

SERVICE UTILIZATION AND PARTICIPATION OF CHILDREN WITH  
DISABILITIES

FACTORS OF SERVICE UTILIZATION AND PARTICIPATION OUTCOMES OF  
CHILDREN WITH DISABILITIES

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### **Lay Abstract**

This study examines the relationship between factors of service utilization and participation outcomes for children with disabilities. Currently, there is little knowledge pertaining to the characteristics of children receiving rehabilitation services and the influence of these services on health outcomes. Such information is vital to understand how health conditions, service utilization, service planning, and service satisfaction differ across children with disabilities.

Use of health services (type and number of rehabilitation services used, duration of services), environmental barriers, maternal leisure practices, and socioeconomic factors are examined with consideration to the child's diagnosis and complexity in relation to scores of participation. This is the only study in Canada so far to comprehensively explore relationships between rehabilitation utilization and participation. The study informs health care providers and researchers about patterns and variations in children's needs that can be utilized to improve service quality and plan services, as well as to understand participation patterns.

## **Abstract**

Home and community participation is measured by a multitude of determinant factors based within the context of a health system. Three studies were completed to understand relationships between environment and personal factors with service utilization and outcomes of participation among children with disabilities.

In the first study, a scoping review was completed to identify factors that influenced rehabilitation service utilization among Canadian children with disabilities. Key findings of this review indicated higher rates of service utilization are associated to younger age, males and those with lower cognitive or motor functioning. Occupational therapists, physiotherapists and speech language pathologists were the most commonly utilized disciplines. Higher perceptions of service satisfaction related to increased presence of family-centered practices. Areas requiring further research include family needs, barriers, personal health practices and participation outcomes.

Based on the findings of this review, a survey was created to administer to parents using a large children's rehabilitation treatment centre in Ontario. Findings from the survey conducted with 279 parents are reported in the second study by providing a descriptive profile of families and children using geographically-based rehabilitation services. Families using the centre typically have younger aged children, with more boys than girls, and a large proportion use the centre for speech services. Complexity scores correlated significantly and positively with service need and service utilization, indicating children with lower functioning desired and received more rehabilitation services. Age, sex, and diagnosis did not predict total time in therapy, but complexity was a significant

predictor of total time in therapy. Participation frequency scores showed weaker relationships to complexity in comparison to participation involvement scores.

The final study explored the relationship between environmental and personal factors of service utilization and participation using structural equation modeling. Predictors of participation include child's age, environmental barriers, complexity, and mother's participation. Findings support that exploring children's complexity and promoting mother's participation by removing environmental barriers and modifying inaccessible structures are important to examine from a young age.

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*My dissertation is dedicated to my former and future students, my lovely sister, Aisha, and my brother, Amir, who left me too soon.*

*I will spend the rest of my life searching for the meaning that I lost when I lost you. In every goal I pursue, I will ensure that my work centers on promoting children's happiness, because laughter and happiness were the essence of your soul. Your love for children and making them happy will always guide me.*



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## **List of Abbreviations**

ABI	Acquired Brain Injury
AMC	About My Child
CBCL	Child Behavior Checklist
CDN	Canadian
CEOs	Chief Executive Officers
CHIEF	Craig Hospital Inventory of Environmental Factors
CIHI	Canadian Institute for Health Information
CNPHS	Canadian National Population Health Survey
COPM	Canadian Occupational Performance Measure
CP	Cerebral Palsy
CSQ	Client Satisfaction Questionnaire
DCD	Developmental Coordination Disorders
DD	Developmental Delays
desc stats	Descriptive Statistics
FCP	Family-Centred Practice(s)
FIM	Functional Independence Measure
HPAS	Health Promoting Activities Scale
ICF-CY	International Classification of Functioning, Disability and Health – Children and Youth Version
MPOC	Measures of Processes Of Care
OT	Occupational Therapist(s)/Occupational Therapy
PDD	Pervasive Developmental Delay



PDMS-II	Peabody Development Motor Scales, second edition
PEDS-QL	Pediatric Quality of Life Inventory
PEM-CY	Participation Environment Measure for Children and Youth
PPVT-IV	Peabody Picture Vocabulary Scale
PREP	Pathways and Resources for Engagement and Participation
PT	Physical Therapist(s)/Physical Therapy
SAS	Supports and Service Questionnaire
SEM	Structural Equation Modeling
SES	Socioeconomic Status
SLP	Speech-Language Pathologist(s)/Speech-Language Pathology
SP	Service Provider(s)
SW	Social Worker(s)/Social Work
TBI	Traumatic Brain Injury
TR	Recreational Therapist(s)/Recreational Therapy
US	United States
VABS	Vineland Adaptive Behavior Scale
WPPSI	Weschler Primary and Preschool Scale of Intelligence
YC-PEM	Young Children's Participation Environment Measure

### **Declaration of Academic Achievements**

This manuscript consists of five sections to compose my doctorate dissertation. The first and last chapters are respectively the introduction and conclusion. Chapters two to four consist of studies conducted to examine the area of focus – the relationship between children’s participation with crucial factors of service utilization. Chapter two has been submitted for publication. Chapters three and four will be compressed and sent to academic journals for publishing.

The role and contribution of each committee member is highlighted below.

Dr. Mary Law, FCAOT, retired during the course of this study and received the title of Professor Emeritus at McMaster University. Dr. Mary Law is the co-founder of CanChild Centre for Childhood Disability Research, to which this study is affiliated. Her primary areas of research interest included the creation and validation of participation measures, as well as exploring personal, family and environmental factors which impact participation trajectories of children with disabilities. Dr. Law’s secondary areas of interest include evaluation of family-centered services and evidence based best practice.

Dr. Steven Hanna’s area of expertise is statistical analysis. Dr. Hanna’s research includes social aspects and clinical measures of childhood disability. He ensured methodology and analysis were accurately conducted. Dr. Hanna is a professor in the Department of Clinical Epidemiology and Biostatistics, and the Assistant Dean of the Health Research Methodology Graduate Programs at McMaster University.

Dr. Jan Willem Gorter, FRCPC, is a pediatric physiatrist, an associate professor in the Department of Pediatrics at McMaster University, director of CanChild, and currently

holds the Scotiabank Chair in Child Health Research. Dr. Gorter's research assesses health outcomes such as quality of life measures including physical participation among children with disabilities.

For all three studies, Uzma Williams and Mary Law worked collaboratively to refine research questions and develop manuscripts. Under the supervision of Mary Law, Uzma produced all written documents, obtained ethics approval from the Hamilton Integrated Research Ethics Board (HIREB), designed and implemented the survey, conducted analysis, and prepared the manuscripts. All members of Uzma's committee reviewed and provided input to each chapter in this manuscript.

## **Chapter Two**

Chapter two is titled *Scoping Review of Rehabilitation Service Utilization Literature for Children with Developmental Disabilities* and authored by U. Williams, M. Law, J.W. Gorter, and S. Hanna. The article was submitted to the Open Journal of Occupational Therapy. This scoping review was conducted from January 2013 to June 2015. Uzma organized the database searches to identify the literature while Mary provided further articles that were not found by the database search. Uzma produced the manuscript and Mary reviewed the accuracy of the analysis. Jan Willem and Steve reviewed the manuscript by refining research questions and providing comments to optimize study design, interpretation, and organization.

## **Chapter Three**

Chapter three is titled *Part 1: A Profile of Families Using a Children's Rehabilitation Service Centre in Ontario, Canada* and authored by U. Williams, M. Law,

J.W. Gorter, and S. Hanna. This manuscript will be submitted to Child: Care, Health and Development for publishing simultaneously with chapter four. Uzma produced the manuscript which was reviewed respectively by Mary, Jan Willem, and Steve. The committee members reviewed the manuscript by refining the research questions, optimizing study design, interpretation of results, improving organization, and correcting grammatical/sentence errors.

#### **Chapter Four**

Chapter Four is titled *Part 2: Personal, Environmental, and Family Factors of Participation of Children Using a Rehabilitation Service Centre in Ontario* by U. Williams, M. Law, S. Hanna, and J.W. Gorter. This manuscript will be submitted to Child: Care, Health and Development for publishing. Steve assisted in the analysis of the data using structural equation modeling via Mplus by identifying key processes (e.g., maximum likelihood estimation), demonstrating the input of unique syntax, ensuring testable hypotheses and models, and identifying limitations. Uzma produced the manuscript respectively reviewed by Mary, Steve, and Jan Willem. The committee members reviewed the manuscript by refining research questions, optimizing study design, interpretation of results, improving organization, and correcting grammatical/sentence errors.

## **Chapter One – Introduction**

### **Study Background**

The period from birth to adolescence is marked by rapid progression of cognitive, social, emotional, and physical abilities. The World Health Organization in the International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) identifies that contextual systems of a child are major determinants of children's development (World Health Organization, 2007, p. xv-xvi). A contextual system consists of personal and environmental factors that shape childhood development (p.15), and many of these determinant factors can be modified to improve daily living and health outcomes. When optimizing health and functioning, it is important to focus on improving mutable factors (i.e. the propensity that a factor can change as a result of an intervention; Andersen, 1995). As a result, health outcomes such as participation should be an important focus in therapy, and setting goals in therapy to remove barriers within the environment may be conducive to improving participation in the home, school and community. For example, if a child is physically unable to type on a computer keyboard, enabling voice command can mitigate this issue allowing the child to competently use a computer. On the other hand, other determinant factors such as age, gender, and diagnosis are impossible or very difficult to alter.

### **Participation**

The ICF-CY defines participation as the, “involvement in a life situation” (World Health Organization, 2007, p. 12) and activity as the, “execution of a task or action by an individual” (World Health Organization, 2007, p. 12). The quantity and type of activities

are indicative of a person's participation, thus participation serves as an umbrella term. Law (2002) enhances the definition of participation and clarifies the relationship between these two terms: "For children and youth with disabilities, participation in activities is the context in which they learn skills, do tasks and activities, develop friends, and find satisfaction. Participation is extremely important for a child's development." (p. 1). Specifically, participation is taking part in daily life activities ranging from sedentary reflective activities to physical activities done socially or alone. Participation is a holistic health outcome and indicates significant patterns and behaviors towards engaging in a wide variety of life activities in home, school, and community settings.

Participation is important to measure among children with disabilities because participation indicates significant life patterns on how children engage in different activity settings such as service utilization. Higher participation levels in children are tied to better outcomes and health functioning (Bedell et al., 2013; Calley et al., 2012; Coster et al., 2013; Law et al., 2013; Williams & Willmott, 2012). As a result, participation is a strong focal point to measure health outcomes.

Participation including activities has been examined in different ways among children with disabilities since it was included in the ICF-CY in 2003. Since this time, researchers have measured participation through multiple dimensions. For example, participation can be measured by the frequency and level of involvement within the home, preschool/school/daycare, and community setting using the Participation Environment Measure for Children and Youth (PEM-CY; Coster et al., 2012). Researchers have created additional measures that report children's pleasure in activities,

variety of activities engaged, and parental perceptions of children's participation.

Environmental supports and barriers have also been an important focus when assessing factors that facilitate or hinder participation. A range of indirect factors have been considered when assessing children's participation, specifically health conditions or disorders, severity, and complexity (Law et al., 2004).

### **Participation and Living with a Disability**

Developmental disability can be caused by hereditary dispositions, chromosomal errors, or injury. Disorders of childhood range from mild to severe impairments, often depending on the diagnosis. Disorders become more complex when multiple areas are limited including physical, social and cognitive functioning. The impact of any disability can be quite significant on all areas of life. A 2006 report from Human Resources and Skills Development Canada presents that 1.7% (27,540) children aged 0 to 4 years live with a disability. The rate of disability rises to 4.6% (174,810) across 5 to 14 year olds. Communication and chronic health conditions are the most common disabilities among Canadian children aged 5 to 14 years. Approximately half of families report an increase or decrease in working hours in response to an intensified need to provide care for their child or cover health care costs. Out of pocket costs are incurred for older children (5 to 14 years) more often than for younger children (0 to 4 years). Furthermore, children 5 to 14 needed more visits to health professionals than younger aged children. Finally, the report indicated that access to childcare among children 0 to 4 years was difficult to obtain. Thirteen percent of parents reported that their children were refused care because of the requirements of their condition.

In this 2006 report, parents indicated their children from 0 to 4 years-old encountered many obstacles participating in home-based activities. As children grew older, they began to encounter additional barriers in school and community settings. Children aged 5 to 14 years experienced a considerable amount of physical and verbal violence in school. The high school dropout rate among 15 to 19 year old youth with disabilities is 14.2%, compared to 9.7% of youth without a disability. Access and inclusion are hindered due to the interference that a physical or non-physical disability has on participation. The United Nations organization, among health professionals, recognizes the rights of children with disabilities to access and equality.

Children with disabilities should have full enjoyment of all human rights and fundamental freedoms on an equal basis with other children, and recalling obligations to that end... 1. Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children. 2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration. 3. Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realize that right. (UN Convention on the Rights of Persons with Disabilities cited in World Health Organization, 2007).

The promotion of participation to improve daily living is imperative for families of children with disabilities. Health systems and services play a central role to improving physical and mental functioning of all Canadians as explicated by the Canada Health Act of 1984.

### **Health Systems and Services**

One avenue to optimize participation among children with disabilities is exploring services received at children's treatment centres. Rehabilitation therapists at children's



treatment centres are a crucial point of contact for promoting participation. An individual's health structure consists of "services, systems and policies for preventing and treating health problems, providing medical rehabilitation and promoting a healthy lifestyle" (World Health Organization, 2007, p. 219). The health system consists of a variety of contexts that include personal factors, family factors, and environmental influences such as service center characteristics including the number and use of health services. Exploring these components comprehensively provides insight into the relationship between an individual and their health, as well as an assessment of client profiles, service utilization, health behaviors, and health outcomes.

Receiving effective health services appears to have a positive relationship with health outcomes (Feldman, Swaine, Gosselin, Meshefedjian, & Grilli, 2008; Law et al., 2005). Unfortunately, however, services can have no impact or even a negative impact on families if services are inadequate to address individual needs. Health systems require evaluation to ensure they are valuable and effective. Evaluation ensures services are being optimized and provide evidence-based practice (Duckett, 2012). More importantly, services should reflect values that are family-centred (Rosenbaum & Gorter, 2012). Accordingly, it is crucial to assess service delivery through an evaluation model with well-established efficacy. Evaluation of health programs and organizations require a theoretical model, on top of the traditional summative and formative evaluation, to thoroughly examine multiple constructs of interest.

### **Theoretical Models Exploring Health Systems and Participation**

Service evaluation has been an important aspect for when organizations refine and optimize their programs to clients. Obtaining knowledge about factors influencing service utilization can help develop such evaluations. The research questions that explore health systems for children with disabilities revolve around, “what services and gaps are encountered within health care systems?”, “how do these impact and link to different areas of health and functioning?” and, “how does receiving rehabilitation services impact the child's outcomes, are parents satisfied with these services?”.

Over the years, multiple health models have been proposed to explore relationships between health users and health systems. This section will describe the Bioecological Systems Theory, ICF-CY, and Andersen Health Care Utilization Model including advantages and disadvantages of each model. The model best suited for this research study will be justified and discussed.

### **Bioecological Systems Theory**

The Bioecological Systems Theory was developed by Urie Bronfenbrenner and Stephen CeCi (1994). The objective of this model is to describe an individual and their environmental systems with consideration to biological dispositions. This model integrates the different dimensions of an individual's life, such as personal factors of the individual (hereditary and personality), direct environment (community, family, church, peers, school), and higher structures such as government policies. All influences impact different areas of health (emotional, social, mental, physical, and spiritual). A model adapted to children's health utilization using Bronfenbrenner's model has been proposed by Newacheck, Rising, and Kim (2006). This adaptation of the model to children with

chronic health conditions exemplifies the different levels of bioecological systems and its crucial factors (see Figure 1).

The Bioecological model is advantageous because it is comprehensive and considers all dimensions of health and environments across the lifespan of an individual. On the other hand, the broad high-level incorporation of all the levels in an individual's life makes it difficult to accurately assess the relationship between individuals' outcomes and their health systems. Important areas such as consideration of service utilization and client satisfaction are also missing. As a result, the Bioecological Systems Theory is inadequate to measure the research questions concisely and undesirable to use in this study.

### **The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY)**

The ICF-CY manual is used by a host of professionals and lay persons to obtain information on health impairments and disorders in children ages 0 to 18 years. The use of the ICF-CY allows users to share a common language to discuss health and functioning. The ICF-CY uses a biopsychosocial approach integrating biological, psychological and social dynamics in consideration of health (p. 19). The components of the ICF-CY model include body structures and functions, activity and activity limitations, participation and participation restrictions, and environmental factors and personal factors (see Figure 2).

This model excels with identifying prominent contextual factors, including personal (including family), environmental and physical abilities and impairments. One

key disadvantage exists with using the ICF-CY for evaluating health systems of children with disabilities in a rehabilitation setting to assess participation. While this model encompasses the biopsychosocial approach, it does not consider in-depth aspects of health services and utilization. As a result, a model that incorporates the contextual factors as well as service utilization is required.

### **Andersen's Health Care Utilization Model**

The Andersen's Health Care Utilization Model (see Figure 3) assesses health care services and outcomes in rehabilitation (Andersen, McCutcheon, Aday, Chiu, & Bell, 1983; Andersen, 1995). This model is described in *Revisiting the Behavioral Model and Access to Medical Care: Does it Matter?* The utilization of this model allows for an organized and consistent approach to health services assessment. The Andersen model is beneficial with assisting in organizing factors of health services that are important to health researchers for examination. The conceptual model is currently in its fourth iteration and represents factors of health that are prevalently measured by investigators (Guilcher et al., 2012). The Andersen model has four major domains and categories: i) Environment: health care system and external environment; ii) Population Characteristics: predisposing characteristics, enabling resources and need; iii) Health Behavior: personal health practices and use of health services; and iv) Outcomes: perceived health status, evaluated health status, and consumer satisfaction.

The Andersen Model was formulated to assess the quality and efficacy of health services to aid improvement with health systems. The initial development of this model had three goals: i) describe use of families health services, ii) operationalize and measure

health services, and iii) enhance policy development to increase access and inclusion for individuals disadvantaged in the health system. The model has undergone several revisions, however, remains focused on exploring health service utilization and outcomes.

The model is able to aide with summative examinations of an overall program or examination of a specific component, such as client satisfaction with services. The environment domain considers environmental supports and barriers, as well as treatment centre characteristics like family centred practices and private or public funding. Population characteristics consist of predisposing characteristics, enabling resources and need. Predisposing characteristics are personal factors named by age, gender and ethnicity. Enabling resources are characterized by elements that mediate the use of services, for example living arrangements, family income, parental education, parental work status, and social supports. Needs are assessed by complexity or severity of health conditions that result in families the need to acquire health services. Personal health practices of children and their parents are captured under health behaviors; incorporated are the use of health services exploring the type and amount of services utilized. Perceived health status can be measured by participation. Perceived health status is an important indicator because it represents how families and children assess their personal well-being and health – in line with values of family-centred practices.

Using Andersen's Model promotes the use of a common language for health professionals and lay persons. McKenna emphasizes good models, "guide the investigator through the conceptual, empirical and interpretative parts of a project" (McKenna, 1997, p. 435). Research by Graves (2009) indicates that Andersen's Model can be used to

design theoretically driven research methodology (Graves, 2009). This adaptation, as used by Graves, helps to guide researchers through a systematically structured framework in conducting research.

An advantage to this model is its applicability to multiple populations (e.g., children or adults with disabilities) in a variety of contexts (e.g., dentistry, mental health programs). The Andersen Model can be adapted to evaluate health service utilization among children with disabilities because of its ability to explore crucial factors in understanding children with disabilities. However, a measure of psychological health is not included in the standard model proposed by Andersen. One study has adapted the Andersen model to include psychological framework among adolescent health care utilization (Vingilis, Wade, & Seeley, 2007). Andersen has reflected on the inclusion of psychological concepts within his model as proposed by Vingilis and colleagues. However, the difficulty in accommodating psychological components is the multitude of complex concepts that exist, ranging from locus of control to self-efficacy. Nonetheless, investigators should consider psychological factors should these play a role in the initiative being evaluated. Another disadvantage to Andersen's Model is that factors are not standardized with specific units of measurement. The Anderson model has not been used frequently in children's rehabilitation; therefore a challenge exists to identify key factors that play a role in the measurement model.

Abstract constructs such as health and participation are difficult to define and measure (Smith, O'Grady, & Jadad, 2009). A complex construct requires a multidimensional assessment. Furthermore, in order to assess complex relationships

among factors, a theoretical model composed of multiple measures to account for human complexity is required (Whyte, 2008). While researchers cannot explain all interactions, significant relationships between factors can be described by using Andersen's model. Additionally, rehabilitation sciences research requires the contribution of a host of inter-professionals to adequately assess best practice (Reinhardt & Stucki, 2009). For rehabilitation research, a broad, unified approach to measuring service delivery such as Andersen's Model accounts the inputs of different disciplines and perspectives.

In summary, Andersen's Model of Health Care Utilization has the capability to assist health professionals with improving delivery of services for families. This model is appropriate to use when assessing health systems utilization and outcomes research. Andersen's Model is desirable to use in this study to assess the relationship between health systems and health outcomes by: i) describing use of health services, ii) operationalizing measurement of health care services, iii) improving equitable access to services, and iv) providing a common language.

### **Statement of Problem and Research Objectives**

Little knowledge exists on relationships between children's rehabilitation service utilization and participation. Researchers have found a relationship between characteristics of an effective rehabilitation systems and children's quality of life (Colver, 2009), maternal well-being (Bourke-Taylor et al., 2013), and family-centered practices (Law et al., 2003). No study thus far has comprehensively examined relationships that exist between rehabilitation systems and participation outcomes among children with disabilities. This study will report on the existing knowledge of children with disabilities

in Canada, a description of the families using services, and the relationships between prominent factors (e.g., the role of diagnosis or complexity on the use of health services and participation outcomes). The main goal of this study is to explore the current state of a rehabilitation health system, with a focus on service utilization and participation.

While there is a vast amount of research on health systems and outcomes of children with disabilities in the United States, little literature of this research exists in Canada. Accordingly, the second chapter explores health care utilization among Canadian children with disabilities. The next step of this study involves using the factors of a rehabilitation health system identified in the scoping review to create a questionnaire. The questionnaire consists of multiple items and measures to describe relationships between factors. The results of the survey, a description of the Canadian families using rehabilitation services, and relationships between the factors are presented in chapter three. As well, 100 individualized reports were sent to families who requested their survey results. The final chapter presents a measurement model via Structural Equation Modeling to assess the impact of specific factors within the Andersen model on rehabilitation service utilization and participation among children in the study.



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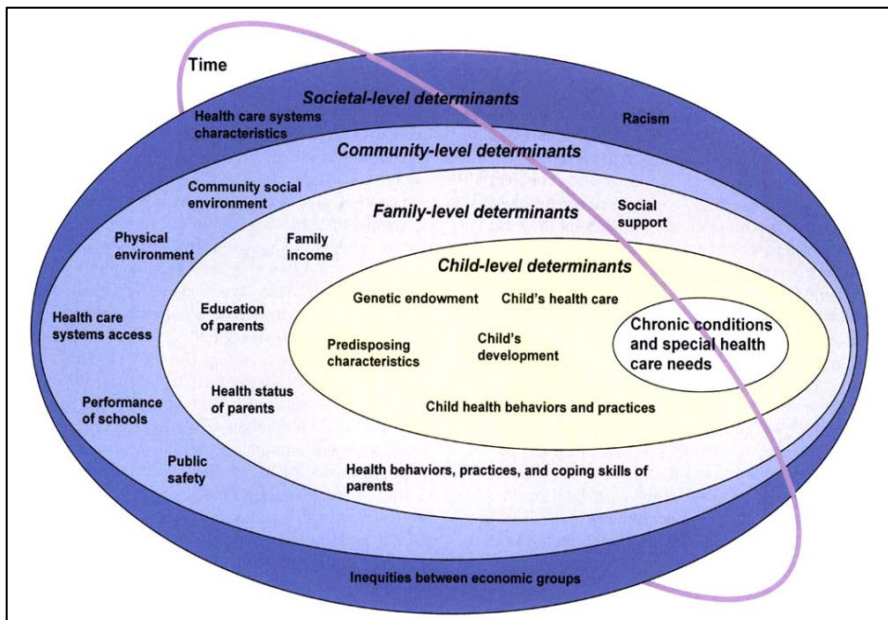
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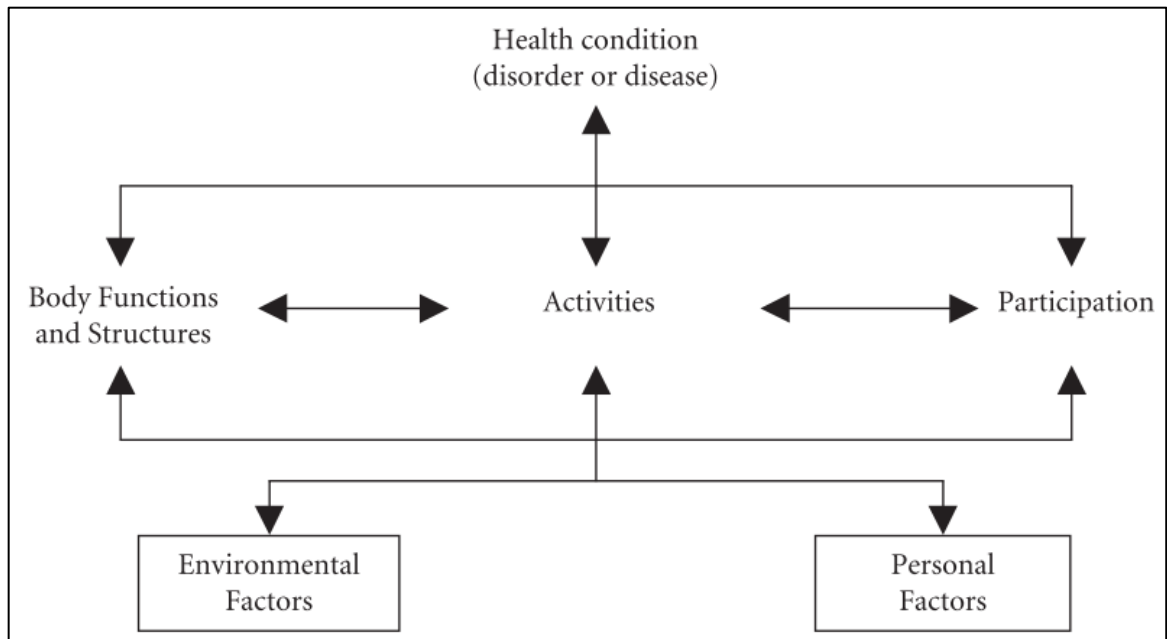
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*Figure 1.* Newacheck, Rising, and Kim (2006) bioecological conceptual model of risk factors influencing chronic conditions and special health care needs of children.



*Figure 2.* Biopsychosocial Model of The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY).

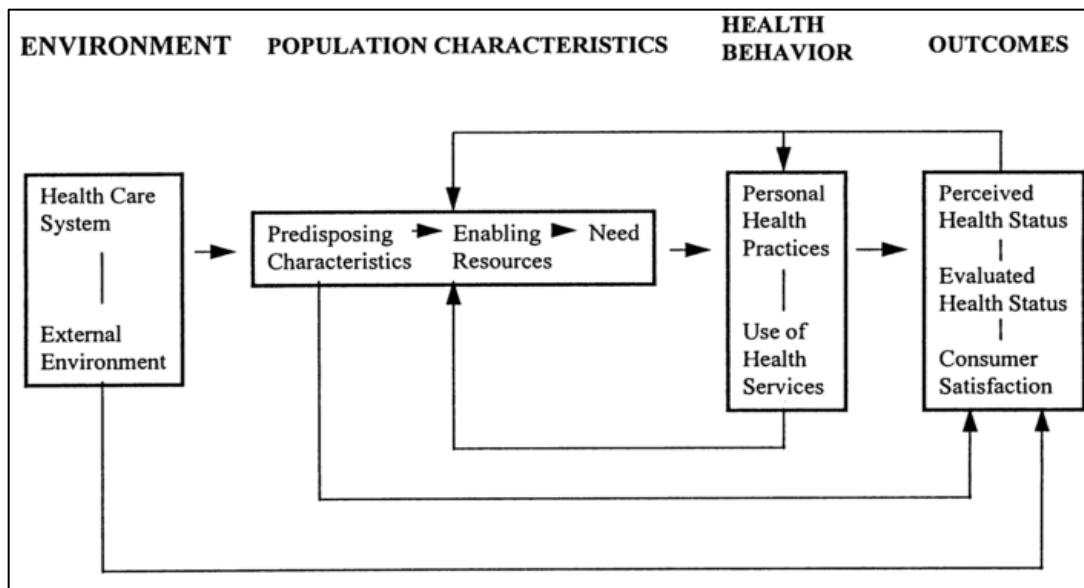


Figure 3. Andersen's Model of Health Care Utilization (1995).

## **Chapter Two – Scoping Review of Rehabilitation Service Utilization Literature for Children with Developmental Disabilities**

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This chapter contains a manuscript entitled: “Scoping Review of Rehabilitation Service Utilization Literature for Children with Developmental Disabilities”. This manuscript was submitted to the *Open Journal of Occupational Therapy*. The section on appraising the quality of the articles in the manuscript was removed to meet submission guidelines on length.



### **Abstract**

**Background:** Currently, two knowledge gaps in children's rehabilitation research need to be addressed. First, there is a need to explore factors and outcomes of children's service utilization in a comprehensive manner, which is of interest to readers globally. Second, the current state of knowledge in children's rehabilitation system in Canada is unknown, requiring a review of the existing literature to identify trends and areas understudied.

**Objective:** The objective of this review is to identify key factors shown to influence utilization and areas understudied in children's rehabilitation services based on Canadian literature.

**Methods:** Eleven peer-reviewed articles were selected for review. Andersen's Model of Health Care Utilization was used as a lens to extract the data, and the findings of the studies were examined through the domains of Andersen's Model.

**Results.** Studies focused heavily on exploring family-centred practices and consumer satisfaction. The analysis revealed that higher rates of service utilization are associated to a younger age, males, and lower cognitive or motor functioning. Occupational therapists, physiotherapists and speech-language pathologists were the most utilized disciplines, and higher perceptions of service satisfaction were related to increased presence of family-centred practices at the centre. Personal health practices, participation and functional outcomes in relation to service utilization are areas requiring more research.

**Conclusions.** We recommend future researchers examine interactions between key factors identified in this scoping as well as explore factors in understudied areas to obtain

a comprehensive understanding of children's rehabilitation utilization.

Scoping Review of Rehabilitation Service Utilization Literature for Children with  
Developmental Disabilities

**Introduction**

To date, research on recent trends and patterns of rehabilitation usage for children in Canada is limited. No study has examined a rehabilitation system for children with developmental disabilities comprehensively, in terms of individual, family, and environmental factors. As well, no review has examined the current state of existing literature. Examining the current state of service utilization is vital to understand how health conditions, service utilization, service planning and service satisfaction differ across children and factors that influence utilization and outcomes. The purpose of this scoping review is to examine rehabilitation service utilization research among children with disabilities in Canada to identify major factors that influence service delivery outcomes and areas that require more research.

The complexities of examining service utilization and outcomes in a scoping review require a conceptual framework that is capable of making a multifaceted assessment such as Andersen's Healthcare Utilization Model (1,2). Andersen's Model has been commonly used to describe service utilization and outcomes in healthcare among different populations (3–5). Andersen's model comprehensively describes children's rehabilitation service utilization because of its broad health perspective, which allows us to appropriately examine a service system. Andersen's model has four major domains with categories (see Figure 1): I) Environment – healthcare system and external environment; II) Population Characteristics – predisposing characteristics, enabling

resources and need; III) Health Behavior – personal health practices and utilization of health services, and IV) Outcomes – perceived health status, evaluated health status and experience of services. Under each domain in Andersen's model, factors are measured as variables of interest, for example: predisposing characteristics: age, gender, ethnicity, enabling resources: income, social support, family health habits, and need: diagnosis, severity, perceived needs and level of functioning. Studies selected for this review will be examined using the domains and categories from Andersen's Model to inform us on important factors influencing service utilization and outcomes. Optimizing functioning and adult health outcomes of children with disabilities is the goal of every children's treatment or pediatric rehabilitation centres. The extent to which these goals are achieved depends on the quality and quantity of services received. Rehabilitation treatment received in childhood improves transition patterns of service utilization and healthcare status in adulthood (6), so service delivery is essential to evaluate. Evaluating services in relation to the outcomes also assists with crucial management processes such as cost-analysis, allocation of resources, and policy making at treatment centres. Senior managers in healthcare systems strive to lower administrative expenditures, increase equity of access to services, and increase awareness of initiatives occurring in similar regions to optimize healthcare delivery (7) in addition to optimizing the value of services and reducing waste.

Program planning and assessing the efficacy of health services, however, does not consistently involve considering the input of families or their needs. Crucial aspects that play a role in understanding healthcare utilization and service satisfaction are missed if

family and environmental factors are not fully considered (1). For example, families who have children with special care needs have much higher health related expenses, many of which are out of pocket (8) causing a strain on families that is not mitigated by the service system. Another study conducted in the United States supported that families of children receiving services for chronic pain experienced a large degree of direct (e.g., costs of services) and non-direct (e.g., loss of missing work to attend appointments) financial burden (9). Although these findings may not generalize to Canada due to a different health system, the goals of the studies are significant to the Canadian health system. By gaining a better understanding of the relationship between key factors of service utilization, such as the influence of financial burden, service managers can improve service delivery and health outcomes to families. In examining children's rehabilitation services, it is imperative to adequately assess the interplay between healthcare utilization, client outcomes and family satisfaction with services.

An important measure of health quality is the amount and type of service utilization. In comparison to the United States (n=265), mean minutes per month spent with physiotherapists (PTs) and occupational therapists (OTs) were less for children with cerebral palsy (CP) in Canada (n=134) (10). On the other hand, many similarities exist between Canadian and American findings with respect to service utilization. First, the most commonly utilized disciplines are PTs, OTs and speech-language pathologists (SLPs) (10–15). Second, both countries show associations between better-reported health status and lower levels of service utilization, meaning children with better functioning use less services (16–18). In addition, service need determined by functioning shows

differences in service utilization. Children who present two or more conditions or lower cognitive or motor functioning show increased utilization of services and an increased level of unmet needs (10,13,19). These patterns are informative because they confirm trends in service utilization exist across countries and provide evidence about some of the factors that directly influence utilization. Information on dosing, such as amount of therapy (total time and period), types of therapy (group versus individual, range of motion versus functional training), and disciplines utilized can provide information on comparing the effectiveness of services and programs. Such trends are important to identify because improvements in service can be made based on these challenges through sharing knowledge between treatment centres in different regions.

Amount of service utilization has also been reported by researchers globally. Researchers identified 212 parents of children from the Northern Ireland CP Register. The researchers found rehabilitation therapy sessions for children aged 4 to 14 years with moderate to severe CP consisted of 30 minutes twice a week, and services were used at seven different centres within a six-month period, indicating high service utilization (20). In Canada, 76% of families using services desired to have more service usage and reported difficulties coordinating multiple services. While this study was published in 2002, families continue to desire more services (15) and experience complications using multiple agencies (14,21,22). The importance of reporting families health service usage are further substantiated by a study conducted in Finland. Parents' (n = 496) perception of service delivery factors are associated to health outcomes as a result of receiving rehabilitation therapy (23). The strongest predictor of better psychosocial and physical

functioning exhibited higher attendance for outpatient rehabilitation. This research indicates families perceive and report benefits of improved functioning when spending more time in therapy.

Research shows supporting evidence that socioeconomic status (SES) and other demographics play a key role in service utilization, which provides important implications for service managers. Parents who reported low or no access to care or inconsistent access to care in Nevada, respectively, included 7% and 10% of children (n = 11,073) who had medical conditions (24). Young and/or single guardian families are another group who are at higher risk for lower utilization patterns of healthcare services (25). The researchers found a larger disparity for participation in parenting groups among lone or young moms in comparison to middle or older aged mothers. Lone and/or young-mid aged mothers (13-21, 22-30 years) showed slightly lower clinical visits compared to older mothers (31-48 years). This research confirms the potential importance of demographic influences on service utilization.

## **Methods**

Based on the stages specified by previous researchers (26–28), a scoping review was conducted. The five stages included: identifying the research question, identifying relevant studies, selecting appropriate studies, documenting and analyzing data, and synthesizing results. The research inquiry we made was, “what is the current state of knowledge about factors that have been studied and influence service utilization? As well, what areas are understudied in children’s rehabilitation service utilization in Canada?”.

### **Identifying Relevant Studies**

A search conducted on January 30, 2015 identified relevant studies. The database search scanned OVID, EMBASE, AMED, CINAHL, and Pubmed from January 2003 to January 30, 2015. The rationale for the 2003 was to span 10 years from the initial start date of the review. The keyword searches used the following terms: “children *or* youth *or* juvenile *or* adolescents *or* preschool *or* toddler” *and*, “rehabilitation *or* healthcare *or* service” *and*, “developmental disabilities *or* developmental disorders”. This search produced 4,125 articles. One article was added manually that held relevance to the interest area that was not populated in the literature search. Studies selected for further review were based on relevance of title and abstract screening. The final selection of articles ensured the following key inclusion criteria: i) the study focuses on rehabilitation service utilization, ii) services are provided to clients that centres categorize as children (0 to 21 years), and iii) the study is conducted in Canada and published since 2003. From a total of 141 articles, 17 duplicates were identified and removed, leaving a total of 124 articles for further analysis.

### **Selection of Studies**

In the first step of the selection review, titles that appeared to refer to countries other than Canada were excluded, and 104 articles remained. In the second step, abstracts were read. Studies pertaining to children with disabilities and utilization of rehabilitation services were selected for inclusion. Studies including other populations, for example mental health, were excluded. After all abstracts were reviewed, 23 studies remained. Articles were read in their entirety to assess content during the third step. A total of 11 articles were selected for the final review. The review decision to include or omit each



study was by the first and second author. The first author conducted the initial three-stage review, and then final confirmation to include or exclude articles was completed by the second author. Discrepancies between the two reviewers were discussed in detail based on content of the studies, and all discrepancies were resolved through this discussion.

Figure 2 shows the flow diagram of the article selection process.

### **Data Extraction**

Two tables were created for charting information from the 11 studies selected for the final review. Table 1 provided a descriptive comparison of the studies including the study citation, population, site, sample size, children's age in years, instruments used, study design, data collection and analysis, and main purpose of the article. A checklist reporting on the domains described in each study is also included. Table 2 was formed based on the primary and secondary objective reported in each study. The primary and secondary objective of each study was mapped onto categories in Andersen's model to organize the findings of the studies in order to explore children's rehabilitation service utilization in Canada.

## **Results**

### **Study Designs, Features and Characteristics**

Eight studies reported on factors from the environment domain, focusing on examining, "physical, political, and economic" structures of the external environment and characteristics of the service centre (1, p. 6). Nine studies reported factors from the population characteristics domain, exploring factors such as age, gender, SES, diagnosis, and perceived/evaluated service need. Five studies examined factors from health

behaviors (for example, personal health practices and utilization of health services), and six studies examined factors of perceived/evaluated health status under the health outcomes domain.

### **Domains Studied and Understudied in Children's Rehabilitation Based on the Research Objective of Each Study**

**Domains Studied.** The primary purpose of Table 2 is to explore the main objective(s) of the studies. Six out of the 11 studies focused on the health care system sub-category under the environment domain. The majority of studies under health care system conducted an overall assessment of the program and/or centre and its practices. Five studies looked at utilization of health services in the health behaviors domain, exploring factors such as frequency, duration and type. However, these studies mainly focused on children with CP. The four studies that evaluated health status in the outcomes domain focused on examining physical functioning, skill improvement and goal attaining behaviors. Nine studies explored consumer satisfaction, with the majority of studies exploring family-centred practices (FCP).

**Domains Understudied.** Two studies under the external environment domain focused on assessing factors such as region, supports and barriers and transportation. Need, under population characteristics, was described in two studies that focused on assessing diagnosis, severity and perceived needs. No study explored predisposing characteristics, enabling resources, or personal health practices as key factors of children's rehabilitation service utilization. Two studies focused on perceived health status (17,18).

### **Factors Influencing Service Utilization**

The purpose of this section was to examine the relationship between the domains and service utilization by aggregating the content of the studies.

**Environment.** Studies from the environment domain discussed un-formalized processes (defined as non-standardized practices at the clinics). FCP (29) and clinical methods such as observations, interviews and steps in therapy with parents (22) were not formalized procedures among therapists. These non-formalized procedures resulted in lower perceptions of FCP (29). In one study, therapists charted 45% of their time in direct therapy; 30% in consultation, education and training; and 17% in meetings (22). The authors of the study suggest that a lack of standardization precludes making confident conclusions from these data, but standardizing procedures may lead to further efficiency at centres. This implication is important when considering research with other work. Families identify not enough time with therapists as a barrier (30), so improving services can improve efficiency and reduce barriers faced by families. Family-centred processes, goal setting and coordination of children's services, such as a successful transition to school, were three additional common components assessed in the programs across these two studies (22,29).

Studies with qualitative components provided detail to the perceptions of rehabilitation service delivery at children's treatment centres. Service providers who work with immigrant families caring for a child with a disability shared five key challenges. The therapists described: they desired more cultural sensitivity training, they desired more time to build relationships with families, communication barriers existed, differing views

among parents and service providers existed on disability, and families lacked awareness of resources available in the community (30). Similarly, the qualitative portion exploring a program that assisted with transition to school by providing extra OT and PT services found complimenting themes surrounding communication and empowerment. While the first language of parents using the community rehabilitation program was not identified, parents were satisfied with having open communication with their therapists and felt empowered by therapists who kept families informed and showed empathy (22). Other practices parents liked about the centre included coordination among services and coordination with external resources, flexibility of scheduling to meet with therapists for appointments, and improvements in participation, especially in school based activities (22).

Perceived environmental issues and concerns of families waiting or receiving services identified in various studies in this scoping review included: obtaining information on services (31), costs of bills and services (15,31), babysitting services (22), and busy schedules/obtaining a referral (15,22). The top two external environment barriers to service utilization and participation as reported by the Craig Hospital Inventory of Environmental Factors (CHIEF) are, 1) the physical and structural barriers, and 2) services and assistances (31). Differences existed between reported environmental barriers between children 5 years and younger, and 5 years and older (31). These prominent environmental barriers may be non-meaningful to vastly different regions.

**Population Characteristics.** Higher rates of utilization were associated with younger age (10,13), male children (10,13,18,21) who had lower cognitive and/or motor

functioning (10,13) - however, it is important to note this description is based on a very small number of studies.

**Personal Health Practices.** No study explored the impact of personal health practices on service utilization.

**Use of Health Services.** OTs, PTs, and SLPs are the three most utilized disciplines in rehabilitation and those perceived as needed most often by families (10,13,15,31). The distribution of utilization was 64% for PTs, 53% for OTs, and 34% for SLPs among children with CP (13). Wait times reflected nine months for public rehabilitation services in one study. During the waiting period of nine months, a decrease in psychosocial quality of life scores and mobility scores was noted (18). Nearly half of families with children around 3.5 years of age paid out of pocket to utilize private services during the waiting period (18), but less than 5% of families sought private services for children with CP seven years and older (13), indicating differences in utilization associated to age, need, and financial resources over a long period of time.

Canadian children with CP ages 2 to 6 years in both educational and clinic settings spent on average 164 minutes in PT and 106 minutes in OT per month, with 2 to 4 sessions per month (10). Young children (18 months to 5 years) with CP utilized services most commonly through clinical settings (10). In contrast, school aged children and adolescents with CP more often used rehabilitation services from school rather than a treatment centre (13). A higher proportion of children and adolescents received services if they attended a specialized classroom rather than a regular classroom (13). Mean time spent with PT and OTs were higher if a child was in a specialized school (13) or received

services in both educational and clinic settings (10). Children receiving educational resources on top of rehabilitation services showed significant differences on intelligence and adaptive tests (15). Furthermore, approximately 85% of children with CP received at least one type of rehabilitation service during their early school years, but service utilization decreased in adolescence (13). In the Alberta region, challenging transitions were observed from a clinic approach to a school-based therapy approach among children with CP (29).

Children with congenitally malformed hearts who also had developmental delays received minimal educational or rehabilitation services (15). This finding indicates there might be a barrier among children who may possess multiple diagnoses and/or chronic conditions leading to a higher need.

**Health Outcomes.** No study explored evaluated or perceived health status in relation to service utilization.

**Consumer Satisfaction.** Family satisfaction was a central focus for several studies. Improved perceptions of services are associated with higher ratings of family satisfaction and child quality of life outcomes (17,18,21). Number of service locations (21,22), child's health conditions (21), and FCP (17) influence family satisfaction (21) and quality of life (17,18). Specifically, family satisfaction increased with fewer location of services (21,22), increased accessibility to therapists (22), ease of accessing external resources (22), lower number of health conditions (21), greater perceived FCP (17), and coordination between services and therapists (22). A moderate correlation exists between severity (as scored by the FIM), physical and psychosocial scales of quality of life (as

measured by the PEDS QL) and FCP (as scored by the MPOC) (17). Moreover, 17% of variance in total quality of life scores is accounted by FCP for children with neurological conditions (17).

FCP can be evaluated by using the Measures of Processes Of Care (MPOC) measure, and many studies evaluating FCP used the MPOC. Families and service providers reported overall service quality to be high. Respectful care received the highest scores, whereas providing general information received lowest scores (22,31–33). Lower MPOC scores were associated with families who acquired additional years of education (33) and among older children (31,33). Lower scores on all MPOC scales were reported by parents with older children (5 years and up) than parents with children younger than 5 years (31).

## **Discussion**

These findings reveal important patterns and trends among studies conducted on children with disabilities using rehabilitation services in Canada. Key factors identified in this review will provide researchers with direction to examine relationships between service utilization and outcomes of children with developmental disabilities. In this scoping review we identify areas requiring further examination that need to be assessed comprehensively within the context of a health system that explores individual, family, and environmental aspects of children with disabilities. This scoping review shows that minimal or no information exists on population characteristics, personal health practices, or evaluated/perceived health status in relation to service utilization.

## **Environment**

Unique environmental factors exist across Canada, including weather, road conditions, distance and driving time to centres from rural and urban locations, public and private funding systems, as well as unique governmental programs that give access to special funds or school programs. The findings of this scoping review provides evidence of key barriers encountered in the environment by families, such as physical structures and health services (31,34). The barriers identified in this scoping review are likely a modicum of obstacles encountered by families living in different health regions of Canada. Due to the unique environmental circumstances and geographical location of each centre, we encourage researchers to explore barriers encountered by families using a standardized measure to increase knowledge of barriers and supports within their jurisdictions.

### **Population Characteristics**

Literature in Canada and the United States identifies that utilization of rehabilitation services is related to younger age (10,11,15), males (27,11,8,15,9), and presence of more than one chronic condition (11,13). Children younger than 5 years typically receive greater amounts of service (13), therefore differences should be explored between younger and older children. Also, a study from Sweden found that younger single mothers were at risk for lower healthcare service utilization for their children (25). This one study alone raises the importance of exploring predisposing characteristics and enabling resources in order to identify vulnerable populations to enhance supports and well-being of families.



Eight studies have explored unmet service needs and barriers among families with children using rehabilitation services across the world (9,12,40–44). Different diagnoses led to varying needs and patterns of service utilization (12,16,45,46). As number and severity of disorders increase, so do types and amount of services (10–12). The direct role of need was not assessed in any article within the scoping review; however, a study from 2007 based on annual national survey reported that need is a key determinant factor for service utilization in Canada (5). This study conducted by Vingilis and colleagues concluded that perceived physical and psychological needs are crucial factors for determining healthcare utilization. Because need is indicated by health condition and functioning, using a measure of that describes services currently received and needed by families can improve knowledge about types and number of services required by families (31).

### **Health Behaviors**

No study explored health practices of families. A fewer number of studies explored health behaviors which primarily focused on service utilization and outcomes among children with CP. Differences and similarities existed among children in the United States and Canada with CP. Differences were found in the amount of utilization (e.g., higher service utilization in the United States (45), but similarities were found in patterns (e.g., PTs, OTs, and SLPs as most commonly utilized disciplines (10,13)) and lower motor or cognitive functioning showed higher utilization (10,13). A great deal of descriptive information on service utilization is required to answer queries exploring the amount and type of services across disability types and levels of functioning.

## **Health Outcomes**

A key finding of this scoping review is that no study to our knowledge, in the scoping review or elsewhere, has examined the relationship or impact of service utilization on health outcomes, for example, amount and intensity of participation. Participation has strong implications for clinical practice because it is a mutable factor (1), meaning levels of participation can change greatly due to changes in implementing healthier habits, notably during younger ages (47). Therefore, participation along with personal health practices of children and families, are important factors to measure and change in clinical practice, unlike population characteristics or environment, which are much more rigid and difficult to change. Studies in Canada and internationally have substantiated a link between participation and quality of life (48), personal and family factors (49,50), and environmental factors such as supports and barriers (49,51). These factors can facilitate or hinder participation. Perhaps, participation frequency and involvement is associated to higher levels of service utilization (5). A comprehensive study that examines the relationships among child and family characteristics, service utilization and health outcomes is required to provide insight into the nature of the interactions between these factors.

Our findings support that families and service providers value FCP, standardized procedures, and desire more general information to help identify and coordinate services. Jeglinsky and colleagues (35) advocated conducting regular evaluation of FCP using the MPOC to assess if providing general information is improving. The MPOC-20 was feasible for completion by families and provided valuable information to both families

and service providers (31), thus its use should be continued to evaluate satisfaction with FCP. Only a few studies have measured the MPOC longitudinally (36–39), so more studies are required to report on the ability of the MPOC's sensitivity to change. Similar findings with respect to high scores on respectful and supportive care and lowest scores on providing general information have been found (35,40), in regards to FCP evaluations using the MPOC among children's rehabilitation.

### **Quality of Articles Selected for Review**

The purpose of scoping reviews is to summarize relevant literature in the area of interest in order to draw conclusions about the state of the current literature (26).

Identifying inclusion and exclusion criteria is a necessary step. However, there is no standard process to assess the quality of articles for a scoping review. Currently, authors who contributed to popularizing the scoping review contend that a quality assessment is not required but identify this lack of standardization as a limitation of the review process (27). Researchers have suggested that selection of articles for scoping reviews requires a methodological process (52).

Of the 11 studies, 7 were quantitative, 3 used mixed-methods, and 1 employed a qualitative approach. Because no standard criterion for scoping reviews has been established, the first author appraised the quality of the quantitative and mixed-method articles based on a checklist format created by Child Care & Early Education Research Connections (Appendix A; 53). The completed quantitative checklist for the studies is included in Table 3. It is important to note that the assessment is based solely on the first

author's evaluation. Thus, examiner error could result in inaccuracy by missing an aspect in the article that is in fact present in the article.

The advantage of using this checklist is that it could be used with the different types of quantitative designs in the studies. Based on the checklist for the quantitative studies, the articles included in the scoping review met several of the important criteria within the checklist. Limitations of the studies included selecting a subgroup of the population rather than the entire population, low to moderate sample size, lack of random selection, low or moderate response rate, and lack of describing the handling of missing data. The articles provided primarily descriptive statistics. A missing checklist item from a study does not make the article weaker than others because the criteria are not always applicable. For example, the study might be more descriptive than inferential, so testing for significant main effects is not appropriate.

A qualitative checklist is also available from Child Care & Early Education Research Connections. However, this checklist was not used because many of the criteria were not applicable to the qualitative study. Lindsay's article (34) and the qualitative components from the mixed-method articles (i.e., Stewart et al., (22); Darrah et al., (29); and Kertoy et al., (31)) provided much detail on the themes and interpretation, but there was less detail on the items listed in the qualitative checklist for describing the methods and analysis section. The qualitative findings for the mixed-methods article were complimentary to the quantitative findings in terms of obtaining feedback on new program structures (22), triangulation of data for interpreting policy and practice change (29), and supporting utility and feasibility of measures used in therapy (53).

Overall, the articles selected for this review were peer-reviewed and published in well-reputed journals. The authors of the articles are considered to be experts in the area of children's developmental research, so their knowledge and work is well-known in the area of developmental research. The methods used by the researchers were deemed to be sound based on the level of detail provided in the articles. Further research should improve the rigor of this area of research through increasing sample sizes to represent the population of interest, achieving a higher response rate, selecting participants randomly, and incorporating a technique to handle missing data. Each article was unique so considered crucial for contributing to the findings of this scoping review.

### **Limitations**

We identified a few limitations in conducting this scoping review. A limitation of this scoping review was the ambiguity of classifying article features such as identifying themes, or mapping study factors onto domains from Andersen's model that required the author's discretion. A structured approach to classifying and categorizing the studies mitigated misplacing information, resulting in reliable information. For example, FCS was reflected in both the environment and consumer satisfaction domain. FCS was classified in the environment domain when the researchers of the study explored FCS as practices of the centre; whereas, FCS was classified into the consumer satisfaction domain when FCS was assessed in the study as an outcome of service satisfaction.

A second limitation of the scoping review was the inclusion of three articles that did not restrict population to only developmental disabilities, and used other populations such as children with congenital malformed hearts (15), neurological conditions (17), and

a comparative sample in the United States (10). However, considering the limited number of studies available, we decided to use these studies as they included children with developmental disorders and rehabilitation service utilization.

A third limitation of this review was using Andersen's model without evidence of this model's capability to report on factors comprehensively within the domains. Even though previous studies have used Andersen's model to explore factors (54,55), no study has examined strength of the relationship between factors and domains presented in the model within children's rehabilitation research. In order for researchers to continue applying Andersen's model and create implications of relations between factors and domains, an assessment to validate the model's vigor is required. Nonetheless, Andersen's model allowed for a comprehensive structural approach to organize multiple factors of rehabilitation service utilization as supported by this scoping review.

### **Conclusion**

As specified by the number of studies published each year within the past decade, there is a paucity of evaluation in this area. Research in rehabilitation utilization is a focal point to improve health services. Because treatment centres are a key point of contact for children with disabilities, services are important to determine health trajectories and interactions of children with disabilities with their health system. We hope that our scoping review provides information that will inform researchers about factors that influence, or have the potential to influence, utilization and outcomes in children's rehabilitation health systems.

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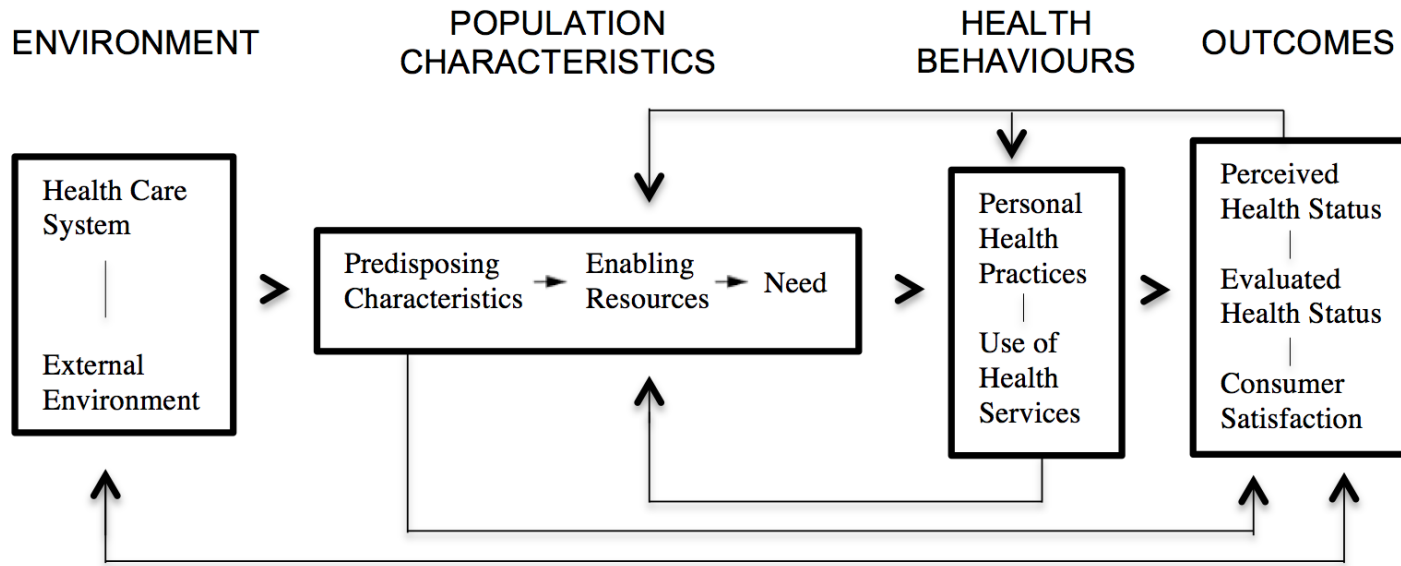


Figure 1. Andersen's Healthcare Utilization Model

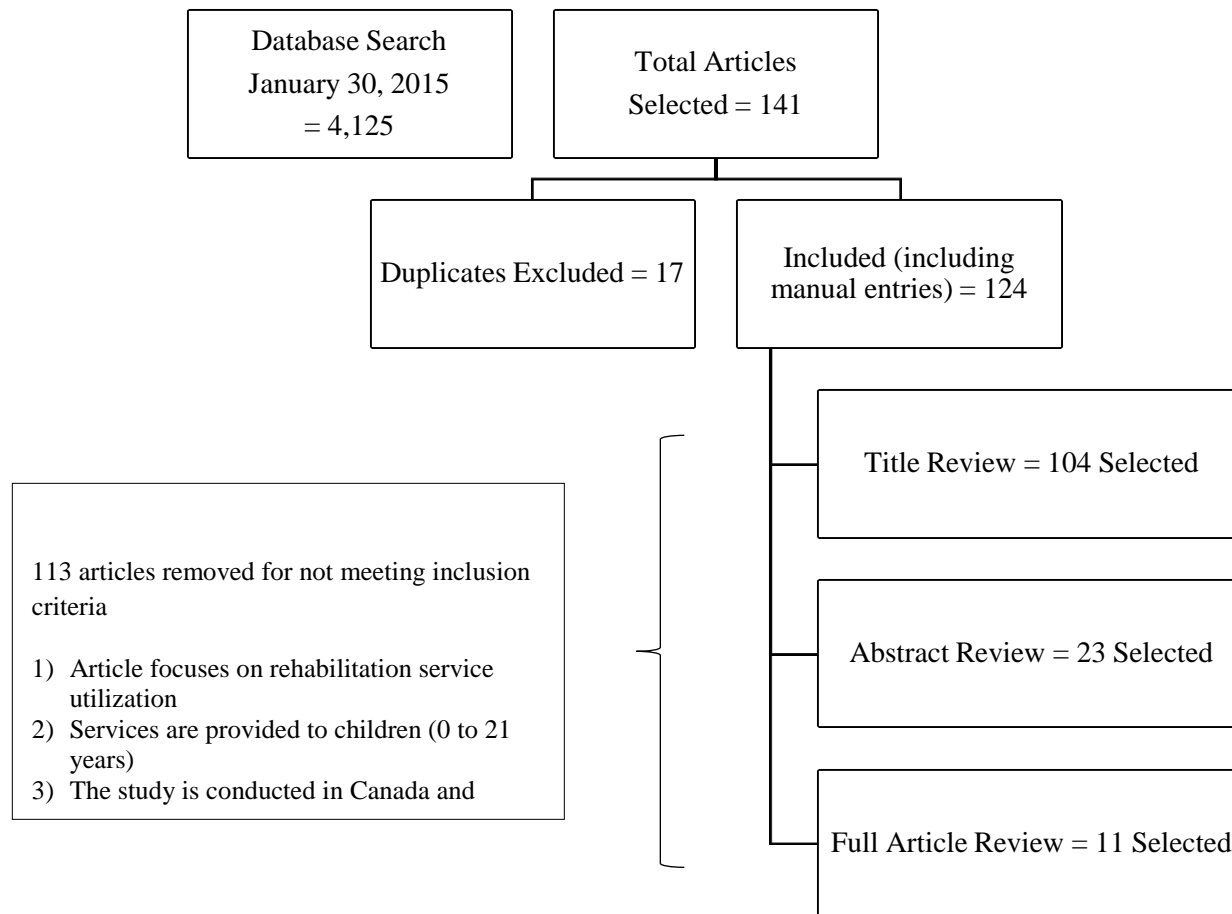


Figure 2. Flowchart of Review Process for Selecting Studies

Table 1.

*Assessment of Children's Rehabilitation Centre Services*

Citation	Population	Site	Sample Size	Age (years)	Measures	Study Design	Data Collection	Data Analysis	Purpose	Environment	Pop. Char.	Health Behaviours	Outcomes
Camden et al., 2010	DD, dyspraxia, speech and language, motor	out-patient centre	222 families, 129 SP	0-21	MPOC-SP, MPOC-56	3-year longitudinal, phenomenology	survey	desc stats, chi-square, ANOVA, thematic analysis	program evaluation	x	x		
Darrah et al., 2012	CP	out-patient centre	37 program managers, 54 OTs/PTs, 39 parents	0-3, 3-6, 6-18	MPOC-SP	cross-sectional, phenomenology	survey, 11 semi-structured focus groups, 2 interviews	desc stats	program evaluation	x			
Feldman et al., 2008	all disabilities except cognitive disorders	out-patient centre	124 parents	2-9	WEE-FIM, PEDS-QL 4.0, service system subscale of the family empowerment scale	cross-sectional	face to face (initially) and telephone survey	desc stats, survival curve, multiple linear regression	perception of health		x	x	x

Kertoy et al., 2012	all disabilities	3 community centres	phase 1: 14 researchers, 7 policy makers, 7 families; workshops (45 stakeholders); phase 2: 182 families	0-16	phase 2: ICD-10, about my child, LIFE-H, CHIEF, MPOC-20, support and services	cross-sectional, phenomenology	phase 1: focus groups; phase 2: mailed survey	desc stats	program evaluation	x	x	x
Law et al., 2003	CP, SB, various syndromes, DD, communication disorder, ABI, autism, PDD, and muscular disease.	community centre	494 parents, 324 SP, 15 CEOs	infancy-late adolescence	Measures of beliefs about participation in FCP, CSQ, MPOC	cross-sectional	survey	SEM	program evaluation	x		
Lindsay et al., 2012	undefined	out-patient centre, hospital	13 service providers	0-17	n/a	phenomenology	focus groups, interviews	thematic analysis	perception of health	x	x	x
Majnemer et al., 2008	congenitally malformed hearts	rehabilitation hospital, community centre, school, and private practice	98 children	0-27 months, 5.8-11.1 (follow-up)	WPPSI, VABS, FIM, PDMS-II, CBCL, PPVT-IV	5- year longitudinal	telephone survey	desc stats, t-tests, chi	service utilization		x	x
Majnemer et al., 2014	CP	school, community centre, hospital, and home	92 children, 167 adolescents	6-12, 11-19	GMFM-66, Leiter Intelligence Scale, VABS	cross sectional	survey	desc stats, chi, t-tests	service utilization	x	x	x
Moore et al., 2009	neuromuscular disease, epilepsy, SP, brain tumour, TBI, hydrocephalus.	children's hospital	187 family caregivers	8-18	FIM, PEDS-QL 4.0, MPOC	cross-sectional	survey	desc stats, correlation, regression	program evaluation, perception of health	x	x	x

Palisano et al., 2012	CP	children's hospitals, community centre, and private practices	134 (CDN; total sample including US = 399)	18 months - 5 years	GMFCS, Service Questionnaire, Parents perceptions of the focus and family-centred processes of intervention	cross-sectional	telephone, survey	1-way ANOVA	service utilization	x	x	x
Stewart et al., 2004	CP, SB, DD, syndromes, other behavioural or communication disorder.	community centre	13 parents	3.10-6.4	GAS, MPOC, CSQ, chart audit tool	cross-sectional, phenomenology	paper survey, interview	desc stats, thematic analysis	program evaluation	x	x	

Abbreviations: ABI, acquired brain injury; CBCL, child behavior checklist; CDN, Canadian; CHIEF, Craig Hospital Inventory of Environmental Factors; CEOs, Chief Executive Officers; CNPHS, Canadian National Population Health Survey; CP, cerebral palsy; CSQ, Client Satisfaction Questionnaire; DCD, Developmental coordination disorders; DD, developmental delays; desc stats, descriptive statistics; FCP, family-centred practices; FIM, functional independence measure; OTs, occupational therapist(s); PDD, pervasive developmental delay; PDMS-II, Peabody development motor scales; PPVT-IV, Peabody picture vocabulary scale; Pop. Char., population characteristics; PT, physical therapist(s); SEM, structural equation modeling; SLP, speech-language pathologist(s); SP, service provider(s); SW, social worker(s); TBI, traumatic brain injury; US, United States; VABS, Vineland Adaptive Behavior Scale; WPPSI, Weschler Primary and Preschool Scale of Intelligence.

Table 2.

*Main Objective Examined in Studies Mapped onto Andersen's Domains*

<b>ENVIRONMENT</b>	<b>POPULATION CHARACTERISTICS</b>	<b>HEALTH BEHAVIOURS</b>	<b>OUTCOMES</b>
<b>Health Care System</b>	<b>Predisposing Characteristics</b>	<b>Personal Health Practices</b>	<b>Perceived Health Status</b>
Darrah 2010, unformalized practices Camden 2010, reorganization of services and assessment of service quality after changing care delivery model*, Kertoy 2012, system planning, outcome measurement framework* Stewart 2004, supports and barriers of service, program evaluation* Feldman 2008, wait-times* Lindsay 2012, cultural sensitivity	<i>none</i>	<i>none</i>	Feldman 2008, change in quality of life* Moore 2009, quality of life*
	<b>Enabling Resources</b>	<b>Use of Health Services</b>	<b>Evaluated Health Status</b>
	<i>none</i>	Majnemer 2013, location, frequency, type of services, and funding type Majnemer 2008, type of rehabilitation services and school services Palisano 2012, frequency and type of services** Stewart 2004, number and type of services** Law 2003, number of service sources**	Feldman 2008, change in function* Moore 2009, functional assessment** Palisano 2012, functional assessment** Stewart 2004, setting goals on functioning outcome**
<b>External Environment</b>	<b>Need</b>		<b>Consumer Satisfaction</b>
Kertoy 2012, environmental barriers (accommodation, resources, access and equality)** Stewart 2004, supports and barriers of service**	Kertoy 2012, social supports; service and supports questionnaire ** Law 2003, child health complexity**		Law 2003, satisfaction and parental perception** Stewart 2004, client satisfaction** Darrah 2010, FCP Camden 2010, FCP evaluation Kertoy 2012, FCP evaluation Moore 2009, FCP evaluation* Stewart 2004, FCP evaluation Law 2003, FCP evaluation* Palisano 2012, FCP evaluation**

\* = main study objective or measure

\*\* = secondary study objective or measure

Note: The study is listed twice (or more) if the studies had a primary and secondary objective indicated respectively by “\*” and “\*\*”. If studies had two primary foci, this is listed as “\*” for each time it was listed.

Table 3.

*Appraisal of Quantitative Articles*



		Quantitative Articles							Mixed Methods Articles		
		Camden 2010	Feldman 2008	Law 2003	Majnemer 2008	Majnemer 2014	Moore 2009	Palisano 2012	Darrah 2010	Kertoy 2012	Stewart 2004
Population and Sample	1. Population [1] [0] [-1] [NA]	0.5	0	0	0	0	0	0	1	0	0
	2. Randomized Selection of Participants. [1] [0] [-1] [NA]	0	0	1	0	0	0	0	NA	0	0
	3. Sample Size. [1] [0] [-1] [NA]	0	0	1	0	0	0	1	0	0	-1
	4. Response and Attrition Rate. [1] [0] [-1] [NA]	0	-1	1	0	-1	0	-1	NA	0	0
Measurement	5. Main Variables or Concepts. [1] [0] [-1] [NA]	1	1	1	1	1	1	1	1	1	1
	6. Operationalization of Concepts. [1] [0] [-1] [NA]	1	1	1	1	1	1	1	1	1	1
Analysis	7. Numeric Tables. [1] [0] [-1] [NA]	1	1	NA	1	1	1	1	1	1	1
	8. Missing Data. [1] [0] [-1] [NA]	0	0	1	-1	-1	1	-1	NA	0	0
	9. Appropriateness of Statistical Techniques. [1] [0] [-1] [NA]	1	1	1	1	1	-1	1	1	1	0
	10. Omitted Variable Bias. [1] [0] [-1] [NA]	1	1	1	1	1	1	1	1	1	1
	11. Analysis of Main Effect Variables. [1] [0] [-1] [NA]	1	1	1	NA	0	1	1	NA	NA	NA

**Chapter Three – Part 1: A Profile of Families Using a Children’s Treatment Centre  
in Ontario, Canada**

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This chapter contains a manuscript entitled: “Part 1: A Profile of Families Using a Children’s Treatment Centre in Ontario, Canada”. This manuscript length will be reduced and submitted to the journal of *Child: Care, Health and Development*. The second part of this manuscript, and justification for presenting the research in two parts, is presented at the beginning of chapter Four.

### **Abstract**

*Background:* Use and need of rehabilitation services for children with disabilities in relation to care experiences and outcomes is under studied. Factors that describe client's utilization of a children's treatment centre with respect to service need, service use, participation outcomes, and evaluation of family-centred practices are presented. The objective of this study is to describe the relevant key factors and interaction of key factors of families using a geographically-based children's treatment centre in Canada.

*Methods:* A cross-sectional survey was administered to 279 families using a children's treatment centre in Canada asking information about their child's complexity, service and supports needed and received, participation, and perceived evaluation of family-centred practices. Service utilization data from when families started using the children's centre was reported by types of disciplines utilized and number of minutes within an average one-year period. Descriptive statistics were used to describe the sample's profile. Correlations, multiple regression, Kruskal-Wallis and Mann-Whitney tests were used to explore relationships between child's primary diagnosis, complexity (cumulative number of functional concerns), service utilization, and participation.

*Results:* The sample consisted of a higher number of younger children, with more boys than girls and more children with a speech disability. A statistically significant difference was found between children with motor/cognitive disabilities versus children with speech/communication disabilities for complexity of their health condition, service need

and service utilization. While age, sex, and diagnosis did not predict total minutes in therapy, complexity was a significant predictor of service utilization. Participation frequency scores showed a weak relationship to complexity and primary diagnosis in comparison to participation involvement scores. Results of the family-centred practice measure showed similar findings to data from other published studies.

*Conclusions:* This study provides important information from a children's treatment centre about service need, service utilization, parental concerns regarding children's functioning, and participation as well as relationships between these key factors that are crucial to explore globally. We recommend therapists and service managers explore barriers and unmet needs of families using the centre. Planning services should take into account children's complexity when planning service allocation. Complexity is related to service utilization and participation; further research is suggested to determine the exact nature of this relationship.

Part 1: A Profile of Families Using a Children's Rehabilitation Service Centre in Ontario,  
Canada

**Introduction**

Children and adolescents with disabilities encounter barriers and obstacles in their daily living. Structural barriers such as access to buildings (Temple & Walkley, 2007), inclusion to social participation (Bedell, Cohn, & Dumas, 2004; Law, Petrenchik, King, & Hurley, 2007b; Muschalla, Vilain, Lawall, Lewerenz, & Linden, 2012), and equal access to effective healthcare and rehabilitation services (Majnemer, Shevell, Rosenbaum, Law, & Poulin, 2007) are common issues facing families with members who have disabilities. These environmental hindrances inhibit opportunities for youth with disabilities to lead lives similar to youth without disabilities (Majnemer et al., 2014). It is difficult to change attitudes and societal norms so challenges remain for integration into school and community activities (Kelly, Altiok, Gorzkowski, Abrams, & Vogel, 2011). However, providing effective and meaningful rehabilitation services is achievable through ongoing evaluation initiatives (Duckett, 2011). Assessing rehabilitation services is a starting point to understand and plan services in order to support children and families in optimizing outcomes such as participation in social and physical activities.

Successful service delivery is indicated by a progressive improvement of outcomes and health status (Bier, Prince, Tremont, & Msall, 2005; Turkel & Pao, 2007). Conversely, knowledge about factors that influence patterns of service usage and their outcome is limited (Majnemer, Shevell, Rosenbaum, & Abrahamowicz, 2002; Weller, Minkovitz, & Anderson, 2003). Within the context of rehabilitation services, it is

important to understand key factors that influence service utilization and health outcomes.

The Andersen Healthcare Utilization model (Andersen, 1995) can be used to explore factors of health service utilization from a comprehensive perspective (Graves, 2009; Kuhlthau, Hill, Fluet, Meara, & Yucel, 2008; Vingilis, Wade, & Seeley, 2007).

### **Application of the Andersen Framework to Study Service Utilization and Outcomes**

The Andersen Healthcare Utilization model (Figure 1) was introduced in the 1960s and has undergone several revisions since to provide an assessment of health utilization. An advantage of the Andersen model is researchers can identify which factors have the highest importance and require investigation. Domains in Andersen's model include the environment, population characteristics, health behaviors and outcomes. The model has been used to describe children's utilization of service and their outcomes (chapter two). This study utilizes Andersen's model to provide an organizing framework on factors that are important to assess when exploring a health care system in children's rehabilitation.

Various factors within the environment, predisposing characteristics, and health behaviors domains have been associated to the outcomes domain. The environment domain in Andersen's model has two categories: health care system and external environment. Population density (Hammal, 2004; Forsyth, 2010; Kozyrski et al., 2002), presence of family-centred practices (Moore, Mah & Trute, 2008, Law, Hanna, King, Hurley, King, Kertoy & Rosenbaum, 2001) and perceived community environmental barriers (Fauconnier, 2009; Law et al, 2009) show a positive relation to service utilization and participation outcomes under the environment domain. The health care system is described by policies that mandate the service centre or characteristics of the health centre

such as regional catchment. The external environment category refers to factors that influence access to the service centre which include use of public or personal transportation or distance to the centre. Environmental supports and barriers have been identified in studies with families who have children with disabilities to describe the external environment. Researchers using the Participation Environment Measure for Children and Youth (Coster et al., 2012; PEM-CY) have looked at supports that enhance participation and barriers that hinder participation between children five years and older with disabilities. In the home setting, parents identified a lack of adequate services, help and money as barriers to participation (Law et al., 2013). Weather was identified as a barrier in both the school and community (Bedell et al., 2013; Coster et al., 2013), and barriers of sensory qualities were identified in the school (Coster et al., 2013). Across all three settings in the home, community and school, parents with children with disabilities identified barriers with physical, cognitive, and social demands in activities (Bedell et al., 2013; Coster et al., 2013; Law et al., 2013). Perceptions of environmental barriers increased with age into adolescence and with lower functional ability to complete tasks (Law, Petrenchik, et al., 2007). Physical and structural barriers, as well as a lack of services and assistances have also been identified as barriers in the environment among families with children up to 16 year-olds from Ontario, Canada (Kertoy et al., 2012). Currently, barriers among younger children using a children's centre are unknown.

Population characteristics are captured by three domains: predisposing characteristics, need and enabling resources. Predisposing characteristics refers to personal factors such as age (O'Neill; Kuhlthau et al., 2008; CSHCN, 2004), sex (Law et

al., 2006), and ethnicity (Dusing, Skinner, & Mayer, 2004; Kuhlthau et al., 2008).

Predisposing characteristics including age has demonstrated differences in utilization and outcomes among client groups, for example older children show lower levels of service utilization compared to younger children (Law, et al., 2007). Typical population characteristics of children using rehabilitation services are described as younger, male, with increasing service need indicated by lower cognitive or motor scores (chapter two).

Enabling resources are family demographics that facilitate or hinder access to services including household income, living arrangements and parental work status.

Family factors such as number of social supports, young or single parental status (Vingilis et al., 2007; Wallby, Modin, & Hjern, 2012), non-English speaking, residence in isolated areas and low income ((Fulkerson, Haff, & Chino, 2013; O'Neill; CSHCN, 2004) show lower or inconsistent service utilization among parents with children with disabilities.

The Andersen Model defines *need* as a mixture of perception of social structure as well as evaluated judgement. *Perceived needs* is described from the client's perspective and *assessed needs* is evaluated from a health professional (Andersen, 1995, p. 3). Need is directly measured by health conditions and impact of disability on the individual's functioning. Unmet needs are measured by number of needs identified by parents for which their child did not receive service or services were not enough to satisfy needs. Diagnostic category (Bitsko, 2009), number of health/development conditions (Bitsko, 2009; Kuhlthau et al., 2008; Tomiak, 1998), severity (Majnemer; Parkes, 2002; Tomiak, 1998), and perceived needs (Kuhlthau et al., 2008) show direct relationships with service utilization. Complexity, unlike severity, may be a better indicator of need. Complexity



indicates to what degree functional limitation impacts the child based on concerns identified by parents (Brehaut, Rosenbaum, & Kohen, personal communications, June 2013). While a condition may present high severity, for example minimal mobility, the effects of the condition on each child's ability to execute tasks is different. If the child's activity is not impacted by a condition, then their complexity score is lower for mobility. As a result, complexity is in line with family's perceptions of the disability's impact, and two children with identical diagnosis and severity scores may score differently on a complexity measure.

Researchers in English speaking countries found that as number and impact of disorders increase, so do types and amount of services (Hodgkinson, Veerabangsa, & Drane, 2000; Kuhlthau et al., 2010; Palisano et al., 2012; Vingilis et al., 2007). One study has explored the relationship between diagnosis and participation (Law et al, 2006). The researchers found no significant relationship between diagnosis and participation as supported conceptually by other researchers (Rosenbaum & Gorter, 2012), but this relationship requires further examination with consideration to complexity.

In the Andersen model, health behaviour includes two domains, personal health practices and use of health services. Personal health practices consist of physical exercise, balanced diets, and parents health habits. Parental health habits include sleeping, alcohol consumption, body mass index, or engagements in social/recreational activities (Bourke-Taylor et al., 2013; Helen Bourke-Taylor, Pallant, Law, & Howie, 2013). On the other hand, use of health services is measured by number of disciplines, amount (sessions or time over a year), type (range of motion, functional skills, group or individual therapy),

and number of service locations. Currently, this domain is the most understudied requiring an exploration of this area further, especially its relationship with other factors (chapter two).

Little information exists to describe the specific number and amount of rehabilitation services utilized by families. Occupational therapists (OTs), speech-language pathologists (SLPs), and physiotherapists (PTs) at children's treatment centres typically provide services most frequently utilized (Dusing, Skinner, & Mayer, 2004; Majnemer et al., 2013; Majnemer et al., 2008; Palisano et al., 2012). In a study from 2000, children who receive rehabilitation services in Canada typically had three or more services, usually provided once a month (King et al., 2000a).

There are few studies exploring service utilization, and these have focused almost exclusively on children with cerebral palsy (CP). Children with CP from ages two to six in Canada and the United States have 2 to 4 therapy sessions per month (Palisano et al., 2012). Median time spent with OTs or PTs in clinical settings is 120 minutes, with time increasing as gross motor functioning scores decrease. While approximately 85% of children with CP in Quebec, Canada received at least one type of rehabilitation service during their early school years, service use decreased in adolescence (Majnemer et al., 2013). Researchers in the United Kingdom found families with a child with CP used seven rehabilitation services during a six-month interval, and the majority of families used services at least twice weekly for 30-minute intervals. Children receiving services twice weekly were characterized as younger children with an inability to walk (severe CP) and moderate learning disabilities (Parkes, Donnelly, Dolk, & Hill, 2002). The

number and amount of services may vary not only by country, but also by region due to different governing health jurisdictions. As a result, it is important to understand jurisdictional trends so health systems can be compared. Each health jurisdiction has unique factors such as differing programs, access to transportation, weather conditions and policies. Understanding different health systems gives service providers an opportunity to optimize services by exploring these crucial factors at their own centre and adopting best practices, all while making their services more efficient.

The last domain in Andersen's model is health outcomes captured by perceived health status, evaluated health status and satisfaction with services. Parent's satisfaction and experiences with the service centre impact children's psychological well-being (Crais et al., 2006; Stein & Jessop, 1984, 1991), skill development (Caro & Deverensky, 1991), family emotional well-being (King, King, Rosenbaum, & Goffin, 1999), and parent's self-efficacy (Dunst, Trivett, Davis, & Cornwall, 1988), etc.). Satisfaction of services is indicated by a lower number of service locations, lower number of health conditions, and more family-centred practices (Law et al., 2003). Family-centred practices are characterized by respect and consideration to all family members, autonomy of decision-making and involvement, and collaborative and equal involvement in decisions with therapists (King et al., 1998). Family-centred practices are important because it allows families to be active responsible drivers of service utilization (King et al., 1998). Often, satisfaction is measured directly by evaluating family-centred practices. Practices that are family-centred for children with disabilities indicate lower parental stress, higher parental satisfaction with services, and further positive outcomes for children (Law et al., 2003).

In recent years, rehabilitation research has focused on enhancing participation, an important health outcome. Participation is defined as the engagement in life activities whether sedentary, physical, social or solitary (Law, 2002). Participation is often measured by amount and level of involvement in an activity. A three-year longitudinal study conducted by King and colleagues (2009) collected data every 9 months from a total of 402 parents and their children (6 to 15 years) who had physical disabilities. The researchers determined that intensity of recreation and physical activity are influenced by age and sex. As children grew older, types of activity engaged in changed. Also, the type of activity determined the level of intensity. Children's physical limitations were associated with their level of ability in a physical activity. However, changes to levels of participation did not show a relationship to physical ability. Researchers inferred that participation was determined by a wide array of factors and not only by physical competency. The significance of this study indicates that health outcomes of children with disabilities are not dependent on physical ability alone; participation needs to be considered in conjunction with service needs.

### **Need for a Comprehensive Understanding of Children and Their Families using Rehabilitation Services**

Assessing utilization of hospitals, facilities for the elderly, and pharmaceuticals services have been described thoroughly and show great benefits for implementing best practices. The same exploration to examine key factors of children's rehabilitation services is required in order to share a common understanding of crucial factors relevant of clients using a rehabilitation centre in order to optimize services (Guttmann, Shipman,

Lam, Goodman & Stukel, 2010; Morgan, Raymond, Mooney & Martin, 2008). Reporting on important factors of children's rehabilitation services provides direction to which factors need to be assessed among centres (chapter two). Evaluation of these key factors assist with planning and meeting needs of families. Currently, very little or no data exists on children's rehabilitation from a comprehensive lens including individual, family, and environmental factors. More specifically, there is a paucity of data with information about children's service needs, service utilization, child outcomes or parents' perceptions of services. Without reliable information regarding types of families utilizing services and children's health conditions and needs, it is challenging to formulate effective evidence-based policies, establishing a centre that enhances daily living of clients by providing high quality services. The information collected in this study will enable decision makers to understand more about important key factors that will lead to healthier child development by providing information on service need, child's complexity, service utilization, participation and family-centred practices to inform our knowledge on crucial factors that should be considered for service planning and allocation of resources.

In this study, we report on the clientele of one large children's rehabilitation centre in Ontario, Canada. Many of the studies researchers have conducted on childhood disability and rehabilitation services are limited in their narrow focus on one diagnostic category or one component of health or outcomes of a specific program, for example consumer satisfaction (chapter two). In this study, a survey was administered that explored personal, environmental, and family factors as well as rehabilitation services utilization patterns, derived from domains from Andersen's model (Andersen, 1995). This

comprehensive approach helps to understand how health conditions, service utilization, service planning, and consumer satisfaction differ across children, and the factors that influence utilization and outcomes. This study explores multiple factors that add to the existing limited knowledge of profiles of families who use rehabilitation services.

The purpose of this study is to describe service utilization and outcome information from a geographically organized children's rehabilitation centre in Canada, providing information on child and family characteristics that are related to use and outcome. The advantage of the children's treatment centre used in this study is that services are organized on a geographic basis thus are population based. Region based centres, including the one used in this study, may have one large central location that is accessed by large population regions, as well as smaller satellite centres allowing access to families living in more remote areas. This study is relevant and unique in the field of rehabilitation because it is one of the first studies to apply domains from Andersen's model and comprehensively examine the relationship among factors in children's rehabilitation service utilization.

## **Methods**

### **Centre Used in the Study**

The centre provides rehabilitation services to children from birth to 18 years of age who have developmental delays, physical disabilities and/or communication disabilities. The number of full-time staff are as follows: PT 6.6, OT 14.6, SLP 27, social workers (SW) 7.5, and Recreational Therapists (TR) 2.2. The number of clients on caseload in 2014 was 3,808. Each full-time member has 40 to 70 clients. The centre

serves three regions that have a population of 330,048. The centre in this study uses a classification matrix system of functional ability to categorize its clients to assess functional need and allocation of services rather than using diagnosis. Two separate matrices assess children on cognitive/physical functioning and the other for communication (sender/receiver and independence). The 3 x 3 grids contain six different classification categories varying from low to a higher range on both axis. The classification system in this study was not reported though since it is used with children ages 18 months and over.

### **Participant Sampling and Recruitment**

An online survey was created to collect information from parents of children who actively used services in the past year at the children's treatment centre located in Southern Ontario, Canada. Every 5<sup>th</sup> client from a total of 700 families from the entire caseload of 3,808 clients was invited to participate in the cross-sectional study. Of the 700 parents, 500 parents were invited through a mailed invitation and 200 parents were invited through email. Invitations to participate in the study were sent by staff at the centre. Of those 700, 279 (40%) partially completed the survey and 171 (24%) fully completed the survey. Ethics approval was obtained from Hamilton Integrated Research Ethics Board.

### **Response Rate**

The Dillman Total Design method (Dillman, 1991; Hoddinott & Bass, 1986) was implemented to maximize the response rate. The Dillman method was modified in this study to use email communication (Dillman, Tortora, & Bowker, 1998). A total of three

invitations were sent to the 700 recruited participants. The initial communication occurred April 25, 2014 via email or letter to the home address, which constituted 21.5% of the respondents who completed the entire survey. A post-card (via email or post) was sent on May 12, 2014 after the initial correspondence constituting 52.0% of all respondents who completed the survey. Incentives were offered to families for completing the survey in the second reminder. Incentives included entering a random draw to win one of several gift card certificates to online music or bookstore. The final email or letter was sent on June 11, 2014 and constituted 26.5% of the 171 completed surveys. Family members were given an option to provide their email address in the survey if they wanted an anonymous customized report with their individualized scored results and interpretations from the measures. One hundred customized reports were completed and emailed to family members.

### **Representativeness of Sample**

Data for the centre's service utilization was abstracted from clinical records for each survey respondent for the entire time the child used services at the centre.

Comparisons on service use were made to evaluate if the sample was representative of the entire clientele using the children's service centre based on heavy or low service usage.

The analysis showed higher service use for this sample. Over the course of a year, the average service usage was 18 hours per year for all users at the centre and for our sample was 24 hours per year (mdn = 19, Q1 = 12, Q3 = 31).

### **Measures**

The survey consisted of the About My Child, Supports and Service Questionnaire,



Participation Environment Measures, and Measures of Processes Of Care. To meet age specifics and requirements of some of the measures, the online survey software allowed us to structure the survey. For example, if the child was under 5 years-old, the respondent was directed to the Young Children's Participation Environment Measure; if the child was over 5 years-old, the respondents were directed to the Participation Environment Measure for Children and Youth.

**About My Child Measure.** The About My Child (AMC) Measure questionnaire (CanChild, retrieved 2013b) has a total of 19 questions assessing level of parental concern about specific functional issues. The questions focus on functions such as mobility, toileting, sleeping, dressing, seeing, hearing, understanding, communicating, learning, behaviours, and moods. The responses are evaluated on a four-point likert-style scale ranging from not at all, a little, somewhat, to a lot (with a range of possible scores from 0 to 76). The accumulation of issues is indicative of the child's complexity from the parents' perspective (as opposed to the degree or severity of the conditions). Total complexity is defined as the total number of individual, "biological, psychological, social and environmental issues in a child's life that impact their health and care, and particularly the well-being of their families" (Williams, Rosenbaum, Gorter, McCauley, & Gulko, 2016). The distinction between complexity and function is that complexity focuses on the aggregation and impact of functional issues. A functional limitation such as low mobility may exist, but the child or parents may have no concern over mobility; however, the same limitation in another child may cause a higher concern with that child's family. Currently, psychometric assessments for this measure show good test re-

test, internal consistency and correlations to constructs of service need (Ritzema, Lach, Rosenbaum, & Nicholas, 2016; Williams et al., 2016).

**Supports and Services.** The Supports and Services (SAS) questionnaire from the Family Quality of Life measures focuses on the rehabilitation services provided to youth and their families in the course of the past 12 months (Summers et al., 2007). The focus of the questionnaire is to identify the parents' perspective on services both received and needed by their child, as well as the adequacy of the amount of service. Due to the nature of the inventory, no psychometric assessments have been conducted.

We created a scoring method to calculate a SAS total score in order to explore the relationship between SAS scores with motor/cognitive and speech/communication disabilities. The responses were scored on a likert scale if respondents indicated they currently needed the service identified in one of 28 items. A score of 1 was provided for “enough” services received, 2 for “some but not enough” services received, and 3 for “none” services received.

**Participation and Environment Measure.** The Participation and Environment Measure for Children and Youth (PEM-CY) measure is designed to measure participation of children and youth with and without disabilities (Bedell, Khetani, Cousins, Coster, & Law, 2011). The tool assesses participation activities of 5 to 17 year olds in the home, school, and community with consideration to environmental factors within the context of each setting. Psychometric evaluation of the PEM-CY indicates good reliability and validity (Coster et al., 2011). The assessment of test re-test reliability indicated a moderate to good score ranging from .58 to .84 across a four-week span. Internal

consistency indicated moderate to good scores on the scales ranging from .59 to .83.

For children under 5 years of age, the Young Children's Participation and Environment Measure (YC-PEM) was used. The YC-PEM shows good internal consistency ranging from .67 to .96. Test re-test reliability coefficients for home (.69 to .82) and community settings (.59 to .94) are fair to good but not for daycare/preschool (.31 to .92). The YC-PEM demonstrates good construct validity with consideration to age and disability/non-disability comparisons (Khetani, Graham, Davies, Law & Simeonsson, 2014).

The first section of the PEM-CY and YC-PEM explores the frequency of participation in activities; specifically, the question asked is "Typically, how often does your child participate in 1 or more activities of this type?". The scores range from 0 to 7, where 0 = never and 7 = daily indicating greater frequency of participation. The second section of the participation and environment measures explore the level of involvement of participation in activities on a 1 to 5 range, where, 1 = minimally involved, 3 = somewhat involved, and 5 = very involved. The third section explores if parents would like their child's level of participation to change. This score provides an indirect indicator of the parent's satisfaction with the children's current participation. Higher percentages suggest less satisfaction with the children's participation within the setting, while lower percentages suggest greater satisfaction. The fourth section explores environmental supports and barriers listed by respondents.

**Measure of Processes of Care.** The Measure of Processes Of Care (MPOC-20) is a measure of parental perceptions about family-centred practices (FCP) (King,

Rosenbaum, & King, 1999). This self-report inventory assesses the quality of care provided by healthcare professions from the parent's perspective. The inventory takes 15 to 20 minutes to complete. The 20 items are rated on a 7-point likert-type scale that answers if care providers demonstrated particular behaviours over the course of one-year. A score of 7 indicates high engagement of behaviour ("to a very great extent") and a score of 1 indicates the care provider did not demonstrate the behavior ("not at all"). A score of 0 indicates the item is not applicable. Each item on the MPOC is part of one of five subscales: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, and respectful and supportive care.

The MPOC-20 has demonstrated good reliability and validity. Test-retest reliability based on the intraclass correlation coefficient ranges from .78 to .88. The internal consistency based on Cronbach's alpha has shown a minimum score of .63 and a maximum score of .96. The MPOC has positive correlations to scales measuring satisfaction, and negative correlations to scales measuring stress to support its validity.

**Service Utilization Data.** Service utilization data from the time the child started using the centre was obtained from the centre. The number of visits and time spent in direct face-to-face and group therapy with OTs, PTs, SLPs, SWs, and TRs is presented over a one-year average period. Indirect minutes spent in planning, consultations, and report writing as well as total time (direct and indirect minutes) was also captured. Comparisons are made between children classified with primary diagnosis of a speech/communication disability versus motor/cognitive (all other) disability. The

rationale for this comparison is the authors want to explore differences in services need, services received, and participation based on primary diagnosis and complexity (Williams et al., 2016).

### **Analysis**

While 171 respondents completed the entire survey, 108 participants, 39%, did not complete the participation and environment measure but completed everything else on the survey. An analysis was conducted to compare families who partially completed the survey and families who fully completed the survey. No significant differences among distributions on all demographic variables were found. Respondents who did not complete the PEMs and two other measures (e.g., AMC, SAS, or MPOC) were removed from the analysis. For each analysis, the entire 279 sample size was used. However, the test determined the selection within the sample. For example, the respondents who completed the YC-PEM were analyzed for the appropriate tests reporting on young children and respondents who completed the PEM-CY were excluded. The sample size for each test is provided in the results.

Descriptive statistics were used to describe distributions, means, and standard deviations. Spearman, Mann Whitney and Kruskal Wallis tests were used because the variables included ordinal data and did not meet statistical assumptions of other tests. Spearman correlation coefficients were used to explore relationships. Mann Whitney and Kruskal Wallis tests were used to explore group differences.

Multiple regression was used to predict exploratory factors of time spent in therapy. The goal of this assessment was to explore the role of diagnosis versus

complexity to time in therapy. The relationship between diagnosis, complexity and time in therapy is of interest because complexity may be a more optimal predictor of services needed and received in comparison to diagnosis. We hypothesize parents' knowledge about the extent that a disability impacts the daily living of their child is a better predictor than diagnostic category, because each person's disability ranges in complexity despite diagnosis (Williams et al., 2016). As a result, families need for services may be greater or less depending on complexity for any given disability, making complexity a better predictor of services needed and received.

## **Results**

The survey took parents 45 to 90 minutes to complete. The sample consisted mainly of younger children from ages 0 to 4 years (70%) not currently in school (45%), males (62%), with a primary diagnosis of communication or speech delay (29%); as well as secondary conditions of communication (29%), behavior (13%), and learning (13%). The children's demographics are in Table 1, and parent demographics are in Table 2. The mean age of children in the study was years 4 years and 4 months. Biological mothers were the most common respondent in the survey (86%).

## **Environment**

### **External Environment Supports and Barriers from the Participation**

**Environment Measures.** The highest number of environmental supports that parents perceive for young children were supplies, sensory quality of an activity, access to personal transportation, and time. The highest numbers of barriers for young children are physical demands of activity, services, cognitive demands of activity, and relationships

with peers. The aspects that were both identified as both supports and barriers for young children are attitudes, policies and procedures, access to public transportation, social demands of activity, and money. Among children 5 years and older, the supports identified by families across the home, community, and school settings was physical layout; whereas, the main barrier across all three settings was physical demands of activity. Attitudes and safety were identified as main supports. Cognitive demands of activity, weather conditions, and public or personal transportation were identified as the most frequent reported barriers among older children. A full list of supports and barriers are provided in Table 3.

### **Population Characteristics**

**Enabling Resources.** The majority of families had 1 (21%), 2 (40%), or 3 (21%) children in the household, and the number of children in the household with a health or development condition was typically 1 (58%) or 2 (16%). Forty-three percent of families lived within 10 kilometers from the service centre; while, 30% lived within 11 to 20 kilometers from the centre, and 26% lived 21 kilometers and more. Most children received a diagnosis around 1 (26.9%) or 2 (27.4%) years-old and started using rehabilitation services at 1 (24.5%) or 2 (28.3%) years-old. Most families lived in a large urban population area consisting of 100,000 and more people (66%). The majority of children lived with both mom and dad (87%). Eighty percent of parents stated their child using the centre had no hospitalizations in the past year. Among the parents who stated their child was hospitalized in the past year, 11.8% of the children had one hospitalization and 8.2% had two or more hospitalizations.

**Need.** The most common disabilities among the sample were communication disorder/speech delay (n=63, 26.9%), developmental disabilities (51, 21.8%), Autism/PDD (25, 10.7%), cerebral palsy (20, 8.5%), and chromosomal/syndrome (16, 6.8%), with parents reporting concerns of communication (29%), behaviour (13%), and learning (13%) as secondary concerns. AMC scores indicating complexity ranged from 1 to 56 (Q1 = 4, Q2 = 14, Q3 = 29). A crosstab table of AMC scores and most frequent categories of the primary diagnosis (Table 5) showed that children with autism presented the highest median complexity scores (mdn = 30.5); followed by similar scores for syndrome (e.g., Down Syndrome; mdn = 24.5) and cerebral palsy (mdn = 22.5), then by children with developmental delays (mdn = 18.5) and children diagnosed with two or more conditions (mdn = 13.5). The lowest complexity scores were presented by children diagnosed with speech and communication disorders (mdn = 4, Q1 = 2, Q3 = 10). A significant difference was found between children with a motor/cognitive disability (n=153, mean rank = 114.8) versus a speech and communication disability on complexity (n = 46, mean rank = 50.6) using the Mann Whitney test ( $U = 1248, p < .001$ ).

## **Health Behaviors**

**Use of Health Services.** The SAS survey explores the question: “Please tell us about the type of services your [child/family] needs and receives”. Table 4 describes supports and services needed and/or received by the child and next, family. Children’s needs were predominately physical and/or occupational therapy service (58%) and speech and/or language services (83%). Respondents said both services were enough



(respectively 53% and 48%). Families stated they needed more help with childcare (37%) with 42% saying they are getting none.

Children with motor and cognitive disabilities were compared to children with speech and communication disabilities to examine scores on service need. The median need score was 11.8 for children with motor and cognitive disabilities and 4.4 for children with speech and communication issues. The highest unmet needs of parents of children with motor and cognitive disabilities were for physical and/or occupational therapy with (78.3% of stating a need) and speech and/or language services (77.4% stating a need). Among children with physical and cognitive disabilities, the majority of parents stated they felt they had “some but not enough” (42.6%) or “none” (52.7%) services provided for PT and OTs. A similar pattern existed for speech services. Parents with children with motor/cognitive disabilities stated they had some but not enough (42.4%) or no (44.8%) services. The highest family need was for childcare at 42.9%. Approximately 43% of parents with children with motor/cognitive disabilities stated they had enough childcare services versus 57.1% who stated they needed more.

Among children with communication and speech disabilities, parents stated their highest need for speech and language services (98.3%) followed next by behaviour support services (6.7%). Parents stated they felt they had “some but not enough” (37.9%) or “none” (56.9%) services provided for speech therapy. The highest family need for parents with children who have communication/speech disorders was also for childcare, but much lower at 23.7%, however, they received “some but not enough” (17.6%) or “none” (52.9%) services.

A statistical difference using the Mann Whitney test was found on service need between children with a motor/cognitive disability ( $n = 164$ , mean rank = 131.2) and speech/communication disability ( $n = 58$ , mean rank = 55.9). A higher ranking indicates higher perceived needs for services among children with motor/cognitive disabilities ( $U = 1533$ ,  $p < .001$ ).

Annual median number of visits and number of minutes in occupational therapy, physical therapy, speech therapy, recreation therapy and social work for families who accessed the centre from the time they started using services is detailed in Table 6. Service utilization patterns were similar regardless of speech/communication disability or mental/cognitive disability. The most frequent visits were for occupational therapy, physical therapy and speech therapy.

The relationship between complexity scores and service utilization from the time children started using services were explored using one-tailed ( $\alpha = 0.01$ ) Spearman's correlation coefficient. AMC scores were significantly correlated with time spent in direct face to face visits ( $r = 0.41$ ,  $n = 182$ ), time spent on telephone calls ( $r = 0.43$ ,  $n = 132$ ), time spent on indirect tasks ( $r = 0.45$ ,  $n = 182$ ), and total amount of time (direct and indirect;  $r = 0.46$ ,  $n = 182$ ). A significant difference was found between children with motor/cognitive disabilities ( $n = 155$ , mean rank = 116) and speech/communication disabilities ( $n = 55$ , mean rank = 77.3) on the total amount of time spent in therapy over a year ( $U = 2713$ ,  $p < .001$ ) using the Mann Whitney test.

Multiple regression was conducted to predict total amount of time in therapy from age, sex, diagnosis, and complexity. Preliminary analyses were conducted to ensure no

violation of the assumptions of normality, multicollinearity, and homoscedasticity by removing outliers. Outliers were removed based on Mahalanobis distance leading to a sample size of 158. While the model was statistically significant ( $F(5, 157) = 11.5, p < .001, R^2 = 0.28$ ), only complexity significantly predicted total minutes in therapy,  $p < .001$ . This finding supports that higher scores of complexity are indicative of higher service utilization, and complexity is significantly related to service utilization as compared to diagnosis.

### **Health Outcomes**

**Perceived Health Outcomes - Participation Frequency and Intensity for Younger Children.** The items in Table 7 are summary scores of participation activities in the home, daycare/preschool and community environments for young children reported by the YC-PEM. The highest amount of participation, reported by, “how often” was in the home ( $n = 137, x = 5.14, s.d. = 1.1$ ) in comparison to daycare/preschool ( $n = 133, x = 4.71, s.d. = 1.9$ ) and community ( $n = 133, x = 2.67, s.d. = 0.9$ ). Parents reported similar levels of involvement across home ( $n = 125, x = 3.78, s.d. = 0.7$ ), followed by daycare/preschool ( $n = 108, x = 3.74, s.d. = 1.1$ ) and community ( $n = 118, x = 3.67, s.d. = 0.9$ ). Parents reported they desired to see change (either increase or decrease in specific activities) in daycare/preschool (68%), followed by 56% change desired in home and 53% change desired in the community.

**Perceived Health Outcomes - Participation Frequency and Intensity for Older Children.** The items in Table 8 are summary scores of participation activities in the home, school and community environments, reported by using the PEM-CY. The

highest amount of participation, reported by, “how often” was in the home ( $n = 34$ ,  $x = 4.86$ ,  $s.d. = 1.24$ ) in comparison to school ( $n = 34$ ,  $x = 2.37$ ,  $s.d. = 1.34$ ) and community ( $n = 33$ ,  $x = 2.10$ ,  $s.d. = 0.95$ ). Parents reported level of involvement highest in the community ( $n = 28$ ,  $x = 3.49$ ,  $s.d. = 0.90$ ) and home ( $n = 29$ ,  $x = 3.39$ ,  $s.d. = 0.53$ ) settings, followed by the school setting ( $n = 27$ ,  $x = 2.99$ ,  $s.d. = 0.88$ ). Parents reported they desired to see most change (either increase or decrease in specific activities) in the home (70%), followed by 61% change desired in school and 54% change desired in the community.

**Correlations between YC-PEM and AMC.** Spearman’s correlation coefficient was used to explore the relationship between young children’s frequency and involvement participation scores in each setting to complexity scores. The significant correlations ( $\alpha = 0.05$ , 2-tailed) of frequency were  $r = -0.39$  ( $n = 140$ ) for the home setting and  $r = -0.23$  ( $n = 130$ ) for daycare/preschool. The correlation between involvement scores and complexity scores were higher than the correlation between frequency scores and complexity scores. Involvement and complexity scores was  $r = -0.61$  ( $n = 126$ ) for home,  $r = -0.60$  ( $n = 106$ ) for daycare/preschool, and  $r = -0.57$  ( $n = 107$ ) for community.

**Relationship between Participation and Cognitive/Motor versus Speech/Communication Disabilities.** A Kruskal Wallis analyses indicated no significant differences for participation on the YC-PEM across age or sex. Mann Whitney tests were conducted on the YC-PEM frequency and involvement scores to children with speech diagnosis in comparison to all other diagnosis (Table 9). Children with speech disorders ( $n = 46$ , mean rank = 101.8) in comparison to other motor or cognitive disabilities ( $n =$

115, mean rank = 72.7) scored significantly higher in the home, “how often” participation score ( $U = 1688$ ,  $p < .001$ ,  $r = -0.28$ ). Participation scores for involvement in the home setting were significantly different between children with speech disorders ( $n = 41$ , mean rank = 95.5) and children with physical or cognitive disorders ( $n = 104$ , mean rank = 64.2;  $U = 1211.5$ ,  $p < 0.001$ ,  $r = -0.34$ ). In the daycare/preschool setting, involvement participation scores were significantly higher for children with speech disabilities ( $n = 35$ , mean rank = 72.3) than children with motor or cognitive disabilities ( $n = 82$ , mean rank = 53.3;  $U = 970.5$ ,  $p = 0.005$ ,  $r = 0.26$ ). There was a significant difference between children with speech disabilities ( $n = 36$ , mean rank = 74.7) and children with physical/cognitive disabilities ( $n = 83$ , mean rank = 53.6) for involvement in the community setting ( $U = 965$ ,  $p = 0.002$ ,  $r = 0.28$ ).

**Satisfaction with Services.** The overall patterns of MPOC scale scores (Table 10) are relatively high and on par with other Canadian centres with published data on family-centred practices using the MPOC (Kertoy et al., 2013; King et al., 2000; McDougall et al., 2006). In examining scores for MPOC scales, differences that are greater than 0.5 points or have standard deviations greater than 1.5 are worthy of examination as they can be indicative of clinically important differences.

## Discussion

The purpose of this study was to explore important factors of children’s service utilization based on findings of a previous literature review (chapter two). This study explored these important factors, and the study describes the profile of families and their utilization of a large rehabilitation centre in Canada using Andersen’s model as the

organizing framework. We found, however, some factors present to be more important than others – these are identified as key factors in our study. The crucial areas described are service need, service use, participation patterns, and outcomes of family-centred practice. This discussion will highlight the factors we identify as important factors in children's service utilization and their relationships with one another.

### **General Implications**

A unique aspect of this study was using Andersen's model to design the survey, thus providing the ability to evaluate complex relationships among factors. We gathered information on factors of service utilization, as well as the state of these factors and understudied areas of children's rehabilitation in Canada. We found severally clinically important relationships: 1) higher complexity is associated with higher perceived service need; 2) higher complexity is associated with motor/cognitive diagnoses in comparison to speech/communication disorders, and there is a significant difference between motor/cognitive and speech/communication disorders with respect to complexity; 3) a significant difference exists between children with motor/cognitive and speech/communication disorders with respect to perceived service need; 4) complexity is associated with service utilization and specifically with time spent in direct visits, telephone calls, indirect tasks, and total amount of time (direct and indirect); 5) complexity is predictive of total time spent in therapy rather than age, sex, and diagnosis; 6) complexity is associated with both frequency and involvement of young children's participation, but complexity is more strongly associated to involvement than frequency among young children; 7) no significant differences exist for age or sex for young

children's participation; and 8) children with motor/cognitive disabilities have significant lower scores than children with speech/communication on young children's participation levels for frequency in the home and involvement in the home, daycare/preschool, and community. We recommend that service managers use the factors presented in this study that are relevant to their centre to explore their clientele to obtain a comprehensive understanding of relevant key factors of children's rehabilitation in private or public settings. The factors explored in this study include barriers, demographics of children and their families (including resources and needs), type and amount of services used, and participation as a health outcome.

### **Environmental Barriers**

Based on previous findings (Bedell et al., 2013; Coster et al., 2013; Law et al., 2013) and our study, physical demands of activity are a key barrier to participation among older children and younger children. Other demands for families with young children included: social demands of activities and services in the home. This study is one of the first studies in Canada that reports on barriers of young children. Because barriers are jurisdiction dependent, we recommend that service providers ask families the main perceived barriers to their children's participation in home, school/daycare, and community settings with a focus on exploring how physical demands of activity can be mitigated.

### **Enabling Resources**

The key predisposing characteristics we explored included number of children living in the home with a condition or disability, distance to centre (and access to

transportation), living arrangements, and income (for a private centre). We reported these as key factors to measure in a comprehensive evaluation based on previous research findings (chapter two). Researchers have found that a grouping in one of the more disadvantaged categories or vulnerable populations can decrease utilization. We recommend service managers and therapists take note of these factors and explore them thoroughly to provide more equity to vulnerable families. Based on the proportions reported in our research, a low number of families using the centre reported low income and being single parents, and this possibly suggests difficulties with access among these groups. A lower proportion of families with two children in a household and distance to centres may be expected due to families having, on average, two children households and using other centres in the catchment area.

#### **Need: Unmet Needs (SAS) and Complexity (AMC)**

This study is one of the first to measure unmet needs and complexity. Centres in metropolitan regions of Canada may have clientele with similar trends so service managers may want to explore needs with their clientele by asking, 1) does the client's complexity correspond to their level of service utilization? and 2) what services are clients using the centre for?, and to what degree are these needs being met or not?

Many researchers have explored the relationship between diagnosis with service use and health outcomes. However, conflicting findings have been found, with some studies supporting a relationship between diagnosis and outcomes (Cosbey, Johnston, & Dunn, 2010; Soref et al., 2012) and some studies supporting no relationship between diagnosis and outcomes (Law et al., 2004). We suggest this is the case because



differences rely on complexity, whereas other studies have tried to demonstrate differences between groups without the notion of a complexity measure. Comparing complexity and diagnosis to identify which factor is a better predictor of time in therapy is important for service planning and allocation. In our study, complexity significantly predicted service utilization while diagnosis did not. We believe that complexity is a better predictor of time in therapy because complexity relates better to service needs of families rather than diagnosis, so parents who perceive a higher need for services may ask and receive more services.

One of our key findings is that we found higher complexity scores among children with motor and cognitive disabilities in comparison to children with speech and communication issues. We found children with higher complexity scores (i.e., motor/cognitive disabilities) received more services; however, we are mindful children with speech issues may require the same amount of time (or more) as children with higher complexity scores to clinically improve their abilities. We also suggest using a language assessment that assesses complexity within the speech/communication domain in order to allocate services. For children with motor/cognitive disabilities, the AMC is a beneficial tool to identify and prioritize services most needed. Further efforts of research and knowledge translation are required to assess how meaningful the tool is in clinical practice.

This study described unmet needs of families and found differences between parents with children who have a diagnosis of motor/cognitive disabilities and speech/communication disabilities. The proportion for both groups indicates they are not

receiving enough services to satisfy their needs. Furthermore, the differences of need between these groups brings to attention that diagnostic category is indicative of the types of unique needs that families require. However, despite diagnostic category, the same trends for a higher unmet need of physical therapy/occupational therapy and speech/language services has been reported, supporting our findings (Kertoy et al., 2012).

The current state of knowledge from this study suggests that needs may not be met for service users due to high demand and/or lack of resources. We recommend conducting an ongoing assessment of clients to understand if their needs are being met. However, improved efficiency of services (to optimize and increase time with families), increased funding for more staff, or new centres may be required to meet the demands. Perhaps, the best strategy to promote daily functioning of children using treatment centres are to acquire community resources and to focus on enhancing current status by focusing on “family, fitness, fun, friends, function (i.e., play, tasks), and future” (Rosenbaum & Gorter, 2012). Through education and a proactive perspective, families are empowered and enabled to manage, adapt, and optimize current circumstances. We recommend rehabilitation centres use the SAS and AMC or a similar easy to complete checklist to assess service and family need.

### **Service Utilization**

Currently there is minimal research evidence regarding the relationships of Health Behaviours to rehabilitation utilization (Vingilis et al., 2007). Conceptual linkages were assessed in this study between amount of service hours and types of disciplines utilized. Analysis of the service utilization data showed a large number of visits to SLPs, OTs, and

PTs, and the utilization of these disciplines in rehabilitation is supported by other studies (Dusing et al., 2004; King et al., 2000; Kuhlthau et al., 2008; Majnemer et al., 2013; Majnemer et al., 2008; Palisano et al., 2012).

Supported by findings that parents are requesting more services, utilization of services is lower than average compared to other centres which report 3 or more services and a higher use of services per month compared to clinics in the United States (Palisano et al., 2012). Nonetheless, minutes and number of visits per month were similar to other reports of service utilization in Canadian sites (Palisano et al., 2012). The implications of low service may be reflected in unchanging complexity scores, low satisfaction with family-centred services, and higher service need with lower the quality of services. Furthermore, researchers have found that therapy for clinically important change requires goal-directed, activity focused interventions (therapy and practice) (Ahl, Johansson, Granat, & Carlberg, 2005; Darrah et al., 2011; Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Law & Darrah, 2014; Löwing, Bexelius, & Brogren Carlberg, 2009; Salem & Godwin, 2009; Sorsdahl, Moe-Nilssen, Kaale, Rieber, & Strand, 2010; Ustad, Sorsdahl, & Ljunggren, 2009). The dosing required for meaningful change includes a frequency of 1 to 5 days per week, intensity up to 3 hours per day (practice not quantified), and timing of 15 days to a six-month period for each goal. The Welcome Home Study (Law et al., 2005) is a dosing study that found similar clinically important changes in groups of children receiving 6 to 10 or greater than 11 therapy sessions over 6 months. This centre may not be providing sufficient services for change in health outcomes. It is out of this studies scope to assess whether further funding or opening more

services and programs are required, but there does appear to be a need for more services to satisfy the needs of families. While in this study we focus on individual level implications, efforts are currently ongoing that identify rehabilitation service, optimized with consideration to frequency, intensity, duration, and types of disciplines at a group level (Gannotti et al., 2016). A study assessing a causal link between service utilization to health outcomes, for example participation is required to assess how utilization relates to better participation outcomes. This study is presented in the next chapter and requires a sophisticated test for prediction and data sorting technique, such as structural equation modeling.

This study found AMC scores moderately correlated with service utilization (direct face to face minutes, direct telephone minutes, indirect minutes, and total direct minutes). Children in this study showed an increase in time spent in rehabilitation service utilization as complexity scores increased. These findings are significant because they support children who present higher complexity have higher perceived service needs and receive more health services. More research is required in each health jurisdiction to attain knowledge if the amount and types of services received are adequate for families, and if this additional time in therapy leads to improvements.

This study found that perceived service need and amount of service utilization was higher among children with motor/cognitive disabilities than children with speech/communication disabilities. This finding supports other literature that has reported an association between health status and healthcare utilization. Children who present lower cognitive and motor functioning have higher health service use than children with

higher cognitive and motor functioning (Majnemer et al., 2013; Palisano et al., 2012; Vingilis et al., 2007), also indicative of a relationship between complexity and service use (Williams et al., 2016). The centre in this study allocates resources based on an internal classification system that focuses on functioning rather than diagnosis, supporting that complexity is indicative of functional limitation. Nonetheless, it is unknown if children with speech disabilities would fare better with increased service usage despite complexity because this is a question that needs to be examined by reporting on clinical differences.

It is well established that higher rates of utilization are associated with younger (Majnemer et al., 2013; Palisano et al., 2012; Vingilis et al., 2007), males (Feldman, Swaine, Gosselin, Meshefedjian, & Grilli, 2008; Law et al., 2003; Majnemer et al., 2013a; Palisano et al., 2012) who report a chronic disability (Palisano et al., 2012; Vingilis et al., 2007). The first author of this study initially predicted that younger, male children would spend more time in therapy based on previous research that found more males than females use rehabilitation services (Keene & Li, 2005). However, the relationship between age and sex to time spent in therapy was not significant. The authors also predicted that higher complexity scores and diagnosis (e.g., physical/motor categories) would show a higher number of minutes with therapists. Complexity was a predictive factor for total minutes children spent in therapy while diagnosis did not explain time spent in therapy. The correlation between complexity and service use in this study is expected since this centre allocates services to its clientele based on a similar classification system rather than disability diagnosis. Nonetheless, a relationship exists between complexity and service utilization. This finding indicates that children using the

centre for speech services may use the services as frequently as children with physical/cognitive diagnoses, such as CP or autism, if they have similar complexity scores. Children with higher complexity scores spent more time in therapy at the centre than children with lower complexity scores. We highlight that this supports complexity rather than diagnosis is better for planning and allocating health services.

### **Participation**

Participation in daily life activities provides objective data regarding quantity and quality of engagement. Patterns of participation in this study were similar to an American study with young children with disabilities (Khetani, Graham, Davies, Law, & Simeonsson, 2015) with consideration to frequency and level of involvement scores decreasing from home to school to community setting. Percent desired change in Khetani's study and this study were respectively, 42% and 56% in the home, 68% in daycare/preschool for both studies, and 28% and 53% in the community. The difference between change desired in the community between the two countries is an area for further exploration. These similar outcomes across the YC-PEM present similar participation patterns of young children with disabilities in Canada and the United States. Patterns of frequency and involvement in participation are similar, possibly due to cultural values and practices. Levels of daycare/preschool community participation are low, and parents' indicated a desire for change. Community initiatives that are inclusive and allow for structural adaptations may improve involvement and parental satisfaction with participation.

Levels of participation were lower for older children than younger children.

Participation among older children indicated frequency was higher in the home setting followed by the school setting and community setting. This finding suggests there is room to improve extracurricular and community involvement among children who use rehabilitation services. The highest level of involvement was in the community setting followed by home and school. This finding indicates children may have accessible community activities despite infrequently accessing community centres. Generally, scores were higher for frequency than involvement supporting that determinant factors have a stronger influence on frequency than involvement.

This study found a significant relationship between participation and complexity scores. The negative correlations indicate an inverse relationship between complexity and young children's participation scores; that is, as complexity scores increase, participation scores decrease. Complexity scores were weakly/moderately correlated to "how often" participation occurs in the home and daycare/preschool but not community activities. Complexity scores were more strongly correlated to level of involvement in home, daycare/pre-school, and community settings in line with other findings (Anaby et al., 2013; King et al., 2009). As complexity increases it becomes more difficult to take part in social and/or physical activities. Increasing environmental supports such as availability of leisure programs with structural accommodations and adopting warm attitudes are crucial to facilitating participation among children with higher complexities. The findings support the importance of environment modification to increase participation involvement. Participation frequency, on the other hand, is less influenced by complexity,

but rather, other factors contribute to the frequency of participation such as parental perceptions and involvement (King et al., 2010; Soref et al., 2012).

Participation has significant implications for clinical therapy, and, as seen in this study, there is an interesting relationship between participation scores and type of disability (i.e., speech versus motor and cognitive disabilities). “How often” and, “how involved” participation scores changed based on children categorized with a speech versus motor or cognitive disability. Children with speech disabilities scored significantly higher on home, “how often” scale and all three, “how involved” participation scales in comparison to children with motor and cognitive disabilities. Children using the rehabilitation centre for speech related needs presented significantly higher participation scores in the home than children with motor or physical disabilities. This relationship was not supported with preschool/daycare or community settings. The level of involvement across all three settings had a small to medium effect when considering differences between speech or motor/cognitive disabilities.

An interesting finding is that children with speech issues have higher participation at home than in public settings. Thus, a more minor disability can still lead to important participation issues outside the home. Because participation is a mutable factor, that is, can be changed through lifestyle changes, encouraging participation by increasing children’s self-esteem and confidence should be an important focus among children regardless of complexity. While attitudes may be a barrier to social engagement, finding social programs and activities that value positive atmospheres and have accessible



structures for children, whether they have minimal or major disabilities, is important to promote participation (Law, 2002).

Overall, this study found new relationships between participation with diagnostic category and complexity. A contribution is the reported differences between motor/cognitive and speech/communication disorders as well as levels of complexities among young children (less than five years-old). The relationship between participation with diagnosis has been previously assessed, but not with consideration of comparing motor/cognitive disabilities and speech/communication issues. The relationship between young children's participation and complexity is the first time that this relationship is reported. The next step is to assess this relationship in a predictive model to see how much complexity predicts participation scores.

### **Satisfaction with Services**

Family-centred practices have a direct relationship to satisfaction with services (Law et al, 2001; Lawson, 2010). The MPOC has quite often been used as an indication of consumer satisfaction (Law et al., 2003; Moore, Mah, & Trute, 2009). Similarities of MPOC patterns exist across other studies (Dickens, Matthews, & Thompson, 2011; King et al., 1998; Stewart, Law, Russell, & Hanna, 2004), and this study supports trends of family-centred practices as a measure of service satisfaction. The findings indicate that parents believe the centre is succeeding in providing a family-centred environment, especially in areas related to service providers' interpersonal behaviours. Highest ratings for all sites were associated with providing respectful and supportive care, with relatively lower scores on the scale associated with providing general information. This finding

indicates that service centres are providing services that support excellent interpersonal behaviours while focusing on ways to improve the provision of specific and general information to families. For the MPOC findings for this centre, the scale for Providing General Information was about one full point lower than the other four scales. A recommendation made to the centre was to focus on changes to improve the provision of general information, such as information on services offered at the centre or in the community, various models of information (e.g., books, videos, websites), and general information on the disability such as causes and future outlook. Since that report was provided to the centre, a patient satisfaction task committee was established. One of the tasks of this committee is improving general and specific information provided to families over the next few years.

### **Implications for Service Managers and Providers**

This study provides a comprehensive overview of characteristics and needs of children in Ontario, Canada from a large publically funded and geographically-based children's centre. This paper calls to attention the importance of sufficiently gaining knowledge on key factors that play a role in the health system. The implications for this centre may not directly generalize to other centres due to differences in clientele but can be used as the basis for further surveys and planning in areas where services are similarly organized. The findings help service managers gain perspective on important areas to examine within their centres. Understanding the trends of other centres and regions helps to improve our understanding of trends currently occurring in different areas, which will lead to enhancing best practices.

More broadly, no large database exists for obtaining information on standards and quality indicators on children with disabilities. This study explores important quality indicators, such as demographics, need (service and complexity), participation health outcomes, and satisfaction with family-centred practices. Each health jurisdiction is unique, so presenting information will enhance our current state of knowledge, and this will provide information about specific factors to build towards a comprehensive and standardized method of enhancing knowledge on key factors and their relationships.

### **Limitations**

There are a few limitations to this survey. First, the length of the survey, as calculated by the online survey software, took respondents longer to complete than initially predicted. We speculate the length of the survey hindered respondents' desire to complete the survey. Hence, we saw a lower completion of the PEM measures in comparison to the other measures. Second, due to the wide variety of families and children included in the study, some of the components did not apply or could not be assessed. For example, some parents commented that they could not respond to all items in the YC-PEM since their child was too young or did not participate in some areas (e.g., items in daycare/preschool). A third criticism of the survey was some respondents mentioned it was difficult to evaluate certain sections, such as the MPOC or SAS, because the family only used the centre a few times in the past year. While considering the findings of this study, we recommend keeping in mind that the usage time for a few respondents is low and high for others because the respondents in this study are only a sample from the centre. The final limitation is representativeness and generalizability of

the sample.

The demographics of the families in this study are similar to other samples described in Canadian studies from Ontario (Law et al., 2007; Law et al., 2013). However due to the lack of data about each centre's service recipients, it is difficult to make a conclusive decision if the sample in this study is similar to other centres. The majority of children in this study primarily consisted of males and younger ages, even though ages 0 to 19 years were reported. This study also reported on a wide variety of disabilities. However a high proportion of children used the centre primarily for speech services in comparison to other children's treatment centres, who see a larger number of children with developmental disorders. Trends of child's sex and urban living was similar to other studies (Law et al., 2007). Parental education and income were higher in comparison to the 2011 education attainment (Statistics Canada CANSIM, 2006) and 2013 median family income (Statistics Canada CANSIM, 2015). Educational attainment across Canada for a university degree is 25.9% (based on a 2011 consensus survey), which is slightly lower than the attainment of a university degree reported in this study at 37%. Median family income in Ontario for 2013 is \$76,510 whereas median family income in this study for 2014 was more than \$90,000, indicating families who participated in this study have higher education and income than the average population.

The representativeness of the sample indicates that they have higher education and income. While the characteristics of this sample may be reflective of a voluntary sample (Kanuk & Berenson, 1975, p. 448), exploring the characteristics of the centre could provide further insight into the representativeness of the sample. The first author could

not locate data from other Ontario centres in terms of types and amounts of services provided. Due to the lack of information, it is difficult to posit if the sample in this study is representative of families from other centres. Nonetheless, given the few studies in this area, the patterns and key factors found in this study are of interest to explore at other Canadian rehabilitation centres as well as globally.

The lack of information available on service utilization raises concerns on the need to report on the amount of services in a standardized manner to explore the relationship between the efficiency and amount of services as well as having knowledge readily available to understand the true state of rehabilitation service delivery to families. Collecting service utilization data from more than one centre would have been ideal. Incorporating multiple centres in the study would allow for regional comparisons for amounts and types of services, providing more information on this centre's amount of services and sample representativeness.

### **Conclusion**

Overall, this study provides support that higher complexity is related to higher service need and utilization and lower involvement in participation, but not necessarily frequency in participation. Participation frequency is low in school and community settings than in the home regardless of complexity level. A positive note for parents' and health practitioners is that participation can be increased by removing environmental barriers and actively promoting participation. Similar patterns of participation exist across

North America. Changes in life practices can be promoted by modifying structural environments, removing negative attitudes and encouraging participation.

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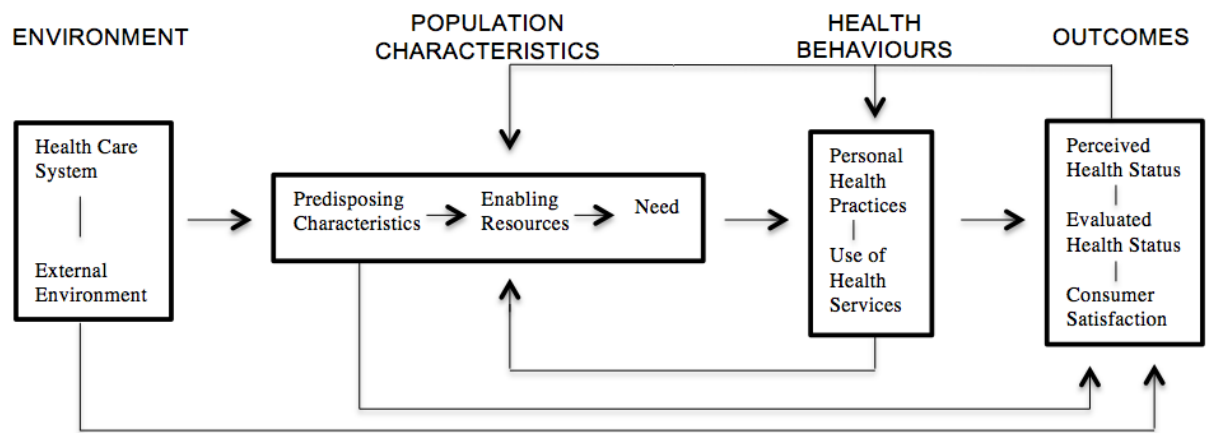
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*Figure 1.* Andersen's Health Care Utilization Model (1995)

Table 1

*Child Demographics*

Factor	N (%)
Child's age (missing = 3)	
0-4 years 11 months	194 (70.2)
5-9 years 11 months	63 (22.8)
10-14 years 11 months	14 (5.0)
15-19 years 11 months	5 (2.0)
Child's sex (missing = 2)	
Male	171 (61.6)
Female	106 (38.4)
Primary Health Condition (missing = 45)	
Acquired brain injury	15 (3.4)
Autism/PDD	25 (10.7)
Cerebral palsy	20 (8.5)
Chromosomal/Syndrome (e.g., Down Syndrome)	16 (6.8)
Communication disorder/speech delay	63 (26.9)
DD	51 (21.8)
Two or more conditions	8 (6.4)
Other*	36 (15.4)
Secondary Health Conditions (missing = n/a)	
Communication	124 (29.1)
Behaviour	56 (13.1)
Learning	55 (12.9)
Vision	39 (9.2)
Sleeping	35 (8.2)
Mood	30 (7.0)
Seizures	19 (4.5)
Pain	12 (2.8)
Motor/Physical Development	11 (2.6)
Other**	45 (10.6)
Type of Classroom (missing = 5)	
Preschool	76 (27.8)
Regular classroom	55 (20.1)
Both, a regular and special classroom	8 (2.9)
Special education classroom	9 (3.3)

Not currently in school	123 (45.1)
Other	2 (0.7)
Living Arrangement (missing = 9)	
Mom and Dad family	217 (86.8)
Mom and Dad but at different times (e.g. shared, split or joint custody)	8 (3.2)
Mom only	20 (8.0)
Dad only	2 (0.8)
Other***	3 (1.2)

*DD = developmental delay; PDD = pervasive developmental disorder*

*\* “Other” primary conditions include Spina Bifida/ Hydrocephalus (N=3), Muscle Disease (N=4), Motor and Sensory Disabilities (N=4), etc.*

*\*\* “Other” secondary conditions include sensory processing, toilet training, speech delay, etc.*

*\*\*\* “Other” living arrangements include grandparents and same-sex marriages.*

Table 2

*Parent Demographics*

Factor	Responding Parent	Other Parent
Parent's age (years)	N (%)	N (%)
20-34	114 (45.8)	84 (36.7)
35-49	130 (52.2)	138 (60.3)
50-64	5 (2)	7 (3.1)
Highest level of education completed by respondent		
Less than high school	11 (4.5)	24 (11)
Completed high school	28 (11.3)	28 (12.8)
Some college or technical training (at least 1 year)	17 (6.9)	16 (7.3)
Completed college or technical training	64 (25.9)	61 (27.9)
Some university (at least 1 year)	14 (5.7)	9 (4.1)
Completed university degree	113 (45.7)	81 (37)
Full-time status		
Stay at home caregiver	99 (39.8)	10 (4.4)
Recovering from illness or disability	2 (0.8)	1 (0.4)
Working full-time	101 (40.6)	198 (87.6)
Looking for work	4 (1.6)	6 (2.7)
Working part-time	30 (12)	6 (2.7)
Going to school	5 (2)	3 (1.3)
Other	8 (3.2)	2 (0.9)
Family income		
Less than 15,000	14 (5.7)	--
15 000-29 999	21 (8.5)	--
30 000-44 999	21 (8.5)	--
45 000-59 999	30 (12.2)	--
60 000-74 999	30 (12.2)	--
75 000-89 999	25 (10.2)	--
More than 90 000	105 (42.7)	--

Table 3

*Environmental Barriers and Supports*

	Participation Environment Measure for Children and Youth						Participation Environment Measure for Young Children					
	Home		School		Community		Home		Daycare/PreSchool		Community	
	% Support	% Barrier	% Support	% Barrier	% Support	% Barrier	% Support	% Barrier	% Support	% Barrier	% Support	% Barrier
Physical layout	80.6	2.8	79.4	8.8	71.9	18.8	84.6	2.5	87.7	2.2	75.2	6.8
Sensory quality	88.9	2.8	61.8	23.5	64.5	19.4	89.7	0.6	87.1	3.6	64.9	17.6
Weather conditions	n/a	n/a	34.4	28.1	34.4	31.3	n/a	n/a	60.9	5.1	52.2	12.7
Physical demands of activity	51.4	25.7	36.4	30.3	34.4	40.6	78.6	9.1	74.8	7.9	73.1	10.0
Cognitive demands of activity	51.4	22.9	36.4	42.4	48.4	22.6	68.2	11.7	70.1	10.9	65.2	9.8
Social demands of activity	66.7	16.7	41.2	32.4	46.9	21.9	59.7	13.6	60.0	13.6	56.0	17.9
Attitudes	82.4	17.6	79.4	8.8	62.5	6.3	89.3	0.7	81.9	0.7	64.2	7.5
Relationships with family members	65.7	5.7	n/a	n/a	n/a	n/a	88.2	0.7	n/a	n/a	n/a	n/a
Relationships with peers	n/a	n/a	67.6	2.9	59.4	6.3	n/a	n/a	0.0	0.0	63.2	10.5

Safety	n/a	n/a	91.2	8.8	78.1	6.3	n/a	n/a	n/a	n/a	74.4	9.0
Personal transportation	n/a	n/a	45.5	6.1	87.5	3.1	n/a	n/a	90.8	3.8	85.5	6.1
Access to Public transportation	n/a	n/a	50.0	6.7	81.3	6.3	n/a	n/a	92.6	3.0	89.2	4.6
Access to Programs and services	0.0	0.0	33.3	18.2	53.1	18.8	68.2	17.9	83.8	2.2	66.4	6.3
Policies and procedures	n/a	n/a	36.4	12.1	n/a	n/a	77.9	8.7	93.3	1.5	n/a	n/a
Equipment and Supplies	80.0	5.7	72.7	9.1	56.3	18.8	94.2	2.6	71.2	9.1	73.8	10.0
Information	54.3	2.9	75.8	15.2	59.4	6.3	66.2	4.5	74.0	8.4	60.9	7.5
Time	55.6	5.6	51.5	9.1	46.9	9.4	63.4	3.9	72.7	5.3	53.0	7.6
Money	50.0	13.9	63.6	6.1	59.4	12.5	68.9	7.9	64.4	12.1	54.9	12.0



Table 4

*Supports and Service – Child Results*

Does your child currently need?	If YES, how much service does your family get?				
	Yes (%)	No (%)	None (%)	Some, but not enough (%)	Enough (%)
1a. Special equipment to help your child live, learn, and grow (assistive and communications technology)	58 (25.4)	170 (74.6)	8 (13.8)	30 (51.7)	24 (41.4)
1b. Health services (medical evaluations, nutrition, nursing)	57 (24.9)	172 (75.1)	3 (5.3)	15 (26.3)	39 (68.4)
1c. Hearing and/or vision services	54 (24.0)	171 (76)	4 (7.4)	8 (14.8)	42 (77.8)
1d. Physical and/or occupational therapy	134 (58.3)	96 (41.7)	7 (5.2)	55 (41)	71 (53)
1e. Speech and/or language services	189 (82.9)	39 (17.1)	20 (10.6)	76 (40.2)	90 (47.6)
1f. Special education services	48 (21.3)	177 (78.7)	8 (16.7)	20 (41.7)	19 (39.6)
1g. Counseling and psychological services	21 (9.3)	206 (90.7)	9 (42.9)	4 (19)	9 (42.9)
1h. Behavior support	46 (20.1)	183 (79.9)	19 (41.3)	18 (39.1)	10 (21.7)
1i. Transportation and/or mobility services	19 (8.4)	207 (91.6)	4 (21.1)	3 (15.8)	12 (63.2)
1j. Self-care skills (help with dressing/bathroom)	51 (22.5)	176 (77.5)	28 (54.9)	15 (29.4)	8 (15.7)
1k. Service coordination	29 (12.8)	197 (87.2)	5 (17.2)	12 (41.4)	12 (41.4)
1l. Transition services	22 (9.9)	200 (90.1)	5 (22.7)	10 (45.5)	9 (40.9)
1m. Employment or vocational services	2 (0.9)	223 (99.1)	0 (13.8)	1 (50)	1 (50)

*Supports and Service - Family Results*

Does your family currently need?			If YES, how much service does your family get?		
	Yes (%)	No (%)	None (%)	Some, but not enough (%)	Enough (%)
2a. Child care	84 (37.2)	142 (62.8)	35 (41.7)	18 (21.4)	34 (40.5)
2b. Money to help pay bills	61 (26.6)	168 (73.4)	22 (36.1)	27 (44.3)	15 (24.6)
2c. Homemaker and/or housekeeping services	41 (18.3)	183 (81.7)	32 (71.1)	8 (19.5)	5 (12.2)
2d. Support groups	47 (20.6)	181 (79.4)	24 (51.1)	14 (29.8)	9 (19.1)
2e. Counseling	44 (19.5)	182 (80.5)	25 (56.8)	10 (22.7)	9 (20.5)

Table 5

*About My Child Score by Primary Diagnosis*

		Autism / PDD	CP	DD	Speech Delay	Syndrome	Two or more conditions
Sample Size		24	20	46	46	16	14
Missing		1	0	5	17	0	1
Mean		30.7	24.9	18.5	6.6	22.9	16.8
Std. Deviation		15.7	13.9	13.1	5.6	12.4	13.9
Median		30.5	22.5	16.0	4.0	24.5	13.5
Percentiles	25	16.0	12.5	7.7	2.0	9.7	7.0
	50	30.5	22.5	16.0	4.0	24.5	13.5
	75	41.7	37.7	26.0	10.0	31.5	26

Table 6

*Number of Visits and Total Minutes Therapy from when Families Started Using the Centre Per Year*

<b>All Children</b>	<b>Sample (number of children)</b>	<b>25<sup>th</sup> Percentile</b>	<b>50<sup>th</sup> Percentile</b>	<b>75<sup>th</sup> Percentile</b>
Face to Face Visits with Occupational Therapists	160	1.4	3.4	6.4
Face to Face Visits with Physical Therapists	124	0.7	2.8	9.3
Face to Face Visits with Speech Language Pathologists	199	4.1	8.2	11.8
Face to Face Visits with Social Workers	95	0.5	1.0	2.4
Face to Face Visits with Recreation Therapists	40	0.3	0.7	2.3
Total Number of Face to Face Visits	249	7.0	11.6	17.5
Total Direct Minutes (Face to Face Visits and Group Therapy)	250	368.3	613.2	1091.7
Total Direct Minutes Spent in Telephone Calls	249	12.2	23.6	47.4
Total Indirect Minutes (case planning, consulting, etc.)	167	332.1	528.4	852.4
Total Direct (face to face, group, and telephone) and Indirect Minutes	250	739.9	1171.3	1931.2
<b>Children with Speech/Communication Disability</b>	<b>Sample (number of children)</b>	<b>25<sup>th</sup> Percentile</b>	<b>50<sup>th</sup> Percentile</b>	<b>75<sup>th</sup> Percentile</b>
Total Number of Face to Face Visits	56	5.8	12.3	17.6
Total Direct Minutes (Face to Face Visits and Group Therapy)	56	320.3	666.0	1224.4
Total Direct Minutes Spent in Telephone Calls	39	13.4	24.0	44.0

Total Indirect Minutes (case planning, consulting, etc.)	56	314.7	533.1	875.6
Total Direct (face to face, group, and telephone) and Indirect Minutes	56	658.6	1331.0	2125.4
<b>Children Motor/Cognitive Disability</b>	<b>Sample (number of children)</b>	<b>25<sup>th</sup> Percentile</b>	<b>50<sup>th</sup> Percentile</b>	<b>75<sup>th</sup> Percentile</b>
Total Number of Face to Face Visits	154	7.1	10.7	17.1
Total Direct Minutes (Face to Face Visits and Group Therapy)	154	369.4	600.5	1047.6
Total Direct Minutes Spent in Telephone Calls	102	11.2	23.6	48.9
Total Indirect Minutes (case planning, consulting, etc.)	154	324.3	505.1	839.2
Total Direct (face to face, group, and telephone) and Indirect Minutes	154	732.6	1159.1	1822.9

Table 7

*YC-PEM Outcome*

Statistic		Home	Daycare/ Preschool	Community
How Often	Number of Children	137	133	133
	Mean*	5.14	4.71	2.67
	Standard Deviation	1.1	1.9	0.9
How Involved	Number of Children	125	108	118
	Mean**	3.78	3.74	3.67
	Standard Deviation	0.7	1.1	0.9
Change Desired	Yes	56%	68%	53%

\*Possible score range is from 0 to 7

\*\*Possible range score is 1 to 5

Table 8

*PEM-CY Outcome*

	Statistic	Home	School	Community
How Often	Number of Children	34	34	33
	Mean*	4.86	2.37	2.10
	Standard Deviation	1.2	1.3	0.9
How Involved	Number of Children	29	27	28
	Mean**	3.39	2.99	3.49
	Standard Deviation	0.5	0.8	0.9
Change Desired	Yes	70%	61%	54%

\*Possible score range is from 0 to 7

\*\*Possible range score is 1 to 5

Table 9

*Participation (YC-PEM) and Speech versus Cognitive/Motor Diagnosis*

	Child Primary Condition	Number of Children	Mean Rank	P
Home How Often	Speech	46	101.8	
	Cognitive/Motor	115	72.6	
	Total	161		.000
Daycare/Pre-School How Often	Speech	42	80.9	
	Cognitive/Motor	104	70.4	
	Total	146		.174
Community How Often	Speech	38	76.0	
	Cognitive/Motor	97	64.8	
	Total	135		.134
Home How Involved	Speech	41	95.4	
	Cognitive/Motor	104	64.1	
	Total	145		.000
Daycare/Pre-School How Involved	Speech	35	72.2	
	Cognitive/Motor	82	53.3	
	Total	117		.005
Community How Involved	Speech	36	74.6	
	Cognitive/Motor	83	53.6	
	Total	119		.002



Table 10

*MPOC Scale Scores and previous MPOC Studies*

Scale	Number of Children	Mean (standard deviation)	Kertoy et al. (2013)	McDougall et al. (2006)	King et al. (2000)
Enabling and Partnership	188	5.53 (1.3)	5.04 (1.4)	5.20 (1.5)	5.46 (1.5)
Providing General Information About Your Child	148	4.56 (1.5)	4.39 (1.6)	4.67 (1.7)	4.28 (1.8)
Providing Specific Information About Your Child	184	5.11 (1.5)	5.08 (1.6)*	5.53 (1.2)	5.54 (1.5)
Coordinated and Comprehensive Care for Child and Family	172	5.56 (1.2)	5.20 (1.4)	5.22 (1.5)	5.49 (1.4)
Respectful and Supportive Care	197	5.87 (1.0)	5.47 (1.3)	5.45 (1.1)	5.72 (1.3)

**Chapter Four – Part 2: Personal, Environmental, and Family Factors of  
Participation of Children Using a Rehabilitation Service Centre in Ontario**

Authors: Uzma Williams, Mary Law, Steven Hanna, and Jan Willem Gorter

This chapter contains a manuscript entitled: “Part 2: Personal, Environmental, and Family Factors of Participation of Children Using a Rehabilitation Service Centre in Ontario”.

This manuscript will be reduced in length and will be submitted to the journal of *Child: Care, Health and Development*. Part Two of the manuscript is an extension of the analysis from Part One.

### **Abstract**

**Background:** Research on participation of young children with disabilities is a relatively new area, especially in the context of a rehabilitation health system. The purpose of this study is to assess the influences of environment, population characteristics, and service utilization on health outcomes of participation frequency and involvement among children 0 to 5 years of age who receive services at a children's treatment centre.

**Methods:** The Anderson healthcare utilization model was used as a guiding conceptual framework for data collection and analysis. Data was collected through an online survey from parents of 236 children (mean age 3 years and 5 months, s.d. = 1.30, females = 152, and males = 84) using a children's treatment centre in Ontario. Children presented a broad range of disabilities with 135 (69%) presenting motor/cognitive disabilities and 61 (31%) presenting speech/communication disabilities. Models for four participation outcomes were assessed using structural equation modeling: 1) home frequency, 2) home involvement, 3) pre-school/daycare and community frequency, and 4) pre-school/daycare and community involvement. In addition to participation as the primary outcome, each model also explored predictors of service utilization and mother's participation. The factors in the models included child's age, child's sex, child's complexity (cumulative number of concerns as measured by the About My Child measure), number of environmental barriers, income, mother's participation (as measured by the Health Promoting Activities Scale), and service utilization.

Results: Age and barriers predicted participation frequency in the home, preschool/daycare and community settings. Age, mother's participation, and complexity influenced participation involvement in the home, preschool/daycare and community. An increase in child's age or complexity significantly influenced service utilization across all models. Complexity reduced mother's participation in both the frequency and involvement models.

Conclusion: This study is one of the first in Canada to obtain knowledge to understand and promote participation of young children within the context of receiving rehabilitation services especially with differentiating differences between frequency and involvement models. The findings support considering age and complexity as important predictors of service utilization. Complexity, measured in a new way, allowed us to measure the impact of disability on participation more directly than other need indicators. We recommend using a measure of complexity with families to understand their needs and to promote participation involvement. The impact of complexity on participation frequency and involvement could potentially be mediated from a young age by removing environmental barriers and promoting mother's participation.

Part 2: Personal, Environmental, and Family Factors of Participation of Children Using a  
Rehabilitation Service Centre in Ontario

**Introduction**

In children's rehabilitation, participation is defined as taking part in daily life activities in the home, school and community, ranging from sedentary reflective activities to physical activities done socially or alone (Coster et al., 2012). Participation is a holistic health outcome and typically includes significant patterns and behaviors towards engaging in a broad variety of life activities (Law, 2002b). Frequency and level of involvement are often measured to indicate participation of children, both for typically developing children and children with a disability. Researchers also report on the diverse range of activities, children's enjoyment in activities, and parental perceptions of desired amount of change in participatory activities.

Studies have explored determinants of participation but none have predicted participation based on key factors within a rehabilitation service system. An individual's health system is influenced by personal (age, gender) and environmental (physical, family, social, attitudes, supports) factors (World Health Organization, 2007). King and colleagues (2006) conducted a study on the participation of children with disabilities using structural equation modelling (SEM; King et al., 2006). The researchers examined three age groups (6 to 8, 9 to 11, and 12 to 14 years) of males (229) and females (198) through data collected by home interviews and self-report questionnaires completed by parents. The researchers found significant predictors of participation are the child's overall functioning, environmental barriers, family's participation and supportive

relationships, and child's interest in activities. King's study identified key factors of interest among older children with disabilities, and the study also identifies the important role of investigating child's functioning, role of family members, and environmental barriers. The researchers recommended further investigating personal, family, and environmental factors.

No study has examined the influence of a rehabilitation health system or other factors on young children's participation. In this study, we addressed two knowledge gaps: 1) measurement of young children's participation and 2) the predictors of participation as a health outcome. The purpose of the present study is to assess the influence of personal, family, and environmental factors on service utilization, participation frequency, and participation involvement among children 0 to 5 years of age who are receiving services at a geographically-based children's treatment centre.

### **Children's Participation, A Significant Health Outcome**

The operationalization of participation in the World Health Organization's International Classification of Functioning, Disability and Health has been valued as a crucial and integral component to study human functioning (World Health Organization, 2007). Since 2002, when an editorial called to attention the importance of investigating this area (Law, 2002a), participation has been steadily explored among children with disabilities. Participation is appropriate to be a critical focus in therapy because of its importance for child development and because of its mutable nature (Andersen, 1995). Mutability refers to the potential of a factor to change due to intervention. Assessing participation and creating initiatives to improve participation continues to be an important

issue because children with disabilities have significantly lower participation even though parents and children desire increases in participation (Heah, Case, McGuire, & Law, 2007). Researchers state that lower rates of participation among children with disabilities are influenced by negative attitudes and fewer opportunities to participate (Anaby et al., 2013; Brewster & Coleyshaw, 2011; Harding et al., 2009; Heah et al., 2007; Law, 2002b). Recent studies show that participation can be increased because of intervention. By working close with families and removing environmental barriers, clinical improvements in performance scores and diversity in leisure activities was evident among six youth aged 14 to 17 years with a total of 17 goals across a 12-week intervention (Law, Anaby, Imms, Teplicky, & Turner, 2015). As well, an increase in participation has been associated with improved health outcomes such as quality of life (Ronen, Rosenbaum, Law, & Streiner, 1999), lower physician utilization and fewer sick days off work (Muschalla, Vilain, Lawall, Lewerenz, & Linden, 2012), and generally experiencing self-efficacy as well as feeling happy (Heah et al., 2007).

### **Health Systems for Families and Children with Disabilities**

Receiving therapy at a children's treatment centre may be a slow yet potentially beneficial journey for families. Service satisfaction with rehabilitation has been associated with family-centred practices, lower number of health concerns, and fewer locations where services are received (Law et al., 2003). Researchers have found that parents who indicate higher satisfaction with family-centred practices also experience higher perceptions of health-related quality of life outcomes (Moore, Mah, & Trute, 2009). While there may be long wait times to begin services in Canada, typically families

are accessing two or more services (Feldman, Champagne, Korner-Bitensky, & Meshefedjian, 2002; Majnemer, Shevell, Rosenbaum, & Abrahamowicz, 2002) on average twice a week (Majnemer et al., 2002; Parkes, Donnelly, Dolk, & Hill, 2002) in clinical practice or schools (Darrah, Wiart, Magill-Evans, Ray, & Andersen, 2010; Majnemer et al., 2013; Majnemer, Mazer, et al., 2008; Palisano et al., 2012). Because centres are a key point of access to health care, therapists play a central role in encouraging and setting participation goals (Ziviani, Poulsen, Kotaniemi, & Law, 2014).

### **Andersen's Model of Healthcare Utilization: Application to Children's Health Systems**

Andersen's model has been used to assess health care services and outcomes in various rehabilitation and health care research disciplines (Graves, 2009; Guilcher et al., 2012; Vingilis, Wade, & Seeley, 2007; Walter, Webster, Scott, & Emery, 2012). The model has been used to describe theoretical relationships and test statistical relationships (Almasri et al., 2011; Dusing, Skinner, & Mayer, 2004; O'Neil, Costigan, Gracely, & Wells, 2009). Andersen's model has four major domains including i) Environment: health care system and external environment; ii) Population Characteristics: predisposing characteristics, enabling resource and need; iii) Health Behavior: personal health practices and use of health services; and iv) Outcomes: perceived health status, evaluated health status, and consumer satisfaction. In each category, researchers identify factors to measure in their evaluation of a health system.

Pathways specified in the model represent multiple influences on health behaviors and health outcomes. One of the four main pathways is from the environment to



outcomes domain. This relationship is accounted by environmental supports and health behaviors and their influence on participation. Another relationship explores the role of factors from the population characteristics domain on health outcomes. Finally, an indirect relationship is presented from environment to population characteristics to health behaviors to outcomes. Typically, environment, predisposing characteristics, and health behaviors have a direct relationship to outcomes, as indicated by the model. The domains of Andersen's model, predisposing characteristics, environment, health behaviors, and outcomes constitute a health system. Previous work by has incorporated Andersen's model as a guiding framework to identify key factors of children's service utilization (chapter 2). The authors further identified relationships among key factors such as correlational associations between complexity and service use, service need, and participation (chapter 3). However, in the first two studies, the authors incorporated the Andersen model as a descriptive model rather than using it as the basis for an evaluative analysis. In this study, we adapt Andersen's model to examine factors that have the potential to explain the relationship between environmental, population and health behaviour characteristics and outcomes of participation.

### **Using Andersen's Model as a Framework to Examine Factors within A Service System**

**Environmental Supports and Barriers.** A scoping review using the ICF framework examined literature from 1990 to 2011 that reported on environmental supports and barriers among children with disabilities (Anaby et al., 2013). Social support and region of residence were the two most prominent supports that facilitated

participation. The most common barriers were negative attitudes, barriers in the physical environment, lack of adequate services and policies, and unsupportive care providers. Enriched environments allow for higher participation whereas environments with many obstacles and non-modifiable environmental structures/policies lead to lower participation (Anaby et al., 2013).

Parents with children with disabilities report fewer environmental supports and more barriers within the home setting than children without disabilities (Law et al., 2013). Lack of supports for children with disabilities (5 to 17 years-old, n = 576) centred around the “availability/adequacy of resources” such as money, help, time, information and supplies (p. 63). In comparison to home and community settings, parents perceive the strongest barriers in school settings among both male and female children ages 6 to 14 years with physical disabilities (Law, Petrenchik, King, & Hurley, 2007). Parents with children in younger age cohorts encountered greater barriers if the child presented lower physical functioning. Children in older age cohorts (12 to 14 years), on the other hand, experienced more barriers to participation overall than children in younger age cohorts. In addition to age and physical functioning, children with behavioral and emotional difficulties of any age encountered an increased number of environmental barriers to participation than children without behavioral or emotional difficulties.

Using a different approach than administering a measure to families, interviews with 20 parents of children with Down Syndrome (ages 2 to 17 years of age) were analyzed using a phenomenological approach to find themes on supports and barriers to participation (Barr & Shields, 2011). The main environmental facilitators of physical

activity were: positive family dynamics, social opportunities with friends and environmental adaptations in structured programs. Environmental barriers to physical activity included a lack of adequate programs that meet needs of children with Down Syndrome.

To summarize, supports and barriers encountered by children with disabilities have been explored in various settings and through different methods (i.e., scoping review and qualitative analysis). The findings reveal that environmental factors can have both a direct and indirect influence on participation.

**Population Characteristics.** Population characteristics in the Andersen model explores differences in health service utilization and outcomes based on individual characteristics and need (Andersen, 1995). This domain is composed of the three categories: predisposing characteristics, enabling resources, and need. Relevant predisposing characteristics that potentially influence both service utilization and participation outcomes include age (Kuhlthau, Hill, Fluet, Meara, & Yucel, 2008; Palisano et al., 2012) and gender (Dusing et al., 2004; Kuhlthau et al., 2008). Among children with disabilities, important factors of enabling resources include socioeconomic (SES) factors such as family income, parental education, and work status (Fulkerson, Haff, & Chino, 2013; Newacheck, Rising, & Kim, 2006; Soref et al., 2012; Wallby, Modin, & Hjern, 2012). Received or needed supports and services also influence enabling resources (Bourke-Taylor, Cotter, & Stephan, 2014; Weller, Minkovitz, & Anderson, 2003). Factors under the need category include diagnosis (Bitsko et al., 2009; Kuhlthau et

al., 2008) and complexity, defined as the cumulative number of health concerns (Law & Jaffer, 2007).

Diagnoses that typically lead to a higher number of functional concerns such as autism will have higher complexity scores (chapter 3). As a result, complexity appears to be a better indicator of service use in contrast to diagnosis. Severity, on the other hand, indicates the degree of activity restriction (World Health Organization, 2007), but the limitation of severity is it does not explain life concerns from the perspective of family members. While an individual might have high severity, he or she can still lead highly satisfactory lives, so severity is not always an accurate indicator (Williams, Rosenbaum, Gorter, McCauley, & Gulko, 2016). For example, an individual who is not able to walk but is independent in many areas may show lower complexity.

Research exploring participation has found that diagnosis is not always a determinant of participation. In a study with 427 children with disabilities, participation scores were similar across children with central nervous or musculoskeletal disorders (Law et al., 2004). Age, sex, and physical function, however, were predictive of participation scores. As supported by Law et al. (2004), other studies have found a relationship between lower cognitive/physical functioning and lower participation (D. Anaby, Law, Hanna, & Dematteo, 2012; Soref et al., 2012), poorer outcomes (Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001) and higher use of services (Majnemer et al., 2013). A study by Simeonsson and colleagues (2001) found differences in participation when comparing children with different classes of conditions that present

a wide difference in complexity (e.g., attention and language disabilities versus intellectual, neurological problems, or multiple disabilities).

**Health Behaviours.** Very little research has examined whether service utilization (e.g., amounts and types of services) has a significant impact on participation outcomes. One study found that youth who received services from one or more health professionals showed higher work/school participation and higher physical activity even with one reported disability (Table 3 from Vingilis, Wade, & Seeley, 2007).

### **Hypotheses: Specification of Relationships**

Barriers have been shown to be a strong indicator of participation, with a lower number of barriers indicating higher participation levels (Anaby et al., 2013; King et al., 2003). Accordingly, we expect to see a direct relationship between the number of environmental barriers and participation. There is no previous research that predicted the amount service utilization changes due to the number of barriers.

Age and sex are identified as important indicators of participation in children's rehabilitation literature. Younger aged children have higher levels of informal and formal participation in diversity intensity, and enjoyment (Klaas, Kelly, Gorzkowski, Homko, & Vogel, 2010). Based on this finding, we predict that younger children in the 0 to 5 year range will have higher scores in frequency and involvement across different settings. A study by Klaas et al. (2010) found that females with spinal cord injury (6 to 18 years) present higher levels of participation in comparison to males. While the research done by Klaas is based on children in an older age group, we predict females will have higher levels of frequency and involvement. We acknowledge differences that are found will be

minimal or unclear with respect to age and sex (versus gender in other studies) because this sample consists of very young children.

For family factors, higher incomes that are sufficient to support participatory activities of families are an important determinant of family participation (King et al., 2003). We predict families with higher incomes will have children with higher participation scores. A direct relationship has been established between maternal recreation and social interest and child's participation (Dollman, 2010; King et al., 2003). Furthermore, mothers of children with less complex disorders demonstrate better health outcomes (Bourke-Taylor et al., 2013). The impact of mother's participation on children's health outcomes, particularly participation, is currently unknown.

We predict service utilization will increase with higher child's complexity (Kuhlthau, Hill, Fluett, Meara, & Yucel, 2008; Majnemer et al., 2013), higher family income (King et al., 2003), lower child's age (Kuhlthau et al., 2008; Majnemer, Mazer, et al., 2008; Palisano et al., 2012), and higher parental participation (Holland et al., 2012; Wallby et al., 2012). Maternal involvement plays an important role in service utilization (Wallby et al., 2012), and maternal health impacts children's health outcomes (Canadian Paediatric Society, 2004). We predict mothers with lower recreation/social activities (discussed in this paper as mother's participation) will show lower levels of health utilization for their children (Wallby et al., 2012). Finally, service utilization is predicted to have a direct relationship with participation frequency and involvement.

Indirect relationships in Andersen's model are depicted from the environment domain to each category in population characteristics to health behaviors and to

outcomes. In our model, we define the indirect relationships that lead to the outcome in all the models consist of income and mother's participation; income and service utilization; children's complexity and mother's participation; and, finally, complexity and service utilization in our study. These relationships were hypothesized based on the indirect relationships depicted in Andersen's model.

### **Purpose of Current Study**

Based on previous work that has identified significant factors for exploration in children's rehabilitation, the next step is to assess the structure of relationships among young children within a geographically based service system. The purpose of this study is to assess the influences of environment, population characteristics, health behaviours and health outcomes on service utilization, participation frequency, and participation involvement among children 0 to 5 years of age who are receiving services at a children's treatment centre.

## **Methods**

### **Participants**

Participants for this cross-sectional online survey were recruited from a children's treatment centre in Southern Ontario. The organization provides a broad range of services to children with physical, communication, and developmental disabilities from birth to 18 years of age. The sample size of 165 was determined using Poisson simulation generation. Poisson simulation was used because at the beginning of the study, the specific analytic tests that would be used for this dissertation were not yet fully determined.

Poisson distribution describes the probability of an independent event based on the average of another specified variable (Poisson, 1837). Poisson simulation can be used as a strategy to calculate sample size to estimate an average rate of sufficient response, which allows researchers to ensure a large enough sample size in order to meet the requirements of multiple types of analyses. Calculations of sample size are typically based on a specified statistical test and assume that the collected data will be normally distributed (Cundill & Alexander, 2015). Cundill and Alexander contend that if data is suspected to be skewed, better predictors of sample size may be calculated by poisson or binomial simulations rather than traditional tests of sample size.

Poisson simulation works on the Bernoulli Trial principle. The Bernoulli principle is based on the probability of an event occurring for example, based on  $x$  visits, we need a sample size of  $x$  to have a power of 0.98. By using poisson simulation, we assume that the prediction of a wide number of factors is in relation to service utilization factors, namely average number of visits to the centre. By using poisson simulation, we are able to calculate a sample size based on our key factors rather than a sample size calculator for a specific statistical test. Also, poisson simulation has been used for general linear models, which is a basis of SEM. Using the poisson simulation method also met the average sample size recommendation for a moderate model falling in between  $n = 100$  for a simple model and  $n = 200$  for a complex model (Kline, 2011, pp. 11-12).

## **Measures**

Factors such as age, sex, income, and diagnosis were asked as single item questions on the questionnaire. Service utilization data was obtained from the centre's



database. The rest of the survey consisted of the following measures. Figure 1 presents the Andersen model and the corresponding factors measured in this study.

**About My Child Measure.** The About My Child (AMC) Measure (CanChild, retrieved 2013b) has a total of 19 questions assessing the level of parental concern about specific functional issues such as mobility, toileting, sleeping, dressing, seeing, hearing, understanding, communicating, learning, behaviours, and moods. The responses are evaluated on a four-point likert-style scale ranging from not at all, a little, somewhat, to a lot (with a range of possible scores from 0 to 76). The accumulation of issues is indicative of the child's complexity (as opposed to the degree or severity of the conditions). Total complexity is defined as the cumulative number of individual issues that interfere with a child's daily living and requires healthcare supports (Williams et al., 2016). Complexity is considered through parents' personal perspective in terms of participation. That is, perception of complexity ("I can" or "I cannot do this") can influence participation outcomes in social and recreational activities. Initial psychometric assessments are in progress and show evidence of good test re-test, internal consistency and convergent validity (Ritzema, Lach, Rosenbaum, & Nicholas, 2016; Williams et al., 2016).

**Health Promoting Activity Scale.** The Health Promoting Activity Scale (HPAS) (Bourke-Taylor, Law, Howie, & Pallant, 2013) has eight items that assess the ability of a mother to participate in health promoting recreational activities. The questions focus on mental well-being and sociability with friends within the context of leisure participation, and the measure is normed on mothers of children with disabilities. The range of possible scores is from 8 to 56. A higher score indicates more participation whereas a lower score

indicates less frequent participation. Assessment of 152 participants revealed good internal consistency (Cronbach's  $\alpha = 0.78$ ). The HPAS was compared to the Short Form 36 to assess construct validity and demonstrates moderate correlations between the two measures (Bourke-Taylor et al., 2013).

**Service Utilization Data.** Service utilization data from the time the child started using the centre was obtained from data analysts from the treatment centre. The total time spent in therapy includes direct individual and group-based therapy with occupational therapists (OTs), physical therapists (PTs), speech-language pathologists (SLPs), social workers (SWs), and recreational therapists (TRs) as well as indirect minutes (time therapists spent on case planning, consultation, and report writing). Total time spent in therapy was divided by a one-year constant in order to compare the sample across a one-year time period.

**Young Children's Participation and Environment Measure.** The Young Children's Participation and Environment Measure (YC-PEM) measures participation frequency and involvement of children under five years of age with and without disabilities. Frequency is measured by items "how often has your child participated in this type of activity over the last four months?". The likert scale ranges from (7) daily, (6) few times a week, (5) once a week, (4) few times a month, (3) once a month, (2) few times in last four months, (1) once in last four months, and (0) never. The level of involvement in activities is assessed by a response scale ranging from (5) very involved, (3) somewhat involved, and (1) not very involved. Counts of environmental barriers were used as the environment domain in the model to assess its relationship to outcomes.

The YC-PEM shows good internal consistency ranging from 0.67 to 0.96. Test re-test reliability coefficients for home range from 0.69 to 0.82, and test re-test for daycare/preschool/community settings range from 0.31 to 0.94. The YC-PEM demonstrates good construct validity with consideration to age and disability/non-disability comparisons (Khetani, Graham, Davies, Law & Simeonsson, 2014).

### **Procedure**

**Recruitment.** Seven hundred parents of children who were actively receiving service programs from the treatment centre within the past year were invited to complete the survey. Of the seven hundred families invited to complete the survey, the initial invitation sent on April 25, 2014 elicited 60 (21.5%) participants. A random prize draw incentive was offered to families on the second invitation. The second (sent May 16, 2014) and third (sent June 11, 2014) invitation, respectively, elicited 145 (52.0%) and 74 (26.5%) number of respondents, totalling 279 participants in the three round response technique within the nine-week and three-day span. This method applied the Dillman Total Design method to elicit a good response rate (Dillman, Tortora, & Bowker, 1998; Dillman, 1991).

**Final Sample Selection.** From the 279 participants, 236 were eligible for completing the YC-PEM because of the 0 to 5 year age range used in this analysis, while others completed the Participation Environment Measure for Children and Youth (PEM-CY) measure for school-aged children. A total of 171 respondents fully completed the entire YC-PEM survey, but the entire eligible sample of 236 respondents was used in the analysis. A comparison to ensure data from missing respondents is comparable to

respondents with complete data is discussed shortly. A total of 236 children (females = 152 and males = 84) were used to assess the 8 parameters, exceeding the minimal required sample size of 165 by 156 (236-80).

**Additional Features.** During the completion of the survey, an online support chat link was embedded on the survey webpage. The author (UW) remained on the chat support page if participants encountered difficulty with the survey. If the author was not available, questions were routed to email. Only two participations had questions and these issues were resolved. The survey took each respondent approximately 45 to 90 minutes to complete. Due to the length of the survey, a save option was enabled and respondents were able to complete the survey in more than one sitting.

**Dissemination/Knowledge Translation.** Participants were provided an opportunity to provide their email in the survey if they wanted an anonymous customized report with their children's individualized scored results and interpretations from the survey. One hundred customized reports were completed and emailed to family members. The purpose of the reports were to provide parents feedback on the scores of the measures they completed on the HPAS and YC-PEM as well as contacts at the treatment centre who can provide additional resources if required.

## **Analysis**

SEM was conducted using the statistical package Mplus. Direct and indirect relationships were examined in our conceptual model (See Figure 2), which represents a modification of Andersen's model into a testable SEM model. Researchers have identified that SEM models are appropriate and necessary to assess complex relationships

between service utilization and health practices/outcomes (Phillips, Morrison, Andersen, & Aday, 1998). The SEM model, Figure 2, was over-identified ( $8(8+1)/2 = df = 36 > 0$ ), providing support that the number of factors assessed in the model represents a good conceptual model. The chi-square test was used to assess the model's fit (Hayduk, 2014). In addition to the chi-square, the comparative fit index (CFI), Tucker-Lewis Index (TLI), root mean square error of approximation (RMSEA), and the standardized root mean square residual (SRMR) were used to assess goodness of fit of the models. The researchers set the acceptable values according to guidelines reported in literature, CFI  $>.93$  (Byrne, 1994), TLI  $>.90$ , RMSEA  $<.08$  (Browne & Cudeck, 1993), and SRMR  $<.08$  (Hu & Bentler, 1999).

The factors in the model with missing data were examined to assess if respondents with missing data were different than respondents with complete data. Differences were not found in proportions or patterns (i.e., bar charts, skew) between respondents with missing versus respondents with complete data on each of the factors examined, so Maximum likelihood estimation was used to incorporate the missing cases under the assumption that the missing values are lost because of the survey's length (Hox, 1999). Missing cases were identified of those who completed less than 50% of any YC-PEM domain.

The factors in the model include age, sex, number of environmental barriers, family income, child's complexity, service hours in rehabilitation therapy, and mother's participation to predict the frequency and level of involvement in participation (see Figure 2). These factors and other factors were originally explored using i) correlation

coefficients, ii) the existence of conceptual relationships, and iii) relationships previously reported in literature. If a relationship between participation or service utilization and the factor existed based on the above criteria, the factor was incorporated into the model.

The participation models were examined in 2 settings: 1) home and 2) preschool/daycare and community. Typically, Preschool/Daycare and Community are separate settings for the YC-PEM, but they were combined for this analysis due to the similar levels of group mean scores. Each of the two settings were examined by frequency of participation and level of involvement in participation. In sum, the four models using different participation outcomes that were examined are: Frequency of Home Participation, Level of Involvement in Home Participation, Frequency of Preschool/Daycare and Community (PDC) Participation, and Level of Involvement in PDC Participation. All the models included the original factors included in the hypotheses and refinements to the model were not made. That is, once our hypotheses were established and the model was graphically depicted, no further additions or deletions of factors were made.

## **Results**

The age range of children was 0 to 5 (females:  $\bar{x} = 3.39$  and s.d. = 1.24; males:  $\bar{x} = 3.37$  and s.d. = 1.33), and the children presented a broad range of disabilities with 135 (69%) presenting motor/cognitive disabilities and 61 (31%) presenting communication disabilities. Participant demographics presenting means, standard deviation and ranges of each determinant factor are in Table 1.

The unstandardized regression coefficients of one observed predictor factor to the observed criterion factors can be found in Table 2. For every unit of change in each determinant factor, the corresponding estimate (mother's participation, one-year service use, or one of the four types of participation) is increased by the amount indicated (Schroeder, Sjoquis, & Stephan, 1986). Figure 3 and Figure 4 present the direct significant and non-significant paths for the frequency and involvement models, respectively.

### **Frequency of Home Participation**

Frequency of home participation ( $n = 236$ ) presented a good fit model (Hayduk, 2014),  $\chi^2 (9) = 8.51$ ,  $p = 0.48$ ; RMSEA = 0.00, CFI = 1.00 TLI = 1.00, SRMR = 0.032. An increase in age by one-year showed an increasing score of participation frequency in the home by .35 ( $p = 0.001$ ). A direct inverse influence was seen between barriers (-0.07,  $p = 0.001$ ) and home frequency participation. As the number of home barriers increased by one, a decrease of 0.07 occurs in how often a child participates in home based activities. While one barrier does not appear to have a large impact, the accumulation of barriers may make a large difference in the frequency of participation – making each barrier noteworthy. Two of four factors significantly predicted one-year service use. An increase in child's complexity indicated approximately 2.75 more hours per year spent in therapy ( $p < 0.001$ ). A one-year increase in age showed on average 2.78 hours less per year spent in therapy ( $p = 0.003$ ). Together these differences of over 6 hours service for a child who is younger and more complex equates a large amount of missed service utilization. As complexity increased, mother's participation score decreased by 0.43 ( $p =$

0.005), once again leading to large differences if complexity is high. R-square values revealed that 33.2% ( $p < 0.001$ ) of the variance in home frequency was explained the predictor factors while 18.4% ( $p < 0.001$ ) of variance for service utilization was explained by the model. No indirect relationships were observed for each of the four following: from income to mother's participation, income to service utilization, complexity to mother's participation, and complexity to service utilization, all which led to participation in the home frequency.

### **Level of Involvement in Home Participation**

The model for level of involvement in home participation ( $n = 161$ ) demonstrated a good fit (Hayduk, 2014),  $\chi^2 = (6) = 9.79$ ,  $p = 0.13$ ; RMSEA = 0.06, CFI = 0.97 TLI = 0.90, SRMR = .04. The score for involvement in home based activities increased by 0.09 with child's age ( $p = 0.01$ ) and by 0.06 with mother's participation ( $p = 0.03$ ). These factors show a small, but significant, impact on of involvement in home-based activities. An increase in complexity decreased involvement in home activities (-0.13,  $p < 0.001$ ). Service utilization increased by 2.87 hours as a result of one unit increase in child's complexity ( $p < 0.001$ ) while an increase in child's age showed lower service utilization (-3.26,  $p = 0.007$ ). Increased child's complexity was related to decreased mother's participation (-0.28,  $P < 0.001$ ). A large proportion of variance for involvement, 45.9% ( $p < 0.001$ ), was explained. Precisely 19.7% ( $p = 0.001$ ) variance accounted for service utilization. No indirect relationships were found in the model for income, mother's participation, service utilization, and complexity.

### **Frequency of Preschool/Daycare and Community Participation**



The model for frequency of PDC participation ( $n = 160$ ) showed a good fit (Hayduk, 2014),  $\chi^2 = (6) = 12.05$ ,  $p = 0.06$ ; RMSEA = 0.08, CFI = 0.90 TLI = 0.70, SRMR = 0.04. Scores for frequency in community participation decreased by -0.06 when the count of barriers increased by one ( $p = 0.04$ ). An increase of 0.18 of PDC frequency scores was seen with an increase in age ( $p = 0.01$ ), showing a much lower increase in comparison to the participation frequency in the home. Service utilization increased by child's complexity (2.85,  $p < 0.001$ ) and decreased by child's age (-3.32,  $p = 0.006$ ). Mother's HPAS scores decreased by 0.23 when the child's complexity increased by one point ( $p = 0.001$ ). This model explained 14.3% ( $p = 0.009$ ) of the variance in frequency of PDC participation and 9.7% ( $p = 0.001$ ) for the variance in service utilization. No indirect relationships were found in the model.

### **Level of Involvement in Preschool/Daycare and Community Participation**

The level of involvement in PDC participation ( $n = 160$ ) showed good model fit based on indices score (Byrne, 1994),  $\chi^2 = (6) = 14.06$ ,  $p = 0.03$ ; RMSEA = 0.09, CFI = 0.93 TLI = 0.78, SRMR = .04. PDC involvement scores increased with age (0.15,  $p = 0.001$ ) and mother's participation (0.09,  $p = .02$ ). These scores, compared to level of involvement in the home, constitutes a higher degree of impact of age and mother's participation in level of involvement in the PDC setting. On the other hand, a significant predictor that reduced PDC participation was complexity (-0.15,  $p < 0.001$ ), similar to the impact of complexity of participation involvement in the home setting. A one-year increase in child's age was associated to lower service utilization by 3.31 hours per year ( $p = 0.006$ ), and a one-point increase in complexity scores was associated to increasing

service utilization by 2.86 hours per year ( $p < 0.001$ ). Complexity was a predictor of a decreased score in mother's participation by -0.225 ( $p = 0.001$ ). The proportion explaining PDC involvement accounted for 44.2% of the model's variation ( $p < 0.001$ ). Factors explained 19.8% ( $p = 0.001$ ) of the variance for service utilization. No indirect relationships were found.

### **Discussion**

Factors related to service utilization and participation among young children using a regional treatment centre were assessed using SEM. Child's age and environmental barriers were the most influential predictors of home and community participation frequency. Participation involvement had significant relationships with child's age, complexity level, and mother's participation. We propose mothers who are actively engaged in participation at home and in the community are more likely to encourage and facilitate involvement for their child. The chi-square and index tests of the models revealed good fitting models (Byrne, 1994; Hayduk, 2014) with the home frequency model being the best fit to explain participation among young children. The predicting factors (i.e., age, sex, complexity, barriers, income, mother's participation, and service utilization) explained one third to almost one half of the variance in home frequency and home and community involvement. For PDC frequency in particular, a large amount of variance remains unexplained. Nonetheless, this research is a good starting point for exploring patterns of young children's participation.

A key contribution of this study has been that it is the first model of young children's participation to highlight key differences between frequency and involvement.

Using four models of participation outcomes was beneficial for differentiating between frequency and involvement across different settings. The factors present in the frequency models as well as the involvement models were consistent in predicting the participation and service utilization outcomes. Across the service utilization and participation models, the findings show similarities amongst child's age and complexity. Increase in participation frequency is larger in the home setting than the PDC setting with age, indicating that children's frequency of participation doesn't increase as much in the PDC setting as it does in home participation. On the other hand, the increase in participation involvement is slightly larger in the PDC setting than the home setting. Complexity scores across the home and PDC involvement models were small yet consistent and provide a start point to explore young children's participation. We encourage service providers and families to examine and implement methods to improve environmental barriers, child's complexity, and mom's participation to promote increased frequency and involvement of young children's participation. While scores were small for barriers among young children, we speculate these may have a stronger impact as children grow older.

For service utilization, the findings from this study indicate that two factors, age and complexity, relate significantly to service utilization over one-year. These factors, however, explain less than 20% of the variance in service utilization so further research is needed to examine other potential influential factors. Researchers may want to consult staff at treatment centres to explore if, for example, organizational structure, policies and staffing levels could potentially influence utilization patterns.

## **Environment**

**Environmental Barriers and Participation Scores.** Environmental barriers were significant in presenting a change in frequency of home and PDC participation. This finding is expected because environmental barriers create obstacles in engaging in participation activities limiting the frequency that a child participates (Anaby et al., 2013, 2014; Bedell et al., 2013). The influence of barriers was higher for participation frequency in the home than the PDC setting, possibly due to a larger amount of time that young children spend at home compared to PDC settings.

The most prominent barriers for young children are inadequate access to programs and services such as findings babysitters and visits from therapists, social demands of typical activities for example communicating and interacting with others, and cognitive demands of activities (chapter 3). A focus on reducing home and PDC barriers is a potential method to increase the frequency of participation. Recent studies focused on reducing environmental barriers for adolescents with physical disabilities have demonstrated improved community participation, and this intervention could also be tested for younger children (Anaby, Law, Majnemer, & Feldman, 2015; Law et al., 2015). We recommend clinicians probe and identify home barriers with families of children with disabilities. Information resources can be created by centres for parents regarding ways to reduce home barriers. If resources allow, therapists can do a home visit and focus on strategies to improve participation because the most important contextual factors are within the home for young children (Ketelaar et al., 2010; Law et al., 2005; Law, et al., 2007). Researchers report most of the children receiving services were seen most often at

the centre many times without parents, and clients were not seen at home. For PDC barriers, providers can improve children's participation by informing parents of community initiatives that exist in the community for children with physical disabilities. Currently, the greatest need of families in the United States and globally is requiring information on their child's disability and how to promote better living as well as interacting with other parents who have a child with a disability (Siebes, Ketelaar, Gorter, Alsem, & Jongmans, 2012). Providing information on community initiatives can lessen the information gap and improve participation. Furthermore, we recommend community partners mitigate physical demands of activities by modifying the activity or adding assistive devices to assist children with disabilities to engage in activities.

### **Population Characteristics**

**Predisposing Characteristics of Service Utilization.** Current literature reports perceptions of family-centred practices and environmental barriers (Kertoy et al., 2012) as well as service utilization (Majnemer et al., 2008) is lower among school aged children (> 5 years) than younger children. Our study contributed to knowledge in this area by adding further support that age is a predictor of service utilization, and specifically, that increasing age leads to lower service utilization. There are several reasons for this, including the fact that children ages 4 to 6 years in Ontario are spending more time in school (and may receive services there). As well, pressures to provide services with current staffing levels may lead centres to prioritize services to younger children.

Regarding the level of services, studies have found that the optimal amount of service utilization required for functional change is 1 to 5 days per week, intensity up to 3

hours per day, and 15 days to 6 month period for each goal (Ahl, Johansson, Granat, & Carlberg, 2005; Darrah et al., 2011; Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Löwing, Bexelius, & Brogren Carlberg, 2009; Salem & Godwin, 2009; Sorsdahl, Moe-Nilssen, Kaale, Rieber, & Strand, 2010; Ustad, Sorsdahl, & Ljunggren, 2009). In addition, clinically important changes were observed in groups of children receiving 6 to 10 or greater than 11 therapy sessions over 6 months (Law et al., 2005). The services received by our cohort are lower than these levels and become even lower as children grow older, indicating the children in this study may not be receiving adequate amounts of service to facilitate change in participation outcomes.

**Predisposing Characteristics of Participation.** Age and sex were tested as personal factors of participation. We were not surprised to see that sex was not a significant predictor of participation because young-aged children of both sexes may have similar participation patterns. Age was a significant predictor across all models. While the scores were small, our findings support that older children are more likely to engage in and be involved in home and PDC participation. This seems contrary to current literature that suggests participation scores decrease as children get older based on 3 age cohorts of 6 to 8, 9 to 11, and 12 to 14 year olds (Law et al., 2007). As seen in Part A (chapter three), the overall mean of frequency and involvement is lower among older children in a wider age group from 0 to 19 years. This indicates that the trajectory of participation is less for children in higher age cohorts.

This study also found higher scores for frequency and involvement in the home setting than the PDC setting for age as a predictive factor. This supports that children face

more challenges to participation outside their homes even during their younger years. This finding is supported by a study discussing restrictions of family participation that occur during infancy to toddlerhood (Rentinck, Gorter, Ketelaar, Lindeman, & Jongmans, 2009). Access and inclusion are a challenge for children with disabilities of all ages. An intervention focused on enabling participation emphasized using standardized tools for goal setting (Ziviani et al., 2014). Incorporating the use of the Canadian Occupational Performance Measure (COPM) and Belief in Goal Self-Competence Scale provides insight into the child's confidence and appraisal of self-performance. Along with these tools, provision of resources to enhance children's participation (<https://canchild.ca/en/research-in-practice/participation-knowledge-hub>) can assist families in promoting participation (CanChild, 2015).

**Enabling Resources of Service Utilization.** The model indicated that income was not a significant predictor of service utilization. The respondents of the survey showed a higher mean average of family income, typical of a volunteer survey sample. While it is possible that families with lower incomes would demonstrate a relationship between income and service utilization, these services are publically funded so that relationship may not be present.

**Need: Impact of Complexity on Service Utilization.** The centre in this study does not use a classification system based on a child's diagnosis to allocate resources. Rather, a matrix classification system based on service provider perceptions of functional ability is used to understand the needs of the children. Two classification systems exist: one for cognitive/physical functioning and the other for communication. The grids for

each contain six different classification categories varying from low cognitive and low physical functioning to a higher range. The classification system was not reported in this study because it is used only for children 18 months and over. Instead, we used the AMC measure so we can report on complexity for children of all ages, and found that higher complexity was a significant predictor of service utilization. The use of the matrix system may have however influenced the observed relationship between complexity and service utilization. Nonetheless, the relationship between need and service utilization indicates the centre is providing services based on need. This finding is potentially useful for service allocation based on a child's complexity (with consideration to clinical determinants). Managers may want to consider complexity and use the AMC measure or a comprehensive measure of family needs such as the Family Needs Inventory – Paediatric Rehabilitation (Alsem et al., 2014), as one additional tool to allocate services. Allocating services based on higher parental concerns or using the tool to prioritize tools may assist families who have more obstacles with their daily functioning tasks.

**Need: Impact of Complexity on Participation.** Our findings support our hypothesis that child's complexity significantly influences the level of involvement but not the frequency of participation. This finding indicates young children with disabilities, despite complexity level, can have high levels of how often they participate even if their level of involvement is limited. Decreasing barriers by modifying the environment with respect to areas identified as concerns of child's complexity can further promote involvement in participation, for example by ensuring all areas are accessibly by wheelchairs. Furthermore, complexity impacts PDC involvement more strongly than



home involvement. We encourage establishing and/or adapting more activities in the community that are geared toward children with disabilities to increase both frequency and involvement. This message is supported through a qualitative approach with adolescents (9 to 21 years) and their parents in the Stay-FIT study that similarly concluded the need to improve community access to promote participation. This finding on the impact of complexity on participation also highlights the need to explore social and psychological aspects of participation that hinder children with disabilities. Exploring perceptions of children with disabilities in regards to attitudes and beliefs about participation may lead to better inclusion and involvement. Much research exists on promoting the participation of children with mental health concerns (Biddle & Asare, 2011), so there is a need to explore social and psychological aspects of children with physical, cognitive and speech disabilities.

Children's complexity also significantly decreased mother's participation scores. Findings in the literature show lower health outcomes among mothers of children with disabilities compared to mothers of children without disabilities (Bourke-Taylor, Howie, Law, & Pallant, 2012). Our findings show that, even at a young age when all children require a lot of parental attention, complexity significantly reduces mother's participation. This finding is supported by qualitative research confirming a relationship between children's complexity and family participation (Heah et al., 2007; Rentinck et al., 2009). As children grow older, complexity scores may increase and have even more of an impact on mother's participation. The relationship between children's age in a wider age range

(e.g., 0 to 21) and complexity on mother's participation score needs to be explored in more depth in a future study.

## **Health Behaviors**

### **Mother's Participation on Service Utilization and Child's Participation.**

Mother's participation score is not significantly predictive of frequency of service utilization. We had initially predicted that mothers who are more engaged would spend more time in therapy. However, mother's participation is not a determinant of time spent in therapy likely because service centres use specific factors other than mother's participation to allocate services. Mother's participation can influence engagement in therapy; however, higher levels of mother's participation may not be strong enough to statistically measure changes in amounts of service utilization.

A mother or caregiver who facilitates participation among children with disabilities is crucial for promoting participation. Our study indicates a mother's participation score was significant in increasing the child's level of involvement in the home and PDC settings. Other research indicates a link between higher maternal self-efficacy to increased levels of participation among children ( $\bar{x}$  = 5 years-old) with mild motor disabilities (Soref et al., 2012). This study and Soref's study indicate the important role of maternal factors on children's participation. We recommended promoting participation not only among children in therapy but the entire family, in particular the mothers, to engage in meaningful activities with her children. Parents show a large investment and importance on their child's participation (Piškur et al., 2016). However, parents encounter many challenges to participation such as discords with education and

health professionals, negative and discriminatory attitudes of other people regarding disability, and limited equipment to facilitate participation (i.e., minimal options for activities, inaccessible layouts, etc.). One of the best strategies to identify challenges for families to participate in activities is through using a family-centred approach to assess needs in order to understand how to best enable participation (Piškur et al., 2012).

Older children may have lower participation scores than younger children (chapter three) because younger children receive more assistance in activities from care providers. Another explanation for our finding is that a higher participation score of mothers is significantly predictive of a higher score of children's involvement scores. That is, the child begins to model and adopt participation characteristics of his or her mother. This supports the work of King and colleagues (2006) with respect to participation having a strong social component between mothers and their children.

**Service Utilization and Children's Participation Scores.** Ziviani (2014) examined the impact of rehabilitation (service model, service focus, and amount of services) on quality of life PEDS-QL and occupational performance/satisfaction (as measured by the COPM) but found no statistical significance among 167 youth of 0 to 18 years-old, indicating no significant relationship between rehabilitation service utilization and quality of life and occupational performance outcomes. To date, no studies have examined young children's rehabilitation service utilization in order to understand its relationship to participation outcomes. We initially hypothesized that an increase in service hours received may show higher levels of participation. The amount of service utilization did not significantly predict children's frequency or involvement participation

scores in the home or PDC settings. Similarly, a Canadian study explored service utilization and occupational performance abilities reported no statistical relationship using SEM among 167 children ages 0 to 18 years (Law et al., 2005). Law and colleagues offered possible explanations. First, with respect to our study, as discussed earlier, the sample in this study received relatively low amounts of services in comparison to other studies of service levels (Ahl et al., 2005; Johanna Darrah et al., 2011; Ketelaar et al., 2001; Law et al., 2005; Löwing et al., 2009; Salem & Godwin, 2009; Sorsdahl et al., 2010; Ustad et al., 2009), so not enough service was received to statistically impact participation scores. An alternative explanation is we did not assess the types of services children were receiving. Service utilization may not directly influence participation because participation or functional improvement may not have been defined as the goal of therapy. Service utilization and participation needs to be measured and studied longitudinally by identifying participation as a goal of therapy to adequately examine the relationship between the two factors over time.

### **Indirect Findings**

Indirect relationships of participation were explored for all four models of frequency and involvement, but none of these indirect relationships were significant:

- Income on participation mediated by service utilization
- Income on participation mediated by mother's participation
- Complexity on participation mediated by service utilization
- Complexity on participation mediated by mother's participation

The non-significant indirect relationship between complexity and participation is interesting for the participation involvement model because the direct relationship from

complexity to participation was significant without the mediators. While it is not possible to determine why these indirect relationships were not significant, it could occur because the indirect relationships are not strong enough to influence participation over and above the direct relationship between complexity and participation, or, perhaps, the relationships between the constructs become too complex to statistically measure.

### **Utility of Andersen's Health Care Utilization Model of Young Children's Rehabilitation System**

This was the first study to utilize Andersen's model as a framework and adapt the framework to an SEM assessment model in children's rehabilitation. Andersen's model was beneficial with identifying and selecting prominent factors of children's rehabilitation. This study represents a starting point to describe a young child's rehabilitation health system and factors influencing service utilization and participation. Due to the use of the Andersen Model, service utilization and mother's participation were identified as important factors to explore in building the model. Furthermore, the Andersen Model was validated as a guiding framework, and its use was beneficial to organize and select factors crucial to children's health systems and health outcomes.

The Andersen model had only moderate utility in specifying the direction of the relationships. For some relationships, such as the direct relationship from the environment domain and the population characteristics domain to the outcomes, the model predicted our findings. However, there is a key limitation with using the Andersen model as an assessment model via SEM. While there is a conceptual relationship between all the determinant factors and the outcome factors of participation, these relationships are

difficult to measure mathematically, and, therefore, researchers need to adapt the model to a testable format. Some of the determinant factors cannot be grouped together as latent variables because it does not make sense empirically. For example, age and sex do not theoretically correlate so these factors cannot be grouped as a latent variable. Similarly, factors that measure enabling resources (e.g., income, education, and service needs) cannot be combined to create a latent variable because they do not make sense empirically. As a result, the constructs have to be entered into the software with caution and not how they are presented in the Andersen model. As a result, the models tested are the authors' model (i.e., Figure 2). Andersen's model is suitable as a descriptive model rather than a deterministic one to describe a service system (Andersen, 1995; Phillips et al., 1998).

### **Recommendations to Families and Service Providers**

Rehabilitation can have important benefits for children with a disability and their families. Prior to modifying services, it is imperative to understand the factors that influence a health system. This study found that important factors that impact utilization and participation are environmental barriers, child's age, mother's participation, and child's complexity. Of all the factors explored, mother's participation and complexity are newly identified factors that influenced young children's participation. While the relationship between mother and child's participation is embedded with many socio-psychological interactions, the impact of complexity on participation is easier to understand. Complexity, concerns due to the impact of a disability, allows us to measure the impact of disability on participation more directly than other need indicators. We

recommend using a measure of complexity with families to understand the impact of child's complexity on daily living and participation.

In intervention, there has been a focus on exploring environmental barriers because these could be modified by removing barriers (Anaby et al., 2013, 2014; Bedell et al., 2013). Reducing barriers is important because it can increase the frequency of participation, in particular in those children and families who may not benefit from the services they need otherwise. Regardless of disability and complexity, children can still increase how often they engage in participation. Complexity does impact the level of participation involvement, and examining ways to increase involvement is important. A strong emphasis of this study is to encourage parents and therapists to promote healthy participation practices from a young age since we saw that age is a prominent factor in involvement across all models. This study showed service utilization significantly decreased as children's age increased. Consistent and adequate amounts of services especially during critical times of development may improve patterns of participation in work, school, and recreational activities as children grow older. Further study of this relationship is needed.

### **Strengths and Limitations**

The outcomes of this study should be interpreted in the context of this study. This study was conducted from a region in Ontario so results may not generalize to other provinces with differing policies on health care or access to treatment centres. Nonetheless, while the results do not apply directly, the results are of interest to countries where services (amount and type) are similar to children with disabilities in this sample.

Researchers have found participation patterns show many similarities based on a research study using 1076 participants aged 6 to 20 years with cerebral palsy in the United States, Canada, and Australia (King et al., 2013). After controlling for participant's gender, family income, and parental education, participants showed no differences on recreational, social, and skill-based activities scales from the Children's Assessment of Participation and Enjoyment measure, with the exception of geographical differences for participants in the United States who show lower scores on physical activities scale than Canada. More so, the models in this study provide insight into key factors and relationships between key factors of families using children's treatment centres. The factors presented in this study are identified as important factors to explore in other health jurisdictions, and examining these factors in other jurisdictions will allow for comparisons to be made among different service users in Canada and internationally. The generalizability of this study could have been enriched by obtaining a large sample and using multiple centres.

A final limitation of this study was the long survey. A pause and save option on the online questionnaire was available and utilized by parents, allowing relief from the questionnaire if required. Generally results and patterns were consistent, so the quality of the results are reliable.

### **Conclusion**

The objective of this study was to examine key factors of young children's service utilization and participation. This study described clientele of a geographically based sample in Ontario, Canada, and the findings from this study can assist service managers



and therapists with service level data on utilization and participation. We measured direct and indirect factors of young children's participation in the context of rehabilitation services. The prominent factors that influenced service utilization included age and complexity. The data from this research supports identification and exploration of key factors of interest in therapy, for example considering environmental barriers, complexity, and mother's participation to promote participation from a young age. Participation, a complex construct, was influenced by different factors depending on the domain. Participation frequency was influenced by age and barriers, whereas participation involvement was influenced by age, mother's participation, and complexity.

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Table 1

*Descriptive Statistics of Factors in the Structural Equation Model*

<b>Variable</b>	<b>Sample Size</b>	<b>Mean</b>	<b>Standard Deviation</b>	<b>Variance</b>	<b>Minimum</b>	<b>Maximum</b>
Child's Age	236	3.38	1.30	1.69	0.00	5.00
Family Income (1 = <\$44,999, 2 = \$45000-\$89,999), 3 = \$90,000+)	209	2.21	0.78	0.61	1.00	3.00
Complexity (AMC score)	165	2.92	2.46	6.03	0.18	9.82
Mother's Participation (HPAS score)	176	5.87	1.95	3.81	1.60	10.60
Service Utilization (1 year average in hours)	211	26.39	16.87	284.75	4.40	109.54
YC-PEM Home Frequency	164	5.23	1.13	1.27	0.69	7.00
YC-PEM Home Involvement	148	3.79	0.68	0.46	2.00	5.00
YC-PEM PDC Frequency	151	3.12	1.15	1.32	0.13	7.50
YC-PEM PDC Involvement	133	3.68	0.88	0.78	1.00	5.00
YC-PEM Home Barriers	238	0.54	1.12	1.25	0.00	6.00
YC-PEM PDC Barriers	238	1.47	2.92	8.52	0.00	19.00

Table 2

*Beta Scores of Factors of Young Children's Participation*

<b>Home Frequency Participation n = 236</b>		
Factor	Estimate on Home Participation Frequency R <sup>2</sup> = .332, p < 0.001	Estimate on 1 Year Service Use (in hours) R <sup>2</sup> = .184 p < 0.001
Age	0.35**	-2.79*
Sex	-0.09	--
Complexity	-0.07	2.75**
Barriers	-0.07**	--
Income	--	-0.12
Mother's Participation	0.03	1.22
Service Utilization	-0.002	--
<b>Home Involvement Participation n = 161</b>		
Factor	Estimate on Home Participation Involvement R <sup>2</sup> = .459 p < 0.001	Estimate on 1 Year Service Use (in hours) R <sup>2</sup> = .197 p = 0.001
Age	0.09*	-3.26*
Sex	-0.03	--
Complexity	-0.13**	2.87**
Barriers	-0.02	--
Income	--	-0.40
Mother's Participation	0.057*	1.51
Service Utilization	-0.003	--

<b>PDC Often Participation n =160</b>		
Factor	Estimate on PDC Participation Frequency R2 = .143 p = 0.009	Estimate on 1 Year Service Use (in hours) R2 = .197 p = 0.001
Age	0.18*	-3.31*
Sex	-0.14	--
Complexity	-0.04	2.85**
Barriers	-0.06*	--
Income	--	-0.37
Mother's Participation	0.06	1.47
Service Utilization	-0.001	--
<b>PDC Involvement Participation n = 160</b>		
Factor	Estimate on PDC Participation Involvement R2 = .442 p < 0.001	Estimate on 1 Year Service Use (in hours) R2 = .198 p = 0.001
Age	0.15**	-3.31*
Sex	-0.07	--
Complexity	-0.15**	2.86**
Barriers	-0.03	--
Income	--	-0.38
Mother's Participation	0.09*	1.47
Service Utilization	-0.002	--

*Significant at least  $p < 0.05$ \* or  $p < 0.001$ \*\*.*

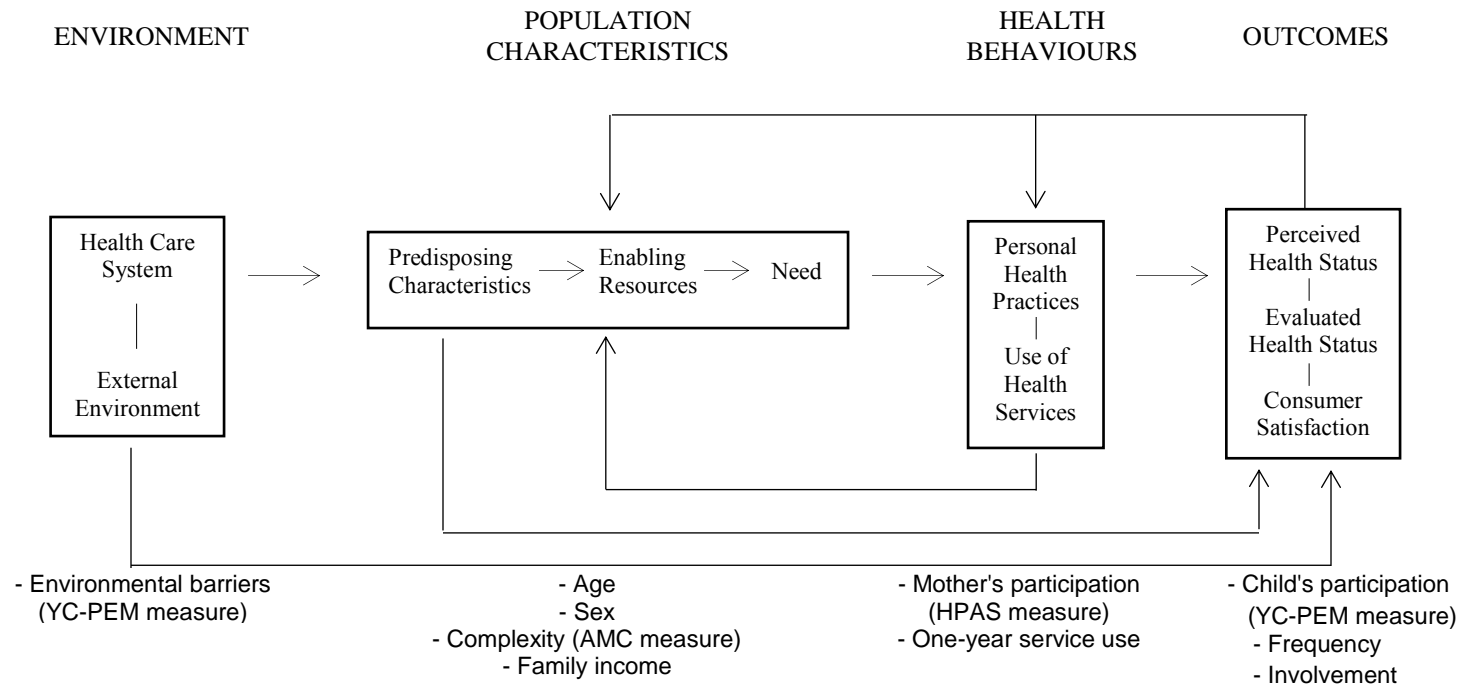
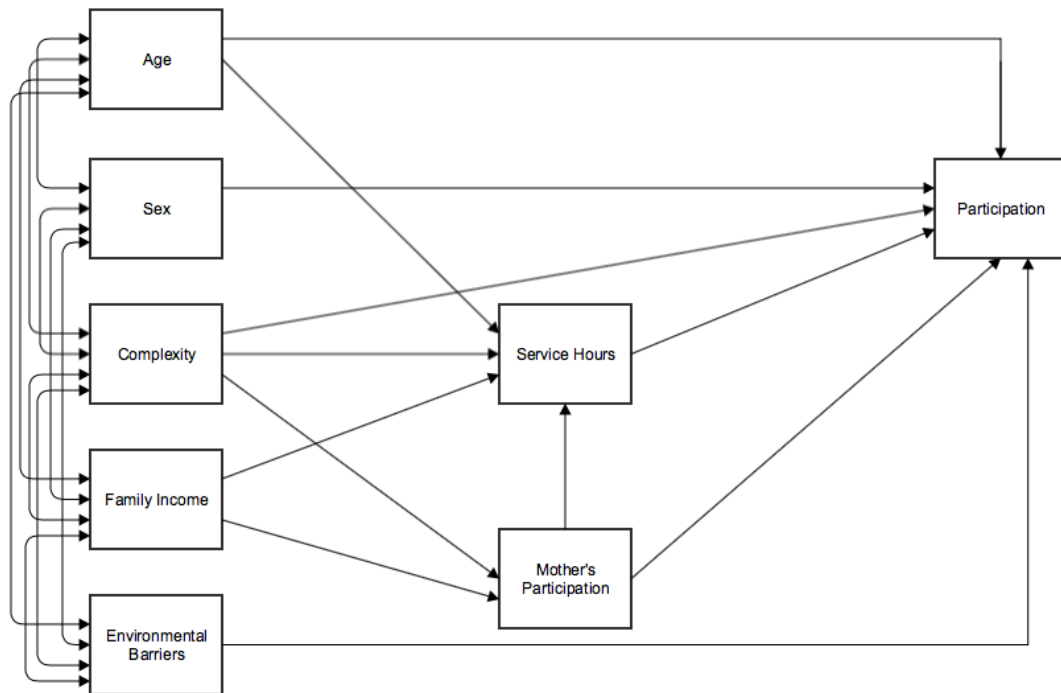
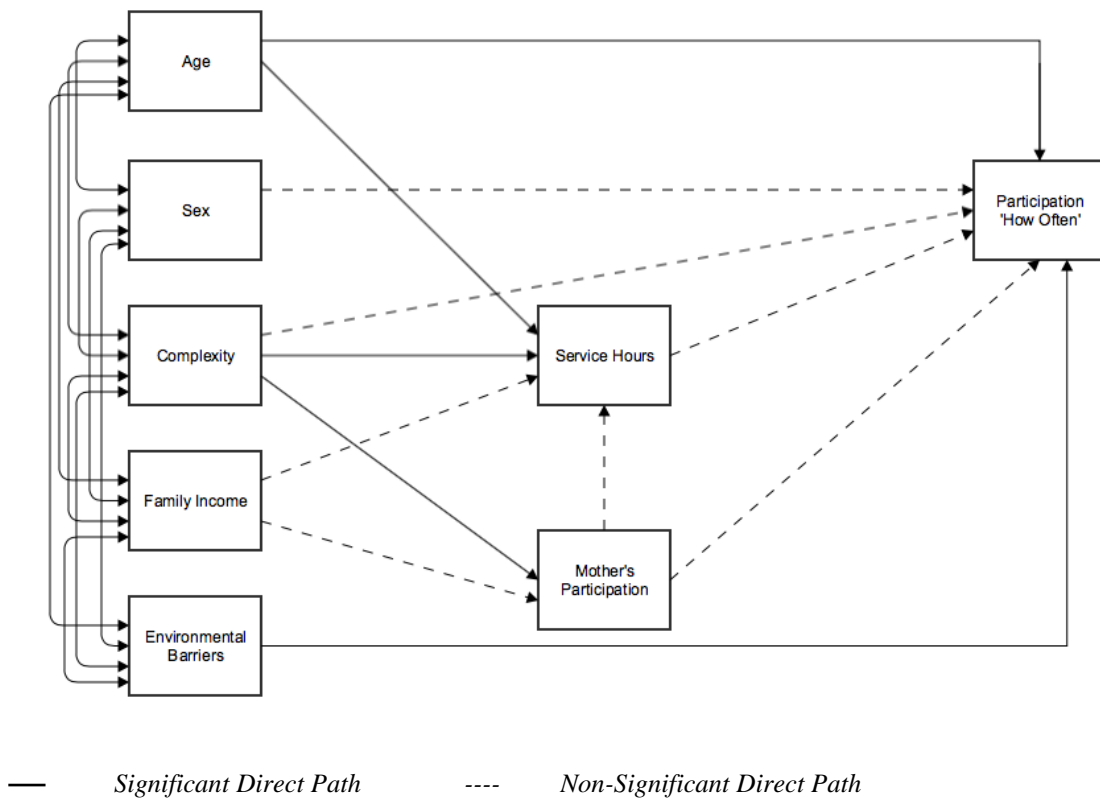


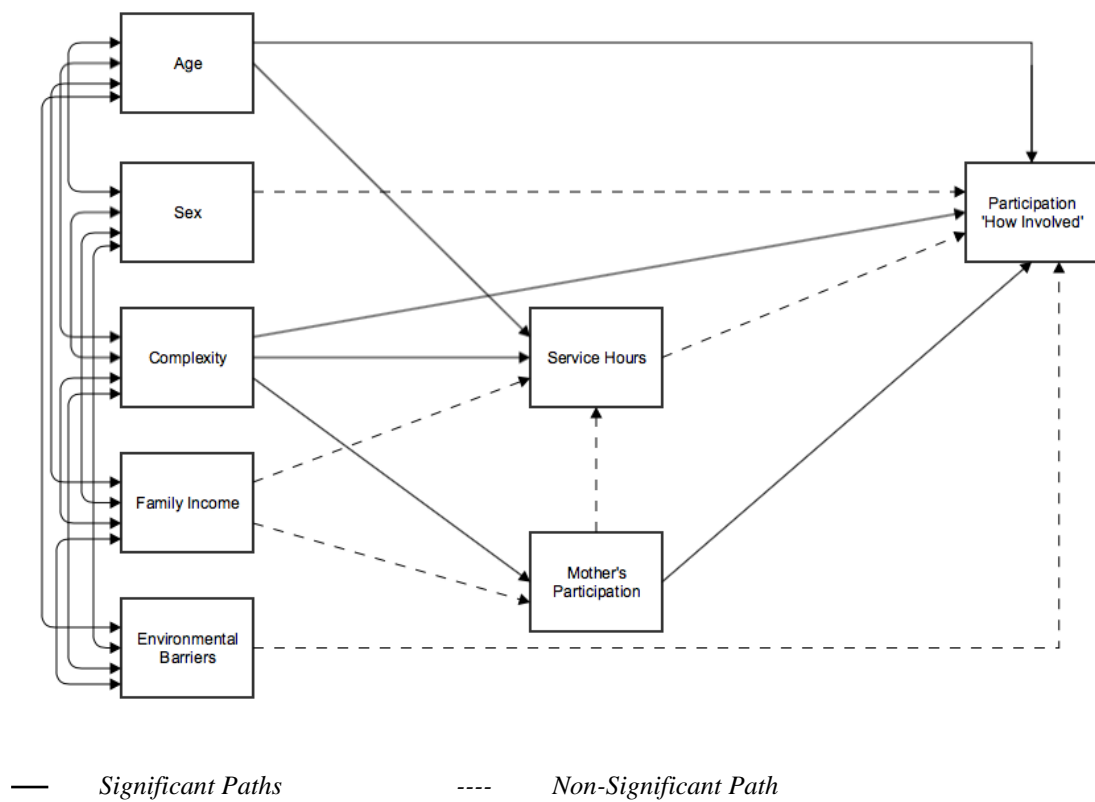
Figure 1. Andersen Health Care Utilization Model (1995) and corresponding measures in this study.



*Figure 2.* Conceptual Model of Young Children's Participation (direct paths only).



*Figure 3. Model of Young Children's Frequency of Participation in the Home and Preschool/Daycare, Community settings.*



*Figure 4.* Model of Young Children's Level of Involvement in Participation in the Home and Preschool/Daycare, Community setting.



## **Chapter Five – Discussion and Conclusions**

Participation involves learning new skills for completing tasks and taking part in daily life activities, which enhances development in many areas for children with disabilities (Law, 2002). Researchers in the past fifteen years have advanced the definition of participation, operationalized participation as a health construct, and explored levels of participations among children with disabilities. Participation represents happiness, acceptance, and freedom - qualities that should be present in every child's life. Participation is a crucial health aspect because partaking in participation improves physical health (Temple & Walkley, 2007; Temple, 2009), social skills (Bedell, Cohn, & Dumas, 2004; Cosbey, Johnston, & Dunn, 2010) and development (Verdonschot, de Witte, Reichrath, Buntinx, & Curfs, 2009). Participation is a pattern of living that enhances all other areas of daily living by promoting individuals to be active participants (Biddle & Asare, 2011). Children who have higher levels of participation show better outcomes of health and service utilization as adults (Turkel & Pao, 2007).

Participation levels among children with disabilities are much lower compared to children without disabilities (Axelsson et al., 2013; Bedell et al., 2013; Calley et al., 2012). Nonetheless, children with cognitive, physical, and speech-communication disabilities enjoy participating in activities as much as children without disabilities (Heah, Case, McGuire, & Law, 2007). Some significant systems that have been explored to enhance participation among children with disabilities include the home environment (Law et al., 2013), school environment (Coster et al., 2013), and community environment (Bedell et al., 2013). Additionally, factors of participation have been explored within

these different settings because factors influence increases or decreases in the frequency and level of involvement.

So far, no study has explored factors of participation within a rehabilitation service setting. This study is significant because it progressed knowledge about patterns of participation of younger children within the context of a rehabilitation health care system. The purpose of this study was to understand the profile of families accessing a rehabilitation centre by examining key factors -- especially participation, family need, service utilization, and complexity -- in order to understand the factors that might lead to improvements in everyday living among children with disabilities. Participation levels are highly modifiable (Anaby et al., 2014), so we need to examine factors comprehensively and their interactions to understand which influence participation the strongest.

Andersen's framework allowed us to adequately explore significant factors of families utilizing rehabilitation services. A wide number of comparisons were made based on a multitude of factors on different dimensions of participation. Understanding such factors provides therapists and families with focal points that can be modified to optimize children's participation. Therapists at rehabilitation centres can create important differences in the lives of families by assisting children with disabilities to set and achieve participation goals. This final chapter presents summaries of the chapters, contributions to the field of Rehabilitation Science, and discusses the implications of this study's findings for rehabilitation therapists and managers as well as future directions.

## **Chapter Summaries**

### **Chapter Two Summary**

A scoping review was conducted using research about children with disabilities in Canada who are receiving rehabilitation services. The content of the articles selected for the scoping review was reviewed using Andersen's model. The Andersen model allowed us to explore the interactions and complexities between healthcare utilization, client outcomes and satisfaction with services. The 11 articles that were selected provided insight into patterns and relationships between environmental factors, demographics, service utilization and outcomes but also on the type of literature that exists and gaps in information. The scoping review was needed to: 1) look at all factors and outcomes together in a comprehensive format, and 2) specifically identify gaps and areas understudied in the area of children's rehabilitation utilization in Canada. This comprehensive examination allowed us to select relevant factors for our survey. We identified key factors that were sufficiently studied to be included in future research and other factors that required more research. The data evaluated in the studies was comparable in regards to the identified population (i.e., children 0 to 19 years receiving rehabilitation services in Canada). A key finding from the scoping review revealed that the amount of research conducted in children's rehabilitation systems is low in Canada. The existing literature focuses on family-centered practices and environmental characteristics of the centres.

All studies reported some demographic factors. The articles supported that younger age, male children, living in a single parent home, and with lower cognitive and motor functioning showed higher service utilization. As well, physiotherapy, occupational therapy, and speech-language services were the most commonly utilized services.

One of the main findings of this scoping review supported current literature that family-centered practice is a key theme in delivering satisfying services to families (King, Teplicky, King, & Rosenbaum, 2004). The studies focused on promoting the importance of standardized procedures in therapy, goal setting, coordination of children's services, successful transitions to schooling, and adequate communication to families as key aspects for successful family-centred practice. The majority of studies exploring family-centered practices and parental satisfaction used the Measures of Processes Of Care (MPOC) instrument. In all the studies that reported on the MPOC, parents identified a need for improvement in providing general information, once again affirming findings from other literature (Siebes, Ketelaar, Gorter, Alsem, & Jongmans, 2012).

An area that requires further exploration is health behaviors such as health practices and use of health services of families of children with disabilities, and their relationships to utilization and outcomes. The studies that described the amount of service utilization were based on children with cerebral palsy. There was no literature available that described personal health practices or amount of service utilization of children with various disabilities in Canada. No study selected in the scoping review explored evaluated or perceived health status in relation to service utilization, so there is no literature – until this dissertation – on the impact of service utilization on participation. We identified the need to collect information on health practices of children and parents as well as the number and type of rehabilitation services utilized.

### **Chapter Three Summary**

The findings of the scoping review assisted the researchers in developing the

questionnaire used in this study. The purpose of the survey was to explore the key factors of children utilizing rehabilitation services identified in the scoping review as well as explore some factors that have been understudied. Obtaining information on key factors built a detailed profile of families using a large geographically based rehabilitation centre. This knowledge is beneficial to identify 1) key factors that are important to evaluate at other rehabilitation centres trying to build a client profile, 2) interactions and relationships between key factors, and 3) findings that are applicable to other centres such as the importance of the notion of complexity to plan services.

Based on the descriptive data, key factors of children's rehabilitation emerged: perceived need for services, child complexity, mother's participation, and child's participation. The relationship between the key factors was explored if a conceptual relationship was identified. Correlations, K-Wallis, and multiple regression tests were used if hypothesized relationships between factors were significant. For example, child complexity and level of participation involvement presented a higher correlation than child complexity and participation frequency.

The key findings from this study showed the majority of parental respondents had children who were younger, slightly higher number of males, and received services for either a speech and language problem or a more complex disability requiring multiple rehabilitation services. Family income was higher than the average reported median to other reports (Statistics Canada, 2015) however this trend is common in voluntary surveys due to higher education levels in samples (Kanuk & Berenson, 1975, p. 448). The highest MPOC scale was Respectful and Supportive Care while the lowest was Providing

General Information, in line with other research findings (Dickens, Matthews, & Thompson, 2011; King et al., 1998; Stewart, Law, Russell, & Hanna, 2004).

Environmental supports and barriers to participation have been well described for children over 5 years of age using the Participation Environment Measure for Children and Youth (PEM-CY) (Anaby et al., 2013). Environmental barriers have not been described for children under 5 years in Canada because the Young Children's Participation Environment Measure (YC-PEM) is a new measure. Our study reported that the highest numbers of barriers for young children are physical demands of activity, services, cognitive demands of activity, and relationships with peers.

Parents of children with motor and cognitive disabilities showed a statistically significant difference of higher perceived service need (using the supports and service questionnaire) compared to parents of children with speech and communication disabilities. Both parents of children with motor/cognitive and speech/communication disabilities reported that the highest family need was for childcare. Similarly, children with motor and cognitive disabilities were statistically higher in complexity scores (as measured by the About My Child measure; AMC) than children with speech and communication disabilities.

All children with disabilities showed lower participation scores in preschool, daycare, and community settings as compared to the home setting. This indicates that children with any sort of disability face issues of participation outside their homes. An inverse relationship exists between complexity and participation, indicating that as complexity increased, participation decreased. This relationship between complexity and

participation was further supported by comparing participation of children with physical/cognitive disabilities versus children with speech/communication disabilities who showed higher participation scores. A stronger relationship was found between complexity and level of involvement than complexity and frequency of participation, supporting children with disabilities can be involved in participation despite having a disability. The strongest barriers for younger and older children were physical, social and cognitive demands of activities as well as transportation.

Complexity scores were correlated significantly and positively service utilization (e.g., total time in therapy). Age, sex, and diagnosis did not show a relationship to service utilization or predict service utilization whereas complexity was significantly related and predictive of service utilization.

In summary, this chapter concluded multiple key findings. First, this study described environmental barriers to young children's participation including physical demands of activity, services, cognitive demands of activity, and relationships with peers. Second, children with motor/cognitive disabilities in comparison to children with speech/communication disabilities are statistically different on scores of service need and complexity. Third, while age, sex and diagnosis did not predict total minutes in therapy, complexity was a significant predictor of service utilization. Fourth, service utilization increased as complexity increased, and we recommend using complexity to plan services. Finally, a stronger relationship exists between complexity and level of participation involvement than between complexity and frequency of participation.

#### **Chapter Four Summary**

Based on the analysis in chapter three, the researchers built a structural equation model (SEM) exploring the relationships among key factors of children's rehabilitation service utilization in more depth. A larger number of families with young children (five years and under) used the children's rehabilitation centre compared to families with older children. As a result, a larger number of YC-PEM surveys used only by children 5 and under were completed. Thus, for the analysis, the researchers excluded the PEM-CY and conducted analysis on families who completed the YC-PEM.

Factors were selected within the SEM based on previous research that explored participation using the Children's Assessment of Participation and Enjoyment among older children with physical disabilities (King et al., 2006). The model for our study included age, sex, number of environmental barriers, family income, child's complexity, service hours in rehabilitation therapy (utilization), and mother's participation to frequency and level of involvement in participation factors that are considered crucial for young children. The direction of these factors were different compared to SEM of older children reported in research (King et al., 2006), and this is because we posit younger children have different dynamics especially with respect to different types of participation (e.g., frequency and involvement). Four models, one for each outcome listed below, were examined:

- Frequency in home participation
- Frequency in preschool/daycare and community participation
- Level of involvement in the home
- Level of involvement in preschool/daycare and community



The most important factors across multiple participation models were age, barriers, complexity and mother's participation. Age was significantly related to increasing frequency and involvement across all the settings. Environmental barriers were significant in predicting a lower frequency of participation. Lower complexity and higher mother's participation significantly predicted higher involvement in participation. Significant predictors of higher service utilization included a younger age and higher complexity. Finally, lower child complexity predicted higher mother's participation.

### **The Role of the Andersen Health Care Utilization Model in This Dissertation**

While the Andersen model has been used in an array of research examining health utilization, this is the first study to use the model to examine children's rehabilitation health system. The Andersen Health Care Utilization Model was very useful in guiding this research study. The Andersen Model assisted the researchers with organizing the scoping review analysis in chapter two, deciphering the factors for use in the survey, organizing the factors for analysis in chapters three and four, and organizing the presentation of factors within each chapter. By using the Andersen Model to define and organize the rehabilitation health system, we were able to incorporate personal factors, family factors, environmental factors, and health behaviors to understand health outcomes, which in this study was participation.

Overall, the Andersen Model had high utility in this study for organizing factors of children using rehabilitation services and participation. There were, however, issues that limited the utility of Andersen's model in the study. First, a challenge that was encountered was the selection and elimination of factors in the fourth chapter for building

the measurement model. Many conceptual relationships as proposed in the model could not be measured mathematically. For example, we hypothesized a low score on mother's participation, as measured by the Health Promoting Activities Scale (HPAS), would be indicative of lower service utilization scores. However, this conceptual relationship cannot be assessed using SEM because mother's participation has no role in determining how amounts of services are allotted. Second, relationships as specified in the model were not similar to the ones that we wanted to test. For example, the Andersen model does not specify service utilization should be related to outcomes. Other relationships did influence outcomes, such as age, complexity and service need. We recommend using the Andersen Model for assessing health systems of children with disabilities as a theoretical framework. However as an assessment model, it was crucial to adapt Andersen's model to a distinct model that researchers can use conceptually and mathematically (discussed in more detail below).

### **Contributions of this Research to Paediatric Rehabilitation**

This dissertation has made several contributions to the field of pediatric rehabilitation research. First, we were able to accurately describe the key factors of children using a geographically based children's rehabilitation centre. Second, we appraised the use of the Andersen model in children's rehabilitation research both as an organizing framework and a direct assessment model to examine service utilization and outcomes. Third, a contribution of this research study was exploring service need, complexity, and participation of preschool children in-depth. Finally, in addition to describing factors and relationships, we explored causal factors not examined in previous

research, including mother's social and recreational activity pursuits, complexity and service utilization. These findings have important implications for parents, therapists and service managers, and researchers working with children with disabilities, which will be discussed in the next section.

### **Key Factors of Families Using A Children's Rehabilitation Centre in Canada**

Domains from Andersen's model were explored to assess the extent to which factors were adequately studied in literature or required further investigation. Newly identified factors, such as complexity under need, were assessed if they held conceptual relevance to predicting participation.

A finding relevant to rehabilitation research was the limited knowledge available on personal health practices of families receiving rehabilitation services. Information on the characteristics of the external environment and demographics are also limited. Accordingly, the questionnaire that we created for this study tried to capture and describe demographics (including service need), external environment characteristics (supports and barriers, kilometers distance to the centre, living arrangements), health behaviours, and service utilization. While many factors were not significant, key factors emerged such as age, complexity, service need, and mother's participation. The factors that were conceptually significant to participation and service utilization were explored in the questionnaire as well.

The sample used in this study was preschool aged children who received services from a large rehabilitation centre in Ontario, Canada. Our findings show that key factors such as age, service need, service utilization, complexity, and mother's participation have

important relationships to participation outcomes. This conclusion discusses the value of each key factor and significant relationships found between the factors. We recommend future studies should continue examining and advancing knowledge of these factors especially in relation to children's participation.

### **Application of Andersen's Healthcare Utilization Model**

Among the different models that can provide insight into the client profile, we chose Andersen's Healthcare Utilization Model. Alternative models included Bronfenbrenner's Bioecological Model and the International Classification of Functioning, Disability and Health model (ICF-CY). The advantage of Andersen's model is its focus on healthcare utilization, a major conceptual component in this dissertation. The domains within Andersen's model provided an excellent organizational framework for examining factors and organizing our analyses. Prior to this study, Andersen's model has not been used to describe families using rehabilitation services. Furthermore, Andersen's model has not been used as an assessment model. This study validated the utility of Andersen's model with identifying and organizing relevant factors of children's rehabilitation, showing support that the Andersen model is an adequate organization framework in children's rehabilitation research. A suggestion for improvement is that Andersen and colleagues describe *how* and *why* each category is related, and clarify reverse arrow relationships (e.g., health behaviors influence on predisposing characteristics).

The evaluation of Andersen's model as an assessment model for the SEM proved to be more challenging. First, it is difficult to measure the domains and categories as

proposed in the Andersen model within SEM. That is, the Andersen model is not measurable in its current graphical depiction. Researchers need to consider if the factors within each category and direction of the arrows in the current model make sense mathematically. Even if a conceptual relationship exists, a mathematical relationship may not show a relationship among the factors, thus presenting a Type II error. That is, the model being tested must be entered into the SEM software differently than how Andersen graphically depicts the model otherwise the relationships may not show statistically even if there is a conceptual relationship that exists – this requires breaking the model down into smaller components. The model is best used as a descriptive model (Phillips, Morrison, Andersen, & Aday, 1998). The Andersen model needs to be recreated both conceptually and mathematically if researchers incorporate it as an assessment model.

### **Service Need, Service Utilization, Complexity, and Participation**

This study described factors that were conceptually relevant to service utilization and participation. The key factors that influence utilization and participation are service need, utilization, complexity, mother's participation, and children's participation. These factors assessed in relationship with one another and showed to be relevant of children's rehabilitation health system. These factors should continue to be examined in future research of families using rehabilitation services.

Complexity, as measured by the AMC, is a newer concept distinct from diagnosis and severity since it focuses on cumulative number of concerns impacting everyday living as perceived by parents (Brehaut, Rosenbaum, & Kohen, personal communications, June 2013; Williams et al., 2016). Service need increased with higher complexity, indicating

families with higher complexity perceive a higher need for more services. A relationship between service utilization and complexity was also evident. However, this may have been influenced by practices of the centre that allocates services based on a rating system of functional ability. Nonetheless, this supports complexity is a function of functional limitation and children with higher complexity scores are receiving more services. Higher proportions of need and utilization of services is likely due to lower functional ability among children who require more assistance than children who are less complex. Overall, children with higher complexity require more services due to an increased need. Because the notion of complexity is quite new, we recommend that complexity be used in future research to consider the strength of the relationship between services needed/received and to advance our understanding on complexity.

Findings from this study indicate that overall service utilization was low among the sample. The optimal amount of service utilization required for functional change is 1 to 5 days per week, intensity up to 3 hours per day, and 15 days to 6 month period for each goal (Ahl, Johansson, Granat, & Carlberg, 2005; Darrah et al., 2011; Ketelaar, Vermeer, Hart, van Petegem-van Beek, & Helders, 2001; Löwing, Bexelius, & Brogren Carlberg, 2009; Salem & Godwin, 2009; Sorsdahl, Moe-Nilssen, Kaale, Rieber, & Strand, 2010; Ustad, Sorsdahl, & Ljunggren, 2009). While our finding reflects the services from only one centre, there is a concern that this pattern may be similar across other centres, and services are insufficient to impact children's participation and other outcomes. Centres, such as this one, that are providing lower amounts of service utilization compared to benchmark standards for clinical differences may not be assisting their

clients to reach their full potential in therapy. The lower amounts of service may hinder the study sample in showing significant differences in health outcomes, such as participation. As we found, the relationship between service utilization and participation was non-significant. This can be due to either the former explanation (i.e., participation levels do not change due to more or less time spent in therapy) or because, secondly, goals specific to improving participation in therapy were not set and measured longitudinally. A third possibility is there is simply no relationship between service utilization and participation.

The authors propose the best explanation of why a non-significant relationship between participation and service utilization was examined is due to both the first and second explanation. Specifically, in our sample, participation outcomes were not impacted by service utilization because service usage was too low and participation goals were not set or measured longitudinally in therapy. The authors suggest a more rigorous statistical design is required that focuses on increasing participation as the goal of therapy and ensuring service utilization is at benchmark standards.

Complexity as measured by the AMC is a cumulative list of concerns impacting everyday living identified by parents. Complexity turned out to be an important factor in this study with a strong relationship with service need, participation, and primary diagnosis. The role of complexity is significant because it explores parents' perception of how many problematic concerns need to be addressed with the assistance of therapists. More so, complexity played a central role with service utilization and participation. Complexity may be used to understand service allocation because it is indicative of

service need and amount of utilization. Children with higher services tend to be those with many different areas impacted, such as children with autism. Because many areas are impacted with more complex disorders, a higher amount of assistance is required to address the multiple areas of concern.

Possibly one of the most important contributions of this study is understanding the relationship between complexity and participation. Complexity impacted level of participation involvement much more strongly than frequency of participation. This supports that children can have high levels of participation frequency despite their complexity -- even though participation involvement may be constrained due to complexity. We also found that environmental barriers influenced participation. Level of involvement could potentially be improved with the correct environmental modifications by adding supports and removing barriers. This finding emphasizes the importance of encouraging the frequency of participation despite complexity levels and removing barriers to enhance participation involvement.

This study is the first to describe participation patterns of young children in Canada through the YC-PEM, an area more newly explored. In general, participation is lower among children with all disabilities, but participation becomes lower when children report a higher complexity or motor/cognitive disabilities versus speech/communication disability. Participation is lower in the school/daycare and community settings compared to the home setting. These findings support more initiatives are required to improve participation among children with disabilities. Achieving high levels of participation is possible through increasing supports and reducing barriers.



### **Causal Factors of Services Utilization and Children's Participation**

This was the first study to the researchers' knowledge to present a SEM of young children's service utilization and participation. Significant predictive factors included age, child's complexity, environmental barriers, and mother's social and recreational pursuits. Unfortunately, while we proposed strong conceptual models, these factors only explained a small amount of variance for participation so further research in identifying factors of participation is required. Other factors that could be examined in the future to predict participation include child's observed functional abilities (physical, cognitive, communicative), child and family preferences, social and resource supports, and identity or personality styles.

Age and complexity predicted service utilization in that a younger age and higher complexity indicated higher service utilization. Based on other research showing service utilization data and standards for clinical change (Law et al., 2005), service utilization among this sample is low. Research has shown that a higher amount of service utilization is required during peak developmental periods as children age to have clinical differences as a result of therapy. Because service utilization is low among children from 0 to 5 years, they may not be receiving as much benefit from therapy as possible nor attaining functional changes that are desired from therapy.

When conducting research in the area of young children's participation, the factors used in this study are a good starting point for collecting information. Age and number of environmental barriers are important considerations to frequency participation of young children; whereas, age, complexity, and mother's participation play a vital role

with level of involvement. Implications of these factors for therapy are discussed in the next section.

## **Recommendations for Rehabilitation Services**

### **Service Utilization**

The key findings of this study are that service utilization is low and only two of the four factors (i.e., age and complexity) influenced service utilization. Compared to benchmark standards that demonstrate minimal amounts for achieving clinical meaningful differences, this sample has a much lower amount of time spent in therapy required for change in health outcomes. Furthermore, this study showed evidence that time in therapy significantly decreases as children grow older, putting children at risk for not receiving sufficient therapy during key developmental periods. Receiving 6 to 10 or greater than 11 therapy sessions over 6 months promotes clinically different changes in children (Law et al., 2005).

A relationship existed between complexity and service use, indicating complexity is a good indicator of functional limitation and service need. As an implication, service providers may use complexity to plan services. The AMC can be used as a tool between therapists and parents to build rapport and open discussion on therapy goals. The AMC is easy to use, can be quickly completed, and covers an array of areas that parents may be concerned about (Williams et al., 2016). Most importantly, the AMC allows parents to identify and prioritize areas that impact their families most, making the AMC a tool that follows principles of family-centered care.

### **Participation**

The findings of this study support that diagnosis is not significantly related to participation, and children's participation should not be hindered based on their diagnosis. Complexity does not impact frequency of participation but does play a role in the level of involvement. Modifying the environment can potentially mitigate this influence. Complexity also plays a role in service utilization. Children's rehabilitation centres and therapists are a key contact for increasing participation among children with disabilities (King et al., 2002, 2003). Therapists can assess complexity, environmental influences and make a participation plan based on their assessment of the child's interest and abilities. Based on these two findings, the researchers recommend that therapists focus on setting goals of participation for children as a way of linking service use more directly to participation outcomes.

The researchers of this study previously worked on a knowledge translation project to promote participation of children with disabilities by creating short clip videos. Two of the videos are of children who shared their experiences and their journey from not engaging in activities to setting participation goals and achieving them. These two examples of youth provide insight into the value of promoting participation, which improves daily life in many ways including psychological aspects such as self-efficacy and confidence. The first youth, who walks using assisted walking devices, discussed he set goals and was able to accomplish all his favorite activities such as using all-terrain vehicles and being able to engage in employment. The second youth discusses how his interest in basketball flourished from viewing to playing and now coaching a basketball team.

Tools have been presented in order to support, systematize, and standardize the promotion of participation in therapy to ensure its success. The success of the two youth described above was done using the Pathways and Resources for Engagement and Participation (PREP) tool (Law, M., PREP manual, September 2015). The PREP tool implements 5 steps to monitor participation: Step 1) Set goals; Step 2) Make a plan; Step 3) Make it happen; Step 4) Measure the process and outcomes; and Step 5) Move forward. Similarly, a study by Ziviani and colleagues (2014) confirmed the benefits of setting goals in therapy using formal tools to successfully set participation goals. The Belief in Goal Self-Competence Scale tool is used in compliment with the Canadian Occupational Performance Measure (COPM) to document pediatric clients level of confidence.

In addition to setting therapy goals to improve participation, parents require more initiatives or need more information on participation initiatives. The theme on parents requiring further information is based on multiple countries (Siebes et al., 2012). Furthermore, in the study by Siebes and colleagues, parents identify they want supports from families in similar situations. Perhaps this will improve participation outside the home and engagement in community initiatives, and this will also allow families to build supports and friendships. This suggestion is crucial with consideration that mother's participation is significantly predictive of increasing child's involvement in the home and the community. Providing social and resource supports to mothers or other family members will also indirectly promote children's involvement in activities. Accordingly, we recommend providing more supports, information, and resources to families.

Some crucial factors identified in this study include the role of mothers as well as modifying the environment (e.g., removing barriers or adding assistive devices as supports) to improve participation. These two factors have previously been reported as crucial factors of children's participation (King et al., 2006). The mother's role was significant in improving participation involvement. Perhaps, other family members such as siblings and fathers may also promote children's participation. We suggest promoting participation amongst family members is crucial because there is a strong socio-psychological aspect involved with keeping someone motivated to participate. If there are two or more individuals participating in activities consistently, the experience might be more committed and enjoyable. Once children are motivated to participate, its key to ensure there are no barriers preventing them to reach their potential. This is accomplished by modifying activities, ensuring adequate supports are available, and eliminating barriers. All these factors will improve level of involvement, and an improved pattern of daily living will surface.

### **Strengths and Limitations**

The greatest limitation of this research was the long survey, which perhaps impacted the sample size due to a lower completion rate. Pilot runs of the survey showed an approximate time of 30 minutes. The survey times for completion by parents were closer to 45 minutes. Long surveys create fatigue effects and sources of distortion such as random or extreme responding to complete the survey. In hindsight, the researchers would have removed some of the demographic questions. Nonetheless, we examined each

datum by being attentive to self-report response biases and achieved an adequate sample size.

One of the two largest limitations of the study is identified for the SEM conducted in chapter four. Our small variances indicate that there are more factors that can be identified to describe the frequency and involvement of participation among young children. We recommend identifying other factors, possibly through using the framework of the ICF model or psychological factors to explore participation of young children in future studies.

Possibly, the largest limitation of this study is generalizability. This study's sample represents one children's treatment centre in Ontario. Due to differences in rehabilitation systems and geography, the findings of this study do not generalize to other regions. Nonetheless, the factors and the directions of the factors identified in this study are important to explore among clientele using rehabilitation centres across Canada. We urge research teams of scientists and therapists to report on the significance of these factors within their health jurisdictions so the rehabilitation health system of children with disabilities throughout Canada can be better understood.

The implementation of the Dillman Total Design Method and gift incentives to parents was an advantage. The waves of invitations as well as the introduction of the gift incentives showed improvement in response rates. The collaboration from members of the centre was crucial because they sent out invitations to families.

Using an online survey was desirable. This option allowed ease of access to parents as well as options to pause the survey and continue at a later time. The survey

provided a chat link and when the key researcher was offline the messages would be routed to email. Another advantage was the customization of the survey. For example the HPAS is only designed for parents who define themselves as the mother role in the family unit. If a participant identified that he was a father, the survey would skip over the HPAS section. Another example of survey branching was with age. Parents who indicated whose children were 5 or younger and not in elementary school were routed to the YC-PEM, and parents who indicated a child 5.5 and older or in elementary school were routed to the PEM-CY.

Approximately one hundred parents requested individualized reports from the researchers. Parents were provided feedback on the possible ranges of scores for frequency and involvement of participation, and received their child's participation scores. Scores on the HPAS were also provided back to mothers. The reports were completely anonymized and built in Microsoft Excel. Two reports were also created for the staff of the Centre: one was an executive summary (12 pages) and one final report of the Service Utilization and Outcome study (46 pages).

### **Future Directions**

Based on the information collected and reported, the investigators main goal was to advance knowledge in the area of young children's participation and the relationship between factors within the environment, family, child, service utilization and participation. The investigators took an explorative approach to understand prominent factors that play a role in the daily lives of families who use a children's rehabilitation centre, with a focus on service utilization and participation. While this study identified

two powerful predictors of young children's service utilization (age and complexity), a further study is required to identify more significant factors of service utilization.

We further suggest that a study to understand the social and psychological components of participation will be beneficial to enhancing participation. This suggestion is based on the lack of literature on social and psychological components of children with disabilities in regards to participation from a rehabilitation context. Previous studies such as King's and chapter four suggest participation is influenced by mother's participation – suggesting a strong social component. By understanding the child's motivation and doubts, changes on an individual level can enhance participation for children with disabilities. Inquiry into psychological and social dimensions of participation among children with disabilities requires an interprofessional approach. A partnership between interprofessionals will allow collaboration for a holistic approach in understanding participation – a complex dimension of human behavior.

The growing notion of complexity is also an important factor to explore for service utilization and participation. This research demonstrated that complexity plays a large role among children using a rehabilitation centre, and more specifically predicting service utilization and participation. Its relevance in this dissertation makes it a prime focus of interest in future studies to explore how complexity impacts other areas of living among children with disabilities.

The most beneficial future direction is conducting alike research on a large-scale by using a comprehensive framework and exploring a multitude of relevant factors. A large-scale study can allow for comparisons across regions. Comparing regional data



across the province or nationally provides insight into patterns and trends occurring within Canada. A national comparison allows for benchmarks and sharing of best practices with common national goals, similar to data reported and used for decision making by Canadian Institute of Health Research (CIHI). Conducting a large-scale study can also provide a nationally representative sample in order to compare the quality and quantity of services to other countries. The benefits of conducting a large scale study will provide key findings, key challenges facing families who use rehabilitation services, areas for improvement, advice into best practices of conducting methods among large scale studies among families with disabilities, and provide merit to longitudinal studies. A large-scale study may also decrease burden on families to complete surveys because much of the information can be derived from patient charts in order to obtain complete and standardized data elements.

### **Conclusion**

The focus of this study was to identify key factors of families with children using a rehabilitation centre through a holistic lens with a focus on service utilization and participation outcomes. This research has identified key factors and relationships among these factors of children with disabilities. However, many areas explored in this study require further advancement or refinement. Some areas for advancement include describing Health Behaviors of families because there is lack on knowledge in this area, and complexity because this is a new notion in rehabilitation research. A refinement of this study is to more precisely measure the relationship between service utilization and participation. This can be achieved by concretely focusing on clients who set goals in

therapy to improve participation, and accordingly describe outcomes after specific amounts of time spent in therapy to achieve their participation goals. Future research may also focus on enhancing knowledge on children's complexity, mother's participation, and social-psychological components because these factors showed to be prominent factors of promoting participation but were not explored in depth.

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## Appendix A

### Quantitative Research Assessment Tool

The purpose of this assessment tool is to help users quickly evaluate the merit of quantitative research studies that are listed on the CCEERC Web site. The assessment tool provides guidelines on two issues: 1) information that should be included in study reports, and 2) standards for good research. This tool should be used for general guidance when assessing the merit of research studies. For some child care and early education research, it may be difficult to implement the most rigorous research designs. When comparing scores derived through this assessment tool, studies with lower scores -- especially when examining research exploring the same questions -- should be viewed with more caution than studies with higher scores. Studies that do not include sufficient information to answer the questions asked in the assessment tool should also be viewed with caution.

#### Population and Sample

1. Population. Does the population that was eligible to be selected for the study include the entire population of interest? Or, is the eligible population a selective subgroup of the population of interest? For example, are all the children in the nation eligible to be selected for the study (the entire population of interest)? Or, were only children in New York City eligible to be selected for the study (a selective subgroup)? Or, were only children in one day care center in New York City eligible to be selected (a very selective subgroup)?

[ 1 ] Eligible population includes entire population of interest or a substantial portion of it

[ 0 ] Population represents a limited, atypical, or selective subgroup of the population of interest

[-1 ] No description of the population

[NA] Not applicable

2. Randomized Selection of Participants. Were study participants randomly selected for the study? Or, did study participants volunteer (nonrandom)? Or, were they located through specific organizations (nonrandom) or through acquaintances of the researchers (nonrandom)?

[ 1 ] Random selection

[ 0 ] Nonrandom selection

[-1 ] No description of the sample selection procedure

[NA] Not applicable

3. Sample Size. How many participants were selected for the study? Does the sample include enough participants from key subgroups to accurately assess subgroup differences? This is best used in comparison to other studies.

[ 1 ] Sample size larger than similar studies

[ 0 ] Sample size the same as similar studies

[-1 ] Sample size smaller than similar study or sample size not given

[NA] Not applicable



4. Response and Attrition Rate. What proportion of the selected sample completed the study? In longitudinal studies, what proportion of sample members participated in follow-up studies?

[ 1 ] High response or participation rate (over 65% response rate, over 90% participated in follow-up studies)

[ 0 ] Moderate to low response rate (response rates of less than 65%)

[-1 ] No information on response rate or participation rate

[NA] Not applicable

### **Measurement**

5. Main Variables or Concepts. Are each of the main variables or concepts of interest described fully? Can the main variables or concepts be matched to the variables in the tables?

[ 1 ] Accurately described and can be matched

[ 0 ] Vague definition or cannot be matched

[-1 ] No definition of main variables or concepts

[NA] Not applicable

6. Operationalization of Concepts. Did the authors choose variables that make sense as good measures of the main concepts in the study? Have these variables been used in previous studies or are they an improvement over previous studies?

[ 1 ] Key concepts are measured with variables that make sense. Or, variables have either been previously used in research or are improvements over previous measures.

[ 0 ] Key concepts are measured with variables that do not make sense, and variables have not been used in previous research studies

[-1 ] Variable operationalization is not discussed

[NA] Not applicable

### **Analysis**

7. Numeric Tables. Are the means and standard deviations/standard errors for all the numeric variables presented?

[ 1 ] Means and standard deviations/standard errors presented

[ 0 ] Means, but no standard deviations/standard errors presented

[-1 ] Neither means nor standard deviations/standard errors presented

[NA] Not applicable

8. Missing Data. Are the number of cases with missing data specified? Is the statistical procedure(s) for handling missing data described?

[ 1 ] Number of cases with missing data are specified and the strategy for handling missing data is described

[ 0 ] Number of cases with missing data specified, but these cases are removed from the

analysis

[-1 ] Missing data issues not discussed

[NA] Not applicable

9. Appropriateness of Statistical Techniques. Does the study describe the statistical technique used? Does the study explain why the statistical technique was chosen? Does the study include caveats about the conclusions that are based on the statistical technique?

[ 1 ] Statistical techniques, reasons for choosing technique, and caveats are fully explained

[ 0 ] Statistical technique is explained, but the reasons for choosing technique or the caveats are not included.

[-1 ] Statistical technique, reasons for choosing technique, and caveats are not explained.

[NA] Not applicable

10. Omitted Variable Bias. Could the results of the study be due to alternative explanations that are not addressed in the study?

[ 1 ] All important explanations are included in the analysis

[ 0 ] Important explanations are omitted from the analysis

[-1 ] Variables and concepts included in the analysis are not described in sufficient detail to determine whether key alternative explanations have been omitted

[NA] Not applicable

11. Analysis of Main Effect Variables. Are coefficients for the main effect variables in the statistical models presented? Are the standard errors of these coefficients presented? Are significance levels or the results of statistical tests presented?

[ 1 ] Model coefficients and standard errors or hypothesis tests for the main effects variables are presented

[ 0 ] Either model coefficients or hypothesis tests for the main effects variables are presented

[-1 ] Neither estimated coefficients or standard errors for the main effects variables are presented

[NA] Not applicable