

Université de Montréal

**Access to Rehabilitation for Young Children with
Physical Disabilities**

par
Lisa Grilli

École de réadaptation
Faculté de médecine

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Université de Montréal
Faculté des études supérieures

Ce mémoire intitulé :

Access to rehabilitation for young children with physical disabilities

présenté par :

Lisa Grilli

a été évalué par un jury composé des personnes suivantes :

Jacqueline Rousseau
président-rapporteur

Debbie Feldman
directrice de recherche

Bonnie Swaine
codirectrice de recherche

Régis Blais
membre du jury

Résumé

L'intervention thérapeutique précoce chez les enfants ayant des incapacités peut mener à une amélioration de leur niveau de santé. Cependant, l'accès aux services de réadaptation peut être problématique. **Objectifs:** 1) décrire le temps que les enfants ayant des incapacités physiques doivent attendre avant d'avoir accès aux services de physiothérapie (PT) et d'ergothérapie (OT) dans les centres de réadaptation ; 2) examiner les facteurs associés avec le temps d'attente pour ces services ; 3) déterminer l'association entre le statut fonctionnel des enfants et leur qualité de vie (QV) ; 4) explorer les facteurs associés au statut fonctionnel et à la QV. **Sujets:** Les parents de 224 enfants (<6 ans) ayant des incapacités physiques référés entre 2002 et 2004 par l'Hôpital de Montréal pour Enfants et l'Hôpital Sainte-Justine aux centres de réadaptation pédiatriques. **Mesures:** Les données ont été obtenues à partir des bases de données informatiques de chaque hôpital, et pendant une série d'entrevues effectuées avec les parents entre le moment de la référence en réadaptation et le premier rendez-vous en réadaptation. **Résultats:** La moitié des enfants de notre échantillon ont dû attendre plus de 7 et 13 mois respectivement avant de recevoir des services de PT et OT. Un temps d'attente court a été significativement associé avec un jeune âge (RR ajusté = 0.5 ; 95% IC= 0.36-0.82) et la référence à un centre de réadaptation en particulier (RR ajusté = 3.0 ; 95% IC = 1.8-4.8). Le score total au MIFmômes était modérément associé au PedsQL4.0 score total ($r=0.39$). Les enfants présentant un retard de développement non-spécifique ont obtenu des scores plus élevés que ceux ayant un diagnostic précis aux aspects physiques et de mobilité de chaque mesure. **Conclusion:** Les enfants présentant des incapacités physiques subissent des temps d'attente très longs avant de recevoir les services en réadaptation. **Mots-clés:** services de réadaptation, temps d'attente, réadaptation pédiatrique, mesures des résultats, statut fonctionnel, qualité de vie relative à la santé

Abstract

Early intervention of therapy for children with disabilities may improve health outcomes. However, access to rehabilitation can be problematic. *Objectives:* 1) to describe waiting time to receive physical therapy (PT) and occupational therapy (OT) services at pediatric rehabilitation centers for children with physical disabilities; 2) to examine factors associated with waiting time to these services; 3) to determine the association between functional status and health-related quality of life (HRQL); 4) to explore factors associated with functional status and quality of life (QL). *Subjects:* Parents of 224 children (< 6 years) with physical disabilities referred in 2002-2004 from the Montreal Children's Hospital and Sainte-Justine Hospital to pediatric rehabilitation centers. *Measurements:* Data were obtained from hospital computer databases, and during a series of parental interviews from time of referral to time of first PT and OT appointment at the rehabilitation center. *Results:* Half of our sample waited more than 7 and 13 months for PT and OT services, respectively. Shorter waiting time was significantly associated with younger child's age (adjusted HR = 0.5; 95% CI = 0.36-0.82) and referral to one particular rehabilitation center (adjusted HR = 3.0; 95% CI = 1.8-4.8). Total WeeFIM was moderately correlated to total PedsQL4.0 ($r=0.39$). Children with non-specific developmental delays scored higher on physical and mobility aspects of both tests, than those with specific diagnoses. *Conclusion:* Children with disabilities experience long waiting times before receiving appointments for PT and OT rehabilitation services.

Keywords: waiting times, pediatric rehabilitation, pediatric outcome measures, functional status, health-related quality of life

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List of Abbreviations

PT	Physiotherapy
OT	Occupational therapy
SLP	Speech and language pathology
WeeFIM	Functional Independence Measure for Children
PedsQL	Pediatric Quality of Life Inventory
QL	Quality of life
ADL	Activities of daily living
HMO	Health Maintenance Organization
NHIS-D	National Health Interview Survey on Disability
GDD	Global developmental delay
HR	Hazard ratio
CI	Confidence interval

*To my husband, John, and children,
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CHAPTER 1 INTRODUCTION AND STUDY OBJECTIVES

1.1 Introduction

Major advances in neonatology and pediatrics have led to significant increases in infant survival. Subsequently there has been a rise in childhood disability (1, 2). As many as 6.3% of Canadian children 0 to 9 years of age have been identified as having some form of disability which represents an important proportion of all Canadian children (3). Many of these children require rehabilitation interventions, including physiotherapy (PT) and occupational therapy (OT), for ongoing long-term problems (1, 4). Rehabilitation is the mainstay of treatment in children with physical disabilities. The primary goals of rehabilitation are to reduce a child's long-term disabilities and handicaps and maximize potential (5, 6).

Since the early 1990's in Québec, specialized pediatric rehabilitation centers rather than tertiary care centers have been mandated to provide long-term rehabilitation services to children with physical disabilities. Children are therefore diagnosed in the tertiary care center and then transferred to the appropriate community resources for their long-term rehabilitation needs (5, 7). In 1992, the Office des personnes handicapées du Québec, stated that rehabilitation services need to be available upon confirmation of the child's problems. Specialized pediatric rehabilitation centers are to provide rehabilitation services that are timely, comprehensive, and multidisciplinary (7). This is especially relevant to preschool-aged children. Once they enter the school system, services are to be received at the school.

In Montréal, despite reforms, parents of preschoolers with physical disabilities face long waiting times, approximately 12 months, to receive

rehabilitation services (8-10). In the United States, Msall and colleagues found that as much as 66% of older (school-aged) children with major functional disability were not receiving ongoing medical and rehabilitation services (11). Children with disabilities, of varying severities, should have equal access to rehabilitation services, since PT and OT have been shown to minimize effects of physical disabilities in these children (6). Rehabilitation services should be readily accessible and available to all children. However, as of 2002, formal and coordinated interdisciplinary programmes for children with developmental delay were yet to be implemented in Québec (10), despite the fact that, in 1992, it was recommended that provision of these services needed to be assured (5, 8).

Waiting times for rehabilitation services may also have an impact on the families of children with disabilities. Significant waiting times can prevent a child from optimizing his or her functional abilities, which may, in turn, lead to poorer perceived health-related quality of life (HRQL) for the child and the family. The impact of a chronic condition on the child's well being is a concern for parents (12), and is often assessed by HRQL measures (rather than functional outcome measures). Parent's perceptions of their child's quality of life (QL) may be related to their child's level of function, but may also be associated with whether or not they receive services (12, 13).

A number of factors may influence delays to receipt of long-term pediatric rehabilitation services. These include factors related to the child (diagnosis, severity, age), to the family (family income, ethnicity, maternal education) or to the organization of rehabilitation services (receipt or referral to PT/OT).

The general objective of this study is to describe the factors related to waiting time for receipt of pediatric rehabilitation services for preschool-aged children (0-5 years) with physical disabilities, and examine QL in these patients.

1.2 Objectives

Specifically, primary objectives were to:

1. Describe waiting time to receive PT or OT services at a rehabilitation center for preschool-aged children (6 months to 72 months) with physical disabilities.
2. Examine the factors associated with waiting time to PT or OT services, including the child's age and severity of the physical disability.

Secondary objectives were to:

1. Evaluate whether parental perceived quality of life is related to functional status among preschool-aged children.
2. Explore factors associated with functional status and quality of life in preschool-aged children with physical disabilities.

1.3 Hypotheses

Hypothesis 1:

We hypothesized that access to pediatric rehabilitation for children with physical disabilities is problematic. This can be shown by lengthy waiting times to receive PT and OT services at pediatric rehabilitation centers. We hypothesized

that at least half of the children referred for rehabilitation wait more than six months to receive services.

Hypothesis 2:

We hypothesized that younger children and those with more severe functional disabilities would wait less time to receive PT and OT services at the rehabilitation centers. Early intervention would allow children to maximize their function and prevent further disabilities. There may be a propensity towards providing services sooner to children with severe disabilities.

Hypothesis 3:

We hypothesized that:

- a) Quality of life, as measured by the Pediatric Quality of Life Inventory (PedsQL4.0) would be moderately related to functional status, as measured by the Functional Independence Measure for Children (WeeFIM) in preschool aged children with physical disabilities, since both measure the physical dimension of functioning.
- b) Lower scores on the physical subscale domain of the PedsQL4.0 would be highly associated with receipt of PT services. The need for PT intervention may be identified earlier as delays in gross motor milestones are usually recognized earlier than delays in other domains of development, such as fine motor skills.

Hypothesis 4:

We hypothesized that diagnoses categorized by the non-specific term global developmental delay (GDD) would be associated with higher scores on the WeeFIM-mobility subscale as compared to a more specific diagnosis (example: cerebral palsy, spina bifida, genetic syndromes).

CHAPTER 2 - REVIEW OF PERTINENT LITERATURE

2.1 Magnitude of the problem: Children with disabilities

The World Health Organization's (WHO) definition of disability reflects a child's inability to carry out essential tasks of daily living appropriate for age, such as difficulty with self-care, mobility, and/or communication (14). In Canada, as many as 6.3% children aged 0 to 9 years have some type of disability (3). Within the province of Québec, the disability rate for children 0 to 14 years, was 8.6% in 1998, which translates to 116 400 children. The higher rate found in Québec, is in part explained by the fact that the national study had a higher proportion of preschool-aged children than the provincial study, who typically tend to have a lower rate of disability as compared to school-aged children (3, 15). In the United States, 6.5% of all US children aged 0 - 18 years are disabled or report having a disability (16). Although these statistics illustrate the prevalence of childhood disabilities, they provide no indication about levels of severity or health services needs. In terms of severity of disability, Msall and colleagues described school-aged children participating in the 1994-1995 National Health Interview Survey on Disability (NHIS-D), by degree of functional disability: 4.1% had a mild functional disability, 5.9% had a major functional disability and 1.9% had a multiple functional disability (11). Functional disability was based on the severity of functional limitation across four domains: mobility, self-care, communication and learning-behavior (11). Another study estimated severity of children with developmental disabilities (including functional, behavioral and language delay) as 5% to 10% (17). Variability in severity among studies may reflect differences in operational definitions of target populations, and the heterogeneity of the measures used to assess disability.

The needs and effects of childhood disability on the health-care system, including rehabilitation, are profound (16). The American Academy of Pediatrics

Committee on Children with Disabilities (18) recognizes that developmental surveillance is fundamental in the medical care of children, and that identification of children with developmental disabilities is crucial to ensure that appropriate early childhood intervention can be instituted (19, 20). Young children with developmental delay benefit from early rehabilitation intervention to allow them to develop to their full potential and maximize their function (5, 6, 9, 10, 19-22). Conversely, a lack of accessibility (for example, long waiting times) for appropriate rehabilitation services for children with physical disabilities could have a significant impact on a child's functional status and subsequent social integration and well being. Lengthy waiting times were demonstrated in a pilot study of 172 children with physical disabilities, residing in Montreal (9). Given the potential impact of such long waiting times (greater than 6 months) for the child and family, efforts by policy-makers, pediatricians, and developmental specialists, should be made to reduce these waiting times.

In summary, many preschool-aged children present with some form of disability that requires rehabilitation to prevent and minimize long-term disabilities. These children often have to wait a long time before they can access rehabilitation services. Several factors may be hindering access to these rehabilitation services such as service-related factors (mandates of centers), certain family-related factors (socio-economic status, desired language of service delivery and region of residence) and certain child-related factors (age, diagnosis, severity). These are discussed in further detail in the next sections.

2.2 Service related factors associated with access to rehabilitation

2.2.1 Mandates of rehabilitation centers

Historically in Québec, developmental specialists, including physiotherapists, occupational therapists, and speech language pathologists in the tertiary care hospitals, have provided regular rehabilitation services for children under age 6. In the early 1990's, there was a reform in the organization of these rehabilitation services. The goal was to provide rehabilitation services within the community or general sector with the intent to implement comprehensive coordinated services in one place (5, 7). Specialized pediatric rehabilitation centers rather than tertiary care centers were then mandated to provide long-term rehabilitation services to children with physical disabilities. Since this policy shift, children with disabilities who are diagnosed in the tertiary care center by pediatric developmental specialists are transferred to the appropriate pediatric rehabilitation center for their long-term rehabilitation needs (5, 7, 8).

A study was commissioned by the Office des personnes handicapées du Québec in 1992 to describe the organization and function of pediatric rehabilitation services for children with disabilities in Québec (5). This study confirmed that families often encountered a lack of available and coordinated services, as well as poor organization of services. The study recommended the implementation of early access to rehabilitation services upon the confirmation of the child's impairment regardless of the degree of severity, to ensure timely, comprehensive and well-coordinated services (5).

The issue of early access to rehabilitation services has also been addressed in the United States. In 1986, the US Congress passed the Public Law 99-457 which mandated the early identification and the organization of comprehensive programs of early intervention services (including physiotherapy and occupational-therapy) of infants and young children with developmental delays (22, 23).

Despite mandates for coordinated services, comprehensive services have yet to be fully implemented at rehabilitation centers (1, 8, 24). In 1999, a report was published regarding a year-long study commissioned by the Institute de Réadaptation en Déficience Physique du Québec to describe the current collaboration between developmental specialists and parents of young children with physical disabilities (24) in six pediatric rehabilitation centers in four major regions of Québec. As one would expect, the study confirmed that an increase in resources and a reduction of waiting lists facilitated better parent-therapist collaboration. The majority of the participants involved in this study also reported that they highly valued a family-centred approach (24).

Many developmental specialists now work in partnership with the child and his/her parents to promote and enhance the child's health and well-being within his/her environment (20, 25, 26). This notion of partnership has brought about a dramatic change to traditional rehabilitation approaches and service delivery for children with disabilities (25, 27, 28). This highly valued approach to service delivery, known as family-centred service (FCS), is based on the acknowledgement of a partnership between children with disabilities, their parents, and service providers, in the decision-making process concerning the child's rehabilitation services and needs (25, 27, 29). It also recognizes and considers the parents as experts regarding their children's needs (25-27, 29). These needs may be associated with the child's functional status as well as with the availability of and satisfaction with rehabilitation services (26).

The literature reveals that eligibility and accessibility of pediatric rehabilitation services remains an ongoing problem for many individuals (9, 10, 22, 30). A study by Fox and colleagues (30) found that Health Maintenance Organizations (HMOs) in the US restricted access to a majority of children with special needs, who did not meet the established criterion that the child is expected

to make significant improvement over a short period of time. Such policies impose barriers to care for children with chronic disabilities. In addition, parents of these children do not have the choice to seek providers outside their HMO. Majnemer and colleagues' study (10) on early rehabilitation service utilization patterns in young Canadian children with developmental delays, residing in a large metropolitan area (Montreal, Canada), found that long waiting times and lack of resources may limit access to comprehensive services. This is consistent with Feldman and colleagues' pilot retrospective study (9) where long waiting times (greater than 6 months) for rehabilitation services for children with physical disabilities in the Montreal region were observed: six months after referral, of 172 children, 50% and 36%, respectively, had not yet received OT services and PT services at the rehabilitation center. Simpson and colleagues report that 69-83% (or an estimated 558 000) of infants and young children with developmental delay in the US do not receive intervention services (22). Thus, it appears that access to timely services for these children is a problem both in Québec and elsewhere.

2.3 Family related factors associated with access to rehabilitation

2.3.1 Desired language of services and region of residence associated with receipt of rehabilitation services

Certain factors, such as desired language of services and region of residence may influence waiting times for receipt of pediatric rehabilitation services. In Montreal, services can be provided in either English or French. Feldman and colleagues found that families of children with physical disabilities residing in the Montreal area, whose language of preference was English, received OT services sooner than those preferring services in French (9). In addition, the families residing in the city itself had shorter waiting times for

transfer to long-term pediatric rehabilitation centers than those families who lived in the surrounding regions (9). Lack of resources and reduced coordinated care in rural areas may influence waiting times to specialized pediatric rehabilitation services. Studies have shown that substantial travel distance to access comprehensive health care for many families of children with chronic disabilities may pose an obstacle to health care (9, 31) and can have a negative impact on cohesion of immediate family relationships (31), which may influence perceived well-being and quality of life of the child and his family.

There are only a few studies that analyze waiting times for service delivery for children with disabilities and the factors associated with these waiting times. Moreover, little is known about the impact of these waiting times on the family (8, 9).

2.3.2 Socio-economic status (SES)

Socio-economic status is often measured by using maternal education or family income (2, 32, 33). The literature has shown that poverty deters developmental performance (2, 33). Parents with low incomes and lower education possibly have lower expectations of their children's developmental skills (32, 33). The associations between lower family SES and higher incidence and severity of disability in children have also been well established (1, 2, 22). Simpson and colleagues reported a 40% higher chance of having a child with a functional delay among parents who had less than a high school education as compared to parents with higher levels of education (22).

Family socio-demographic characteristics (e.g., low income, insurance coverage) have an impact in determining children's access to care, use of services, and adherence to home programs (1, 34). However, two studies in Montreal found no association between parental education and receipt of public rehabilitation

services, for children with physical disabilities (9, 10). On the other hand, use of private services was associated with higher SES (10).

Although all Canadian families are covered for receipt of PT and OT services by provincial public health insurance programs, some parents may seek additional private services for which they must pay themselves or in some cases are covered by supplemental private insurance. Parents may opt for private services especially in view of the long waiting times for receipt of public services. In general, parents with lower SES do not have these resources, which consequently could limit their access to early rehabilitation services. Since early intervention may prevent long-term disabilities and handicaps (6) and waiting lists for services are long (9, 10), children of low income families may be at risk of developing further problems (33). In order to address these issues, programs for prioritizing children with low maternal SES have been instituted in some areas. These include access to early intervention programs (mainly psycho-educational in nature) and social services such as Head Start Programs (since the mid 1960s) (6). In 1978, the Québec Ministry of Education agreed to implement pre-kindergarten programs for 4-year-old socio-economically disadvantaged children. Unfortunately, many regions of the province have yet to provide these services to families (5). Most programs tend to focus mainly on cognitive, language and behavioral skills; however more global programs for children with physical disabilities need to be implemented, as children's problems span over other domains, such as functional independence of daily skills and psychosocial skills (6).

2.4 Child related factors associated with early access to rehabilitation

2.4.1 Age as a factor influencing receipt of rehabilitation services

There are consistent findings in the pediatric rehabilitation literature that age may be a determining factor related to the receipt of pediatric rehabilitation services (9, 10, 25, 34). Shevell and colleagues found that physicians were more likely to refer younger children to medical specialty evaluations (35). Majnemer and associates found that children with developmental delays receiving PT were significantly younger than those receiving speech language pathology services (SLP) and children receiving OT were also older (10) than those receiving PT. This may reflect the notion that early rehabilitation intervention maximizes outcome (6) and also may be a consequence of earlier recognition of gross motor milestone delay than fine motor or speech problems (10). Feldman et al. also found that younger children (mean age of 2.5 years) residing in Montreal tended to be transferred sooner to PT than older children (cut off of 9 years of age) (9). Similarly, CanChild Centre for Childhood Disability Research reports that younger children (0-4 years) with developmental disabilities receive more services than older children (5-16 years) (25).

In Québec, eligibility for long-term rehabilitation services can be further compromised for children 4 to 5 years of age, who are entitled to enter the educational system, such as pre-kindergarten or kindergarten in regular elementary schools. Children with severe disabilities most likely attend specialized schools where all rehabilitation services, including PT, OT and SLP (speech and language pathology) are available (8). However, children with milder disabilities who are integrated into a regular school are not eligible to receive the same services. This is because the school boards employ OT and SLP

professionals (although not PT) to enable school age children to receive rehabilitation services at school. However, because resources are insufficient, the frequency and intensity of treatment is at a minimum for these children. More importantly, these children are not entitled to receive services from rehabilitation centers due to the government policy that duplication of public services is prohibited. Unfortunately, children with mild disabilities are not only difficult to diagnose at an early age, but now appear to have difficulties receiving appropriate rehabilitation services (8). No formal programs have been implemented to treat these children (10). Discrimination regarding eligibility and access of long-term rehabilitation services for 4 and 5-year-old children based on severity of disability, may be a significant problem.

2.4.2 Diagnosis: the when, where and how of diagnosing children with disabilities

Other factors that may be associated with early access to rehabilitation may include recognition of the problem and referral practice of primary care practitioners, parental maneuvering within the health care system or priorities of the rehabilitation facility. These are discussed below.

Physical disabilities in children are the result of many different underlying childhood conditions, some more easily identifiable than others, possibly influencing when a child is referred to rehabilitation. Children in high-risk or within specific diagnostic groups such as cerebral palsy, prematurity and neuromuscular disease have implicit criteria for receipt of rehabilitation services and are typically well-serviced (6, 34). However, children with a less specific diagnosis such as global developmental delay (GDD) do not have well-defined criteria for receipt of services and no formal programs have been implemented for these children (10, 25, 32). Consequently, this latter group may experience longer

waiting times for access to rehabilitation services based on an unclear diagnosis (8, 34).

Children who are referred to rehabilitation early in life are those with a clear diagnosis (e.g. spina bifida, Trisomy 21, and neonatal seizures) with the nature of their disabilities known. These patient populations tend to be followed immediately by specialists for comprehensive investigations and confirmation of specific diagnosis (10, 35). In addition, neurodevelopmental evaluations by PT and OT in the tertiary care hospital setting are completed and children are referred to appropriate community rehabilitation centers for long term rehabilitation intervention (7, 8).

The identification and diagnosis of children without prenatal/perinatal risk factors or congenital neurological conditions, but who begin to show signs of developmental delay later in infancy or during preschool years, are more problematic as the certainty of diagnosis is more unclear and challenging (1, 10, 17-19, 34). Most children are born 'normal', therefore neither parents nor pediatricians have concerns regarding the child's development when he/she is very young (34). However, once a pediatrician or family physician suspects a child of having a developmental delay, the child is typically referred to a pediatric neurologist or developmental pediatrician for investigation of underlying aetiology and confirmation of a more specific diagnosis within the spectrum of developmental delay (such as a GDD, a language disorder, or an autistic spectrum disorder). This in turn has implications regarding treatment, and implementation of prevention programs (17, 35).

In the US, pediatricians are mandated by the Individuals With Disabilities Education Act (IDEA) to refer children with suspected developmental delays in a timely manner to early intervention programs (18-20, 34). Despite this mandate,

458 000 American children, in the 1994-95 National Health Interview Survey on Disability (NHIS-D), were not identified with developmental delay based on the results of the two questionnaires used in the survey (22). This implies that both parents and pediatricians failed to recognize a delay (22). Primary care physicians may not have adequate training or knowledge of more complex disabilities (that is, those not originating from identifiable lesions of the central nervous system), the most appropriate treatment, and the best monitoring practices (1). In addition, perceived diagnostic certainty by physicians has been shown to highly influence their decision in referring children to rehabilitation (23, 35). The higher the certainty that a child has cerebral palsy, the higher the odds of referral to rehabilitation (23). Some physicians do not sufficiently use available therapies and early-intervention services; they may recognize children who have a developmental disability, yet they do not refer them to rehabilitation (23). This undermines the premise for provision of early rehabilitation intervention to children with developmental disabilities irrespective of specificity of diagnosis (5, 18).

2.4.3 Severity of physical disability

The degree of severity of physical disabilities among children can be widely and unevenly distributed across the different developmental domains (motor, speech, cognitive or social). Milder degrees of physical disabilities in young children are often more difficult to identify given that children develop in spurts and at a non-constant rate within each developmental domain (18). Conversely, severe developmental delays are more easily identified when major developmental milestones, in motor, speech, cognitive, or social skills areas, are not attained at age appropriate time frames and persist over the preschool years. Severe delay is typically defined as performance at two or more standard deviations below the mean on standardized norm-referenced measures (2, 17, 35).

There are conflicting findings in the literature regarding the influence that severity of disability has on the receipt of services (10, 23, 30). In general, it is presumed that children with severe disabilities are not expected to improve significantly over a short period of time given the chronic nature and the severity of their disabilities. This in turn affects the child's eligibility for services. Fox and colleagues' study revealed that the criterion that a child is not expected to improve significantly over a short period of time, actually served to exclude these types of children from accessing services in HMOs in the US (30). However, Campbell and colleagues found that the more severe a physician perceived the child's disability, the more likely the child was referred to PT (23). Interestingly, physicians preferred to refer children with more severe disabilities to 'early-intervention' programs rather than to regular PT services. 'Early intervention' programs were not clearly defined in this study, but presumably consisted of mainly 'educational' programs rather than 'therapeutic' programs. In contrast, Majnemer and colleagues did not find that severity of developmental delay influenced receipt of rehabilitation (PT, OT, and SLP) services (10). However, the issue of severity was not clearly addressed in this study, as only three children in their sample of 129 children (2%) were classified as having severe developmental delays (10). There were also methodological differences in assessing severity making direct comparisons of findings in these studies impossible (10, 23, 30). Moreover, in the Canadian system, services are publicly funded for all residents which is not the case in the United States.

Measuring disability in the pediatric population is challenging for both researchers and developmental specialists. These issues are discussed in the next section

2.4.3.1 Challenges in measurement of disability

Measuring disability based solely on a child's primary diagnosis (example: cerebral palsy, spina bifida, Trisomy 21) is insufficient in providing an accurate portrait of a child with a physical disability. This is because most children with physical disabilities experience multiple problems in conjunction with the primary diagnosis (25). For example, a child with a primary diagnosis of cerebral palsy (typically presenting with spasticity) may have difficulties walking, feeding or communicating without adaptive aids, yet another child with the same diagnosis, may be functioning independently in these skills (despite the underlying spasticity). Accurately portraying children with a broader diagnosis such as global developmental delay becomes an even bigger challenge, given the heterogeneous nature of its definition, which implies different degrees of physical disabilities across several domains (17, 35).

In the WHO's International Classification of Impairment, Disability and Handicap, *disability* reflects the inability of the child to carry out essential tasks of daily living appropriate for age, such as difficulty with self-care, mobility, and/or communication (14). Within this framework of *disability*, *function* is the child's ability to perform daily activities independently in a timely and safe manner within his/her environment (14). Daily activities incorporate multidimensional domains such as feeding, dressing, continence, mobility, cognition, and socialization, which have an impact across health, developmental, educational and community settings. Indeed, only the use of appropriate measures of functional status with consideration of these domains will provide a clear portrait of a child with a physical disability.

Many different functional outcome measures have been developed to assess functional status in preschool-aged children, each of which are delineated by the conceptual definition for *disability* by the World Health Organization (14). They include the Pediatric Evaluation of Disability Inventory (PEDI) (36), the

Vineland Adaptive Behaviour Scales (VABS) (37), the Functional Independence Measure for Children (WeeFIM) (38, 39) and the Gross Motor Function Classification System for Cerebral Palsy (GMFCS) (40). A major limitation of functional outcome measures is the inability to define a child's quality of life, a broader perspective of a child's well-being in life situations (41-45). In the recent WHO International Classification of Functioning, Disability and Health (known as ICF), the child's physical, psychological, and social aspects of well-being are addressed. Here, the notion of multidimensional health and well-being is further related to various factors (contextual: environmental and personal) (46). The ICF model is related to the notion of *health-related quality of life* (HRQL), which is the child's report of his/her feelings of well-being that can be influenced by his/her life experiences (41, 44-46). This notion of *quality of life* has given rise to the recent development of new outcome measures defined as HRQL measures, such as the Pediatric Quality of Life Inventory-Version 4.0 (PedsQL4.0) (41-45). HRQL measures incorporate environmental, physical and psychosocial factors, which have an impact on the child's social adaptation and well-being within his/her society. As such, they may be useful for developmental specialists, as children with the same functional limitations may have a very different perceived well-being and quality of life. Incorporating this concept into clinical practice has influenced a change with regard to how developmental specialists set up rehabilitative goals for children with physical disabilities. However, criticisms of HRQL measures include their subjectivity and the broadness of the concept of HRQL, making it difficult to define (29, 42, 47, 48).

The recent expansion of health concepts by the WHO to include environmental factors has further implications for rehabilitation interventions. The setting of rehabilitation goals has shifted towards promoting and enhancing health and well-being, rather than the traditional emphasis on preventing and minimizing long-term disabilities. Further research needs to investigate the

association between the concepts of function and quality of life in order to address this new focus of health outcomes. Therefore, in order to better portray a child with a disability, descriptions of function and HRQL may need to be used.

Both Feldman et al. and Majnemer et al. have begun to look at service delivery of pediatric rehabilitation (by measuring waiting times or service utilization patterns) for children with developmental or physical disabilities, living in the Montreal region (9, 10). Their studies were limited to only one of two local pediatric tertiary care hospitals, and used a cross-sectional design, relying on parental self-reports and their recall. Feldman et al. (9) included school-aged children who often tend to use resources allocated by the school system rather than in local rehabilitation centers while Majnemer et al. (10) included children with pervasive developmental delay (autistic spectrum disorders) who received services at centers specialized in treating intellectual disability. Neither study measured disability in a consistent standardized fashion nor did they incorporate broader outcomes, such as HRQL. Our study has tried to address some of the limitations of the previous studies.

2.5 Summary

In Canada, a substantial number of children need long-term rehabilitation services. Research agrees on the importance of early identification of children with developmental disabilities, so that appropriate early rehabilitation intervention can be instituted (5, 6, 9, 10, 19-22). However, accessibility of rehabilitation services may not be easily available to families of children with physical disabilities. Recently, researchers in the Montreal region have undertaken initiatives to study waiting times and service utilization patterns of pediatric rehabilitation centers (9, 10) but these studies have limitations.

Nonetheless, these findings are important because they show the lack of equitability of services to children with disabilities. Further research is indicated to analyze waiting times for service delivery for children with disabilities and the factors associated with these waiting times. It is particularly important to study these issues among preschool-aged children with physical disabilities, since school-aged children are supposed to receive their services at school rather than at the rehabilitation center. Children with cognitive disabilities are excluded since it is centers specialized in treating intellectual disabilities that provide their rehabilitation services. It is also important that children be recruited from both of Montreal's two tertiary care pediatric hospitals for more accurate representation of our study population and generalization of our results. Factors that may hinder accessibility are numerous, including mandates of rehabilitation centers, family's socio-economic status, family's desired language of services, family's region of residence, child's age, child's diagnosis, and severity of the child's physical disability. Disability severity may need to be assessed by both function and HRQL measures, since functional outcome measures do not define a child's quality of life, which is a broader perspective of a child's well-being. Our study will analyze the association between the concepts of function and quality of life in preschool-aged children with physical disabilities. It is important to investigate their association in order to address the new focus of the WHO with respect to health outcomes, and the inclusion of contextual factors.

CHAPTER 3 - METHODS

3.1 Study design

The study was a prospective cohort study.

3.2 Study population

All preschool-aged children referred between September 1, 2002 and December 31, 2003 to pediatric rehabilitation centers for PT and/or OT services, in the Montreal region, from either the Montreal Children's Hospital or Hôpital Sainte-Justine were recruited for the study. Subjects were children aged 0-5 years inclusive, residing in Montreal and surrounding areas (within a 50-km radius), who were referred by the hospital's outpatient services to PT and/or OT services at a pediatric rehabilitation center for a physical disability. Children with a disability due exclusively to a cognitive delay were excluded. Parents had to have an adequate comprehension of English or French to participate in the study.

Children diagnosed with a physical disability (including cerebral palsy, prematurity, GDD, Trisomy 21, musculo-skeletal conditions, neurological conditions, and other syndromes) often require long-term rehabilitation to maximize their potential and minimize disability. Upon medical referral, the hospital's PT and OT departments evaluate these children. If long-term rehabilitation is indicated, a transfer request is made to the appropriate rehabilitation center. The pediatric rehabilitation centers implicated in this study included the Mackay Center, the Centre de Réadaptation Marie-Enfant, the Centre Montérégien de Réadaptation, the Centre Le Bouclier, and the Jewish Rehabilitation Hospital. While awaiting treatment at one of these centers, the children may have received some PT or OT services at the tertiary care hospital on an occasional outpatient basis.

3.2.1 Recruitment

Participants were identified through the rehabilitation discharge coordinator, hospital rehabilitation departments, and developmental clinics at both tertiary care hospitals. Both hospitals have computerized databases that include the following information for children transferred to rehabilitation: date of first appointment at the PT or OT department at the hospital, date of transfer request for out-patient rehabilitation services, name of the rehabilitation center where the child is being referred, information about the child (identification number, name, date of birth, address, phone number), diagnosis, and language (English or French). The date of transfer request for this study was defined as the date when all the necessary documentation was forwarded to the rehabilitation center by the hospital rehabilitation discharge coordinator. This documentation includes a form signed by the parent/guardian to release information for the transfer of medical and paramedical information to the rehabilitation center. At the time of transfer request, parents were contacted by telephone by a research assistant and invited to participate in this study. If the parent agreed, the research assistant arranged for an interview.

3.3 Data Collection

3.3.1 Data sources: interviews

The parents of all preschool-aged children with a physical disability who were referred to one of the five rehabilitation centers were asked to participate in a series of interviews. The initial interview took place within two to four weeks following the date of the transfer request. A face-to-face interview was conducted with one of the parents, at the family's residence or the hospital, whichever was most convenient for the family. It was felt that by meeting the parents in person, it would be easier to administer the measures and obtain their cooperation and interest in the follow-up interviews. Written parental informed consent was

obtained at the time of the initial interview (Appendix II). The follow-up interviews were administered by telephone to the same parent at three-month intervals following the initial interview and until the child received services at the rehabilitation center. Since the parents were familiar with the study tools, follow-ups were easily administered by telephone. The final interview was also administered by telephone to the same parent one to two weeks following transfer to the rehabilitation center, defined as the date of the first appointment with either the physiotherapist or occupational therapist at the rehabilitation center.

The interviews were conducted by one of two research assistants who were trained using structured questionnaires and standardized measures. The interviewers used a series of valid and reliable tools to measure child function and quality of life. The function of the child as reported by the parent was evaluated using the Functional Independence Measure for Children (WeeFIM), which is described in detail in section 3.3.2.1. Perceived quality of life of the child as reported by the parent was evaluated using the Pediatric Quality of Life Inventory-Version 4.0 (PedsQL4.0), which is described in detail in section 3.3.2.2. In addition, parents were asked to provide baseline demographic data (e.g. parental educational level) and answer questions regarding rehabilitation service use in the interim waiting period (i.e. public setting or private, frequency, duration, and costs of services).

The waiting time for rehabilitation services was defined as the time between referral request to rehabilitation from the tertiary care hospital and the child's first physiotherapy or occupational therapy appointment at the rehabilitation center. In some case, children were referred to both PT and OT services and the waiting time for each service was not necessarily the same. The final interview was conducted following the child's first appointment in either service. The parents were then contacted by telephone at a later date to obtain the

waiting time for the other service. The telephone interviews were conducted from December 2002 to December 2004.

3.3.2 Study questionnaires

There were three different study questionnaires, one for each series of interviews. The first questionnaire (initial interview) documented sociodemographic data (educational level of parent, ethnicity, family income) and the services the child had ever received (PT/OT at the hospital setting or private) (Appendix III). The second questionnaire used at the follow-up interviews documented the ongoing waiting time, parental report about whether the child was improving or deteriorating while waiting for rehabilitation services, parental satisfaction with the transfer process of the child's file and the services the child was currently receiving, including public and private services (Appendix IV). The third questionnaire (final interview) documented waiting time for rehabilitation services, parental satisfaction with the transfer of services from hospital to rehabilitation center, the services the child was receiving since the previous interview (public and private services), parental opinion about the amount of time to wait for rehabilitation services once having been referred, problems with the system and any suggestions for improvement (Appendix V). Parental concerns and comments regarding the child's rehabilitation or lack thereof were documented at each interview.

3.3.2.1 Functional outcome measure

Several functional outcome measures are commonly used for preschool-aged children with physical disabilities. These include the Pediatric Evaluation of Disability Inventory (PEDI) (36), the Vineland Adaptive Behaviour Scales (VABS) (37) and the Functional Independence Measure for Children (WeeFIM)

(38, 39). Although the VABS and the PEDI are evaluative instruments of child function that can be administered to parents, the WeeFIM was chosen for this study. Both the VABS and the PEDI require 45-60 minutes to administer, considerably longer than the 15-20 minutes for the WeeFIM. Ease of administration and scoring were important selection criteria. In addition, the reliability between face-to-face and telephone interview methods of administration (49), as well as test – retest reliability (50) for the WeeFIM was demonstrated on children with developmental disabilities.

The WeeFIM (Appendix VII) was adapted from the adult Functional Independence Measure (FIM) and designed as an evaluative measure that operationally defines tasks pertinent to a child's independence across different settings (38, 39, 43, 49, 50, 51). The WeeFIM is used to determine the level of independence and the need for assistance as a result of disability, when performing basic daily skills. It consists of 18 items that measure six domains (self-care, sphincter control, transfers, locomotion, communication and social cognition tasks) for non-disabled children aged 6 months to 8 years of age, and for children with developmental disabilities and mental aged less than 7 years (38, 39). It has excellent inter-rater reliability when used with children with disabilities ($\kappa = 0.44-0.82$) (51). The intraclass correlation coefficient (ICC) for total WeeFIM test – retest reliability is excellent ($ICC = 0.98$) when examined in children with disabilities (50). In addition, concurrent validity between the WeeFIM and the PEDI was found to be high in children with developmental disabilities and acquired brain injuries (Spearman correlation coefficient, $\rho = 0.53-0.96$) (52). Content and criterion-related validity was high in preschool-aged children with developmental disabilities, such as cerebral palsy, spina bifida, Down's syndrome, limb deficiency, and extreme prematurity ($r = 0.80$) (38, 39). Total and subscale scores can be compared to established norms.

Each item is scored on a seven-point ordinal scale, 1 indicating complete dependence and 7 signifying complete independence (38, 39, 43, 49). Scoring consists of calculating *quotients* for the three subscales (self-care, mobility, and cognition), and for the total score, with lower quotients representing higher levels of disability (53). WeeFIM scores were obtained for all children at each interview. The WeeFIM was administered through interviewing the parent. WeeFIM scores obtained at the first interview served as a baseline measure of severity of the child's disability. Subsequent WeeFIM scores obtained at the follow-up interviews served as indicators of improvement or deterioration of the child's function over time.

3.3.2.2 Child's quality of life

The child's quality of life was assessed by the Pediatric Quality of Life Inventory – Version 4.0 (PedsQL4.0) (Appendix VIII). The PedsQL4.0 was selected because it is considered an excellent generic tool used for paediatric populations with acute and chronic health conditions. Ease of administration (less than 5 minutes) to parents was an important selection criterion. In addition, the PedsQL4.0 has been translated into French (unpublished data).

The PedsQL4.0 is designed to measure physical (8 items), emotional (5 items) and social health (5 items) as well as school/daycare functioning (3-5 items) at developmentally appropriate stages for children ages 2-4, 5-7, 8-12, 13-18 years (44, 45). It is a reliable and valid tool. Internal consistency reliability for the parent-report was high (Cronbach's alpha = 0.86-0.90 depending on the scale) (44, 45). Test-retest reliability is not reported for this measure. There is response equivalence between in-person and telephone administration mode (44). The PedsQL4.0 proxy-report distinguished between children with or without a chronic condition (known-groups comparisons) (44, 45).

Items of the PedsQL4.0 are scored on a 5-point ordinal scale, 0 corresponds to “never being a problem” and 4 corresponding to “almost always being a problem”. Items are reversed scored and linearly transformed to a 0-100 scale, with higher scores indicating a better HRQL. Three scores are calculated: the *Psychosocial Health Summary*, the *Physical Health Summary* and the *Total Scale* scores (54).

PedsQL4.0 scores were obtained during each interview via a parent proxy-report for children 2 years and older. The baseline PedsQL4.0 scores obtained during the first interview served as a measure of the child’s quality of life at inception of the study. Subsequent PedsQL4.0 scores obtained at the follow-up interviews served as indicators for changes in parental perception of their child’s quality of life, during the waiting period for rehabilitation services.

CHAPTER 4 - MANUSCRIPTS

The results of this research project are presented in the following manuscripts:

4.1 Associations between scores on a Functional Independence Measure (WeeFIM) and the Pediatric Quality of Life Inventory (PedsQL4.0) in Young Physically Disabled Children Aged 2-5 years.

Lisa Grilli, Debbie Ehrmann-Feldman, Annette Majnemer, Melanie Couture, Laurent Azoulay, Bonnie Swaine (submitted to the *Journal of Developmental and Behavioral Pediatrics*).

4.2 The Influence of Age, Diagnosis and Severity of Disability on the Waiting Time for Rehabilitation Services for Preschool-Aged Children with Physical Disabilities.

Lisa Grilli, Debbie Ehrmann-Feldman, Bonnie Swaine, Julie Gosselin, François Champagne, Raynald Pineault (to be submitted to the journal *Association of Pediatrics*, in the spring 2005).

The principal author confirms her original contribution to the data collection and interpretation of the results as well as in the writing of the research articles.

4.1 Associations between a Functional Independence Measure (WeeFIM) and the Pediatric Quality of Life Inventory (PedsQL4.0) in Young Physically Disabled Children Aged 2-5 years

**Lisa Grilli^{1,2,3} PT, BSc, Debbie Ehrmann Feldman^{1,2,3,4} PT, PhD,
Annette Majnemer^{3,6} OT, PhD, Melanie Couture^{1,5} OT, MA, Laurent
Azoulay^{1,5} MSc, Bonnie Swaine^{1,2} PT, PhD**

1 Université de Montréal, École de réadaptation

2 Centre de recherche interdisciplinaire en réadaptation (CRIR)

3 McGill University Health Centre: Montreal Children's Hospital

4 Université de Montréal, Groupe de recherche interdisciplinaire en santé (GRIS)

5 Centre de recherche Hôpital Sainte-Justine

6 McGill University, School of Physical and Occupational Therapy

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Corresponding Author:

Lisa Grilli BSc (PT) MSc (cand)
McGill University Health Centre
Montreal Children's Hospital, Physiotherapy Department
2300 Tupper
Montreal (QC) Canada H3H 1P3
Tel: (514) 412-4407
Fax: (514) 412-4398
Email: [REDACTED]

4.1.1 Abstract

TITLE: Associations between a functional independence measure (WeeFIM) and the Pediatric Quality of Life Inventory (PedsQL4.0) in young physically disabled children aged 2-5 years.

AIMS: To determine the association between functional status, measured by the WeeFIM and health-related quality of life (HRQL), measured by the PedsQL4.0 for children with physical disabilities.

PATIENTS: Parents of 115 children (2-5 years) with physical disabilities. Mean age of the children was 3 years 7 months (10 months), 79 were boys and 67 were diagnosed with global developmental delay.

MAIN RESULTS: Children had more difficulties with self-care tasks and cognitive abilities, as compared to mobility activities on the WeeFIM. Total WeeFIM was moderately correlated with total PedsQL4.0 ($r=0.39$). WeeFIM mobility and self-care quotients were each weakly to moderately correlated with PedsQL-Physical Health Summary Score ($r_s=0.29$ and $r_s=0.28$ respectively). There was no significant association between WeeFIM cognition quotient and each of PedsQL scores ($r_s=0.03$ to 0.05).

CONCLUSION: There may be a need to incorporate complementary measures, such as the WeeFIM and PedsQL4.0 when measuring general health of children with disabilities.

4.1.2 Introduction

Pediatric outcomes research in the past decade (1-7) indicates that a multidimensional measurement instrument best reflects a child's overall status and well-being within his society. These instruments are for the most part based on the concepts developed by the World Health Organization (WHO) including the current classification of the terms disability and functioning. Disability reflects an individual's functional performance and activity level (2,8), whereas participation limitation/restriction refers to how well a person fulfills his or her societal roles (2). Participation level can be positively or negatively altered by the individual's experiences in his or her environment, which could subsequently have a direct influence on the individual's outlook of his or her well-being and quality of life (9,10).

The rehabilitation literature recognizes that both function and quality of life are important health outcomes (1,4,5,8,10). Historically, functional outcomes were used as they measure objective dimensions, such as mobility and activities of daily living (ADL) (4). More recently, health-related quality of life (HRQL) outcomes have gained popularity for their inclusion of both objective and subjective dimensions. The latter component tends to be more valued by children and their parents, whereas the former is typically more informative for the service provider's needs (4).

The field of pediatric rehabilitation needs to perform more outcomes research using appropriate measurement tools, which will provide valuable information to researchers, therapists, and families. A popular, well validated and highly reliable pediatric functional outcome measure is the Functional Independence Measure for Children (WeeFIM) (11). The Pediatric Quality of Life Inventory (PedsQL) 4.0 is a relatively new health outcome measure (12,13) designed to evaluate HRQL, and covers a broader concept of health. There is a

paucity of information on the association between these two concepts, notably in pediatrics. In the adult literature, Desrosiers and colleagues (14) have studied the association of two functional independence scales with a participation measure in post-stroke geriatric patients. Their results support the use of complementary measures, such as participation measures that cover domains other than physical function (14). Service delivery is another factor to consider, that may be associated to parental perceptions of their child's quality of life (4,10,15,16). We hypothesized that parents whose children are receiving some form of intervention may have a more positive perception of their child's well-being as compared to those whose children are not receiving services.

The primary objective of this study was to evaluate whether parent's perception of their child's quality of life is related to parental report of functional status among preschool-aged children with physical disabilities. A second objective was to explore child, parent and service-related factors associated with each measure: function and quality of life.

4.1.3 Methods :

4.1.3.1 Subjects

Our study sample consisted of parents of children aged 2 to 5 years with physical disabilities such as cerebral palsy, spina bifida, Trisomy 21, global developmental delay, and other syndromes. The children were being referred to various pediatric rehabilitation centers in the Montreal area from two pediatric tertiary care teaching hospitals, the Montreal Children's Hospital (MCH) and Hôpital Ste. Justine (HSJ). The children and their parents were recruited within the context of a larger study whose goal was to analyze factors influencing waiting time for pediatric rehabilitation services in preschool-aged children. In that study, parents of 205 children accepted to participate. Of the 205 participants, 115 were parents of children aged 2 to 5 years who were therefore eligible for the

present study, given that the WeeFIM can be administered to parents of children as young as 6 months of age, however the PedsQL4.0 parent-proxy report can only be administered to parents of children as young as 2 years of age. Inclusion criteria were: referrals from a hospital setting for community based Physical or Occupational Therapy for a physical disability, parent's comprehension of English or French, and families residing within a 50 km-radius of Montreal. In Québec, public rehabilitation services (PT and OT) are covered for all residents by the provincial public health insurance although parents may pay for any desired supplemental private services. Recruitment was done over a 16-month period, from September 2002 to December 2003.

The study protocol was approved by each of the two hospital's research ethics committees. Written parental informed consent was also obtained.

4.1.3.2 Procedure

Children eligible for our study were identified through the rehabilitation discharge coordinator, hospital rehabilitation departments, and developmental clinics at both hospitals. Information collected about the children from computerized databases at the tertiary care hospitals included: demographic data, child's diagnosis, language of requested services, and date of transfer request. At the time of transfer request, a research assistant contacted the family and asked one of the parents to participate in an interview 2 to 4 weeks later. The face-to-face interview took place at the family's residence or at the hospital; whichever was most convenient for the parent. The interview was conducted in either English or French, according to the family's preference, and lasted between 30 minutes to an hour. The interview consisted of administration of three questionnaires, i.e. a 'study' questionnaire specifically developed for this project, and two measures: the WeeFIM and the PedsQL4.0 parent-proxy report, which are described below.

4.1.3.3 Measures

The 'study' questionnaire included questions regarding district of residency, preferred language of service delivery, the parent's educational level, ethnicity, family income, and receipt of any rehabilitation services (physiotherapy and/or occupational therapy) including public and private sources, anytime since birth of the child.

The WeeFIM is a validated and reliable tool (11,17-20) adapted from the adult Functional Independence Measure (FIM), and designed as an evaluative measure that operationally defines tasks pertinent to a child's independence across different settings (1,11,17,20). It measures usual performance to criterion standards and includes 18 items across 3 subscales (self-care, mobility, and cognition) for children with developmental disabilities ages 6 months to 12 years (19). The child's performance on each item is scored on a seven-point level ordinal scale, 1 indicating complete dependence and 7 signifying complete independence (1,11,18,19). Subsequently, *quotients* are calculated from the scores obtained for the 3 subscales and for the total score, with lower *quotients* representing higher levels of disability (21). The *quotient* is calculated by dividing the child's raw score by the 'normal' mean for a specific age. The *quotients* are normalized data - the raw data are transformed based on the average score for a given age. This tool was chosen because methods of administration include interviews (face-to-face or telephone) or direct observation (17,18). There is excellent equivalence reliability of observation and interview administration methods (ICC = .93 for total WeeFIM score) (18).

The PedsQL4.0 is a valid and reliable tool (12) designed to measure physical (8 items), emotional (5 items) and social health (5 items) as well as school/daycare functioning (3-5 items) at developmentally appropriate stages for children ages 2-4, 5-7, 8-12,13-18 years (12,13). The child's performance on each

item is scored on a 5-point level ordinal scale, 0 corresponds to “never being a problem” and 4 corresponds to “almost always a problem”. Items are reversed scored and linearly transformed to a 0-100 scale, with higher scores indicating a better HRQL. Three scores can be calculated: the *Psychosocial Health Summary*, the *Physical Health Summary* and the *Total Scale Score* (22). Administration was by parent proxy-report because child self-report is only appropriate for children age > 5 years (12). The internal consistency of the self-report and proxy-report generally exceeds a Cronbach α of 0.70 (12,13). One of the co-authors (AM) has been involved in forward and back translation of the PedsQL4.0 to Canadian French (unpublished data).

4.1.3.4 Analysis

Descriptive statistics were used to summarize the characteristics of the sample. Pearson correlation coefficients were calculated to study the associations between the WeeFIM and PedsQL4.0 subscale and summary scores. When normality was not observed, non-parametric measures (Spearman’s rho) was used. Unpaired t-tests and ANOVA were used to estimate differences between categories of factors related to the child (diagnosis, age, gender), family (income, maternal education) and service delivery (referrals to PT/OT and receipt of PT/OT) and the mean scores for each measure separately. All tests were two-tailed. We used Statview version 5.0 (SAS Institute, Cary, NC) to perform the analyses.

4.1.4 Results

4.1.4.1 Sample

Characteristics of the sample are presented in Table 1. Most (n=67) were diagnosed with global developmental delay (this diagnosis was assigned by the

referring physician). More children (n=104) were referred to OT services than to PT (n=65).

4.1.4.2 Measures

Mean quotients, standard deviations and ranges for the subscales and total scores on the WeeFIM, as well as the mean scores, standard deviations and ranges for the summary and total scores on the PedsQL4.0 are described in Table 2. The children's scores were low on all the subscales of both outcome measures, and there was substantial variability in scores. The percentages with quotients below 75 (i.e. cut-off for identifying children with disabilities) (23) for our sample are as follows, self-care: 62.6%, mobility: 32.2%, cognition: 73.9% and total: 49.6%. These scores indicate that children were perceived to have more activity limitations and required more adult assistance with self-care tasks and cognitive abilities, as compared to mobility activities. Regarding HRQL, the children were perceived by their parents to have a higher quality of life with respect to physical health as compared to their psychosocial health.

Table 3 describes the correlation between the children's scores on the WeeFIM and the PedsQL4.0 scales. Pearson correlation coefficients were used throughout, except for correlations involving the PedsQL-Physical Health Summary score and the WeeFIM cognition quotient, since these scores were highly negatively skewed indicating the use of Spearman's rho. The total WeeFIM score was statistically significantly correlated to the total PedsQL4.0 score. The WeeFIM mobility quotient was moderately correlated with the PedsQL-Physical Health Summary score, as was the WeeFIM self-care quotient. The WeeFIM mobility quotient was also correlated with the total PedsQL4.0 score. The lowest correlations were between the WeeFIM cognition quotient and each of the PedsQL4.0 scores.

Table 4 presents the results of unpaired t-tests and ANOVAs for categories of factors related to the child, family or receipt of services with the WeeFIM and the PedsQL4.0. Parental income and maternal education were not significantly associated with either the WeeFIM or the PedsQL4.0. Diagnosis categorized as global developmental delay (GDD), was significantly associated with higher mobility quotient of the WeeFIM ($p < 0.001$) as compared to diagnosis of non-global developmental delay. Older children (>3.6 years) scored significantly higher on the mobility and self-care quotients of the WeeFIM ($p < 0.001$, and $p < 0.01$, respectively) as compared to younger children. Males had higher PedsQL-Physical Health Summary scores than females ($p < 0.055$). There was an association between receipt of PT services and each of the following: the PedsQL-Physical Health Summary score ($p < 0.001$), the PedsQL-Total score ($p < 0.001$), and the WeeFIM mobility quotient ($p < 0.001$) such that children who received services had lower scores.

4.1.5 Discussion

We found a high degree of variation in the PedsQL4.0 and WeeFIM scores reflecting the heterogeneity of diagnoses in our sample, and presumably their functional and quality of life status. Parental perception of quality of life was moderately correlated with functional status and mobility. We found an association between receipt of PT services and lower PedsQL-Physical Health Summary and Total scores, as well as greater limitations on the WeeFIM self-care and mobility domains.

The WeeFIM scores within our study sample indicated that children had more difficulties with self-care tasks and cognitive abilities than with mobility activities. This corresponds well with greater referrals for OT services, as requested by developmental specialists. A primary goal for OT intervention is the acquisition of personal and instrumental activities of daily living, whereas, PT

intervention focuses primarily on acquisition of independent mobility. This leads us to infer there is agreement between parental perceptions and therapeutic needs.

The moderate associations between the PedsQL-Physical Health Summary score and the WeeFIM selfcare and mobility quotients suggest there is some congruence as both measure the physical dimension of functioning. The WeeFIM was designed to measure the child's level of independence in performance of daily activities across two physical domains and one cognitive domain. The PedsQL4.0 was designed to measure how much of a problem the child has with items across several domains: physical, emotional, and social functioning. Conversely, the poor association between the WeeFIM cognition quotient and each of the PedsQL4.0 summary scores indicates that different constructs are assessed by the tools. The WeeFIM was not designed to measure a child's psychosocial integration and well-being, unlike the PedsQL4.0. Given the fact that individuals with equal degrees of functional limitations may exhibit a range of different scores for HRQL, the need for HRQL measures to provide additional information from that offered by traditional functional measures is justified (24,25). Consequently, the PedsQL4.0 can be used as a complementary measure to the WeeFIM in providing a more comprehensive portrait of the child's well being for clinicians and researchers.

Schneider and colleagues studied (24) school-aged children with cerebral palsy (CP) and found no correlation between the WeeFIM self-care and mobility subscales and a generic HRQL measure, the Child Health Questionnaire (CHQ). The difference between their study and the present study may be explained by the differences in the age level, extent of mobility limitation, diagnosis of the cohorts and the use of different tools for measuring HRQL. Our sample had a high degree of variation in severity and diagnoses, whereas their sample was restricted to children with cerebral palsy (CP) and 73% were classified as severe on the Gross

Motor Functional Classification System. However, in this same study, a fair correlation was found between the WeeFIM total score and the Caregiver Questionnaire (CQ), which suggests some overlap in the constructs of these two assessments (24).

Other studies have found that higher maternal education was associated with higher functional status in children who had undergone open-heart surgery, and with both physical and psychosocial health in children who had undergone a liver transplant (7,26). However, maternal education was not associated with either physical or psychosocial health in our study, which may be explained by the differences in the samples. Children with congenital heart defects tend to have functional disabilities (7) and pre-operative baseline neurodevelopmental evaluations are presumably a standard practice for these children. Parents are aware of their children's disabilities early on and can readily assist in the rehabilitation process. In our study, the majority of children had a diagnosis of GDD who tended to be older at time of diagnosis. Given the multidimensional nature of this diagnosis, diagnostic confirmation is more complex (27). Parents of these children often encounter difficulties accessing early rehabilitation services (28,29) in order to optimize their children's function, regardless of their level of education.

Receipt of PT services was highly associated with PedsQL-Physical Health Summary score and WeeFIM mobility quotient, indicating that lower scores on these subscale domains may be indicative of children requiring PT intervention. The need for PT intervention may be identified earlier than OT, as delays in gross motor milestones are usually recognized at an earlier age than delays in other domains of development. There was no association between WeeFIM self-care quotients and receipt of OT services, which may be explained by the sample size as almost all were in fact receiving some OT services.

Children who had a diagnosis of GDD scored higher than children with other diagnoses on the WeeFIM mobility quotient and the PedsQL-Physical Health Summary score. Generally, children with diagnoses such as cerebral palsy, spina bifida, trisomy 21 and other genetic syndromes (i.e. non-GDD) have difficulties with basic mobility activities such as transfers, crawling, walking and stair climbing which are the main items covered in the mobility subscale of the WeeFIM. In addition to the items in the mobility subscale of the WeeFIM, the Physical Health Summary subscale of the PedsQL4.0 assesses more advanced motor skills such as walking, running and participation in exercise which are typically quite difficult for most children with physical disabilities.

4.1.6 Limitations

The PedsQL4.0 for children 2 to 5 year of age incorporates functioning (physical, emotional, social) for all children, however, participation (i.e. school functioning) is only used for those children who attend daycare or school (example: pre- kindergarten, kindergarten). Thirty-eight children (33.6%) in our cohort did not attend some type of “school” system, possibly biasing some of our results and underestimating these children’s difficulties in these areas.

4.1.7 Conclusion

The WeeFIM self-care and mobility subscales, as well as the PedsQL-Physical Health Summary scores appear to measure somewhat similar physical dimensions of health and functioning. Our results indicate that these scores for children with physical disabilities are moderately correlated. The WeeFIM subscales and the PedsQL-Psychosocial Health score however measure different aspects of a child’s health and well-being. It should be emphasized that parents of children with lower functional skills can nevertheless perceive a good quality of

life for their children. The results of the study support the need to incorporate complementary measures that are not only focused on function but also include general health and life quality when measuring the overall status of children with disabilities. This would provide professionals with a better indicator of physical, social and emotional well-being and how well a child is performing and integrating in his environment. This would shift the focus of rehabilitation goals to promoting and enhancing health and well-being, rather than the traditional emphasis on preventing and minimizing long term disabilities and impairments, which would be in accordance with the recent expansion of the health concept by the WHO (2001).

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Table 1. Demographic data for children with physical disabilities (n=115)

Mean Age (SD)	3 years 7 months (10 months)
Gender (% Male)	79 (68.7%)
Types of disabilities	
Global developmental delay	67 (58.3%)
Prematurity	12 (10.4%)
Genetic syndrome other than Trisomy 21	12 (10.4%)
Neurological conditions	11 (9.6%)
Cerebral palsy	7 (6.1%)
Trisomy 21	3 (2.6%)
Musculoskeletal/peripheral n. conditions	3 (2.6%)
Ethnicity	
Canadian	70 (60.9%)
Other	45 (39.1%)
Preferred language of service	
English	62 (53.9%)
French	53 (46.1%)
Family structure	
Two-parent family	95 (82.6%)
One-parent family	20 (17.4%)
Relationship of respondent to child	
Biological parent	111 (96.5%)
Foster parent	4 (3.5%)
Educational level of mother	
Some high school or less	16 (13.9%)
High school diploma	36 (31.3%)
Junior college diploma	28 (24.3%)
University degree	35 (30.5%)
Family income (n = 111) (\$Canadian)	
0-\$19999	22 (19.8%)
\$20000-\$39999	28 (25.2%)
\$40000-\$59999	35 (31.5%)
> \$60000	26 (23.5%)
Services ever received	
Physiotherapy	
Public	56 (48.7%)
Private	6 (5.2%)
Both	3 (2.6%)
Never been referred	50 (43.5%)
Occupational therapy	
Public	98 (85.2%)
Private	6 (5.2%)
Never been referred	11 (9.6%)

WeeFIM Subscales (n=115) Quotients	Mean (SD)	Range
Self-care	66.3 (21.0)	18.6 - 137.0
Mobility	81.1 (22.4)	15.1 - 131.0
Cognition	66.9 (18.1)	28.1 - 148.4
Total	72.2 (15.3)	19.8 - 108.2
PedsQL4.0 Subscales (n=113)		
Physical Health Summary Score	77.9 (21.8)	3.1 - 100.0
Psychosocial Health Summary Score	69.3 (15.5)	27.5 - 100.0
Total	72.7(15.7)	29.2 - 100.0

WeeFIM	PedsQL4.0		
	Physical Health	Psychosocial Health	Total
Self-care	$r_s=0.28^*$	$r=0.25$	$r=0.35^*$
Mobility	$r_s=0.29^*$	$r=0.25$	$r=0.42^*$
Cognition	$r_s=0.05$	$r_s=0.03$	$r_s=0.04$
Total	$r_s=0.29^*$	$r=0.25$	$r=0.39^*$

r = Pearson correlation coefficient

r_s = Spearman's rho

* Coefficients significant at $p \leq 0.05$

Table 4. Comparison of WeeFIM and PedsQL4.0 scores by patient – parent – service related factors									
Factors	Patient related	WeeFIM: Means of Quotients				PedsQL: Means			
		Self Care	Mobility	Cognition	Total	Physical	Psycho-social	Total	Total
Diagnosis	GDD	68.9	86.3*	66.8	74.9	82.2	69.4	74.5	
	non GDD	61.3	72.7*	68.1	67.8	73.0	69.7	70.9	
Sex	Males	64.9	81.9	65.4	71.5	80.5 [†]	68.7	73.5	
	Females	69.5	79.1	70.2	73.7	72.1 [†]	70.6	71.1	
Age	> 3.6 years	71.9 [†]	89.0*	64.2	75.8 [†]	80.0	68.2	72.8	
	< 3.6 years	60.8 [†]	73.3*	69.5	68.7 [†]	75.9	70.3	72.6	
Parent related	Income	<20,000	64.7	78.3	62.5	68.3	70.6	66.2	67.8
		20-60,000	66.3	82.4	65.8	72.4	82.6	71.4	75.9
		>60,000	66.2	79.9	73.8	74.8	73.3	67.1	69.4
Maternal Education	≤ high school	68.8	83.7	66.8	73.5	81.6	70.6	75.0	
	> high school	63.3	78.2	67.6	70.7	75.9	68.6	71.4	
Services									
Referred to OT	Yes	65.7	79.9	67.3	71.6	77.9	69.3	72.7	
	No	72.6	84.9	63.5	75.9	80.0	67.9	72.5	
Received OT	Yes	65.5	80.0	66.9	71.6	77.4	68.9	72.3	
	No	81.8	99.4	66.5	83.5	86.5	77.0	80.9	
Referred to PT	Yes	63.4	75.5	72.2	70.0	63.8*	63.7	63.7*	
	No	68.5	83.9	63.2	73.4	87.9*	72.9	78.9*	
Received PT	Yes	61.3	75.3*	69.5	69.3	69.8*	66.9	68.0*	
	No	73.4	89.1*	63.3	76.2	88.9*	72.6	79.1*	

* p < 0.001 † p < 0.01 ‡ p = 0.0554

GDD = global developmental delay

PT = physical therapy

OT = occupational therapy

4.2 The Influence of Age, Diagnosis and Severity of Disability on the Waiting Time for Rehabilitation Services for Preschool-Aged Children with Physical Disabilities

**Lisa Grilli^{1,2,3} PT BSc, Debbie Ehrmann Feldman^{1,2,3,4} PT, PhD,
Bonnie Swaine^{1,2} PT, PhD, Julie Gosselin^{1,5} OT, PhD, François Champagne⁴
PhD, Raynald Pineault⁴ MD PhD**

1 Université de Montréal, École de réadaptation

2 Centre de recherche interdisciplinaire en réadaptation (CRIR)

3 McGill University Health Center: Montreal Children's Hospital

4 Université de Montréal, Groupe de recherche interdisciplinaire en santé (GRIS)

5 Centre de recherche Hôpital Sainte-Justine

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Corresponding Author:

Lisa Grilli BSc
McGill University Health Center
Montreal Children's Hospital
Physiotherapy Department
2300 Tupper
Montreal (QC) Canada H3H 1P3
Tel: (514) 412-4407
Fax: (514) 412-4398
Email: [REDACTED]

4.2.1 Abstract

BACKGROUND: Early intervention of therapy for children with physical disabilities may improve functional outcomes. However, access to pediatric rehabilitation services can be problematic.

OBJECTIVES: To describe waiting time to receive physical therapy (PT) and occupational therapy (OT) services at pediatric rehabilitation centers for young children with physical disabilities. To examine factors associated with waiting time to these services.

DESIGN: Prospective cohort

SUBJECTS: All children with physical disabilities, aged 6-72 months, referred in 2002-2004 from the Montreal Children's Hospital and Sainte-Justine Hospital to pediatric rehabilitation centers.

MEASURES: Data on date of referral, age, gender, and diagnosis were obtained from the hospital computer databases. Data on date of first PT or OT appointments at the rehabilitation center, family socio-demographics, and disability severity (Functional Independence Measure for Children) were obtained during parental interviews.

RESULTS: Parents of 201 children with physical disabilities referred to rehabilitation centers participated in a series of interviews from time of referral to time of first PT or OT rehabilitation appointment. Half of our sample waited more than 7 and 13 months for PT and OT services, respectively. Shorter waiting time was associated with younger child's age (adjusted HR = 0.5; 95% CI = 0.36 – 0.82) and referral to one particular rehabilitation center (adjusted HR = 3.0; 95%CI = 1.8-4.8).

CONCLUSION: Children with disabilities experience long waiting times before receiving appointments for PT and OT rehabilitation services. Younger children wait less time. One rehabilitation center has significantly shorter waiting times than the other four in our study.

4.2.2 Introduction

Health services research regarding the needs, delivery and utilization of pediatric rehabilitation is an emerging field of interest given the increase in infant survival and subsequent growing focus on childhood disabilities (1-5). Childhood disability has a substantial impact on the health-care system since children who have restrictions in activities have an elevated use of health care services, including rehabilitation (6). Early identification of children with physical and developmental disabilities is crucial to ensure that appropriate intervention is instituted as soon as possible, to allow children to develop to their full potential, maximize their function and prevent further disabilities (2,4,7-12). Conversely, barriers that limit accessibility, such as long waiting times for appropriate rehabilitation services could have a significant impact on a child's functional and health status.

In the early 1990's, in Quebec, services were reformed to better meet the needs of families of children with disabilities. Pediatric out-patient rehabilitation services for children under 6 years of age were no longer provided at acute care pediatric hospitals; children who required these services had to be referred to specialized pediatric rehabilitation centers. Although, the intent was to implement comprehensive coordinated services within the community (7,13,14) this was not readily achieved (1, 13,15). The problem of accessibility to pediatric rehabilitation services affects not only Quebec residents but it is also an important issue for many elsewhere (4,10,11,16). One factor associated with earlier receipt of rehabilitation services is younger age of the child (4,10,17,18). Generally, very young children who are referred for rehabilitation are more likely to have an identifiable pathologic condition (e.g. genetic syndrome, seizure disorder) or risk condition such as prematurity. Older children are more likely to be referred for problems related to developmental delay (17). Severity of the disability may be another factor influencing accessibility. For example, children may be denied

access to rehabilitation services provided by Health Maintenance Organizations (HMO) if the child cannot improve significantly over a short period of time, which is often the case among children with severe disabilities (16). In other cases, the more severe a physician perceives a child's disability, the more likely the child may be referred to physiotherapy (PT) (19). Furthermore, diagnosis may also influence referral. Pediatricians may be reluctant to refer children with developmental delays and those they deem to have less severe disabilities to early intervention services (17). Thus it is unclear whether severity enhances or impedes access to rehabilitation.

Two studies have explored service delivery (by measuring waiting times or service utilization patterns) for pediatric rehabilitation services in Montreal. These studies however were limited to only one of the two pediatric tertiary care hospitals, and used a cross-sectional design (4,10). Feldman et al. (10) included school-aged children who often use resources allocated by the school system as opposed to rehabilitation centers. Majnemer et al. (4) included children with pervasive developmental delay (autistic spectrum disorders) receiving services at centers specialized in treating intellectual disability. Neither study measured disability in a consistent or standardized fashion.

Our study has tried to address some of the limitations of previous studies. We followed a prospective cohort of preschool-age children with physical disabilities, recruited from the two tertiary care pediatric hospitals in Montreal, and measured their performance with a well accepted functional measure. The objectives of this study were to describe waiting time to receive physical therapy (PT) or occupational therapy (OT) services at rehabilitation centers for preschool-aged children with physical disabilities, and to examine the factors associated with waiting time, including the child's age, diagnosis and severity of the physical disability. We hypothesized that access to rehabilitation was higher for children

who were younger, within specific diagnostic groups and those with more severe disabilities.

4.2.3 Methods

4.2.3.1 Study population

The study population included all preschool-aged children referred to out-patient PT or OT at five local rehabilitation centers over an 18-month period (September 1, 2002 to February 28, 2004) from the two tertiary care pediatric hospitals in Montreal. Children with purely cognitive problems were excluded, as were those who resided further than 50 kilometers from the city. Parents had to have adequate comprehension of English or French to participate. In Quebec, public rehabilitation services (including PT and OT) are covered for all residents by the provincial public health insurance plan although parents may pay for any desired supplemental private services.

4.2.3.2 Referral sites

There are five out-patient rehabilitation centers in the Montreal area where children with physical disabilities can receive services. The main factor determining place of referral is the family's residence.

4.2.3.3 Data collection

Recruitment: Participants were identified from the hospital central referral databases. These computerized databases provided the following information: the name of the rehabilitation center where the child was being referred, the date of referral to the rehabilitation center, demographic data about the child and family, and the child's diagnosis. At the time of referral, parents were contacted by telephone and asked to participate in the study, which included a series of interviews. The initial interview, conducted within four weeks of hospital

referral, was a face-to-face interview with one of the child's parents, at the family's residence or the hospital, whichever was most convenient for the family. The follow-up interviews were all administered by telephone to the same parent at three-month intervals following the initial interview or until their child received PT or OT services at the rehabilitation center, at which point a final interview was conducted. The interviews were conducted by one of three research assistants, who were trained using structured questionnaires and standardized measures. The study protocol was approved by the Research Ethics Committees of the two hospitals. Written parental informed consent was obtained during the initial interview.

Interviews: The interviews included several questionnaires. First, a structured questionnaire that had been pretested in a pilot study (10) was administered. This consisted of questions regarding district of residency, mother's educational level, family income, and receipt of rehabilitation services (PT and/or OT) including public and private sources. Next, the Functional Independence Measure for Children (WeeFIM) was administered. The WeeFIM is a valid and reliable tool used to determine the level of independence and the need for assistance as a result of disability, when performing basic daily skills (20-25). Scoring consists of calculating quotients for the three subscales (self-care, mobility, cognition) and for the total score, with lower quotients representing higher levels of disability (26). A quotient of 75 or higher represents a mild disability, a quotient between 50-75 represents a moderate disability and that below 50 represents a severe disability (27).

4.2.3.4 Analysis

Analysis consisted of descriptive statistics to summarize the characteristics of the cohort: means and standard deviations for continuous variables and proportions for categorical variables. Survival analysis (Cox regression) was used

to determine the association between earliest time to rehabilitation (i.e. waiting times for PT or OT) and the various factors (28,29). For the purpose of this study, we dichotomized maternal education at the college level, age by the median (29.6 months), and diagnosis as global developmental delay (GDD) or non-GDD. Since one of the rehabilitation centers had significantly shorter waiting times than the others ($p = 0.003$), we dichotomized the variable center with the other four centers grouped together. Disability severity was classified as a trichotomous variable using mild, moderate, and severe cut-offs for WeeFIM total score quotients (as established by Lowen et al.) (27), therefore two design variables were created with mild severity as the reference group. All children still waiting for services on November 30, 2004 were censored.

SAS version 8.02 (SAS Institute, Cary, NC) was used to perform the analyses.

4.2.4 Results

Cohort: There were 282 parents who met the inclusion criteria for our study, of whom 205 agreed to participate (response rate = 72.7%). Among these, four were later excluded as their diagnosis changed from global developmental delay to autism spectrum disorder and they no longer met the inclusion criteria. The characteristics of the non-participants ($n=77$) were similar to those of the participants ($n=201$) in terms of the child's age ($p=0.12$), gender ($p=0.89$) and diagnosis (proportion of children with developmental problems ($p=0.13$)). Characteristics of the cohort are presented in Table 1. Out of the 201 participants, 131 were referred to PT, 193 were referred to OT, and 122 were referred to both PT and OT at the rehabilitation center.

More of the older children were diagnosed with global developmental delay (GDD), whereas more of the younger children tended to have an identifiable pathologic diagnoses or risk condition, such as, genetic syndromes, neonatal seizures, neurological conditions, spina bifida, cerebral palsy and prematurity. In fact, 62.1% (54 out of 87) of children under 24 months of age had a diagnosis other than global developmental delay (non-GDD) whereas only 23.1% (15 out of 65) of children older than 48 months of age had a non-GDD diagnosis (Figure 1). Univariate analysis (unpaired t-test) revealed that the child's age and diagnosis were correlated. Those with a diagnosis of GDD were older (mean age = 36.8 ± 15.4 months), whereas those with a diagnosis of non-GDD were younger (mean age = 24.3 ± 15.0 months; $p < 0.001$).

In terms of disability severity, as measured with the WeeFIM, 103 (51.2%) children had mild functional disabilities, 82 (40.8%) had moderate functional disabilities, and 16 (8.0%) had severe functional disabilities. Figure 2 represents the distribution for functional disability severity by age group and indicates that those over 48 months of age were referred mainly with mild disability severity.

Among the 125 children who did receive PT or OT services within the study period, the mean waiting time from date of referral at the hospital to the child's first PT or OT appointment at the rehabilitation center was 6.1 ± 4.6 months (median time = 5.7, IQR = 4.1), and 6.8 ± 4.5 months (median time = 5.9, IQR = 4.9), respectively.

For the survival analysis, 76 children were censored, 49 of whom were still waiting for services at the rehabilitation center. Twenty-seven were censored for other various reasons: two families moved out the province, one child passed away during the course of the study, 10 parents dropped out of the study due to

dissatisfaction with waiting times or no longer interested in participating in the study, 9 families could not be contacted during follow-up, and 5 children no longer required services at the rehabilitation center.

Graphical representation of the waiting times for children to receive PT or OT services at the rehabilitation centers is shown in Figure 3. Fifty percent of children who were initially referred to PT (65/131) waited longer than 7 months for their first appointment, and 50% of the children who were initially referred to OT (96/193) waited greater than 13 months for their first appointment at the rehabilitation center.

The crude and adjusted hazard ratios (95% confidence intervals) are described in Table 2. Children older than 29.6 months (median age) waited approximately twice as long to receive rehabilitation services (adjusted Hazard Ratio (HR) = 0.54; 95% CI = 0.36–0.82) than children less than 29.6 months.

Although children with a diagnosis of GDD had a significantly longer waiting time than children with a non-GDD diagnosis in the survival analysis model without covariates (crude HR = 0.64; 95% CI = 0.45–0.91), the adjusted HR was not statistically significant (adjusted HR = 0.73; 95% CI = 0.49–1.08; $p=0.11$). Families living in the city waited less for PT or OT services than those living in the suburbs, (crude HR = 1.62; 95% CI = 1.10–2.36), however, again, this difference was no longer statistically significant after adjustment for demographic variables, diagnosis and disability severity (adjusted HR = 1.0; 95% CI = 0.61–1.60). Children referred to one rehabilitation center in particular had a significantly shorter waiting time than those referred to the other four centers (adjusted HR = 3.0; 95% CI = 1.83 – 4.79). Maternal education or severity of the child's functional disability did not appear to be associated with waiting time.

4.2.5 Discussion

Parents of preschool-aged children with physical disabilities were found to experience lengthy waits for rehabilitation services. Half of those referred to PT waited longer than 7 months and half waiting for OT waited more than 13 months. Of those that did receive services during the study period, the average wait for PT and OT were 6.1 months and 6.8 months, respectively – higher than the 4.3 and 5.2 months reported five years earlier (10). Lengthy waits for rehabilitation services may have a detrimental impact for attainment of primary pediatric rehabilitation goals, which include maximizing function and minimizing disabilities. Despite provincial governmental recommendations for implementation and assurance of coordinated pediatric rehabilitation programs following concerns (of reported long waiting times) raised by the Regional Health Board in the early 1990's (7,13), our findings suggest that in the past several years there has been an increase rather than a decrease in waiting times for delivery of PT and OT services in rehabilitation centers. It is imperative that further evaluation of service delivery at local rehabilitation centers be conducted to identify exactly why the waiting times are so long.

Younger children waited less time for services at the rehabilitation center, which is consistent with the literature (4,10,17,18). These results suggest that coordinators at rehabilitation centers may prioritize younger children to ensure the greatest benefits from rehabilitation intervention since it is believed that early identification and intervention are believed important (2,7,9,12,30-32) in order to minimize disabilities and maximize outcomes. Perceived diagnostic certainty by physicians has been shown to influence referral of children to rehabilitation (4,19,32). For instance, one study found that the higher the certainty that a child had cerebral palsy, the higher the odds of referral to rehabilitation (19). Physicians may recognize that children have a developmental disability, but do not refer them to rehabilitation (7,17,19,30). Others may refer children with

developmental difficulties for specialty evaluations for etiologic determination and confirmation of diagnosis, which in turn can delay rehabilitation intervention since in most cases rehabilitation is prescribed only after medical evaluation has been completed by all specialists (31,32). Once referred, waiting time is further compounded by administrative delays such as the discharge coordinators actually sending out the referral along with the required supported documentation. Young children with developmental delays have been known to receive services at the tertiary care hospital rather than at the rehabilitation center as stipulated by the governmental reforms, raising concerns of over-utilization of services at tertiary care facilities while awaiting services at the rehabilitation centers (4). This affects the system by increasing waits to be seen at the hospital further delaying the referral process to the rehabilitation centers.

A child's functional level is considered the most important factor in the clinical decision-making regarding PT service delivery in schools for children (33). However, we found no differences in waiting times between children who were identified as having moderate or severe functional disabilities and those who had mild disabilities. Our initial hypothesis was that children with mild disabilities would have waited longer for rehabilitation services, since there may be a propensity towards providing services sooner to children with severe disabilities (19). Our results may reflect a phenomenon whereby those who are diagnosed at a younger age may have a more severe degree of disability. We performed separate survival analysis for those less than 29.6 months and those over 29.6 months, and did not find disability severity to be a predictor of waiting times in either of the age strata, although there was a tendency towards shorter waiting time for the younger children with moderate disabilities ($p=0.06$). Further, the WeeFIM may not be sensitive enough to differentiate the levels of functional disability severity for younger children (unpublished data from the authors of the present study) and therefore may account for the lack of significant

differences between waiting times for severity groups. Chen et al, studied functional outcomes in children and restricted their samples to children older than 12 months, since younger children are dependent on almost all WeeFIM items (34).

Families referred to one rehabilitation center waited 1/3 the time as those referred to the other centers. This result can be partly explained by the fact that the other rehabilitation centers provide their service delivery by thematic programs as opposed to the availability in the therapists' schedules. Implementation of services by programs may not work well for children with a diagnosis of global developmental delay, as they don't fit well into a defined diagnostic group. There may be a need to re-examine policies, re-organize the referral process and also re-evaluate the efficacy of current service delivery in order to best meet the needs of children with physical disabilities and their families. Alternative models of service delivery may be considered. For example, intermittent intensive therapy characterized by short intensive therapy periods followed by long rest periods has been shown to have greater benefits than conventional therapy in children with cerebral palsy (35). More research evaluating this and other models of service delivery in children is indicated. Another possibility is that resources in the various centers may not be proportional to their needs (example: not enough therapists to service the referred patients). We did not evaluate this aspect.

4.2.6 Limitations

Our study relied on parents as informants regarding receipt of rehabilitation services for their child. However, the design was prospective and we followed families at three-month intervals, potentially minimizing problems with recall.

Also, as mentioned previously, the WeeFIM measure of functional disability may not have been sensitive enough to determine the level of disability for the younger children. If that is the case, this lack of sensitivity may have precluded our finding an association between severity and waiting time.

4.2.7 Conclusion

Our results demonstrate that older preschool-aged children have waits longer than 6 months for rehabilitation services. The findings may support the need to augment PT and OT resources in pediatric rehabilitation centers. Moreover, there may also be a need for the development of alternative models of care delivery for children with disabilities in order to provide timely rehabilitation to maximize the children's functional abilities and well-being. Emphasis on implementation of new policies in order to improve accessibility of services to physically disabled children is extremely important as this may prevent repercussions later during the school years.

4.2.8 References

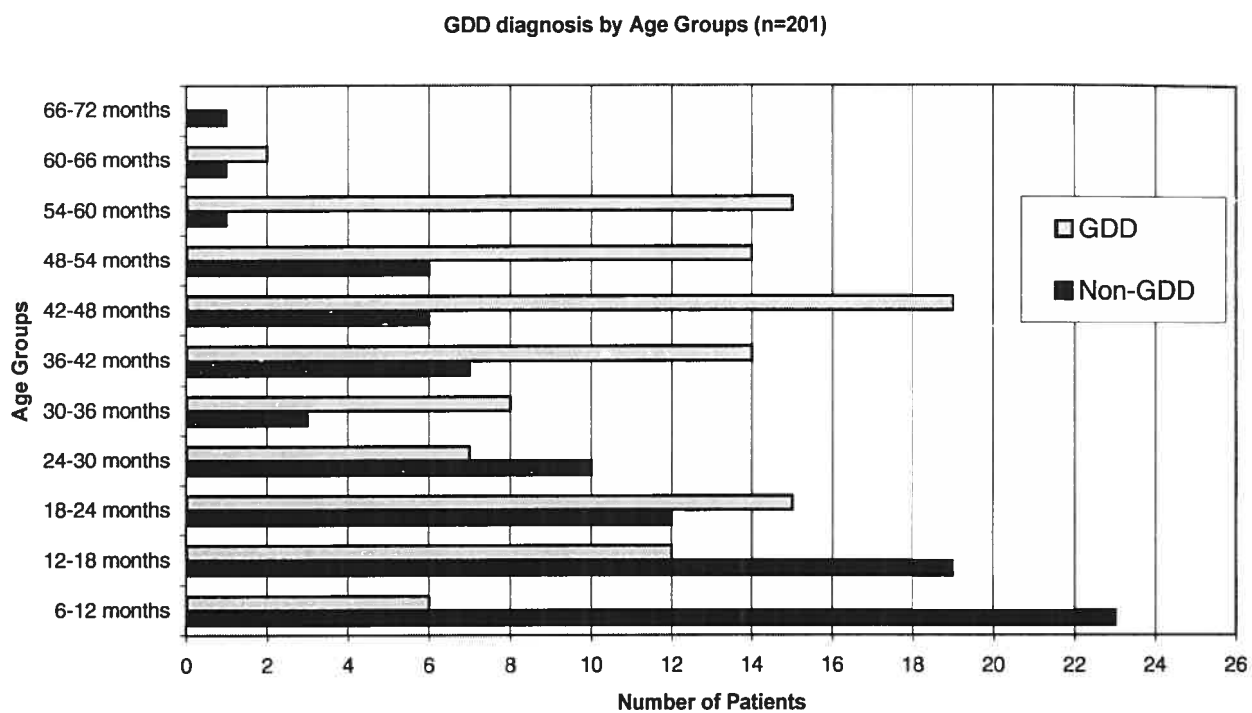
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Table 1. Frequency distribution of demographic data for children with physical disabilities (n=201)	
Mean Age (SD)	31.2 (16.4) months – range of 6.8 – 69.4
Gender (% Male)	131 (65.2%)
Diagnosis	
Global developmental delay	87 (43.3%)
Prematurity	25 (12.4%)
Seizures/neurological conditions	24 (12.0%)
Spinal bifida	3 (1.5%)
Trisomy 21	10 (5.0%)
Other syndromes	27 (13.4%)
Cerebral palsy/hypotonia	25 (12.4%)
Educational level of mother	
Completed high school or less	80 (39.8%)
Junior college diploma or higher	121 (60.2%)
Family income (n = 192) (\$Canadian)	
\$0-\$19999	45 (23.4%)
\$20000-\$39999	43 (22.4%)
\$40000-\$59999	51 (26.6%)
\$60000-\$79999	24 (12.5%)
\$80000 and above	29 (15.1%)
Place of residence	
City dweller	126 (62.7%)
Suburb	75 (37.3%)
Referred to rehabilitation services	
Physiotherapy (PT)	131 (65.2%)
Occupational therapy (OT)	193 (96.0%)
Both PT and OT	122 (60.7%)

Figure 1. Diagnosis (GDD, non-GDD) by Age Groups (n=201)

GDD = global developmental delay

Figure 2. WeeFIM severity by Age Groups (n=201)

WeeFIM Severity by Age Groups (n=201)

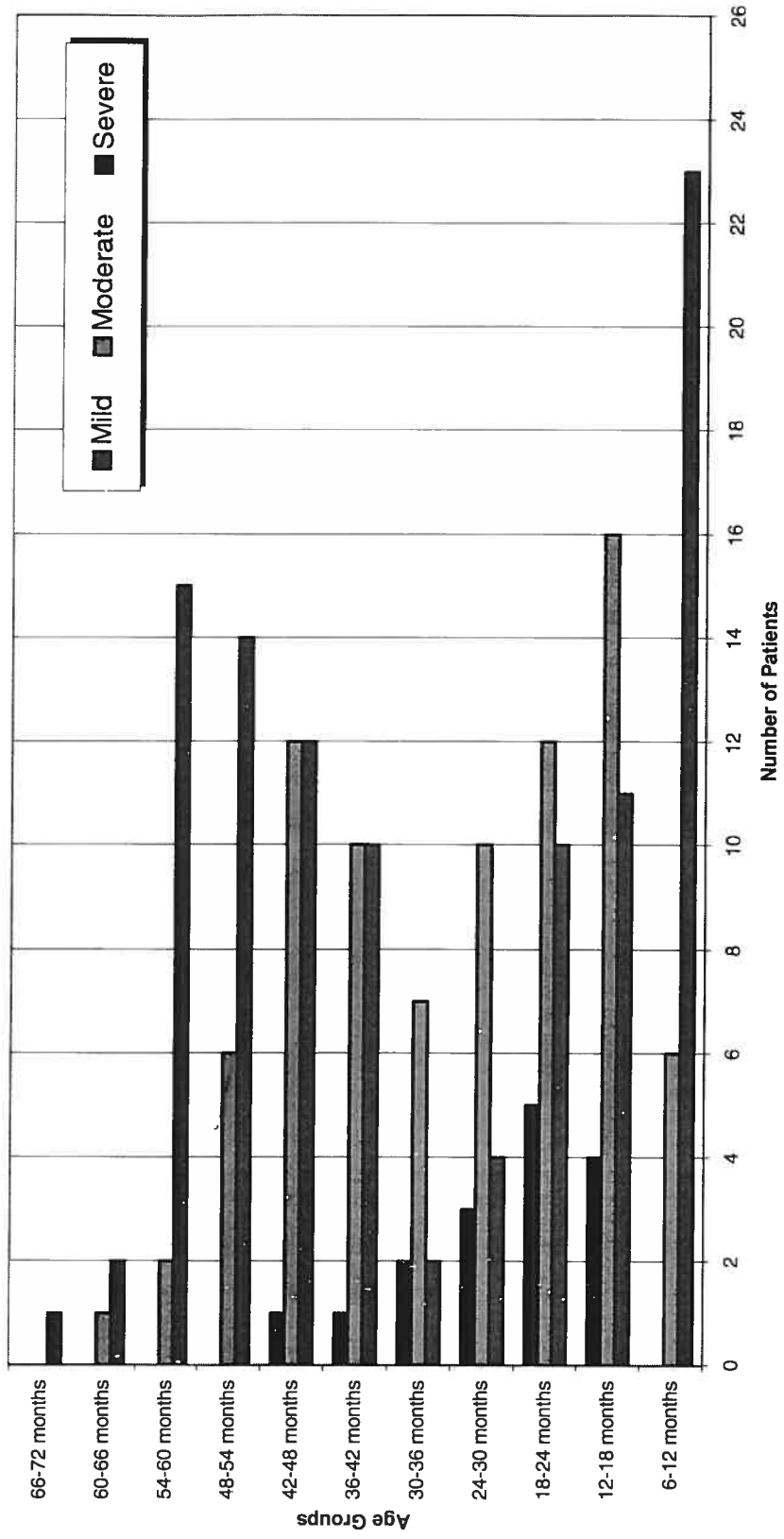


Figure 3. Survival analysis for first PT and OT appointment at the rehabilitation center (in months)

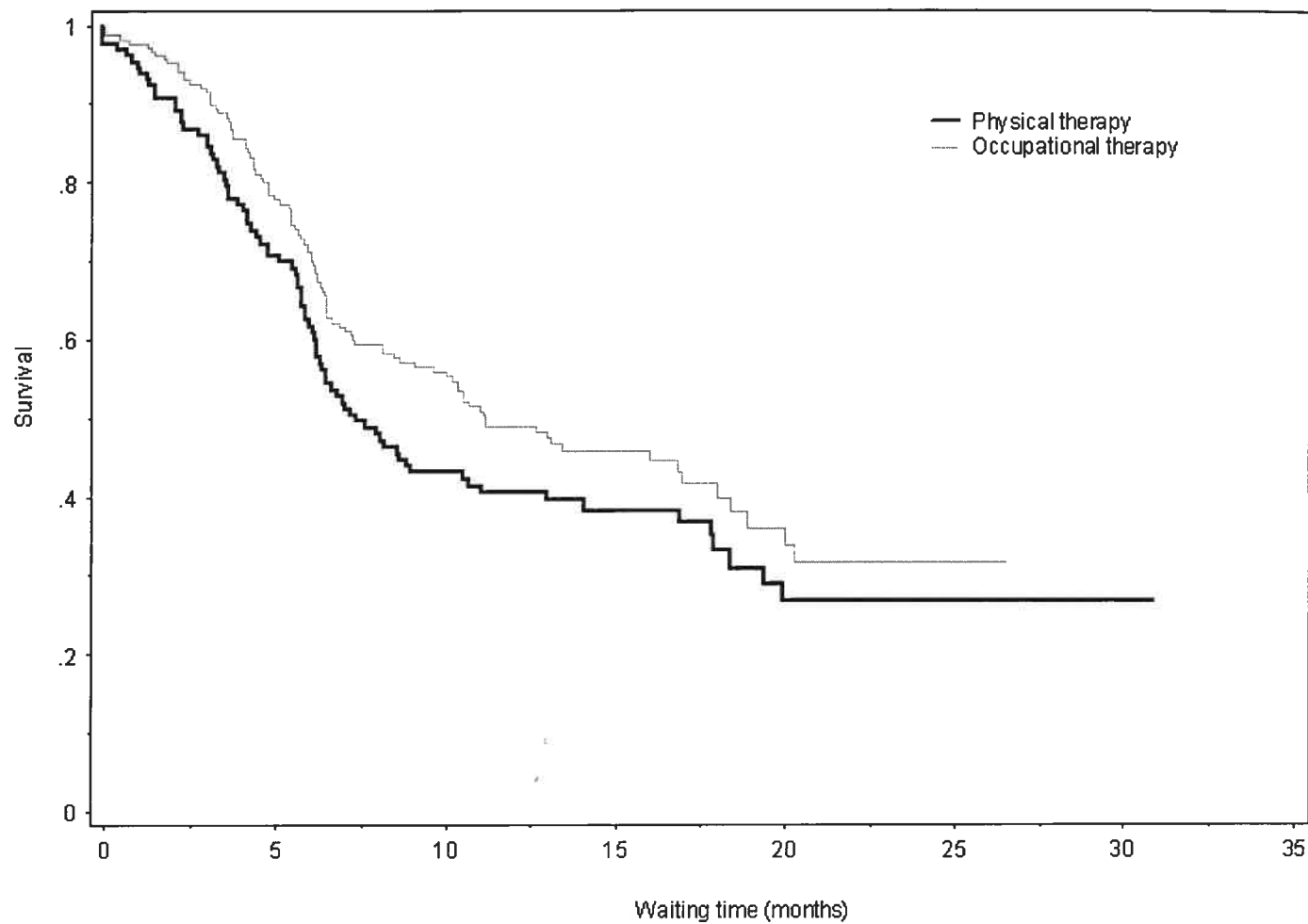


Table 2. Factors associated with lower waiting time to rehabilitation center		
Factors	Crude HR (95% CI)	Adjusted HR (95% CI)[‡]
Maternal education (>College)	1.17 (0.81 - 1.70)	1.04 (0.72 - 1.51)
Rehabilitation center (1)	2.29 (1.59 - 3.29)*	2.96 (1.83 - 4.79)*
Age (> median; 29.6 months)	0.64 (0.45 - 0.91) †	0.54 (0.36 - 0.82)**
Place of residence (city)	1.62 (1.10 - 2.36) †	1.0 (0.61 - 1.60)
Diagnosis (GDD)	0.64 (0.45 - 0.91) †	0.73 (0.49 - 1.08)
Disability Severity (WeeFIM moderate)	0.79 (0.55 - 1.14)	0.74 (0.50 - 1.09)
Disability Severity (WeeFIM severe)	1.5 (0.86 - 2.63)	1.08 (0.60 - 1.97)

[‡]Adjusted for the covariates in the table

* p < 0.0001

** p = 0.004

† p = 0.01

†† p = 0.02

HR: hazard ratio

HR is the ratio of the measure of 'risk' of transfer to rehabilitation at a point in time

CHAPTER 5 - DISCUSSION

The main results of this study were discussed in the two manuscripts presented in Chapter 4. The present chapter will therefore include a general discussion of the results presented with an emphasis on how a child's age, diagnosis and severity of disability influence waiting times to receive rehabilitation services for young children with physical disabilities. Finally, we discuss possible strategies that may be used to improve waiting times for children with physical disabilities. Other possible factors not investigated in the study that may influence waiting times to receive rehabilitation services are also discussed.

Waiting times for PT and OT services

In the present study, preschool-aged children with physical disabilities experienced long waits for rehabilitation services. Half of those referred to PT waited longer than 7 months and half waiting for OT waited more than 13 months, corroborating our first hypothesis. Our findings suggest that since the Regional Health Board reported long waiting times in the 1990's (5, 8), there has been an increase, rather than a decrease, in waiting times for delivery of PT and OT services in rehabilitation centers in the Montreal area (9). Despite provincial governmental recommendations for implementation and assurance of coordinated pediatric rehabilitation programs following the Health Board's concerns, there appears to be a lack of improvement in the receipt of rehabilitation services for young children with physical disabilities at rehabilitation centers. Long waiting times for rehabilitation services may have a detrimental impact on the attainment of primary pediatric rehabilitation goals, including maximizing function and minimizing long-term disabilities. Furthermore, long waiting times to rehabilitation centers from tertiary care hospitals can result in the over-utilization of services at the tertiary care facility (10) and possibly lead to heavier therapist caseloads and poorer quality of care. Ultimately, this would increase waiting

times to be seen at the tertiary care hospital and delay the referral process to the rehabilitation centers. In addition, long waiting times may lead to parental dissatisfaction with the delivery of rehabilitation services which may deter optimal coping strategies and negatively affect the family's well being. Therapists need to guide, educate and support parents beginning at the evaluation session, continuing during the transfer process, and until receipt of PT and OT services at the rehabilitation center.

Child's age and diagnostic certainty

In the present study, we determined that younger children and those with a specific diagnosis waited less time to receive rehabilitation services than older children with a nonspecific diagnosis of GDD. Univariate analysis revealed that the child's age and diagnosis were correlated. Those with a diagnosis of GDD were older, whereas those with a diagnosis of non-GDD (i.e. an identifiable pathologic diagnosis or risk condition) were younger. On the other hand, children with GDD of unspecified etiology may not be identified early enough (19, 34). This raises concerns since early identification of children with developmental delay is considered important in order to fully benefit from rehabilitation services which aim to maximize a child's functional outcome (6, 19, 20, 22, 34, 64). The lack of early identification of children with developmental problems may be a result of the way pediatricians are assessing the development of children in their practice, using *developmental surveillance* rather than *developmental screening* (34). Surveillance is endorsed by the American Academy of Pediatrics, Committee on Children with Disabilities as the means of identifying children with developmental disabilities (18, 19, 34), however it may be important to re-examine whether, in fact, this is best practice. This is important since children diagnosed with specific conditions or "at risk" profiles (example: prematurity) have shorter waiting times for early intervention services (8, 10, 25, 34, 71).

Older preschool-aged children do not appear to be receiving services at the rehabilitation center in a timely manner. There is a possibility that these children may forfeit services at the rehabilitation center, if while waiting they enter the educational system. Not only will the families of these children wait in vain for services at the rehabilitation center, but also there is a high probability that once the children enter school, they will be put on at the end of another waiting list at the school, that will more than likely further delay their receipt of rehabilitation services.

Severity of child's functional disability

In the present study, we did not find that the severity of a child's functional disability influenced waiting times to receive PT or OT services at a rehabilitation center. Our initial hypothesis was that children with mild disabilities would wait longer for rehabilitation services, since there may be a propensity towards providing services sooner to children with severe disabilities (23). Possibly those who are diagnosed at a younger age may have a more severe degree of disability. However, the WeeFIM may not be sensitive enough to differentiate the levels of functional disability severity for younger children. This may account for the lack of significant differences between waiting times across severity groups. Chen et al, who studied functional outcomes using WeeFIM scores restricted their sample to children older than 12 months, since younger children are dependent on almost all WeeFIM items (69). Therefore, the lack of sensitivity of the WeeFIM to determine the severity of the disability may have precluded our finding an association between severity and waiting time.

In addition, the lack of association between severity and waiting time may be partly explained by the fact that referrals to rehabilitation centers are primarily made with respect to the child's diagnosis, rather than the level of severity of the

child's functional disability. Delivery of services at these rehabilitation centers is discussed in the next section.

Service delivery

Interestingly, in the present study, the waiting time to one of the rehabilitation centers was significantly shorter (1/3 the time) than that of the other centers. This result may be partly explained by differences in service delivery among the centers. The rehabilitation centers with longer waiting times had restructured their service delivery by thematic programs. This is in contrast to those without thematic or diagnostic programs where children are seen based on availability in the therapists' schedule. Although thematic programs have certain advantages, such as higher therapist specialty, better intervention specificity, greater opportunity for parents to find support from other parents of children with similar disabilities, they may cause longer waiting times by virtue of the fact that certain programs will be full while others will have room to accept other patients. The availability of services is dependent on unfilled space in the required program. We did not measure resources versus needs.

At present, younger children and those with a specific diagnosis appear to get priority for rehabilitation services. There may be some justification for this. First, as mentioned above, early intervention to younger children may facilitate and maximize the children's outcome potential. Second, early intervention needs for children with specific diagnosis (such as spina bifida, neonatal seizures and cerebral palsy) have been identified and are recognized as beneficial. Third, implementation of services by programs may not work well for children with a diagnosis of GDD. GDD is not a specific diagnosis but is representative of a heterogeneous population of children who have abnormal development as compared to age-appropriate, standardized norms. Delay is not necessarily

uniform across the different domains of development (such as fine motor, gross motor, speech and ADL), therefore it may be more difficult to implement a formal program for these children.

Another challenge of service delivery relates to whether and how to render services to those children with mild functional limitations who may have some decreased level of activity and participation and possibly a lower quality of life. Although these children may not get priority for rehabilitation services, since they tend not to require intensive rehabilitation, they still need some form of monitoring or counseling to ensure successful progression of developmental milestones and integration into the school setting. Limitations may become more apparent with age as the children interacts more within his/her community. Therefore, administrators and therapists at rehabilitation centers need to re-evaluate their role in promoting optimal health for all children with disabilities. More research needs to be conducted to determine the efficacy of service delivery and outcomes of pediatric rehabilitation interventions (69). Alternative models may need to be developed.

Implementation of alternative models of service delivery for children with physical disabilities may ensure that children get the appropriate services within a shorter waiting time than that found in our study. Alternative models of service delivery that go beyond the conventional therapeutic approach towards a holistic community-based approach, may reduce waiting times for receipt of rehabilitation services by better addressing the needs of children with physical disabilities within their society. One-to-one PT and/or OT interventions may not be the best choice of therapy for all children with physical disabilities. Increased parental participation in their child's rehabilitation, as well as increased support programs to families of children with physical disabilities may need to be implemented in order to facilitate the attainment of the best outcome possible for both the child

and family. Parental involvement is of utmost importance in a child's rehabilitation (5, 6, 25, 28). Parents who are more knowledgeable help maximize the developmental performance of their children (6) and tend to cope better (9, 19). The Life Needs Model of Pediatric Service Delivery proposed by King et al. (28) provides a guide for a comprehensive holistic approach whereby all professionals implicated in the service delivery of the child can work together to determine service priorities to best meet the complex needs of children, families, as well as communities.

Other authors have studied alternative models specifically addressing PT and OT interventions (70, 72). Trahan and Malouin showed that motor performance improved when using short intensive PT periods followed by longer rest periods in children with severe cerebral palsy (70). The authors concluded the need to reconsider the way rehabilitation programs are organized, as more does not seem better than less (70). Dreiling and Bundy determined that a consultative model was equally effective as a direct-indirect model in meeting OT therapeutic objectives for preschool-aged children with mild motor disabilities (72). Kaminker et al. suggested that pediatric PT's recognition of the benefits of peer modeling, and also the size of the caseloads, may affect their decision to advocate group services as opposed to a traditional individually-based intervention. The authors also determined that the most prevalent choice for physical therapists working in the school-setting (including 3 to 5 year olds) is a model which includes both integrated and isolated interventions (68). Policy makers, administrators and therapists in rehabilitation centers need to re-evaluate policies and develop new ones to ensure best evidence-based practice.

Other factors

Despite the mandate of tertiary care hospitals to refer children with physical disabilities who require long term rehabilitation as soon as possible to

rehabilitation centers, consideration of the child's and family's well-being are paramount. Therapists need to empathize and use good judgement regarding the best time to discuss with parents referral to the rehabilitation center. Some parents may require several visits before being able to discuss their child's transfer needs. Therapists must exercise good judgement when dealing with parents at this delicate time in order to maximize cooperation and reduce potential negative reactions. Due to the complexity of factors that may affect waiting time for rehabilitation, more research on the impact of waiting times on family well-being is needed.

Quality of life and functional status

In this study, we found that quality of life, as measured by the PedsQL4.0 was weakly to moderately correlated to functional status, as measured by the WeeFIM in preschool-aged children with physical disabilities. More specifically, the subscales of both measures, which assess the physical dimensions of functioning, were more highly correlated than the other subscales. This would suggest that there is some congruence in these measures, thus corroborating our hypothesis.

Lower scores on the PedsQL-Physical Health Summary score and the WeeFIM mobility quotient were highly associated with receipt of PT services. This confirms our initial hypothesis that lower scores on these subscale domains may be indicative of children requiring PT intervention, since a primary goal for PT intervention is the acquisition of independent mobility. Delays in mobility translate to delays in gross motor milestones, which in turn are usually recognized at an earlier age than delays in other domains of development, such as self-care, cognitive and social functioning.

In our study, children with a nonspecific diagnosis of GDD scored higher on the WeeFIM-mobility subscale as compared to children with a specific

diagnosis. This was in agreement with our hypothesis. Items on the WeeFIM-mobility subscale cover basic mobility activities such as transfers, crawling, walking and stair climbing. Thus we would expect that children with a diagnosis of GDD would score higher since these children are generally diagnosed at a later age and they are usually independent ambulators, although qualitatively the walking pattern may not be mature or adequate for their age. On the other hand, children with specific diagnoses such as cerebral palsy, spina bifida or genetic syndromes would have difficulties performing basic motor developmental tasks.

Ethical considerations

The study protocol was approved by the Research Ethics Committees of both hospitals (Appendix I). Written parental informed consent (Appendix II) was obtained during the initial interview.

All files were kept in a locked filing cabinet at the university. Information entered in the computer was denominalized and subjects were classified by identification numbers only.

CHAPTER 6 – CONCLUSION

In conclusion, our study has shown that preschool-aged children with physical disabilities wait on average greater than 6 months to receive PT or OT services at local pediatric rehabilitation centers. Lengthy waits for rehabilitation services may have a detrimental impact for attainment of primary pediatric rehabilitation goals, result in the over-utilization of services at the tertiary care hospital, and may lead to parental dissatisfaction with the delivery of rehabilitation services.

Longer waiting time was associated with a child's older age and with a nonspecific diagnosis of GDD. Children with a specific diagnosis tend to be younger and have implicit criteria for receipt of rehabilitation services and are typically well-served. However, children with a less specific diagnosis such as GDD do not have well-defined criteria for receipt of services and no formal programs have been implemented for these children. The complexity of confirming a diagnosis such as GDD ultimately contributes to the waiting times to receive services, because most rehabilitation centers are based on thematic or diagnostic programs.

Interestingly, severity of the physical disability did not appear to influence waiting time. The WeeFIM (the tool we used to measure severity) may not be sensitive enough to differentiate the levels of functional disability severity for younger children and therefore may account for the lack of significant differences between waiting times for severity groups. Furthermore, referrals to rehabilitation centers are primarily made with respect to the child's diagnosis, rather than functional disability severity, which may partly explain the lack of association between severity and waiting time.

Parental perceived quality of life was weakly to moderately correlated with functional status among preschool-aged children with physical disabilities. Higher correlations were found between the PedsQL-Physical Health Summary

score and the WeeFIM selfcare and mobility quotients suggesting there is some congruence as both measure the physical dimensions of functioning.

Our study found that receipt of PT services was highly associated with the physical domains of functioning on both the WeeFIM and PedsQL4.0. Children with lower scores on these subscale domains have difficulties with mobility skills, which are generally indicative of the need for PT services.

Surprisingly, we did not find that higher maternal education was associated with higher functional status, which is found in other studies. This may be explained by the fact that the majority of children in our study had a diagnosis of GDD. Given the multidimensional nature of this diagnosis, diagnostic confirmation is more complex. In addition, formal programs are difficult to implement for children with a diagnosis of GDD since they represent a heterogeneous group with delays varying across the different domains of development. Parents of these children often encounter difficulties accessing early rehabilitation services in order to optimize their child's function, regardless of their level of education.

Clinical implications

The results of this study are important for pediatric rehabilitation services in Montreal. Long waiting times accentuate the need to re-evaluate the current method of service delivery and to possibly consider developing alternative models (example: more joint programs and partnership with communities) in order to best meet the needs of children with disabilities and their families. We need to broaden our thinking beyond the provision of traditional one-to-one treatment intervention, towards the provision of regular consultative services whereby the goal of rehabilitation is the integration of children in their communities. This would imply that therapists work in collaboration with daycare educators, teachers,

coaches and family members. There may be a need to augment PT and OT resources in rehabilitation centers to be able to handle the number of children needing rehabilitation services. Also, PT and OT will need to support and educate families appropriately as to how to access available resources for long-term needs.

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APPENDIX I
Ethics Committee Approval Certificate



June 27, 2002

Dr. D. Feldman
Physiotherapy Department
Montreal Children's Hospital

Re. MCH002-16 Access to rehabilitation for children with physical disabilities

Dear Dr. Feldman,

The research proposal entitled above received Full Board review at the convened meeting of the Montreal Children's Hospital Research Ethics Board on May 27, 2002, was found to be within ethical guidelines for conduct at the McGill University Health Centre, and was entered accordingly into the minutes of the Research Ethics Board (REB) meeting. At the MUHC sponsored research activities that require US federal assurance are conducted under Federal Wide Assurance (FWA) 00000840.

We are pleased to inform you that final approval for the clinical protocol, the informed consent documents and informed assent documents was provided on June 25, 2002.

All research involving human subjects requires review at a recurring interval and the current study approval is in effect until May 27, 2003. It is the responsibility of the principal investigator to submit an application for Continuing Review to the REB prior to the expiration of approval, to comply with the regulation for continuing review of "at least once per year".

Any further modification to the REB approved and certified consent document must be identified by a revised date in the document footer, and re-submitted for review prior to its use.

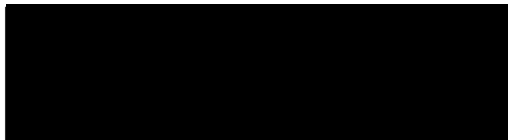
The Research Ethics Boards (REBs) of the McGill University Health Centre are registered REBs working under the published guidelines of the Tri-Council Policy Statement, in compliance with the "Plan d'action ministériel en éthique de la recherche et en intégrité scientifique" (MSSS, Qc) and the Food and Drugs Act (7 June, 2001), acting in conformity with standards set forth in the (US) Code of Federal Regulations governing human subjects research, and functioning in a manner consistent with internationally accepted principles of good clinical practice.



We wish to advise you that this document completely satisfies the requirement for Research Ethics Board Attestation as stipulated by Health Canada.

The project was assigned Montreal Children's Hospital REB Study Number MCH002-16 that is required as MUHC reference when communicating about the research. Should any revision to the research, or other unanticipated development occur prior to the next required review, you are obligated to report in writing promptly to the REB. It is not permitted by regulation to initiate a proposed study modification prior to REB approval.

Sincerely,,



*Jane McDonald, M.D., F.R.C.P©
Chair
Montreal Children's Hospital Research Ethics Board*

Cc: Danuta Rylski, MCH RI

LE COMITÉ D'ÉTHIQUE DE LA RECHERCHE

xc

Un comité de l'Hôpital Sainte-Justine formé des membres suivants:

Jean-Marie Therrien, président
Anne-Claude Bernard-Bonnin, pédiatre
Geneviève Cardinal, juriste
Daniel Caron, représentant du public
Hugues Charron, infirmier de recherche
Josette Champagne, hémato-oncologue
Françoise Grambin, représentante du public
Andréa Maria Laizner, scientifique
Suzanne Lépine, psychiatre
Lyne Pedneault, pharmacienne
Andrea Richter, scientifique
Chantal Van de Voorde, représentante du public


CENTRE
DE RECHERCHE
DE L'HÔPITAL
SAINTE-JUSTINE
*Le centre hospitalier
universitaire mère-enfant*

Pour l'amour des enfants

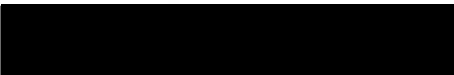
Approbation valide pour une durée d'un an

Les membres du comité d'éthique de la recherche ont étudié le projet de recherche clinique intitulé:

*Effects of Transfer Delay to Rehabilitation Services for Children /
L'impact du délai de transfert vers les services de réadaptation
pédiatrique pour les enfants.*

soumis par: *Julie Gosselin Ph. D., co-investigateur et Debbie Feldman, Ph.D. (principal investigateur). Autres co-investigateurs: Bonnie Swaine, Ph.D., François Champagne, Ph.D. et Raynald Pineault, Ph.D.*

et l'ont trouvé conforme aux normes établies par le comité d'éthique de la recherche de l'Hôpital Sainte-Justine. Le projet est donc accepté par le Comité.


Jean-Marie Therrien, Ph.D., éthicien
Président du Comité d'éthique de la recherche

Date d'approbation: 06 juin 2002

APPENDIX II
Consent Forms



Accès aux services de réadaptation chez les enfants atteints d'une incapacité physique

Groupe de recherche interdisciplinaire en santé (GRIS)
Université de Montréal
CP 6128 succursale Centre-Ville
Montréal (Québec) Canada H3C 3J7

Investigateur principal : D^r Debbie Feldman Université de Montréal (514) 343-6111, poste 1252
Hôpital de Montréal pour Enfants (514) 412-4407

L'Université de Montréal, en association avec l'Hôpital Ste-Justine et l'Hôpital de Montréal pour Enfants, réalise une étude sur les services de réadaptation à Montréal pour les enfants atteints d'incapacités physiques. Le but de notre recherche est de documenter les attentes, de cibler les problèmes pouvant survenir avec les services, et de trouver des stratégies pour améliorer l'accessibilité et la qualité des services de réadaptation destinés aux enfants.

Nous aimerions que vous répondiez à une entrevue individuelle, d'environ 30 minutes, portant sur vos expériences en tant que famille concernant le processus de réadaptation de votre enfant. Un interviewer communiquera avec vous par téléphone (entrevue de 15 minutes), à tous les trois mois, jusqu'à la prise en charge de votre enfant par le centre de réadaptation, afin de connaître vos expériences ultérieures avec les services de réadaptation de votre enfant. Bien qu'il n'y ait pas d'avantage immédiat pour votre famille, votre expérience nous permettra d'évaluer le processus avec l'objectif d'améliorer la disponibilité et l'accessibilité des services aux enfants atteints d'incapacités physiques. Il n'y a aucun risque pour vous ou votre enfant.

Vous ne serez pas identifié dans aucune publication découlant de ce projet de recherche et aucune données recueillies ne pourra vous retracer. Tous les renseignements demeurent strictement confidentiels. Votre participation est volontaire. Vous pouvez, à tout moment, refuser de répondre à une question ou décider de vous retirer de l'étude, sans subir de préjudice aux soins de votre enfant.

Si vous désirez avoir des renseignements supplémentaires vous pouvez communiquer avec le D^r Debbie Feldman au 343-6111, poste 1252. Vous pouvez aussi communiquer avec la protectrice des malades, Mme Elisabeth Gibbon au 412-4400, poste 22223 si vous n'êtes pas satisfait des services ou de l'étude et concernant vos droits en tant que sujet participant à une étude.

Je consens à participer à cette étude

Signature du parent/tuteur

Signature du chercheur

Date

Date

INSTITUTIONAL REVIEW BOARD
approved for 12 months

from 25/10/98

25/10/98



MONTREAL CHILDREN'S HOSPITAL
OF THE MUHC

RESEARCH ETHICS BOARD
APPROVED FOR 12 MONTHS



HÔPITAL DE MONTRÉAL POUR ENFANTS, THE MONTREAL CHILDREN'S HOSPITAL
3000 Avenue de la Guérison, Québec, Montréal, Québec H3T 1M5
Téléphone: (514) 412-4400





Informed Consent; Access to rehabilitation for children with physical disabilities

Groupe de recherche interdisciplinaire en santé (GRIS)
Université de Montréal
CP 6128 succursale Centre-Ville
Montréal, Québec, Canada H3C 3J7

Principal Investigator :Dr. Debbie Feldman Montreal Children's Hospital (514) 412-4407
Université de Montréal (514) 343-6111, poste 1252

The Université de Montréal together with Hôpital Ste. Justine and the Montreal Children's Hospital is conducting a research study regarding rehabilitation services in Montreal for children with physical disabilities. The goal is to document waiting time, any problems with services, and to try to find strategies to improve accessibility and quality of rehabilitation services for children.

We ask that you complete one face-to-face interview, lasting about 30 minutes, regarding your experiences with respect to your family and your child's involvement in the rehabilitation process. An interviewer will contact you by telephone (15-minute interview), at 3 month intervals until your child is accepted at a rehabilitation centre, to ask you about any subsequent experiences with rehabilitation for your child. Although there is no direct benefit to your family, your experiences will enable review of this process with a goal towards improving availability and accessibility to services for children with physical disabilities. There is no risk whatsoever to you or to your child.

You will not be identifiable from any publication resulting from this research study, nor will any data collected be traceable to you or your child. All information is strictly confidential.

Your participation is completely voluntary. You may refuse, at any time, to answer any question or withdraw from the study altogether, without any effect on your child's care.

Should you require any further information regarding the study, you may contact Dr. Debbie Feldman at 343-6111, extension 1252. You may also contact the hospital ombudsman Ms. Elisabeth Gibbon at 412-4400, extension 22223, to discuss any dissatisfaction with services or the study and with regard to questions concerning your rights as a research subject.

I agree to participate in this study :

Signature of parent/guardian

Signature of Investigator

Date

MONTREAL CHILDREN'S HOSPITAL
OF THE MCHC
RESEARCH ETHICS BOARD
APPROVED FOR 12 MONTHS

L'HÔPITAL DE MONTRÉAL POUR ENFANTS / THE MONTREAL CHILDREN'S HOSPITAL
2300 rue Tupper, Montréal (Québec) H3T 1J3

SIGNED: [Redacted]

INSTITUTIONAL REVIEW BOARD
approved for 12 months
from date below
25/02

[Redacted]



FORMULAIRE D'INFORMATION ET DE CONSENTEMENT

1. Titre de l'étude

Impact du délai de transfert vers les services de réadaptation chez les enfants présentant des problèmes de développement

2. Nom des chercheurs

Ce projet est dirigé par Debbie Feldman Ph.D. chercheure adjointe, du Groupe de recherche interdisciplinaire en santé à l'Université de Montréal. Il implique également l'étroite collaboration des chercheurs suivants : Julie Gosselin Ph.D., Bonnie Swaine Ph.D., François Champagne Ph.D. et Raynald Pineault Ph.D.

3. Source de financement

Cette étude reçoit le soutien financier du Fonds de la recherche en santé du Québec.

4. Invitation à participer à un projet de recherche

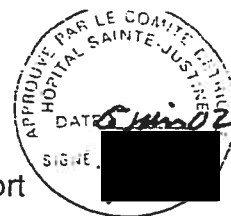
Le Groupe de recherche interdisciplinaire en santé, en collaboration avec l'Hôpital Ste-Justine et l'Hôpital Montréal pour Enfants, réalise une étude sur l'impact des délais d'attente pour l'obtention de services en réadaptation chez les enfants présentant des problèmes de développement. Nous sollicitons la participation de votre enfant. Nous vous invitons à lire ce formulaire d'information afin de décider si vous êtes intéressé(e) à ce que votre enfant participe à cette étude.

5. Quelle est la nature de ce projet ?

Votre enfant présente des problèmes de développement pour lesquels votre médecin vous a référé en réadaptation (ergothérapie et/ou physiothérapie). Le but de notre recherche est de mieux comprendre la situation actuelle dans les délais de transfert vers les services de réadaptation. Une meilleure compréhension des facteurs qui influencent ces délais devrait permettre de développer des stratégies pour faciliter l'accessibilité à de tels services et, éventuellement, à en améliorer la qualité. Pour ce faire, nous comptons recruter entre 400 et 450 enfants ayant bénéficié d'une évaluation médicale ayant mené à une référence en réadaptation. Ces enfants auront dû être évalués à l'Hôpital Montréal pour enfants ou encore à l'Hôpital Sainte-Justine.

6. Comment se déroulera le projet ?

L'étude comporte deux volets. Le premier volet vise à documenter le délai de transfert et les facteurs qui ont pu l'influencer. Il nécessitera la consultation des banques de données pour le suivi des soins de votre enfant au Service de réadaptation de l'Hôpital Sainte-Justine. Il faudra également consulter le dossier médical de votre enfant afin d'obtenir des informations le concernant qui sont pertinentes au projet de recherche (la date de référence, la date de premier rendez-vous avec un thérapeute et l'information sur les besoins de votre enfant). Le second volet vise à mieux comprendre votre situation durant cette période d'attente et impliquera des entrevues. La première entrevue sera faite à l'intérieur des 15 jours suivant la référence au centre de réadaptation et sera réalisée de façon directe en face-à-face. Les autres entrevues seront complétées par téléphone chaque trois mois jusqu'au moment du premier rendez-vous au centre de réadaptation. La première entrevue servira à recueillir des données concernant votre manière de gérer la situation d'attente, vos initiatives pour prendre en charge votre situation, le fonctionnement global de votre enfant ainsi que votre situation familiale. Les autres entrevues permettront de réévaluer les mêmes aspects auxquels s'ajouteront votre niveau de satisfaction face au



transfert incluant l'utilisation de services privés, les problèmes vécus en rapport avec le système et des suggestions pour améliorer la situation. Chaque entrevue durera approximativement 45 minutes et pourra être complétée au moment de la journée qui vous convient le mieux.

7. Quels sont les avantages et bénéfices ?

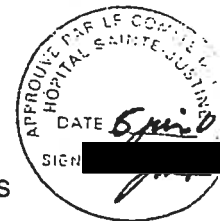
Cette étude n'aura aucun bénéfice direct sur la santé de votre enfant puisque nous n'analyserons que les facteurs influençant les délais d'attente pour obtenir des services en réadaptation. Les entrevues ne pourront pas servir à accélérer le processus de prise en charge de votre enfant en réadaptation. Il n'en demeure pas moins que votre participation à cette étude permettra d'améliorer les connaissances et éventuellement les services de réadaptation requis par des enfants comme le vôtre.

8. Quels sont les inconvénients et les risques ?

Cette étude ne comporte aucun risque pour votre enfant ou vous-même. Néanmoins, comme cette étude implique au moins deux entrevues, vous devrez être disponible à ces deux moments. Ces entrevues seront faites selon vos disponibilités afin de créer un minimum d'inconvénients pour vous. Il est important de rappeler que certains critères devront néanmoins être respectés (à l'intérieur des 15 jours suivant la demande de transfert et ensuite à chaque 3 mois suivant cette demande jusqu'au moment du premier rendez-vous au centre de réadaptation).

9. Comment la confidentialité est-elle assurée ?

Les données recueillies seront gardées dans une filière informatique sous un code numérique. Cependant, aux fins de vérifier la saine gestion de la recherche, il est possible qu'un délégué du comité d'éthique de la recherche et des organismes commanditaires consultent les données de recherche et le dossier médical de votre enfant. Par ailleurs, les résultats de cette étude pourront être publiés et communiqués dans un congrès scientifique mais aucune



information pouvant identifier votre enfant ne sera alors dévoilée. De fait, tous les renseignements obtenus sur votre enfant dans le cadre de ce projet de recherche demeureront confidentiels, à moins d'une autorisation de votre part ou d'une exception à la loi.

10. Responsabilité des chercheurs

En signant ce formulaire de consentement, vous ne renoncez à aucun de vos droits prévus par la loi ni à ceux de votre enfant. De plus, vous ne libérez pas les investigateurs de leur responsabilité légale et professionnelle advenant une situation qui causerait préjudice à votre enfant.

11. Y a-t-il une compensation prévue pour vos dépenses et inconvénients ?

Aucune compensation financière n'a été prévue.

12. Liberté de participation

La participation de votre enfant est volontaire. Toute nouvelle connaissance susceptible de remettre en question sa participation vous sera communiquée. Si vous choisissez de ne pas faire participer votre enfant ou de le retirer de l'étude, ce sera évidemment sans aucun préjudice pour les soins apportés à votre enfant.

13. En cas de questions ou de difficultés, avec qui peut-on communiquer ?

Pour plus d'information concernant cette recherche, contactez le chercheur responsable de cette étude, Dre Debbie Feldman à (514) 343-6111, poste 3141. Pour tout renseignement sur les droits de votre enfant à titre de participant à ce projet de recherche, vous pouvez contacter la conseillère à la clientèle de l'Hôpital Ste-Justine au (514) 345-4749.



14. Consentement

On m'a expliqué la nature et le déroulement du projet de recherche. J'ai pris connaissance du formulaire de consentement et on m'en a remis un exemplaire. J'ai eu l'occasion de poser des questions auxquelles on a répondu. Après réflexion, j'accepte que mon enfant participe à ce projet de recherche. J'autorise l'équipe de recherche à consulter le dossier médical de mon enfant et les informations le concernant qui sont conservées dans les banques de données de l'Hôpital Sainte-Justine pour obtenir les informations pertinentes à ce projet.

Nom de l'enfant (Lettres moulées)

Nom du parent (Lettres moulées)

Consentement du parent, tuteur (Signature)

Date



15. Formule d'engagement du chercheur ou de la personne qu'il a déléguée

Le projet de recherche a été décrit au participant et/ou à son parent/tuteur ainsi que les modalités de la participation. Un membre de l'équipe de recherche (chercheur ou infirmière de recherche) a répondu à leurs questions et leur a expliqué que la participation au projet de recherche est libre et volontaire. L'équipe de recherche s'engage à respecter ce qui a été convenu dans le formulaire de consentement.

Signature du chercheur/délégué qui a obtenu le consentement

Date

Nom du chercheur ou du délégué et fonction (Lettres moulées)

Date

APPENDIX III
Baseline Study Questionnaire to Parents

Nom:

MCH/SJH # d'identification:

Date: ____/____/____
 jj mm aa

ENTREVUE 1: QUESTIONNAIRE POST-RÉFÉRENCE: Face à face

RENSEIGNEMENTS PERSONNELS: *Maintenant, je vais vous poser des questions générales concernant votre enfant et vous.*

1. Dans quelle municipalité (ou région de la ville) demeurez vous?

2. Quel est le diagnostic de votre enfant?

3. Quand votre enfant a-t-il été diagnostiqué? _____

4. Quelle est la date de naissance de votre enfant? _____

5. Quelles langues parle votre enfant? _____

6. Quelles langues votre enfant comprend-il? _____

7. Quelles langues parlez-vous? _____

8. Préférez-vous recevoir des services en anglais ou en français ? _____

9. Quel parent s'occupe habituellement des soins de votre enfant? _____

10. Qui d'autre est impliqué dans les soins pour votre enfant?

11. Quel est le plus haut niveau de scolarité que vous ayez complété?

secondaire non terminé

secondaire 5 (terminé)

DEC (CEGEP terminé)

Diplôme universitaire, spécifié _____

Diplôme professionnel ou études graduées

12. Quelle est votre origine ethnique:

- Canadienne Canadienne française Îles britanniques
 Française Sud-Américaine Caraïbes
 Aborigène Asie de l'est et du sud-est Origines arabes
 Sud-asiatique Africaine autre: _____

13. Parmi les choix suivant, lequel décrit le mieux votre revenu familial brut.

- 0-\$19,999 \$20,000-\$39,999 \$40,000-\$59,000
 \$60,000-\$79,000 \$80,000 and above

14. Qui vit avec votre enfant? _____

15. Lequel parmi ces énoncés décrit le mieux votre lien avec votre enfant?

- | | | |
|-------------------|-------------|----------------------|
| Parent biologique | Beau parent | Famille d'accueil |
| Parent adoptif | Tuteur | Autre, svp expliquer |

16. Vous êtes : homme femme

17. Combien d'enfants avez-vous ? _____

Si vous avez d'autres enfants:

18. Combien sont plus âgés que cet enfant ? _____

19. Combien sont plus jeunes que cet enfant? _____

20. Lequel de ces énoncés décrit le mieux votre statut d'emploi actuel? Vous pouvez en cocher plus d'un :

- Sans emploi en raison de la santé de mon enfant.
- Sans emploi pour d'autres raisons.
- À la recherche d'un emploi à l'extérieur de la maison.
- Emploi à temps plein ou partiel (à l'extérieur ou entreprise à la maison)
- À la maison à temps plein

21. Si vous avez un emploi quel genre de type d'arrangement de garde utilisez-vous? Vous pouvez en cocher plus d'un.

- garderie
- à la maison avec un membre de la famille
- gardienne à la maison
- garderie en milieu familial
- assez vieux pour rester seul

22. Avez vous eu de la difficulté ou avez-vous de la difficulté à trouver un arrangement pour garder vos enfants?

Oui

Non

23. Si oui, quelles ont été ou sont les difficultés rencontrées? (ex. refuse l'intégration, problème de santé trop lourd etc.)

24. Qui vous a référé aux services de réadaptation (ergothérapie ou physiothérapie)?

25. Selon vous, quel serait un délai d'attente raisonnable pour recevoir des services de réadaptation suite à une référence du médecin?

26. Votre enfant a-t-il déjà reçu des services de réadaptation, si oui, lesquels parmi les suivants

NON, mon enfant a reçu aucun service.

	Ergothérapie	Physiothérapie	orthophonie	Psychologie	Éducation spécialisée
Services reçus					
Emplacement des services:					
1. hôpital					
2. centre de réadaptation					
3. services communautaires					
4. garderie					
5. à la maison					
6. autre					
Publique (✓) ou Privé (\$):					
Fréquence des services: *					
Durée des services Ou date de début					

* 1=hebdomadaire, 2= tous les 2 semaines 3=1 X par mois, 4=consultation seulement, 5=autre.

27. Dans le passé, avez-vous consulté d'autres thérapeutes pour aider le problème de votre enfant.

Oui Non

28. Quel autre type de thérapie avez-vous consulté? SVP veuillez indiquer le type de traitement, la fréquence des traitements, qui a payé pour ces services, et indiquez comment ce traitement a aidé la condition de votre enfant (veuillez utiliser l'échelle ci-dessous):

1 = pas d'amélioration

2 = un peu d'amélioration

3 = amélioration modérée

4 = beaucoup d'amélioration

Type de traitement	Nombre de visites au cours des 3 derniers mois	Qui a payé? (i.e., vous, RAMQ, assurance privée, gratuit)	Dans quelle mesure ce traitement a-t-il aidé la condition de votre enfant? (voir échelle ci-haut)
Chiropractie			
Acupuncture			
Ostéopathie			
Massothérapie			
Homéopathie			
Naturopathie			
Hypnothérapie			
Réflexologie			
Guérisseur			
Diète spéciale			
Autre (spécifié): _____			

29. Avez-vous d'autres commentaires au sujet des services de réadaptation de votre enfant ?

Merci de votre collaboration à notre étude.

Name:
MCH/HSJ identification #:
Date: ____/____/____

INTERVIEW 1: QUESTIONNAIRE FACE TO FACE
PERSONAL DATA QUESTIONS: *Now, I will ask you some general questions.*

1. In what area of town do you live (if living in Montreal, ask which district)?

2. What is your child's diagnosis?

3. When was your child diagnosed?

4. What is your child's date of birth?

5. What language does your child speak (if any)?

6. What language(s) does your child understand?

7. What language(s) do you speak?

8. Would you prefer to receive services for your child in English or French?

9. Which parent (s) is/are the usual caregiver(s) for the child? _____
10. Who else is involved in caring for your child? _____
11. What is the highest grade of school you have completed?
 some high school or less
 secondary V (finished high school)
 DEC (finished CEGEP)
 university degree, specify _____
 professional or graduate degree

12. Ethnic origin:

- | | | |
|--------------------------------------|---|--|
| <input type="checkbox"/> Canadian | <input type="checkbox"/> Canadian-French | <input type="checkbox"/> British Isles |
| <input type="checkbox"/> French | <input type="checkbox"/> South American | <input type="checkbox"/> Caribbean |
| <input type="checkbox"/> Aboriginal | <input type="checkbox"/> East and Southeast Asian | <input type="checkbox"/> Arab origins |
| <input type="checkbox"/> South Asian | <input type="checkbox"/> African | <input type="checkbox"/> other: _____ |

13. What income range best corresponds to the combined income (before taxes) for the household?

- | | | |
|--|---|--|
| <input type="checkbox"/> 0-\$19,999 | <input type="checkbox"/> \$20,000-\$39,999 | <input type="checkbox"/> \$40,000-\$59,000 |
| <input type="checkbox"/> \$60,000-\$79,000 | <input type="checkbox"/> \$80,000 and above | |

14. Who lives with your child? _____

15. Which of the following best describes your relationship to your child?

- | | | |
|-------------------|-------------|-----------------------|
| Biological parent | Step parent | Foster parent |
| Adoptive parent | Guardian | Other, please explain |

16. Are you: male female

17. How many children do you have? _____

If you have other children:

18. How many are older than this child? _____

19. How many are younger than this child? _____

20. Which of the following best describes your current work status? (check all that apply)

- not working due to my child's health
- not working for other reasons
- looking for work outside the home
- working full or part time (either outside the home or at a home-based business)
- full time homemaker

21. If you are currently working what type of care arrangement are you using? You may choose more than one.

- daycare
- at home with a family member
- sitter at home
- family day care
- old enough to stay alone

22. Did you have or are you having difficulties finding care arrangement for your child?

Yes

No

23. If yes, what type of difficulties have you had? (ex. refuse integration, health problem too demanding etc.)

24. Who referred you to the rehabilitation services? _____

25. What do you think is a reasonable amount of time to wait for rehabilitation services, after having been referred by the doctor?

26. Rehabilitation Services: (interviewer asks the following questions and completes table)

* Which of the following services has your child ever received?

(See table below)

* If your child has received services,

- a) where did you receive them?
- b) did you pay for these services privately?
- c) estimate how often you received them

	Occupational Therapy	Physical Therapy	Speech Language Pathology	Psychology	Special Education
Services received (if yes, answer below)					
Location of services:					
1. hospital					
2. rehab. center					
3. community					
4. day care					
5. home					
6. other					
Public (✓) or Private (\$):					
Frequency of services: *					
Duration of services Or Beginning date					

* 1=weekly, 2=biweekly (every two weeks), 3=monthly, 4=consultation only, 5=other.

14. In the past, have you consulted other therapist to help your child's problem?
15. Which of the following Treatments have you ever used for your child's problems in the past? Please indicate the **type** of treatment your child received, **how often** you used this treatment, **who paid** for it, and how much it **helped** to improve your child's arthritis (please use the scale below to rate from 1 to 4 the level of improvement you observed as a result of treatment):

- 1 = No improvement
- 2 = Slight improvement
- 3 = Moderate improvement
- 4 = Much improvement

Type of treatment	Number of visits or use <u>in the past</u>	Who paid for it? <i>(i.e., yourself, medicare, private insurance, free)</i>	How much did this treatment help improve your child's condition? <i>(use the above scale 1 to 4)</i>
Chiropractor			
Acupuncturist			
Osteopath			
Massage therapist			
Homeopath			
Naturopath <i>(herbal medicine)</i>			
Hypnotherapist			
Reflexologist			
Spiritual healer			
Dietary changes <i>(special diets, vitamins)</i>			
Folk remedies <i>(specify)</i> _____			
Other (specify): _____			

16. Do you have any other comments on the subject of your child's rehabilitation services?

Thank you for participating in our survey.

APPENDIX IV
Follow-up Study Questionnaire to Parents

ENTREVUE: QUESTIONNAIRE DE SUIVI TOUS LES 3 MOIS

Nous aimerions vous poser quelques questions concernant le processus de transfert en réadaptation et les listes d'attente. L'objectif de cette recherche est d'améliorer les services pour les enfants qui requièrent de la réadaptation. Nous apprécions votre participation.

1. Depuis combien de temps attendez-vous les services de physiothérapie ou d'ergothérapie? ERGO _____ PHYSIO _____

2. Pendant ce temps, diriez-vous que la condition de votre enfant s'est:
beaucoup amélioré
un peu amélioré
est resté la même
un peu détérioré
beaucoup détérioré

3. D'une façon générale, êtes-vous satisfait de l'organisation des services de réadaptation pour votre enfant?
très satisfait
plutôt satisfait
indifférent
plutôt insatisfait
très insatisfait

4. SVP, veuillez mentionner toute autre préoccupation ou problème concernant les services de réadaptation de votre enfant.

5. Votre enfant reçoit-il présentement des services:

NON, mon enfant reçoit aucun service. **Allez à la QUESTION 7**

	Ergothérapie	Physiothérapie	orthophonie	Psychologie	Éducation spécialisée
Services reçus					
Emplacement des services:					
1. hôpital					
2. centre de réadaptation					
3. services communautaires					
4. garderie					
5. à la maison					
6. autre					
Publique (✓) ou Privé (\$):					
Fréquence des services: *					
Durée des services Ou date de début					

* 1=hebdomadaire, 2= tous les 2 semaines 3=1 X par mois, 4=consultation seulement, 5=autre.

6. Combien d'argent avez-vous dépensé pour ces services depuis notre dernière entrevue\$ _____

7. Depuis notre dernière entrevue, avez-vous consulté d'autres thérapeutes pour aider le problème de votre enfant.

Oui Non

8. Quel autre type de thérapie avez-vous consulté? SVP veuillez indiquer le type de traitement, la fréquence des traitements, qui a payé pour ces services, et indiquez comment ce traitement a aidé la condition de votre enfant (veuillez utiliser l'échelle ci-dessous):

- 1 = pas d'amélioration
- 2 = un peu d'amélioration
- 3 = amélioration modérée
- 4 = beaucoup d'amélioration

Type de traitement	Nombre de visites au cours des 3 derniers mois	Qui a payé? <i>(i.e., vous, RAMQ, assurance privée, gratuit)</i>	Dans quelle mesure ce traitement a-t-il aidé la condition de votre enfant? <i>(voir échelle ci-haut)</i>
Chiropractie			
Acupuncture			
Ostéopathie			
Massothérapie			
Homéopathie			
Naturopathie			
Hypnothérapie			
Réflexologie			
Guérisseur			
Diète spéciale			
Autre (spécifié):			

9. Avez-vous d'autres commentaires au sujet des services de réadaptation de votre enfant ?

MERCI!

INTERVIEW : FOLLOW-UP QUESTIONNAIRE (EVERY 3 MONTHS)

We would like to ask you a few questions about how you are feeling while waiting for transfer to the rehabilitation centre. The goal of this research is to improve services for children who require rehabilitation. We appreciate your participation.

1. How long has it been since you are waiting for occupational or physical therapy services for your child? OT _____ PT _____

2. During this waiting time, do you feel your child's condition:

- is improving a lot
- is improving a little
- staying the same
- worsening a little
- worsening a lot

3. In an overall general sense, how satisfied are you with the organization of rehabilitation services for your child?

- very satisfied
- mostly satisfied
- indifferent
- mildly dissatisfied
- quite dissatisfied

4. Please discuss any other issues or concerns you may have regarding rehabilitation services for your child.

5. Is your child currently receiving any services:

NO, my child is not receiving any services. **GO TO QUESTION 7**

	Occupational Therapy	Physical Therapy	Speech Language Pathology	Psychology	Special Education
Services received (if yes, answer below)					
Location of services:					
1. hospital					
2. rehab. center					
3. community					
4. day care					
5. home					
6. other					
Public (✓) or Private (\$):					
Frequency of services: *					
Duration of services Or Beginning date					

* 1=weekly, 2=biweekly (every two weeks), 3=monthly, 4=consultation only, 5=other.

6. How much money did you spend on private services for your child?

\$_____

7. Since our last interview, have you consulted an alternative therapists to help your child's problem

Yes No

8. Which of the following Treatments have you used for your child's problems in the past 3 months ? Please indicate the **type** of treatment your child received, **how often** you used this treatment, **who paid** for it, and how much it **helped** to improve your child's arthritis (please use the scale below to rate from 1 to 4 the level of improvement you observed as a result of treatment):

- 1 = No improvement
- 2 = Slight improvement
- 3 = Moderate improvement
- 4 = Much improvement

Type of treatment	Number of visits or use <u>in the past 3 months</u>	Who paid for it? (i.e., yourself, medicare, private insurance, free)	How much did this treatment help improve your child's condition? (use the above scale 1 to 4)
Chiropractor			
Acupuncturist			
Osteopath			
Massage therapist			
Homeopath			
Naturopath (herbal medicine)			
Hypnotherapist			
Reflexologist			
Spiritual healer			
Dietary changes (special diets, vitamins)			
Other (specify):			

9. Do you have any other comments on the subject of your child's rehabilitation services?

THANK YOU!

APPENDIX V
Post-transfer Study Questionnaire to Parents in
French and English

ENTREVUE : QUESTIONNAIRE POST-TRANSFERT

Nous aimerions maintenant vous poser quelques questions concernant le processus de transfert des services de réadaptation pour votre enfant. Nous faisons référence à la période entre votre rendez-vous médical au moment où vous avez reçu la référence et le moment où vous avez eu votre premier rendez-vous au centre de réadaptation. Le but de cette étude est d'améliorer les services de réadaptation pour les enfants. Nous apprécions grandement votre participation.

1. Combien de semaines ou de mois avez-vous attendu, à partir du moment de la référence médicale, pour recevoir les services d'ergothérapie ou de physiothérapie au centre de réadaptation?
ergo_____ physio_____.
2. Que pensez-vous du temps d'attente pour le transfert au centre de réadaptation?
très satisfait
plutôt satisfait
indifférent
plutôt insatisfait
très insatisfait
3. Pendant ce temps d'attente, diriez-vous que la condition de votre enfant s'est:
beaucoup amélioré
un peu amélioré
est resté la même
un peu détérioré
beaucoup détérioré
4. Trouvez-vous que le centre de réadaptation a offert une bonne continuité de soins par rapport aux soins débutés au centre hospitalier?
oui, tout à fait
oui, en partie
non, pas vraiment ou très peu
non, pas du tout
5. De façon générale, jusqu'à quel point êtes-vous satisfait (e) des services que votre enfant a reçu du centre de réadaptation?
très satisfait(e)
plutôt satisfait(e)
indifférent(e) ou légèrement insatisfait(e)
très insatisfait(e)

6. Avez-vous trouvé que les professionnels du centre de réadaptation avaient une bonne connaissance de la condition et de l'état de santé de votre enfant?

oui, tout à fait
oui, en partie
non, pas vraiment ou très peu
non, pas du tout

7. SVP veuillez nous mentionner toutes préoccupations que vous auriez eu au sujet du processus de transfert pour les services de réadaptation de votre enfant.

8. Quelles suggestions (si vous en avez) feriez-vous au sujet du processus de transfert des dossiers des enfants pour l'obtention de services de réadaptation

9. Comme parent ou comme proche soignant, croyez-vous que *vous* devriez être impliqué(e) comme partenaire dans la réadaptation de votre enfant?

oui, sans hésitation
oui, je crois
non, je ne pense pas
non, pas du tout

10. Jusqu'à quel point les professionnels de la réadaptation vous impliquent-ils dans la réadaptation de votre enfant?

Les professionnels m'impliquent ...
de façon importante
de façon modérée
de façon minimale
ne m'impliquent pas du tout

11. Est-il important pour vous de connaître d'autres ressources en réadaptation pour votre enfant que vous pouvez contacter vous-même ou aux quelles vous pouvez vous référer?

- oui, sans hésitation
- oui, je crois
- non, je ne pense pas
- non, pas du tout

12. Avez-vous l'impression que les professionnels de la réadaptation ont augmenté votre connaissance des ressources disponibles pour vous aider à solutionner les problèmes liés à la réadaptation de votre enfant?

- oui, ils m'ont beaucoup aidé
- oui, ils m'ont un peu aidé
- non, ils ne m'ont pas vraiment aidé
- non, ils ne m'ont pas du tout aidé

13. Depuis notre dernière entrevue, quels sont les services que votre enfant a reçu?

NON, mon enfant reçoit aucun service. Allez à la QUESTION 7

	Ergothérapie	Physiothérapie	orthophonie	Psychologie	Éducation spécialisée
Services reçus					
Emplacement des services:					
1. hôpital					
2. centre de réadaptation					
3. services communautaires					
4. garderie					
5. à la maison					
6. autre					
Public (√) ou Privé (\$):					
Fréquence des services: *					
Durée des services ou date de début					

* 1=hebdomadaire, 2= tous les 2 semaines 3=1 X par mois, 4=consultation seulement, 5=autre.

14. Combien d'argent avez-vous dépensé pour ces services depuis notre dernière entrevue\$ _____

15. Depuis notre dernière entrevue, avez-vous consulté d'autres thérapeutes pour aider le problème de votre enfant.

Oui Non

16. Quel autre type de thérapie avez-vous consulté? SVP veuillez indiquer le type de traitement, la fréquence des traitements, qui a payé pour ces services, et indiquez comment ce traitement a aidé la condition de votre enfant (veuillez utiliser l'échelle ci-dessous):

1 = pas d'amélioration

2 = un peu d'amélioration

3 = amélioration modérée

4 = beaucoup d'amélioration

Type de traitement	Nombre de visites au cours des 3 derniers mois	Qui a payé? (i.e., vous, RAMQ, assurance privée, gratuit)	Dans quelle mesure ce traitement a-t-il aidé la condition de votre enfant? (voir échelle ci-haut)
Chiropractie			
Acupuncture			
Ostéopathie			
Massothérapie			
Homéopathie			
Naturopathie			
Hypnothérapie			
Réflexologie			
Guérisseur			
Diète spéciale			
Autre (spécifié): _____			

17. Selon vous, quel serait un délai d'attente raisonnable pour recevoir des services de réadaptation suite à une référence du médecin?

18. Avez-vous d'autres commentaires au sujet des services de réadaptation de votre enfant?

MERCI D'AVOIR PARTICIPÉ À NOTRE ÉTUDE

INTERVIEW : POST TRANSFER QUESTIONNAIRE

We would like to ask you a few questions about what you felt about the transfer process of rehabilitation services for your child. I am referring to the period of time between when you first saw a doctor at the hospital and when your child started his or her rehabilitation treatments at the rehabilitation center. The goal of this research is to improve services for children who require rehabilitation. We appreciate your participation.

1. How many weeks did you have to wait between referral for services and your child's first appointment *at the rehabilitation center*?
OT _____ PT _____.
2. How do you feel about the time you had to wait before being transferred to rehabilitation?
very satisfied
mostly satisfied
indifferent
mildly dissatisfied
quite dissatisfied
3. During this waiting time, do you feel your child's condition:
improved a lot
is improved a little
stayed the same
worsened a little
worsened a lot
4. Do you feel that the rehabilitation centre provided good continuity of care that was started in the hospital centre?
yes, thoroughly
somewhat
a little bit
not at all

5. In an overall general sense, how satisfied are you with the transfer process of services for your child?

- very satisfied
- mostly satisfied
- indifferent or mildly dissatisfied
- quite dissatisfied

6. Did the staff at the rehabilitation centre appear to be well versed in your child's condition and health status?

- yes, thoroughly
- somewhat
- a little bit
- not at all

7. Please discuss any other issues or concerns you may have regarding the transfer of rehabilitation services for your child.

8. What suggestions (if any) would you have with respect to the process of transferring children for rehabilitation services?

9. Do you feel, as a parent or caregiver, that *you* should be involved as a partner in the rehabilitation of your child?

yes, definitely

yes, I think so

no, I don't think so

no, definitely not

10. To what extent are the rehabilitation professionals involving you in the rehabilitation of your child? (the rehabilitation professionals involve me...)

to a great extent

to a moderate extent

to a minimal extent

not at all

11. Is it important for you to know about available resources that *you* may contact *yourself* regarding your child's rehabilitation?

yes, definitely

yes, I think so

no, I don't think so

no, definitely not

12. Do you feel that rehabilitation professionals increased your awareness of available resources to help *you* work out problems relating to your child's rehabilitation?

yes, they helped a great deal

yes, they helped somewhat

no, they rarely mentioned anything

no, they did not help me at all

13. Since our last interview, which services has your child received?

NO, my child is not receiving any services. **GO TO QUESTION 15**

	Occupational Therapy	Physical Therapy	Speech Language Pathology	Psychology	Special Education
Services received (if yes, answer below)					
Location of services:					
1. hospital					
2. rehab. center					
3. community					
4. day care					
5. home					
6. other					
Public (✓) or Private (\$):					
Frequency of services: *					
Duration of services Or Beginning date					

* 1=weekly, 2=biweekly (every two weeks), 3=monthly, 4=consultation only, 5=other.

14. How much money did you spend on private services for your child? \$_____

15. Since our last interview, have you consulted other therapists to help your
child's problem

Yes No

Which of the following other Treatments have you used for your child's problems in the past? Please indicate the **type** of treatment your child received, **how often** you used this treatment, **who paid** for it, and how much it **helped** to improve your child's arthritis (please use the scale below to rate from 1 to 4 the level of improvement you observed as a result of treatment):

- 1 = No improvement
 2 = Slight improvement
 3 = Moderate improvement
 4 = Much improvement

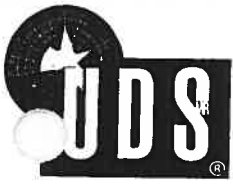
Type of treatment	Number of visits or use <u>in the past 3 months</u>	Who paid for it? (i.e., yourself, medicare, private insurance, free)	How much did this treatment help improve your child's condition? (use the above scale 1 to 4)
Chiropractor			
Acupuncturist			
Osteopath			
Massage therapist			
Homeopath			
Naturopath (<i>herbal medicine</i>)			
Hypnotherapist			
Reflexologist			
Spiritual healer			
Dietary changes (<i>special diets, vitamins</i>)			
Folk remedies (<i>specify</i>) _____			
Other (specify): _____			

16. What do you think would be a reasonable amount of time to wait for rehabilitation services, after having been referred by the doctor?

17. Do you have any other comments on the subject of your child's rehabilitation services?

THANK YOU FOR PARTICIPATING IN OUR SURVEY

APPENDIX VI
Research License Agreement



**The
Functional
Assessment
Specialists**

February 10, 2005

Dr. Debbie Feldman
Universite de Montreal (GRIS)
C.P. 6128
Succursale centre-ville
Montreal, Quebec H3C 3 J7

Dear Dr. Feldman:

Enclosed please find a copy of the fully executed Research License Agreement between Uniform Data System for Medical Rehabilitation and Universite de Montreal for your records.

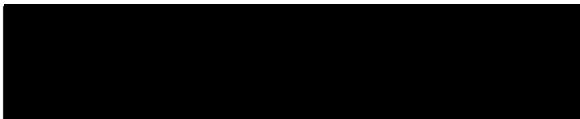
Limited Permission is hereby granted to use the WeeFIM® instrument for the purpose of your project entitled "An Analysis of Preschool-Aged Children Waiting for Rehabilitation Services in Montreal," as more fully described on Schedule C of the above-mentioned Agreement.

Please refer to the enclosed documentation regarding the correct uses for our trademarks and service marks. When you are ready to write about your project please be sure to follow the guidelines as described in the Research License Agreement. If you create any Tables or Figures that include mention of the instruments, the following acknowledgments must appear below them:

"The WeeFIM® instrument. Copyright © 1998, 2000 Uniform Data System for Medical Rehabilitation (UDSMR), a division of UB Foundation Activities, Inc. (UBFA). All rights reserved."

If you need any further assistance, please do not hesitate to contact Amiee Van Hout, Legal Services Assistant at 716-817-7809. Thank you.

Sincerely,



Carl V. Granger, M.D.
Director Emeritus

Enclosure

CVG/avh

Uniform Data System

**for Medical
Rehabilitation**

Telephone
716.817.7800

Facsimile
716.568.0037

E-mail


Website
www.udsmr.org

270 Northpointe Parkway
Suite 300
Amherst, New York
14228



APPENDIX VII
WeeFIM Score Sheet

WEEFIM SYSTEM (SM) - ASSESSMENT CODING FORM

VERSION 5.0

CASE IDENTIFICATION

1. Facility Code *

2. Patient Code *

3. Admission Date *
MM / DD / YYYY

59. WEEFIM (R) INSTRUMENT

ASSESSMENT INFORMATION

50. Assessment Type *
5-Baseline 1-Admission 2-Interim 3-Discharge 4-Follow-up

51. Assessment Date *
Enter date assessment performed MM / DD / YYYY

52. Information Source
1-Staff 2-Parent 3-Caregiver 4-Patient 5-Other

53. Living Setting *
1-Home 2-Transitional living center 3-Skilled nursing facility 4-Died 5-Other

54. Living With
(only if living setting above is 1-Home)
1-Two parents 2-One parent 3-Relatives 4-Foster care 5-Shelter 6-Other

55. Educational Category
1-Not a student 2-Early intervention program 3-Preschool 4-Kindergarten through 12th 5-Other

56. Educational Setting
(only if educational category above is 2 to 4)
1-Regular class 2-Special class (approximately 12:1) 3-Special class (approximately 6:1) 4-Home-based 5-Day care/nursery school / Center-based / Community

FAMILY CENTERED FEEDBACK

57. Communications and Partnership
To what extent do the people who work with your child...

.1 discuss with you everyone's expectations for your child so that all agree on what is best?
1-Never 2-Sometimes 3-Frequently 4-Always

.2 make sure you have opportunities to explain what you think are important goals for your child?
1-Never 2-Sometimes 3-Frequently 4-Always

.3 make you feel like a partner in your child's care?
1-Never 2-Sometimes 3-Frequently 4-Always

58. Support and Advocacy
To what extent does the center where you receive services...

.1 provide support to help you cope with the impact of childhood disability by advocating on your behalf?
1-Never 2-Sometimes 3-Frequently 4-Always

.2 give you information about the types of services offered in your community?
1-Never 2-Sometimes 3-Frequently 4-Always

.3 satisfy your needs for family centered care?
1-Never 2-Sometimes 3-Frequently 4-Always

SELF-CARE	ASSESSMENT *	GOAL **
.1 Eating	<input type="text"/>	<input type="text"/>
.2 Grooming	<input type="text"/>	<input type="text"/>
.3 Bathing	<input type="text"/>	<input type="text"/>
.4 Dressing - Upper	<input type="text"/>	<input type="text"/>
.5 Dressing - Lower	<input type="text"/>	<input type="text"/>
.6 Toileting	<input type="text"/>	<input type="text"/>
.7 Bladder	<input type="text"/>	<input type="text"/>
.8 Bowel	<input type="text"/>	<input type="text"/>
Self-care Total:	<input type="text"/>	Quotient: <input type="text"/>
MOBILITY		
.9 Chair, Wheelchair	<input type="text"/>	<input type="text"/>
.10 Toilet	<input type="text"/>	<input type="text"/>
.11 Tub, Shower	<input type="text"/>	<input type="text"/>
.12 Walk/Wheelchair	<input type="text"/>	<input type="text"/>
.13 Stairs	<input type="text"/>	<input type="text"/>
Mobility Total:	<input type="text"/>	Quotient: <input type="text"/>
COGNITION		
.14 Comprehension	<input type="text"/>	<input type="text"/>
.15 Expression	<input type="text"/>	<input type="text"/>
.16 Social Interaction	<input type="text"/>	<input type="text"/>
.17 Problem Solving	<input type="text"/>	<input type="text"/>
.18 Memory	<input type="text"/>	<input type="text"/>
Cognition Total:	<input type="text"/>	Quotient: <input type="text"/>
WeeFIM Total:	<input type="text"/>	Quotient: <input type="text"/>

W-Walk
C-wheelChair
L-crawl
B-combination

A-Auditory
V-Visual
B-Both
V-Vocal
N-Nonvocal
B-Both

Leave no blanks. Enter 1 if not testable due to risk.
** Data item is for facility use only and is not transferred to UDSMR.

WEEFIM RATING LEVELS

INDEPENDENT - No helper
No Assistance - "no hands on"
(Applicable to Self-Care and Mobility Domains)

7 Complete Independence (No device, timely and safely)

6 Modified Independence (Device, not timely or not safely)

DEPENDENT - Helper

5 Supervision or set-up (Subject = 100%)
Assistance - "Hands on"
(Applicable to Self-Care and Mobility Domains)

4 Minimal Assistance (Subject = 75% to 99%)

3 Moderate Assistance (Subject = 50% to 74%)

2 Maximal Assistance (Subject = 25% to 49%)

1 Total Assistance (Subject less than 25%)

Family Centered Feedback section is adapted from:
King, S., Rosenbaum, P., and King, G.,
The Measure of Processes of Care (MPOC).

APPENDIX VIII
PedsQL4.0 Parent – Report

ID# _____

Date: _____

PedsQLTM
Pediatric Quality of Life
Inventory

Version 4.0

PARENT REPORT for TODDLERS (ages 2-4)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the **past ONE month** by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE month**, how much of a **problem** has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in active play or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Bathing	0	1	2	3	4
6. Helping to pick up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Playing with other children	0	1	2	3	4
2. Other kids not wanting to play with him or her	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

**Please complete this section if your child attends school or daycare*

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Doing the same school activities as peers	0	1	2	3	4
2. Missing school/daycare because of not feeling well	0	1	2	3	4
3. Missing school/daycare to go to the doctor or hospital	0	1	2	3	4

ID#

Date: _____

“

PedsQL

Pediatric Quality of Life Inventory

Version 4.0

PARENT REPORT for YOUNG CHILDREN (ages 5-7)

DIRECTIONS

On the following page is a list of things that might be a problem for **your child**. Please tell us **how much of a problem** each one has been for **your child** during the past **ONE** month by circling:

- 0 if it is **never** a problem
- 1 if it is **almost never** a problem
- 2 if it is **sometimes** a problem
- 3 if it is **often** a problem
- 4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

In the past **ONE** month, how much of a problem has your child had with ...

PHYSICAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Walking more than one block	0	1	2	3	4
2. Running	0	1	2	3	4
3. Participating in sports activity or exercise	0	1	2	3	4
4. Lifting something heavy	0	1	2	3	4
5. Taking a bath or shower by him or herself	0	1	2	3	4
6. Doing chores, like picking up his or her toys	0	1	2	3	4
7. Having hurts or aches	0	1	2	3	4
8. Low energy level	0	1	2	3	4

EMOTIONAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Feeling afraid or scared	0	1	2	3	4
2. Feeling sad or blue	0	1	2	3	4
3. Feeling angry	0	1	2	3	4
4. Trouble sleeping	0	1	2	3	4
5. Worrying about what will happen to him or her	0	1	2	3	4

SOCIAL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Getting along with other children	0	1	2	3	4
2. Other kids not wanting to be his or her friend	0	1	2	3	4
3. Getting teased by other children	0	1	2	3	4
4. Not able to do things that other children his or her age can do	0	1	2	3	4
5. Keeping up when playing with other children	0	1	2	3	4

SCHOOL FUNCTIONING (problems with...)	Never	Almost Never	Some-times	Often	Almost Always
1. Paying attention in class	0	1	2	3	4
2. Forgetting things	0	1	2	3	4
3. Keeping up with school activities	0	1	2	3	4
4. Missing school because of not feeling well	0	1	2	3	4
5. Missing school to go to the doctor or hospital	0	1	2	3	4

N° d'identification :

Date :

Peds QL

Inventaire de la qualité de vie des enfants

Version 4.0

**QUESTIONNAIRE DESTINÉ AUX PARENTS DE BAMBINS
(2 à 4 ans)**

MARCHE À SUIVRE

Sur la page suivante, nous avons dressé une liste de problèmes. Pour chacun, veuillez indiquer **avec quelle fréquence votre enfant a éprouvé ce problème le mois dernier** en encerclant une des affirmations suivantes :

- 0 Jamais
- 1 Presque jamais
- 2 À l'occasion
- 3 Souvent
- 4 Presque tout le temps

Il n'y a pas de bonne ni de mauvaise réponse.
Si vous ne comprenez pas une question, demandez des explications.

À noter que dans le présent document, le masculin englobe le féminin et vice versa.

Bambins (2-4)

Au cours du dernier mois, votre enfant a-t'il éprouvé certains des problèmes suivants :

FONCTIONNEMENT PHYSIQUE	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A de la difficulté à marcher.	0	1	2	3	4
2. A de la difficulté à courir.	0	1	2	3	4
3. A de la difficulté à participer à une activité ou à un exercice intense.	0	1	2	3	4
4. A de la difficulté à soulever un objet lourd.	0	1	2	3	4
5. Avons de la difficulté à lui donner son bain.	0	1	2	3	4
6. A de la difficulté à nous aider à ramasser ses jouets.	0	1	2	3	4
7. Éprouve des douleurs.	0	1	2	3	4
8. Manque d'énergie.	0	1	2	3	4

FONCTIONNEMENT ÉMOTIONNEL	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A peur.	0	1	2	3	4
2. Se sent triste.	0	1	2	3	4
3. Ressent de la colère.	0	1	2	3	4
4. A du mal à dormir.	0	1	2	3	4
5. Se tracasse.	0	1	2	3	4

FONCTIONNEMENT SOCIAL	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A du mal à jouer avec les autres enfants.	0	1	2	3	4
2. Les autres enfants ne veulent pas jouer avec lui.	0	1	2	3	4
3. Les autres enfants l'agacent.	0	1	2	3	4
4. N'est pas capable de faire des choses comme les autres les enfants de son âge.	0	1	2	3	4
5. A du mal à suivre lorsqu'il joue avec d'autres enfants.	0	1	2	3	4

**Veuillez remplir la section suivante si votre enfant va à l'école ou à la garderie.*

FONCTIONNEMENT SCOLAIRE	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A du mal à faire les mêmes activités que les autres.	0	1	2	3	4
2. Ne va pas à l'école ou à la garderie parce qu'il ne se sent pas bien.	0	1	2	3	4
3. Ne va pas à l'école ou à la garderie pour aller chez le médecin ou à l'hôpital.	0	1	2	3	4

N° d'identification :

Date :

Peds QL \ \

Inventaire de la qualité de vie des enfants

Version 4.0

QUESTIONNAIRE DESTINÉ AUX PARENTS DE JEUNE ENFANTS (5 à 7 ans)**MARCHE À SUIVRE**

Sur la page suivante, nous avons dressé une liste de problèmes. Pour chacun, veuillez indiquer **avec quelle fréquence votre enfant a éprouvé ce problème le mois dernier** en encerclant une des affirmations suivantes :

- 0 Jamais
- 1 Presque jamais
- 2 À l'occasion
- 3 Souvent
- 4 Presque tout le temps

Il n'y a pas de bonne ni de mauvaise réponse.

Si vous ne comprenez pas une question, demandez des explications.

À noter que dans le présent document, le masculin englobe le féminin et vice versa.

Au cours du **dernier mois**, votre enfant a-t-il éprouvé certains des **problèmes** suivants :

FONCTIONNEMENT PHYSIQUE	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A de la difficulté à marcher plus loin que le coin de la rue.	0	1	2	3	4
2. A de la difficulté à courir.	0	1	2	3	4
3. A de la difficulté à faire du sport ou de l'exercice.	0	1	2	3	4
4. A de la difficulté à soulever un objet lourd.	0	1	2	3	4
5. A de la difficulté à prendre un bain ou une douche sans aide.	0	1	2	3	4
6. A de la difficulté à faire des petits travaux comme ranger ses jouets	0	1	2	3	4
7. Éprouve des douleurs.	0	1	2	3	4
8. Manque d'énergie.	0	1	2	3	4

FONCTIONNEMENT ÉMOTIONNEL	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A peur.	0	1	2	3	4
2. Se sent triste.	0	1	2	3	4
3. Ressent de la colère.	0	1	2	3	4
4. A du mal à dormir.	0	1	2	3	4
5. Se fait du souci au sujet de ce qui va lui arriver.	0	1	2	3	4

FONCTIONNEMENT SOCIAL	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. A du mal à s'entendre avec les autres enfants.	0	1	2	3	4
2. Les autres enfants ne veulent pas de lui comme ami.	0	1	2	3	4
3. Les autres enfants l'agacent.	0	1	2	3	4
4. N'est pas capable de faire des choses comme les autres enfants de son âge.	0	1	2	3	4
5. A du mal à suivre les autres enfants.	0	1	2	3	4

FONCTIONNEMENT SCOLAIRE	Jamais	Presque jamais	À l'occasion	Souvent	Presque tout le temps
1. N'est pas attentif en classe.	0	1	2	3	4
2. Oublie des choses.	0	1	2	3	4
3. A du mal à faire tous ses devoirs.	0	1	2	3	4
4. Manque l'école parce qu'il ne se sent pas bien.	0	1	2	3	4
5. Manque l'école pour aller chez le médecin ou à l'hôpital.	0	1	2	3	4

APPENDIX IX

**Abstract presented to the 58th Annual Meeting of
the American Academy for Cerebral Palsy and
Developmental Medicine. Los Angeles, California,
2004.**

Association between quality of life and functional status in preschool aged children with developmental disabilities

LISA GRILLI BSC, PT, MSC(CAND); DEBBIE FELDMAN PHD,PT ; ANNETTE MAJNEMER PHD,OT; MELANIE COUTURE MA,OT, PHD(CAND); LAURENT AZOULAY MSC,PHD(CAND); BONNIE SWAINE PHD,PT.

(UNIVERSITÉ DE MONTRÉAL – ÉCOLE DE RÉADAPTATION, C.P. 6128, SUCC. CENTRE-VILLE, MONTRÉAL., CANADA H3C 3J7).

Background: Function and health related quality of life are two outcome measures frequently used in rehabilitation. There is a paucity of information on the association between these two concepts, notably in pediatrics.

Objectives: To determine the association between functional status as measured by the Functional Independence Measure for Children (WeeFIM) and health related quality of life as measured by the Pediatric Quality of Life Inventory (PedsQL4.0) for preschool children (2 to 5 years) with physical disabilities. To explore child, parent and service-related factors associated with each of these measures.

Design: Cohort study

Setting: Urban community

Patients: Participants included 98 caregivers of preschool children with physical disabilities who were referred to occupational (OT) or physical therapy (PT) in 2002-2003. Two-thirds of the parents were of Canadian origin, 88% had at least completed high school, and 23% had an annual income over \$60,000. Mean age of the children was 3.5 ± 0.8 years, 68.4% were boys and 56.1% were diagnosed with global developmental delay.

Measurements and Main Results: The WeeFIM and the PedsQL4.0 were administered at each child's home. Overall, children had more difficulties with self-care tasks and cognitive abilities, as compared to mobility activities on the WeeFIM. The total WeeFIM was moderately correlated with the total PedsQL4.0 (Pearson $r=0.40$, $p<0.001$). The WeeFIM mobility and self care quotients were each moderately correlated with the PedsQL-Physical Health Summary score (Pearson $r=0.47$, $p<0.001$ and Pearson $r=0.39$, $p<0.001$, respectively). There was no significant association between the WeeFIM cognition quotient and each of the PedsQL scores (Pearson $r=0.01$ to 0.07). The receipt of PT services was associated with lower scores on the PedsQL-Physical Health Summary score ($p<0.001$), total PedsQL score ($p=0.003$), WeeFIM mobility quotient ($p=0.003$),

as well as WeeFIM self-care quotient ($p=0.001$). Maternal education or family income were not associated with any WeeFIM or PedsQL4.0 score.

Conclusion: The WeeFIM and the PedsQL4.0 appear to assess different, although related constructs. This supports the need to incorporate complementary measures that are not only focused on function but also include general health and well being when measuring the overall status of children with disabilities.

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APPENDIX X
Co authors Accord

ACCORD DES COAUTEURS

1) Identification de l'étudiant et du programme

Lisa Grilli
 Département de réadaptation, faculté de médecine
 MSc. Sciences Biomédicales – option réadaptation

2) Description de l'article

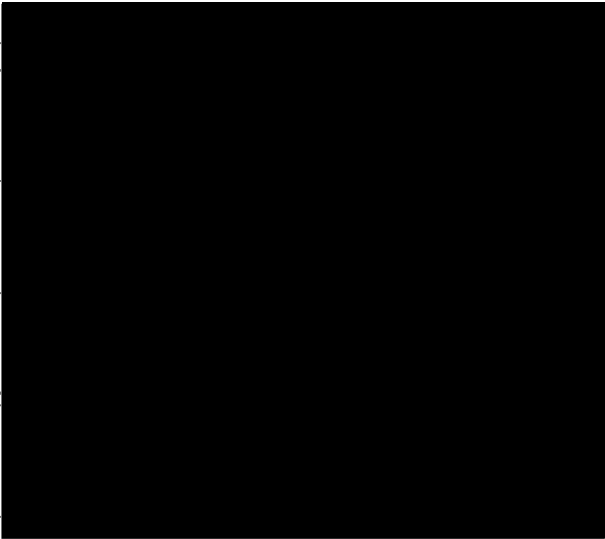
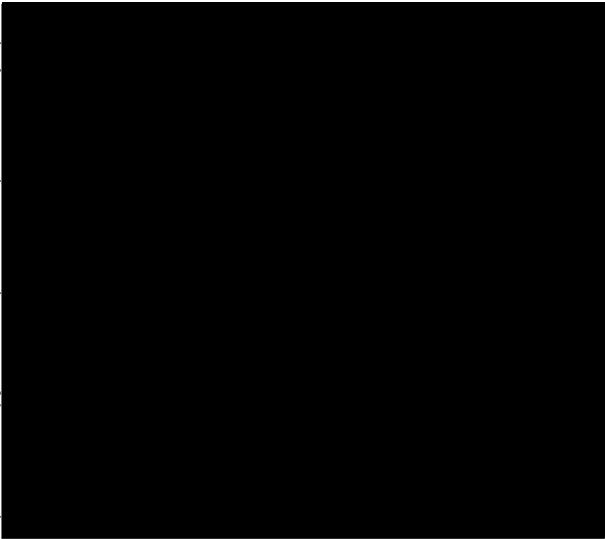
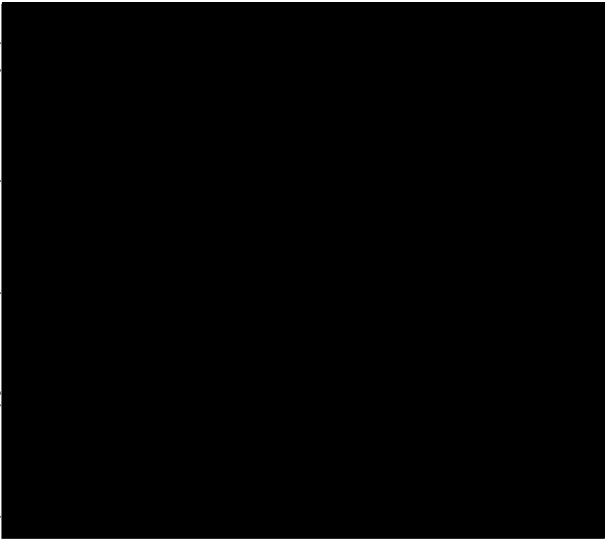
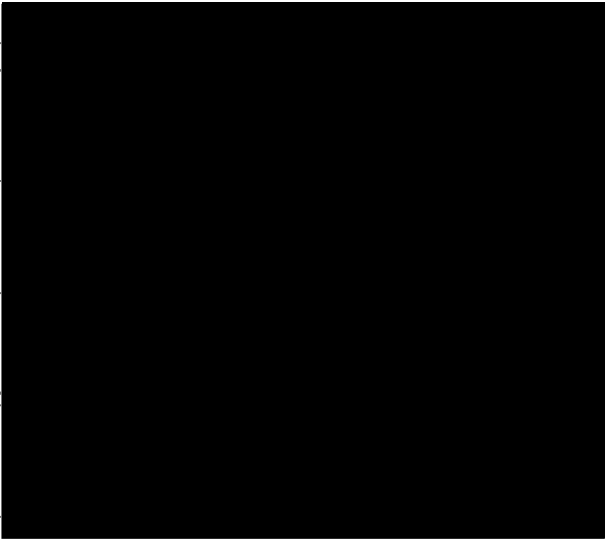
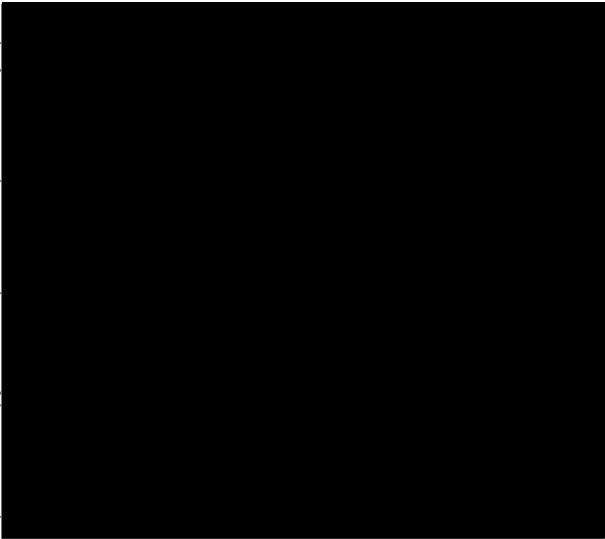
The Influence of Age, Diagnosis and Severity of Disability on the Waiting Time for Rehabilitation Services for Preschool-Aged Children with Physical Disabilities

Lisa Grilli PT, Debbie Ehrmann-Feldman PT PhD, Bonnie Swaine PT PhD, Julie Gosselin OT, PhD, François Champagne PhD, Raynald Pineault MD PhD

L'article est en phase finale de préparation.

3) Déclaration de tous les coauteurs

A titre de coauteur de l'article identifié ci-dessus, je suis d'accord pour que Lisa Grilli inclue cet article dans son mémoire de maîtrise qui a pour titre : Access to Rehabilitation for Young Children with Physical Disabilities.

<u>Debbie Ehrmann Feldman</u> Coauteur		<u>Jan 28/05</u> Date
<u>BONNIE SWAINE</u> Coauteur		<u>Feb 8, 2005</u> Date
<u>JULIE GOSSELIN</u> Coauteur		<u>25-02-2005</u> Date
<u>FRANCOIS CHAMPAGNE</u> Coauteur		<u>Feb 15/05</u> Date
<u>RAYNALD PINEAULT</u> Coauteur		<u>10 Jan. 2005</u> Date

ACCORD DES COAUTEURS

1) Identification de l'étudiant et du programme

Lisa Grilli
 Département de réadaptation, faculté de médecine
 MSc. Sciences Biomédicales – option réadaptation

2) Description de l'article

Associations between a Functional Independence Measure (WeeFIM) and the Pediatric Quality of Life Inventory (PedsQL4.0) in Young Physically Disabled Children Aged 2-5 years

Lisa Grilli PT, Debbie Ehrmann-Feldman PT PhD, Mélanie Couture OT MA, Laurent Y. Azoulay MSc, Annette Majnemer OT PhD, Bonnie Swaine PT PhD

L'article est en phase d'être soumis à *Developmental and Behavioral Medicine*.

3) Déclaration de tous les coauteurs

A titre de coauteur de l'article identifié ci-dessus, je suis d'accord pour que Lisa Grilli inclue cet article dans son mémoire de maîtrise qui a pour titre : Access to Rehabilitation for Young Children with Physical Disabilities.

DEBBIE EHRMANN FELDMAN
 Coauteur

Jan 28/05
 Date

MELANIE COUTURE
 Coauteur

Jan 28/05
 Date

Laurent Azoulay
 Coauteur

Jan 28/05
 Date

Annette Majnemer
 Coauteur

Feb 8/05
 Date

BONNIE SWAINE
 Coauteur

Mar 07/05
 Date

