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Home is Where Their Wheels Are:  
The Homemaking and Housing  
Experiences of Mothers Who Use  
Wheelchairs for Full-time Mobility



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**Home is where their wheels are:  
The Homemaking and Housing Experiences of  
Mothers Who Use Wheelchairs for Full-time Mobility**

**July 2001**

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## **Executive Summary**

In July, 2000 a contract between Canada Mortgage and Housing and the principal investigator was signed to begin a project aimed at understanding the experiences of women who have mobility impairments around issues of home and community accessibility, and the impacts on their roles as parents and homemakers. With support from agencies and resources such as the Centre for Independent Living in Toronto, the MS society, and the Canadian Paraplegic Association, and Abilities magazine we recruited eleven mothers into our study.

They were all mothers who used wheelchairs for full-time mobility. They were interviewed concerning the ways in which they accommodated or modified their physical and social environments in order to fulfil homemaking and mothering responsibilities. The results of our interviews showed how mothers described social and environmental facilitators and challenges to the care of their bodies, homes and families.

Women complained about the lack of reliable and consistent services they received for personal care and homemaking services. In some cases, women were managing several different people at one time with varying levels of training and ability. The inconsistency in the training levels and expertise of care providers varied tremendously and as a result placed an inordinate amount of pressure on the women receiving their help. In addition, there currently does not exist any guidelines or supports for mothers who are procuring services, providing training for staff and for evaluating staff.

The Centre for Independent Living in Toronto has undertaken a project to promote 'nurturing assistance' as an option of care to be made available for disabled parents through existing program structures. Many of these mothers would benefit from nurturing assistance which is a program to facilitate parents in the caring and carrying out the parenting task with their children.

Women's full access to their communities and within their living environments was restricted. While many inroads have been made with regard to designing within a barrier-free environment, there are still numerous areas that are inaccessible.

The women in this study struggled with transportation issues. They had little control over the times for booking special transportation.

In trying to make the necessary accommodations and modifications to their homes some women expressed the resistance from architects to perform the work and the frustration over the long delays in finding suitable help. Finding sources of funding for renovations was limited and frustrating for the women in this study. There needs to be more creative programs developed that can be accessed within a reasonably short period of time.

Many women reported having no choice to the location of where they lived. In many instances their home was not suitable to their needs. They reported having difficulty trying to arrange new living accommodations for fear of losing existing services.

Having a wheelchair was a necessity and viewed relatively positively by most women. There needs however government programs that need to go beyond what currently is available through the Assistive Devices Program. There needs to be funding for power wheelchair as this contributes significantly to the quality of life of wheelchair users. The seasonal weather restricted community participation among our women. We live in Canada and there are winter conditions such as snow which is an issue of people who use mobility equipment.

One woman proposed a solution that would enable increased participation in real estate shopping. She discussed accessing internet real estate sites that not only list home prices and locations but provide a virtual tour. This is extremely useful if you are in a wheelchair and

cannot physically get into the home. Also included at the end of the report is a list of recommendations.

## Résumé

En juillet 2000, la Société canadienne d'hypothèques et de logement et le chercheur principal ont signé un contrat en vue de lancer une étude visant à comprendre ce que vivent les femmes ayant une mobilité réduite relativement aux questions de l'accessibilité dans leur logement et dans leur collectivité, et l'influence que ces questions peuvent avoir sur leur rôle de mère et de ménagère. Avec l'aide d'agences et de ressources telles que le Centre for Independent Living de Toronto, la Société de la SP, l'Association canadienne des paraplégiques, et le magazine *Abilities*, nous avons pu recruter onze femmes pour participer à notre étude.

Ces femmes sont toutes des mères qui doivent se déplacer en tout temps à l'aide d'un fauteuil roulant. Nous les avons interrogées sur les différents moyens qu'elles ont pris pour changer ou adapter leur environnement physique et social afin de pouvoir assumer leurs responsabilités parentales et domestiques. Ces entrevues montrent avec quels éléments sociaux et environnementaux, favorables ou non, ces femmes ont à traiter pour prendre soin de leur corps, de leur logement et de leur famille.

Elles se plaignent du manque de fiabilité et d'uniformité des services de soins personnels et de soins à domicile qu'elles reçoivent. Dans certains cas, des femmes devaient composer avec différentes personnes à la fois dont les niveaux de formation et de compétences variaient énormément. Ce manque d'homogénéité chez les soignants quant à leur niveau de formation et leur savoir-faire exerce une pression considérable sur les femmes qui reçoivent leur aide. De plus, aucune ligne de conduite ou assistance quelconque n'existe actuellement pour guider les mères qui reçoivent des services, pour donner de la formation au personnel ou pour l'évaluer.

Le Centre for Independent Living de Toronto a entrepris de promouvoir le « soutien moral » comme option faisant partie des soins offerts aux parents handicapés, et ce, à l'intérieur des

programmes actuels. Bon nombre de ces mères pourraient ainsi profiter d'un programme de soutien moral qui consiste à aider les parents à prendre soin de leurs enfants.

Selon les participantes, l'accès complet à la collectivité ainsi qu'à leur environnement est assez limité. Bien que de nombreuses percées aient été faites en ce qui concerne la conception d'un milieu sans obstacles, beaucoup d'endroits demeurent inaccessibles.

De plus, ces femmes sont toutes aux prises avec des problèmes de transport. Elles n'ont pratiquement aucun contrôle sur les heures de réservation pour le transport adapté.

Certaines d'entre elles ont tenté d'apporter les changements nécessaires à leur logement afin de l'adapter, mais elles ont avoué s'être butées à des architectes qui refusaient d'accomplir le travail, et avoir été frustrées par les longs délais pour obtenir l'aide nécessaire. La recherche de sources de financement pour les travaux de rénovation était difficile et déprimante. On doit donc mettre sur pied davantage de programmes créatifs auxquels elles pourront accéder dans un délai assez court.

Bon nombre d'entre elles affirment ne pas avoir eu le choix de l'endroit où elles habitent. Souvent, leur logement ne convient pas à leurs besoins. Elles ajoutent avoir de la difficulté à trouver un nouveau logement de peur de perdre les services qui leur sont offerts.

Le fauteuil roulant leur est indispensable et la plupart de ces femmes l'acceptent assez bien. Cependant, on doit créer de nouveaux programmes gouvernementaux qui iront au-delà de ce que le Programme des appareils et accessoires fonctionnels offre actuellement. En outre, l'achat de fauteuils roulants électriques doit être financé, car ils améliorent considérablement la qualité de vie des personnes à mobilité réduite. En effet, les changements de saisons empêchent ces femmes de s'impliquer dans leur collectivité. Nous vivons dans un pays où les conditions hivernales telles que la neige constituent un obstacle à la mobilité des personnes qui utilisent un véhicule adapté.



L'une des participantes a proposé une solution qui permettrait d'augmenter la participation des femmes à l'achat de biens immobiliers. Elle a expliqué qu'il est possible d'accéder à des sites Web relatifs à l'immobilier qui non seulement fournissent le prix des maisons et donnent leur emplacement, mais offrent également une visite virtuelle des lieux. Lorsque vous êtes en fauteuil roulant et qu'il vous est physiquement impossible de visiter un logement, cette option s'avère très utile. On trouvera aussi à la fin du présent rapport une liste de recommandations.



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**Abstract**

Eleven mothers who used wheelchairs for full-time mobility were interviewed concerning the ways in which they had accommodated to or modified their physical and social environments in order to fulfil homemaking and mothering responsibilities. Mothers described social and environmental facilitators and challenges to caring for themselves, homes and families. Housing accessibility, wheelchair design, and attendant care had effects on their household and caregiving activities and experiences. Further, the manner in which mothers obtained, trained, and used various types of human and mechanical assistance was both a honed skill and source of significant, and continuous stress. There are implications for care providers, housing planners and wheelchair designers to improve the quality of life for women with disabilities and their families.

### **Acknowledgements**

The authors would like to warmly thank the mothers who participated in the research, the Centre for Independent Living Toronto (CILT), the Multiple Sclerosis Society, The Canadian Paraplegic Association, and Abilities magazine, who supported our recruitment endeavour, and the Canada Mortgage and Housing Corporation (CMHC) for recognizing the importance of the work. We would also like to extend our appreciation to Lucia Cacciaccaro for her research assistance, and to Fran Odette and the anonymous reviewers for their sage advice on earlier drafts of this report.

## **1.0 Introduction**

Health professionals increasingly are being called upon to deal with issues relating to people with disabilities within home environments (Henderson, 1999). Advances in medicine and technology and the changes in long term care occurring across Canada, specifically the continuing shift from institutional to home and community care, mean that more and more individuals who use wheelchairs full time for mobility are living in their own homes (Health Canada, 1999). Estimates indicate that over 200,000 Canadians utilize wheelchairs (Kirby, Coughlan & Christie, 1995), and there is evidence that many more people with disabilities need a wheelchair but do not own or have access to one (Statistics Canada, 1991). However, the expectations that wheelchairs will improve the personal independence and social participation of the people who use them are not always achieved (Pierce, 1998; Smith, McCreddie & Unsworth, 1995). Physical barriers such as poor planning and design interact with society's treatment of the disabled to hinder full participation in social and domestic life (Dartington et al, 1981; Mathews and Vujakovic, 1995 ).

The home as a context for living is no longer conceptualized purely in terms of its physical boundaries, but also as a psychosocial environment constructed through the activities conducted within it by occupants (Bowlby, Gregory & Mckie, 1997). This expanded view of the home has implications for research that examines how home environments enable and constrain wheelchair users in fully engaging in domestic life. However, linking housing design with barriers and facilitators to the in-home activities undertaken by people with disabilities is "a formidable task" (Connell, Sanford, Long, Archea & Turner, 1993, p. 9 ). A "new way of thinking about domestic environments and disability...goes beyond stair lifts and ramps" (Oldman & Bersford, 2000, p.429 ) to explore the constraints of physical and social space upon

family, homemaking, leisure and employment participation. This is critically important for women who use wheelchairs, since women with disabilities have been described as “doubly handicapped” as gender intersects with physical impairments to circumscribe women’s life and employment opportunities (Dyck, 1995, p. 307). Moreover, it is women who bear the overwhelming responsibility for homemaking and caregiving activities (Angus, 1996; Morris, 1995; Thorne et al., 1996; Young, 1996).

In this study, eleven mothers who used wheelchairs on a full-time basis were interviewed concerning the ways in which they adapted to, or modified, their physical and social environments to fulfil daily household and mothering responsibilities. Mothers explained that attendant care, housing accessibility, and wheelchair design had profound impacts upon their homemaking and caregiving experiences. They identified social and housing facilitators and barriers to the care of their bodies, homes and families. Mothers further commented that obtaining, training and utilizing the various types of human and mechanical assistance that they needed was a honed skill and source of significant, daily and ongoing stress. There are implications for care providers, housing planners and wheelchair designers in order to improve the quality of life for mothers with disabilities and their families.

## **2.0 Background**

### **2.1 Housing, Homemaking and Disability**

Oldman and Beresford (2000) argue that a comprehensive literature exists on housing and disability from a medical rehabilitation perspective, however, information on the role of domestic space on the lives of disabled people is largely missing. Few empirical studies have been conducted to examine the perspectives of people who use wheelchairs on a full-time basis



regarding the constraining and/or enabling aspects of their home environment and the consequences on their daily activities. From a Canadian perspective, works such as Hickling (CMHC, 1996) are a beginning first step towards user-identified, fully accessible housing design that is not medically based. Yet the array of needs of parents who have disabilities, and specifically those of mothers, has not been fully assessed. Research suggests that domestic physical and social circumstances have a far greater influence on occupational performance than the ability or inability to perform a number of activities independently (Dyck, 1995; Jongbloed, 1994; Moss, 1997).

A few studies have explored issues that women living with arthritis and multiple sclerosis faced with respect to restructuring the physical spaces and social relationships in their homes in an attempt to carry out their daily activities (Dyck, 1995; Moss, 1997). These studies contribute to our understanding of how gender, the physical and social circumstances of the home environment, and socio-political and economic contexts interweave and influence the lives of women who are disabled and live at home. However, since the type of mobility device and its level of use varied significantly, generalizations to full-time wheelchair users cannot be made. Further, the centrality of motherhood and related responsibilities to the lives of disabled women were not a primary concern of the studies.

## **2.2. Mothering and Disability**

Furminger-Delisle (1996) notes that as a result of social prejudice, women with disabilities are often urged to avoid pregnancy, marriage or motherhood. In Able Lives: Women's Experiences of Paralysis, newly paralysed women indicate that one of the ways in which they measure their return to 'normalcy' is through,

(A) return to the pressures of looking after other people. Aids and adaptations which are supposedly about helping us to be [physically independent] are in fact often about enabling others to be dependent on us for the tasks which keep a house clean and a family fed. Society's expectations of women being what they are, it is not surprising that many of us measure our 'success' or 'failure' in terms of whether we can return to the role of housewife and mother (Morris, 1989:52 cf. Morris, 1995, p. 76 ).

However, Morris cautions strongly that such commitment to traditional female roles should not be seen as "some kind of false consciousness". She continues,

Having sexual relations (whether they are heterosexual or lesbian relationships), family relationships, bearing and rearing children, making a home – all these are important human and civil rights which, if denied to *nondisabled* women, would be the subject of outrage. (Morris, 1995, p.76, emphasis in original).

Indeed, an American rehabilitation team once described a mother with spinal cord injuries as having "unique goals" since she wanted to care for her infant and be mobile in her home and community (Somers & Garant, 1993 ).

A perusal of contemporary medical products catalogues finds that they are largely devoid of devices that assist disabled mothers in meeting the needs of their newborn, preschool and school-age children. Women are often required to "reinvent the wheel" in terms of crib and wheelchair adaptations (see for example, [www.disabledparents.com](http://www.disabledparents.com)), or they are forced to make do with inadequate equipment. Care services often do not recognize to women's obligations as carers-of-others within the household. Thus, while personal care is relatively accessible and available to women, support for their roles as mothers is not. Further, inaccessible public spaces such as day cares, schools, classrooms, libraries, community centres, swimming pools and local parks prevent women from fully participating in their children's education and leisure activities. This lack of community and institutional support is seen as "particularly oppressive" to mothers with disabilities (Morris, 1995).

The combination of paid employment with mothering responsibilities places further strain on women with disabilities. Women must deal with specialized transportation systems that are poorly organized, a lack of services designed to facilitate their roles as working mothers, and punitive income support programs that provide poorly for families and limit how much supplementary income women can earn (Dyck & Jongbloed, 2000).

### **2.3 Models of Care Services**

In a recent comprehensive review, Hollander (2001) identifies that the “discussion of systems of care for adults with disabilities is still in its infancy.” While adults with disabilities are able to access a variety of home and residential care programs, in general, the research and policy focus is on services for the elderly. Research has identified that the needs, values and expectations regarding care services and personal autonomy differ significantly among adults and elderly people (Eustis & Fischer, 1992; Simon-Rusinowitz & Hofland, 1993). The main issue for younger people, according to Hollander, is that of self-managed care: “that is, to what extent could and/or should adults with disabilities have the right to manage their own care?”

Self-managed care is an innovative model of care in which people with disabilities are able to exercise control over the selection, duration, and frequency of the type of care and the care providers (Hollander, 2001; Simon-Rusinowitz & Hofland, 1993). Under the self-managed model, clients hire, train and fire their own attendants, direct the type of treatment they provide, and maintain consistency and continuity of care. This challenges the familiar home care agency model in which agencies choose and deploy care providers, often without client input or with the client’s social participation in mind (Hofland & David, 1990 cf. Simon-Rusinowitz & Hofland, 1993; Beckett & Wrighton, 2000 ). In comparison to clients of agency-directed care, those who

manage their own care have been shown to have more positive health outcomes, fewer hospitalisations and unmet needs, and feel a greater sense of security and satisfaction (Benjamin, Matthias & Franke, 2000; Hollander, 2001). However, there are significant economic, professional rights-of-practice, and funder or third-party payer concerns that limit the utility or widespread availability of this option at this time in Canada (Hollander, 2001). Nonetheless, Benjamin, Matthias and Franke (2000) note that consumer-directed models offer a cheaper, less bureaucratic option for organizing home care services.

The above studies are notable for the lack of attention paid to the specific vulnerabilities of women in accessing support services for themselves. Women with disabilities may face a range of gender-mediated complications in relation to care provision. They may be perceived and treated as helpless or dependent children; may be at risk for emotional, physical or sexual assault by care providers; may be economically vulnerable and unable to privately purchase additional or alternative care services; may face discrimination as lesbians; and/or may have additional care concerns related to their roles and responsibilities as mothers and spouses/partners. (Beckett & Wrighton, 2000; Morris, 1995; DAWN). Nasa Begum (1990, p.79) elaborates,

The issues that nondisabled women have to confront in relation to power, sexuality, body image and so on become particularly ferocious when confronted in the private domain of the personal care situation. A lack of power, control and choice over how one's basic needs are met leaves [disabled women] at the mercy of others, compromising and negotiating for the things other people take for granted every day. The costs of receiving personal care can be astronomical both in emotional and practical terms (cf. Morris, 1995, p. 92).

Clearly, any examination of women's access to care services must be sensitive to the unique gender challenges that they face.

### **3.0 Objectives and Scope of Research**

This study used qualitative research methods to examine the mothering, homemaking and housing experiences of women who use wheelchairs for full-time mobility. The research questions were:

- *How do women who use wheelchairs adapt and respond to their **physical** home environments to perform their daily household occupations?*
- *How do women who use wheelchairs structure and restructure their **social** home environments so that they can fulfil their occupational roles?*

The first objective of the research was to illuminate women's physical and social experiences within the home, as well as to explore the interactions among parenting, homemaking activities, wheelchair use, and the home environment.

The second objective was to provide housing and wheelchair designers with information that would enable them to be more responsive to women with mobility needs, and to broaden understandings of the ways in which physical designs can act as facilitators and/or barriers to mothering activities within and outside of the home.

Based on women's feedback during the qualitative interviews, the scope of the research expanded from private dwelling spaces and activities conducted therein, to include the exterior and public spaces they frequented or relevant to their daily lives. Further, our understanding of the challenges to mothering and homemaking activities evolved to include women's involvement in procuring and managing attendant care for themselves.

#### **4.0 Methodology**

In-depth, focused, open-ended interviews were conducted with eleven mothers with disabilities who lived in the greater Toronto area. Women were recruited in a purposeful sample through advertisements in disability-targeted newsletters and through local flyers. In order to be eligible for the study, mothers had to be English-speaking, between 20 to 55 years of age, use a wheelchair or scooter as the primary means of mobility, live in a unit not specifically designated as a wheelchair accessible unit, and care for at least one biological or adopted child who lived in the same household. Following the audio taped interview, a short demographic questionnaire was completed. A \$25.00 honorarium was offered to mothers in acknowledgement of their time.

The qualitative interviews lasted from 45 minutes to 2.5 hours. All interviews were conducted by the fourth author. During the interviews, three infants or children were in attendance, and in two cases home care attendants or nurses were in the home. Two of the interviews ended abruptly as one mother needed to attend to her crying infant, and another mother was concerned about missing Wheel-Trans and being late for work. As a consequence, the first mother sent two follow-up emails to augment the description of her dwelling and the types of assistance she received; the other mother completed the demographic questionnaire by telephone.

Five topic areas guided the interview: 1) home and modifications; 2) activities (homemaking, parenting/caregiving and leisure); 3) family, friends and support network; 4) neighborhood and community and 5) wheelchair use. While the interview guide was designed to facilitate comparable data analysis (Fry & Keith, 1986), all interviews were recursively defined. Issues were probed when they were mentioned by mothers, rather than waiting for when that issue was outlined in the guide (Schwartz & Jacobs, 1979). As the aim of the interview was to

obtain the informant's point of view (Lincoln & Guba, 1985), open-ended questions were utilized. Mothers were able to express their viewpoints about the specific questions, and had the opportunity to discuss other issues of importance to them. Such flexibility led to women moving beyond their homemaking experiences within private dwellings. Women indicated that attendant care, and public accessibility and attitudes were integral to any discussion of accessibility, or lack thereof, upon quality of life and the facilitation of their roles as mothers and homemakers.

Mothers were assigned an identification number and a pseudonym to protect their privacy. Taped interviews were transcribed and then coded into categories based on the research questions using a computerized qualitative analysis package, NUD\*IST 4.0 (Non-numerical unstructured data indexing, searching and theorizing). Next, data within each code were organized according to thematic content, moving from lower-order to higher-order themes as the analysis progressed. Finally, a review of the final report by stakeholders, including mothers and scholars with disabilities, confirmed the validity of researchers' interpretations and analyses.

## **5.0 Discussion**

The pertinent findings from the interviews are organized into seven sections:

- I. Descriptions of the Mothers
- II. House and Body Care
- III. Mothering and Disabilities
- IV. Housing
- V. Mobility Devices
- VI. Recommendations for CMHC and Wheelchair Manufacturers
- VII. Conclusions

### **5.1. The Mothers**

Selected demographics of the study participants are presented in Table I. Mothers were on average 42 years old, with a range from 32 to 51 years of age. All women were white and the majority had a college or university degree (72%) or were married (63%). Three mothers had lived with disabilities since birth (cerebral palsy, muscular dystrophy, spina bifida), two women had acquired disabilities at childhood (rheumatoid arthritis, spinal cord injury), four women developed multiple sclerosis as adults, and two women were injured in accidents as adults that resulted in amputation or quadriplegia. Women had a mean of 1.45 children, with an equal representation of children from the ages of 0-10, and those between 11-18 years old. There was one child less than a year old, two between 2 and 5 years, five between 6 and 10 years, six between 11 and 14 years, and 2 between 15 and 18 years. Approximately two-thirds (61%) of women identified themselves as full-time homemakers or unemployed, and were reliant upon spouses, long-term disability or the Ontario Disability Support Program for income support. One-third of women worked outside the home, either full or part-time, at the time of the interview, and one-third performed community or volunteer work.

A little over half of the women rented their dwellings (54.5%) (see Table 2). Almost three-quarters of women resided in multi-family dwellings such as apartments or cooperatives (54.5%) or condominiums (18.2%), while just over one-quarter (27.3%) resided in single-family dwellings. Nine (81%) were satisfied with their living accommodations, and two women (18%) were on waiting lists for subsidized or accessible housing. One woman had applied to the March of Dimes for a home renovation grant. Eight women (72.7%) had made renovations to their homes, with the overwhelming majority of renovators making structural changes. Fifty percent



of mothers who had had major renovations done to their homes were renters and 50% were home owners. On average, mothers had lived at their current addresses for 8 years, with a range from 1 to 18 years in length.

Women's use of mobility devices is captured in Table 4. Six mothers used power wheelchairs (54.5%), three used standard or manual chairs (27.3%), and two used a scooter (18.2%). On average, mothers had been wheelchair users for 12 years, although this ranged from 1 to 35 years. Women had been using their most frequently used wheelchair for approximately 3 years, and 81% were satisfied with that device. Three (27%) of women identified problems with maintenance or overall design.

Mothers' utilization of homemaking, personal and childcare assistance is captured in Table 5. Further details on house and body care are provided in the next section. Five (45%) of women received attendant care for personal care such as toileting and showering. Four (36%) of women received nursing care for personal care for urinary tract problems, showers, and help with bowel program. Four women (36%) received home care attendant or homemaking services and one woman had a health care aid. One woman employed a private housekeeper and a part time babysitter to help with child care. The family was a great source of support for the women. Spouses and children provided assistance with household chores such as cooking, dishes, and grocery shopping, and with personal care tasks such as toileting, and getting in and out of bed.

## **5.2 House and Body Care**

### **5.2.1 Types of Care**

The women received a variety of care services depending upon their abilities and need requirements, personal and family preferences, and affordability factors (see Table 5). Ten

women were receiving personal care or home care assistance. Services ranged from daily assistance with meals, to weekly or bi-monthly assistance with laundry, washing floors or housecleaning. Nine mothers were either receiving, or had been in previous receipt of, personal care assistance. The care varied from daily bladder catheterization, assistance with dressing, or exercising, to assistance twice or more per week with showering or bathing. Most women had identified that they did or wanted to make changes in the amount or the type of care they received, and a two mothers were on waiting lists to receive more personal and homemaking care.

For the women who required personal care from providers,<sup>1</sup> such care was understood to be as fully connected to their mothering and homemaking roles as was the household help they received. For example, the lack of attendant assistance and physical access difficulties that prevented one participant from showering in the morning caused her to feel “sweaty and grimy” and therefore “grumpy” with her children. In contrast, another mother noted that she had to decrease her showering assistance from daily to twice a week because she found that she was often too fatigued afterwards to comfortably mother her active, inquisitive toddler.

Two women received care from registered nurses on a regular basis and one was in temporary receipt of nursing services due to an acute illness. For the other mothers, a crossover of care provision meant that the home care aides whom undertook tasks such as washing dishes and sweeping floors were also called upon to assist with toileting and bathing.

“[Attendant] vacuums and washes the floor. She makes my bed. She does the bathrooms usually on one visit. The second visit...she will help me shower because I can't do it on my own.”

“[Housecleaner] comes on Saturday, helps me get dressed, she helps me use the bathroom as well as doing the cleaning.”

It was the decisions by care organizations and/or insurance companies that determined whether personal care should be performed by professionals, paraprofessionals or untrained workers, and to what extent. In one case, for example, the initial practice had been that registered nurses performed her personal care, while home care assistants met her homemaking needs. The insurer subsequently determined that only registered nurses would be permitted to bathe her, at a frequency of every other day, and that home care aides would take over the routine, non-specialized body care that nurses had previously undertaken. While this mother was quick to point out that her home care assistants were, in general, extremely competent, she felt that a severe health crisis in which she almost died could have been averted had nurses been monitoring her daily. Further, following discharge after hospitalization, she was distressed that the frequency of nursing care was neither increased nor returned to its initial level.

### **5.2.2 The Work of Care**

The centrality of attendant care to mothers' lives was clearly articulated. One mother noted that due to her level of disability, "I have assistance through attendants, and so my accommodation is in the form of human support." Another explained that if she did not have attendant care, "like, I don't know what I would do. I think I would maybe have to, I hate to say it, but maybe I would have to go into hospital." One mother commented that having assistance "makes our house run". Yet, for mothers with disabilities, the requirement of assistance with everyday household and personal body care mandated their ongoing efforts towards *procuring* and *managing* attendants and services. Mothers had to work, and work hard, at ensuring that the care that they received was timely, continuous, appropriate and satisfactory.

### **5.2.2.1 Procuring Satisfactory Care**

Mothers perceived that the practices, policies and regulations of the care agencies were the first challenge they faced in procuring appropriate assistance. They commented that the care agencies were “disjointed” and “disorganized”, and that care was compromised by the “high turnover” of management and front-line staff. Mothers also criticized the agencies for failing to provide them with information regarding staff changes or holidays, or to follow-up on their requests for additional assistance.

Mothers expressed difficulties in comprehending the logic behind particular practices and policies. One mother commented that since her attendants “were not allowed up on chairs,” they were unable to retrieve items that she could not reach herself. In another case, a mother was frustrated by the agency’s insistence on pre-booking for grocery assistance. One mother explained,

“I wanted them to meet me at the grocery store and help me pick this up, but they wanted eight days notice, I mean to do this. I do not know eight days in advance that I'm going to be out of groceries. (Y)ou know, the consumption goes like this, right?[mother motions up and down with her hand]...it's not predictable.”

In terms of service consistency, an unevenness of policies across agencies meant, for example, that procuring laundry services for the entire family was dependent upon where woman lived and hence, the agency for which she was eligible. Some mothers were unable to obtain laundry services for clothes that were not their own. A mother with a 2 year old child, noted,

“That’s always been one thing, like the homemaking service that’s available here in the building on site...they do laundry only for the person that’s in the wheelchair. Only for the person that has the disability.”

At the time of her daughter's birth, one mother was obliged to obtain assistance from another agency in order to receive assistance with laundering the newborn's clothes. In contrast, another mother was able to successfully convince the agency that a "family approach" to household duties made the most sense. A mother commented,

"(T)hey'll help with [the entire family's laundry]. I guess every place is run differently. My services are provided by [name of agency] and basically in my service agreement, I just worked it out. I didn't want them to just help me with the things I needed. It makes more sense for me if I'm doing a laundry to just do all the laundry, and if [husband's] making dinner, he's making it for everybody, if he's grocery shopping, he's grocery shopping for everybody. Because I didn't want them to go grocery shopping for my groceries and help me make my meals. When you live in a family, you either do things together or you don't. So I negotiated that as part of my service agreement, and that's satisfactory to the organization. So, that's the way I've been doing things."

Challenging and adapting to the agency's policies were common activities undertaken by the mothers in order to facilitate their own homemaking roles. In some cases, resistance involved actively persuading care agencies and individual providers to break established rules. One mother explained,

"I wanted (the attendant) to do laundry and I was out of laundry soap...So I wanted her to go out and get some and she wouldn't go out because it's against their policy...and I said, 'well, you might as well go home because I need the laundry done'...So then she phoned her agency and the woman said, 'Okay, for this one time, you can go and get what you have to get.' But she wanted to walk to the corner store because that's their policy... (It's ridiculous, so I told her, 'Take your car.' 'Oh no', she said, 'I'm just to walk to the corner store, that's their policy'. So I said, 'Drive, drive', so finally she said 'okay'. So she drove, got laundry detergent, came home and did laundry, but it was a big hassle..Just typical!"

In some instances, adapting to the rules of an organization meant figuring out which attendants could be counted on to help out, regardless of any prohibitions. One mother commented,

"Most of [the attendants] are pretty good with cleaning up the bathroom. There's only one that I have that seems really, really focused on helping me in and out of the bathroom. She does clean up the kitchen a bit... She would do

that but she doesn't do the laundry. I haven't really asked her because I think it's not worth it. It'll last until tomorrow because I know the next person who [comes] does do the laundry really well and she gets stuff folded and put in the kids' rooms and that sort of thing."

Attendants who agreed to undertake additional tasks were highly valued by mothers. One mother explained, "These ladies know that they are here for me and yet they help out in the home, so it's kind of nice that way." Another commented on the helpfulness of one worker, despite the organization's "list of what they couldn't do":

"The woman that actually came to us from there eventually she did act just like a housekeeper. She didn't sort of say, well, that's not your bed, I'm not making it. She'd watch the kids, because I couldn't even get in my children's bedroom at the other house."

The second challenge to procuring adequate care was mothers' perceptions of workers' skill levels, work ethics, and their attitudes towards the disabled. One mother was highly critical of the lack of standardized training, and of the absence of client involvement:

"There is no standard for attendant care. They don't even have to have a course. A lot of them do here now have the course or, or they've got ah several years experience, but there isn't a regulation or standard for the people coming into it. So most often they are hired because they've had previous experience. But then again, the client, myself as client, we don't have any input into who they're hiring."

This lack of choice or control regarding care providers meant that women were often frustrated by workers whom they felt provided inadequate services. One mother elaborated,

"It just put me in a bad frame of mind the whole day because I couldn't trust her. (She was) doing white with burgundy coloured stuff. I really wondered what colour my, my whites would be coming back as. And some of the time, (she showed) no common sense at all."

Because of the personal nature of the care provided, mothers' own definitions of "adequate services" were highly subjective. One mother drew distinctions between "an excellent worker" and one with whom she was greatly dissatisfied:

“She is good, kind, quiet and takes initiative. She does things...She remembers what I like... I had another woman, who was training to be a nurse. But I found out she didn't like working. It was like, 'could you do this?' 'Uh well, I don't know. I don't know if I can do that'. Then I needed personal care. And I couldn't stand the way she did my hair! She got it all in my face. Don't do my hair like that! Whereas with [current attendant], she just sort of watches what I do, and she does it exactly the way I like it. So, she is a good worker. A very good worker.”

At various times, subtle or outright power struggles existed between mothers and particular home care workers. Another mother noted,

“(I)t really depends on the person. Like there's some people I've had a good working relationship with, and then with the turnover, there's a lot of other people and it's like, you have to tell them each step. Like, if you want to clear off the table, people who have worked with me a lot, I can say, 'Can you help me clear off the table?' and they'll be picking up things and they know where things go and they can put them back. But with somebody who doesn't know that, or someone who's kind of just digging in for the sake of digging in about something they resent doing, you'll have to say, 'Can you pick up this bill and put it over there? Can you pick up this book and put it over there?' You have to name each item and you get sick of doing that for a solid hour or whatever. And the time it takes to explain all that, which someone else would do in five or ten minutes, you've suddenly used up half an hour or 45 minutes doing.”

A few mothers attributed conflict to the workers' assumptions of the extent of household tasks that family members should do simply because they were able-bodied, and therefore “capable” of doing them. One mother noted that attendant resistance to particular tasks was “psychological...if I see able body people living here with me ...then the able body person should be doing more of that.” However, she also noted that conflict with attendants occurred in repetitive “cycles” and if not related to her able-bodied husband, then, “something else would come up in its place.” Another mother acknowledged, “I'm sure the staff get tired of picking up the same stuff day after day, when the kids really should be picking it up for themselves.” However, she alluded to more complex and long-term conflicts when she suggested that the failure of attendants to adequately perform their jobs was a “quality control issue that I think

could get addressed once proper management's in place, and people are getting reinforcements for doing the kinds of things they should be doing.”

Mothers felt “out of control” when they were not able to obtain the quality of care or services that they desired. In order to prevent, avoid or minimize events that would evoke such feelings, they developed multiple strategies. For example, mothers broke down activities into specific components and only requested assistance for those components that could be successfully executed to their standards; they cancelled or modified activities; substituted or augmented attendant care with assistance from immediate and extended family, friends and neighbours; and they volunteered on organizational committees that mediated between care providers and care recipients. However, the primary strategy to ensure quality control of homemaking and personal assistance was mothers’ strict management of the attendant workers.

#### **5.2.2.2 Managing Care**

Mothers often felt compelled to supervise, control or micromanage the performances of untrained or paraprofessional workers in order to obtain the quality of care or services they required.

“So I’m there when they’re providing my services to direct or request what I want, so I need to be able to look over their shoulder or look around their side at what they’re doing, you know, if I’m concerned that it be done a particular way. And if people have been working with me for a while, and their standards or way of doing things are similar to mine, I don’t have to be on top of them quite so much. And that’s nice because then they can be off doing something, while I’m doing something else.”

“It’s not easy having people coming into your home period, and three different people is tricky because when they’re unloading the dishwasher, putting dishes away, you have to tell them where things go, and then the next time to tell them what to do or where to put different things.”



One strategy used to control or manage the performance of the attendants was the mother's emphasis on routine. Seamon (1980) has argued that a "routine is made up of appropriate activities occurring automatically through time. Hence, repetitive aspects of daily living free people's cognitive attention for more significant events and needs." However, for mothers with disabilities, routine was itself something that had to be planned and carefully orchestrated. Establishing and maintaining routine so they "would not have to think about it" ironically necessitated a great deal of cognitive energy and preparation. One mother provided a detailed explanation of the daily, weekly, biweekly and seasonal "bookings" that she required. Since this mother needed body as well as home assistance, she had to book attendants for daily morning care such as bathing, dressing and brushing out her hair (timed so as to not interfere with her husband's variable work departures), as well as assistance with breakfast and lunch preparation and clean-up for herself and her child. She also had to organize weekly housekeeping such as vacuuming, washing floors and doing laundry, tasks which had to be scheduled with her toddler's nap and active periods in mind. Weekend and evening care required particular forethought because of the availability of her husband to perform certain tasks, her daughter's participation in community activities such as 'Afternoon Story-Time' at the local library, and the desire for family privacy. Finally, seasonal bookings were organized around holiday baking and family celebrations. For example, she recalled with pleasure how she had previously pre-booked forty-five minutes each afternoon for "a month of Tuesdays" in order to bake Christmas treats for her family.

The ability to control an attendant's routine was perceived as avoiding or mitigating unnecessary delays or disruptions to the woman and her family. One mother explained,

"I do have quite a routine (laughs) and I have actually got it written down for people. I even make it as specific as what I have for breakfast so I can just

say “regular” and they’ll know what times to catheterize me and that sort of thing. So it’s a set wake up. It’s hard to explain constantly.”

Another had developed a weekly and monthly task list so that duties could be performed while she was not present.

“(T)hey’ll do mopping, vacuuming, dusting, tidying, that kind of thing. I have a list that I’ve made for them that they go through. And then there’s some things that are done maybe once a month or less often, so each week they’ll pick one of those things to do as well and go through that. And that’s happening when I’m not here. Usually they’re doing that while I’m at work.”

For many mothers, routine represented mastery over their lives and bodies. Despite her ongoing difficulties in obtaining the quality of care she wanted from attendants, another mother was adamant that even having them arrive at the same time each day would be an immense improvement. She explained, “I would at least know what to expect and when to expect it. I still might not get things done right or the way I want them, but after a while they would learn and it would work out better.” Consequently, the loss of routine was experienced as a profound transgression against women’s bodies, and their homes and families. A mother recalled,

“The [primary attendant] had..her usual annual summer vacation and the [replacement]..was later and made my apartment, my home inaccessible for that time because it was just so disruptive...The major thing was that she came at a different time and, so of course, you know, you get your body and you get your, your life kind of organized to that. And you get that routine and, and it becomes a habit so you don’t have to think about it. But once something goes wrong, you..get so frustrated and mad about it.”

In some cases, mothers had developed unique strategies to avert either the more onerous aspects of management, or the negative impact that poorly managed care might have. One mother noted, “I try not to have them do much cooking because then I have to sit there and supervise and tell them how to do, like, even peeling potatoes.” Another mother took a contrasting approach: “(S)ometimes because there are various backgrounds of people, I get them to make a meal that’s like theirs. That way I don’t have to think about it”. She also purposively

encouraged her attendants to choose the activities that they enjoyed the most: “I try to tailor it to whatever they like to do. Some of them don’t like to cook and so we do something else, and I have cooking done for them. Some of them like to drive, and some of them don’t.”

For her part, this mother had been extraordinarily resourceful in resolving her quandaries in securing care given the “difficult health care market” and the high turnover of attendants which she attributed to the low pay and poor treatment of workers by their organizations. She had encouraged an attendant to leave her agency and start up her own company with the mother as her main client, a position in which she also assisted with the recruitment of other attendants. This mother was now in a position where she was purposively and “creatively hiring” attendants. She explained, “I made up an interview sheet. And the final question was ‘what brought them to this profession?’ And if I liked the answers, that was a big thing.” The result, this mother noted, was that workers “are very kind and considerate, right from the start.” Of all the mothers interviewed, this mother indicated the greatest satisfaction with her home care providers. Although her model of care provision was a hybrid between agency-directed and self-managed models due to the de-skilling restrictions introduced by her private insurer, this example offers some common-sense evidence that increased client control over attendant hiring and training is associated with higher levels of satisfaction in particular areas.

While mothers described in great detail their skills at directing and managing their own care, they often seemed concerned that they would be perceived as “pushy” or “bossy”. One mother elaborated,

“I’m not really a naggy kind of a person. I just don’t ask people. I sort of assume that if they’re going to see that something needs to be done, they’re going to do it and that’s how I function... but I find that you really have to make it very clear with people, ‘could you do this, could you do that’.”

Similarly, the mother , who had demonstrated astute entrepreneurial and managerial qualities, explained, “I’m not very good at ordering people around. So I expect some of them to be self-starters because then I don’t have to be constantly supervising.”

For some women, despite their best efforts at controlling the kind and quality of care they received, the reliance on attendants meant that their homes were never quite the way they would have them if they could perform the activities unassisted. Another woman deliberately refrained from having family, friends and co-workers visit. She noted,

“I find just in terms of the home or being as tidy as I would want it, or as organized as I would want it, or decorated the way I would want it, like it's just never done, because I'm always relying on the other people to do it and I don't want to push people too far. With attendant staff they all have their different standards as I say, and their own ways of doing things. And with the limited time, you're sharing service. You're not going to say, 'I want this done this way' and 'that done that way'.”

Another mother indicated that the overall clutter, and the chronic difficulties she experienced in getting attendants to wash all of her dishes in one booking, meant that she was immediately stressed upon hearing of an impending visit by her parents or in-laws. In response, she would “start giving orders” to her able-bodied husband, which caused some level of conflict between them.

### **5.2.3 Changing Care**

Augmenting or changing care provision was fraught with challenges for the mothers in the study. One mother noted that meeting and training new caregivers provided a source of stress that the able-bodied interviewer would not be able to grasp: “You don’t know the drudgery of just introducing yourself to another person and, and saying the way you like things or ah..the rapport that you’ll have.” Another mother was uncertain whether she would be able to receive

assistance from an attendant she favoured, as the organization that was procuring the additional care did not hire from the same company.

When women were satisfied with the attendant that they had, they were loath to make any changes that would jeopardize that care. Despite increasing symptomology of pain, another woman deliberately refrained from requesting additional assistance. When questioned, she replied,

“Because I don't want to have to go with someone else. I don't want to...because [attendant] is really comfortable. I don't want to have to go to another homemaker. Home care is stressful enough.”

When mothers expressed a willingness to have increased attendant care, it was often with the well-being of their children in mind. A mother noted,

“The (attendant) would come to help me do the shower thing...mostly I wanted her there so that I didn't fall down. You know, I wanted to be able to have a shower when the kids were gone and I didn't want the kids coming home with Mom on the floor.”

Similarly, in describing the body assistance she required, and the gaps in care on the weekend that meant she did without, another mother referred to her children:

“(W)hen you have troubles with incontinence which happen occasionally and you have your period, you really feel like you need to have a shower almost every day if not more sometimes. So I have someone as I said 5 days a week and that has been much better for me, feeling that I can at least have a shower or rinse off areas that, you know, I feel a little bit self conscious about...The weekends are a bit harder. I feel awful that my kids have to see this kind of thing.”

Even when additional care would facilitate homemaking tasks, women were concerned primarily about the impact it would have on their families. One mother was sensitive to the impact that 24-hr care had upon her family: “(I)t's difficult as you can imagine in a small space to have home care and providers all the time. And my husband deals very well with it but it's frustrating I'm sure sometimes.” Another noted that her husband and son experienced attendant care “as an intrusion. They don't like to hang around if there's somebody else here.” A third described her apprehension to news that she would receive assistance with her infant's laundry:

“At first when I was thinking about it I thought...oh god, how am I going to handle another person coming in? And they’re going to be here twice or three times a week and you know, I’m only used to the daily people that I’ve seen and I’ve got a new baby, I don’t want everybody and anybody coming in and interrupting my time with her.”

In the same fashion, despite an obvious need for additional body care and “feeling really guilty” that she was not able to prepare a “fancy” Sunday dinner similar to what her own mother prepared, one mother was reluctant to obtain weekend assistance because of her children. She explained, “They feel it’s a bit of an intrusion. They feel that they have no more privacy anymore, there’s always someone coming in. They know the workers pretty well now, but they still feel ashamed that they don’t have a normal life.”

#### **5.2.4 The Meaning of Care**

Women explained that receiving attendant care not only involved additional work for themselves, but a reordering of their self-perception. For many individuals with physical and health challenges, “the reality of life is not the heroic overcoming of dramatic obstacles, but the daily struggle with the mundane activities through which identity is expressed and confirmed” (Williams, 1993). Receiving attendant care meant that mothers struggled with the identity markers that attendant care conferred: that of “care recipient,” “disabled woman,” and a highly conflicted understanding of “mother”. For one mother, her increasing level of disability facilitated a growing comfort with the identity of “care recipient”. One mother explained,

“It’s hard for me to (ask for help) but now that I can less obviously do (the task), I guess it’s a little bit easier for me to ask that “would you mind putting those groceries away?” that type of thing...Now that I’m in the chair all the time,... I don’t feel quite so bad about asking people to do things. When I was walking around, it’s more difficult to expect them to do things just automatically because I’m sure they were thinking, ‘she can do this herself,’ you know, ‘why is she asking me to do that? I’m not her slave’, you know that type of thing. But now it truly is more difficult for me to do it.”

Women's requirements for assistance alternately supported, challenged and extended their conceptions of themselves as "good mothers" and homemakers. While her husband was away, one woman noted that assistance was instrumental in helping her "be respectable..with the kids" in front of the neighbours. Another woman explained that all of the tasks that the attendants undertook were tasks that she wished that she could do herself. She described in detail those task components that she could perform without assistance, such as rinsing the diapers before they were laundered, and drying and putting away dishes. Another woman noted that part of her responsibility as a homemaker was to "have my home, you know, the best I can" and to "keep negatives out of the home." She therefore focused a great deal of energy on what she perceived was a significant part of her homemaking and mothering role as a disabled woman: maintaining harmony and equilibrium among her care providers. She went to great lengths to ensure that workers were not unhappy or displeased with her, each other, or with her husband and teenage daughter. Her primary concern was that worker unhappiness would negatively impact on her family.

### **5.3 Mothering**

#### **5.3.1. Participation and Planning**

The mothers in our study engaged in a full complement of indoor and outdoor activities with their children. Mothers described "entertaining and stimulating" infants, reading to or singing with toddlers, going bike riding, skiing and skating with youngsters, and teaching adolescents to sew and cook. Mothers also described breast feeding, travelling with children by bus and train, assisting with homework, attending parent-teacher meetings, and acting as fierce advocates for their children.

Societal lack of support for mothers with disabilities has resulted in an absence of commercially produced, parenting-related assistive devices and adaptive technology. Therefore, in order to participate as fully as possible in the physical care of their children, women individually developed strategies and techniques to facilitate a wide range of mothering activities. Mothers described designing homemade slings in order to pick up immobile and crawling infants from the floor, changing diapers with their teeth when their hands could not manage the diaper tabs, and utilizing futons as large play mats. Family members and friends demonstrated support through the adaptation of cradles, cribs, and change tables. One mother described how her brother modified an existing crib:

“My brother developed a crib. And the side that normally goes up and down, he made into a rigid side that was turned into two doorways which you opened. And the crib was set at the very lowest level right from the outset, like even when the babies were newborn. And you opened up these doors and then you could wheel right under the crib, change them on the crib and then close the doors. And then you had a couple of locking mechanisms to keep it shut. So that was really, really helpful. Incredibly helpful.”

Further, since transporting infants and toddlers was difficult when women’s hands were needed to propel or manoeuvre their wheelchairs, women compensated by using commonly available infant carriers, and their own bodies. One woman explained,

“Umm, you can also carry them in a "snugly" or in a carrier on your person and that’s the way I often do it a lot. Umm. Ah mine has straps that go over my shoulder and then he’s in a little pouch that will detach from the strap and when he was very young he faced in and now that he’s older he sits on my lap basically facing out but he’s restrained so my hands are free to do the wheeling. So that’s how we’ll travel a lot and how we’ll go for walks... it’s just easier. And when my husband and I and [baby] go for a walk that’s usually how we do it as well. Instead of taking a stroller, I’m like a human stroller. [baby] sits on my lap.”

However, the lack of appropriate accommodations could at times cause mothers significant physical pain and discomfort. A mother noted that steering her daughter’s stroller with her feet caused her knees and hips to ache terribly. Another mother commented,



“The real difficulty I've found with little ones is carrying them. I wish they had a better way of carrying babies. Now with [eldest son], I didn't have a cushion, I didn't have any kind of padding between the wheelchair seat and my bum and I used to find the weight of him was unbearable. Because he got to be quite fat, quite young, he was over 20 pounds at a fairly young age, long before he was mobile, and just the weight of carrying him just seemed so [emphasis] difficult. I found that those car seats were be helpful, those infant car seats, you know carrying them in the infant car seats, but he got to be too big for that pretty quickly and while they still can't hold themselves, that's the thing I found the most challenging.”

For women with disabilities, each change in their child's development or weight marked, in one mother's words, an “adjustment phase” for both mother and child. She elaborated,

“Anytime she had a change in weight or height, you know, I had to kind of get adjusted to it. Ah, anytime that I thought about going back to work and saying, you know maybe she's better off with a full-time paid caregiver was usually at a time when she had changed height and weight or abilities and I was feeling kind of like I wouldn't be able to handle it or, or that it was getting too much. But one or two weeks and we'd both be adjusted...but you know, with each height and weight change comes ah, a different strength. And also a strength for her, she can hold onto me, instead of me having to hold onto her only. So she, she's changed quickly, and ah, so have I.”

Similarly, another mother noted,

“There's a lot of you know injuries to perhaps yourself and potentially your child that you have to really work around... especially if they start to get larger and heavier. That's one of the big things I've had to work with, work around in my mind thinking of how will I do it so I don't get injured or he doesn't get injured.”

While mothers greeted their infants' milestones with joy and pride, developmental transitions from crawling to walking also initiated apprehension and forward planning. Mothers had to problem-solve how they were going to best manage their children's corresponding increases in size and activity. Routine childcare was envisioned as discrete steps or stages of activity in which the child's current physical status was accounted for, and mothers planned for future development. This mother provided a lengthy description of her concerns and preparations involving the bathing of her infant. The following words provide an indication of the complexity

of planning as she considered, over the course of time, the interactions among her own and her child's body, her wheelchair, and the home environment.

“And once the, the bath is ready or set-up I, usually put his bathtub on the floor of the shower...and fill it up right there. I get down out of my chair onto the ground with him. Then I transfer him out of his stroller into the tub and then dry him off on the floor and then he'll go back to the stroller. I'll go back to my chair... Umm, once he's, you know, out of the baby bath into the big boy bath, my husband may, may end up having that duty. One of the options is of course getting right in the tub and having a bath with him. Either having a bath, bath, or being in a bathing suit. And in that way I would get in and I would take him out of his stroller and bring him in with me and then just plop him back out into his stroller and then get back up myself. Umm, I perceive that happening more on a regular basis when he gets bigger because it would just be easier than trying to lean over the tub and when they're this small you want to be right there. Knowing that I'm in a [wheelchair] and not at a good level. I could sit on the edge of the tub and lean over but that is not really practical or comfortable I don't think. So it'll probably be a case where I, I, get in and out. Or, once he gets more accustomed to water, I'll be able to take him into the shower as well and ah he'll be able to stand there because of the hand post... it's only a hand held, it's not one that comes out of a spout so to speak. Umm, so I'd be able to bring the hand held close to where I need it for him. So he could sit on the floor of the shower and I could sit beside him and he could have a shower when he gets a bit older as well. So those are my ideas of what I might do.”

In the same fashion, someone else provided an in-depth explanation of the sophistication of planning and practice that had preceded her first playground trip with her child.

“I wasn't quite sure how I was going to do it with her this summer because I'd never taken her out without the stroller before. So that was a whole bunch of thinking about okay, what am I going to do here to be safe and sound with her? and, yet get her out and, and enjoying the summer ...it's quite a range of thoughts and at first, well maybe I'll just, you know, ask [husband] to take her out when he gets home, you know so she can get out every day. And then kind of thinking well maybe attendants will be like they were last summer and take her out for a couple of minutes with me or while I was eating my lunch. Umm, o.k. maybe I'm gonna have to pay somebody to come out with me everyday. I was told that this was a service that could be covered with my attendant care program. So I was saying okay, get rolling on that. Well, here it is you know six months later and I never did get any assistance with the Attendant Care Program that way... I just wanted someone to be my legs and arms outside in case, because of course she's two ah so in case she darted there or in case she fell there or was about to fall and I couldn't reach her in time or have the strength to reach her and catch her... I did

take her on a test run with the leather harness one day just to check the mail downstairs and that did not go too well at all. She ended up like behind me. And I'm not sure which direction to go because I can't really see her and of course she just, you know, ah just so much energy and going this way and going that way - you know going everywhere. . And, and like the elevator was the first part of it because she was either out and I was in or I was in and she was out. So it didn't go too well. And I thought oh my god I can't her out on the sidewalk like that - that's for sure...I actually paid a girl. I asked her and said, 'Would you come out with me for a couple of hours? I want you to be there in case but I do want to try this out on the sidewalk.' And that's what I did the first time. And she was actually quite reasonable. It was only ten dollars for like two hours."

As toddlers progressed from walking to running, mothers' vigilance in safety and long-term planning increased. One mother commented,

"You know those people that had kids that ran away on them? You know, they were constantly chasing after them? Well, I simply could not do that. And right from the outset, if the kids ran away, we never gave chase. And we've never had kids that went on the road. That was the one thing, and actually the parents were like, 'Oh, how could she ever do it? Because, my kids are always running away from me and I have to run after them.' And that was the one thing, you just teach them right from the very beginning. You never engage in the game of chase with them, and you [let them run away] in a sort of safe environment at first, and then they learn to stay with you and not run. So that's the one psychological adaptation you have to be wary of early on."

As children aged, mothers with disabilities described a lessening of the more physical challenges of parenting. She further explained,

"The kids are now four and nine..So they require less, a lost less hand-on stuff...Increasingly, as both of them get older, the activities seem to be more and more intellectual rather than physical. I mean, when you have really small babies they require so much physical tending and so it becomes increasingly easier to become a parent as they get older."

Mothers described their mobility devices as influential in their mothering activities. In one family, the children were emotionally attached to the mother's mobility device and "very distressed" when another chair replaced it. A mother explained, "It was the only one they really

remembered, right? And it was the one they'd ridden on and it was the one they'd sat on..they just didn't want to let it go. I mean there were tears...They were very upset." Mothers recounted that young children delighted in their mothers' wheelchairs and would gladly ride foot pedals or clamber up for short rides or to be driven to school. Another woman recalled,

"When [son] was small and growing up, I used to put him on my knee on the scooter and we'd go somewhere... Anyway, we bought gum at the store, bubble gum, and on the way back because he's sitting right in front of me, on me, I taught him how to blow bubbles with bubble gum. And I remember doing that all the way home, teaching him how to do bubbles. Anyway that was just something I remembered on one of those scooter rides."

Someone else relayed,

"when my son was younger, the scooter was really fun because I used to ride up to the school. And school was just a couple of blocks up, and he's right on the scooter with me so he was really, it was really a neat thing for him and he was the envy of his friends because his mom had a scooter. He's getting older now so he's not able to ride on the scooter with me anymore."

The expectation by children that mothers would accompany them to school meant that women had to plan for the effects of inclement weather, and prepare themselves and their children for worst-case scenarios. One woman hired someone to walk her child to school when she could not. Another one indicated that she was going to teach her six year old child to go to school on his own. She explained,

"I've sort of told myself that over the next few weeks, I'm going to go over (to his school) with him and I'm going to go a little less far each time. He likes to ride on the (scooter) seat and it's a nice little thing in the morning, we spend a couple of minutes together and it's good, but I want him to be able to walk out that door and bring himself to school the first time there's a snow storm."

In contrast to young children's delight with their mothers' wheelchairs and scooters, mothers with pre-teens or teenagers most often described their children's embarrassment of the device. One mother explained, "My daughter is...just very self-conscious." She worried aloud that since her son was fast approaching adolescence that his previously accepting nature would

change. Similarly another woman noted her daughter was as embarrassed by the wheelchair as she had been upon her mother's first use of a cane: "it's appearances...she's at that age". She commented on a recent social event in which her daughter had initially experienced discomfort about having her friends meet her mother. The woman recalled,

"Afterwards my daughter said, 'you know what [friend] said? She said you are so nice!' And she was smiling. And I was smiling too 'cause that would make [daughter] feel better that I am not some kind of freaky mom. And she is not going to be, um, ostracized because her mom looks different than other moms."

Some mothers were unsure whether their adolescents' reticence to be seen with them in public was a result of their disability, or simply 'normal' teenage preference for the company of their peer group. One mother explained:

"One day we went to - and I had my manual chair because he was pushing me - we went to a movie that was over at the [movie theatre] and we got in there and we were going to line up to get tickets and all of a sudden he saw some friends of his and he pushed me until I was facing into a brick wall. There's a brick wall and I'm facing it Because, I don't know, he went to talk to his friends. So I took that as being, he didn't want to be seen with me. But I don't think it was just because I was in a wheelchair, I just think anybody going to a show with their mother is not to be reckoned with, like, embarrassed. ...But I don't think it had anything to do with the wheelchair. Although he did push me aside pretty good, fast, and so after awhile I said, 'do you think I can come away from the wall?' because I was in the corner. Anyway, that was the only time he's done that."

### **5.3.2 Social and Environmental Challenges to Parenting**

Mothers articulated the joys of parenting with a disability, and the ways in which their roles as mothers were made exponentially more difficult by a lack of services, societal attitudes, inaccessible houses and classrooms, unsuitable parks, poverty, and lone parenting. As women with disabilities, their mothering skills, and very often the mere fact of their mothering, came under scrutiny by outsiders. Women recounted public idealization or being treated as a curiosity, excessive monitoring by

professionals, as well as offers of assistance that were sometimes misguided or frightening. One mother explained,

“You get stopped by people who think you're doing something you shouldn't be doing - who want to help you. I had a complete man stranger want to push “[baby]” to wherever and, ‘Ah no, I'm fine.’ ‘But you look like you're having a really hard time.’ ‘No, I'm fine thanks.’ And I had to be quite insistent. I, I don't want a complete and utter stranger pushing my child. I mean how do I know that's he really on the up and up and wants to help? And not just acting as if he is?...You know, I will have to expect to be more tolerant of the outside world because people will assume that I'm...doing something that might endanger my baby's life or, that why the heck am I doing it. You know, why isn't somebody else doing it for me type of thing.”

She was also deeply distressed by the professional scrutiny she was under as a mother with a disability, and the ways in which she was being forced to present herself in order to apply for child care assistance. She continued,

“The nasty public health nurse told the supervisor from [agency] that [baby] was basically not developing at a rapid enough pace and that I would need help with him in developing his milestones...She also seemed to want me to “say” that I needed help changing [baby], dressing [baby], feeding [baby] which I felt really weird about because I don't!”

In order to receive assistance for the tasks that she did want help with such as “general assistance in terms of laundry, getting the bath ready so I can bathe him, going out for walks and stuff which is kind of new,” she was being forced to present herself as incompetent in tasks she could accomplish quite well independently. Further, when she did receive child assistance, the care was characterized in such a way that it did not recognize the primacy of the mother's mothering role. She explained, “I didn't really fit the bill for someone that they provide care for. Often they come to help out people who have special needs. It isn't very often that it is the other way around. All the workers who have come were told that [baby] is their client.” This erroneous characterization may explain, in part, the failure of the attendant

to accept that her role was to assist this mother in her parenting activities, not to mother her child. She explained,

“I spoke to the [agency supervisor] very openly and told her that the worker wasn’t working out...I explained that although I really appreciated the having the help, that it wasn’t what I needed. I had to do this even at the risk of losing the service cause it was driving me crazy! I told her how she expected to come in and do everything for me, and how she kept trying to interfere with [baby’s] playing, or general care by trying to move him, straighten him, when I request politely that she not. ..The other problem is that she never wanted to go for walks, and this was a big part of the reason that I was requesting the help.”

Another mother had dismissed her care agency’s initial lack of attention to her role as a disabled mother as an indication of earlier social mores. She had rationalized, “Well, you don't see a lot of families really living in attendant care settings. More so these days but when the kids were coming along, twelve years ago now, it wasn't quite as common then.” However, despite her optimism that the situation has changed for new mothers, the one mother’s experience demonstrates otherwise. For her part, despite having made clear and repeated requests for child care assistance over a period of several months, another mother never received any child care through attendant services.

Another barrier to mothering was the lack of wheelchair accommodations to assist with parenting and inaccessible community pathways. As a result, mothers with disabilities were often isolated from other mothers in the community. One mother explained,

“There is a mother-baby group drop-in at the community centre but again it’s getting there that’s a little more difficult. It’s hard getting there with the stroller because it’s such a long process to push and go. If I take him in a carry [snugly], then he pretty much lives on my lap once he’s there so not great in way.”

Similarly, another woman commented that the building where her daughter’s girl guides troupe met was inaccessible. She had to wait outside for her or have another parent escort her home which denied her the opportunity to mingle socially with other parents. In order for her to participate in fundraising for the troupe, the mothers had to meet in an accessible coffee shop. Another mother explained that because

her child's friends houses were not accessible, she was not able to meet the parents in their own homes and had to invite parents over to her own home.. This prevented her from seeing fully "how they lived" which, she felt, would have provided her with a more full sense of the teenagers that her daughter was befriending.

As children progressed through the school system, the accessibility of the schools impacted on mothers' abilities to easily and comfortably participate in their children's education. One woman admitted feeling "kind of removed from the situation" and "that it's a burden on my ex-husband to do more of the parenting" because she could no longer access her child's school. She continued,

"If I want to speak to the teacher, we can meet at the nurse's office and that's what happened on Friday. Parent-teacher interview after report cards in the nurse's office. But I can't fit in the classroom. She is in an alternative school which we choose because parent involvement is encouraged. I used to be able to get right into the classroom and work with kids..I can't do any of that now."

Another woman had deliberately enrolled her children in a school outside their catchment area so that she would be able to participate in parent-teacher meetings without the requirement of access concessions on her behalf. She explained,

"The day care was never accessible..and it was a drag not being able to go down to the classroom whenever I wanted to see them. So I actually enrolled them in [school] so that I could go to their classroom for the parent-teacher nights and the curriculum nights and that sort of thing at the school, and not have to have the teacher make special arrangements to come down and away from the classroom."

Another woman had been involved in ensuring that each of her son's schools became accessible. As her son progressed from primary to intermediate to secondary school, she would contact her local parliamentarians and school trustees to ensure permanent ramps were built and she was able to access and fully participate in her son's education.



Poorly designed community spaces such as parks, playgrounds, libraries and pools also hindered mothers' abilities to actively and comfortably participate in, or supervise, their children's leisure activities. One woman commented,

“[Park] is a park that I almost never use. Really, that hill is so steep, I'm very disinclined to use it. I'm really disinclined. I mean there's no way that if somebody got hurt at the bottom of the hill that I would be able to go and help them in any kind of reasonable fashion. So that tends to be the park I least use.”

Poverty was another barrier that severely impacted on women's ability to mother their children.

One mother commented that her child would have a quality of life if she had more support economic and housing support:

“I'm on Ontario Disability support so I get less than \$1,000/month to live on. Because of my background with accounting, I can manage. But, I shouldn't have to... Why do I have to be like this? If Harris lived a month in my shoes, he would wake up fast.”

### **5.3.3 Inversion of Care**

The perceived impact of the mothers' disability on parenting, and on children's experiences, were issues that caused some women great distress. Mothers often commented that without adequate health services and home care support, their children were often called upon to perform home and body tasks for their mothers that should be performed by attendants.

One woman noted that on her sore days, her son “feeds himself”, “makes himself hotdogs” and “does what he can”. Another explained that her eldest child prepared Thanksgiving dinner because she could not. Another commented that her toddler has learned to put away dishes, and that she expects that in several years the child will be doing the dishes which will help her mother avoid conflicts with the home care attendants. However, some mothers commented that their children were actually called upon to do less in the home than

“normal”. Another noted that in terms of the kind of housework she was expected to do as a child, her own children’s tasks are completed by the home care attendant. Another noted that her teenage son is dissatisfied with the way in which attendants have washed his clothes and so he has placed a ‘do not touch’ sign on the hamper of his dirty clothes and cleans his clothes himself. Another mother explained that while she considers her daughter’s room a mess, the teen had made a convincing plea for privacy and to have her room left the way she wanted it. Because of the other tasks she does for her mother, she acquiesced to the demand and “looks the other way” when she wheels down the hallway past her daughter’s room.

Mothers commented that they relied on their children to assist them in the absence of home care providers, who had the primary responsibility of completing the tasks. One mother explained,

“In the evening the kids help with things like ah [attendant] has made supper but they will serve it. They will clean up after, umm, any snacks they want they get themselves. If I need something they’ll get it for me...They help me with toileting in the evening. They come in and help me pull my pants down, get on the toilet safely, and that kind of thing. Umm, and that will be like once in the evening and once at night before I go to bed... You know, there is a lot of responsibilities on them because I’m disabled.”

Similarly, another mother explained how she had taught her daughter to assist her mother cope with leg spasms, although she noted, “I don’t want her to (have to) do this too many times.”

Mothers were concerned about the impact of children’s assistance on the children, and on their roles as mothers. Another mother explained,

“My daughter helps me very, very much. One day she had to be my nurse for the day because no one else was here and she was quite happy to do it...It’s not easy to have to expect any child to be a caregiver because sometimes they can resent it.”

In the same fashion, another woman commented,

“So one of the kids usually has to help me get my feet right and get settled into bed almost so that’s hard for the kids to have to do, to help your mom get into bed. It’s bad enough that she pees her pants occasionally (laughs) but to actually have to help her get into bed and get comfortable at night, it’s hard for them.”

These comments underscored the ambivalence and struggles that mothers experienced when their children assisted in their care,

“Sometimes [son] helps take care of me and that’s not fair. It should be the other way around...It’s not fair...I’m the parent and he’s the child. He shouldn’t be taking care of me.”

One mother was adamant, however, that had she an accessible apartment where she could move around freely, without discomfort and with greater independence, the more responsibilities she could fulfil as a mother, and the less her son would be called upon to do.

## **5.4 HOUSING**

### **5.4.1 Description of the physical context:**

Participants who lived in apartments described them with mixed feelings. The greatest source of dissatisfaction was the restricted mobility and lack of access to parts of their apartment. In some instances, women spoke of their struggle to get around indoors in their wheelchair without causing extensive damage to the walls due to the limited space. The bathrooms and bedrooms were particularly problematic for many women. Limited access because of their wheelchair to their children’s bedrooms greatly interfered with their parenting role. Manoeuvring the wheelchair from the bed to the change table to diaper the baby was a problem for one mother. Cleaning their children’s rooms was also not possible for others due to inability to manoeuvre the wheelchair around the beds. Adding extra shelving to the walls in the bedroom to remove the clutter from the floor had been done but did not improve the limited space for wheelchair

mobility. Not being able to perform these routine household duties necessitated hiring a housekeeper in one case to help with the chores. Doing laundry was another household chore typically performed by an attendant or homemaker because the mother was not able to physically access the laundry facilities with the wheelchair.

The bathroom was described by many women as lacking space. In some instances the wheelchair was left outside the room. In another, the bathroom door was removed. “there’s a problem in a my bathroom.. The bathroom has not been made wheelchair accessible. I’ve taken off the door for my bathroom so that I can get the wheelchair in and on good days I can get up and transfer to the toilet.”

While a roll in shower was felt to be a good thing to have, the lip on the floor created access problems reducing the amount of independence and requiring assistance with bathing. “Well right now it’s very hard to use the bathroom the way it is. To get in and out of the shower (attendant) has to do a lot of lifting and transferring that makes it very hard for her. I feel that I can be more independent by having the wheelchair accessible bathroom.”

Some women in apartments complained about the old plumbing that prevented them to have built-in dishwashers therefore, increasing the amount of time spent doing dishes at a sink which in most cases was not at an appropriate height for them especially for those in inaccessible apartments. Kitchens had many accessibility issues. Women were not able to reach into cupboards above their heads. Many who lived in houses were able to do renovations to the kitchen building lower counter surfaces and installing appliances with counter controls and side opening doors.

Among the comments that described positive features to apartment living was having access to a roof garden or a balcony. However, in some cases gaining access to the balcony was

a problem for some due to the tracking on the floor of the sliding doors. Having an open-concept design to the living space was preferred by one participant. The only disadvantage was the lack of privacy once you were no longer in the bathroom or bedroom. Access into the home was a problem for some who lived in apartments. One participant commented on the work she had done as part of a housing complex committee to secure funding from the Trillium Foundation for renovations to make the front of the building accessible to wheelchair users. At the present time she and others with disabilities in her building were forced to use the side entrance. This had implications for other things in her life. For example, she had to negotiate with disabled transport (Wheeltrans) to pick up and drop her off at the side entrance. Until she was able to negotiate this new arrangement, she had missed her transportation because of the extra time it took her to manoeuvre her wheelchair out the side of the building to the front of the building. Aside from missing her transportation, the necessity of entering and exiting your home from a side entrance or 'tradesmen's entrance' was humiliating and demeaning to these participants. One participant spoke of her attempts to receive funding for renovations to their apartments through the March of Dimes. Others who had not applied for funding were able to recommend changes to their living space. Changes recommended included the need for structural renovations such as moving walls and building wheelchair height countertops to adaptive devices such as ramps, special door handles, automatic door openers, and easy-open windows. It is possible that many of these women were unaware of programs such as the Residential Rehabilitation Assistance Program through Canada Mortgage and Housing Corporation which provides loans to homeowners and landlords so that they can make their dwellings more accessible. There are a number of eligibility criteria for this program which are related to household income, where the

home is located, and the value of the home. These may have precluded attempts by some of the participants to accessing this assistance, however we don't know for sure.

#### **5.4.2 Interface between mobility device and housing**

Participants spoke about their need to plan ahead and think about how to arrange their living space not only to accommodate their needs as wheelchair users but to accommodate the needs of their attendants and homemakers. Space was a priority spoken about to make the home a safer and user friendlier place to live in. Attraction to a neighbourhood was cited as a main reason for locating and securing housing. While the home required renovations it was the location of the house was that important. In shopping for a house, one participant spoke of her struggles being disabled. She recommended that more internet virtual tours of home be provided to enable easy access into real estate shopping for wheelchair users. Another participant discussed the problems she had finding an architect willing to make the accessible renovations to her home. This delay in finding a reputable and willing architect was a considerable source of frustration.

Not many participants spoke of the leisure occupations they engaged in at home. One participant spoke of her accessible garden as a source of leisure activity. There were some concerns expressed over seasonal changes. Anticipating mobility and transportation out of the home in winter created anxiety for some. This is a real concern for these participants who live in this climate. More needs to be done at the government program level to consider needs of people living at home who are wheelchair users in Canadian winters.

The limited space in households prevented even basic tasks such as dusting and cleaning. When in homes other than their own, problems persisted. One participant tells of her experiences

when she visits her family. Their home not being wheelchair accessible causes the participant to be completely dependent on others. Her freedom is seriously restricted and limits her attempts to socialize outside her home because of the lack of attention to accessibility.

For those living in apartment buildings, the elevator was a problem. People living on top floors were restricted in their access to the top numbers on the control panel from their wheelchairs. In one case it was interesting to note that only a few years ago the elevator had been renovated. The way the house was configured and the lack of space caused the participants to move and position themselves for tasks that were unnatural. For example, one participant spoke about how she had to face everything in a sideways position in the kitchen. She spoke of wanting to face appliances from the front position. In moving in her home she spoke of always needing to travel in one direction and backing up. There was insufficient space to turn around. This way of moving was also very tiring and time consuming. When participants could not use their wheelchair due to a lack of space, they were forced to use canes or a walker. This was not a comfortable solution and it restricted their independence. “ The walker. It’s hard. If I don’t feel safe, then I’ll just use the walls and I’ll just do what I can.” This practice was viewed as unsafe and potentially negatively influencing the mother’s health.

#### **5.4.3 Design And Access Barriers**

For all, the greatest barrier was the lack of space for mobility inside the home. The limited space compromised the ability of the participants in fulfilling their roles as parents and homemakers. The design of the home also presented barriers to wheelchair use. “its kind of got too many right angles to it so I, I have taken out. I’ve kind of hit the wall, slipped into the wall a couple of times and so its something that you know you don’t like to see but on the other hand it

hasn't been too much damage." This wear and tear would necessitate constant repairs to the walls. In designing the space at times different people's needs came into play. A counter height that was adequate for the participant in the wheelchair was too low for the attendant. Counter heights were problematic for some. Doing dishes was particularly difficult on some participants because it placed too much stress on her shoulders. To get the job done, participants were forced to problem solve and take the dishes to another sink in the bathroom which was not as deep as the kitchen sink. All this rearranging took time, but was necessary in order to get the chore done. Renovations to the counter tops to make them lower could have been possible but were not done.

The placements of cupboards was a barrier to mostly all women because they couldn't reach them. The carpeting with its soft underpad restricted free wheeling in the home and was seen as a big barrier. "I am going to have the underpad taken out because I feel like I'm in sand or something. Every time I go to move I get sort of trapped in it, like I sink into the carpet. It drives me crazy." Removing the underpad from the carpet was possible for the women who lived in houses but was not a possibility for those living in apartments.

Another poorly designed home prevented sufficient space to install a chair glide for access up and down stairs. "I had to go up the stairs on my behind because there was no landing to put a chairlift in so we didn't have one, and when I came home from the hospital I got one of those Canadian Tire slider mats and that got me around, and I could get into my kids bedroom that way but it always hurt me because the floor was hard and I couldn't reach anything anyway." Participants were creative in their quest to provide access within their homes even it was considered unsafe for them as this was acknowledged by themselves.

The bathroom presented barriers as well. Lack of space required doors to be removed eliminating any degree of privacy. The roll in shower which was liked by most participants



caused some problems because of the lip that the wheelchair got stuck on. The lack of tub bars prevented some participants from transferring independently into the tub.

Hardwood floors were welcomed to most. Having a deck built to move about outside the immediate home was seen as a plus by one woman. While others had balconys they were not accessed well because of a step or sliding door tracking that prevented the wheelchair from going over it.

Finally additional personal factors beyond the primary disability caused barriers to participants. Some complained of pain and lack of strength as factors preventing them to access things such as getting in and out of the tub.

#### **5.4.4. Design and Access Facilitators**

Graded sidewalks and ramps into the building were seen as facilitators. Many participants found the roll in shower despite its lip problem to be a facilitator to them for bathing. It eliminated to need for assistance from an attendant to transfer and lift. Renovating the home by removing walls to expand the living space allowed more space to manoeuvre the wheelchair that was highly accepted. Also, to increase the freedom of movement, hardwood floors were added to the homes.

Customizing things like lowering counters, providing open space under counter tops, building low cupboards for storage of kitchen items, building shelving were seen as facilitators. Installing lever door handles and light switches at waist level were easier to use. Equipment such as ovens with side doors were easier to use.

Designing closet spaces with lower shelves and bars for hanging clothes was also important. However, only one woman reported having done this.

On average the women used a total of 11 assistive devices (Table 3). These included kitchen aids, self care aids, mobility aids and transfer aids to assist them with their homemaking roles. They also used other devices that made their lives easier such as touch lamps, child leather harness, Canadian Tire slide mat, computer, air conditioner, and cell phones.

#### **5.4.5. Modifications**

Generally participants modified their living space with minor renovations or with equipment. Installing ramps was regularly done. Using poles installed from floor to ceiling was also done in the bedroom and bathroom. Removing carpet and installing hardwood floors was done to permit easy mobility. Installing customized cupboards below ovens was done. Installing a roll in shower was done frequently. In some cases people installed chair lifts or planned to do so. There was also a plan to install an elevator by one participant who lived in a home and an outdoor chair lift to the entrance of her home.

Those participants living in homes did the structural renovations, They moved walls to make rooms bigger, enlarged doorways into rooms, and removed existing cupboards and pantrys to enlarge space. One participant applied for a March of Dimes Home Renovation Program grant to renovate her entire bathroom making it wheelchair accessible. She had been on a waiting list for over 6 months and the application had not been approved as yet. There were several eligibility criteria for approval. There were plans to install automatic door openers for those apartment dwellers. Another way participants made modifications was through the arrangement of furniture, not placing furniture in access areas.

## **5.4.6 Policy Implications**

### **5.4.6.1 Housing Policy and Regulations**

The following comment reflects a common sentiment among the sample of participants we interviewed.

“My dream home is a house that is fully accessible, even if it’s a townhouse. I don’t see why the government isn’t building more accessible housing for disabled because I think over 50% of the people in housing have one disability or another and out of all the housing in Toronto, there is only 5% that is accessible, fully accessible, so you’re on a waiting list for God knows how long and it’s not fair.”

It is clear they don’t perceive that there are adequate efforts made on the part of the government to provide adequate housing. The participants spoke of the limited housing available to people with disabilities. Only a small number of apartments (n=14) out of an entire apartment complex of over 40 units were designated as wheelchair accessible in one participant’s apartment building. A few participants discussed the frustration over applying for new housing arrangements and the long and cumbersome process they were forced to live through. The challenge of finding affordable housing is real as reported in a recent report “Where’s Home” from the Cooperative Housing Federation of Canada. Non-profit and co-operative housing has declined between 1994 and 1998 and it has been at zero for the last several years following the provincial government’s cancellation of the program in 1995.

For those living in regular households, they spoke of the city’s municipal rules in applying for renovations to be made to the house. In one instance, one participant was required to go forward to the city’s committee of adjustment in seeking permission to make the entrance to her home more accessible. The process required that the neighbours agreed to the changes to be

made. This was considered unfair as their neighbours appeared to have the decision power over the housing needs of the participant.

Participants living in apartments discussed the building rules that prevented them to make any changes to their living quarters, and that refused to spend the money to undertake the changes on behalf of the participant. Such changes included automatic door openers, built in dishwashers, and accessible pools. This restricted their mobility function, and social participation. Many participants undertook options available to them to secure adequate housing. Two were on waiting lists for accessible apartments. One participant due to her part-time work status and limited income applied for subsidized housing with the help of a social worker provided through Comprehensive Occupational Therapy and Mental Health Services (COTA), a community based service organization for people with disabilities that contracts their services through the Community Care Access Centres (CCAC). There were several reasons expressed for needing better housing. Included were that participant's health and functional status was changing or deteriorating with age, their children were growing therefore they required more space, and their mobility was getting worse therefore required space to manoeuvre their wheelchair easily.

A fear mentioned by participants related to their efforts involved in applying for better housing was the possible negative spill over effect. They were hesitant to move out of their CCAC area where current services such as their homemaker were provided. Therefore, they felt restricted in the choices available to them for possible new housing. This is a major issue as for many women it took considerable time for them to find a reliable, trustworthy service provider, and to move out of the catchment area of the CCAC who provided this service meant that they would have to start the process all over again in finding reliable services.

#### **5.4.6.2 Health Care Policy and Regulations**

Participants acquired the equipment and services they required through different avenues. Few of them had personal insurance plans that payed for regular homemaking and nursing services. Many accessed nursing, homemaking and Occupational Therapy services through their CCAC. They expressed gratitude over receiving these services. The nursing services which were in some cases discontinued and replaced with homemakers or a health care aid left participants unhappy. The quality of the work was felt to be inferior to that of greater trained individuals. As well the frequency of nursing services was criticized by the participants. The major role of the OT was to help with wheeled mobility prescription. The manner which most participants received funding for their wheelchair was through the Ontario Assistive Devices Program (ADP) program. There were concerns expressed over this program. Although the program covers up to 75% of the cost there were restrictions regarding the type of equipment ordered, and the length of time between ordering a new chair leaving some people frustrated over the need to wait for adequate seating, and they needed to cover the remaining 25 % of the cost. As well, there was concern over the fact that the eligibility for funding under this program ceased when people turned 65. In some cases, the wheelchair was not the preferred one because it lacked some features that the participant wanted such as a tilt back.

There were many complaints around finding affordable repair services for the special equipment participants owned. In some cases the contract with the wheelchair supplier was broken because of the expense and creative strategies were implemented to solve the repair problem. Luckily for one participant her husband found a cycle shop who was willing to repair a

wheelchair cable for a cost of \$7.00 as compared to the \$100 charge that the wheelchair supplier was asking for.

In one instance, Vocational Rehabilitation Services (VRS) a program of the Ontario Ministry of Community and Social Services funded the modifications for a van to enable a participant to drive. Under this program devices are funded for homemakers who has care for a spouse and a family as an occupation. This was an unusual situation which was the result of a great deal of self-advocacy on her part as a former Vocational Rehabilitation Counsellor with the VRS. In another instance, a participant received \$50/month from the MS society for assistance with homemaking.

#### **5.4.8 Interface Between Mobility Device and Neighbourhood**

Generally participants described their neighbourhoods as being acceptable in terms of accessibility. They however were responsible for many of the changes to ensure its accessibility. They mentioned their role in encouraging schools to put in ramps so they could visit their children's schools. In one case, the church renovated the entrance and installed a chair lift to make it more accessible. Another participant complained about not being able to continue singing in the church choir due to a lack of a ramp to the podium. Grocery stores, libraries, and banks were generally accessible because of the automatic doors. Drug stores presented more problems because of steps and narrow aisles. Having curb cuts installed in front of their homes was very important as it made Wheeltrans pick up so much easier. Having most stores within walking distance was very important to them so that they did not have to propel their wheelchairs a great distance.

A major problem was the winter with the snow and poorly shovelled sidewalks that prevented access. This restricted community participation severely during the winter. One participant was unable to access the dressing rooms at her son's hockey rink because of limited space.

Overall participants spoke of people trying hard to accommodate them in their businesses and schools. What was required though was self advocacy in many instances to increase the level of awareness.

## **5.5 Mobility Devices**

### **5.5.1 Description of Devices**

Participants used both manual and power wheelchairs, and scooters. They indicated their satisfaction and dissatisfaction with their devices. Generally they liked their wheelchairs and felt safe. Features they liked included its collapsibility, the backward tilt mechanism, the basket on the scooter, the power feature of the wheelchair, anti-flat tires, and direct drive chairs allowing for better wheel traction. With respect to power, the benefits were that it increased a sense of freedom, lessened fatigue levels and increased their opportunities for independence. Other benefits described with wheelchair use included the improved posture and decreased body pressure resulting in more comfortable seating. Propelling manual wheelchairs was made easier by moving the wheels more forward, a strategy suggested by one of the wheelchair suppliers.

Participants recommended changes to their scooters. These included a larger basket, more leg room, and better wheelchair shock absorbers.

### **5.5.2 The Wheelchair as an Enabler**

Overall the wheelchair was viewed by the participants as a friend. They described it as device that enabled them to be more independent to perform the occupations that were relevant to them. The following quotes reflect this idea.

“ The wheelchair has given me more independence. A lot more independence.” “I used it everyday for work.. I could do things like shopping and things like that.” It has given me so much more independence. I love it. I do my shopping. I love the freedom.” “This is really liberating.” Participants spoke about how the wheelchair allowed increased opportunities for social participation. “ I rented a scooter for the summer so that I could get around with him (son) and I found it to be great.” The freedom to perform occupations that were previously not possible was also the result of using a wheelchair. “Before I got the wheelchair, I really didn’t do much at all because it was just too difficult and then if there was stuff on the floor which there is, you know, that’s an added barrier for me it was you know and I would get the kids to clean up as best as they could so that I could come into their rooms but the reality is that they weren’t very good at doing that and you can tell if you just glance into the kid’s rooms I mean things don’t get hung up, they get dropped on the floor. Now that I’m in a wheelchair, I can go into the rooms.”

The use of power wheelchairs was highly accepted. “Just having a power wheelchair has given me a lot more freedom...with the wheelchair I mean they can’t keep up with me when we go out. They keep telling me to slow down cause I’m going to fast.” The increased mobility was very liberating to participants who had lived with manual wheelchairs. “I was that much weaker that it was just too hard to push all those distances and it took an inordinate amount of time, it was silly, so I got an electric chair at that time, which I really liked. I felt like I was in a rocket.”



Some participants mentioned that they could not live without their wheelchair. There was a real sense of dependency on the wheelchair in their lives. It provided them a comfortable sitting position as well as a means of mobility. One participant mentioned how she would be confined to bed if her chair was taken away for repairs. Her chair supported her neck and her posture and without it she would have to be in bed.

Along with the sense that the wheelchair was a necessity for users, it was described as a safe place. “ Now that I have it, I use it all the time which I don’t know if that’s the best thing except I feel safer with it and I think you know, I haven’t had a fall cause I used to fall routinely at home even. Again because I am not walking as much around the home, I don’t have those risks anymore you know. I feel much safer with the wheelchair so I use it way too much.”

Many participants, because of the nature of their disabilities had personal factors that were made easier by using their wheelchair. For example, fatigue was a big issue for many, and the wheelchair enabled them to conserve energy.

## **6.0 Recommendations for Housing and Wheelchair Designers**

The greatest wish was for more space in the home. There were a number of other things participants specified as wanting in order to make their roles as parents easier. These were: automatic door openers, front loading washing machines, larger garbage chutes, an accessible roof garden area, central air conditioning, adjustable counters, and an elevator. One woman had plans to install an elevator in her house. No women mentioned robot cleaners, which are now available. Many women did use reaching aids.

There were a few changes or recommendations for design changes to wheelchairs and scooters. The back wheel on the scooter was a problem as it often got stuck in a hole or rut

outdoors. Having a good size basket on scooters was recommended. The wheelchair feature most participants who used wheelchairs preferred was the backward tilt mechanism. For those who didn't have wished they had. The ability to manoeuvre the wheelchair around in circles or around comers was desired. Some participants had wheelchairs that allowed this while others did not and wished they had. The cost of wheelchairs which allow a small radius of turning is quite substantial and newer models such as the Rocket which was designed by at Sunnybrook Health Sciences Centre is a motorized chair which raises and lowers and pivots but it is around \$20,000.

Having good wheel traction was also desired. This enabled speed of travel and going up ramps easier. Participants complained about the quality of the wheelchair upholstery and the metal painting on the chairs. The material would crack and need replacing and the paint would peel off making the wheelchair look worse for wear which was not appreciated.

One participant felt that the sound volume on the scooter horn should be made louder as she frequently needed to say "excuse me" to passersby which was frustrating.

## **7.0 Conclusions**

Women with young children pointed to the dearth of services and supports available to assist them in their new mothering roles, while mothers with older children spoke, most often tearfully, of an 'inversion of care' in which their children augmented their body and home care in the absence of adequate housing and support services.

For the mothers in this study, attendant care for their bodies and their homes was critical to fulfilling their homemaking and mothering roles. However, women's efforts to obtain suitable,

satisfactory care were alternately assisted and stymied by the policies and procedures of care providers and third party payers. As Dear and Wolch (1989) explain,

Individuals experience multiple influences in their 'daily life environments' that stem from outside factors relating to social, economic and political processes. Therefore, influences are usually experienced in the same locale, although they are frequently initiated from these outside factors.

That women were unable to exercise control over the expanse and standard of services that they wanted, or from workers whom they preferred, underscores what has been termed the 'power ladenness of health care interactions' (Dyck and Kearns, 1995). This lack of choice and control in care provision is a unique vulnerability faced by women with disabilities as they perform their homemaking and mothering activities. For mothers with disabilities, women's 'ordinary labour' (Dyck, YR) within the home is transformed not only by the addition of "extra hands", but through mothers' attempts to control the effects of those hands upon their bodies, homes, activities and families.

A place to live as one woman stated that is fully accessible would provide the necessary space to carry out daily occupations. Lack of space seriously compromised these mothers to be as independent as possible. Physical barriers in the home and outside further restricted these women's access and full participation. Institutional and political environmental factors precluded changes and accommodations to be made regarding the living situation.

Women did not have the freedom or economic resources to seek out new living arrangements, nor make modifications to existing environments. Nor did they have control over the type of mobility device they owned. Universal access to appropriated health technology which includes wheelchair systems is needed. Designers of wheelchairs should be better aware of the issues facing mothers so that newer designs in wheelchairs could be made.

## **8.0 RECOMMENDATIONS**

Women complained about the lack of reliable and consistent services they received for personal care and homemaking services. In some cases, women were managing several different people at one time with varying levels of training and ability.

**It is recommended that the Ministry of Health develop policy that will provide better integration, consistency, and continuity of home care services to care recipients.**

The inconsistency in the training levels and expertise of care providers varied tremendously and as a result placed an inordinate amount of pressure on the women receiving their help.

**It is recommended that the Ministry of Health develop policy to ensure a high level of standard in the training of staff regarding the provision of care giving, attendant and homemaking services.**

There currently does not exist any guidelines or supports for mothers who are procuring services, providing training for staff and for evaluating staff.

**It is recommended that the Ministry of Health and related government agencies develop guidelines and training opportunities to assist mothers who are seeking new services.**

The Centre for Independent Living in Toronto has undertaken a project to promote 'nurturing assistance' as an option of care to be made available for disabled parents through existing program structures. Many of these mothers would benefit from nurturing assistance which is a program to facilitate parents in the caring and carrying out the parenting task with their children.

**It is recommended that the concept of Nurturing Assistance be understood and promoted as a viable service option to be made available to women with disabilities with young children.**

Women's full access to their communities and within their living environments was restricted.

While many inroads have been made with regard to designing within a barrier-free environment, there are still numerous areas that are inaccessible.

**It is recommended that we advocate for barrier free living environments and especially with the building of new homes, apartment units and community facilities. Involving persons with disabilities in the design phase is recommended.**

The women in this study struggled with transportation issues. They had little control over the times for booking special transportation.

**It is recommended that the Wheeltrans and Disabled transit programs develop a more coordinated and responsive system for booking transportation.**

In trying to make the necessary accommodations and modifications to their homes some women expressed the resistance from architects to perform the work and the frustration over the long delays in finding suitable help.

**It is recommended that the Canada Mortgage and Housing through the architect associations develop a practice to advertise and promote the services of those architects trained in designing for the disabled.**

Finding sources of funding for renovations was limited and frustrating for the women in this study. There needs to be more creative programs developed that can be accessed within a reasonably short period of time.

**It is recommended that Canada Mortgage and Housing work collaboratively to develop new programs that are available for home owners and tenants of varying income levels to access to be able to make renovations to their home environments.**

Many women reported having no choice to the location of where they lived. In many instances their home was not suitable to their needs. They reported having difficulty trying to arrange new living accommodations for fear of losing existing services.

**It is recommended that Canada Mortgage and Housing working collaboratively develop application procedures and programs for relocation of living environments without the risk of losing care and homemaking services in place.**

Having a wheelchair was a necessity and viewed relatively positively by most women. There needs however government programs that need to go beyond what currently is available through the Assistive Devices Program. There needs to be funding for power wheelchair as this contributes significantly to the quality of life of wheelchair users.

**It is recommended that the Assistive Devices Program develop guidelines for funding power wheelchairs for women who are mothers.**

The seasonal weather restricted community participation among our women. We live in Canada and there are winter conditions such as snow which is an issue of people who use mobility equipment.

**It is recommended that municipal government programs address the needs of the disabled and provide snow shovelling services to assist them in getting out of their homes. The city should also improve the sidewalk cleaning in all communities following a snowstorm.**

One woman proposed a solution that would enable increased participation in real estate shopping. She discussed accessing internet real estate sites that not only list home prices and locations but provide a virtual tour. This is extremely useful if you are in a wheelchair and cannot physically get into the home.

**It is recommended that more internet sites be developed with virtual tour features to enable the disabled community access to this market. Canada Mortgage and Housing may be instrumental in encouraging this area of development.**

**10.0   Dissemination Plans:**

We will submit two copies of our report to Canada Mortgage and Housing as per the agreement. Following approval of the report we plan to submit two papers for publication to peer-reviewed journals and at least one abstract to a scientific conference.



## Tables

**Table 1.** Socio-demographics of sample (n=11)

Age (yrs)		
Mean	42.68	
SD	5.34	
Diagnosis	Percentage	Frequency
Spinal Cord Injury	18.2	2
Multiple Sclerosis	36.4	4
Cerebral Palsy	9.1	1
Muscular Dystrophy	9.1	1
Rheumatoid Arthritis	9.1	1
Amputation	9.1	1
Spina Bifida	9.1	1
Race		
White	100	11
Education		
Never attended/only kindergarten	0	0
Grades 1-8	0	0
High school diploma	9.1	1
Completed some college/university	18.2	2
College/university diploma/degree	72.7	8
Marital Status		
Single	0	0
Married	63.6	7
Separated	36.4	4
Divorced	0	0
Widowed	0	0
Occupational Status		
Unemployed (stay at home mom)	36.4	4
Unemployed (ODSP, LTD)	27.3	3
Employed (Part-time)	18.2	2
Employed (Full-time)	18.2	2
Average Personal Income (n=9)		
\$0-\$19,999	33.3	3
\$20,000-\$59,999	33.3	3
\$60,000 or more	33.3	3

**Table 1.** (continued)

Average Annual Household Income (n=10)		
\$0-\$19,999	10	1
\$20,000-\$49,999	40	4
\$50,000-\$70,999	30	3
\$80,000 or more	18.2	2
Number of children in household		
Mean	1.45	
SD	0.52	
Number of other individuals in household		
Mean	0.6	
SD	0.5	
Number of children in household by age (n=16)		
	Percent	Frequency
0-1	6.3	1
2-5	12.5	2
6-10	31.3	5
11-14	37.5	6
15-18	12.5	2
Relationship of other individuals in household		
Spouse/partner	63.6	7
Other	36.4	4
Current, most frequent wheelchair used		
Standard/manual	27.3	3
Power	54.5	6
Scooter	18.2	2
Types of wheelchairs currently owned		
Standard/manual	18.2	2
Power	18.2	2
Scooter	18.2	2
Standard and power	9.1	1
Standard and scooter	0	0
Power and scooter	18.2	2
Standard, power, and scooter		
Number of years as wheelchair user		
Mean	12.2	
SD	12.6	

**Table 1.** (continued)

Number of years using most frequent, current wheelchair		
Mean		3.0
SD		2.1
Total number of wheelchairs used		
Mean		1.6
SD		0.8

**Table 2.** Housing characteristics (n=11)

Housing Location	Percent	Frequency
Urban	100	11
Rural	0	0
Home Type		
Apartment	54.5	6
Townhouse	0	0
House	27.3	3
Condominium	18.2	2
Housing Tenure		
Tenant	54.5	6
Owner	45.5	5
Housing Duration (yrs)		
Mean	0.8	
SD	4.3	
Renovations made to home	Percent	Frequency
Yes	81.8	9
No	18.2	2
Structural renovations		
Yes	54.5	6
No	45.5	5
Modifications		
Yes	63.6	7
No	36.4	4

**Table 3.** Assistive Technologies/Modifications (n=11)

Total number of assistive technologies used	
Mean	11.5
SD	2.7
Total number of kitchen aids used	
Mean	0.9
SD	0.9
Total number of self care aids used	
Mean	2.4
SD	1.6
Total number of mobility aids used	
Mean	2.7
SD	1.4
Total number of transfer aids used	
Mean	1.3
SD	0.8
Total number of vehicle aids used	
Mean	1.4
SD	0.7
Total number of other assistive technologies used	
Mean	2.8
SD	1.9

**Table 4.** Medical characteristics of participants (n=11)

<b>Number of Chronic Diseases</b>		
Mean	0.4	
SD	0.7	
<b>Chronic Disease (n = 11)</b>	<b>Percent</b>	<b>Frequency</b>
Arthritis	9.1	1
Circulatory Disease	9.1	1
High Blood Pressure	0.0	0
Intestinal Disorders	0.0	0
Post Polio Syndrome	0.0	0
Thyroid or Glandular Disorders	0.0	0
Heart Disease	0.0	0
Urinary Tract Disorder	18.2	2
Cataracts	0.0	0
Diabetes	9.1	1
Stroke	0.0	0
<b>Number of Additional Conditions</b>		
Mean	0.5	
SD	0.9	

**Table 5.** Types of Care (n = 11)

<b>Type of Care</b>	<b>Frequency</b>
<b><u>Personal Care</u></b>	
Attendant care	5
Nursing	4
<b><u>Home Care</u></b>	
Attendant care	4
Homemaker	4
Health care aid	1
<b><u>Private</u></b>	
Housekeeper	1
Child care helper	1
<b><u>Family assistance</u></b>	
Spouse	4
Children	7
Church (meals)	1
Friends	1

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<sup>i</sup> Body care services were those defined as received from either professional or lay caregivers and included a range of personal support services such as bathing, toileting, washing hair, assistance with eating, assistance with exercising or medical procedures. Homemaking services were defined as housecleaning, laundry, ironing, shopping, assisting with food shopping and preparation. Community support services were defined as transportation services, meal services, social or recreational services, and the prescription and provision of equipment and supplies by trained health professionals. Child care assistance was defined as assistance procured for the purpose of facilitating activities related to the physical and psychological care and safety of children.

Throughout this report, we use the terms “care providers”, “home health workers” and “professional care givers” interchangeably to describe persons paid to provide body care and homemaking services.