to children with physical disabilities. The use of both quantitative and qualitative methods would serve to validate the findings of this study regarding the contributing factors to continued powered mobility use and the type of client who is considered for powered mobility. Research with this group could also explore the value that professionals place on powered mobility as a movement option for children with physical disabilities. This is important information as professionals' attitudes and perspectives may influence parents' willingness to explore powered mobility with their children. Finally, the effect of long-term powered mobility use on children's health and motor abilities also requires evaluation.

References

Becker, R.D. (1975). Recent developments in child psychiatry-clinical paediatrics liaison consultation. (I) The restrictive emotional and cognitive environment reconsidered: A redefinition of the concept of therapeutic restraint. Israel Annais of Psychiatry & Related Disciplines, 13, 239-258.

Berry, E.T., McLaurin, S.E., & Sparling, J.W. (1996). Parent/caregiver perspectives on the use of power wheelchairs. Pediatric Physical Therapy, 8, 146-150.

Bottos, M., Biolcati, C., Brunati E., Merlo, V., Pullini, F., Sciuto, L., & Ruggeri, C. (1999). Powered assistive devices and independence in severely disabled children: A study of 29 cases with tetraplegia. In: C. Bühler & H. Knops (Eds.), Assistive Technology on the Threshold of the New Millennium (pp. 362-366). Ohmsha: IOS Press.

Breed, A. & Ibler, I. (1982). The motorized wheelchair: New freedom, new responsibility and new problems. Developmental Medicine and Child Neurology, 24, 366-371.

Brinker, R.P. & Lewis, M. (1982). Making the world work with microcomputers: A learning prosthesis for handicapped infants. Exceptional Children, 49, 163-170.

Burton, A. & Davis, W. (1992). Optimizing the involvement and performance of children with physical impairments in movement activities. Pediatric Exercise Science, 4, 236-248.

Butler, C. (1986). Effects of powered mobility on self-initiated behaviors of very young children with locomotor disability. Developmental Medicine and Child Neurology, 28, 325-332.

Butler, C. (1988). High tech tots: Technology for mobility, manipulation, communication, and learning in early childhood. Infants and Young Children, 1, 66-73.

Butler, C., Okamoto, G.A. & McKay, T.M. (1983). Powered mobility for very young disabled children. Developmental Medicine and Child Neurology, 25, 472-474.

Cook, A.M. & Hussey, S.M. (2002). Assistive Technologies: Principles and Practice (2nd ed.). St Louis, MO: Mosby Yearbook Publishing.

Darrah, J., Law, M., & Pollock, N. (2001). Family-centered functional therapy - A choice for children with motor dysfunction. Infants and Young Children, 13, 79-87.

Darrah, J., Wessel, J., Nearingburg, P., & O' Connor, M. (1999). Evaluation of a community fitness program for adolescents with cerebral palsy. Pediatric Physical Therapy, 11, 18-23.

Davis, W. & Burton, A. (1991). Ecological task analysis: Translating movement theory into practice. Adapted Physical Activity Quarterly, 8, 154-177.

Deitz, J., Jaffe, K., Wolf, L., Massagli, T., & Anson, D. (1991). Pediatric power wheelchairs: evaluation of function in the home and school environments. Assistive Technology, 3, 24-31.

Furumasu, J., Guerette, P., & Tefft, D. (1996). The development of a powered wheelchair mobility program for young children. Technology and disability, 5, 41-48.

Kibele, A. (1989). Occupational therapy's role in improving the quality of life for persons with cerebral palsy. The American Journal of Occupational Therapy, 43, 371-377.

Law, M., Darrah, J., Pollock, N., King, G., Rosenbaum, P., Russell, D., Palisano, R., Harris, S., Armstrong, R., & Watt, J. (1998). Family-Centred Functional Therapy for children with cerebral palsy: An emerging practice model. Physical and Occupational Therapy in Pediatrics, 18, 83-102.

Miles-Tapping, C. (1997). Power wheelchairs and independent life styles. Canadian Journal of Rehabilitation, 10, 137-145.

Paulsson, K. & Christoffersen, M. (1984). Psychosocial aspects on technical aids - how does independent motility affect the psychosocial and intellectual development of children with physical disabilities? Proceedings of the 2nd International Conference on Rehabilitation Engineering, 282-286.

Phillips, B. & Zhao, H. (1993). Predictors of assistive technology abandonment. Assistive Technology, 5, 36-45.

Pope, P.M., Bowes, C.E., & Booth, E. (1994). Postural control in sitting the SAM system: Evaluation of use over three years. Developmental Medicine and Child Neurology, 36, 241-252.

Portney, L.G. & Watkins, M.P. (1993). Foundations of clinical research: Applications to practice. Toronto: Prentice Hall.

Richardson, S. (1972). People with cerebral palsy talk for themselves. Developmental Medicine and Child Neurology, 14, 524-535.

Rose, J., Gamble, J.G., Medeiros, J.M., Burgos, A., & Haskell, W.L. (1989). Energy cost of walking in normal children and in those with cerebral palsy: Comparison of heart rate and oxygen uptake. Journal of Pediatric Orthopedics, 9, 276-279.

Schleien, S.J., Germ, P.A., & McAvoy, L.H. (1996). Inclusive community leisure services: Recommended professional practices and barriers encountered. Therapeutic Recreation Journal, 30, 260-273.

Tefft, D., Guerette, P., & Furumasu, J. (1999). Cognitive predictors of young children's readiness for powered mobility. Developmental Medicine and Child Neurology, 41, 665-670.

Verburg, G. (1987). Predictors of successful powered mobility control. In K.M. Jaffe (Ed.), Childhood powered mobility: developmental, technical, and clinical perspectives. Proceedings of the RESNA First Northwest Regional Conference. (pp. 70-104), Seattle, WA: RESNA.

Wiart, L., Darrah, J. (2002). Changing Philosophical Perspectives in the management of children with physical disabilities: Their effect on the use of powered mobility. In press.

Wolf, L.S., Massagli, T.L., Jaffe, K.M., & Deitz, J. (1991). Functional assessment of the Joncare Hi-Lo Master power wheelchair for children. Physical and Occupational Therapy in Pediatrics, 11, 57-72.

World Health Organization (1999). ICIDH-2. International classification of functioning and disability. Beta-2 draft. Short version. Geneva: World Health Organization.

World Health Organization (2001). ICF. International classification of functioning, disability and health. Geneva: World Health Organization.

York, J. (1989). Mobility methods selected for use in home and community environments. Physical Therapy, 69, 736-747.

Zazula, J.L. & Foulds, R.A. (1983). Mobility device for a child with phocomelia. Archives of Physical Medicine and Rehabilitation, 64, 137-139.

CHAPTER 4

MOTHERS' EXPERIENCES WITH THEIR CHILDREN'S USE OF POWERED MOBILITY

Introduction

Physical and occupational therapists frequently assist and support parents of children with physical disabilities throughout the process of selecting and implementing mobility devices, including powered wheelchairs, with their children. The shift away from traditional, expert driven models of health care service provision toward family centered, collaborative models has resulted in increased parental involvement in the choice of appropriate mobility options for their children. Parents' lifestyles and personal beliefs will influence their choices and perceptions of assistive mobility devices.

To date, research regarding children's use of powered mobility has addressed performance of particular powered wheelchairs designed for children (Deitz, Jaffe, Wolf, Massagli, & Anson, 1991; Pope, Bowes & Booth, 1994; Wolf, Massagli, Jaffe, & Deitz, 1991), young children's abilities to drive powered wheelchairs (Butler, Okamoto, & McKay, 1983; Zazula & Foulds, 1983), the effects of powered mobility on self-initiated behaviours of young children (Butler, 1986), and the clinical and technical aspects of powered mobility (Furumasu, Guerette, & Tefft, 1996; Teft, Guerette, & Furumasu, 1999; Verburg, 1987). Two groups of researchers (Berry, McLaurin & Sparling, 1996; Wiart, Darrah, Cook, Hollis, & May, 2002) explored children's use of powered mobility and reported outcomes such as age of attainment of powered mobility, hours and locations of powered wheelchair use and barriers to successful use of powered mobility. No researchers have focused specifically on parents' personal experiences with the introduction of powered mobility to their children. An understanding of the meaning parents associate with their children's use of powered mobility would enable physical and occupational therapists to assist families more effectively with the exploration and use of powered mobility with their children.

The purpose of this study was to explore the experiences of parents whose children use powered mobility. A qualitative approach, phenomenology, was selected as the most appropriate methodology for this purpose. As the phenomenological approach is not frequently used in rehabilitation research, the procedures and methods used are described in the corresponding sections of this paper.

Methodology

Nature of the Phenomenological Approach

Phenomenology is a research approach derived from the philosophical perspective of phenomenology and is based on the work of Husserl, Heiddeiger, Merleau-Ponty, Giorgi and others (Cresswell, 1998). Phenomenology is used by the researcher to explore the meaning of lived experiences for a group of individuals who have experienced a phenomenon of interest. The purpose is to discover the common structure or "essence" of the phenomenon (Moustakkas, 1994), thus facilitating insight and understanding of the lived experience of the participants.

Hypotheses are not determined "a priori"; rather the researcher allows the data to emerge from the words of the participants. A procedure called bracketing or "epoche" is employed by the researcher to identify and "suspend" his or her personal presuppositions, assumptions or biases that may influence researchers' interpretation of participants' experiences (Osborne, 1990). Although it is not always possible to completely "suspend" all biases, bracketing serves the valuable purpose of informing readers of the perspective from which data were analyzed. This study was conducted and summarized from the perspective of the first author.

My Experiences With and Perspectives Regarding Pediatric Powered Mobility

I have worked with children with physical disabilities and their families in rehabilitation and educational settings. I am particularly interested in the perceptions of both rehabilitation professionals and parents that influence the selection of mobility options for children with physical disabilities. I believe children with physical disabilities need independent, efficient methods of mobility in order to experience spontaneous play and meaningful exploration of their environment. Families should be provided with an array of options from which they can choose the best fit with their lifestyle and mobility requirements of their children.

In my experience working with families of children with physical disabilities, I have encountered a variety of reactions from parents towards the use of wheelchairs by their children. Some parents welcome another method of mobility while other parents are hesitant to "give up" on walking or explore a device they perceive as stigmatizing to their child. I believe that gaining insight into parents' experiences will enable me to be more effective in my collaborations with families.

Procedure

Ethical approval from the appropriate ethical review board was obtained prior to initiation of the study.

Participant Selection

For this study, five participants were randomly selected from a group of 66 participants who participated in a study evaluating children's use of powered mobility (Wiart et al., 2002). Although individuals with acquired injuries were included in the quantitative evaluation study, they were not included in the selection pool for this study because of concern that the experiences of families who are faced with the decision to use powered mobility following an acquired injury would differ from the experiences of families of children with non-progressive neurodevelopmental disorders such as cerebral palsy or spina bifida. Five subjects is an acceptable number of participants for a phenomenological study (Polkinghorne, 1989).

Table 4-1 Participant Information

Participants*	Child's Name	Age	Age first powered wheelchair received	Medical Diagnosis
Gail	Trevor	11	3	CP
Sheri	David	10	4	CP
Helen	Cheryl	18	5	SB
Elaine	Mary	10	7	CP
Linda	Zachary	10	5	CP

Legend

*Pseudonyms have been substituted to ensure anonymity of the participants

CP = Cerebral Palsy

SB = Spina Bifida

The mothers of the selected children participated in the qualitative interviews. Table 4-1 provides some descriptive details about the mothers who participated in the study and their children who use powered wheelchairs.

Data Collection

In phenomenology, data are collected through personal interviews with the participants. Data collection in this study occurred in two phases: 1) a one hour data collection interview in the homes of the participants and, 2) an opportunity to corroborate the interpretation of the data with the participants. Informed consent was obtained prior to initiation of data collection.

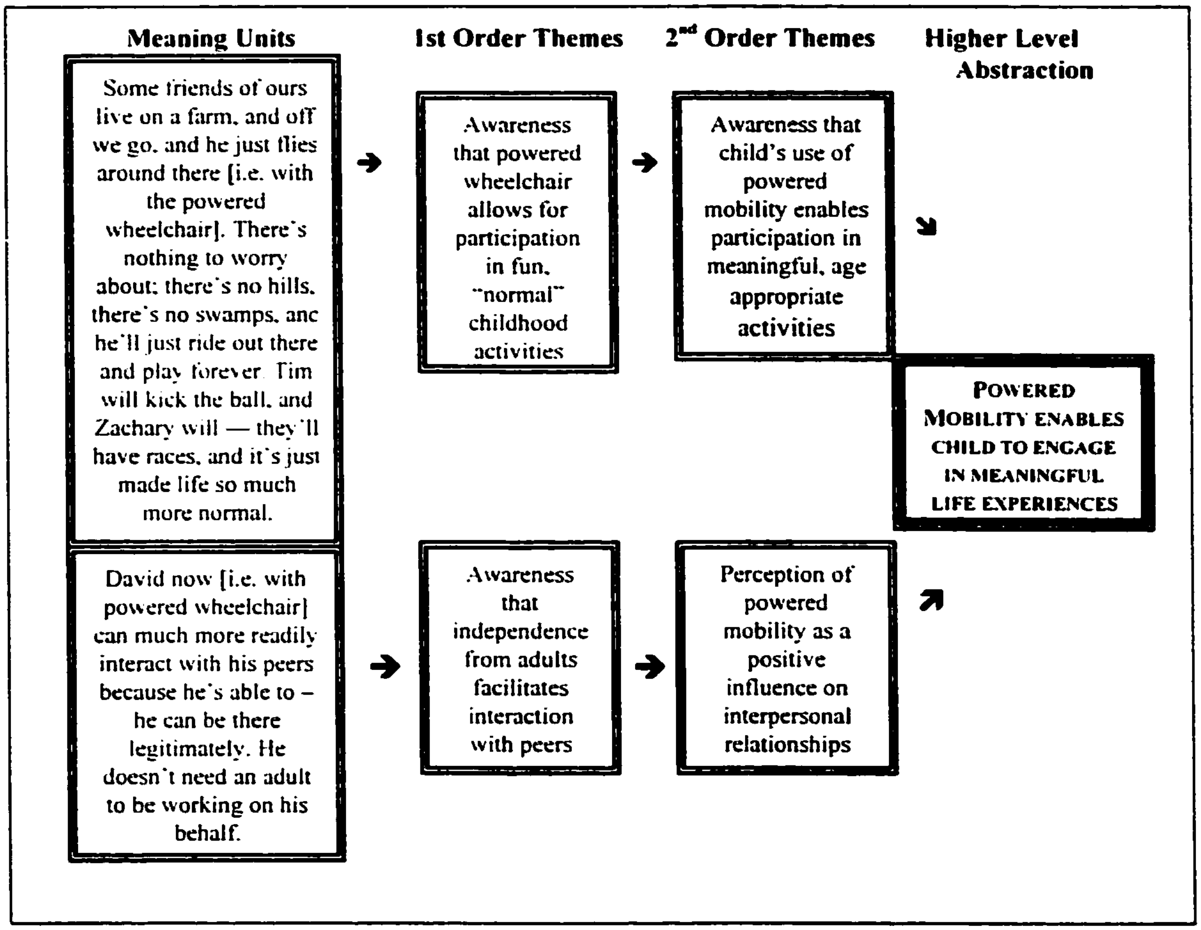
The data collection interviews with the participants were guided by semi-structured, open-ended questions (Appendix B) designed to explore their lived experience with their children's use of powered mobility. The interviews took place in the homes of the participants. Interviews were tape recorded and subsequently transcribed for data analysis. Names and other identifiable information were altered to ensure anonymity of the participants and their families.

Corroboration of interpretation of data occurred over the telephone with the participants. The results of the data analyses were received by the participants prior to the corroboration interviews to allow them to reflect upon the accuracy of interpretation of the data.

Data Analysis

The methods of phenomenological data analysis described by Collaizzi (1978) and Osborne (1990) were used to analyze the data. The first author read all the transcripts and extracted meaning units, excerpts revealing of participants' experiences with their children's use of powered mobility. A total of 112 meaning units were identified from the transcripts of the five interviews. The meaning units were paraphrased to facilitate accurate abstraction of first order themes. Meaning was abstracted from the paraphrases to create first order themes (Appendix C). Next, the first order themes were clustered into eight, more abstract, second order themes (Appendix D). Finally, the second order themes were consolidated into five, more general, higher level abstractions. The higher levels of thematic abstraction were used as the framework to guide presentation of the results. A visual representation of the process used to analyze the data using two examples is presented in Figure 4-1.

Figure 4-1 Visual Representation of Data Analysis Process



Results

Results of the study are presented in Table 4-2. The 5 higher level abstractions identified across the participants are presented. The eight second order themes are presented as subcategories under the higher level abstractions. The higher level abstractions are used as the framework for the presentation of results.

Table 4-2 Higher Level Abstraction of Second Order Themes

1. **Experiences Associated with Dealing with Child's Disability**
    - Adjusting to child's physical disability
    - Perception that wheelchair is last resort mobility option: giving up on hope
2. **Powered Mobility Enables Child's Independence and Increased Personal Control**
    - Perceived importance of and desire for child's independence
    - Positive perception of degree of independence and increased personal control powered mobility allows for child
3. **The Environmental Barriers to Powered Mobility Use**
    - Awareness of environmental (i.e. physical, attitudinal or political) barriers that interfere with use of powered mobility
4. **Powered Mobility Enables Child to Engage in Meaningful Life Experiences**
    - Perception of powered mobility use as a positive influence on interpersonal relationships
    - Awareness that use of powered mobility enables child's participation in meaningful, age appropriate activities
5. **Awareness of the positive effect of child's use of powered mobility on attitudes of others**
    - Perceived impact of the use of powered mobility on other's perception of child, knowledge of disability issues and attitudes toward individuals with disabilities

Experiences Associated with Dealing with Child's Disability

The mothers in this study experienced feelings of sadness and despair that occurred when they became aware of their children's physical disabilities. Most of the participants shared that the decision to consider manual wheelchairs for their children was a very difficulty experience. The wheelchair served as a salient, unwanted indication of their child's disability. Linda shared:

> Then when we came to "Okay, now we have to look at a manual wheelchair," I really struggled with that, 'cause that was just a real — it's in your face he's got a disability, and you've got to deal with it, so that was really tough.

Although negative reactions towards their children's exploration of manual wheelchairs were prevalent, the nature of the mothers' reactions to the suggestion of powered wheelchairs varied. Linda struggled with accepting the powered wheelchair more so than the manual wheelchair. She remained hopeful that her son would eventually walk even though he used a manual wheelchair, and the suggestion of a powered wheelchair was a distinct indication that walking was not possible:

> The power wheelchair was the really big step, although when we first started talking wheelchairs and they had said, "Oh, possibly a power wheelchair," I got my back up, thinking going in a manual wheelchair was hard enough....At that time, I was still thinking, "Okay, maybe one of these days, he'll get up and he'll walk, and we don't need this." Then going into a power wheelchair, it was kind of a realization that "No, he isn't going to be able to walk, and in order to have some independence, we have to look at power mobility." So it was a little tough.

Other participants described considering a manual wheelchair for their children as more difficult than exploring powered mobility. The powered wheelchair, as hope for their children's independence, was welcomed with relief:

> I have a distinct recollection of this [manual] wheelchair sitting in our house, and feeling very, very sad, and... thinking, "This is what our life is going to be like."... I wasn't ever quite sure how we were going to get beyond that point. So when the idea of a power chair was presented...that actually was a great source of relief for me and it was a good thing.

Although Linda was the only mother who expressed the exploration of powered mobility for her son as a negative experience because it forced her to deal with his disability, she described a life altering realization that enabled her to accept her son's disability as part of his identity:

> ...as a parent, you're always a little bit self-conscious [i.e. of having a child with a disability], and I think that was more my issue, that wasn't Zachary's. At that time, that was when my husband and I came to the realization that if we want Zachary to be proud of who he is, we have to be proud of who he is, and we can't care about what other people think. I mean, everybody knows that, but to actually live it and practice it is another story. After that, it was "That's right, this is who he is, and we're very proud of who he is and how well he's done."

The participants frequently referred to powered mobility as the last mobility option considered because their children were not successful at moving in other ways. Receipt of a wheelchair, either manual or powered, was viewed as a symbol that walking was not a possibility for their children and, as such, it symbolized giving up on hope: "At first [after receiving the powered wheelchair], it was a realization that he's not going to independently walk, more than likely, ever, unless some miracle cure comes up. So that was kind of sad." Sheri shares her experience:

> The greatest challenge was dealing with David having a manual chair...because what that said to us was that the health professional did not believe that David had potential to be independent on his own, or mobile on his own. So that was a real struggle for me and for all of us.

The experiences shared by these parents reveal how they viewed the receipt of wheelchairs for their children as synonymous with giving up hope for other independent methods of mobility.

Powered Mobility Enables Child's Independence and Increased Personal Control

All of the mothers expressed a desire for their child to have a means of independent mobility. One mother recalled her experiences with health care professionals; trying to convince them she was being reasonable in her expectations for her son: "I don't expect him to be an NHL star, but I would like to see him having as much independence as possible". Gail shared a similar perspective: "Just the more independent he can be, the prouder we are. We've always tried to give him that sense of independence, and the self-esteem is very important, and he's got that."

All of the participants shared positive experiences with the amount of independence powered mobility afforded their children. Clearly, the experiences with their children's use of powered mobility were a source of tremendous excitement, joy and pride. Sheri described an emotional moment of emancipation:

> David got in his chair, and even though this was a completely new environment and a new thing for him — he'd never been at this before — he just sailed on into the camp meeting area where registration was, and he was going around — and he's a real social butterfly — chatting with everybody...I was just blown away, because I had never, ever understood that David had the capacity nor would have the opportunity to do something like that, and it was just a real emancipation moment for

> everybody — for me, as a parent — knowing he can easily negotiate life on his own, and he has the ability to be independent.

A similar realization is experienced by many parents as they realize their children have begun to live their lives independently from their parents. The experience Sheri articulates, however, is greatly intensified, as she had never realized that David had the potential to be independent.

The mothers repeatedly expressed how powered mobility enabled their children to make meaningful and age appropriate decisions on a daily basis. Gail shares her experience:

> Just makes a big difference to him to be included. Just like any other kid, he wants to do the same thing and he wants to be with them. That's the benefit that the chair has....Or he can be away from them [i.e. his peers] if he wants to. That's his choice.

The Environmental Barriers to Powered Mobility Use

Participants shared their experiences with barriers to obtaining powered mobility and then in using it successfully. One mother described the initial attitudes of professionals when she wanted to pursue powered mobility for her son:

> ...they were a little bit tentative at first, the professionals, in dealing with us in what we wanted for him, so I think there was a little bit of education that went on both ways. Our desire to make him more mobile so he can do more things, and their reluctance in fitting him with different things, and part of that was probably the cost.

Participants also shared their experiences with the presence of physical barriers in the environment. One of the parents expressed frustration with the difficulties associated with transporting the powered wheelchair: "...we have this wonderful power chair, but we can't take it anywhere! So that became a source of frustration."

Powered Mobility Enables Child to Engage in Meaningful Life Experiences

The mothers frequently identified the independence gained with powered mobility as necessary for their children to be able to establish meaningful relationships with other children. Linda articulates her perception:

> ...it [i.e. powered wheelchair] gives him independence to go play with his friends. At lunch hour, he can go out and wander around the playground with the kids, do everything within his ability that the other kids do, and they don't look at him as, "Oh, God, we have to push the wheelchair, we have to bring him along." It's not like that, 'cause he can join in. So again, I think that's really helped build strong relationships. They look at him as a whole person.

Clearly, Linda views the powered wheelchair as the means for removing the "burden" that other children may experience should they have to make an effort to include Zachary in their play activities.

Participants also expressed how their children's participation in age appropriate, enjoyable and meaningful activities is facilitated by the use of powered mobility. Statements by a few of the participants exemplify the joy they experience from watching their child participate in everyday childhood activities as expressed in the following examples:

> We'll go out to the park, and we'll put him in number 4 speed, and we'll go out on the field by the school, and my husband hooked up a kite, and he'll just go, and the kite's flying, and it's a beautiful thing to see, for him to be able to do that.

> David played baseball this year, so he was able to run the bases in his power chair, which he could never have done beforehand. He would have been really relying on somebody pushing him around, which isn't the same thing.

> He helps now with setting the table. Again, that's what an 11-year-old boy or 10-year-old boy should be doing. He should have responsibilities. Whereas beforehand, when he was in his manual chair, I'd push him over, he'd get hand over hand assistance, and I'd push him back. And I'm thinking, "I could have this done in 5 seconds. This is taking me half an hour!" And it's not a dignified experience for David....[i.e. now, with the powered wheelchair] he's doing what is appropriate for him, given his limitations, but also it's what should be expected of him.

Awareness of the Positive Effect of Child's Use of Powered Mobility on Attitudes of Others

Many of the parents commented and shared stories about how they perceived their child's use of a powered wheelchair affected other's attitudes towards their children:

> So for him to be able to be in his power wheelchair and not have somebody

> hovering over him ...for him to be able to go and drive up somebody's driveway and go, "Hi, how are you?" right away, they see him for who he is. He's not this pathetic little thing. He's quite independent, he talks, he understands. So I think for him for relationship-building, it allows people to see him as a whole person, rather than the token little disabled kid who everybody needs to feel sorry for. So that's made a huge [her emphasis] difference for him.

Linda describes how the independence gained by her son with his powered wheelchair enables him to actively engage in interactions with others, thus shifting others' perceptions away from considering him as an object of pity towards acknowledging him as a typical boy who has a physical disability.

Another theme that emerged from the interviews was the participants' perceptions that powered mobility encouraged others to focus more on their children and less on their physical disabilities. The notion of powered mobility enabling the consideration of the child as a "whole person" was brought up by several of the parents in the context of interpersonal relationships with their children's peers.

The participants shared examples of how the use of powered mobility in their communities increased awareness of disability issues. In a specific situation, Sheri shared that her church community became concerned when they realized the independence David had with his powered wheelchair was hindered by lack of access to transportation for the powered wheelchair. The group committed to working together with Sheri and her family to ensure access to transportation. Sheri reflects on the effect the powered wheelchair had on community awareness of disability issues:

> I see the power chair has an impact, because it's increased the level of

> awareness of disability — like, things don't just happen — and it's an opportunity for them, as a community, to respond to someone's needs that are beyond the ability of just the family.

Sheri perceived the identification of her needs and the opportunity of her community members to assist in meeting these needs as a positive step towards a better understanding of disability issues and a step towards interdependence in her community.

Discussion

Initially, the exploration of wheelchairs with children with physical disabilities may evoke strong emotional responses from their parents. Similar perspectives to the mothers in this study have been shared by others as they adjust to their child's disability (Landsman, 1998). Landsman (1998) suggests that mothers redefine their perceptions of the meaning of disability, normalcy and perfection as they realize their children are no less valuable than children without disabilities. As parents undergo this process of reconceptualization they may eventually consider disability as the inability of their children to participate fully as opposed to their original perception of disability as the presence of a physical limitation. As a result of this shift, the value they place on alternative mobility methods, such as powered mobility, may change. Clinicians can facilitate this process by emphasizing the importance of participation and inclusion early in their interactions with families.

The shift in emphasis on physical impairment to a focus on participation and successful societal inclusion shared by the mothers in this study parallels the recent philosophical shift of the most prevalent model of disablement used to guide practice in rehabilitation, the International Classification of Functioning, Disability and Health (ICF)

(WHO, 2001). This contemporary model of disablement encourages consideration of participation in society as the most valued outcome for all individuals. If we are to support families of children with physical disabilities effectively, we must align ourselves with this redefinition of disability and impairment. Providing children with physical disabilities with effective and efficient independent mobility to enhance their participation and inclusion in their communities is one way to ensure that professionals address meaningful life outcomes.

The interviews with the parents in this study were rich with descriptions of how powered mobility had profoundly affected their lives and the lives of their children. The stories the participants chose to tell provide us with insight into what life outcomes are valuable and meaningful to them. The ability of their children to experience choice, independence, personal control, participation in age appropriate activities and meaningful relationships are all valued life outcomes that have previously been identified by other parents of children with disabilities (Giangreco, 1998).

Participants' perception of powered mobility as a last resort mobility option for their children raises an interesting question: Do we inadvertently contribute to this perception by adhering to traditional rehabilitation models that value the "most normal" mobility methods? If so, it is not surprising that parents may perceive the exploration of powered mobility as giving up hope on walking or manual wheelchair propulsion. As clinicians, we must realize that, although many parents are now more actively involved in the direction of rehabilitation programs for their children, they may still be highly influenced by the opinions of professionals (Tishelman & Sachs, 1998). It is imperative, therefore, that we, as rehabilitation professionals, reflect on our own conceptualizations of disability and impairment as we may unknowingly present families with the only options we perceive as viable (Canter, 2001).

Introducing young children with disabilities and their families to an array of early movement options can help change parents' assumptions that powered mobility is considered as a movement option only when other methods have been deemed ineffective (Wiart & Darrah, 2002). This approach would enable children with physical disabilities to explore different movement methods simultaneously and may change some of the negative parental responses to the introduction of manual and powered wheelchairs.

The participants perceived powered mobility as a positive influence on their children's interpersonal relationships with their peers because it eliminated the need for assistance from others. Independent mobility altered the power differential inherent in the helper/helpee relationship (Van der Klift & Kunc 1994). Van der Klift and Kunc (1994) suggest that it is often assumed that children with disabilities require help from those without disabilities. This assumption implies that children with disabilities are somehow deficient, a burden and inferior to individuals without disabilities. As genuine friendship between children with and without disabilities occurs when mutual respect exists, we must be sensitive to situations when children with disabilities are constantly receiving help from their peers. The provision of effective, independent mobility to children who otherwise may not be fully independent with other methods of mobility may actually contribute to the development of more fulfilling and mutual friendships with other children (Priestley, 1998).

Some mothers identified how their children's lack of independence culminated feelings of pity in others. Although the consideration of children with disabilities as objects of pity is so embedded in our culture that this perspective is rarely questioned (Middleton, 1999), advocates for societal inclusion argue that successful community integration will never occur as long as this perception remains prevalent. Condeluci (1995) points out that pity and respect are mutually exclusive ideals and therefore the presence of pity towards a child with a disability precludes respect or consideration of that child as an equal to children without disabilities. These perspectives emphasize the importance of maximizing independence and participation in order to address the attitudes of others that may serve as barriers to successful community inclusion.

Several of the parents perceived that powered mobility encouraged others to consider their child as a "whole person". Dembo, Leviton and Wright (1975) described a societal tendency to apply generalized perceptions based on stereotypical beliefs to all individuals with disabilities. These stereotypical beliefs dominate perceptions of all individuals with disabilities despite many other characteristics that are more defining than their disabilities. Clearly, some of the mothers perceived a shift in others' attitudes toward their children as they intuitively identified the effect of their children's independence and participation on others' tendencies to focus on disability as the most defining characteristic of their children.

Conclusion

Parents may experience an initial hesitancy to explore powered mobility. The receipt of a powered wheelchair may signify giving up hope on the attainment of more typical movement methods. Rehabilitation professionals can change the perception of powered mobility as a movement option of last resort by providing families with an array of movement options when their children are young. Parents who are considering powered mobility for their children may benefit from the information shared by the mothers in this study. Although every family's experience is unique to their particular circumstances, insight into the experiences and changing perspectives of other parents may facilitate the shift towards focussing on independence and participation for their children.

A family centered approach to the exploration of mobility options will allow children and families to experience participation and inclusion by enabling them to establish the best fit between movement options and specific activities and environments. Therapists who adopt clinical approaches that encourage a focus on more "typical" movement methods, without providing families with information on all options available to them, may inadvertently deprive families of information they require to make informed decisions for their children.

Limitations of the Study and Implications for Future Research

The children of the mothers in this study had all continued to use powered mobility and therefore their mothers were more likely to share positive experiences with powered mobility than mothers whose children have discontinued powered mobility use. In addition, it should be noted that, since only mothers were included in this study, fathers may experience their children's use of powered mobility differently.

Additional qualitative research regarding powered mobility could explore the experiences of families whose children did not continue using powered mobility. In addition, information from professionals about which children they consider as appropriate candidates for powered mobility would provide a clinical perspective on the prescription of powered mobility to children.

References

Berry, E.T., McLaurin, S.E., & Sparling, J.W. (1996). Parent/caregiver perspectives on the use of power wheelchairs. Pediatric Physical Therapy,8, 146-150.

Butler, C. (1986). Effects of powered mobility on self-initiated behaviors of very young children with locomotor disability. Developmental Medicine and Child Neurology, 28, 325-332.

Butler, C. Okamoto, G.A., & McKay, T.M. (1983). Powered mobility for very young disabled children. Developmental Medicine and Child Neurology, 25, 472-474.

Canter, R. (2001). Patients and medical power. British Medical Journal, 323, 414.

Collaizzi, P.F. (1978). Psychological research as the phenomenologist views it. In: R. Valle & M. King (Eds.), Existential-phenomenological alternatives for psychology (pp.48-71). New York: Oxford University Press.

Condeluci, A. (1998). Interdependence: The route to community 2nd edition. Washington, D.C.: St. Lucie Press.

Creswell, J.W. (1998). Qualitative inquiry and research design: Choosing among five traditions. Thousand Oaks CA: Sage.

Deitz, J., Jaffe, K., Wolf, L., Massagli, T., & Anson, D. (1991). Pediatric power wheelchairs: evaluation of function in the home and school environments. Assistive Technology, 3, 24-31.

Dembo, T., Leviton, G.L., & Wright, B.A. (1975). Adjustment to misfortune: A problem of social-psychological rehabilitation. Rehabilitation Psychology, 22, 1-100.

Furumasu,J., Guerette, P., & Teft, D. (1996). The development of a powered wheelchair mobility program for young children. Technology and Disability, 5, 41-48.

Giangreco, M.F., Cloninger, C.J., & Iverson, V.S. (1998). Choosing outcomes and accommodations for children. 2nd ed. Baltimore: Paul H. Brookes Publishing Co.

Landsman, G.H. (1998). Reconstructing motherhood in the age of perfect babies: Mothers of infants and toddlers with disabilities. Signs, 24, 69-99.

Middleton, L. (1999). Disabled children: challenging social exclusion. London: Blackwell Science.

Moustakas, C., (1994). Phenomenological Research Methods. Thousand Oaks CA: Sage.

Osborne, J.W. (1990). Some basic existential-phenomenological research methodology for counsellors. Canadian Journal of Counselling, 24, 79-91.

Polkinghorne, D.E. (1989). Phenomenological research methods. In: R.S. Valle & S. Halling (Eds.), Existential-phenomenological perspectives in psychology: Exploring the breadth of human experience (pp. 41-60). New York: Plenum Press.

Pope, P.M., Bowes, C.E., & Booth, E. (1994). Postural control of sitting in the SAM system: evaluation of use over three years. Developmental Medicine and Child Neurology, 36, 241-252.

Priestley, M. (1998). Discourse and identity: Disabled children in mainstream highschools. In: S. French & M. Corker (Eds.), Disability Discourse. Buckingham: Open University Press.

Tefft, D., Guerette, P., & Furumasu, J. (1999). Cognitive predictors of young children's readiness for powered mobility. Developmental Medicine and Child Neurology, 41, 665-670.

Tishelman, C. & Sachs, L. (1998). The diagnostic process and the boundaries of normality. Qualitative Health Research, 8, 48-60.

Van der Klift, E. & Kunc, N. (1994). Hell-bent on helping: Benevolence, friendship, and the politics of help. In: J. Thousand, R. Villa & A. Nevin (Eds.), Creativity and collaborative learning: a practical guide to empowering students and teachers. Baltimore: Paul H. Brookes.

Verburg, G. (1987). Predictors of successful powered mobility control. In K.M. Jaffe (Ed.), Childhood powered mobility: Developmental, technical, and clinical perspectives. Proceedings of the RESNA First Northwest Regional Conference. (pp. 70-104). Seattle, WA: RESNA.

Wiart, L., Darrah, J. (2002). Changing Philosophical Perspectives in the management of children with physical disabilities: Their effect on the use of powered mobility. In press.

Wiart, L., Darrah, J., Cook, A., Hollis, V., May, L. (2002). Evaluation of Powered Mobility Use in Home and Community Environments. Manuscript submitted for publication.

Wolf, L.S., Massagli, T.L., Jaffe, K.M., & Deitz, J. (1991). Functional assessment of the Joncare Hi-Lo Master power wheelchair for children. Physical and Occupational Therapy in Pediatrics, 11, 57-72.

World Health Organization (2001). ICF. International classification of functioning, disability and health. Geneva: World Health Organization.

Zazula, J.L. & Foulds, R.A. (1983). Mobility device for a child with phocomelia. Archives of Physical Medicine and Rehabilitation, 64, 137-139.

CHAPTER 5

CONCLUSION

Summary of results

The results of this study provide valuable information and contribute to our knowledge and understanding of children's use of powered mobility. We now know that a large proportion of children who receive powered wheelchairs continue to be successful long-term users of powered mobility. The main barriers to successful use of powered mobility are physical barriers in the environment, specifically difficulties with transportation and physical accessibility. Interestingly, it appears that children with less severe physical disabilities may not have opportunities to consider powered mobility as one of their movement options.

Powered wheelchairs may serve as powerful indicators of disability and therefore mothers may hesitate to explore powered mobility with their young children. In addition, parents may perceive the acceptance of powered mobility as giving up on more "normal" methods of mobility such as walking or manual wheelchair propulsion. For families who choose to explore powered mobility with their children, the independence and increased personal control gained from powered mobility can have a dramatic and positive influence on their lives. Powered mobility can provide their children with opportunities to participate in age appropriate activities and to develop meaningful relationships with their peers. By enhancing participation in meaningful, age appropriate activities, powered mobility may facilitate a shift in others' attitudes toward individuals with disabilities by encouraging a focus on the child instead of their disability.

Clinical Implications

The results of this study have implications for the practice of rehabilitation professionals who work with children with physical disabilities and their families. The provision of an array of mobility options with families of very young children may change the perception that powered mobility is only explored as a movement option when other methods have been explored and deemed unsuccessful. By providing families with an array of early movement options from which they can choose, families are able to establish the mobility options that will best suit their lifestyles.

Dissemination of Results

The results and clinical implications of this study will be disseminated in a variety of ways. Chapter 2 has been accepted for publication in Disability and Rehabilitation as a clinical commentary article. The results of the quantitative portion of the study, as presented in Chapter 3, are currently under peer review with Physical and Occupational Therapy in Pediatrics. The results of the qualitative portion of the study, as outlined in Chapter 4, will be submitted to a peer-reviewed journal within six weeks of the thesis defense.

The results of the study will also be shared in a presentation to staff at AADL and to interested clinicians at the Glenrose Rehabilitation Hospital and the Alberta Children's Hospital, the two facilities in Alberta where the majority of paediatric powered chairs are prescribed. Two abstracts for podium and poster presentations, using the contents of Chapters 3 and 4, respectively, will be submitted to the American Academy for Cerebral Palsy and Developmental Medicine in January 2002. Families who participated in the study and who indicated an interest in the results will receive a summary of the findings and a synopsis of information that may be helpful to them, including a list of resources mentioned by other participants.

Implications for Future Research

Future research regarding paediatric powered mobility could explore the value professionals place on powered mobility as a movement option for children with physical disabilities. This is important information as professionals' attitudes and perspectives may influence parents' willingness to explore powered mobility with their children. The effect of long-term powered mobility use on children's health and motor abilities also requires evaluation.

The use of both quantitative and qualitative methodologies could be used to a greater extent for research in the field of paediatric rehabilitation. The combination of the two approaches in this study demonstrated their complementary nature for the objectives of this particular study. Use of a quantitative approach provided concrete information about a large group of individuals who use powered mobility while the qualitative approach enabled the exploration of mothers' experiences on a more personal and deeper level. Evaluation of the same topic from different perspectives resulted in a greater understanding of paediatric powered mobility than would have been obtained by using either approach in isolation.

APPENDIX A

Telephone Interview Questions

1. Background information

   Date of Birth ___________ Gender ____ Medical Diagnosis ______________

2. Model of current/last powered wheelchair ____________________

3. How many powered wheelchairs have you had? ____

4. How old were you when you received your first powered wheelchair? ______

5. Do you still use your powered wheelchair? YES ☐ NO ☐

6. How often, on average, do you use your powered wheelchair? Think about your use in the last year.

   a) 6-7 days per week
   b) 3-5 days per week
   c) 1-2 days per week
   d) less than 1 day per week
   e) not applicable

7. In total, how long are you in your powered wheelchair on an average day? (hours)

   _____hours Not Applicable ☐

8. We are interested in knowing how many different ways you have to move around. Please indicate **all** other ways you use to move around independently.

   ☐ walking with a walker
   ☐ manual wheelchair (I can push it myself)
   ☐ manual wheelchair (someone pushes me)
   ☐ creeping/crawling/rolling
   ☐ walking with crutches (or canes)
   ☐ stroller (someone pushes me)
   ☐ no other way
   ☐ other, please explain ________________________________

9. Do/did you need help to get in and out of your powered wheelchair?

   YES ☐ NO ☐

10. Do/did you need help to get your powered wheelchair ready to drive (e.g. positioning of the joystick)?

YES ☐ NO ☐

11. If the answer to either question 9 or 10 is yes, are there times when you can't/couldn't use your powered wheelchair because someone is/was not there to help you?

YES ☐ NO ☐

If yes, please explain ______________________________

____

12. Indicate **all** of the places where you use/used your powered wheelchair.

- ☐ home
- ☐ school
- ☐ work
- ☐ recreational facilities (e.g. fitness centre, local gym)
- ☐ other community buildings (e.g. church, bank)
- ☐ other, please explain ______________________________

13. Indicate **all** of the places where barriers make/made it difficult for you to use your powered wheelchair. This includes physical, policy and attitudinal barriers.

- ☐ home
- ☐ school
- ☐ work
- ☐ recreational facilities (e.g. fitness centre, local gym)
- ☐ other community buildings (e.g. church, bank)
- ☐ other, please explain ______________________________

14. Please describe anything that has made it difficult or easy for you to use you powered wheelchair.

____

____

____

15. Do/did you feel that the need to repair and maintain your powered wheelchair interfere(d) with successful use of powered mobility?

YES ☐ NO ☐

Please explain

____

____

16. In your opinion, was your positioning in your powered wheelchair appropriate?

YES ☐ NO ☐

If no, please explain

____

____

17. Did you attend a seating clinic to check or improve your positioning in your powered wheelchair?

YES ☐ NO ☐

When did you last attend seating clinic?

YES ☐ NO ☐

Do you currently attend seating clinic for follow-up?

YES ☐ NO ☐

18. Do/did problems with transportation of your powered wheelchair limit the places where you can/could use your powered wheelchair?

YES ☐ NO ☐

If yes, please explain ____

____

19. Indicate **all** of the ways that you have/had to transport the powered wheelchair.

☐ personal van
☐ public transportation
☐ I drive/drove my wheelchair between locations
☐ none

20. Have you ever received powered wheelchair training?

YES ☐ NO ☐ DON'T KNOW ☐

If yes, please describe the training that you received (i.e. length of training, frequency of training and specific tasks included in training)

____

____

____

21. Indicate all of the locations where training took place.

☐ school
☐ health centre (e.g. community hospital, Glenrose Rehabilitation Hospital or Alberta Children's hospital)
☐ your community
☐ home
☐ not applicable
☐ Other, please explain ________________________

22. Who provided the training?

☐ family members
☐ school staff
☐ health care professionals
☐ not applicable
☐ other, please explain ________________________

23. In your opinion, was the training appropriate?

YES ☐ NO ☐ Not Applicable ☐

24. Do you feel that your opinion was considered in the selection of your powered wheelchair?

As a powered mobility user? YES ☐ NO ☐

As a parent/guardian? YES ☐ NO ☐

Please explain

____

____

____

25. Did the associated cost of your powered wheelchair influence successful powered wheelchair use?

YES ☐ NO ☐

If yes, please explain ______________________________

____

____

26. We are interested in knowing how your powered wheelchair has made your everyday activities easier. Indicate all of the activities that are/were easier to do because you have (had) a powered wheelchair.

- ☐ moving around at my school/work
- ☐ walking with my friends/colleagues at school/work
- ☐ participating in physical education at school
- ☐ participating in recreational and sporting activities in my community (e.g. floor hockey, basketball)
- ☐ going shopping or to the movies, etc.
- ☐ going out with my friends

27. Would you like to participate in a more in-depth interview, at your convenience to discuss issues regarding powered mobility further? (This will take approximately one hour of your time.)

YES ☐ NO ☐

28. Are you interested in receiving a summary of the results of this study?

YES ☐ NO ☐

Thank you for participating in this study

APPENDIX B

Qualitative Interview Questions

I. General

1. How did __________ move around before the powered wheelchair?

2. How old was ___________ when he/she received his/her first powered wheelchair?

3. How did you discover that powered mobility was an option for __________? (How did you feel about this?)

4. Tell me about your experiences with the process of selecting mobility options for ___________. This can include the powered wheelchair but may also refer to other mobility options such as walkers or manual wheelchairs.

5. How did you feel when ____________ received his powered wheelchair?

6. Is there a particular experience with the powered wheelchair that you would like to share?

7. Describe situation(s) when ____________ experienced difficulty with using his powered wheelchair.

8. Describe a positive experience with ___________using the powered wheelchair.

II. Influence on Self and Child

9. How do you perceive the powered wheelchair has changed _________ life?

10. Describe how the powered wheelchair has affected your life.

III. Influence on Family and Friends

11. How has the powered wheelchair affected relationships within your family?

12. How has the powered wheelchair affected relationships with individuals in your community?

IV. Professional Support

13. Describe your experiences with health care professionals throughout the process of obtaining the powered wheelchair and then using it.

14. How do you feel about the support (or lack of support) you received?

APPENDIX C

Table 1 Thematic Abstraction of Gail's Experience

MEANING UNIT	PARAPHRASE	FIRST ORDER THEME
1.It [powered wheelchair] just really improved his sense of independence and self-esteem.	Use of powered wheelchair increased Trevor's independence and self-esteem.	Powered mobility allows independence and promotes self-esteem.
2.I think the best picture I have of him is driving away from me. I get teary every time I see it, because he's on his own and he's able to get somewhere by himself without any help.	Trevor driving away is a wonderful memory; picture elicits tears of happiness and pride because he is moving independently	An emotional realization: child's ability to be independent from parents
3.it [powered wheelchair] changed his peers' attitude towards him, because they saw that he could do something on his own and that he could actually think on his own	Powered wheelchair affected peers perception of him; attributes this to son's independence and demonstration of his cognitive abilities	Perceives child's ability to be independent with powered wheelchair changes perceptions of others
4.the kids were really curious about how he was able to drive it, and how smart he was and how good he was, and so he really did get a lot of praise and a lot of respect	Kids were curious about powered wheelchair, Trevor's intellectual abilities and driving skills; they praised and respected him	Use of powered wheelchair elicits curiosity, praise and respect from peers
5.they [i.e. people in her town] put in a ramp, a wheelchair ramp, because we're so visible in the community.	Attributes community change to being "visible" in the community	Increased awareness of need for accessibility facilitates community change
6.we've always taken him with us, so it's been an education for the people in the community	Presence in the community has increased community understanding of disability issues	Presence in the community facilitates increased understanding of disability
7.I'm pretty hurtful [when people make assumptions about Trevor's mental abilities]. I'm hurt, especially when they're people that I work with. They should know better. Then I remember that they're just really ignorant, and I just have to educate them. I always keep in mind to try and be positive, because that may be their only contact, and the next time it happens, they could handle it a little better. We find that we're educating people all the time.	Feelings are hurt when people make assumptions about Trevor's cognitive abilities, Colleagues should "know better"; reminds self that they are "ignorant" and require education; reminds self to be positive as this may be the only opportunity to make change; perhaps it will affect future reactions to persons with disabilities; education is an ongoing process	Moving past the hurt: positive education regarding disability will change attitudes toward people with disabilities
8.I think it changes his attitude in relation to how he sees the	Perceives powered wheelchair as changing Trevor's	The ability to play with peers: Powered wheelchair

world, because he's able to be with his peers in the schoolyard.	perception of the world because he can be with his peers	changes perception of world
9.Just makes a big difference to him to be included. Just like any other kid, he wants to do the same thing and he wants to be with them. That's the benefit that the chair has.	Perceives inclusion as very important to son; He wants to be like the other kids; powered wheelchair allows this	Powered wheelchairs allows inclusion with peers
10.Or he can be away from them [peers] if he wants to. That's his choice.	He can choose not to be with peers if he wants to	Powered mobility enables increased personal control
11.It [powered wheelchair] has been a positive thing for him. It allows him to be with his peers. It's also changed the opinion of everybody in town. He's not just a disabled boy; he's Trevor.	Powered wheelchair has positively affected son's life; he can be with his peers; it has changed attitudes towards him in the community; people focus on him, not his disability	Changing community attitudes: powered wheelchair encourages a focus on the individual, not the disability
12.they're out cutting the curbs and installing wheelchair ramps in all the old curbs in town for their infrastructure improvement. That's because we're obvious. that's because of Trevor being visible and being in the community, because they wouldn't have looked at it before	Attributes changes toward universal accessibility in the community to "being visible" in the community	Towards universal accessibility: presence in the community increases community awareness of need
13.It [powered wheelchair]... gives him the option of being independent. When people see that he is independent, then it changes their attitude towards him.	Powered wheelchair allows Trevor to be independent; Independence changes others perception of him	Independence positively affects others' attitudes towards child
14.They [i.e. Trevor's peers] see that he's intelligent [when he drives powered wheelchair]. That there's actually something in that little head. Like I was talking before about people, how they just assume that if they're in a wheelchair, there's something mentally wrong as well. It's the attitude. So I think we've changed that in our own little way in this community, for sure.	Ability to drive powered wheelchair demonstrates his intellectual abilities; people assume physical disability means mental disability; it's an attitude; feels they have changed that attitude in their community	Use of powered mobility addresses other's assumptions regarding disability
15.the first place we took him [after he received his powered wheelchair] was to the hospital to physio, and he just got out	When Trevor initially drove on his own and he was unfamiliar with that environment; feels strong sense of pride	Independence from mother evokes strong feelings of pride

and went in the doors and away he went. He was gone! He'd never even been in there before, but! [laughs] So that to me was [pause] it just fills you with a sense of pride		
16.Just the more independent he can be, the prouder we are. We've always tried to give him that sense of independence, and the self-esteem is very important, and he's got that.	Proud of Trevor's independence; always tried to instill independence; recognizes importance of self-esteem; Trevor has self-esteem	Parents are proud of independence and value self-esteem
17.I think it was fairly obvious to us that the chair was going to be — and he couldn't — because he can't physically move his left hand, the manual chair was out of the question....So the powered chair was really the only option.	Feels it was "fairly obvious" that Trevor couldn't use a manual wheelchair; powered wheelchair only option	Powered mobility perceived as a "last resort" mobility option
18.It would be wonderful if he could walk. That's something that we would love to see, but have to be realistic, too.	Hope exists for Trevor to walk; that is not realistic, however	Balancing realism with hope: the desire for son to walk
19.they were a little bit tentative at first, the professionals, in dealing with us in what we wanted for him, so I think there was a little bit of education that went on both ways. Our desire to make him more mobile so he can do more things, and their reluctance in fitting him with different things, and part of that was probably the cost.	Professionals were initially hesitant to provide what they wanted for Trevor; it was a two way learning process; they wanted mobility-professionals were reluctant; attributes part of reluctance to cost of equipment	Professionals hesitate to provide mobility despite parental desires: cost may be a factor

Table 2 Thematic Abstraction of Sheri's Experience

MEANING UNIT	PARAPHRASE	FIRST ORDER THEME
20.They [i.e. health care professionals] recognized that David's ability to maneuver a manual wheelchair on his own were really — it wasn't going to happen with any — he wouldn't be able to do it very purposefully, because his left hand was, at that point, very, very weak. So they actually invited us to come in to look at a power chair for David.	Recognized David's inability to purposefully propel a manual wheelchair due to hand weakness. As a result, powered wheelchair was presented as a movement option.	Powered mobility: a "last resort" mobility option
21.the greatest challenge was dealing with David having a manual chair...because what that said to us was that the health professional did not believe that David had potential to be independent on his own, or mobile on his own. So that was a real struggle for me and for all of us	The manual wheelchair was more difficult to handle emotionally than the powered wheelchair due to perception that the health professional believed that David could not be independently mobile; this caused emotional difficulties for the family	Manual wheelchair symbolizes professional's belief that independent mobility is not possible
22.I have a distinct recollection of this [manual] wheelchair sitting in our house, and feeling very, very sad, and ... thinking, "This is what our life is going to be like."	Recalls manual wheelchair eliciting feelings of sadness and despair	Initially, manual wheelchair elicited feelings of sadness and despair about future
23.I guess, a degree of optimism that either this really wasn't happening [i.e. son has a disability], or that David could be mobile.	Experiences optimism: questions reality and her son's ability to overcome his disability	Denial or optimism? Perhaps mobility is possible
24.I was consistently frustrated, I suppose, with David's inability — not frustrated for me, but frustrated for David — about David's limited ability to get around on his own. I wasn't ever quite sure how we were going to get beyond that point. So when the idea of a power chair was presented...that actually was a great source of relief for me, and it was a good thing.	Feelings of frustration with David's inability to move on his own; didn't know how to move beyond these feelings; suggestion of powered wheelchair brings feelings of relief	Inability of son to be mobile is source of frustration: suggestion of powered wheelchair brings relief
25.we have this wonderful power chair, but we can't take it anywhere! So that became a source of frustration	Frustration with difficulties with transporting powered wheelchair	Difficulties with transporting the powered wheelchair: A source of frustration

26.That [using the chair at school or daycare only] worked for him [David], because he had much more fun and independence, and was able to play with the kids and all that sort of stuff.	The powered wheelchair enabled fun and independent interaction with other kids at school and daycare	Powered wheelchair allows fun, independence and interaction with peers
27.But it [i.e. using powered wheelchair at school and daycare] didn't work for me — we didn't ever reap the benefits of that [i.e. use of powered wheelchair] for David at home, so that was a real challenge and a real frustration, I think, for David, because it was like part of his life was very different at home than it was at school.	Dissatisfied with amount of use of powered wheelchair at home; Challenge and frustration for David because use of powered wheelchair was different between home and school.	Perceives son's frustration with inability to use powered wheelchair in his home
28.And I don't think, really, as a parent, I fully understood how important that piece [i.e. using powered wheelchair in his home] was for him was until we'd had the renovations done to the house	Lack of understanding of the importance of accessibility in the home; understanding facilitated by home renovations	Home renovations bring realization of the importance of accessibility
29.What I fully appreciated was how much better quality of life David had [after the renovations to allow accessibility], and I'm only sorry that I didn't realize that a long time ago, because I think it would have been easier for him	Realizes how renovations affected David's quality of life; regrets not recognizing this sooner; feels it would have made it easier for David	Use of powered wheelchair in the home positively impacts quality of life.
30.I think the positive experiences certainly are, for David and for me — for David primarily — is whenever I go and see him at school, is just watching him scoot around the school.	Watching David move around school is a positive experience for both mother and son	A positive experience: the ability of child to be independent
31.David played baseball this year, so he was able to run the bases in his power chair, which he could never have done beforehand. He would have been really relying on somebody pushing him around, which isn't the same thing	Powered wheelchair enabled David to run the bases in baseball; prior to powered wheelchair David was dependent on others to push him; recognizes difference between scenarios.	Powered wheelchair allows participation in age appropriate recreational activities
32.David's a very independent little boy, so it's really important for him, I think, to have opportunities to exert as much	Recognizes David's need to be independent; realizes the importance of as many opportunities to independently	Independent exploration of environment is important

independence on his environment as he can.	explore his environment	
33.David got in his chair, and even though this was a completely new environment and a new thing for him — he'd never been at this before — he just sailed on into the camp meeting area where registration was, and he was going around — and he's a real social butterfly — chatting with everybody…I was just blown away, because I had never, ever understood that David had the capacity nor would have the opportunity to *do* something like that, and it was just a real emancipation moment for everybody — for me, as a parent — knowing he can easily negotiate life on his own, and he has the ability to be independent	Emancipation moment when witnesses David's ability to interact with others independently with powered wheelchair; first realization that he can be independent and can "negotiate life on his own"	An emancipation moment: The realization that her son has the ability "to negotiate life on his own"
34.I do remember bursting into tears in the middle of this big conference, partly to deal with the behaviour, but partly because I just realized how incredibly exhausted I was. It was because I was exhausted lifting David, lifting his manual chair, always being at his beck and call to get from one little minor activity to another minor activity, or from one minor need to another minor need.	Emotional breakdown in public because of David's behaviour and physical exhaustion; exhausted with son's need for constant assistance.	Caring for a child who requires constant assistance is an emotionally and physically exhausting experience:
35.I remember whenever we got that ramp put in, by the time David left for school at 7:30, I was exhausted, because I had got him — he needs total care, physical care — so he needs to be dressed completely, he needs to have personal hygiene done completely, he needs to be carried out to the bus, because there was no way of transporting him any other way. I remember when that was put in [ramp], I couldn't believe the difference. David went off to school, and I thought, "I don't even feel tired	Exhausted by 7:30 in the morning due to David's need for assistance for personal care and carrying him out to the bus; no other way of transporting David than carrying him to the bus prior to ramp in home; Ramp in home (and use of powered wheelchair) made a huge difference to levels of fatigue	Use of powered wheelchair in the home dramatically reduces level of caregiver fatigue
36.…the end of the day, that's [caring for David constantly] not healthy for either him or me. So	Realizes healthiness of David's independence from his mother; with powered wheelchair and	Powered mobility enables age appropriate decision making and independence

now, if David wants to go down and watch TV, he can go and do that and he doesn't need me to get there, and I don't even need to be part of his decision, which is how it should be for an 11-year-old boy.	accessible housing, David can be independent with moving and decision making; this is age appropriate behaviour	from mother
37.He helps now with setting the table. Again, that's what an 11-year-old boy or 10-year-old boy should be doing. He should have responsibilities. Whereas beforehand, when he was in his manual chair, I'd push him over, he'd get hand over hand assistance, and I'd push him back. And I'm thinking, "I could have this done in 5 seconds. This is taking me half an hour!" And it's not a dignified experience for David.	Powered wheelchair enables son to set the table; Prior to powered wheelchair he required assistance - the process was time consuming; acknowledges the lack of dignity in this experience;	A dignified experience: Powered mobility enables independence with daily activities
38.Now the new challenge which we have...is this issue of transportation, because where I still end up being stuck, 'cause I can't transport the power chair.	Transportation remains a challenge because transporting the powered wheelchair is not possible;	Transportation of powered wheelchair is a barrier
39.So that's [difficulty with transfers at home] still an issue, and I think that would always be an issue, and I think, probably with the power chair, it's probably a wee bit more of an issue because they're heavier, and to line them up is a little bit more difficult than maybe with a manual chair. But it's a small price to pay.	Difficulty with transfers in the house is more of an issue with the powered wheelchair; benefits of powered mobility outweigh the disadvantages	Benefits of powered wheelchair outweigh the disadvantages.
40.I think for David, it has just given him a real sense of independence and a sense of power [laugh] and a sense of being able to have influence over his environment	Powered wheelchair offers a sense of independence and personal control and the ability to influence the environment	Powered wheelchair allows independence and increased personal control
41.He was relying on the adults to push him in school, and-or me, or wherever, so he knew how to interact with adults probably better than he ever knew how to interact with kids — with the manual chair	Reliance on adults with manual wheelchair limited opportunities to develop relationships with peers.	Dependence on adults adversely affects social interactions with peers
42.Sometimes the kids would push him around, but they really weren't interested in pushing David around, they were more interested in seeing	Kids pushed manual wheelchair, not to be with David but to play with wheelchair; elicited feelings of fear from David; resulting in negative	Lack of control over manual wheelchair resulted in feelings of fear, negative behaviour and ostracism

how fast the chair could go, and a whole bunch of safety issues that are just very scary [laughs] and David would get very cross and very afraid, and would then lash out, and then he'd end up being ostracized.	behaviour and ultimately ostracism	
43.David now [i.e. with powered wheelchair] can much more readily interact with his peers and be accepted by his peers because he's able to — he can be there legitimately He doesn't need an adult to be working on his behalf.	Powered mobility allows interaction with peers and acceptance from peers because he does not require the assistance of an adult	Awareness that independence from adults facilitates interaction with peers
44.he's actually developed greater and more appropriate, I think, interpersonal skills with his peers as well [i.e. as a result of using powered mobility].	Powered wheelchair facilitated the development of more appropriate interpersonal skills with peers	Powered wheelchair facilitates development of interpersonal skills with peers
45.He has a lot more fun. He plays hockey. There's about six or seven kids. and they play hockey together every lunchtime, or most every lunchtime or recess, whereas on the rare days that he's in his manual chair, or previously, he would never have been able to do that.	Powered wheelchair allows for more fun; David plays hockey now; previous to powered wheelchair, hockey was not possible;	Powered wheelchair allows participation in recreational and leisure activities
46.So he would have really been a little kid being entertained by an adult [i.e. with manual wheelchair], and I don't think — that's not, again, where he should be at. I think that feeds into other behavioural issues and other struggles, social issues as they grow older.	Interaction with adults due to need for assistance with manual wheelchair; this is not age appropriate and it results in behavioural and social issues later in life.	Perception of too much interaction with adults as a source of future behavioural and social issues
47.It's [i.e. powered wheelchair] given David a lot of power, he also knows how to take advantage of that. If he gets mad, he then knows that he has got the ability to have great influence over his environment. He will then turn up the chair, and if people are cross with him, he'll quickly leave the situation, even though he's not supposed to.	Takes advantage of independence; when angered he will leave the situation inappropriately	Powered wheelchair allows control over actions, although sometimes inappropriate
48.David's seeing more natural and meaningful consequences to his behaviour as a result of	Powered wheelchair has enabled David to experience more natural and meaningful	Facilitating learning: Powered wheelchair allows the experience of natural

the power chair. I think that's helped him in his own learning as well.	consequences to his actions; it has also facilitated learning	and meaningful consequences to actions
49.I think, for him, he has much better behaviour at the end of the day than if he were in his manual chair	Perceives powered wheelchair has a positive influence on behaviour	Powered mobility: a positive influence on behaviour
50....if he's not careful [i.e. with powered wheelchair] and not attentive to the needs of the other kids, then he'll lose them. Again, that's a good thing, because I think he needs to know that there are consequences, and that's a good life lesson for later on.	If David is not respectful and careful with other kids, they will not want to be friends with him; acknowledges the importance of experiencing consequences for actions; this is an important life lesson	An important life lesson with powered mobility: learning consequences of actions
51.they [David and sister] can be together if they choose to be together, but they don't *have* to be in each other's pockets, which again, I think, is how it should be at that stage and age, kind of thing. So that's positive	David and sister can choose to be together but they do not have to; acknowledges age appropriateness of this relationship	Powered wheelchair allows age appropriate relationship with sibling
52.The piece that doesn't work for David is that because he has the independence of the power chair at home, it's very hard for him to go to other people's or a family member's home and be completely dependent because their house isn't wheelchair-accessible, and be in the manual chair. So that's a negative thing, but again, it's a small price to pay. It would never cause me to decide it's not worth having a power chair	Independence with powered wheelchair at home makes it difficult to be dependent in other homes in manual wheelchair; benefits of powered mobility outweigh the disadvantages	Environmental barriers are a challenge but benefits of powered mobility outweigh disadvantages
53.I think what they [i.e. peers] have seen in David is they have seen a little boy with a disability who now is just a little boy — is just an ordinary little boy. So I think for them, that's opened their eyes and changed their perspective on things. So I'd say that's a positive incidence	Views powered wheelchair as changing others attitudes towards David by removing the focus on the disability; Others are more enlightened with this different perspective; this is a positive change	Powered mobility causes a positive attitudinal shift: less emphasis on disability, more emphasis on the child
54.I have had so many people come up to me and say that David's gifts does their heart good to see him being as independent as he is and just	Others expressed experiencing happiness after witnessing David's independence and joy with powered wheelchair; creates positive image of	Others share in child's independence and joy

having such joy. Again, I think that creates a good image for people. For everybody, it's a good experience.	individuals with disabilities; positive experience for everyone	
55.There have been a lot of people who have been very, very concerned that David can't use this chair all the time, and they don't understand why that has to be, and why there isn't the support there to help out with transporting	People in community concerned about barriers to powered mobility use; question lack of support with transportation of powered wheelchair	Barriers to powered mobility use increase community awareness of issues
56.So what that [i.e. learning about lack of transportation for powered wheelchair] has done is increased a whole new sense of awareness of that whole area of disabilities	Learning about barriers has increased community awareness of disability issues in the community	Knowledge of barriers increased community awareness of disability issues
57.I see the power chair has an impact, because it's increased the level of awareness of disability — like, things don't just happen — and it's an opportunity for them as a community to respond to someone's needs that are beyond the ability of just the family	Powered wheelchair increased awareness of disability issues families face; opportunity for community to be interdependent	Working towards community interdependence starts with increased awareness of issues
58.health care professionals involved in the whole thing were very clinical, and when you're introducing something as significant to a little kiddy's life, you need to have a humanistic approach to the whole thing.	Health care professionals were "clinical"; introduction of life changing equipment requires a more "humanistic" approach	Health care professionals need to be less clinical-more humanistic

Table 3 Thematic Abstraction of Helen's Experience

MEANING UNIT	PARAPHRASE	FIRST ORDER THEME
59.I guess we relied pretty heavily on the physio and OT to help us choose. I guess once we chose the original one and had it at home, then you really see what — that maybe something else would have been a better choice.	Reliance on professionals to choose powered wheelchair; with experience realized that they may have made a better choice	Reliance on professionals may have resulted in not the best choice of powered wheelchair
60.The only concern that I have is that she's a bit hesitant when we're out in the community, worrying about going off the curb	Concern with child's hesitancy due to concerns with physical safety	Concern with child's hesitancy to drive powered wheelchair
61.you don't have to rely on people to push you; you can just go where you want when you want...if she wants to go somewhere or get something or do something, then she's able to do it a lot more independently.	Powered wheelchair allows decreased reliance on others and freedom	Powered wheelchair allows independence and freedom
62.... she doesn't have to rely on the teacher aide, and the teacher aide doesn't have to be with her constantly, because going from class to class, she can do that on her own. If she didn't have the power chair, then she'd have to rely on the teacher aide, and then the teacher aide's with her constantly. So that kind of interferes with socialization.	Powered wheelchair allows decreased reliance on and independence from teaching assistant (T.A.); dependence on TA interferes with socialization with peers	Independence with powered wheelchair facilitates interaction with peers
63.Maybe if we were more aware of the different kinds of chairs, ...Maybe if they had a video or something explaining the chairs and maybe showing...examples of them or whatever. .... Sometimes out in the street, I'll see somebody in a power chair, and I think, "Oh, gee, that one looks good. I wonder why we never looked at that one," even though we're quite happy with this one, except for the weight issue.	Questions why they were unaware of all of their options despite relative satisfaction with the powered wheelchair they received	Awareness of options is need to make informed decisions

Table 4 Thematic Abstraction of Elaine's Experience

MEANING UNIT	PARAPHRASE	FIRST ORDER THEME
64.So I was really scared to start out with, but by the time she went through all the training and everything, and we got her aide trained in how to use it at school, then she was really meticulous in driving it, surprisingly so.	Initially experienced feelings of fear; following practice and training of TA was surprised by Mary's adeptness at driving powered wheelchair	Initial feelings of fear with powered mobility replaced by surprise regarding daughter's ability to drive powered wheelchair
65.I remember it [i.e. exploring augmentative mobility options] was very upsetting to start out with. I remember Dr. Kendall saying if she didn't sit up by the time she was 2 independently, that she would *never* sit up by herself. And then if she never sat up, she would never walk. So that was really heart-wrenching. ... We wanted her to be walking and mobile.	Initial introduction to other mobility options was very upsetting; information presented by physician regarding prognosis for sitting independently and walking was "heart wrenching"; wished for Mary to walk.	Exploration of augmentative mobility options associated with emotional pain and loss of hope for walking
66.Yeah, it was a manual one [i.e. wheelchair] to start out. It was just heartbreaking. I don't know how else to describe it. Who likes to think that their child's always sitting in a wheelchair?	Receipt of manual wheelchair was a source of emotional pain; distaste with the prospect that Mary may not walk	A heartbreaking experience: the realization that walking is not possible
67.I think the hardest thing was just the fear of her getting hurt or running over somebody and hurting somebody else [i.e. with powered wheelchair].	Fearful of Mary getting hurt or hurting others with powered wheelchair	Use of powered wheelchair elicits feelings of fear regarding safety of child and others
68.The big thing of having a wheelchair kind of got over with, with the manual one, so I think once she got to be really good at driving it [i.e. powered wheelchair], I haven't had a problem with that at all	Adjusting to child's disability occurred when Mary received manual wheelchair; powered mobility was a positive experience.	Adjusting to child's disability occurred with manual wheelchair; powered mobility a positive experience
69.So I often think when she's older and going somewhere by herself, what is she going to do when that [i.e. going off a curb] happens? It just scares me to death about that.	Very fearful about future when Mary is by herself and she goes off a curb	Child's personal safety with powered wheelchair is a concern for the future
70.One thing that I find with the power chair is that if we're going somewhere to eat, that	In restaurants, Mary can not fit under table with powered wheelchair; this is a frustrating	Experiences frustration with environmental barriers

we have to usually keep her back with her tray, because just the way the tables are set up in restaurants, we can't get her underneath. So her joystick doesn't go back far enough that we can get her up to the table. So I find that kind of frustrating,	experience	
71.Even in some restaurants — restaurants and bathrooms just are a nightmare. I can hardly get her in her manual chair in there	Lack of accessibility in Restaurants and bathrooms are significant, even with manual wheelchair	Significant physical barriers exist in public places
72.I guess they don't care about the wheelchair people, if they get in there or not, 'cause they're such a small majority, or minority, or whatever.	Assumes lack of accessibility is due to people not caring about minority of people with disabilities	Perceives environmental barriers as a result of societal apathy toward people with disabilities
73.Makes us happy to see her to be able to take off on her own, though. Like, to be independent totally on her own, even though she's never out of our sight.	Experiences happiness when Mary moves independently; even though she is supervised	Child's independence with powered wheelchair elicits feelings of happiness
74... I think the older she gets, the more it's [i.e. powered wheelchair] going to help her be independent.	Surmises that powered wheelchair will enable independence in the future	Powered mobility may enable independence in future
75.And I'm really glad that she was the one that helped us order it, ...she asked us, but I said, "I don't know." Like, this kind of seat, or that kind of switch, or this kind of clutch or whatever — like, I had never seen a person in a power chair, let alone used one myself, and I really didn't know anything about it.	Pleased with the therapist who helped order powered wheelchair; expressed lack of knowledge regarding specifics with powered wheelchair; lack of exposure and knowledge regarding powered mobility	Welcome assistance: therapist assists with selecting powered wheelchair

Table 5 Thematic Abstraction of Linda's Experience

MEANING UNIT	PARAPHRASE	FIRST ORDER THEME
76.The power wheelchair was the really big step, although when we first started talking wheelchairs and they had said, "Oh, possibly a power wheelchair," I got my back up, thinking going in a manual wheelchair was hard enough,	Getting powered wheelchair was a "big step"; becomes defensive when approached with the idea; manual wheelchair was difficult to deal with	Suggestion of powered wheelchair was emotionally difficult
77.At that time, I was still thinking, "Okay, maybe one of these days, he'll get up and he'll walk, and we don't need this." Then going into a power wheelchair, it was kind of a realization that "No, he isn't going to be able to walk, and in order to have some independence, we have to look at power mobility." So it was a little tough.	Still Hoping her son would walk; use of powered wheelchair evoked realization that walking is not possible; powered mobility is necessary for independence; this realization was emotionally difficult	An emotionally difficult experience: Powered wheelchair signifies walking is not possible
78.At first, it was a realization that he's not going to independently walk, more than likely, ever, unless some miracle cure comes up. So that was kind of sad	Initial realization that walking is not an option; experiences feelings of sadness	Experience of sadness upon realizing that walking is not possible
79.when we were able to watch him go and do things on his own and move from room to room freely, it was a real "Wow! This is great!"	Independence with powered mobility is exciting	Child's ability to move independently: an exciting experience
80. So now, we refer to his power wheelchair as his legs,	Powered wheelchair referred to as part of the child	Powered wheelchair considered as part of child's identity
81.We do everything as a family, and his power wheelchair, if it doesn't go where we as a family are going, then we don't go, because we do; we consider it to be his legs.	Family will only frequent wheelchair accessible locations because powered wheelchair is considered an important part of child	Powered wheelchair considered as part of child's identity
82.The manual wheelchair, again, that was a really hard thing to come to terms with, because in the back of my mind at that time, I was still thinking that he's not going to need a wheelchair forever.	Hope for walking makes accepting manual wheelchair emotionally difficult	Hanging onto hope: Manual wheelchair signifies giving up on walking
83.Then when we came to	No choice but to face disability	It's "in your face": Manual

"Okay, now we have to look at a manual wheelchair," I really struggled with that, 'cause that was just a real — it's in your face he's got a disability, and you've got to deal with it, so that was really tough.	when it was time to look at manual wheelchair; emotionally difficult	wheelchair forces dealing with child's disability
84.As a parent, you're always a little bit self-conscious, and I think that was more *my* issue, that wasn't Zachary's. At that time, that was when my husband and I came to the realization that if we want Zachary to be proud of who he is, *we* have to be proud of who he is, and we can't care about what other people think. I mean, everybody *knows* that, but to actually live it and practice it is another story. After that, it was "That's right, this is who he is, and we're very proud of who he is and how well he's done."	Worried about what others think of her; realizes this was her issue, not Zachary's; realized that they must embrace who Zacchary is to instill a sense of pride in him; realizes necessity of not worrying about what others think; This is a common belief but not easy to practice.	Instilling pride in their child involves embracing his disability
85.So it [i.e. powered wheelchair] just really brought some real normalcy to our life.	Powered wheelchair provides a state of "normalcy"	Powered wheelchair allows participation in "normal" daily activities
86.Like, so what if this is his way; it's his life, so he can go and do whatever he wants.	Use of alternative mobility is not important, choice and participation is	Participation and personal control is important – not method of mobility
87.In our neighbourhood here, he goes out and he plays with the kids. Like I said, we try and keep life as normal as possible	In powered wheelchair Zachary plays with other kids in the neighborhood; tries to keep life as "normal" as possible.	Striving for normalcy: playing with neighbourhood kids is important
88.So again, when it's gone, his complete independence is gone.	Without powered wheelchair Zachary has no independence	Child fully dependent without powered mobility
89.I think that's what's so frustrating about all of this. Even now, it's been gone for a little over 2 weeks, and I haven't got a call as to what the holdup is. I think, "You can't do that." That's like taking away somebody who's perfectly able-bodied, sticking them on a couch, and saying, "You sit there until we, the people who fix it, or the bureaucrats, say	Frustration with length of time powered wheelchair away for repairs; doesn't know why it is taking so long; views taking away powered wheelchair as a form of restraint implemented by "beaurocrats"	When the powered wheelchair is away for repairs: A form of restraint

we'll let you off the couch."		
90.So when I start phoning and ranting and raving, and going, "Come on, people! You don't understand the impact of this [wheelchair in for repairs for extended period of time]... You can't. It takes a part of him away.	Expresses to decision makers that they can't understand the impact of being without powered wheelchair; it is damaging to Zachary's emotional well being	Lack of access to powered wheelchair adversely affects child's emotional well being
91.It's made it much easier [with the powered wheelchair], again, just for the day-to-day things. Zachary is a lot of care, because again, his hands don't work and stuff, but if you can take the scenario of brushing his teeth in the morning and getting him dressed, I mean, that's all hands-on.	Powered wheelchair makes daily activities easier; Zachary requires a lot of assistance due to his disability; intense assistance is required for personal care	Powered wheelchair lessens amount of parental involvement in child's personal care
92.I mean, that [ie. small amount of independence] doesn't even sound like that much, but when you're doing absolutely everything for somebody 24-7, that little bit makes a world of difference.	Affect of powered wheelchair may not be obvious; but when intense assistance is required constantly, it has a large impact	A world of difference: powered mobility offers relief to caregiver
93.We'll go out to the park, and we'll put him in number 4 speed, and we'll go out on the field by the school, and my husband hooked up a kite, and he'll just go, and the kite's flying, and it's a beautiful thing to see, for him to be able to do that.	With powered wheelchair, Zachary can fly a kite	Powered wheelchair allows participation in leisure activities
94.Oh! It's given him so much independence!	Powered wheelchair has provided Zachary with independence	Powered mobility allows independence
95.So when he's got his power mobility, he's just right in there with all the kids.	Powered mobility enables Zachary to play with other kids	Powered wheelchair allows interaction with peers
96.So that's his job, that he vacuums up and down both floors. It takes him forever, but he loves it and he's so careful....It makes him feel like he's accomplishing something. I don't want him growing up feeling like, "Oh, look, I'm just a big burden to the family."	With powered wheelchair Zachary completes household chores; gives him a sense of accomplishment; wants to avoid him feeling like "a big burden to the whole family"	Perception that powered mobility enables contribution to family functioning which prevents feelings of being a burden
97.I think it's [i.e. powered	Powered wheelchair has made	Powered wheelchair

wheelchair] made us stronger. Like I said, there's always going to be certain things that we can't do, and it's our family belief that we do things as a family, and if one can't do it, then we don't do it.	family more cohesive; if Zachary can't participate, family doesn't do it	contributes to strengthened family relationships
98.Some friends of ours live on a farm, and off we go, and he just flies around there. There's nothing to worry about: there's no hills, there's no swamps, and he'll just ride out there and play forever. Tim will kick the ball, and Zachary will — they'll have races, and it's just made life so much more normal.	Zachary is proficient and safe at friends farm; Zachary will play with his brother; makes life more "normal"	Awareness that powered wheelchair allows for participation in fun, "normal" childhood activities
99.Again, that's given him the independence. And people are generally really good, but they still have the idea when you see a child sitting in a manual wheelchair that's not able to do anything, they come and they talk. They don't mean to do it to be mean, but you just automatically assume, "Look at this poor pathetic little thing, sitting here and can't do anything,"	Powered wheelchair allows independence; people are sympathetic to child in manual wheelchair; people assume that child in manual wheelchair is "pathetic" and dependent	Manual wheelchair elicits feelings of sympathy and assumptions of dependence
100.So for him to be able to be in his power wheelchair and not have somebody hovering over him — like I said, when he's out in front, we're always watching — but for him to be able to go and drive up somebody's driveway and go, "Hi, how are you?" right away, they see him for who he is. He's not this pathetic little thing, he's quite independent, he talks, he understands. So I think for him for relationship-building, it allows people to see him as a whole person, rather than the token little disabled kid who everybody needs to feel sorry for. So that's made a *huge* difference for him.	Lack of others "hovering" with powered wheelchair: Zachary independently introduces himself to neighbours; They see Zachary – not a "pathetic" dependent child; he is able to communicate and understand; Powered wheelchair helps to build relationships; it allows people to see a little boy instead of a boy with a disability who needs sympathy; powered wheelchair has made a huge difference to Zachary.	Independence with powered mobility encourages a focus on the child, not the disability
101.They [the government] don't look at it as something that he absolutely needs, they	The government doesn't consider powered wheelchair a requirement; considers	Government views powered wheelchair as privilege not a right

think he's lucky to be able to drive this.	powered wheelchair a privilege	
102.Again, it gives him independence to go play with his friends. At lunch hour, he can go out and wander around the playground with the kids, do everything within his ability that the other kids do, and they don't look at him as, "Oh, God, we have to push the wheelchair, we have to bring him along." It's not like that, 'cause he can join in. So again, I think that's really helped build strong relationships. They look at him as a whole person.	Powered wheelchair allows independence, it allows Zachary to play with other kids; kids don't feel burdened by him because he can participate; it has helped to build relationships because kids focus on Zachary and not his disability	Independence decreases burden on other kids and helps build relationships Decreased focus on disability more focus on individual
103.The first few years, it's all just grieving and you're angry and you want to blame.	Initial reaction to having a child with a disability is grief, anger and blame.	Dealing with having a disabled child: Feelings of grief, anger and blame.
104.So you have to do that whole 10-week wheelchair training thing, or 6-week, whatever it is. Well, for the first 3 weeks, they insisted — because *they* know, *they* are the professionals, and *they* know.	Zachary participated in training; professionals presumed to know what is best for Zachary	Powered mobility training: A negative experience with professional paternalism
105.... I've found that the professionals let us down a little bit, because we weren't given any options, we didn't understand.	Disappointed with professionals for not giving options; didn't understand their options	Let down by professionals: failure to educate regarding options
106.I think it's a good thing that parents are included now. Your point of view is listened to, and they are going with "parents know their kids best," and as long as you're not being unrealistic.	Likes that parents have increased involvement with decision making; there is acknowledgement that parents know their children best; as long as they are not "unrealistic"	Appreciates shift towards family centered service
107."I don't expect him to be an NHL star, but I would like to see him having as much independence as possible.	doesn't expect Zachary to be a star but she wants him to be as independent as possible.	Desires independence for son
108. Again, my opinion, my husband's opinion didn't mean anything. Anything that we had asked, suggested, it was, like, "No, you don't know what you're	Initially her and husband's opinions were not valued; professionals dismissed their opinions; appreciates shift toward valuing parents opinions	A positive experience with health care professionals: the shift towards family centered service

talking about." Then when we've seen that real shift, I found it was pretty good.		
109. I think AADL makes you feel like "We're doing you a favour by allowing you to have this equipment." It's not a partnership; you're going and you're asking, "Can I please have this?" Somebody's who's never met your child, doesn't know you, can sit behind a desk and read the requisition or whatnot from a therapist, and decide yea or nay, and I think that system, it kind of goes back to the old way of thinking with social welfare in Canada and our social safety net — it's a handout? And it's not a handout, it's a right, and these are things that kids need.	Government employees have paternalistic attitude; parents are asking for equipment; stranger decides destiny; considers equipment "handout"; powered wheelchair is a right and a requirement	Powered mobility is a right not a handout
110.Having a power wheelchair or a manual wheelchair, proper seating, bathing equipment, commodes — these are all basic necessities, and for AADL to say, "No, you don't need a bath seat" — but you do — I have a real issue with that. I don't think you should have to go begging and saying, "This is what my child needs."	Self-care equipment is a basic necessity; government decides randomly; feels that parents shouldn't have to beg for equipment	Children's needs should not be questioned by government funding agencies
111.And now with this chair breaking down, I have a real issue that somebody can sit behind a desk and say, "His safety, whether it matters or not, no, you don't get one. You're *not* worthy. *You* are." That's what they make you feel like, as if you're worthy of it. It's a necessity. It's not like we're asking for a bike or a playset.	Powered wheelchair is broken; dislikes that anyone who doesn't know them can judge safety or who is "worthy" of equipment; requesting powered wheelchair is necessary it is not like asking for toys	Frustration with government agencies power to judge who is "worthy" of receiving medical equipment

APPENDIX D

Second Order Themes Shared by Participants

1. Adjusting to child's physical disability

   18,21,22,23,26,65,66,68,76,77,78,82,83,84,103

2. Perception that wheelchair is last resort mobility option: giving up on hope

   17,20,21,66,77,78

3. Perceived importance of and desire for child's independence

   16,19,24,32,107

4. Positive perception of degree of independence and increased personal control powered mobility allows for one's child

   1,2,3,10,13,15,26,30,31,33,36,37,40,43,47,51,61,62,73,79,86,88,91,92,93,94,98,100,102

5. Awareness that environmental (i.e. physical, attitudinal or political) barriers that interfere with use of powered wheelchair

   19,25,27,28,29,38,52,70,71,89,111

6. Perception of powered mobility use as a positive influence on interpersonal relationships

   4,33,36,43,44,51,97,100,102

7. Awareness that use of powered mobility enables child's participation in meaningful, age appropriate activities

   8,9,26,31,33,36,37,45,87,93,95,96,98,102

8. Perceived impact of the use of powered mobility on others' perceptions of child, knowledge of disability issues and attitudes toward individuals with disabilities

   3,4,5,6,11,12,13,14,53,54,55,57,100,102