COMPLEX NEGOTIATIONS AT THE KITCHEN TABLE: A QUALITATIVE ANALYSIS OF PEDIATRIC HOME ASSESSMENT

by

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A thesis submitted in conformity with the requirements for the degree of Master’s of Science
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COMPLEX NEGOTIATIONS AT THE KITCHEN TABLE: A QUALITATIVE
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Abstract

Occupational therapists assess and make recommendations for modifying home
environments to facilitate caregiving of children in their homes. Children who are
profoundly and permanently physically disabled remain dependent for their care throughout
their lifespan. As they mature, the physical demands on family members to provide care
become more challenging requiring major modifications to ease caregiving. Qualitative
interview data of ten educationally influential occupational therapists (EIOTs) were
collected to examine what information the EIOTs collect and how they prioritize and
organize these data to make modification recommendations. The data were analyzed using
grounded theory methodology. The findings detail myriad information required by the EIOT
to make recommendations for modifications. Findings suggest a future oriented and highly
contextualized information gathering process. The themes were integrated into a process
model that suggests how therapists may be developing recommendations. The findings
highlight important implications for research, education, clinical practice and service
delivery policy.
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# TABLE OF CONTENTS

ABSTRACT ii
ACKNOWLEDGMENT iii
TABLE OF CONTENTS v
LIST OF TABLES vii
LIST OF FIGURES viii
CHAPTER 1: INTRODUCTION 1
  Statement of the Problem and Study Purpose 1
  Definition of Terms 9

CHAPTER 2: LITERATURE REVIEW 11
  Introduction to Scoping Review 11
  Stage 1 12
  Stage 2 & 3 13
  Stage 4 16
  Stage 5 17
  Client/Consumer/Family Perspective 18
  Current Home/Environment Assessments 20
  Home Modification Guidelines 26
  Assessments Concerning Assistive Technology 27
  Care of Children with Disabilities 29
  Research Question 34

CHAPTER 3: METHODOLOGY 35
  Introduction 35
  Paradigmatic Reflections 35
  Positionality 39
  Part 1: Survey Methodology 42
  Part 2: Interview Methodology 45
  Ethical Considerations 53

CHAPTER 4: FINDINGS 56
  Introduction 56
  Participant Characteristics 56
  Coding Results 58
  Theme 1 61
  Theme 2 68
  Theme 3 70
  Theme 4 78
  Theme 5 84
  Member Checking & Within Methods Triangulation 92

CHAPTER 5: DISCUSSION 95
  Introduction 95
  Addressing Research Question 1 95
### LIST OF TABLES

<table>
<thead>
<tr>
<th>Table</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Table 1</td>
<td>24</td>
</tr>
<tr>
<td>Table 2</td>
<td>31</td>
</tr>
<tr>
<td>Table 3</td>
<td>109</td>
</tr>
</tbody>
</table>
LIST OF FIGURES

Figure 1 The Kitchen Table Chat Process ...........................................104

Figure 2 The Kitchen Table Chat Structure....................................... 105

Figure 3 Canadian Model of Client-Centred Enablement ..................... 108
CHAPTER 1: INTRODUCTION

Purpose and Statement of the Problem

“The most important work you or I will ever do

will be within the walls of our own home” ~ Harold B. Lee

Children who are profoundly and permanently physically disabled remain dependent on others for their care throughout their lifespan. When they are very young and small, the families of these children may manage their care needs without assistance. However, as the child with profound physical disabilities matures, the demands on family members to provide total care for them become more physically challenging, often requiring major home modifications to facilitate caregiving and maintain the child’s and family’s health and well-being (Roy, Rousseau, Allard, Feldman, & Majnemer, 2008). Occupational therapists assess and make recommendations for modifying home environments where barriers exist so that families can manage the care of their children with severe physical disabilities in their homes as these children mature to adulthood (Stark, 2003). As a consumer and advocate of occupational therapy services, Winfield (2003) suggests that occupational therapy is the best profession to address home modification to facilitate caregiving in the home “precisely because they have the vision and the tenacity to make the physical needs fit the person” (p. 377).

The environment of a child who is physically dependent on caregivers for all of his or her care needs to be examined from both the child and caregiver perspectives. Not only is the child maturing physically, his or her caregivers are aging. Furthermore, the social environment may be changing through, for example, the addition of younger siblings or changes in the social policy environment that alter the level of funding
available to support caregiving roles. The International Classification of Functioning, Disability and Health (ICF) describes the environment as including “factors [that] make up the physical, social and attitudinal environment in which people live and conduct their lives” (World Health Organization [WHO], 2001). The WHO’s definition stresses that environment includes not only the physical, social and attitudinal environment in which people live and conduct their lives but also the people with whom the individual has direct contact. This definition of environment is particularly fitting in the study of home modifications for children who are totally dependent on others for their physical care, since it incorporates the services, systems and policies influencing any modification choices. The maturing of the child combined with the aging of the caregivers (the temporal factor), along with the high financial costs associated with home renovations, the physical and social requirements of other family members living in the home, and the architectural restrictions of the home make the recommendations of home modifications a complex and challenging field of occupational therapy practice. In particular, the prediction of future needs and best possible solutions to address those needs is of paramount importance in recommending home modifications for these children and their caregivers.

Because caregivers are a significant part of the environment of a physically dependent child, the occupational therapist must assess the caregiver’s capacity to perform a caregiving occupation within the given environment. The occupational therapist provides recommendations to reduce the barriers and maintain the caregiving occupation in a safe environment to promote the well-being of the child and the caregiver, and, if possible restore a caregiving function that had been abandoned or
restricted due to the barriers. Given the long term needs of this population it is common practice that the occupational therapist’s intervention does not attempt to change the child’s function. From the ICF’s body, structure and function perspective, these children are completely dependent on family and/or professional caregivers for care, are not independent in their mobility, and their physical functioning is relatively static. The occupational therapist’s intervention is therefore almost exclusively focused on caregiving occupations and the physical and social environment to identify current and potential barriers to the functional performance of the caregiving role. The performance of caregiving roles and activities will be slightly different with each caregiver involved with the child. The caregiving environment must therefore address the needs of a range of caregiver characteristics.

The environment is not exclusive to the physical built environment. It encompasses the caregiver’s physical, cognitive and affective capacity to perform that role in a safe manner. The caregiver may have the capacity to fulfill the role if the same part of the environment that is currently a barrier to caregiving is changed to facilitate caregiving. Since the OT must evaluate the needs of current caregivers as well as potential caregivers whose specific needs can only be generally surmised, it is the overall caregiving occupation required in an individualized environment that must be evaluated rather than the specific function of a specific person currently engaged in that role. The literature search produced a number of peer reviewed and non-peer reviewed home assessments. These assessments will be reviewed with respect to the ICF environmental construct and, because the importance of the occupation of caregiving, whether the assessment addresses caregivers’ capacities to perform their roles.
In Ontario, occupational therapists usually assess and make home modification recommendations in order to uniquely modify a child’s environment to meet the functional requirements of the child and the caregiver(s). Part of the occupational therapist’s assessment is the prediction of the level of care that will be required by the child in the future. Children with long term health and social care needs are served through the Ontario Association of Children Rehabilitation Services (OACRS) Children’s Treatment Centres (CTCs), where occupational therapists are employed. The CTCs embrace a family centred model of care (FCC) which is described by Law et al. (2003) as parents being experts in the care and needs of their children, constants in the child’s life, and wanting what is best for their child. FCC recognizes the importance of families’ well being as central to the child’s well being, and that optimal child functioning occurs within a supportive family. Each family situation is contextually unique and parents have ultimate control over decision making.

The dominant model with which occupational therapists are trained and regulated is the client centred model of care (CCC), described by Sumsion (1999) and Sumsion and Law (2006) as having respect for, and partnership with, people receiving service. CCC is collaborative while recognizing the client’s autonomy and free choice in decision making, and acknowledging the client as an active participant bringing their strengths, experience, knowledge and capacities to their encounters with the occupational therapist. Thus, occupational therapists working within Ontario’s CTC are expected to embrace both client-centred and family focused models of care.

Most children served through CTCs have congenital developmental impairments that result in physical, cognitive or communicative disabilities. Many have combinations
of these disabilities. Those children requiring home modifications have physical impairments which result in barriers to their accessing the home or to the provision of their care in that environment. Children who require the most extensive home modifications are dependent for all of their personal care and mobility, and yet these children may grow substantially until adulthood. The common course of their impairment is normally stable but, as noted above, the child’s social context may change considerably over time. Children with even severe impairments may be relatively easy to care for when they are infants and preschoolers, and their equipment is similarly small. As they age the equipment they use increases in size and volume, since some equipment is not necessary until they have grown and their needs change. For example, a walker is unnecessary until the child is able to propel the walker with assistance, and mechanical lifts only become necessary when the child can no longer safely be lifted by his or her caregivers. Any home modification recommendations made while the child is small must therefore anticipate these types of inevitable changes.

The continuing dependence of this pediatric population is not time limited as it may be with the adult or elderly population where there is a predictable progression to the conclusion of care. Children served by the CTCs are commonly expected to remain with the nuclear family throughout their lifespan. If the care of an adult or senior is too physically demanding or if they are completely dependent, they are often placed in an alternate care setting. Furthermore, when an adult’s care or their health condition becomes too complex, their community participation becomes more limited. Children on the other hand, continue to accompany their family into the community and often participate in their own community activities.
The occupational therapist’s home modification recommendations may be relatively minor (e.g. a portable ramp to the front door) or they may be quite extensive (e.g. requiring construction of a wheelchair accessible washroom or the installation of a lift). Generally an adaptation to an environment involves making non-structural change whereas a modification involves making either structural changes or adding a large piece of equipment which must be integrated into the structure of the home. In either case, the occupational therapist must be knowledgeable concerning the types of assistive technology available to address environmental barriers.

Generally, the larger the home modifications or the more complex the technologies required, the greater the costs. There are several funding options to assist Ontario families with home modifications, as most families are not able to pay for the modifications themselves. In fact, many families are unable to afford renovations beyond what funding agencies will provide. One program that contributes towards home modifications for eligible families is funded by the provincial government and administered by the Ontario March of Dimes. There is also a federal program administered regionally through Canada Mortgage and Housing. This program’s eligibility is based on financial need (income based) and the assessed value of the home. Most families, however, are not eligible because the income cap is too low and house value cap is too high. There are also a limited number of private and not-for-profit charities which will contribute to home modifications. Each charity has a specific set of eligibility criteria and guidelines concerning what will or will not be funded, as well as how often funding can be accessed. Given the high costs of home renovations and assistive technologies that could enhance a child’s mobility, ease of care, and caregiver
well-being, occupational therapists are challenged to make home modification recommendations that are client-centred, family centred and likely to be funded.

The occupational therapist’s recommendations for meeting the environmental needs of a child and his or her caregivers must therefore be supported by a comprehensive assessment of that environment. The ICF’s broad definition of environment provides a framework for comprehensive assessments of the child and caregiver environment. The ICF’s environmental construct includes the child’s support and relationships, the services, systems and policies influencing the child’s environment, the available products and technologies, and the attitudinal environment surrounding the child (WHO, 2001). The ICF acknowledges that the environment can be either a barrier or a facilitator and that environments are highly contextualized to the individual child and his or her family. For example, two children with identical impairments and physical environments may have two very different home modification recommendations because the family social environment is completely different.

The literature provides considerable direction to occupational therapists for assessing and analyzing the physical aspects of a home environment, but there is little guidance available for assessing and analyzing the other components of the environment identified by the ICF (WHO, 2001). These other components include the architectural, financial, social/familial, as well as the service, systems and policy considerations necessary to inform the occupational therapist’s recommendations. The complexity of this environment and the cost of renovations require that the occupational therapist assess not only the current situation but also infer the future status and needs of both the child and the caregivers.
The Joint Position Statement on Evidence Based Occupational Therapy (Canadian Association of Occupational Therapists, Association of Canadian Occupational Therapy University Programs, Association of Canadian Occupational Therapy Regulatory Organizations, & Presidents’ Advisory Committee, 1999) stresses both the importance of client and therapist knowledge and experience, as well as the integration of evidence from scientific literature in clinical decision making. The standardized home assessments tools that are currently available in the scientific literature to assist clinicians in preparing recommendations for home modifications are intended for use with seniors rather than children. They do not address the changing needs and environmental factors associated with child and family development. Lacking theoretically-based, scientifically rigorous assessments designed for children that address all aspects of the child’s changing environment, including caregiver and other family member needs, occupational therapists approach their recommendations for home modifications for children with disabilities and their families in an eclectic and non-standardized manner.

The first step in developing tools such as guidelines or protocols for practice is to determine the current best practice. To determine current best practice, studies that use qualitative methods which ask questions such as ‘What is possible as far as the range of interventions with similar people in similar contexts?’ and, ’’Is there a pattern of routines of those assessing the particular population that predict a successful outcome?’ should be undertaken (Tickle-Degnen & Bedell, 2003). O’Donnell, Kennedy, MacLeod, Kilroy, and Gollish (2006) suggest that in service provision a long term goal is to have all providers delivering consistent service regardless of provider or context. They outline a modified nominal group technique that first clarifies current service before embarking on
the formal guideline development process. Therefore, the purpose of this study is to examine current home modification recommendation practices among occupational therapists who assess the need for home modifications for children who are physically dependent and their family and professional caregivers.

Definition of Terms

Five concepts are defined for the purposes of this study and explained for clarity:

**Caregiver** is defined as an individual “who is responsible for attending to the needs of a child or dependent adult” (Dictionary.com, n.d.-a). The caregiver can be a paid or unpaid position. A professional caregiver is delineated as someone who is being paid to care for the child and may be classified as an attendant or a personal support worker. The term “caregiver” alone will refer to the unpaid care provider of the child and is usually a family member.

**Significant disability** is conceptualized as an impairment that is permanent rendering the individual unable to independently participate in the performance of self care and mobility activities, and is not able to verbally communicate their needs (WHO, 2001).

**Assessment** is an appraisal or judgment of the value, nature or quality of an environment relative to the person occupying the environment (Dictionary.com, n.d.-b). An assessment is the process of collecting and analyzing relevant information in order to formulate and document possible recommendations concerning modification to the child’s environment to improve accessibility and ease of care (Townsend & Polatajko, 2007). Since front line clinicians in Ontario working in the community use the term
assessment to refer to the process of examining the environment for the purpose of developing recommendations for home modification, the term assessment rather than evaluation (Dictionary.com, n.d.-c) will be used for this research.

*Capacity* is defined as “ability; power pertaining to, or resulting from, the possession of strength, intellect, wealth, or talent; possibility of being or of doing” (babylon.com, n.d.-a).

*Safety* is defined as “a state of being certain that adverse effects will not be caused by some agent under defined circumstances” (wordnetweb.princeton.edu, n.d-a).

**Thesis Outline**

In Chapter 2 the relevant literature concerning home assessment for modifications and caregiving is examined relative to the ICF (WHO, 2001) framework. Chapter 3 describes the rationale for the methodological approach, the methodology, sampling, recruitment, data collection, management and analysis, ethical considerations and a reflection on the background and perspectives of the researcher. Chapter 4 presents the findings and the resulting themes. In Chapter 5, the themes are integrated into a process model that suggests how occupational therapists may be developing home modification recommendations. Chapter 5 also answers the research questions, discusses the implication for practice, education, policy and future research and discusses the limitations of the study.
CHAPTER 2: LITERATURE REVIEW

Introduction to the Scoping Literature Review

“The instructions we find in books is like fire, we fetch it from our neighbor, kindle it at home, communicate it to others and it becomes the property of all” ~ Voltaire

This exploratory research is examining an area of occupational therapy practice that has little evidence to guide its assessment and recommendations processes. A scoping literature review is the preferred approach to examining the literature in such circumstances. Davis, Drey, and Gould, (2009) state that “scoping involves the synthesis and analysis of a wide range of research and non research material to provide greater conceptual clarity about a specific topic or field of evidence” (p. 1386). They argue that its “main strengths … lie in its ability to extract the essence of a diverse body of evidence and give meaning and significance to a topic” (p.1398). Given that home modification is a topic with such a diverse body of evidence, a scoping review is an appropriate methodology with which to ascertain the breadth of contributory evidence and to conduct a review of the literature that is found to be pertinent. To guide the scoping literature review of the home modification recommendations practices of occupational therapists for children who require extensive home modifications and are physically dependent on their family and professional caregivers, a framework was required (Arksey & O’Malley, 2005). Arksey and O’Malley’s framework has 5 stages for a scoping review: Stage 1: identifying the search question; Stage 2: identifying relevant studies; Stage 3: study selection; Stage 4: charting data; and Stage 5: collating, summarizing and reporting results (Arksey & O’Malley, 2005, p. 22). Tickle-Degnen (1999) advocates a similar
model in the occupational therapy literature, specifically, formulating questions around a clinical task so that the questions can be answered through a scoping search for relevant evidence. Tickle-Degnen’s model identifies the following three components as necessary parts to the question: (a) the occupation and occupational performance issues relevant to the client population; (b) selecting assessment procedures; and (c) planning intervention. This literature review will use the frameworks suggested by Arksey and O’Malley (2005) to broadly scope and summarize the relevant literature concerning home modifications for physically dependent children and use the Tickle-Degnen framework (1999) to define the searchable question.

Stage 1: Identifying the search question

Tickle-Degnen (1999) argues that the literature review should be guided by a searchable question using a theoretical framework and professional models of practice, and that the researcher should ensure that all sources of “current and best evidence” are searched and reviewed (p. 539). As such, it is necessary to briefly review the professional models of practice relevant to the development of the searchable question. The environment is a central focus in many occupational therapy conceptual and performance models and is commonly described as a central focus of the practice of occupational therapy. Environmental assessments are integral to the process of enabling occupation (Law, Cooper, Strong, Stewart, Rigby, & Letts, 1996; CAOT, 1997; Townsend & Polatajko, 2007; Christiansen & Baum, 1997; Hagedorn, 2000; Keilhofner, 1997; Keilhofner & Forsyth, 1997). The Canadian Model of Client-Centred Enablement (CMCE) (Townsend, Polatajko, Craik & Davis, 2007) describes ten skills involved in the generic process of enabling occupation: adapt, advocate, coach, collaborate, consult,
coordinate, and design/build. Underpinning these key enablement skills are process skills, professional skills, and scholarship skills. The process skills include assessing, evaluating, analyzing, intervening, and planning. Therefore, consistent with Tickle-Degnen’s framework (1999), the following questions provided direction for the literature review:

What are the most reliable and valid methods for assessing the occupation and occupational performance of caregiving for children who require extensive home modifications and are dependent on others for care? And, what are the most effective interventions for decreasing environmental barriers to caregiving?

In the questions guiding the literature search in this study, occupation is defined as that of caregiver, the person is the caregiver of a child with significant disability and the intervention is recommending the elimination of environmental barriers to caregiving. This most closely resembles the Person-Environment-Occupation model of practice (Law et al., 1996).

Stage 2: Identifying relevant studies & Stage 3: Study Selection

Arksey and O’Malley (2005) describe the scoping review as an iterative process rather than a linear process when 1. The topic is broad, 2. There is a requirement to identify all relevant literature and, 3) Familiarity with the literature increases. For this reason, stage 2 and stage 3 will be described together.

The literature review was based on the main concepts embedded in the guiding questions with respect to the generic enablement process skills and occupational therapy literature. These key concepts forming the starting point from which the search terms
were derived, were (a) occupation and occupational performance, (b) assessment procedures and (c) intervention. These concepts were searched using the following major and minor MESH subject keywords in the CINAHL, Medline, and PsychInfo databases:

1. The occupation and occupational performance of the client population – children with disability, caregivers, caregiver burden (subjective and objective), caregiver role, occupational therapy


3. Planning of intervention - architectural accessibility, architectural barriers, assistive technology, safety, interior design and furnishings, and clinical decision making

The articles located from this search were very diverse and included topics such as policy analyses of the implications of the Americans with Disabilities Act (ADA), treatment of children with physical disabilities, home assessment tools for the seniors population, adults with physical disabilities, adults with Alzheimer’s disease, theoretical debates concerning topics such as person-environment interaction and home adaptation, analysis of areas of the home causing the most difficulty for people with motor impairments, home assessment tools, client/consumer perspectives on home modifications and nursing and medical home intervention concerning pharmacology.

The abstracts of the articles derived from this search were reviewed for relevance with respect to the following inclusion and exclusion criteria:
• Inclusion: articles on home assessment and occupational therapy, articles on assistive technology and devices relating to home modifications, and client/consumer perspectives; abstract that provided a clear purpose, constructs, methods, and outcomes; articles which discussed the process of making a home modification recommendation.

• Exclusion: articles that described types of modifications and technological outcomes without consideration of the process of recommending a modification or technological solution, single case studies which focused on the specific needs of one individual rather than the aggregate needs of a group of people with diverse needs, articles of poor quality (i.e. grammatical and spelling mistakes in the abstract, purpose not clearly stated, poor identification of study constructs), articles addressing the development or implementation of the ADA unrelated to home assessments, pre-discharge assessments, articles concerning home management of various medical conditions, and conceptual articles only about universal design.

If the abstracts of the articles met the inclusion criteria, the article was retrieved for full review. This strategy resulted in only nine articles concerning home assessments. When these articles were reviewed it became clear there were more published articles available which had not been identified through the search strategy. This necessitated a hand search through reference lists of the nine articles and the published “grey” literature of professional organizations such as OT Practice by the American Occupational Therapy Association and OT Now published by the Canadian Association of Occupational Therapy. The other strategy employed at this point was using the “find similar” and “find
citing articles” functions available in the search engines OVID and EBSCO Host. These additional strategies resulted in locating a further six articles concerning home assessments. Five articles on assistive technology and seven articles concerning the client/consumer’s perspectives were located in the search.

With respect to the caregiver assessment tools, one review article concerning measures used to assess burden among caregivers of the stroke population was located as well as 12 articles that met the inclusion criteria of evidence of psychometric testing over multiple years by a variety of researchers in addition to the original author. Exclusion criteria included tools which had no psychometric testing and only the original article could be located. Hand searching of reference lists helped to locate original literature not found in the electronic search. This resulted in thirteen articles being reviewed for full review and analysis.

Additionally, the Cochrane Library, OT CATS and OT seeker websites were accessed to determine if the area of home assessment (either adult or pediatric) had been addressed through systematic reviews, critical appraisals or guidelines. None were found.

Stage 4: Charting the data

The content of the 40 papers meeting the inclusion criteria fell into four general areas: the client/consumer perspective concerning home modifications, assessments of home environments, assistive technology to eliminate barriers in the environment, and the occupation of caregiving for the child with physical disabilities. Arksey and O’Malley (2005) suggest using a “descriptive-analytical’ approach within a common analytical framework to charting or synthesizing the literature located. Because the ICF provides a broad definition of the construct of environment and “articulates multidirectional
influences and consequences” (Bartlett et al., 2006, p.1171), available

home/environmental assessments and caregiver assessments were reviewed with respect to how closely the assessment reflected the ICF environmental constructs. Particular attention was given to whether or not the assessment addresses the caregiver’s capacity to fulfill the caregiving role within a child’s unique environment. Since the ICF uses a common and shared multidisciplinary lexicon (WHO, 2001) and is compatible with both the qualitative and quantitative research paradigms (Bartlett et al., 2006), it was felt to be the most appropriate model to examine the multiple interacting factors influencing the environment of children requiring significant home modifications. The literature concerning assistive technology and client/consumer perspectives was analyzed for fit and relevance with the searchable question and what knowledge it contributed to relative to the searchable question.

Stage 5: Collating, summarizing and reporting the results

Arksey and O’Malley (2005) propose that an overview of all of the materials reviewed should be presented using “thematic construction in order to present a narrative account of the existing literature” (p.27). The following section presents the results of the scoping review of the literature with respect to the four broad themes that were derived from the analysis of the content of the 40 papers that met inclusion criteria and addressed the search questions: What are the most reliable and valid methods for assessing the occupation and occupational performance of caregiving for children who require extensive home modifications and are dependent on others for care? And, what are the most effective interventions for decreasing environmental barriers to caregiving?
Client/Consumer/Family Perspectives

This section examines the literature focused on the factors that clients and their families identify as important in the process of occupational therapy assessments and interventions. As part of their development of a measurement tool for assessing environments, McManus et al.’s discussion groups with parents of children with cerebral palsy (2006) revealed that families are the most important resource available to the child, and supporting the family unit is imperative. Green’s (2006) findings from a survey of 81 mothers of children with disabilities in Florida, United States of America, and follow-up interviews with seven of these mothers indicate that the burden of care perceived by these caregivers was a function of socio-structural constraints (objective burden) rather than emotional distress (subjective burden). Green’s sample of mothers found that, overall, caring for a child with a disability was “time consuming, expensive and physically exhausting” (2006, p.155).

In the opinion of a consumer of occupational therapy environmental assessments, Winfield (2003) argues that the best adaptations that are long term solutions happen when recommendations emerge from “a sensitive and holistic assessment of who [the family] is and what kind of life they wish to lead” (p. 376). Similarly, in Ostensjo, Carlsberg and Vollestad’s (2003) study of the everyday function of 95 children with cerebral palsy, they found that the needs of the caregivers of children who provide no substantive assistance in their own care, must be considered equally with the needs of the child. Based on data from the same research, the authors also report that individual, cultural and environmental factors affect caregivers’ utilization of technological devices to facilitate care (Ostensjo, Carlsberg & Vollestad, 2005).
As highlighted by Green (2006), and as found in a qualitative study of parents’ experiences of home adaptations for their children by Roy et al. (2008), many factors must be analyzed when considering a home modification to improve the environment of a physically dependent child. These include: economic and time costs, physical and social needs of other family members, municipal by-law limitations, and the typical functioning of the family. These findings were consistent with McManus et al.’s European study designed to develop content for an ICF based environmental questionnaire for children with cerebral palsy (2006). The parents in this study found dealing with bureaucracy was time consuming and considered a barrier to obtaining financial entitlements (McManus et al., 2006). Overall, access to funding to assist families with home modifications depends both on personal resources and the policies and priorities of available funding agencies (McManus et al., 2006; Roy et al., 2008).

Frequently families must compromise an ideal solution in order to keep the modifications under the financial ceilings of the funding agencies (Roy et al., 2008). The financial burdens of families of children with extensive disabilities, which include reduced parental employment income and increased care costs compared to families with children without a chronic condition, are well documented. For example, Kuhlthau, Hill, Yucel and Perrin’s (2005) national study of the financial burdens experienced by American families’ of children with special care needs revealed that 40% of families of these children experience financial burden related to their child’s condition and that the experience of finance-related problems is negatively associated with both mothers’ and children’s health status.
In Nelson’s (2002) meta-synthesis of twelve studies on mothering “other-than-normal” children, which included a total sample of 79 mothers, daily life revolves around the “ill” child, independent of the diagnosis. Nelson argues that health professionals must address the needs identified by the primary caregiver and families of children with special needs, and that assessment and intervention must involve all family members. No studies were found that examined the perspectives or role of the professional caregiver of children who are physically dependent, perhaps because professional caregivers have specific workplace health and safety requirements. In summary, the literature on the client, consumer and family perspectives focuses on the burden of the occupation of caregiving. The economic, physical and social needs of family members, as well as the physical, social and policy environments including municipal by-law limitations, and typical family functioning are all emphasized in that literature. The next sections of the literature review focuses on assessments of the environment of the child who is physically dependent for care, and assessments of occupation of caregiving.

Current Home/Environmental Assessments

No studies addressing how therapists should proceed with assessing the need for and recommending home modifications for the pediatric client and their caregivers were found. Much of the literature on home modifications focuses on environmental modifications required to make physical environments safe for older adults. Although the literature on home modifications for seniors is relevant since it addresses many home safety considerations, it does not fully address the broad spectrum of environmental concerns described earlier (e.g. aging caregivers, policy changes, requirements of
professional caregivers, temporality and the needs and limitations of other family members in the home of children with disabilities). Additionally, much of the literature on home assessments for seniors addresses how a clinician would assess the environment for relatively minor adaptations rather than structural modifications or large pieces of equipment which must be tied into the structure of the home (Oliver, Blathwayt, Brackley & Tamaki, 1993; Keysor, Jette & Haley, 2005). Finally, when the contextual factors that influence human health are examined, many of the published assessment tools fail to include the environmental constructs identified in the ICF, such as products and technology, natural environment and human-made changes to environment, support and relationships, attitudes, and services, system and policies. The following section will review published home assessment tools relative to the ICF construct of environment.

The Safety Assessment of Function and the Environment for Rehabilitation (SAFER) tool (Oliver et al., 1993) was developed to assess the individual’s ability to carry out activities of daily living in their home. The elements of the SAFER tool are restricted to the perspective of the client with disabilities and whether that environment supports them. If the client is dependent for all care, the SAFER tool does not prompt the clinician to assess the capacity of the caregiver to perform the caregiving duties or the capacity of the environment to support the caregiver. It does not address the services, systems and policies which may be creating a barrier to caregiving or could facilitate caregiving. The SAFER tool does not examine the social context influencing the care of the individual.

Sanford, Pynoos, Tejral and Browne (2002) have developed the Comprehensive Assessment and Solution Process for Aging Residents (CASPAR) assessment protocol
for the development of home modification recommendations. This assessment was designed to be an “off-site” tool that provides comprehensive information about the individual, their occupational performance and their environment. The CASPAR was designed to be used to prescribe modifications by a professional who does not visit the site. While this protocol addresses the physical environment in which a client functions, it does not give direction about assessing the capabilities of family and professional caregivers. In many circumstances the execution of caregiver roles this should be professionally assessed, for example, with respect to how the lifts or transfers are being performed. Presumably ICF factors such as financial resources, services, systems and policies that are either barriers or facilitators, the attitudes of the caregivers, the availability of social supports, the adequacy of communications, and any future needs would be considered by the off-site professional who is prescribing the modification. Further, the CASPAR does not comprehensively address mobility issues, most likely because the assessor is off-site and may never meet the client.

The Home Environmental Assessment Protocol (HEAP) (Gitlin, Schinfeld, Winter, Corcoran, Boyce & Hauck, 2002), evaluates the role of the physical environment in supporting the caregiver’s provision of home care for individuals with dementia. The HEAP is intended for use with people who require supervision to complete their own care, not for people who are dependent on others for all of their personal care. The authors report that the HEAP was designed so that non-professionals could make decisions determining the “fit” of the environment with the capabilities of the person with dementia. Ratings are independent of the unique characteristics of the people living in the home in that it focuses on the physical environmental barriers rather than how the people
“live” in the environment and who might be helping them live in that environment. The HEAP solely addresses the physical environment and does not address any of the other ICF defined environmental constructs.

In developing the Housing Enabler, Iwarsson (1999) used the Enabler concept (Steinfeld, Schroeder, Duncan, Faste, Chollet, Bishop, Wirth, & Cardell, 1979) which operationalizes the idea that a person’s functional capacity and the environmental demands must be congruent when designing accessible housing. While the Housing Enabler (Iwarsson, 1999) addresses both the client’s functional limitations (body structure and function) and physical environment, the author states that it requires special training to use. The Housing Enabler shows promise as an assessment tool to determine the most functional environment for the client’s unique requirements and incorporates the client’s perceptions of accessibility and usability of their housing environment. The limitations of the Housing Enabler are that it does not assess ICF factors beyond the physical environment, such as the needs and attitudes of caregivers or social supports required in managing a person who is completely dependent, financial considerations, or the barriers presented by the services, systems and policies in the client’s environment. The Housing Enabler does not address the temporal facet of home modification recommendations for children. This assessment, while well researched, only addresses the person at a body function and structure level at a particular point in time.
<table>
<thead>
<tr>
<th><strong>Home Assessment Tools</strong></th>
<th><strong>Purpose</strong></th>
<th><strong>Product/Tech</strong></th>
<th><strong>ADL</strong></th>
<th><strong>Mobility</strong></th>
<th><strong>Comm.</strong></th>
<th><strong>Design &amp; Construct’n</strong></th>
<th><strong>Financial Status</strong></th>
<th><strong>Social Supports</strong></th>
<th><strong>Attitudes</strong></th>
<th><strong>Services/Systems/Policies</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>The SAFER Tool (Oliver et al., 1993; COTA, 1991)</td>
<td>Assess elderly person’s ability to function safely in home environment</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The Home and Community Environment (HACE) Instrument (Keysor et al., 2005)</td>
<td>Characterize factors in home &amp; community environment influencing level of participation; only tool based on the ICF</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>The Source Book (Kelly &amp; Snell, 1989)</td>
<td>Assess barriers in a physically disabled person’s home</td>
<td>✓</td>
<td>✓</td>
<td>+/-</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>The Assessment Tool (Maltais et al., 1989)</td>
<td>Assess elderly person’s ability to function safely in home environment</td>
<td>✓</td>
<td>+/-</td>
<td>+/-</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Home Environmental Assessment Protocol (HEAP) (Gitlin et al., 2002)</td>
<td>Examine dimensions which create hazards in the physical environment of persons with dementia</td>
<td>✓</td>
<td>+/-</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Comprehensive Assessment &amp; Solution Process for Aging Residents (CASPAR) (Sanford et al., 2002)</td>
<td>Assessment protocol of occupational performance and environment without a site visit</td>
<td>✓</td>
<td>+/-</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
<tr>
<td>Craig Hospital Inventory of Environmental Factors (CHIEF) (Whiteneck et al., 2004)</td>
<td>Assesses extent to which a person encounters environmental factors &amp; the perceived impact they have on daily life; based on ICIDH-2 (WHO, 1999, 2000)</td>
<td>Limited</td>
<td>X</td>
<td>X</td>
<td>Limited</td>
<td>X</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td></td>
</tr>
<tr>
<td>The Housing Enabler (Iwarson, 1999)</td>
<td>Assessment of housing accessibility</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td>X</td>
</tr>
</tbody>
</table>
Similar limitations are found when the “HACE”, the Home and Community Environment Instrument (Keysor et al., 2005) was reviewed. The HACE tool focuses on the home and community environments in which an elderly person functions but it does not address caregiver requirements, the need to anticipate change in the child and/or caregivers, or the needs of other family members impacting on potential home modifications. Although the HACE provides a template for examining the individual’s physical environment, it can’t assist the pediatric therapist who must consider the social support construct nor the financial environment.

The Source Book (Kelly & Snell, 1989) and the Assessment Tool (Maltais, Trickey & Robitaille, 1989) were developed to examine the extent of an individual’s physical disability and barriers to function within a person’s home. While both tools examine physical environments and provide templates for assessing the physical environment, neither the Source Book nor the Assessment Tool address the ICF constructs of financial status, social supports, attitudes and services, systems, and policies. Both are limited in the area of clients’ level of communication, and the Assessment Tool is further limited in the area of mobility. Finally, neither was published in peer-reviewed journals or underwent any psychometric testing.

From the Model of Competence (Rousseau, Potvin, Dutil, & Falta, 2002) the Home Assessment of Person-Environment Interaction (HOPE) was developed. The authors state that this tool was developed for individuals with motor disabilities and has undergone content validity, test-retest reliability and inter-rater reliability. However, neither the assessment nor the evidence of psychometric testing has been published in a peer-reviewed journal, although these results are cited in recent literature (Carignan,
Rousseau, Gresset, & Couturier, 2008). Repeated attempts at contacting the first author, Rousseau, were unsuccessful. Based on the description of the HOPE in the 2008 article, this assessment does comprehensively address and analyze the person relative to their context. Unfortunately, an in-depth analysis of this potentially promising tool is not currently possible.

There is one assessment which was specifically developed to address the extent to which environmental factors are perceived to be affecting a person’s life. The Craig Hospital Inventory of Environmental Factors (CHIEF) (Whiteneck, Harrison-Felix, Mellick, Brooks, Charlifue, & Gerhart, 2004) was developed using the ICF as a framework for determining assessment categories but as its name suggests, it focused primarily on the environmental constructs in hospitals and pays little attention to the body, structure and function constructs. The inventory also neglects the financial environment which is crucial to the assessment of the need for home modification for children who are dependent and their families.

Home Modification Guidelines

Currently there are no clinical models or guidelines to inform occupational therapists with respect to assessing and recommending home modifications for the pediatric age group. Levine and Gitlin (1990) have outlined preliminary work focusing on teaching student occupational therapists a model for prescribing environmental adaptations using eight steps of service provision. This model was based on the Barris model of the environment (Barris, 1982) which focuses on the fit of the person and environment using unstructured interviews and participant observation in the client’s
home over a ten week period. While this model identifies the need to assess a client’s lifestyle and cultural values as a part of their environment, it cannot assist an occupational therapist in balancing the financial restrictions with the functional needs of the pediatric client and their caregivers, nor does it help the occupational therapist anticipate future needs.

The available literature does not provide specific evidence to guide occupational therapists’ clinical practices in assessments for pediatric clients. While the ICF provides a framework for defining the constructs of environment, these constructs have not yet been operationalized into comprehensive assessment tool. Products and technology are also a part of the ICF framework, as is caregiving. The literature on assistive technology and caregiving will now be examined with respect to home modification assessment and recommendations for children who are physically dependent and their families.

Assessments Concerning Assistive Technology

The assistive technology used in home modifications, for example lifts and elevators, differ from the types of technology generally discussed in the literature, which most frequently describes smaller items such as mobility devices or augmentative communication technology. Some assessments tools of assistive devices take consider caregivers into account (Gitlin & Chee, 2006), but they do not recognize the need to evaluate and anticipate changes in caregiver status over time. Gitlin and Chee’s (2006) clinical guidelines for prescribing equipment for persons with dementia include analyzing the activities which must occur and where these activities take place, as well as integrating both the caregiver’s capabilities and perceived needs. These guidelines cover
many issues similar to a pediatric population such as determining equipment needs, analysis of individual capabilities and family needs. They also include financial considerations and funding constraints as assessment factors. A consideration, however, for the pediatric population that is distinct from an aging population is the necessary growth considerations and changes to caregiver function and needs.

The framework for the conceptual modeling of assistive technology developed by Fuhrer, Jutai, Scherer and Deruyter (2003) could be a conceptual structure for home modification recommendations since it does address the temporal aspect. The authors propose the entry point into the model is the “procurement of a device-type” that is predicated on three considerations: the need for a device, the type of device including extrinsic and intrinsic properties, and the services that may be involved. The model, however, starts at the point at which the device has already been procured. The framework was developed to assess the outcome of a recommendation that results in the procurement of a device but does not provide direction as to how the therapist should develop the recommendations leading to procurement. Fuhrer et al. suggest that device procurement involves complex considerations and should be modeled separately. Indeed this concept of device procurement is reinforced by the work of Ostensjo et al. (2003) described earlier. Occupational therapists are part of the services involved before procurement where decisions are made about which type of device or modification is appropriate to meet the child’s environmental needs. The authors outline a number of factors which are important considerations when recommending a device including the effectiveness and efficiency of the particular device.
Care of Children with a Disability

As a critical element in the environment of the client, occupational therapists must consider the capacity of the caregiver to manage the current and future needs of the client in light of the issues and burdens the caregiver experiences. Common practice in the Ontario health care system is to request that occupational therapists predict the level of care that will be by an individual for purposes of placing the individual in an alternative setting. The occupational therapy intervention therefore involves ease of care recommendations for the caregiver which includes an analysis and prediction of the caregiver’s capacity to fulfill the occupation of caregiver. None of the aforementioned home assessments address caregiver capacity.

In the literature the concept of burden is broken down into “objective” burden which is the time spent on caregiving, tasks performed and financial concerns, and “subjective” burden which is the physical, social, psychological, emotional impact experienced by the caregiver in giving care (van Exel, Brouwer, van den Berg, Koopmanschap, & van den Bos, 2004). Recalling that capacity is defined as the ability; possibility of being or doing (babylon.com, n.d.-a), the occupational therapist must determine whether the caregiver has capacity to manage the burden.

There are a number of psychometrically valid assessments available to clinicians designed to evaluate caregiver burden (Visser-Meily, Post, Riphagen, & Lindeman, 2004). Most, however, do not specifically address caregivers’ current and future capacity to manage the occupation of caregiving. Please see Table 2 below for a summary of these assessments. Only two of the available assessments specifically address or differentiate both subjective and objective burden. The Sense of Competence Questionnaire (Scholte
op Reimer, de Hann, Rijnders, Limburg & van den Bos, 1998) developed for the dementia population is a self-report questionnaire of performance and consequences of caregiving occupation in the caregiver’s personal life. However, this tool does not address the objective burden. The Bakas Caregiving Outcome Scale (Bakas & Champion, 1999) was developed to assess the caregiving of individuals with cerebral vascular accident (CVA). This tool measures adaptation to caregiving, but it does not address capacity, objective burden and prediction of future ability to manage the role. The Caregiver(s) Burden Scale (Elmstahl, Malmberg & Annderstedt, 1996), the Caregiver Strain Index (Robinson, 1983), the Caregiver Reaction Index (Given, Given, Stommel, Collins, King, & Franklin, 1992) and the Zarit Burden Interview/Index (Zarit, Reever & Bach-Peterson, 1980) have similar limitations in that they only address subjective burden. Each of these measures were developed for caregivers of adults with CVA, physical impairment, post operative hip surgery, Alzheimer, cancer and heart disease populations. While the Caregiver(ing) Burden Scale (Grant, 1999), developed from the Caregiver Load Scale (Oberst, Gass, & Ward, 1989) for the cancer population, does address both subjective and objective burden, it does not support the prediction of caregiver’s capacity to perform the caregiving roles over time, nor does it measure current capacity of the caregiver to fulfill those roles. The Generic Lifestyle Assessment Questionnaire (Jessen, Colver, Mackie, & Jarvis, 2003) is a 53 item interview developed for caregivers of children with special needs. This questionnaire asks about subjective and objective burden but not current or future capacity to fulfill the caregiving role. The Self-Rated Burden Scale (van Exel Brouwer, et al., 2004) is a single question with a 0-
100 range indicating overall subjective burden. While informative, this tool does not address any of the other important capacity dimensions or objective burden.

Table 2

<table>
<thead>
<tr>
<th>Caregiver Assessment Tool</th>
<th>Focus on Caregivers Capacity to manage client needs?</th>
<th>Subjective Burden</th>
<th>Objective Burden</th>
<th>Prediction of caregiver’s ability to manage role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sense of Competence Questionnaire</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(Scholte op Reimer et. al., 1998)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bakas Caregiving Outcome Scale</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(Bakas &amp; Champion, 1999)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver(s) Burden Scale (1)</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(Elmstahl et. al., 1996)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver (ing) Burden Scale (2)</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>(Grant, 1999):</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Strain Index</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(Robinson, 1983)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Zarit Burden Interview/Index</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(Zarit et. al. 1980)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Generic Lifestyle Assessment Questionnaire</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>(Jessen et. al., 2003)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Caregiver Reaction Index</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(Given et. al., 1992)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Self-Rated Burden Scale</td>
<td>No</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>(van Exel et. al., 2004)</td>
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</table>

There is no specific caregiver assessment tool which evaluates the caregiver’s overall potential capacity to perform the role. Objective burden is a very important consideration concerning professional caregivers because the amount of time they are funded to provide caregiving service depends on pre-established caregiving units of work and the number of tasks to be performed during one caregiving encounter. None of the
tools addressed burden from the perspective of the professional caregiver. Further, dimensions of burden do not consider the importance the caregiver attaches to each specific dimension; in other words, whether that particular dimension is considered “burdensome” and a barrier to activity participation by the caregiver. There is a need to define and develop the concept of predicting future caregiving capacity. Care requirements funded in the community are often based on occupational therapists’ recommendations, and costly home modification decisions are made based on occupational therapists’ prediction of caregiver’s capacity to perform role over time.

In summary, this review examined and synthesized the literature related to consumer/client perspective, published home modification tools, assistive technology and caregiving burden assessments. Guided by the PEO model (Law et al., 1996), the CMCE practice processes (Townsend & Polatajko, 2007), and based on the ICF concept of the environment (WHO, 2001), it identifies the need to listen to the client/consumer perspective about their needs, the scope of the physical environment assessment available, the scope of tools available for evaluating caregiver burden and capacity, and the need to understand the assistive technology available for home modifications. The review highlights the considerations that should be factored into an occupational therapist’s professional reasoning as home modifications recommendations are constructed. The long term functionality of the home modification must address the needs and functions of the client and the caregiver(s), their energy efficiency (i.e. ease of use), the family’s financial concerns, be sensitive to the family’s lifestyle, and be architecturally feasible with the benefits and restrictions of any proposed technology being well understood in context.
The literature on environmental modifications for the elderly population is growing but the needs of this population differ significantly from the needs of children who are physically dependent. While a senior’s care needs generally evolve and change gradually over time, a child’s physical status transforms very quickly because they are growing over a relatively short period of time. The changing physical status of the child and his or her caregivers are further complexities which must be recognized. Both the child and the caregiver will change due to many factors including but not limited to aging caregivers, changes in professional caregivers and the maturational changes in the child. While some changes are predictable, the exact functional nature of the change cannot be predicted nor can the functional capacity of yet unknown professional caregivers performing the caregiving occupation be predicted. The future status of both the child and the person(s) performing the occupation of caregiver must be inferred. Therefore, the occupational therapist must ensure that any physical environmental recommendations will not create barriers to the performance of any potential caregivers. Accordingly, the longevity of the modification recommendations is a significant aspect when considering a child as opposed to an adult because of the need to predict, to some degree, future physical status of the child and the caregiver (Roy et al., 2008).

Because of these differences, occupational therapists may consider and prioritize different aspects of the environment than are emphasized in the literature pertaining to the senior client. When the breadth of the ICF “environment” construct is examined, it is clear that throughout the assessment process the occupational therapist should be gathering large amounts of information. Since each child has a unique environment, it is important to examine what data occupational therapists consider, and how they distill the large volumes of information down to a few recommendations pertinent to the individual
situation. This “prioritization” of considerations leading to a recommendation is unique to each context.

Research question

The purpose of this research is to first examine what information occupational therapists gather to inform their home modification recommendations and second to examine how occupational therapists evaluate and prioritize that information to develop recommendations for home modifications for children and their families who require extensive home modifications. There are three research sub-questions:

1. What data do occupational therapists gather when assessing the needs for home modifications for completely physically dependent children and their families?
2. What processes do occupational therapists use when gathering, evaluating, and prioritizing these data in order to formulate their recommendations?
3. How do occupational therapists structure their recommendations for home modifications for physically dependent children and their families and caregivers?
CHAPTER 3: METHODOLOGY and DESIGN

Introduction

“Home is where one starts from” ~ T.S. Eliot

Due to the exploratory nature of this research, a qualitative approach to the gathering and analysis of data on therapists’ home modification assessment and recommendation practices is appropriate (Campbell, Fitzpatrick, Haines, Kinmonth, Sandercock, Speigelhalter & Tyrer, 2000). Campbell et al. propose a phased framework to design and evaluate complex interventions which include several components and interconnecting parts. The preceding review of the literature suggests that the practice of home modification recommendations is complex. Since there are no guidelines specific to home modification assessments for the pediatric client, the aim of the research is to define the relevant assessment components and processes of occupational therapists’ home modification assessments and recommendations for this population. Campbell et al.’s first phase of evaluation of complex intervention, in which components and underlying mechanisms of an intervention are described and analyzed, suggest that a qualitative approach is appropriate to help define relevant components influencing outcomes.

Paradigmatic Reflections

This research explores the complex clinical processes involved when occupational therapists recommend home modifications for children who require extensive home modifications. The purpose was to develop a clear picture of how clinicians are currently assessing the environment of activities of daily living (ADL) of dependent children and
to fully understand what factors influence their recommendations. Because the stated research questions combine exploratory and descriptive elements and because there is no literature examining how occupational therapists are assessing the home environments (physical and social) of very physically involved children, a descriptive approach to listing the factors a clinician attends to in making their recommendations was used. Furthermore, since there is no standard of practice, the research question also suggested an exploratory approach to examine how these multiple factors were gathered and considered by the clinician as they develop their recommendations. Descriptive research documents and describes the complex nature of existing phenomena and exploratory research focuses on the relationship among the described factors (Portney & Watkins, 2000). These broad considerations suggest support for situating this research in the qualitative inquiry paradigm.

Survey research using questionnaires was considered because they can span descriptive to exploratory to experimental research (Portney & Watkins, 2000). However, since a clinician’s analysis and clinical reasoning processes are complex, and since there are no available questionnaires which would obtain the type of detail needed to explicate clinical reasoning, a reductionistic approach would therefore not facilitate exploration of how an environmental assessment is performed by the occupational therapist.

While there are, within the qualitative paradigm, a number of approaches to inquiry (Creswell, 1998), grounded theory presented the best methodology for addressing the research question. The objective of a grounded theory study is to develop an explanatory theory or model related to a particular situation where individuals interact or engage in a process in response to a phenomenon (Creswell, 1998). Its unique feature is
that it does not have to begin with any predetermined expectations (Portney & Watkins, 2000). The generated theories are grounded in the data so it is closely related to the context of the phenomenon being studied and explains what is observed. Consequently, it is important to include research participants who have experienced the phenomenon under different conditions (Starks & Trinidad, 2007; West, 2001). The philosophical base of grounded theory is that meaning is negotiated and understood through social interaction, and theory “is discovered by examining concepts grounded in the data” (Starks & Trinidad, 2007, page 1373). Grounded theory research asks about how social structure and processes influence behavior. The audience of grounded theory is those interested in designing intervention processes to support people in social processes (Starks & Trinidad, 2007).

Charmaz (2006) has argued that basic grounded theory guidelines are steps to a research process and researchers can ‘adopt and adapt’ the methods to a variety of epistemological perspectives. The constructivist paradigm posits that knowledge results from a collective process because it is interactive in nature. This perspective is congruent with Charmaz’s (2006) social constructivist grounded theory methodology which she defines as “a theoretical perspective that assumes that people create social reality through individual and collective actions”. A social constructionist “[studies] what people at a particular time and place take as real, how they construct their views and actions, when different constructions arise, whose construction is taken as definitive and how that process ensues” (p.189). Occupational therapists, similar to many health professionals, tend to follow practice norms of their immediate peer group (i.e. those they worked with or trained under) (Jette, Bacon, Batty, Carlson, Ferland, et al., 2003). This is consistent
with the social constructivist perspective that social reality (how to perform a home assessment) is created through collective action. Ontologically therefore, knowledge is relative to the environment to which the clinician is exposed. Knowledge is therefore seen as transactive and co-created.

The constructivist paradigm makes the assumption that individuals develop multiple and varied subjective meanings of their experiences as they seek to understand the world (Creswell, 2003). Because meaning is socially constructed through interaction, the researcher wants complex and diverse perspectives from participants in order to gain access to the full expression of this diversity rather than a narrow truth (Patton, 2002). The researcher wants to understand the contexts of the participant. The constructivist approach additionally fits this study’s research questions because the social context of the family being assessed is complex and multifaceted. It is logical to hypothesize that the occupational therapist will approach the assessment with respect to the context. To fully explore and understand how an occupational therapists would assess this context, the approach to inquiry would have to be open-ended so the OT can fully express this complexity (Charmaz, 2006). The interpretation of the data is not independent of the experience of the researcher because the findings are analyzed through the perspective of the researcher (Creswell, 2003; Patton, 2002). The analysis process is inductive, shaped explicitly by the data but implicitly by the lens of the researcher, and results in a theory that contributes to knowledge and debates concerning the issue (Guba & Lincoln, 2005; Creswell, 2003; Patton 2002).
Positionality

In designing the data collection and analysis methods, it is acknowledged that the student researcher who performed the interviews and was the primary analyst of the data, is a practicing clinician with extensive experience in home assessments. While both West (2001) and Chew-Graham, May, & Perry (2002) suggest that interviews done by colleagues resulted in richer data (which they attributed to common professional identity and experiences permitting the interviewee to be vulnerable), Charmaz (2006) maintains that the researcher’s experience is an important part of ascertaining the credibility of the data. As a practicing clinician experienced in completing home modifications assessments and recommendations, the student researcher recognizes that the knowledge gained will be filtered through this experience and therefore this must be acknowledged throughout the data analysis.

My 19 years of experience as an occupational therapist has been varied. Upon graduation I worked for an adult acute care hospital on the neurology and neurosurgery services. I then moved on to working in the community in home care starting initially with adults and seniors and then gradually moving into pediatric services in both the home and school environments. I have been at a children’s treatment centre (CTC) in southern Ontario for the last nine years. Until I moved to the CTC, where I currently hold the position of Professional Practice Leader, I spent little time reflecting on my personal theoretical perspective. I used the client-centred model of practice articulated in the professional literature of the 1980’s which formed the foundation of my training. I have an undergraduate, four year professional degree. Since moving to the CTC and being exposed to new occupational therapy graduates I have been exposed to the more recently
published models of occupational performance. While I find none of these models completely resonate with my practice, when I reflect on how I organize my client interaction, the PEO (Law et al., 1996) is the most accurate reflection of my practice and basis of my clinical reasoning.

Having faced some uncomfortable ethical situations wherein I felt that the child’s family was more concerned with their home’s perceived monetary value than meeting the child’s needs, as I perceived them, my inclination is to focus on the child’s long term well being while being conscious of the families’ multiple interests. It bothers me when some families are able to continually access funding for home and vehicle modifications while other families are not able to access any funds beyond the annual amounts available from the non-income based funding agencies, which is a small amount compared with the overall cost of most home modifications. I have a great deal of sympathy for families who make just slightly over $70,000 gross family income because they do not qualify for any funding assistance from the Ontario March of Dimes or President’s Choice Children’s Charity, the two largest funding sources that together will provide up to $35,000 for home modifications.

The anticipated audience for this research is occupational therapists who work with children with significant physical disabilities, and possibly occupational therapists who work with adults with chronic, progressive disabilities, as well as those working with people who have significant acquired physical injuries, returning to their families, when the families would be the primary caregivers.

In conclusion, while the value of a number of paradigms and approaches resonate with the overall area of clinical practice, this specific research question fits most
appropriately under a constructivist paradigm using a grounded theory approach. The discussion of the purpose of the research, a review of the literature and a review of various methodologies leads the student researcher to conclude that epistemologically and ontologically, a constructivist approach using grounded theory methodology best suits the research question, the target audiences and the logistical and time limitations of the MSc thesis project. The development of a model will encourage dialogue about an area of practice which has little evidence to support an approach to practice and provide a foundation for further research.

There were two parts to this research project. The first part was a survey that generated the nominations of educationally influential occupational therapists (EIOTs); and in the second part, these EIOTs participated in in-depth interviews. Educational influentials (EIs) are characterized as clinicians who provide a positive learning experience and are willing to provide leadership and share knowledge, are good communicators, and keep up to date and demonstrate a high level of expertise in the practice area (Hiss, Macdonald, & Davis, 1978). There are a number of studies which have employed EI or opinion leader clinicians as the subjects of research in an effort to assemble their current best practice for the purpose of developing practice models or a practice intervention tool (Wright, Simunovic, Coates, & Fitch, 2006; Mirand, Beehler, Kuo, & Mahoney, 2002). Krefting (1991) also suggests that using a nominated sample of informants as a strategy may contribute to the transferability of the findings to other clinical contexts.
Part 1 Methodology: Survey and Recruitment

Phase 1: Sampling and Recruitment

Consistent with the grounded theory approach, an initial purposeful sample of occupational therapists who identified to the College of Occupational Therapists of Ontario (COTO) in 2008 that they provide service to the pediatric population were isolated (Coyne, 1997). The COTO database is publicly available and allows the public to access the name, employer, address and phone number of registrants. By narrowing the sample parameters from the database to a specific age group, the strategy included clinicians working in the Ontario Association of Children’s Rehabilitation Services (OACRS) treatment centers. The OACRS centers provide service to a diverse population of children with physical, communication and developmental challenges and their families’ which includes children who are completely dependent for their care. Because occupational therapists working in these facilities have the most experience in making home modifications recommendations for this population of children, this group was sampled. Since the publically available database does not distinguish what area of practice the therapist services, the only means of eliminating therapists whose area of practice was incongruent with the performance of home assessments for accessibility (e.g. mental health or acute care) was by their employer on record in the database.

Of the approximately 4200 occupational therapists registered to practice in Ontario, 820 identified to COTO in 2008 that the primary age ranges they serve are children less than 17 years of age in Ontario. Occupational therapists who worked in acute care facilities (such as Hospital for Sick Children in Toronto or the Children’s Hospital of Eastern Ontario) or school boards were eliminated since those facilities are
not mandated by the province to provide home assessments. Unfortunately the sample could not be limited any further to avoid surveying OTs who do not have either knowledge of home assessments for children requiring extensive home modifications or who do not conduct home assessments for that population. Consequently the survey sample was larger than it needed to be for the purpose of this research. Had the COTO database provided a means of limiting the sample by area of practice, the survey sample would have been smaller.

A cross sectional survey is an efficient and inexpensive means of collecting data from a geographically diverse sample (Streiner & Norman, 1998). Letters were sent to 701 occupational therapists in the province of Ontario (Appendix A) to ask them to nominate educationally influential occupational therapists (EIOTs) in their field of practice with expertise in home modifications. A modified Hiss questionnaire (Hiss, Macdonald, & Davis, 1978), commonly used to ask health professionals to nominate EI peers (Wright, et al., 2006; Wright, Law, Last, Klar, Ryan, & Smith, 2006; Grzybowski, Lirenman, & White, 2000), was employed for the survey (Appendix B). It has previously been adapted for use with occupational therapists (Craik & Rappolt, 2006; Institute for Work & Health 2008). The respondents were asked to identify EIOTs who were known to them.

Data Collection and Management

The COTO database information was sorted by the ages of the therapists’ clients and a list of clinicians servicing children in Ontario was compiled from the college website. An introductory letter was sent explaining the study, the importance of the study, how the data would be safeguarded and used, and how much time the survey completion
was expected to take (Appendix A), along with a stamped self addressed envelope. The anonymous participant responses were stored as hard copies in a locked cabinet at the student researcher’s employer’s office in a restricted area. The names generated from the survey were sorted based on frequency of nomination. Those those nominees with the highest frequency of nomination were contacted in phase two.

**Phase 2: Recruitment of Educationally Influential Occupational Therapists**

The survey data identifying EIOTs were analyzed to select individuals for the in-depth interviews. These sampling criteria (all occupational therapists who service children in the province of Ontario nominating those they consider to be educationally influential in the area of home modifications) maximized the sample depth and diversity as well as contributed to the completeness of the data by collecting data from multiple sites (Begley, 1996). The sample sizes of qualitative studies using in-depth interviews can range between 8-30 participants (Creswell, 1998). Because the EI OTs, by definition, are considered as adhering to best available evidence and are good communicators, they are expected to provide comprehensive high quality answers, the targeted sample size was 10 EI OTs (Sandelowski, 1995; Lowe, Rappolt, Jaglal, & Macdonald, 2007). The EIOTs were invited by mail (based on the contact information provided by the COTO web site) to participate in an open ended interview designed to achieve a comprehensive description of how these occupational therapists assess the home environment of their pediatric clients and their families who require extensive home modifications (Appendix C). The nominated EIOTs were requested to contact the student researcher by phone or by email in order to arrange the interview at a time, location and method of their
choosing. The student researcher explained during the initial communication the process, answered questions and arranged the interview. When they expressed interest in participating in the study, the participants were sent a copy of the consent form which they returned at the time of the interview.

Stage 2: Interview Methodology

Phase 1: Interview Guide Procedure

Data were collected through face-to-face, confidential interviews. To ensure consistency in question content during the semi-structured interviews, an interview guide was employed (Appendix D). The interview guide was developed based on a comprehensive review of the relevant home assessment literature, the occupational therapy literature and ICF literature concerning the environment (Townsend & Polatajko, 2007; WHO, 2001) and the clinical experience of the student researcher. The questions in the interview guide were designed to probe assessment practices and theoretical frames of reference. They were structured to incorporate indirect and hypothetical questions which reframe and repeat particular topics in order to enhance credibility of the project (Milne & Oberle, 2005; Krefting, 1991). The questions explored clinical opinions and behaviors as well as the recounting of personal experiences, both positive and negative. In order to acquire rich data, questions were worded in a manner designed to elicit narrative responses as opposed to lists of factors (“Tell me about…” rather than “What are…”). Price (2002) suggests using a laddered approach to structuring the interview guide. This method introduces descriptive, action based questions at the beginning of the interview to collect contextual information and develop rapport with the participant. Only after a
degree of comfort is established did the researcher move on to knowledge and philosophical questions. It was anticipated that since the student researcher is a practicing clinician, initially discussing action based case studies with the interview participants would provide an opportunity to build rapport with the interviewee.

Chew-Graham May, and Perry (2002) explored the benefits and problems of professionals interviewing fellow professionals. They found that overall, the peer interview experience resulted in richer data than when a non-colleague conducted the interview because the interviewee permitted themselves to be vulnerable; this was attributed to the powerful set of common experiences and common professional identity. For the purposes of confirmability, this research is entirely focused on the clinical population of children who are completely dependent for their care. By limiting the focus of the questions to that specific physical clinical presentation, there was no ambiguity concerning the case studies presented in the questions.

To gather important demographic data, participants were asked at the end of their interviews, how long they had practiced in pediatrics, when they had graduated from their occupational therapy qualifying program, and occupational therapy degree they attained.

*Interview Pilot Test:*

The interview guide was field tested with four occupational therapists; three who had varying levels of experience practicing in home modification assessments with this population, and one academic occupational therapist who taught and researched in this field. The intentions of this field test was to verify that the questions were not directed toward a particular response concerning a particular clinical population, flowed naturally and were likely to provide rich and extensive answers. This was a convenience sample of
occupational therapists whose practice was with the client population and who were known by the student researcher. They were chosen based on:

1. Years of experience as a practicing clinician (1 was less than 5 years, 1 was less than 10 years and 1 was more than 15 years)
2. Inclusion of one academic OT.
3. Working with children who require extensive home modifications for more than 1 year
4. Had demonstrated a capacity for being comfortable providing constructive feedback

These therapists were personally approached and requested to participate in the field test. All those asked agreed to participate and an interview was arranged at their convenience.

Each interview was tape recorded and transcribed.

The student researcher analyzed the transcriptions for the following criteria:

- evidence of confusion by the participant
- lack of extensive responses
- type and depth of data elicited by the question
- evidence of lack of flow
- determine the length of the interview

After the pilot interview, the researcher debriefed with the participant concerning their perspectives on the interview. This debriefing led to changes in the interview guide. For example, the concept of family readiness was evident in the pilot interviews prompting the researcher to add readiness as a concept to be explored if the participant did not
specifically talk to readiness. The results were recorded in the field journal. The pilot interview transcripts were reviewed with the thesis supervisor.

**Phase 2: Interview Data Collection and Management**

Following the pilot testing and modification of the interview guide, the study sample was recruited as described above. The interview with the EIOTs occurred at the time and location of the participant’s choosing. Seven of the 10 interviews occurred at the participant’s place of employment. Two of the interviews occurred at the researcher’s place of employment and one of the interviews occurred at a law office where the participant had been consulting. No more than two interviews were conducted on the same day and two interviews in one day only occurred when the researcher travelled a significant distance and both participants were at the same location. The interviews lasted between 45 minutes and 90 minutes. In some cases the participant requested copies of the interview guide prior to the interview because they stated that they wanted to get a sense of the questions and to prepare for the interview. When it was requested, the interview questions were provided by email. Consent was obtained to audio-tape, use quotes for reporting purposes and transcription the interviews (Appendix F).

The interview explored the EI’s conceptualizations of best practice and their reports of their own practices in home modifications for children and their families by asking them to imagine they had to explain how they would perform a home assessment and why they did what they did to a student or novice occupational therapist. Since an educationally influential nominee is characterized as an individual who shares knowledge and provides a positive learning experience, this would be a typical experience for them.
All questions from the guide were asked and probes were used to clarify or expand responses.

The interviews were digitally recorded, downloaded to a professional transcriptionist’s web site after an identification code was assigned to the recording. The student researcher ensured that confidentiality was maintained by the transcription service (Appendix E). All identifying information such as names, cities, or facilities was removed during the transcription process. Once the transcripts were returned to the student researcher as MS word documents, the interviews were compared by the student researcher to the original recording to ensure the accuracy of the transcript. The MS Word documents were then used for data analysis.

*Member checking and within-methods triangulation*

At the conclusion of the interview, the participants were asked if they would be willing to be contacted again during data analysis in order to clarify data, obtain additional data to supplement the emerging categories and relationships between categories or to review the emerging model (Strauss & Corbin, 1998; Charmaz, 2006). Additionally, the EIOTs were requested to provide any institutional assessment forms or guidelines pertaining to home assessment and modification for “within-methods” triangulation (Begley, 1996; Charmaz, 2006).

*Data Analysis*

Once the interviews were transcribed, a grounded theory approach was utilized in data analysis. Data were reviewed and coded as soon as the transcript was ready using an iterative process of reading and summarizing transcripts. Initially the transcribed data were read multiple times and the student researcher wrote a summary of what the
participants said in the interview. This facilitated the organization of the data, immersion in the data and preliminary generation of categories and themes. Three interviews were coded independently by the student researcher and the thesis supervisor. The provisional codings were compared and a code book was developed through discussion and consensus building of the coding categories.

Coding Procedures

Using Charmaz’s constructivist grounded theory approach, results were coded line by line (Charmaz, 2006) followed by the development of the code notes (Strauss & Corbin, 1998). Charmaz advocates a flexible process for coding which begins with initial line by line coding followed by focused coding wherein the initial codes are analyzed and combined into categories. The process involves analyzing the initial codes at the level of properties and dimensions and “reassembling” data to form categories which explains the phenomenon relative to “fit and relevance”. Procedurally initial coding lays out the properties and dimensions of a category and focused coding sifts through the initial codes to examine relationships between categories and concepts. By examining a variety of conditions, the actions and interactions of the phenomenon and the consequences associated with the phenomenon are identified and compared.

Grounded theory employs a “constant comparative method” (Glasser & Strauss, 1967) which successively compares data with data, data to category, category with category, and category with concept to form the building blocks of the theory (Charmaz, 2006). This constant comparative method illuminates the data by looking at it from myriad perspectives and a constructivist approach is particularly good at examining these processes. During focused coding the codes were collapsed and combined into larger
categories. The categories were examined and defined. Links between categories were defined and similar categories were collapsed into larger categories. The transcripts were then re-coded using the focused codes and then processes were identified.

Theoretical Coding for Model Development

As the data were analyzed during the focused coding, some theoretical concepts began to emerge which concerned the specific information the EIOTs gathered and the processes they used to gather and synthesize the information to formulate their recommendations. Theoretical coding involved examining and integrating the focused codes into contextual information gathered by the EIOT and the processes employed to achieve a recommendation. Congruent with the theoretical coding stage described by Charmaz (2006), a model explicating the assessment content and process the EIOTs utilized to formulate their home modification recommendation was developed. During the process of model building the occupational therapy literature was reviewed as concepts were identified in order to test the theory at a conceptual and theoretical level.

Rigour and Trustworthiness

Methods of rigour were employed to enhance credibility, transferability, dependability and confirmability of the findings. Credibility is established by comprehensively identifying and describing the field of inquiry. Transferability was supported by purposive sampling of therapists to nominate the EIOTs. Efforts were made to ensure province-wide representation from a large number of Children’s Treatment Centres. Dependability and confirmability methods were incorporated into each stage of the research process. These processes included memo-writing, reflexivity and peer debriefing with the primary supervisor. Additionally, the coding of the initial data
occurred separately as a method of ensuring dependability. This strategy follows Guba’s (1981 as cited in Krefting, 1991) recommendation that the student and the supervisor deal separately with the data and compare results as the codes are determined. In this study, the student researcher and supervisor read each interview several times. Codes, categories and concepts were discussed so that there was triangulation in the coding and category building as well as conceptual development of the themes. The investigator triangulation process of independent data review by members of the committee ensures another point of rigor (Begley, 1996). The researcher spent significant time engaged in the iterative analysis procedure which was reviewed frequently by the primary supervisor.

Since reflexivity is an important criterion by which credibility is established, field notes were completed following each interview. Reflexivity is defined as the assessment of the influence of the researcher’s own background, perceptions and interests on the qualitative research process (Ruby, 1980 as cited in Krefting, 1991). Because the student researcher has extensive experience in home modification recommendations, a field journal was used for audit purposes, included: a schedule and logistics of the study, a methods log, personal reflections concerning the research process and memo writing concerning data analysis.

As data analysis proceeded and the constant comparative method was employed, the focus of the interview questions was revisited and refined based on the analysis of existing data (Glaser & Strauss, 1967). Memo writing and reflexivity was used to provide the researcher with a method to identify and organize data to be checked in the field (Charmaz, 2006). While the initial questions did not change, more specific questions evolved to focus on categories which were emerging or not sufficiently explored. Field
journaling provided the student researcher with an opportunity to reflect on the research process and, specifically concerning the interview process to eliminate questions which were confusing to the participants (Krefting, 1991). For example, the question about practice models was not contributing any information because the participants, particularly with the EIOTs who have practiced for more than 20 years, were not well versed in theoretical practice models and had difficulty answering the questions. As a result, this question group was eliminated. Additionally, the thesis supervisor reviewed the transcriptions. As the categories emerged and there was evidence from the data analysis that certain categories required additional exploration, changes to questions were prompted and implemented. Each of these strategies were recorded in an audit trail, which contributes to the confirmability of the process (Guba, 1981 as cited in Krefting, 1991).

Finally, since peer examination of the thematic findings is useful for determining credibility (Charmaz, 2006), the EI participants were requested to review the model for verification (Appendix I).

Ethical Considerations

The research proposal was submitted to the University of Toronto, Office of Research Ethics for approval which was obtained on November 5, 2008. No recommendations or amendments were advised or requested. Ethics approval was then sought from the researcher’s place of employment as per organizational policy; approval was granted December 2, 2008. The nomination survey was anonymous and the survey sample was drawn from a publically available database. All of the nominated participants were contacted by mail requesting their participation. The participants then contacted the
researcher by phone or email indicating a willingness to participate. The Informed Consent document (Appendix F) was emailed to the participant for their review. The consent form outlined the purpose of the study, the risks and benefits, discussed issues related to data retention and confidentiality, digital audio taping of the interview and the right to withdraw at any time and request that their data not be used in the study. No participant invoked this request. Participants were provided with the opportunity to ask questions and all questions were answered. Participants signed a consent form at the interview and were given a copy; the consent forms were collected at the interview.

**Confidentiality**

Interviews were digitally recorded, given a unique identifier and then transcribed by a professional transcriptionist. Only the researcher knew the names and employers of the participants. The digital electronic data was transferred to the transcriptionist’s secure website. The transcriptionist signed a confidentiality agreement concerning the data and agreed to delete the electronic files (both the digital recordings and the transcribed document) once the transcription was completed and sent to the student researcher. The transcriptionist removed all identifying data from the transcripts. All electronic data were stored in password protected files. Only the researcher and the primary supervisor had access to the transcribed data. Data will be securely retained study results are published. Data will then be destroyed by deleting electronic files and shredding hard copies.

**Risks and Benefits**

The only identified risk to participants was the time taken to participate in the interview. All participants were willing to actively participate in the interview. Participants were not financially compensated for their participation. Although the
researcher works within the same practice area, only one of the participants was known personally to the researcher prior to the interview. The researcher did not nor has ever held a position of power over any of the participants. While there were no direct benefits for participants, some may have benefitted from the opportunity to reflect on their practice. There is also potential to benefit from the results when the findings were sent to them for participant validation.

Summary of Methods

Using a qualitative methodology with a grounded theory design, this study examined how educationally influential occupational therapists assessed and made recommendations for home modifications for families with children who are completely dependent for their care. The data were analyzed using Charmaz’s constructivist grounded theory methods. Findings will be explicated in the next chapter.
CHAPTER 4: FINDINGS

Introduction

“The home is the centre and circumference, the start and the finish of most of our lives”

~ Charlotte Perkins Gilman

This chapter will summarize the findings of the research. The participants will be described with respect to their years of experience, education, geographical representation and employment characteristics. The initial coding of the data will be briefly described, followed by a summary of the categories and preliminary themes derived from their analysis. The thematic results will be described in detail.

Participant Characteristics

There were 95 replies from the 701 surveys sent out to occupational therapists who treat children in Ontario. Nine surveys were returned as undeliverable making the response rate 13.73%. This response rate was not unexpected since, as described earlier, there was no way of reducing the purposeful sample to eliminate those therapists who did not perform home modifications in their practice. A total of 142 individuals received nominations and 19 individuals received more than two nominations. Of these 19, eight EIOTs were selected because they had more than 3 nominations. (The range of the number of nominations received by these eight EIOT was 3-8 nominations). All eight pediatric occupational therapists nominated by their peers as experts in home modifications, good teachers, and willing to share information agreed to participate in the study. The final two participants were selected through a chaining technique (Creswell, 1998) because there was no EIOT representation from a specific CTC which has published some grey literature about home modifications necessitating a purposeful
selection of participants from that CTC to fill the gap. Further details concerning the lack of representation cannot be provided in order to prevent deductive disclosure.

The 10 occupational therapists who were nominated by their peers as educationally influential occupational therapists (EIOTs) ranged in clinical experience from one to 30 years, with seven having greater than 20 years experience in pediatrics. The sample was geographically diverse, within a three and a half hour drive outside the Greater Toronto Area. Six of the participants worked in both urban and rural areas. All were female, which not unexpected given the ratio of females to males in the profession. Eight were graduates of baccalaureate occupational therapy programs, and of these participants one had a post-graduate Masters degree. The other two EIOTs had clinical Masters degrees. The pediatric client mix of the participants was diverse in both age (ranging from 0-19 years) and diagnosis (including cerebral palsy, spina bifida, and neuromuscular disorders). All but one of the participants worked in an Ontario Association of Children’s Rehabilitation Services (OACRS) Children’s Treatment Centre (CTC) or had worked in one in the past. Five different CTCs were represented.

Funding for the CTCs represented in the sample came from a variety of sources including the Community Care Access Centres (CCACs). The four EIOTs who were contracted to local CCACs were restricted in the types and volume of services they could provide to clients because of the CCACs’ budgetary constraints. Two of the participants were private practitioners. Only one of the participants was previously known to the student researcher on a personal and professional level.

The interviews with the participants ranged from 50-90 minutes in length. All participants seemed eager to participate in the interviews. They were all provided with a
letter outlining the research topic area and two participants were asked by their manager to request a copy of the interview guide, which was provided. However when they arrived at the interview both reported that they had not had time to review the questions after all. One participant said that she had explicitly prepared for the interview by writing out some notes. The engaged behaviour and thoughtful responses of the other participants suggested that they had considered the topic and its importance prior to the interview. Each participant indicated that their motivation for participating was a desire to contribute to the knowledge of the profession. Most of the time they freely shared their knowledge and perspectives and their answers to specific questions were often lengthy and elaborate, using specific case examples. All of the participants expressed frustrations with the home modification recommendation process, and they provided similar descriptions of challenges and barriers to the process. Applications for funding of the home modifications were reportedly the area which created the most barriers and resulted in the most tension for the participants. The other area of tension the participants discussed related to not having access to the family decision maker which they felt prolonged the recommendation process.

Coding Results

The transcripts of the 10 interviews produced 179 pages of data. The initial line by line coding, done separately by the student researcher and the student’s primary research supervisor on a subsample of the interviews, yielded 203 codes (Appendix G). The student researcher and the primary supervisor then met to discuss the independent coding. The code book was collaboratively developed and the student researcher then coded each of the interviews using the code book.
Once each of the interviews was coded using the line-by-line method, each of the codes was considered in relation to the research questions and to other codes. At this point code redundancies were omitted or combined because of their similar meanings, resulting in 164 codes. For example, the initial codes of ‘proactive’ and ‘prompting’ both described the participants’ need to have a temporal perspective and begin the discussions about home modifications early in the child’s life. Both codes were consistent with the emerging category of “plant the seed”, the proactive code and prompting code were subsumed into one category of “plant the seed”.

All 164 codes were similarly examined and categorized according to common processes, factors or participant perspectives (Charmaz, 2006). The categories were then grouped with respect to the research questions: the information being gathered by the participants and the processes the participants used to gather, evaluate and prioritize these data as recommendations. The group of the 164 codes resulted in 20 categories including: parent’s interests/conflicts, funding issues, therapist’s tools, parent readiness, physical and functional assessment, environment, future forecasting, client centred care vs. family centred care, selling/persuading, plant the seed, listening, the assessment process, accountability, other stakeholders and peer support. The full list of categories is found in Appendix H.

Attention was paid to alternate perspectives and negative cases. Barriers to the recommendation process were identified. The EIOTs’ actions and the data the EIOTs gathered were examined. The information that the EIOTs used to inform their decision making was examined, and the characteristics of the decision making process were examined in order to refine the concepts into themes. For instance, because the concept of
temporality was represented in many categories, the temporality of processes were examined relative to one another; that is, gathering information about the level of functioning of the child preceded learning about the care processes for the child. Getting to know the family idiosyncrasies was gleaned throughout the process.

This focused coding illuminated the specific dimensions of the categories, for example:

- EIOT assessment having an overt component (i.e. specific questions being asking to gain information) as well as a less explicit component (i.e. they were looking for certain information, not directly asking for that information).
- Environmental barriers and facilitators to the process
- EIOT needing to forecast the future
- Strategies employed by the EIOT to facilitate the information gathering.

Finally, the categories were then examined for possible relationships (Charmaz, 2006). As the themes emerged, how categories inter-related were discussed and refined with the primary supervisor. For example, while time was a pervasive concept because it intersected categories, it did not emerge as a discreet theme but rather as a dimension of many categories. Each of these themes was linked by the type of information it contributed to the recommendation process or the processes used by the EIOT to facilitate or guide the process. This results of these analyses were distilled to five themes:

1. Back of my mind: OTs agenda and tool box
2. An informal walk through their day
3. Get to know the dynamic of the family
4. Future forecasting
5. Funding means everything

1. Back of my mind: the OTs’ agenda and tool box

The participants spoke about a set of values and goals with which they approached each assessment and their formulation of recommendations. These included having a temporal perspective, consideration of the funding context, having a family and client centred approach, priority access issues, acknowledging that it was a ‘privilege’ to be in the family’s home, having a “tool box” of skills and strategies, and personal accountability. Each of these goals and values are described below.

*Future oriented:* All but one of these clinicians knew the families very well and since the CTC service model includes children from 0-19 years of age, they usually had very long relationships with the clients and families. The individual who worked for a vendor was able to boast a long term relationship with the families since the children had myriad equipment requirements from the time they were quite small. From the perspective of this long term relationship the participants approached each client situation with the intention of thinking about the future and not being short sighted in the decision making: “I try to look at not what they need now but what they need in the future. I try to look quite long term.” (P3) Even the participant whose client population was not CTC based felt that this was an important part of the OTs role: “We have and important role to educate the family starting really early on as to what might be suitable” (P6). Participant 8 commented: “That’s what we need to do from a very young age is to help the family plan ahead of what their future needs to be”.

*Available funding:* The concept of time pervaded the narrative of all of the participants, particularly concerning funding of home modifications. Part of what was
informing this perspective was the awareness that sources and amounts of funding were limited, as was the scope of coverage of particular funding sources. Certain funding sources limited the ages of eligible individuals and how frequently funding could be accessed. The participants all spoke of getting the most for the money that was available to the clients and families within the time frames of eligibility.

“A lot of our intervention is really geared a bit by the funding”. (P2)

“They need far more than they can get … What should we pay for using what money so that we can get the max amount of money” (P4)

Client / family-centred: The EIOTs spoke about being both client and family centered in their approach. They wanted to advocate for the child and their needs and inclusion, while simultaneously considering the effect that any home modification had on the entire family. Consideration was always given to the entire family in terms of the modification not creating barriers for other family members living in the home. They all spoke of needing to gather information about who used the space and “what type of family activities they do” (P5). Strikingly, ensuring congruency between the professional standard of client centred practice and the espoused philosophy of the children’s treatment centres, family centred care was the single area which caused the most conflict for the EIOTs.

“I have a big problem with [when] I see that that child is being held back because I don’t agree with that… It’s their culture so I have to learn to accept it. To allow somebody not to be a part of society … I can think of two [families] right now, that still maintain [the child] just on the floor on a mattress, no real stimulation, no getting them up and down the stairs, not being a part of that family… That to me is a big challenge, and that’s a personal challenge, cause I
can’t accept that…So as much as we go in and try to convince them to make that child a part of their home, and in the different environments where the family is, it’s not really going to happen right away”.(P5)

“If it’s a cultural issue and their opinion is not consistent with my professional opinion and its their cultural value then I have to respect it, and tell them from my professional opinion why it might not be in their best advantage but they have to follow their cultural values”.(P7)

“For home modifications where it’s about ease of care for the parents, I figure it’s their issue”. (P4)

“I mean [they] bought the house cause it has a pool. But it doesn’t have a main floor bathroom. [They] have a physically disabled child who will probably never walk, and the bedroom and the only bathroom is upstairs. But [they’ve] got that incredible pool, that [they] only use four months out of the year. Bathroom… we need…”. (P8)

“We have to try and advocate for the child’s needs … how we see the child’s needs is sometimes a little different from how the family see it”.(P3)

Privilege to be in their home: The concept of being in the family’s home as a privilege was stressed by each participant. They spoke about being conscious of being in the client’s homes and the import of being a “guest”; “We are in their space, in their
“territory and we need to respect that” (P6). There was a sense that not only was it a “privilege to be in their house” (P7), but also that to be effective the therapist had to be able to get into the child’s home:

“First of all this is their house and I think we have to be very aware of that…it’s their house and you can’t force your way into the door”. (P3)

Access is the priority: All participants were asked about the most important issues to be addressed in situations where the child is completely dependent for all care. All participants answered access to the house and access to the washroom as the top two issues. Access to the bedroom and ease of circulation (which includes layout, level changes and flooring) throughout the home were also considered extremely important. They spoke about these four issues being the priorities but when asked to choose the top priority, the EIOTs picked access to the house and the washroom as most critical to address. If the EIOT was asked by a family to give information about what to look for when selecting a new home, the EIOT would suggest that circulation is the most important thing to look for since access to the home is more easily addressed than increasing the size or layout of the space. Participant 4 commented about the reasoning which occurs when families are looking to move to a more accessible home:

“What I usually say to families is ‘You know what? The steps to the house are the least important problem or the easiest to change’…There’s usually a way of getting into the house and if it expands the number of places that they can choose from, than that’s great…I want a room on the main floor that can be turned into a bedroom, and a space, if there isn’t a full bathroom on the main floor, space where you can expand an existing main
floor bathroom to include a wheel in shower. So to me those are the biggest... my two biggest things is some room that you [are] willing to give up for a bedroom, and [space] that you can give up for a full bathroom, beyond anything else...I mean you can widen a kitchen door ...

It is not hard to put ramping in to get up to the front door, or buy a porch lift”.

The therapists’ tool box: The participants each identified the “tools” they used in their assessment process. Besides the obvious need of a measuring tape, the EIOTs would bring visual media such as pictures (hard copies or in electronic form), they would use trial equipment like adult sized wheel chairs to help families visually understand the impact that larger equipment would have on the space in the house. Another visual-spatial tool the therapists would use, particularly when contemplating lift devices, is to use cardboard or masking tape to demonstrate the space requirements and impact of the lift device in the proposed location. While the EIOTs were careful to not comment outside of their scope of practice and talk about construction, they did, as part of their tool box, have knowledge of building code that was relevant to the home accessibility issues they typically addressed. While none of the EIOTs specifically noted communication as an important tool, their interviews were replete with references to communication both in terms of gaining and giving information as well as encouraging families to voice their concerns, ideas, and thoughts in order for the EIOT to fully understand their perspective and get to know the family well. Their final tool was the use of other families’ experiences to provide ideas regarding practical ways in which similar barriers to accessing their home or caring for their child could be overcome.
Concerning *personal accountability*, the participants all spoke of professional accountability, and the need for the therapist to be clear about their personal scope of practice, particularly when the family were clearly ignoring their recommendations and making decisions which were short term in nature or compromised safety. They spoke of being diligent in documentation. When asked for a letter of support for funding they would construct the recommendation in such a way as to be clear that they were not endorsing the family’s request and that other options had been recommended.

“*My way of dealing with it was to write a letter outlining indicating I had a concern about it as a plan. But if it was to go through, that he was absolutely not to have a wheelchair upstairs. That he was absolutely to be trained on the use of this thing and what all the safety features had to be. And that I was very concerned about the safety of it*.” (P3)

“If it’s a safety issue I’m very clear that, if they want to be doing something in a situation which is not safe, then I will be stating that it’s not safe to be doing that and I won’t veer from my recommendation ... and I document it”. (P7)

The participating therapists reported going to great lengths to dissuade families from making short sighted plans or unsafe plans. Participant 3 shared a case which illustrated the process she went through to avoid a plan which was she felt was unsafe, although the child’s family insisted it was the only course of action they would consider:

“I really had some safety concerns, I probably had two or three different visits, I talked to the family counselor here [at the CTC] about my
concerns, so that when he was with me on the visits, he could sort of echo the safety issues and we could make sure we’re both on the same page …

In terms of myself, I was concerned about College Standards, and protecting myself, too, … I was protecting the team as well as myself, but I made sure that I documented what I told people and again wrote a summary letter, visited after they got it installed to see and use it… reiterated again that this had to be highly supervised and not to have any wheeled stuff at the top [of the stairs] because I just felt I was really concerned that he could be distracted and come right down the stairs… that all of that stuff had to be highly supervised. That’s probably the one that gave me the most angst”.

Participant 9 recounted a similar example in which she had recommended a course of action which the family was not in favor of and had instead, insisted on pursuing a much less accessible option:

“I had a lot of discussions… finally, literally after two years, I was then very sure that he was not going to move, we had spent a lot of time and I said ‘Okay we’ll put [a stair glide] in’ and so we prescribed it. I put a stair glide in. It’s going to be better than him carrying him upstairs… Does it solve all the problems, … no, but its safer than nothing and I get the funding for it. And meanwhile we do his bathroom and we give him a porch-lift into the house, and they put the stair-glide in, he’s like no, no… I don’t have any space to, to get around stairs… and he told them to take it [the stair glide] out”.

67
2. An informal walk through their day

The participants all spoke of needing to understand the job of caring for the child. They discussed how they would gather information about what care occurred for that child, when during the day the care occurred, where the care occurs, who performed the care, how specifically the care was performed and finally why the care was performed in a particular manner.

“Getting to know kind of what they do in their life…what goes on in the house, how they care for their child… how they go about their day with their child”. (P4)

The participants’ job analysis of caregiving was important because it gave the therapist insight into how best to address the barriers to caring for the child in a sensitive way. Moreover, this analysis gave the therapist insight into use of space, how the physical environment is used, who else used the space. Often alternate uses of the space became obvious to the participants:

“What are the barriers in the physical environment and can anything be moved, reorganized, in terms of even just simple furniture needing to be moved out of the way to make it a more open and accessible floor plan. As well, you’re looking at other things in the environment, basic safety concerns”. (P9)

During their analyses of the child’s care the EIOTs were also doing an analysis of the caregivers. They noted that during the course of doing their “home assessments” they carefully observed the caregivers performing aspects of the care they were analyzing.
“[It is] best to have them actually perform in the space that we are considering needs to be changed”. (P6)

“Through the course of visits, you often see them do the transfers so you are observing without asking them to show [you]... you have to be observant all of the time”. (P5)

They analyzed the caregiving role from a functional perspective to ascertain how the caregiver functioned in the role in order to make the job of caregiving less burdensome and if possible, more efficient. As Participant 7 noted, part of their education to families was the concept that the options being presented improved the safety of the caregiver and the child but did not necessarily make care more efficient: “none of these transfers and all of this equipment is not going to be making this quick. It’s never going to be quicker, it’s always going to be longer, [but] it’s going to be safer”.

The concept of safety was fundamental to each aspect of the EIOTs’ assessment process. Each EIOT spoke about both client and caregiver safety as being of primary importance in the assessment process, and seminal to the occupational therapists’ role in home modifications. Participant 1 commented that “It’s my responsibility, I feel, to judge, assess what this person can do safely”. Participant 9 echoed this sentiment: “It’s just safety, everybody’s”. Their primary concern was the safety of the child and their secondary concern was the safety of the caregiver. Each decision was predicated on the concept of ensuring safety and this was the one thing on which the EIOTs would not compromise:
“If it’s a safety issue I’m very clear that, if they want to be doing something in a situation which is not safe, then I will be stating that it’s not safe to be doing that” (P7).

Even if the family ultimately preferred an option which was not the safest option, the EIOTs would not endorse the option by writing a letter of support. If the family required a letter for funding purposes, the EIOTs were careful to write the letter in a manner which carefully laid out the options considered and specifically stated the requirements of the child but did not sanction any one particular option. Concurrent with safety was the concept of ease of care. Care of the child needed to be accomplished in a safe manner while reducing the physical burden of care.

3. Getting to know the dynamics of the family

While participants’ gathered information about the job of caring for each unique child and the physical barriers being encountered, they also gathered information about the family’s needs, goals, priorities and expectations. They asked questions in order to elicit information about what the family has already tried and what they think will work.

“I always ask the parents what they think would work because so often they’ve mulled it over in their mind as they are functioning in that space...that may lead to a solution, it may help you get a sense of what they are trying to get out of this” (P6)

Another fertile area from which participants gleaned important information pertained to what equipment had been abandoned.
“You want to pull out all the equipment that they are using and also the equipment that has been prescribed that they are not using because that tells you for whatever reason, why past solutions haven’t worked and you learn from that”. (P6)

Financial information is very important to understand because in most situations families cannot afford the expensive home modifications to minimize physical barriers in the home. Whether the family is eligible for funding or whether they have to finance the modifications entirely on their own, there is almost always a need to prioritize. Participants reported needing to understand the family’s needs and expectations relative to financial restrictions in order to make the recommendations:

“I do a physical / environmental assessment and prioritize what their issues are.”(P7)

“I’ll just go out myself on the first time and get an idea of what specifically the family has in mind. [I] want to identify [the] needs, what our funding sources are for this, their time frame, their issues, and then [their] priority. Because we can’t do it all at once, ‘Where do you want to go from there?’…We have a grand scheme of things, of when we can get [the] financial assistance to actualize those dreams…then we have to prioritize”.(P8)

The participants commented at length about understanding who the decision maker is in the family and whether the home is owned by the family and/or whether they are in a rental situation. The participants expressed frustration when the decision-makers were not
involved in the care of the child. As suggested by Participant 7, these decision makers were rarely present during the participants’ visits, which they reported, complicated communications and extended timelines to decision.

“The person that needs to make the decisions is not the person that I’m with, or is never there and then its like ‘Well, I’ll get back to you once I talk to my spouse’ and then the spouse doesn’t see things the same [way]. But [the decision maker] isn’t necessarily doing the caregiving.” (P7)

“Sometimes you’re balancing. The caregiver’s spouse has an agenda sometimes that’s different from the non-caregiving spouse …More likely than not, there’s one that does 80% of the work and one that does 20%.” (P3)

Almost exclusively participants reported that the caregiver was the mother and in a large number of cases the financial decision maker was the father who participated little in the care of the child. Because the decision maker was not the caregiver and had limited direct knowledge of the care burden, the EIOTs reported often working in a vacuum of information concerning the financial resources and limitations relative to home modifications, creating many difficulties in making their recommendations.

“One parent, it’s usually the mother, is the person who’s really seeing most of the caretaking jobs related to the whole family. There could be three other little kids who need physical help too and the father doesn’t really understand the needs. So it’s very often the parents aren’t both on
the same page in terms of what needs to happen, because, if a person’s been out at work all day, and [they don’t] see how hard it’s been.” (P1)

Closely associated with understanding how decisions are made within each unique family system was the need to understand each family’s “idiosyncrasies”. Each participant spoke of needing to thoroughly understand each distinct family.

“You know no two families are the same, and their needs are going to be very different.” (P4)

“…[knowing] the idiosyncrasies of this family’s ways of coping and strengths and weaknesses will help you make good decisions.” (P6)

“I cannot say enough about knowing exactly how they live in that space, and everybody, and how they use it, and how they store things, and where do they keep their toothbrush, and where do they keep their clothes and, do they hang stuff, or do they put it in drawers, and how do they get dressed.” (P5)

The EIOTs reported that culture is an important part of understanding the distinctiveness of the family, because culture often informs the value systems and lifestyle preferences of the family.

“I think a one big thing certainly is culture differences, and not being totally aware of it up front…not really understanding … what they’re willing to do, in different cultures and how they deal with these. With the kids, some of them don’t want to do all of these things that we want to …
we tend to be pushing them towards [cultural norms] here in North America… That’s not seemingly their goal… have to be aware that there’s so many different cultures and beliefs and what their, the goals can be so different.” (P5)

Participants reported that sensitive and functional modifications cannot be accomplished without this understanding. Families will not commit or invest in a modification plan which does not “fit in with the family lifestyle… they are probably not going to go for it.” (P3) Moreover, the value system of the family governs the status of the woman and the child and the expectations and beliefs of the family. Therapists commented that understanding these nuanced roles is vital to the recommendation process.

A further barrier to making recommendation is home ownership. Many technologies which alleviate physical barriers require structural modification to the house and for obvious reasons cannot be done to a rental house without permission of the owner. Participants reported that most landlords do not allow permanent changes to their units and so solutions are immediately limited to those which are not permanent in nature. In some cases EIOTs have had situations where the home is owned by a family member outside of the nuclear family, which complicates funding since funding agencies require permission of the home owner to modify a home. Even if funding is not a consideration, the owner of the home still has to agree to any modification.

The EIOTs spent much time discussing the concept of “readiness”. Readiness is a term that is applied in phases. The first phase of readiness is that the family identifies and discusses future needs and care issues and the permanency of the disability:
“I think parents have a difficult time imagining their… young, light child as an adolescent or an adult and seeing what their abilities may be at that stage. I think a lot of parents can’t imagine their little kids being out on their own … but it’s even more so with parents of children with disabilities … I think the parents, for a long time, are bargaining in that they think, that surgeries and botox and [other] treatments, are going to make a significant difference, and perhaps they won’t need then, the lift, or the equipment because the child will be able to manage without it.”(P6)

“It is so hard for families to hear [the functional future predictions] and understand it and accept it.”(P8)

The second phase that EIOTs identify is the point of readiness to actually move ahead with a modification. Some of the participants hypothesized about how and when this stage is reached:

“Finally it clicks and usually I find that if you’ve got the right mix for them and for the equipment and for the child, you get a click and they go, ‘Okay, that makes sense!’…A combination of things that … they’re physically feeling like they can’t continue the way that they are. It gets to a point where, okay, now they got to do it and they needed to do it yesterday. They’re ready at that point. They’re ready to make the sacrifices within the home, to change it up, and they’re willing to free up the space for the equipment… they’ve had time… to really think it through.” (P5)
“And you know it is hard to for them to think about what they might need in the future in a scenario like this [very dependent child]. [It’s] probably by age eight [that] they’ve sort of seen there hasn’t been a lot, a whole lot of change and progress.” (P2)

In any case, the participants were alert to the attainment of both of these points of readiness and the process moves forward in terms of disseminating information or moving ahead with financing and construction. All participants recognized that the process could only move forward when the family was ready for the process to move forward, “if it doesn’t quite click, it’s not going to happen, and they’re not going to really help to expedite it to happen”. (P5) Participant 7 noted: “my method is really client centre. It’s what they’re ready for doing and when they’re ready to do it. As soon as they’re ready, then I run with it, and I’ll do everything I can to make it happen, once they’re ready”.

Part of getting to know the family is also getting to know the support systems that are in place to sustain the family. These systems could be human or institutional in nature. The EIOTs reported that the various support system resources need to be part of the occupational therapists’ considerations, since the rules and regulations of these systems can impact the home modification recommendations. For example, personal support workers (PSWs) have workplace health and safety rules mandating maximum weights for lifting without a second person or a mechanical lift. Hence, if a child is in receipt of PSW services, the OT must factor workplace safety regulations into any recommendations made for that environment:
“When they need to get support from the [Community Care] Access Centre personal support worker, the first thing is there needs to be the appropriate equipment in place…You’re going to have [one] personal support worker. They’re, they’re not going to send out two to do a two person lift.” (P2)

“…the limits are 40 lbs …for the PSWs and any of the support coming into the homes.” (P5)

Furthermore each of the human resources who provide care to the child has unique needs in terms of their ability to fulfill the role of caregiver. Regarding what the OT looks for, Participant 8 summed it up:

“I look at their age as being a factor, gender as being a factor … those physical characteristics. Then I think of the demands that they have, not just the physical demands on them, in caring for this individual but for…other individuals in that house… then there’s the emotional stress that they have and the workload and worry that they have about the finances and caring for everybody … Whether they work [outside the home or not]. I think that’s really important what support the caregivers have -- other family members.”

The EIOTs evaluated and considered the physical and emotional aspects of the caregiver’s role as an important part of their recommendation concerning modifications. In the case of the PSWs the OT may only consider the safety, and physical job demands whereas with familial caregivers the OT will consider the role more broadly relative to
safety as well as the emotional aspects of the job demands and how not meeting those demands will affect the child.

“That’s a huge thing, ’cause I think you know that goes back to not just looking at the physical environment and barriers, but also looking socially…” What are the supports? Are they appropriate, are they working, what’s good, what’s not? What are the other options and what options [are] available in this catchment area?…” [Be]cause I find that every catchment area of [every] CCAC is different… I don’t want a caregiver to throw out their back and then … have chronic pain, and then they’re not able to care for their child because that impacts the child as well …Caregivers are under stress and they need outside support and that’s kind of driving my situation or my decision to getting equipment.” (P10)

4. Future forecasting: “Planting the seed”

The area that each participant spent the most amount of time discussing was the role of the OT in educating the family about the future care requirements of their child. A number of the EIOTs spoke of “plant[ing] the seed” early at two or three years of age and being “proactive rather than reactive”. Participant 3 spoke at length about the importance of not delaying discussions about the home modification required for the future safe care of the child:

“We have to make a much more concerted effort to get the message across to these families when the kids are younger, that they need to be proactive rather than reactive… I try to look at not what they need now but what
they need in the future. I try to look quite long term...I think that happens where you do plant the seeds and sometimes people will take you up on that in a reasonable length of time. I do find that other times it’s sort of ... they say, “Oh I do remember you talking about that when he was ten, or six, or eight. And now we’re 17 and we realized we should have done this five years ago”. ” (P3)

This was echoed by Participant 2:

“So the family already knows when that kid’s going to get bigger and harder to handle, and one of the things that we often hear from families is, “Well no we’re managing fine you know ... Well it’s okay right now.” Well it’s okay right now. And I try to start very early on, like even from two years old or whatever ... saying it’s alright that they’re 25 pounds but something only needs to happen to the caregiver and they can’t do it...So I really try to emphasize that with parents that in an instant, their back, their shoulder, their anything could make it not possible”.

Participant 5, who currently works as an equipment vendor, spoke about the consequences of waiting too long:

“How big are they now? How heavy are they now? ... If they're too big, then you can’t wait. It’s at a point where they’ve got to do everything and they need to do it quick”.

The introduction of future care issues was seminal to the process of making home modification recommendations, as the EIOTs felt that it was essential that parents were stimulated to start thinking and planning sooner than later.
“We’d like to get the kids in as early as possible, to get them to plan out what we need…parents of our younger kids who don’t necessarily see themselves ten years from now, carrying a heavier, longer child, with high tone, or floppy…and more dead weight…As much as we can we try to get in as early a we can… thinking ahead and mentioning things …Our preschoolers, our babies, that’s where the groundwork needs to be laid for the families, and not just acceptance of the diagnosis but the kinds of equipments that they’re going to need. And that we really need to capitalize on [the] funding sources…It’s planning, and you’ve really got to make the family aware of the planning that is involved and give them… the tools…The whole thing is starting young and just gradually starting to tell them things to get them ready for what we see as a possible future for this child and how involved the equipment needs [will be]… I think the big thing for us, especially, is getting the finances all together, to make it happen for them being able to plan ahead. Really, I see that’s what we need to do from a very young age is, help the family plan ahead for what their future needs can be.” (P8)

Forecasting the future in a manner that was relevant and personal to the family was an important part of the EIOT’s role. Participant 6 reflected: “We have…an important role to educate the family starting really early on as to what might be suitable…[what] we’re working toward. We need to be considering the future right from the first minute, because this child is going to change over time, and get heavier and older. So we really have to think of the child along that dynamic continuum …This whole future piece, and how large you think the child will be when they grow and when they’re full grown
How their physical impairments may look as they grow ... And if there’s any procedures, or surgeries or ... treatments planned, how that may change their function?

How the EIOT engaged a family in this process was often to use stories of clients which resembled the unique situation of the particular family:

“The issue of home renovations, equipment, is [one] that I like to keep talking about and I, because I’m older and I’m obviously older, I have the advantage that I can say ‘a long time ago I did work with a family like you and these are some of the things and that they found helpful, in the end’...
I try to do that as gently as possible, and again I try to use stories of a family that [had similar challenges].” (P1)

“One approach I do an awful lot is I don’t talk in terms of this is what I recommend, but I talk [about] other clients I’ve worked with ...
‘They do it this way ... and it’s worked really well for them.’” (P6)

Participants admitted that in some cases the precise client they are using as an example does not really exist. Their fictitious illustrations were sometimes composites of many clients cobbled together to reflect the unique situation and environment of the client at hand. Another strategy EIOTs used to assist parents in seeing the future needs of their child and envisioning how home modifications will impact on their lives was to have them speak with other families.

“I might link them up with another family ... of a similar situation to [get them to discuss] what worked for them and why”. (P7)
“[Connect them with another family] dealing with the same issues as [they] are, [to] talk to them, or visit their house and see how they managed. [Be]cause I think parents … love having contact with other families, to see what they’ve done, and I encourage that.” (P1)

Both of these techniques were used by the EIOTs to assist families in conceptualizing the future. They argued that others’ experiences are more relevant and personal when families see themselves reflected in that experience.

As part of the process of forecasting the future, the EIOTs presented options to address the barriers to caregiving, the nuanced lifestyle choices of the family and the caregiver job analysis that was filtered through the OT’s agenda of ease of care. Only options which the EIOTs believed would best meet the needs of the family were presented, with the intention of eliciting feedback from the family concerning their “readiness” and their perception of how the proposed option “fits” with the family’s needs. When families reacts and express their opinions about the options provided by the EIOTs, the dialogue provides the EIOT with further insights into the family’s preferences, in addition to giving the EIOT opportunities to educate the family about risks and benefits of various options.

“We’d go through all those options … I would tell them these are the drawbacks of a ramp, these are the drawbacks of a vertical platform lift. I’d go through those options … If some families know right away ‘I want a ramp’ or ‘I want a vertical platform lift’, and I have gone through the pros and cons, but they’re like ‘No I don’t [want] that, I want this’… I won’t
even ... continue to pursue the opposite if they know that they want that.”

(P7)

“[I] present it as: ‘I’m going to give you a bunch of options. You [will] automatically like some of them, You [will] automatically not like some of them and already know that’s not where you want to go. I will state them - give me your immediate impression ...We have to brainstorm outside the box. These are all the options. Then we can narrow it down according to your direction.’ ”(P8)

This process which one of the participants described as “negotiating sort of fluid a process” assists the occupational therapist in finding a solution which is reasonable and acceptable to both the agenda of the OT and the lifestyle of the family. Participant 6 remarked that it was important to her that recommended equipment be used and that it would make a difference. She observed that the OT’s role was to direct the process by critically analyzing the needs, helping the family know what is possible, and introducing products and solutions are suitable to address their identified issues.

“Our contribution has to be the sum of our knowledge, our experience and our analysis of what will work here.” (P6)

She further pointed out that this may only be achieved “in a circuitous way”. Each of the participants spoke about guiding families in this process and ensuring that the proper planning occurs. They all spoke of presenting the advantages and disadvantages of all of the proposed solutions in order to inspire different ways of thinking about the issues and
avoiding the “*Mad magazine version of what can go wrong if you don’t think [it] through properly.*” (P1).

“I can give my suggestions as to other things that they may not have considered, like ‘I think you need to do that’ because we have that ability to see the whole picture while keeping in mind all the little details.” (P8)

5. Funding means everything

The final theme which emerged from the thematic coding was concerning funding. This particular theme pervaded the clinical decision making and influenced the final decisions made by the family. Participant 2 commented: “*A lot of our intervention is really geared a bit by the funding.*” Prevalent in the participant’s narratives was their frustrations with a variety of funding barriers. These barriers ranged from insufficient funding for OTs to do a complete assessment over many visits, to strict eligibility criteria for agencies providing funding to families to complete home modifications. Many of the participants expressed relief that they worked in a model of service which did not limit their visit frequency or volume: “*I’m very fortunate because I’m not limited in the amount of time that I take with clients when we’re investigating what’s necessary ...looking at everything you might need to support that, home renovation, the equipment that you’ll need to use and looking at it as a whole package.*” (P1) Participant 1 also had the unique perspective of working in both pediatric and adult services; she commented on the limits of the Community Care Access Centre’s (CCAC) current fee for service model of care:
“[Therapists] who work for CCACs and have limited visits with families …being limited to just sort of running in and having a glance at something and making quick recommendation, is doing more harm than good …The time [spent on home modifications] is a serious, serious issue.” (P1)

Participant 7 expanded on the frustrations therapists working in the community are facing concerning how community services are funded by government and the lengths OTs must go to in order to ensure that the recommendation process is completed:

“We work with our [CCAC] case managers pretty [well] …If it’s a reason that I need to go back out and we’ve asked for visits, we’ll usually get granted those visits. If we don’t, then unfortunately we’d have to roll them over to Ministry of Health and I’d see [the family] through Ministry of Health. Sometimes it’s a very grey line when I’m seeing somebody through Ministry of Health or through a CCAC funded situation …then there’s just the barrier of time, right? A lot of things are time sensitive for when you get funding …where you’ve got partial funding from some place and you don’t have it from anywhere else, and you have to apply or extend your funding …It’s usually all funding related.” (P7)

Participant 4 echoed the concerns about the amount of time it takes to go through the process, in part because of the barriers created by the home modification funders: “I spend a lot of my time in terms of helping people through funding process.” The process is so resource intensive that EIOTs are making multiple visits over many years. This does not work in the fee for service CCAC model which is time limited. Participant 4 also confided how she addressed the issue of needing to do multiple home visits:
“We, for instance, shouldn’t be doing home visits unless it’s about a home modification issue, about self-care, et cetera, however, I will, because so many of my families don’t drive, or they don’t have a car...[There are] barriers within our system... The really good example is the home visit one, and I totally, totally ignore it. And I probably ignore it more than anybody else does but I feel very strongly that I can get across some [of the] barriers of delivering [service by delivering it] at home... I keep on doing home visits with the family as long as there are issues.”

Participant 1 summed up the shortcomings of both systems issues with the following example:

“[The] CCAC case manager said I must take my therapist off this case because we have other kids on our waiting list and she’s [the OT] been doing this for a year...[The home modification funder] said] We’re sorry, we have changed the process.”...[So the OT had] to [be put back in to the home] just to reinstate the same application...the whole process changed.

So I spent a few months getting everything in order, checking that the items that they had requested on the first application were the same ones, going back to all the vendors to make sure that the quotes hadn’t changed, because usually the quotes are limited in time ...I had to get all the paper work done again, like the family’s T4s, the letters of recommendation, the pictures of the house, even though it hadn’t changed, I had to get it all current again, so that took a long time.” (P1)
Besides the concerns related to the systems obstacles, the participants each commented on intervention being driven to a certain extent by the available home modification funding options:

“Unfortunately quite often, it’s driven by what the funding source pays for. And that’s too bad because it may not always be what the family’s priority is, or what the therapist thinks is needed.” (P6)

“The larger system barriers would probably be the funding issue…[the] group of families that kind of fall through the cracks, and they’re the families who are not, ‘poor enough’ to get social assistance …They’ve had to sit there and wait, until the child is 18 so that they were finally financially independent of their parents, so that they could get home modifications, when it should have happened sooner.” (P4)

“We have to look at [finances as] being a big thing. And, if they’re limited … this can be one project that we could deal all in one. Or is it one that you have to piecemeal … Finances are going to be a big factor…We have windows of opportunity to apply for funding, and we want to utilize that … Some other families have decided to wait until their child [turns 18 years of age]… because they don’t financially qualify for March of Dimes. They [the parents] both work, their income is above [the eligibility limits]… they wait [until] their child’s 18, and they make that conscious decision…I have to watch what my colleagues are doing too … if they’re getting him
"a brand new wheelchair and applying to Easter Seals, I’m losing my opportunity to get equipment.” (P8)

All participants expressed dissatisfaction with recommendations being informed by funding. When presenting options to the families “funding is usually the thing that is at the top of my mind, when we’re talking about renovations and equipment.” (P7)

Participant 8 reiterated the importance of funding considerations: “When they seem to be thinking, ‘Well, we’ll cross that bridge when we come to it’ I feel like I have to tell them ‘The bridge may not be there when you’re ready to cross it’...Then, I guess you have to have the conversation about ‘Well, if you use it all for [this particular purpose], then you got nothing left for the house.’” The EIOTs reported not only giving the advantages and disadvantages of a particular solution, they also ensured that the families had all relevant financial information they needed to make decisions:

“They wouldn’t have an idea of ... how to go about and where to get some of this extra money, and so that’s ... an important job to help guide them so that they don’t miss their windows of opportunity.... Then we have to prioritize - ‘Okay, we’re going to apply for this first and then make sure we’re going to apply for this, so then we’ll do that.’”(P8)

“Sometimes you can do little bits at a time ... some families have friends, family, that can do some of that work, so brainstorming on who they know, and utilizing their own contacts ... to do wall cuts, widen doors themselves ... you know, what can be done by whom. Spread it out a bit. Change the
tub to a shower.…I’ve gone through the same home, four, five, six times, each time coming up with a slightly different scenario.” (P5)

Participant 3 took pains to caution that the therapist had to set aside the financial considerations and determine the best options for each unique family circumstance:

“After that initial visit it’s like, ‘Okay, we’ve just come to sort of talk in generalities about what some of the possibilities are.’ And that’s how I put it, these are some of the possibilities I want you to think about it. And then it becomes ‘Okay, now you’ve thought about some of the possibilities, which are the ones that sound more likely.’ And then we’ll start thinking about ‘Okay, what would that look like for you. How would it work for everybody else? How will we pull this off.’…I sort of say ‘Wait a minute, let’s set the money part aside. First of all money has nothing to do with me. And hopefully it has nothing to do with you ...with the family. So let’s set that aside. Let’s look at what’s the best solution to what’s presenting itself, and then we’ll sort out the money.’ And sometimes the solution isn’t nearly as difficult as what they’ve perceived…I think if you get hung up on the money, as an initial thing, sometimes, your solutions are pretty limited…it is something that I nearly always say to parents, is let’s leave the whole money part of it out right now.”

The last issue that the EIOT participants emphasized was the concept of accountability. The participants identified two areas of accountability affecting funding and the modification recommendation: the building code not being adequate concerning residential access, and the accountability of the funder. Being a vendor, Participant 5 had
a lot of experience in ensuring that building codes were followed appropriately but the participant expressed that in many cases the building code was inadequate.

“Building code is very interesting. Especially in the bathrooms and grab bars, it’s totally ludicrous…But that code doesn’t meet [the client’s] needs. So they put a nice grab bar on the wall behind the toilet but… she can’t reach, can’t use it, so that code is meaningless for that particular individual’s needs. And again, it goes back to that darned needs assessment, ‘What do they need?’” And that’s what building codes should be, they need to have grab bars, yes, but it needs to meet their needs, not because the guidelines [say] they [should] put a grab bar on the angle over here, behind the toilet horizontally….It’s great if it works but … certainly there’s some codes that you have to apply, abide by, and it makes sense, like slopes for example, a ramp. I mean that just makes sense, not to have a… the ramp at such an angle that it’s going to hurt pushing up, and it’s going to get away from you going down”. (P5)

It was clear throughout the interviews that the EIOTs, while not well versed in the details of the Ontario building code, understood the implications of the building code relative to accessibility. They also had an understanding of the best applications for the various equipment solutions and municipal by-laws which have a bearing on the installation of the equipment. They reported that they immediately begin analyzing the physical environment for which possible accessibility option is the best solution for that environment, and whether municipal by-laws will allow the installation of a particular piece of equipment. For example, Participant 2 noted that she immediately began
looking at the height of the steps. “So I’m going to start my measuring those steps to the front door and hope that it might be something nice and low, like 13 inches or something” so that a ramp may be a consideration. Or conversely “if they’ve got a house that’s already on the downhill side of a slope … the land [is] falling away from the house, then you’ll never ever catch up with ramping”. She also noted, similar to Participant 5, that building code does not make sense in some cases and there were times that she wanted to eschew the building code in order to better meet the needs of the client and family:

“One of the things I struggle with a little bit with a client that is totally dependent and [the] one to twelve gradient and funding; It has to be the one to twelve gradient – no they’re never going to push… sometime I’m pushed towards ‘Can we make that one to ten instead of one to twelve?’…I don’t think that that would make a huge safety issue.” (P2)

These types of situations were particularly upsetting to the therapist who worked with populations who qualified for funding and they knew the families often only had one opportunity to receive the funding. Funds are limited and very often did not cover all of the needed modifications so the EIOTs did not want the families or themselves to make irreparable mistakes. Participant 9 summarized her concerns: “This is my problem, that in five years, it’s not going to be useful, or its utility is limited and … I have to make them kind of understand that before we go down that road.” (P9)

Because of all of the obstacles related to securing funding, the EIOTs also expressed frustration about the funder’s accountability:
“I was furious that the program had allowed them to make changes that [diverged] from the recommendation…. ‘You’ve just created a huge accessibility issue’… I called the funding program saying ‘I’ve got some questions about how this process works.’ [The program responded], ‘Well you know it’s their home. ... they don’t have to do what you say. If they don’t want the grab bar, we’re not going to say you have to have the grab bar. They have the choice to make the changes that they want as long as it meets the child’s needs.’ I said, “Well, who is determining whether it meets the child’s needs?” (P2)

“If the family chooses to change in midstream, or if they talk to the contractor on the side and say, ‘Yeah, well we’re going to send this in but this is really what I want. Can you do it for the same price?’ March of Dimes doesn’t know and if the family doesn’t have you back in, all you hear about it is two years later when they say, ‘We needed such and such.’ And I say, ‘Well that was in the original plan, wasn’t it?’… I find with March of Dimes, nobody ever walks in to see what’s been done.” (P3)

**Member Checking and Within-Methods Findings**

At the end of each interview the participants were asked if they would be willing to review the findings of this study and provide their perspectives on the validity of the findings. Once the theoretical coding was completed, the student research sent each
participant a summary of the findings (Appendix I) by email. The participants were asked to review the summary and answer four questions:

1. Do the themes fit with your sense of the information an occupational therapist gathers during the process?
2. Is there anything I missed, misrepresented, or need to emphasize more?
3. Does the process synopsis make sense to you; is there anything you would state differently?
4. Do you have any other feedback for me?

Six of the ten participants replied with one participant stating she was too busy at the time to adequately review the results. Of the five who did review the results, all five indicated that they had nothing to add and that the content of the summary accurately reflected their practice:

“I read through your summary and was pleased to learn that my approach is quite consistent with that of the other OTs – even those who work within different systems. This is especially valuable as the group does work separately and would not have collaborated, or even read literature related to this issue (because it doesn’t exist!)” (P6).

“I think you summarized the process and highlighted the themes extremely well!! I love it! And I appreciate you sharing it with us. I cannot think of anything that you missed or did not expand upon enough; very thorough” (P7).
Although formal assessment protocols were requested, the participants reported that none of their facilities had a formal, institutional assessment. One of the administrators at a participating facility would not allow any textual information to be shared, but it was not clear to the student researcher whether the facility actually had any formal assessments.

Summary of Findings

This chapter summarized the demographic characteristics of the participants and provided a general description of the environment in which each participant works in order for the reader to understand the contextual perspectives of the participants. The findings were presented in terms of initial coding, focused coding and theoretical coding. Five themes were presented. The themes that emerged from the data included, the occupational therapist’s agenda and tool box, gaining information by understanding how the family spent their day caring for their child and understanding the unique needs of each family, forecasting the future and ensuring that any recommendation was enduring, and being aware of how the funding environment affects the structure and content of the final recommendation. The themes were explained and illustrated with participant quotes. This chapter concludes with participants validating the findings of the data analysis. The fifth chapter presents a discussion of how the themes were integrated into a model which illustrates how factors in the context must be considered in a home modification recommendation.
CHAPTER 5: DISCUSSION AND CONCLUSIONS

Introduction

“The most important things in your home are people” ~ Barbara Johnson

This chapter interprets the findings of the study to address the research questions. The findings are integrated into a process model which explicates the how participating occupational therapists developed recommendations for home modifications to facilitate caregiving for children who are physically dependent by families and paid caregivers. In the “Kitchen Table Chat” (KTC) model, it is proposed that the occupational therapist guides an iterative dialogue with family members in order to gather and analyze the information necessary to develop comprehensive home modification recommendations that will result in enduring, optimal performance of caregiver roles. The findings and the model are then analyzed with respect to current occupational therapy theory and conceptual models. The chapter concludes with a statement of limitations to the study, and the clinical, educational, research and policy implications of the findings.

Addressing the research questions

The purpose of this research was to examine what information occupational therapists gather to inform their home modification recommendations and how they evaluate and prioritize that information to develop recommendations for home modifications for children and their families who require extensive home modifications.

Research questions

1. What data do occupational therapists gather when assessing the needs for home modifications for completely physically dependent children and their families?
The participating educationally influential occupational therapists (EIOTs) in this study described in detail the myriad data they gather when completing home assessments. While the order in which participants’ gathered information from clients varied with the individual participants’ personal practice style, the bodies of information collected by the participants were similar in content. The participants focused intensively on exploring the particular characteristics, values and preferences of each family with respect to how their clients carried out their daily activities. They used an approach which not only identified what caregiving tasks they performed each day, but also identified who carried out the care and why it was undertaken by that individual, how, where and when the caregiver performed it, and why it was carried out in that way and at that location and time. The participants also reported that they thoroughly explored particular family habits or events beyond caregiving duties, as this information gave them a great deal of information about the values and priorities of the family.

As well as gathering social-environmental information, the participants analyzed the physical environment. The participants were mindful of specific physical barriers as well as the physical layout of the space. For example, an obvious physical barrier would be steps or an architectural feature which precludes, for example, the installation of an elevator which requires 25 square feet of open, accessible floor space on each level. All participants indicated that the physical layout of the home is crucial as it can dramatically limit or expand options. Overall the participants noted that staying within the current architectural footprint usually makes the most financial sense. As there may also be municipal restrictions concerning additions to the exterior of homes, layout is very important to having the option of efficiently organizing the space within the existing
footprint of the home. Participating EIOTs frequently suggested how a space can be reorganized to facilitate the most accessible and safe options which offers the best longevity and fits with in the financial resources available to the family. They reported how they very quickly appraised the physical environment and spent most of their time and energy learning about the social environment of the family, with the aim of proposing options to the family which were future oriented, safe, inclusive of the child’s needs, and fit the budget. Participants were careful to suggest only architecturally and financially feasible options to families in order to prevent raising unrealistic expectations.

Counter-intuitively, the participants spent relatively little time analyzing the child using the environment. Children who are completely dependent for their care have a relatively stable activity trajectory, since their levels of functioning change very little. However, the capacity of their caregivers to physically manage the caregiving and the increasing size of the child can change dramatically over time. The relative stability of the child’s level of dependence along with the increasing physical size of the child and the generally decreasing capacity of caregivers to manage their care were factors considered by each participating EIOTs. In most cases, the participants were undertaking assessments of parents and caregivers who were not disabled themselves. The participants therefore projected the effects of typical aging patterns and probabilities for the potential for repetitive strain injuries when considering the child’s current and future needs and the caregiver’s capacity for future caregiving. In terms of future planning, the participants discussed with the parents the possibility that there may be professional caregivers involved in the care of their child. During that discussion the EIOTs began educating the families about future care considerations and “planted the seeds”
concerning the responsibility of providing a safe workplace environment for the professional caregiver who may be involved in the care of the child in the future. The Workplace Safety Insurance Board (WSIB) has jurisdiction over the workplace environment of the Personal Support Workers (PSWs) who work with these children. The EIOTs were aware of the regulations which are directly relevant to the physical aspects of providing care. For example, not lifting over 40 pounds is an important WSIB rule that informed many of the EIOT’s recommendations. The EIOTs frequently pointed out that by ensuring that the work environment is safe for the professional caregiver, it would also be safe for the parents if they were ever less able to provide the care.

2. What processes do occupational therapists use when gathering, evaluating, and prioritizing these data in order to formulate their recommendations?

As described in depth in the previous chapter and summarized above, the EIOTs reported using an iterative process to gather, evaluate and prioritize the information they needed to make home modification recommendations. They reported gathering information that would give them a picture of the whole family, exploring what they do during the day, how the interfamilial relationships function, what they have tried in the past and what they think will work, what physical environmental barriers are affecting the child and their caregivers, who lives in the home and how all these data fit together around the child and their care. They then considered all of this information with respect to the options which are available to overcome the barriers within the environment surrounding the child. In their clinical decision making, the EIOTs thought about and evaluated the potential options and anticipated the consequences of alternate options in
order to filter what is presented to the family. Some options are never presented because the EIOT determines that the option is not feasible architecturally or will not be acceptable to the family. Most frequently the options presented by the EIOT were the options which the EIOT feels are the best options, or will cause the family to think about something they had never considered before eliciting further discussion.

The participants spoke about ‘guiding’ the families in their decision making. The EIOTs had an idea about how they thought the situation would be best resolved and indicated that they attempted to lead the family to the same conclusion. The EIOTs saw their role as having a specific set of specialized professional skills and perspectives which pulls together disparate pieces of information to conceptualize options to meet the unique needs of the family. The participants were able to evaluate the physical environment relative to the socioeconomic environment in ways which were sensitive to the caregiving requirements of the child and the capacities of the caregivers. In other words, the participants attempted to eliminate barriers in the environment that presented safety hazards for the child and the caregiver while remaining sensitive to the lifestyle requirements of the family. They were skilled at hearing and understanding the important elements which must be addressed sensitively in order for the family to feel comfortable moving forward with the modification at a time that is right for them. The other key skill that the EIOTs depicted in their discussions of their interactions with their clients was their capacity to communicate the concepts of accessibility and ease of care to the family in a meaningful way. This was part of the guiding and educating process the EIOTs described as central to the therapist’s role. They reported attempting to advocate for the safest, most cost effective and most inclusive option. Their descriptions of their
interactions with families indicated that they were accomplished in engaging the family in an approach which was simultaneously family centred and client centred. The examples and cases participants provided in their interviews showed that when families rejected the home modifications options, the EIOTs listened carefully to the families’ responses and tailored subsequent options to more specifically meet the families’ needs. They reported that many families need time and space to make decisions to be ready to move forward with their own decision making. They also reported that families often need a period of reflection on several options before they settle on one that will best fit with their lifestyle.

3. How do occupational therapists structure their recommendations for home modifications for physically dependent children and their families and caregivers?

There were a number of different circumstances and points in time in which the sample of EIOTs provided formal or informal recommendations to families. The informal recommendation was the fluid recommendation process that the EIOTs engaged in as they collaborated with the parents to solve their individual accessibility, caregiving issues and funding barriers. This process was informal because it is iterative but not formally documented and justified to an external agency. The EIOTs reported presenting options and receiving feedback from the family concerning the family’s views on the viability of those options, relative to their lifestyle and values. The EIOTs said they would often provide families an image of their most likely future, based on the EIOTs’ experiences in providing similar comprehensive home modification assessments, and the most suitable resolutions to the issues identified by other families. The EIOTs constructed portraits of
other families’ futures from which a family could reflect upon their own situations, values and day to day experiences. The EIOTs’ reported using illustrative stories about other families, in similar situations, to convey complex and comprehensive information in ways that families could personalize and see as meaningful. The EIOT adjusted their recommendations with respect to future needs and available financial resources and in ways which reflected family needs but maintained the safety, in the present and in the future, of the client and his or her caregivers. Through a process of communication and negotiation, the portraits changed and elements were removed or changed. Through this process the EIOTs reported that recommendations were co-constructed and negotiated in order to achieve approval from the family. The participants pointed out that this process was at some times just one iterative cycle and at others, multiple cycles over a prolonged period of time, as families work through to a stage of readiness to proceed with home modifications.

The EIOTs described the formal recommendations as being structured to ensure that EIOTs were endorsing the safest and most enduring option both from the perspective of the child and the caregiver and maximized the scope of funded modifications. While the recommendation advocated for the needs of the child and their caregiver, EIOTs stated that they were careful to not support options which the family wanted but were not safe or enduring because they did not want to risk their relationships with families or risk their professional reputation over inadequate or inappropriate recommendations. They reported that they were careful to structure their recommendations in ways which preserved their professional accountability and their relationship with families. When the EIOTs wrote letters of support to a funding agency, their recommendations shifted to
formal processes rather than informal iterative recommendation processes they used while involved with only the family. Because the initial informal process is collaborative and co-constructed, the EIOTs reported that it was rare that they would have had to write a letter of support that was anything less than completely approving of the option. If an EIOT needed to write a letter which outlined an option they did not agree with, they chose to present a number of the options discussed and outlined the benefits and limitations of each option without endorsing any one option.

Model Development

The EIOTs spent much of their time in discussion with the family and caregivers at the families’ kitchen tables. None of the EIOTs used formal or standardized assessment tools. Their recommendations were based on long discussions learning about the particular concerns of the family and their situational contexts. The institutional and social systems that influence home modifications rarely change. These are systems such as municipal bylaws, building code, the occupational health policies and regulations relative to professional caregivers and funding agency guidelines. The technologies and the applications of these technologies available to solve accessibility and caregiving issues were generally fairly limited in their range. These environmental systems and the technologies available provided the context in which the EIOTs and the families made their decisions. The Kitchen Table Chat (Figure 1) was the iterative process directed by the EIOT which contextualizes the unique needs of the child and their caregivers within parameters of these relatively fixed systems. The process is the assessment of an accessibility and/or caregiving issue that prompted the need for the recommendation. The
process co-constructs options to solve the issue(s) and is informed by information
gathering guided by the EIOT. It is co-constructed because the family voices their
preferences as the process evolves and options are eliminated as these preferences are
voiced. The solution is characterized as a picture of how the issue could be solved within
the family’s unique context. As the EIOT and the family moved through the process, the
picture of the solution changes as more complete information is gathered and preferences
are voiced until a final, formal recommendation is written. Since all options must be
compliant with environmental policy and procedure, it (environmental compliance) must
underscore both the information gathering stage and the iterative process which is
refining recommendations so the final recommendation fits with the all of the relevant
environmental systems. For example, if the family states in the information gathering
stage that they are renting their home, then the options available to the family are
immediately limited and the EIOT did not further evaluate the home for permanent
structural changes. The process could consist of one kitchen table chat requiring only
rudimentary consultation with little EIOT input, no formal recommendation and ending
with the family gaining information with which to move forward with their decision
making. Conversely, the process may consist of many conversations over many months
or years before a final recommendation is made. The desired outcome is the performance
of safe and relative ease of care of the child.
Figure 1: The Kitchen Table Chat Process

Figure 2 is a more specific depiction of structural influences in the decision-making process within the home modification recommendation process. Each chair at the table represents a stakeholder in the process. While some stakeholders seemingly have little active participation in the process, they are nonetheless very influential in the decision-making. For example, funding agencies are influential through their allocation policies, and various levels of government through their statutes, regulations and by-laws. The influence of the chair’s occupant during the Kitchen Table Chat varies with the unique context of each family situation, but all need to be considered.
Each of the stakeholders and the themes which emerged from the findings have significance at the table, including the needs of the child and environmental factors, which are relatively stable. Even though the profoundly physically involved child’s voice is silent at the table, they occupy an important seat because they are the primary client. The EIOT’s primary consideration was the safe, long term care of that child or youth and the EIOT assessed caregivers’ capacities with respect to the child’s needs due to his or her physical impairments and dependence in self care. The seat occupied by the environment constitutes the various environmental pressures which are constant and inflexible and provide limits to the options available to the family. The environment is complex and includes the physical environment surrounding the child as well as the services and systems impacting home modification decision making such as building code, funding agencies’ guidelines and mandates, and work place safety legislation related to professional caregivers. All options presented by the OT must compatible with the environmental context.
The third seat at the table is the family. Despite the fact that the family is part of the child’s environment, the EIOTs identified the family members as a separate system and therefore distinguished them as a client. The EIOTs established the occupational demands of the caregiver’s role relative to the needs of the child and the physical barriers of the environment. The one area of conflict for the EIOTs was the need for congruence between the family centred model of care espoused by the children’s treatment centres and the client centred model of care occupational therapy regulatory college. Professionally, the EIOT had to practice in a client centred manner, but their employers’ philosophy of care put the rights of the family ahead of the rights of the child. Consequently the EIOTs mitigated this conflict by considering the caregiver’s needs as almost equivalent to those of the child.

Foremost, the EIOTs aimed to find recommendations that both met the safety needs of the child and supported the caregiver’s requirements. If there was incongruity between those needs, the EIOTs always ensured that the child’s safety needs were protected. Nevertheless, the EIOTs considered the needs of the caregiver as such an important factor that they spent much time exploring the care requirements of the child and consequent occupational demands on the caregiver, the needs of the caregiver and the physical barriers to care.

It is within the Kitchen Table Chat model that the discussions occurred concerning the options available to address the concerns of the family. The EIOTs brought their own agendas, knowledge and skill sets to the kitchen table as specialists who guided the process. For occupational therapists, communication is highly linked to reflective processes. Indeed the College of Occupational Therapists of Ontario (COTO)
sees reflective practice as a core professional competency (COTO, 2000). For example, the EIOTs’ used dialogue with families as a primary tool for gathering information. They provided options to families and reflected on the families’ responses in order to formulate and offer them alternative suggestions. The EIOTs’ analyses and reflections are integral to moving the assessment and recommendations processes forward. Falardeau & Durand (2002) characterize this process as “metacommunication”, that is, being aware of the “possibilities and processes of the interaction” (pp. 139) while the occupational therapist tailors the interaction to provide appropriate and timely information to ensure informed decision-making on the part of the client and family.

In the model, the EIOT also brings the occupational therapist agenda, tool box, accountabilities and capacity for future forecasting to the Kitchen Table Chat. The EIOTs in this study considered these resources crucial to their assessment process and formulation of recommendations. Besides including factors which occupational therapists must consider to ensure that their recommendations were sensitive and enduring, the occupational therapists’ agenda also includes certain priorities the EIOTs wanted to see addressed. The other two themes, “walking through their day” and “getting to know the dynamics of the family” comprise information necessary for occupational therapists to develop recommendations. In their professional capacity, the EIOT guides the communication process, extracts and synthesizes all of the data, interprets the synthesized data with respect to all potential solutions, and eliminates solutions which are not viable and providing sensitive options to the family.
Fit of Kitchen Table Chat Model with generic Occupational Therapy Practice Models

The processes used by the EIOTs to make home modification recommendations in this study are consistent with the enablement skills outlined in the Canadian Model of Client-Centred Enablement (CMCE) (Townsend et al., 2007). This process, that is, the Kitchen Table Chat, enabled and guided by the OT over time to develop a solution which met the needs of all involved and was acceptable to the family.

Figure 3: CMCE

The EIOTs’ employment of CMCE enablement skills became evident throughout the analysis of the interview data and is illustrated in Table 3. The EIOTs adapted their approaches as they engaged and built trust with the families. EIOTs observed and analyzed the needs and readiness of the family. They advocated for the options they felt were most appropriate for the needs of the child and the various caregivers. The CMCE defines coaching as “seeing the big picture” and “pose[ing] the powerful questions”. The
EIOTs thoughtfully painted the portrait so the family could envision the big picture in a way that was personal and relevant to their unique situation. Coaching was enacted by asking thought provoking questions and using stories of other families cobbled together to closely resemble the context and needs of the family they were working with.

The EIOTs expanded the choices available to the family by envisioning and proposing a variety of options, including the option to move, and by asking them specific questions designed to illuminate the future for the family. The recommendations were collaboratively constructed with the family as the consultation process moved forward and options were brainstormed. Part of the process included the OT coordinating with vendors and contractors to provide opinions about the application of specific technologies to address accessibility barriers and funding barriers. An important aspect of the process was to educate the family about the advantages and disadvantages of various choices “prompting transformative learning” (Townsend et al., 2007). In order to inform the family’s decision making the EIOT had a specialized knowledge set which included knowledge about disability, development, technology and institutional policy.

<table>
<thead>
<tr>
<th>Enablement Skill (Townsend et al., 2007)</th>
<th>Characteristics</th>
<th>Illustrative quotes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adapt</td>
<td>Accommodate, adjust, analyze &amp; breakdown, configure &amp; reconfigure</td>
<td>“What are the barriers in the physical environment; can anything be moved, reorganized?” P10</td>
</tr>
<tr>
<td>Advocate</td>
<td>Challenge, champion, politically strategize, lobby, make visible, promote</td>
<td>“I did a lot of letter writing to {the city}.” P 4</td>
</tr>
<tr>
<td>Coach</td>
<td>See big picture, pose powerful questions, reframe options, guide process, expand choices</td>
<td>“We have that, ability to see the whole picture while keeping in mind all the little details”(P8)</td>
</tr>
<tr>
<td>Collaborate</td>
<td>Communicate, facilitate, negotiate, resolve competing interests</td>
<td>“Relatives are in the same house. The brother of the father, who owned ½ the house, was not quite as laissez faire as the father, he was on top of everything.” P1</td>
</tr>
<tr>
<td>------------</td>
<td>---------------------------------------------------------------</td>
<td>------------------------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Consult</td>
<td>Brainstorm options, advise, recommend, suggest, synthesize, summarize</td>
<td>“Help them through that conceptualization.” P5</td>
</tr>
<tr>
<td>Coordinate</td>
<td>Bring together, identify, integrate, document</td>
<td>“The 2nd part of the whole thing is trying to overlap with the contractor.” P3</td>
</tr>
<tr>
<td>Design/Build</td>
<td>Conceive, develop, envision, evaluate, strategize, propose</td>
<td>“Equipment &amp; modifications that will enhance care &amp; safety of the caregiver…match that all together &amp; consider what needs to be done.” P6</td>
</tr>
<tr>
<td>Educate</td>
<td>Inform, enlighten, prompt transformative learning</td>
<td>We have an important role to educate the family, starting early on, as to what might be suitable.” P6</td>
</tr>
<tr>
<td>Engage</td>
<td>Build trust, develop readiness, prompt optimal participation</td>
<td>“My method is very client-centred…there is a lot of psychosocial stuff…you have to move with their readiness.” P7</td>
</tr>
<tr>
<td>Specialize</td>
<td>Apply specialized frameworks</td>
<td>“Our ability has to be the sum of our knowledge &amp; experience &amp; our analysis of what will work.” P6</td>
</tr>
</tbody>
</table>

Models of Care Influencing Occupational Therapy Practice

The declared paradigmatic perspective of each of the EIOTs was, first of all, client centred, which was then embedded within the philosophy of family centred service. This perspective was fundamental to the agenda the EIOT brought to the table. Family centred service has three basic assumptions: (a) parents know their children best and want what is best for their children; (b) families are different and unique; and (c) optimal child functioning occurs within a supportive family and community context (Law, Rosenbaum, King, King & Evans, 2003). In this study, it was apparent that the EIOTs were adhering
to client and family-centred principles because they respected the decision making authority of the family and considered the needs of the whole family. Indeed the framework proposed by Law et al., 2003 outlines behaviors which were championed by the EIOTs throughout their discourses. More recently, Servais, Baldwin and Tucker (2009) describe relationship-centred practice as best practice for pediatric rehabilitation and suggest that relationship-centred practice is the “how to” method of delivering family centred care. This philosophy of practice involves collaborating and agreeing on intervention goals. The EIOTs were focused on maintaining relationships with the families. Professionally, occupational therapists in Canada have been practicing using a client centred approach for the last three decades. Falardeau and Durand (2002) point out that the traditional definition of client centred is ‘led by the client’. In this research the EIOTs were clearly not entirely either family or client focused, they were concerned about negotiating a recommendation which was respectful of the needs of all those involved, and stayed within the confines of the fixed environmental barriers and maintained the relationship with the family. Falardeau and Durand (2002) have proposed a negotiation-centred model of intervention which embraces the philosophy of client, family and relationship-centred care and more aptly describes how the EIOT approached and navigated the home modification recommendation. Indeed the authors outline advantages this perspective reaps including eliminating hesitation to address an issue not identified by the client, finding a common goal, integration of evidence with client “particularities”, encouraging assimilation of client feedback to the options presented, and finally, the “acknowledgement of intrinsicality”, meaning choices are made based on personal values and priorities. Each of the EIOTs discussed how the process was
negotiated and fluid, with the EIOT presenting and modifying options based on client values, priorities and feedback. Moreover, the model describes the occupational therapist’s influence guiding the shared process in which the therapists’ expertise is equal to that of the client. Finally, the negotiated model acknowledges a temporal component to the negotiations preceding any formal recommendations because it is “necessary for the therapist and the client to have some serious discussions, stretched over several days or weeks, where each individual shares his knowledge, experience, opinions, and emotions” (p. 140).

Implications for Occupational Therapy Practice and Education

This study documents the knowledge, skills and behaviors used by a select sample of occupational therapists when making home modification recommendations for children who are totally dependent and their caregivers. The findings of this study, and the propositions developed from the findings provide one formulation of current best practice in home modification recommendations and therefore create a basis for the development of a clinical practice guideline. The study has highlighted the importance of context and temporality in home modification decision making processes. Temporality is a construct which is not currently represented in most published home adaptation assessments nor is it highlighted in the curriculum of contemporary OT educational programs. Clearly, when considering the case studies used in the OT curriculum, temporality should be included in terms of an approach to service provision as both a function of the assessment and the intervention. The Life Needs Model (King, Tucker, Baldwin, Lowry, LaPorta, & Martens, 2002) recognizes the continuum of changing needs relative to the provision of service to children and their families and would be a helpful
adjunct model in the training of occupational therapists because it promotes the temporal consideration of a problem.

The role and status of the caregiver as an occupation within the practice process should also be highlighted in professional curricula. Novice therapists often see the process of ‘home assessment’ as an analysis of the physical environment rather than as an occupation of the individual(s) providing care to the child with significant disabilities. Generic pediatric intervention management strategies should consider the caregiver as an important and dynamic contextual variable because service to these children always involves a caregiver.

The findings of this research demonstrate a consistent approach to the content of the information gathered by elite, experienced OTs. As Rappolt (2003) suggests, assessment and interview skills as well as professional expertise are foundational to the quality of the recommendation constructed. Currently no assessment tool captures the breadth of content and temporal perspective articulated by the EIOTs in this study. Further study of factor analysis and construct development of home adaptation tools is needed.

Further study concerning the construct of time as it pertains to the process of OT practice is also important. Data from this study suggests that “time” is a construct with many dimensions. Time influences the practice of OT in many ways that are not represented in current practice process theories. It is also not reflected in the models of occupation performance as a substantive construct or as a contextual factor influencing performance. The findings of this study suggest that OTs are more conscious of temporality than their theoretical models would suggest.
The families’ readiness to decide to investigate home modifications and then to ultimately move forward with the modification was a concept identified by all of the participants as a focal point of the process. This concept warrants further exploration since the entire process is contingent on client and family readiness to move forward with decision making. Even from the perspective of other populations and clinical situations, elucidation of the constructs of “readiness” concerning assessment and intervention is necessary from both the perspective of the therapist concluding that a family is ready and from the perspective of the family “knowing” they are ready. The literature review of this research did not focus on the concept of readiness but in light of the findings it would be important to replicate this study with greater focus on readiness as a concept that is explored in greater depth from the outset of the project.

Pertaining to the theoretical constructs informing the OT’s approach and philosophy of care, the tension reported by the participants regarding client centred care and family centred care requires examination. Clearly neither model completely satisfied the EIOTs in this study. The results suggest that further work needs to be done concerning the integration of these concepts at a theoretical level. Each of the participants articulated a certain degree of anxiety about situations in which the families’ goals were perceived to be incongruent with the needs of the child, as identified by the EIOT. Falardeau and Durand’s (2002) model of a more negotiation-centred approach seems to be more applicable, this is not the prevailing occupational therapy approach nor is it the approach espoused by the children’s treatment centres in Ontario. Some clarity regarding the operationalization of the constructs of both family-centred care and client-centred care concerning children would be helpful.
One of the striking findings of this research is the function that communication plays in the process of how the EIOTs guide a family’s decision making. The meta-communication (Falardeau & Durand, 2002) of the OT in this process merits further examination. The process involves a bidirectional and cyclical transmission of information whereby the information is received, decoded and interpreted and further information is offered. One’s choice to offer or withhold information implies both the therapist’s and the family’s control over the content, the timing and implicit meaning of the information provided in the communication process. The participants acknowledged that they offer only options which are, in their opinion, congruent with the context and the information provided by the family. Families also control the information they do or do not provide to the OT, and the therapist’s recommendations are necessarily based, in part, on the family’s information. There are many further questions about the communication aspects of the process which require explanation and clarification.

Metacommunication is typically defined as “communication about communication” and is characterized as the communication that conveys to the receiver the how to interpret the communication. Falardeau and Durand suggest that the OT is conscious of this implicit communication. Certainly the findings in this research suggest that the EIOTs were conscious that they were guiding the process and “moving them along”, but what was unclear was the content of the embedded, implicit message the EIOTs were giving. Was the implicit message causing the families to adopt a particular attitude concerning home modifications that they may not have adopted otherwise? Participant 6 commented: “that sell that we have to do, I call it education… But that is a course in itself, how to sell, or how to persuade…gentle persuasion…” perhaps suggesting
discomfort with how the message was being given and received but still feeling like she needed to “persuade” the family to follow her lead and direction. The role of metacommunication, as suggested by Falardeau and Durand, is important in a negotiation centred approach but the character of the communication is less clear and may be less open-minded and genuine than the authors suggest. The term "persuasion" suggests that the OT influences the decision making more than just providing options for consideration; there may be a direction about to interpret the communication implicitly embedded in the recommendation process. This requires further research and exploration.

Implications for Policy and Research

Policy

From a policy perspective the need for long term relationships with families to completely understand the family context was consistently articulated by the participants and as such, the results can inform service intervention models particularly concerning the length of time and number of visits necessary to complete a home modification recommendation. This is not congruent with the current managed care service provision model being implemented by the CCACs. It is clear that a continuum of service is necessary to meet and anticipate the changing needs of children and their families. A more appropriate service delivery model, such as the Life Needs Model (King, et al., 2002), needs to be examined as government policy relative to children rather than a managed care model that has a focus on discharge after consultation. The findings of this research suggest that the process of modifying a home to accommodate significant disability requires ongoing consultation and access to service when the family is ‘ready’ and is not a singular episode requiring no further consultation and follow-up.
The findings suggest that even as the participants attempted to not tailor their assessments and recommendations to funding guidelines, the pragmatics of the situation was that funding considerations weighed heavily into the final recommendation. There is little evidence to support the notion that best practices are driven by the policies of external funding agencies. Future research should examine the economic implications of the human resources devoted to making home modification recommendations multiple times in order to satisfy the criteria of a home modification funding agency. For example, the Ontario March of Dimes (OMOD) is the agent which distributes provincial government funds to modify homes; it has a lottery procedure based on priority of need on a month to month basis. Families of children are forced to apply multiple times over a long period of time in hopes of “winning the lottery”. If their documentation concerning the proposed work is outdated, families must secure new documentation necessitating further OT assessment and guidance. Furthermore, the OMOD may request additional assessment if they disagree with the occupational therapist’s report. Hence a policy of one provincial ministry is negatively impacting the operations of another ministry at an economic cost to both.

Research

A conceptualization which warrants further study is the concept of safety. This research suggests that safety is a seminal concept to the process but it is not a well defined concept. There is the risk that each EIOT’s definition of what constitutes safety may differ. If safety predicates all decisions made by the occupational therapists, the profession of occupational therapy requires a common understanding of safety. One only has to look to sudden infant death syndrome to observe how the simple decision of which
position an infant should sleep in may have catastrophic consequences, and how best practice has evolved in its recommendations about the relative safety of a particular position. Ethically the element of risk also has a role to play in this area of practice. More research is needed to delineate the right of a parent to assume risk and the right of a child to be safe while being physically cared for.

There is significant literature concerning ‘caregiving’ and ‘caregivers’ which needs to be more fully explored as a concept relative to ‘home assessment for home modification recommendation’. The findings of this research suggest that there is a dynamic interaction between meeting the needs of the child and meeting the needs of the caregiver when making home modification recommendations. The concept of the caregiver, being a central part of home modifications considerations, has not been explored in the literature. It would be useful to add to this knowledge by examining the caregiving literature in light of the findings of this research.

This process of decision-making for home modification recommendations is a complex process which is non-linear and does not lend itself well to dichotomous yes/no decision algorithms. It involves complex clinical reasoning on the part of the OT and emotionally and financially complex decision making on the part of the family. Furthermore, there are many policy stakeholders influencing the process. Consequently there can be no “mother of all assessment” tools as one participant put it. There could be however, a decision making framework and clinical practice guideline which provides a standard guide to evaluating the context for making home modification recommendations. The findings of this research provides the foundation for defining the factors influencing the process and subsequently defining the most appropriate tools from
which to gather information to inform the process. The validity of applying of the decision making framework and clinical practice guideline would need to be explored and validated for this area of practice.

Limitations

This study explored how an elite group of ten occupational therapists from five children’s treatment centres in southern, southeastern and southwestern Ontario assess for home modifications for children who are physically dependent and for their caregivers. A provisional model, the Kitchen Table Chat, for understanding the process of considering all of the stakeholders in the process in order to formulate a home modification recommendation was presented. As this research is an exploratory study, the findings and resultant model should be validated through further research to test the content of the constructs. If found to be valid, the Kitchen Table Chat may have application to populations beyond children who are completely dependent for their care and are serviced in a geographical area which has relative resource intensity due to population; to other clinical populations who reside in rural settings with fewer resources and children or other clients who are not serviced by a regional treatment centre in Ontario. Since the service context in these areas may be significantly different, the relative import of the policy stakeholders may differ significantly from the areas in which the EIOTs practice.

The other limitation of this study is the possible influence of the researcher’s clinical practice on the coding and interpretation of the data. Efforts were made to mitigate any bias by having the researcher’s primary supervisor review transcripts as soon as they were completed and to independently complete the initial coding of the data.
The supervisor has no clinical experience with home modifications for children who are completely dependent on caregivers for their care.

Conclusion

In conclusion, the EIOTs reflectively guide a process which is often financially and emotionally difficult for families who require extensive home modifications to facilitate the care of their physically dependent child. They possess specialized knowledge important to enabling this often long and cyclical process. They have specific information which they gather in each situation in order discern the uniqueness of each situation with the aim of developing a recommendation which ensures a safe and enduring environment for the child and their caregivers. The model presented is a negotiated-centred model of intervention, the Kitchen Table Chat, which is enabled by the OT with equal consideration given to the perspectives of each seat at the table. While the information provided by each position at the table is given equal consideration, the recommendation may be weighted more in favor of a particular constellation of factors after the negotiations occur. Each negotiation is unique in its content and outcome determined by the particular values and needs of the child and family. Recommendations are fundamentally client centred embedded within the family’s considerations. The time between the entrance to the process and the conclusion of the process may span many months or years. Participating EIOTs conveyed skill at enabling the home modification decision making process.
“There is no doubt that it is around the family and the home that all of the greatest virtues, the most dominating virtues of human society are created, strengthened and maintained” ~ Winston Churchill
References


Green, S.E. (2006). ‘We’re tired, not sad’: Benefits and burdens of mothering a child with a disability. *Social Science and Medicine, 64*, 150-163.


Appendices

Appendix A: Initial Survey Letter

Graduate Department of Rehabilitation Science

Dear Colleague,

I am conducting my M.Sc. research in the Graduate Department of Rehabilitation Science at the University of Toronto under the supervision of Dr. Susan Rappolt. I am also a practicing Occupational Therapist at ErinoakKids Centre for Treatment and Development. This study, funded by a grant from the Trillium Foundation of Ontario, is intended as the first stage in the development of a provisional clinical practice guideline concerning home modification for children who are completely dependent for their care. Clinical practice guidelines are important to our profession and are also important in the new COTO assessment standard.

You are being asked, as an Occupational Therapist whose practice is with children, to participate in a survey to identify occupational therapists who are characterized as clinicians who provide a positive learning experience, are good communicators, willing to provide leadership and share knowledge, keep up to date and demonstrate a high level of expertise in the practice area. A list of the most nominated clinicians will be compiled and those individuals will be asked to participate in an in-depth interview concerning how they assess homes for the purposes of making modification recommendations. The survey is anonymous and you are under no obligation to participate. It will take approximately 5 minutes to complete the survey. There is no risk to you.

We are hoping to generate the list by February 16, 2009 so we are asking that you please complete the survey as soon as you are able. Thank you for your participation in this survey. Your answers will make a significant contribution to the development of a home modification clinical guideline. If you would like a copy of the final guidelines, please feel free to email me and I will be happy to forward the provisional guidelines when the project is complete.

Sincerely,

Tanya Eimantas B.Sc.O.T. Reg. (Ont.) M.Sc. (candidate)
Graduate Department of Rehabilitation Science, University of Toronto
Professional Practice Leader Occupational Therapy
Home and Vehicle Modification Program
ErinoakKids
teymantas@erinoakkids.ca
905-789-5211

Susan Rappolt PhD, OT Reg. (Ont.)
Associate Professor
Department of Occupational Science and Occupational Therapy, and
Graduate Department of Rehabilitation Science
University of Toronto
160-500 University Ave, 9th floor
Toronto, ON M5T 1W5
s.rappolt@utoronto.ca
416-978-5932
Appendix B: Hiss Survey for Initial Survey

Graduate Department of Rehabilitation Science

Modified Hiss Survey Questionnaire (Hiss, Macdonald, & Davis, 1978):

The following three paragraphs describe characteristics of occupational therapists as they interact with their colleagues on an informal basis during the course of a typical day in practice. Most therapists demonstrate these characteristics, but some therapists demonstrate these behaviours more often and more consistently than others. What we would like to learn from you is: which therapists in your field of practice who do home modification assessments and recommendations best fit the descriptive paragraphs that follow. The identities of the therapists evaluated by their peers to be educationally influential may be used to guide our program and research, but will not be disclosed in any presentations or publications resulting from this study. Please read the paragraphs carefully and indicate the name(s) of occupational therapist(s) and their affiliated organizations that best fit each description. You may name up to 3 occupational therapists for each paragraph and name the same individual in more than one paragraph.

a) They convey information in a way that provides a positive learning experience. They express themselves clearly and to the point, but do not leave you with the feeling that they were too busy to answer your inquiry. They are willing and seem to enjoy sharing any knowledge they have:

NAME: _____________________________________________ ____________________

NAME: _____________________________________________ ____________________

NAME: _____________________________________________ ____________________

b) They are individuals who keep up to date and demonstrate a high level of expertise in home modification recommendations.

NAME: ________________________________________________________________

NAME: ________________________________________________________________

NAME: ________________________________________________________________
c) They are caring occupational therapists who demonstrate a high level of humanistic concern. They never talk down to you. They treat you as an equal even though it is clear that they are helping you.

NAME: _____________________________________________ ____________________

NAME: _____________________________________________ ____________________

NAME: _____________________________________________ ____________________

NAME: _____________________________________________ ____________________
Appendix C: Invitation to Educational Influential Nominees

Graduate Department of Rehabilitation Science

March 9, 2009

Participant
Children's Treatment Centre
123 Any Road
Anyplace, ON
H1H 0H0

Dear Participant,

I am conducting my M.Sc. research in the Graduate Department of Rehabilitation Science at the University of Toronto under the supervision of Dr. Susan Rappolt. I am also a practicing Occupational Therapist at ErinoakKids Centre for Treatment and Development.

I am writing to request your participation in a research project I am undertaking which is part of a larger project funded by the Trillium Foundation. The purpose of this study is to examine how occupational therapists working in Ontario formulate home modification recommendations for children who require extensive home modifications. Since there are currently no clinical practice guidelines to inform practice for home modifications, this study is a first step in developing a practice guideline.

In a survey of occupational therapists (OTs) working with children across Ontario conducted in the first part of the study, your peers identified you as particularly knowledgeable concerning home modification. For this part of the study I am looking for OTs who can provide me with an informed perspective regarding home modification recommendations. As a practicing therapist whose opinion is highly valued by your peers, I invite you to participate in an interview on this topic.

If you agree to participate in this study, the interview will be arranged at a time and place that is convenient for you. The interview will take approximately 60-90 minutes. I will be tape recording the interview to ensure that I have an accurate record of the information that participants provide. The tapes will be transcribed word for word. The tapes, transcriptions and all data arising from the study will be stored securely to protect confidentiality. I will also be requesting copies of any forms developed at your facility used to document a home assessment or any tools developed to inform practice at your facility. These documents will be kept confidential and will be used only as an additional source of data concerning how occupational therapists are conducting home assessments.
None of the textual information will be copied as they are considered property of your facility or agency.

At the end of the interview I will ask you if I may contact you after the interview in order to clarify information or to ask your opinion about new information arising from subsequent interviews. Participants will also be asked to review any direct quotes or statements prior to publication in any research and occupational therapy journals or oral presentations of the results of the study.

You are under no obligation to participate in this study. If you chose to participate, you can withdraw your participation and your data at any time without any negative consequences. There are no risks or direct benefits to you for participating. Please contact me or Dr. Susan Rappolt for any information concerning this study. If you have any question regarding your rights as a participant you may contact the Ethics Review Office (416-946-3273 or ethics.review@utoronto.ca).

If you are interested in participating in this project and are willing to be interviewed, please contact me via phone, (905-789-5211) or by email (teimantas@erinoakkids.ca) in order to arrange an interview at your convenience. Thank you for your consideration in participating in this study.

Sincerely,

Tanya Eimantas B.Sc.O.T. reg. (Ont.) M.Sc. (candidate)
Graduate Department of Rehabilitation Science, University of Toronto
Professional Practice Leader Occupational Therapy
Occupational Therapist
Home and Vehicle Modification Program
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s.rappolt@utoronto.ca
416-978-5932
Appendix D: Interview Guide

Thank you for participating in today’s interview. [Discuss casual matters concerning the weather, traffic etc. to establish rapport.]
I will start out by giving you some background information. I am a Master’s student at the Graduate Department of Rehabilitation Science at the University of Toronto.

Review letters of information and consent; discuss any questions and collect signatures.

The purpose of my research is to examine how occupational therapists working with children who require extensive home modifications assess the environmental needs of those children and their caregivers. I will be asking you to reflect upon how you go about assessing, analyzing and developing recommendations. Which environmental factors do you consider important to your home modification recommendations? I also want to learn about how you structure your recommendations. As well, I will be asking you to think about which practice models inform and influence your practice.

1. What made you decide to participate in this interview?
2. Please tell me about your clinical practice.
3. Could you please walk me through what you generally do when you receive a referral or request concerning home modifications?
   a. Elaborate participant’s answer if brief
Rationale: To uncover what type of information is available to the clinician prior to making the visit. To uncover what preparation a clinician does prior to the visit.

4. Do you have a practice model which you would say most informs your practice concerning home modification recommendations?
   a. Why does [this particular practice] model most inform and influence your practice?
   b. Which part of the practice model is most helpful in determining which factors you consider important in your home modification recommendations?
   c. Describe all of the environmental factors you consider.
   d. Is there anything about this model that does not reflect your practice?
   e. Can you give an example of a situation when the [practice model] does not adequately guide your practice?
   f. What does client centered practice or family centered practice mean to you? How do you provide it?
Rationale: To uncover which practice model informs practice. To uncover situations where the practice model does not satisfy the requirements of the therapist. To uncover the therapist’s frame of reference.

5. Please walk me through a typical assessment you would perform to provide home modification recommendations for a very involved child who is completely dependent on their parents for all aspects of their self care. Imagine that the child is approximately 8 years of age, lives in a 2 story home with steps to all of the doors, bedrooms on the 2nd floor and only a two piece washroom on the 1st floor.
a. Do you use any standardized, published assessments? If so which one(s) and why?
b. If you do not use a standardized, published assessment, why not?

6. Tell me about a challenging or unique home modification situation.

7. If funds were limited which parts of your recommendations to you place the most priority and emphasis and why?

8. How do you think that your recommendations would differ if the child were older? Or younger?

9. If a parent asked you when the child was 2 years of age what to do concerning home modifications, how would you advise them?

Rationale: To explore the myriad factors an OT considers when formulating home modification recommendations; prioritization of issues due to external environment.

10. Tell me about how you factor the caregiver(s), both professional and familial, into your recommendations?

   a. Do you evaluate the caregivers? If so how?
   b. Are there any particularly important considerations concerning the caregivers which you feel most always be assessed or considered by the OT? If so, why those particular factors?
   c. What aspects of the caregiving role do you pay the most attention to when formulating your recommendations? Why those particular ones?

Rationale: To explore what issues the therapists consider important concerning caregivers.

11. Tell me what you do when there appears to be a conflict between your recommendation of what is the best situation for the child and what the parents are wanting.

Rationale: To explore how clinicians navigate between client centered practice and family centered practice; to see if there is a context in which the OT will change a recommendation; to see if prioritization of issues changes due to conflict.

Demographic questions:
   • Year of graduation; years in pediatrics; any post-graduate degrees?
Appendix E: Confidentiality Agreement with the Transcriptionist

Graduate Department of Rehabilitation Science

Title: A Qualitative Analysis of Current OT Practice in Home Modification Recommendations in Ontario

This transcriptionist agrees to maintain the confidentiality of all personal information obtained during this employment. This transcriptionist or their professional company will not, either directly or indirectly, use, publish, communicate or otherwise disclose confidential information or any material or information of any kind obtained during this research study in connection with the services provided under this Agreement.

The responsibilities of this transcriptionist include transcribing all information provided in the digital recordings provided verbatim/as discussed into all transcribed documents. All transcribed documents will be accessed in accordance with provincial privacy legislation, and accessed on a secured website or through the use of encryption in electronic materials. They agree that all electronic and written materials shared with this researcher will remain in a secured place whereby only the transcriptionist and/or their professional company have access to these materials. This transcriptionist agrees to destroy all electronic and written materials associated with this research study after the transcribed documents that been provided to this researcher.

Signature:
I have read my responsibilities as a transcriptionist to this research study and I understand and agree to my responsibilities.

_____________  ________________
Transcriptionist’s Name   Researcher’s Name

_____________  ________________
Transcriptionist’s Signature   Researcher’s Signature

_____________  ________________
Date     Date
Appendix F: Consent Form

Graduate Department of Rehabilitation Science

TITLE: A Qualitative Analysis of Current OT Practice in Home Modification Recommendations in Ontario

DEPARTMENT: Graduate Department of Rehabilitation Science, University of Toronto

Contact and student investigator: Tanya Eimantas B.Sc.O.T. reg. (Ont.) M.Sc. (candidate), teimantas@erinoakkids.ca, 905-789-5211

Faculty Supervisor: Susan Rappolt PhD, OT reg. (Ont.), Associate Professor, Department of Occupational Therapy and Occupational Science, Graduate Department of Rehabilitation Science, University of Toronto

Funding: Trillium Foundation of Ontario

Background & Purpose of Research: This study is the second part of my master’s thesis project which examines how occupational therapists working in Ontario formulate home modification recommendations for children who require extensive home modifications. Since there is currently no clinical practice guideline informing practice for home modifications, this study is a first step in developing a provisional practice guideline. There will be 8-12 tape recorded interviews with educationally influential occupational therapists completed in order to gain insight into how home modification recommendations are formulated by occupational therapists. If you agree to be interviewed, you will be asked to describe how you typically conduct a home assessment for the purposes of accessibility and modification and factors you consider when you make your recommendations.

You are being invited to participate because you were nominated by your peers as an educationally influential clinician. An educationally influential is described as an occupational therapists who, as they interact with their colleagues on an informal basis during the course of a typical day in practice, consistently convey information in a way that provides a positive learning experience, express themselves clearly, do not leave colleagues with the feeling that they were too busy to answer inquiries, willing and seem to enjoy sharing any knowledge they have, keep up to date, demonstrate a high level of expertise in home modification recommendations, caring therapists who demonstrate a high level of humanistic concern, and treat colleagues as equals.

Description of the procedure: You will participate in an interview which is expected to take between 60-90 minutes. I will ask you questions concerning what you typically do when making home modification recommendations, what factors you consider important to your decision making and what practice models tend to guide your clinical reasoning.
I will also inquire about your clinical experience (e.g. years of work experience, number of home visits you are able to do). Finally I will be requesting blank copies of any forms, policies, procedures or guidelines pertaining to home assessments which are used or have been developed by your facility/agency. This interview will occur at a time, date and location which are convenient for you.

**Benefits:** There are no direct benefits to being involved in this study of the interview. You may attain indirect benefits in this study by reflecting on your practice and communicating your experiences and perspectives to the researchers. There will be no compensation offered for participating in this study.

**Risks:** There is no anticipated physical or emotional risk associated with your participation in this study. There may be some inconvenience associated with this study due to the time involved in the study for the interview.

**Confidentiality:** The interview will be tape recorded to ensure that I have an accurate record of the information you provide. You may ask that the recorder be turned off during the interview. I may also take field notes during the interview. During the interview, you may refuse to answer any questions that you do not wish to answer and you may withhold any information in the interests of privacy. You are requested not to use the names of any clients during these interviews to also ensure their anonymity. Prior to the tapes being transcribed word for word, you will be identified by a number and the informed consent will be kept separately from your interview data. The tapes, transcriptions and all data arising from the study will be stored securely to protect confidentiality and will on be accessed by myself or Dr. Susan Rappolt for the purposes of coding the information. During the coding process any identifying information will be removed and the original tapes and transcripts will be stored in a locked location at the University of Toronto separate from the coded material and will be destroyed within 2 years of the completion of the thesis. Transcription will be completed by me or a professional transcription service that has rigorous confidentiality policies which are PHIPA compliant. Any ensuing publications resulting from this study will only include any aggregate results and where quotations are used all identifying information will be removed. In the event that abuse of a client professional misconduct were described by any participant, then this information would need to be communicated to the College of Occupational Therapists of Ontario by this researcher, as per College policies and procedures.

Concerning the textual information you may provide, these forms and/or documents will be kept confidential and are intended to be an additional source of information concerning how OTs are conducting home assessments and what information they are collecting and documenting. You are under no obligation to provide any documents you or your employer does not wish to share. The student researcher will publish the results in a scholarly, peer reviewed journal and make public presentations based on the research.
Withdrawal Statement: You may choose to terminate the interview or withdraw your data (verbal or textual) at any time with no adverse consequence.

Signature:
I have read the explanation of this study. I have been provided with an opportunity to discuss this study and my questions have been addressed to my satisfaction. I hereby consent to take part in this study. I realize my participation is voluntary and that I am free to withdraw from the study at any time.

Signature of Participant..........................................................Signature of Researcher

Name (printed)..........................................................Name (printed)

Date..........................................................Date:

I consent to the use of direct quotations in research publications developed from this research study. I understand that I will be provided with an opportunity to review direct quotations and provide my permission for inclusion prior to publication. I understand that my name and that any other names of people or facilities will be removed from all direct quotations.

Signature of Participant..........................................................Signature of Researcher

Name (printed)..........................................................Name (printed)

Date..........................................................Date:

I consent to the digital recording of this interview. I understand that this interview could be transcribed by a separate transcriptionist and that all of my personal information will be removed prior to transcription.

Signature of Participant..........................................................Signature of Researcher

Name (printed)..........................................................Name (printed)

Date..........................................................Date:
Appendix G: Code book #1

1. Parents’ interests and conflicts
   - Child’s needs first
   - Resale
   - Luxury
   - Marital
     - Control
     - $ authority
     - % Caregiving / work
   - Other family
   - Acceptance of therapist’s advice

2. Geographical differences
   - Incomes
   - Rentals vs ownership

3. Funders
   - Rigid criteria
   - Follow-through to check how funds are used
   - Types:
     - March of Dimes, MCYS, RAPP-D, CMHC, Easter Seals, President’s Choice, Habitat for Humanity, insurance,
   - Funding means everything
   - CCAC restrictions – “OTs can do more harm that good” #1 p. 1

4. Therapists’ tools
   - Tape measure
   - Pictures
   - Other families’ experiences
   - Five feet radius +
   - Masking tape and cardboard
   - Checklist
   - Home renovation flow charts
   - “Growth footprint”
   - CD to leave with parents
   - Spatial conceptualization
   - Lap top
   - Creativity – ingenuity

5. Communication:
   - Occupational Therapist understanding families perspective barriers

6. Aging child
   - Need proactive schedule of visits – prompts
     - Start at age 2
   - Parents’ can’t anticipate
Bathing a 16 year old….

7. Parents’ readiness
   Accepting need for modifications
      Physical, psychological and social
   Can’t foresee / not ready to accept needs of older child
   Hindsight  20/20
   ‘It’s so overwhelming’
   Grieving
   Divorced / separate families
   Cultural norms
   Accepting that it is not a “quick fix”
   Belief that child will grow out of it
   Unrealistic hope for surgical / pharm fixes
   Disabled parents / caregivers
   In denial #1 p1

8. Assessment:
   • Child’s physical status
   • Functional Analysis:
     • functional assessment/evaluation of caregivers
     • job analysis/flow analysis
       o what care happen
       o where does the care happen
       o how does care happen
     • performance analysis of caregiver
     • use of space
       o alternate uses of space
       o how physical home environment is used
   • Safety

9. Family identified needs and goals
   • broad
   • refined
     ▪ Family priorities and expectations
     ▪ lifestyle and desires

10. Environment (ICF):
    • support and relationships
      o Immediate Family
        ▪ culture
        ▪ value system
        ▪ social and emotional
          • personal resources and resiliency
        ▪ decision maker capacity
        ▪ immigration status of
      o Extended Family
      o Community
      o People in positions of authority
        ▪ CCAC
• funders
  o Personal Care providers (PSWs)
  o Health Professionals & other professionals
• Attitudes
  o Immediate Family
    ▪ fear of stigma
  o Extended Family
  o Community
    ▪ vendor
• Services, systems and policies
  o Architecture and construction
  o Housing
  o Communication
  o Associations
    ▪ As funder
    ▪ Related to prof. services
  o Economic
    ▪ vendors
  o Social security and social support
    ▪ Informal care
  o Health
  o Education
  o Political
• products and technology
  o home’s architectural & structural barriers
  o assistive products used in daily living
    ▪ current
    ▪ abandoned
  o products for mobility
  o design, construction & building products for private use
  o Assets
    ▪ financial
    ▪ tangible
      • resale value

11. Caseloads
   Tbi, MD, SB, CP

12. Caregiver Burden
   Carrying child
   Back / shoulder injury – the straw that broke …. 
   Need for understanding
   Need for someone to talk to in own language
   More for a mother #1 p10 (bottom)
   Emotional readiness “1 p.13

13. Future forecasting:
• Future planning
  o education about the future care and capacity
• painting the picture of the future
• future image
  • Occupational Therapist
  • Family
• Time for decision making
  o examine potential futures
14. Client centred care (CCC) vs Family centered care (FCC)
• balancing
  o child’s rights
  o advocacy
• conflict
• ethics
• who is the client
  o family
  o caregiver
  o child
  o funder (CCAC)
  o PSW/professional caregiver
15. Selling
• save them from themselves
• Occupational Therapist knowing what is necessary
  o family wanting something else
• Conceptualizing
• Managing expectations
• Influencing decision making/ persuading
• directing the process
16. “Plant the seeds”
17. Listen, listen, listen
   What are the real family issues?
   Assess family needs
   “how overwhelming is this?”
   Relief or respite?
   Details - Where do they keep their toothbrush
   “It’s their house”
   Other idiosyncracies
18. Accept other cultural norms
   Infantilizing child
   Denigrating women
   Focus on physical / everything
19. Guide and brainstorm
20. Persuading
   “I don’t think this is misleading”
   “I don’t know how to say it – ‘convince’…. Don’t mean to sound like a control thing … want client satisfaction” #6 p.4-5.
“sell” - #6 p. 10 – get around COTO

21. Look for small changes that make a big difference
22. Have to be assertive
   Family - ‘I’m fearful for your safety’ – p#1 p.21 bottom
   Contractors and architects
      Don’t recommend contractors
      Work with contractor
   Don’t be power of attorney
   I’m not an architect

23. Process
   Complex on many levels
      Regulations
      $
      Mixed family interests
   It’s in your head
   Don’t use standardized measures / forms
   Flexibility – never one solution – have many ideas
   Needs first then talk about money
   First visit(s) just talk
      Takes time
         Number of visits
         Number of years
      “Walk me through your day”
      Don’t just start measuring
      Start with the exterior
   Many visits, many discussions
   “Failures” / or when it feels like you failed
   Need standards or guidelines
      #1 p1 – very scattered - need core of knowledge

24. Therapists’ accountabilities
   COTO
      Protecting myself
      Reputation
         Embarrassed by what families do
      Code
         When code doesn’t meet needs – “it’s great if it works” #5 p. 10
      Child and family safety

25. Advocate for child vs family lifestyle
26. Stupid equipment
   Stair glides
   Oval tubs
   Showers with lips
   Elevators - faster to carry
   “Accessible” shower stalls
   Deep sinks
Cushioned flooring

27. Stupid houses
   Move or stay
   Bathrooms
   Getting into house
   Ramps
      Grade
      Security
      Maintenance
   Basements for teens
   Split level on hill

28. Other stakeholder interests
   Vendors
   Contractors
   Extended family
   Paid caregivers and their agencies
   Architects
   Teachers and teaching assistants

29. Peer support
   Make sure you’re thinking of everything possible
   Need “mother of all forms”

30. Continuing Ed
   Courses
      KP

31. Referrals
   Home mod follows long rel’p
   Consultant role following treating therapist vs. being the treating therapist
   Parents self-refer
   Number of visits (ccac)
   Vast diversity

32. Therapists’ roles
   Mixed roles from school-based, private consulting, child centre consultant
      Home therapy / School therapy / strictly home mod
   Assess home before new purchase
### Question: What information do EI OTs gather to inform their home modification recommendations

<table>
<thead>
<tr>
<th>Numbers</th>
<th>Categories &amp; Codes</th>
</tr>
</thead>
</table>
| 1       | Parents’ interests and conflicts  
Care vs control  
Values: child vs financial benefit |
| 2       | Funders: funding means everything; types: OMOD, MCYS, RAPP, CMHC, ES, PC, H for H, insurance  
Rigid criteria  
CCAC restrictions – “OTs can do more harm that good” #1 p. 1 |

### How EI OTs in Ontario evaluate and prioritize that information to develop recommendations

<table>
<thead>
<tr>
<th>Numbers</th>
<th>Categories &amp; Codes</th>
</tr>
</thead>
</table>
| 3       | Therapists’ tools (Tape measure, Pictures, Other families’ experiences, Five feet radius +,  
Masking tape and cardboard, Checklist, Home renovation flow charts, “Growth footprint”,  
CD to leave with parents, Spatial conceptualization, Lap top, Creativity – ingenuity) |
| 4       | Parents’ readiness  
Accepting need for modifications  
Physical, psychological and social  
Can’t forsee / not ready to accept needs of older child  
Hindsight 20/20  
‘It’s so overwhelming’  
Grieving  
Divorced / separate families  
Cultural norms  
Accepting that it is not a “quick fix”  
Belief that child will grow out of it  
Unrealistic hope for surgical / pharm fixes  
Disabled parents / caregivers  
In denial #1 p1 |

### What data do OTs gather when assessing the needs for home modifications?

<table>
<thead>
<tr>
<th>Numbers</th>
<th>Categories &amp; Codes</th>
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</thead>
</table>
| 5       | Child’s physical status assessment  
Ind. vs, Dep.  
Amount & type of assistance required for each ADL  
Type of transfers |
| 6       | Functional Analysis  
functional assessment/evaluation of caregivers  
job analysis/flow analysis  
what care happen  
where does the care happen  
how does care happen  
performance analysis of caregiver  
use of space  
alternate uses of space  
how physical home environment is used  
Safety/Disabled parent or caregiver/caregiver burden |
| 8       | Support and Relationships Environment (ICF) |
| Immediate Family |  
| culture |  
| value system |  
| social and emotional |  
| personal resources and resilency |  
| Financial resources - income |  
| decision maker capacity |  
| immigration status of |  
| Extended Family |  
| Community |  
| People in positions of authority |  
| CCAC |  
| Funders |  
| Personal Care providers (PSWs) |  
| Health Professionals & other professionals |

**9 Services, systems and policies Environment (ICF):**
- Architecture and construction
- Housing: rental vs ownership
- Communication
- Associations
- As funder
- Related to prof. services
- Economic
- Vendors
- Social security and social support
- Informal care
- Health
- Education
- Political

**10 Products and Technology Environment (ICF):**
- home’s architectural & structural barriers
- assistive products used in daily living
- current
- Abandoned
- products for mobility
- design, construction & building products for private use
- Assets
- financial
- tangible
- resale value

**11 Future forecasting**
- Future planning
- education about the future care and capacity
- painting the picture of the future OT
<table>
<thead>
<tr>
<th>recommendations?</th>
<th>future image Family</th>
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<tbody>
<tr>
<td>Time for decision making</td>
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<tr>
<td>examine potential futures</td>
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<td>12</td>
<td>Client centred care (CCC) vs Family centered care (FCC)</td>
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<td>Balancing</td>
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<td>child’s rights</td>
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<td>advocacy</td>
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<td>Conflict</td>
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<td>Ethics</td>
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<td>who is the client</td>
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<tr>
<td>Family</td>
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<td>caregiver</td>
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<tr>
<td>Child; Advocate for child vs family lifestyle</td>
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<tr>
<td>funder (CCAC)</td>
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<tr>
<td>PSW/professional caregiver</td>
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<tr>
<td>13</td>
<td>Selling/Persuading</td>
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<tr>
<td>Communication</td>
<td></td>
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<tr>
<td>Understanding family’s perspective</td>
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<td>Barriers: family wanting something else</td>
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<td>save them from themselves; guide and brainstorm – provide options</td>
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<td>Occupational Therapist knowing what is necessary/options</td>
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<tr>
<td>Look for small changes that make a difference; prioritizing – not ideal solution</td>
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<tr>
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<td>Managing expectations</td>
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<tr>
<td>Influencing decision making/ persuading</td>
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<tr>
<td>directing the process</td>
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<tr>
<td>Negotiation of parameters; Family priorities and expectations and identified needs and goals/options; lifestyle and desires</td>
<td></td>
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<tr>
<td>14</td>
<td>“Plant the seeds”; aging child</td>
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<tr>
<td>Need proactive schedule of visits – prompts, start at age 2</td>
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<tr>
<td>15</td>
<td>Listen, listen, listen</td>
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<tr>
<td>What are the real family issues?</td>
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<td>16</td>
<td><strong>Have to be assertive</strong></td>
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<td></td>
<td>Family - ‘I’m fearful for your safety’ – p#1 p.21 bottom</td>
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<td></td>
<td>Contractors and architects</td>
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<td></td>
<td>Don’t recommend contractors</td>
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<td>Work with contractor</td>
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<td>Don’t be power of attorney</td>
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<td>I’m not an architect</td>
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<thead>
<tr>
<th>17</th>
<th><strong>Process</strong></th>
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<td></td>
<td>Complex on many levels</td>
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<td>Regulations</td>
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<td></td>
<td>Mixed family interests</td>
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<td>It’s in your head; don’t use standardized measures / forms</td>
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<td>No standardization measures/forms</td>
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<td>Need standards or guidelines: Need “mother of all forms”</td>
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<td>#1 p1 – very scattered - need core of knowledge</td>
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<thead>
<tr>
<th>How do OTs structure their recommendations for home modifications for physically dependent children and their families and caregivers?</th>
<th>18</th>
<th><strong>Therapists’ accountabilities</strong>: providing options for informed decision making</th>
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<tbody>
<tr>
<td></td>
<td></td>
<td>COTO</td>
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<td>Protecting myself</td>
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<td>Embarrassed by what families do</td>
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<td>Building Code</td>
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<td>When code doesn’t meet needs – “it’s great if it works” #5 p. 10</td>
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<td>Child and family safety</td>
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<td>Vendors</td>
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<tr>
<th>20</th>
<th><strong>Peer support</strong></th>
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<td></td>
<td>Make sure you’re thinking of everything possible</td>
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</table>
Appendix I: Member Checking Thematic Summary

A Qualitative Analysis of Current OT Practice in Home Modification Recommendations in Ontario

Study Purpose:
The purpose of this research was to:

1. Examine what information educationally influential Occupational Therapists (EI OTs) gather to inform their home modification recommendations
2. Examine how EI OTs in Ontario evaluate and prioritize that information to develop recommendations for home modification for children and their families who require extensive home modifications.

Summary of Findings:
Concerning the type of information the EIOTs gathered, five themes emerged in this research:

1. “Back of my mind”: OT’s agenda and tool box
   a. Future oriented: the participants approached each client situation with the intention of thinking about the future and not being short sighted in the decision making.
   b. Available funding: sources and amounts of funding were limited, as was the scope of coverage of particular funding sources; need to get the most for the money that was available within the time frames of eligibility.
   c. Client / family-centred: advocated for the child and their needs and inclusion while simultaneously considering the effect that any modification had on the entire family so as to not create barriers for other family members living in the home; need to gather information about who used the space and what they did in the space; both client and caregiver safety are of primary importance in the assessment process; concept of ease of care: care needed to be accomplished in a safe manner while reducing the physical burden of care.
   d. Privilege to be in their home: conscious of being in the client’s homes and the import of being a “guest” in the home; that to be effective the therapist had to be able to get into the child’s home.
   e. Priority access issues:
i. access to the house
ii. access to the washroom
iii. access to the bedroom
iv. ease of circulation (which includes layout, level changes and flooring)

The therapists’ tool box:

- measuring tape,
- visual media such as pictures (hard copies or in electronic form),
- adult sized equipment to help families visually understand the impact that larger equipment would have on the space in the house.
- cardboard or masking tape to demonstrate the space requirements and impact of the lift device in the proposed location.
- knowledge of the portion of the building code that was relevant to the home accessibility issues they typically addressed.
- use of other families’ experiences to provide ideas regarding practical ways in which similar barriers to accessing their home or caring for their child could be overcome.

Communication skills

2. “An informal walk through their day”:
   - Understand the job of caring for the child:
   - what care occurred for that child,
   - when during the day the care occurred,
   - where the care occurs,
   - who performed the care,
   - how specifically the care was performed
   - why the care was performed in a particular manner.

Give insight into:

- use of space; how the physical environment is used and who else used the space
- possible alternate use of the space
- caregiving role from a functional perspective

3. “Get to know the dynamic of the family”:
o what the family’s needs, goals, priorities and expectations are
o what was tried and think will work and what equipment had been abandoned
o understanding who the decision maker is in the family and is the decision-makers involved in the care of the child and present during the OT’s visits
o whether the home is owned by the family and/or whether they are in a rental situation
o information concerning the financial resources and limitations; there is almost always a need to prioritize
o understanding each family’s “idiosyncrasies”

o culture often informs the value systems and lifestyle preferences of the family
o “fit” with the family lifestyle must be achieved
o “readiness” has 2 phases:
  ▪ the family identifies and discusses future needs and care issues and the permanency of the disability.
  ▪ when the family actually wants move ahead with a modification.

o getting to know the human and/or institutional support systems that are in place sustaining the family: how the rules and regulations of these systems influencing the recommendations
o evaluated and considered the physical and emotional aspects of the caregiver’s role:
  ▪ PSWs role demands (safety, physical job demands) vs. familial caregivers (relative to safety and the emotional aspects of the job demands and how not meeting those demands will affect the child)

4. “Future forecasting”: plant the seed
   • “plant[ing] the seed” early at two or three years of age
   • being “proactive rather than reactive”
   • presenting options to address barriers to caregiving

5. “Funding means everything”:
   a. knowledge of funding mandate and eligibility and timelines
i. a variety of funding barriers:
   1. insufficient funding for OTs to do a complete assessment over many visits
   2. strict eligibility criteria for agencies providing funding to families to complete home modifications.

b. need to make recommendations work within confines of funding for maximum impact for family

c. need for accountability
   i. personal accountability of the OT
   ii. accountability of the funder
   iii. governmental: building code being inadequate concerning residential access

**Process:**
The therapists went to great lengths to dissuade the family from making short sighted plans or unsafe plans. Funds are limited and very often did not cover all of the needed modifications so the EIOTs did not want the families or themselves to make irreparable mistakes. The options presented by the EIOTs to the families were the aggregate of the analysis the OT does as they gather information about the barriers in the caregiving environment, the nuances of the family and the caregiver job analysis filtered through the OT’s agenda of ease of care. Only options which best meet the needs of the family are presented with the intention of eliciting feedback from the family concerning their readiness and their perception of how the proposed option “fits” with the family. As the family reacts and express their opinion about the options a dialogue is initiated which provides the OT with further insights into the family’s preferences in addition to giving the OT the opportunity to educate the family about risks and benefits of various options. This process which one of the participants described as a “negotiating, sort of fluid process” assists the clinician in finding a solution which is reasonable and acceptable to both the agenda of the OT and the lifestyle of the family. Each of the participants spoke about guiding families in this process and ensuring that the proper planning occurs. They all spoke of presenting the advantages and disadvantages of all of the proposed solutions
in order to inspire different ways of thinking about the issues and hopefully avoiding problems.

None of the EIOTs used formal or standardized assessment tools rather their recommendations are based on long discussions learning about the particular concerns of the family. The institutional and social systems which have influence on home modifications are fixed and rarely change. This would be such systems as municipal bylaws, building code, the occupational health policies and regulations relative to professional caregivers and funding agency guidelines. These systems provide the context in which the OT and the family are making their decisions. The technology available to solve accessibility and caregiving issues are also limited in their range and application. It is the iterative process directed by the OT which integrates the fixed systems with the unique needs to the child and their caregivers. The OT brings their own agenda, knowledge and skill set to the table as a specialist who guides the process. The skill of the EIOT is extracting and synthesizing all of the data, comparing the data with potential solutions, eliminating solutions which are not viable and providing sensitive options to the family. In conclusion, the EIOTs enable a process which is often financially and emotionally difficult for the family. They have specific information which they gather in each situation in order discern the uniqueness of each situation with the aim of developing a recommendation which ensures a safe and enduring environment for the child and their caregivers.

Visually the relationship of the themes to the process is represented on the following page.