Inter-relationships of functional status in children with cerebral palsy: An extension

Emily Dyszuk, The University of Western Ontario

Supervisor: Doreen Bartlett, The University of Western Ontario
A thesis submitted in partial fulfillment of the requirements for the Master of Science degree in Health and Rehabilitation Sciences
© Emily Dyszuk 2014
INTER-RELATIONSHIPS OF FUNCTIONAL STATUS IN CHILDREN WITH CEREBRAL PALSY: AN EXTENSION

(Thesis format: Monograph)

by

Emily Dyszuk

Health and Rehabilitation Sciences

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science

The School of Graduate and Postdoctoral Studies
The University of Western Ontario
London, Ontario, Canada

© Emily Dyszuk 2014
Abstract

The primary aim of this study was to establish functional profiles for children with cerebral palsy (CP), by determining the relationships between three classification systems (the Gross Motor Function Classification System, the Manual Ability Classification System, and the Communication Function Classification System). The secondary aim of this study was to investigate the number and impact of associated health conditions in the most prevalent clusters. Data were analyzed on 222 children with CP with an average age of 6.1 years, from several locations across North America. A total of 56 out of 125 possible combinations were recorded; four most prevalent cell combinations arose. The number and impact of associated health conditions increased incrementally as functional ability decreased. The use of these three functional systems, combined with data on associated health conditions, provides a holistic picture of CP to be used for practical and clinical purposes.

Keywords

Cerebral palsy, children, Gross Motor Function Classification System, Manual Ability Classification System, Communication Function Classification System
Acknowledgments

Without the supervision, guidance, and support from my supervisor, Doreen Bartlett, this thesis would not have been possible. I would also like to acknowledge my committee member, Marilyn Kertoy who provided insight and support throughout this process. Special thanks to the On Track Study for allowing me access to their database (Bartlett D., Westcott McCoy S., Chiarello L., Palisano B., Jefferies L., LaForme-Fiss A., Gorter J., and Hanna S.) and to fellow student, Deepa Jeevanantham, for her assistance in data entry and collection. Finally this study would not have been possible without the financial support from CIHR (Canadian Institutes of Health Research Operating Grant MOP #119276).
# Table of Contents

Abstract ................................................................................................................................. ii
Acknowledgments .................................................................................................................. iii
Table of Contents ................................................................................................................... iv
List of Tables .......................................................................................................................... vi
List of Appendices ................................................................................................................ vii
List of Abbreviations .............................................................................................................. viii
Chapter 1 Introduction .......................................................................................................... 1
Chapter 2 Literature Review .................................................................................................. 2
  2.1 Population of Interest: Cerebral Palsy ........................................................................ 2
  2.2 Non-Functional Classification Systems and Groupings ........................................... 3
  2.3 The International Classification of Functioning, Disability and Health and Cerebral Palsy .. 4
  2.4 Functionality .................................................................................................................. 5
  2.5 Functional Classification Systems ............................................................................... 6
    2.5.1 Gross Motor Function Classification System ..................................................... 6
    2.5.2 Manual Ability Classification System .................................................................. 7
    2.5.3 Communication Function Classification System ............................................... 8
  2.6 Relationships among Functional Classification Systems ............................................ 9
  2.7 Associated Health Conditions ..................................................................................... 11
  2.8 Summary of Literature Review .................................................................................... 13
Chapter 3 Objectives ........................................................................................................... 14
Chapter 4 Methods ............................................................................................................... 15
  4.1 Study Design ............................................................................................................... 15
  4.2 Sample ......................................................................................................................... 15
  4.3 Data Collection Tools .................................................................................................. 17
List of Tables

Table 1: Child Demographics ..............................................................................................................16
Table 2: Parent Demographics ............................................................................................................17
Table 3: Inter-relationships of all Three Functional Classifications .....................................................22
Table 4: Average Number and Impact of Prevalent Associated Health Conditions .........................24
Table 5: Proportion of Each Associated Health Condition in the Four Most Prevalent Groups ..........25
List of Appendices

Appendix A: Western’s Ethics Approval..........................................................................................40

Appendix B: Consent and Assent Forms .......................................................................................43

Appendix C: Gross Motor Function Classification System..............................................................52

Appendix D: Manual Ability Classification System.........................................................................56

Appendix E: Communication Function Classification System.........................................................59

Appendix F: Child Health Conditions Questionnaire....................................................................63

Appendix G: Family Information Form...........................................................................................69

Appendix H: Parents’ Classifications and Booklet Instructions.........................................................77

Appendix I: Assessors’ Classifications and Booklet Instructions.......................................................91
List of Abbreviations

**ASD:** Autism Spectrum Disorder

**CFCS:** Communication Function Classification System

**CP:** Cerebral palsy

**GMFM:** Gross Motor Function Measure

**GMFCS:** Gross Motor Function Classification System

**GMFCS – E&R:** Gross Motor Function Classification System: Expanded and Revised

**ICF:** The International Classification of Functioning, Disability and Health

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

**ICIDH:** International Classification of Impairment, Disabilities and Handicap

**MACS:** Manual Ability Classification System

**MRI:** Magnetic Resonance Image

**r_s:** Spearman’s correlation coefficient

**SCPE:** Surveillance of Cerebral Palsy in Europe

**WHO:** World Health Organization
Chapter 1 Introduction

International consensus was achieved to establish the current definition for cerebral palsy (CP) by Rosenbaum, Paneth, Leviton, Goldstein, and Bax, “as a group of permanent disorders of the development of movement and posture, causing activity limitation, that are attributed to non-progressive disturbances that occurred in the developing fetal or infant brain. The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems.” (1, pg. 9)

CP is the most common physical disability in children occurring in 2 to 2.5 per 1,000 live births. (2) CP is a heterogeneous condition in which every child presents with a variety of different characteristics. Much like the definition of CP was redefined to take into account recent advances in brain development and to improve the lines of communication between families and health professionals, (1) there is a need for meaningful classification systems. Classification systems allow for children to be categorized into various groups for description, prediction, and comparison purposes. (1)

The International Classification of Functioning, Disability and Health (ICF) (3) framework has been adopted by clinicians and researchers who work with children with CP. The ICF has changed how children with CP are classified as it places emphasis on the child’s functional abilities and typical performance rather than their health condition. (3,4) Classification tools have been developed to describe and assess how a child functions in daily activities, (5) like walking, (6) handling objects, (7) and everyday communication. (8) Functional activities in a child’s life can be assessed by using valid and reliable tools such as the Gross Motor Classification System (GMFCS), (6) the Manual Ability Classification System (MACS), (7) and the Communication Function Classification System (CFCS). (8)

Together, the three classification tools provide a comprehensive and meaningful picture of the functional profiles for children with CP, potentially improving communication among researchers, clinicians, and families. The primary aim of this study is to examine the relationships among the possible combinations of GMFCS, MACS, and CFCS levels to establish functional profiles for children with CP, and to describe the associated health conditions in the most prevalent profiles.
Chapter 2 Literature Review

Understanding the definition and diagnosis of CP is an important concept for individuals with CP, their families, and health care professionals to grasp, as it is a diverse health condition. Several classification schemes for CP have been adopted in general practice to aid in this process. There are two general types of classification systems that individuals should be aware of: non-functional and functional. The next section provides a more complete understanding of these two types of classification systems, focusing primarily on the benefits and relationships among functional classification systems. The next section begins with a further description of cerebral palsy and elaborates upon the utility of the ICF with respect to a focus on function.

2.1 Population of Interest: Cerebral Palsy

CP is a lifelong disability that is most noticeably characterized by a motor disorder, as is it defined as a group of non-progressive, non-contagious motor conditions that cause physical disability in human development, mainly in areas of body movement. As previously mentioned, CP is the most prevalent physical disability occurring in children, more frequently occurring in males due to intrinsic differences in chromosomal complements. A diagnosis of CP is typically given in the early years of life when its effects are manifested. CP was recognized more than 150 years ago and since then several revisions have been made to the definition and various classification systems have been developed to provide a more conclusive understanding of this complex condition.

There is no common cause of CP, making the diagnosis difficult at times because CP is an umbrella term for several brain anomalies. Factors like genetics, disease, brain injury, infections, and anoxic injuries to the developing brain can cause CP. Subtypes of CP can be detected in some cases from a Magnetic Resonance Imaging (MRI) scan that identifies the location and type of brain injury. Children who are diagnosed with CP can then be placed into subgroups based on different classification criteria. Various classification systems serve different purposes as they emphasize specific characteristics of CP, often broken down into non-functional and functional classification systems.
2.2 Non-Functional Classification Systems and Groupings

There are three primary methods to classify children with CP from a non-functional perspective: 1. causation and neuroimaging 2. type of motor disorder; 3. distribution of involvement. Etiologic classification is not as popular and has not been found to be successful in addressing the primary goal of prevention. \(^{(16)}\)

Currently there is no singular and definite explanation for the causation of CP, just potential risk factors and associations that by themselves or in conjunction with each other may cause CP. \(^{(17)}\) Previously it was thought that the main cause of CP could be linked to an interruption in oxygen supply to the brain of the fetus. \(^{(18)}\) However, more recent research indicates that asphyxial birth is a small contributor to the cause of CP and disturbances such as malformations, arterial ischemic strokes, and/or exposure to \textit{in utero} infections and inflammation, in term and near-term infants are more predominant causes. \(^{(19,20)}\)

Classifying children by neuro-imaging findings is something that is anticipated to happen in the future, when it becomes more feasible. \(^{(13)}\) Neuro-imaging is currently useful in determining structural or functional relationships with children with CP \(^{(21,22)}\) and aids in the understanding of the etiology and pathologies of CP. \(^{(23)}\) Neuroimaging through the use of an MRI or computed tomography detects abnormal neuroradiological findings in 80 to 83% of children with CP, depending on the study. These abnormal neuroradiological findings show that white matter damage is the most common abnormality. \(^{(15,23,24)}\) In a large population-based study investigating term and near-term infants, 32% displayed acute brain injury that occurred around the time of birth, including acute perinatal focal arterial infraction, hypoxic-ischemic brain injury, and intracranial hemorrhage. \(^{(25)}\) A similar study supports these neuroimaging findings, linking the experience of a perinatal or neonatal event to the development of CP (36%). \(^{(26)}\) In the future, it is anticipated that neuroimaging will continue to assist in increasing understanding of brain abnormalities and further allow establishment of the timing and possible cautions of these brain abnormalities present in children with CP. \(^{(15,27)}\)

The Surveillance of Cerebral Palsy in Europe (SCPE) classifies children with CP in a hierarchical manner based on their predominant medical disability. \(^{(28)}\) The SCPE formed a network in Europe and referred to the definition similar to that of Mutch and colleagues \(^{(12)}\) and developed a
classification system for describing children with CP for population-based registers. (29) Children with CP can be classified into two main physiologic groups: pyramidal and extrapyramidal. Pyramidal refers to CP in which spasticity is the predominant sign. The extrapyramidal subgroup is associated with the type of motor disorder referring to ataxia and dyskinetic, the latter of which is further subdivided into choreo-athetosis and dystonia. (30) This method has been adopted in Europe to classify children with CP, sometimes adding in a final group of “mixed” or other. (29)

Healthcare providers in Europe and Australia further classify individuals with CP based on their predominant limb distribution: quadriplegia, triplegia, diplegia, and hemiplegia adding more detail to the classification. (29) In a surveillance study conducted in Europe, traditional clinical terminology for describing the subtypes of CP referred to the child’s limb distribution or motor impairment, (29) however this method of classification is viewed as unreliable. (31)

Generally, physiologic and topographic classifications like the ones previously mentioned have poor reliability and validity and do not incorporate functional abilities, focusing primarily on impairments of the condition. (32) These classification systems provide limited assistance in therapeutic decision making and do not provide a clear and concise understanding of how a child with CP functions in daily life.

2.3 The International Classification of Functioning, Disability and Health and Cerebral Palsy

The International Classification of Impairment, Disabilities and Handicap (ICIDH) was a model of disablement focusing on the negative aspects of the disability and how it limited an individual or handicapped them. (33) The World Health Organization (WHO) redefined the ICIDH and developed the ICF to provide a common and universal language and terminology for classifying individuals based on body functions and structures, activity and participation, and environmental and personal factors. New to the ICF is the incorporation of two contextual factors: environmental and personal. (3) The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) was later developed to encompass the rapid changes in growth that occur in children and youth physically, socially, and psychologically. (34)
The focus of the ICF shifted from the negative aspects of the associated health conditions, to looking at the functional potential in individuals and replacing the word ‘disability’ with activity limitation and ‘handicap’ with participation restriction. (3) The ICF has both a conceptual framework and a coding system. The ICF conceptual framework can be useful because it demonstrates the nonlinear connection between the associated health conditions (e.g. CP) and body functions and structures, activities and participation, and environmental and personal factors. (35) The coding system, although extensive, lacks the ability to classify children by their developmental functional abilities. (36,37)

The ICF plays a prominent role in the definition and rehabilitative goals of CP (35). As previously indicated, activity limitation involving motor function is a defining feature of CP. (1) Children with CP generally have lower levels and less intensity of participation compared to children developing typically, partially due to their limitations in functional abilities. (38,39) The promotion and emphasis placed on the significance of the ICF concepts activity and participation is an important outcome for children with CP because it helps develop friendships, personal interests, and identities and enhances skills of competencies. (35,40) Focusing on children’s functional abilities can help to enhance participation at school, as a positive relationship was observed between increased levels of participation and Intelligence Quotient levels, as well as increased levels of daily communication. (40,41) The ICF has established this by changing the perspective of CP from a child with a disease to focus on the child’s functional ability. (4)

2.4 Functionality

Functional skills refer to activities that are performed in day-to-day life, like walking, sitting, eating, dressing, and communicating which allow individuals to participate in life situations. (42) As previously indicated, assessing and emphasizing a child’s capabilities rather than their limitations is a key concept of the ICF, playing an integral role in the definition of CP. (3) There is a greater emphasis on the promotion of functional skills in children with CP than there has been in the past. (43,44) Researchers are advocating that rehabilitative goals should focus more on children mastering activities of daily living instead of focusing on the movement impairments. (45) Functional profiles can be used to help improve communication between families and health care professionals and helpful in a clinical setting for rehabilitation purposes. (46) Functional profiles, like the ones proposed in Hidecker’s study, (46) combine more than one classification system, providing
a more holistic picture about the relationships among domains such as mobility, handling objects, and communication.

2.5 Functional Classification Systems

Functional classification systems focus on a child’s functional abilities and what they can do instead of grouping them by their impairments. Functional classifications allow for children with CP to be classified into categories or levels based on similar abilities. In this study, three functional classification systems, the GMFCS, MACS, and CFCS, when combined are proposed to establish a holistic picture of a child’s everyday life.

2.5.1 Gross Motor Function Classification System

The GMFCS is a functional classification system that takes into consideration a child’s self-initiated movement, with emphasis on sitting, transfers, and mobility, providing a standardized system to measure the ‘severity of movement disability’. The expanded and revised Gross Motor Function Classification System (GMFCS – E&R) was developed to expand the inclusion age for children up to the age of 18 years and to incorporate the ICF’s environmental and personal factors into the classification system.

There are 5 levels (I to V) that make up the system and form an ordinal scale. Children, between 6 and 12 years of age, in level I can walk without limitations on all surfaces. Children in level II walk with some limitations, often when walking on uneven surfaces outdoors. Children in level III require a hand-held mobility device indoors and may require the use of a wheeled device outdoors. Children in level IV generally have self-mobility with limitations, control of their head, and may use a powered mobility device. Children in level V typically require a manual wheelchair to move and have severe limitations with head and neck control. Each level is broken down into 5 age bands: before the age of 2, between the ages of 2 to 4 years, 4 to 6 years, 6 to 12 years, and between the age of 12 and 18 years. The differences between each level are based on variations in functional limitations. Although GMFCS levels provide a good understanding of the child’s walking abilities, gross motor function is not the only defining feature of children with CP.

Both the GMFCS and GMFCS – E&R were developed through consensus, by use of the Delphi survey. The GMFCS has a strong interrater reliability with a Kappa coefficient of 0.75 for
children between 2 and 12 years of age. \(^{(5)}\) Higher interrater reliability between therapists, of a Kappa coefficient of 0.98, was examined in a smaller sample of children with CP and periventricular white matter injury. \(^{(48)}\) Excellent construct validity was established for GMFCS levels, by Palisano and colleagues by observing the correlations between GMFCS levels and Gross Motor Function Measure (GMFM) \(^{(49)}\) scores \((r = - 0.91)\). \(^{(50)}\) Content validity has been established for the GMFCS – E&R through Delphi survey \(^{(6)}\) and interrater reliability for the older age group of 12 to 18 years of age has been established for the Turkish, Portuguese-Brazil, and Chinese versions of the GMFCS – E&R. \(^{(51,52,53)}\) The GMFCS is used internationally and is available in several different languages. \(^{(54)}\) Predictions of the average development of GMFCS levels have been constructed and support the validity of the classification system. The Ontario Motor Growth curves relate the Gross Motor Function Measure – 66 (GMFM-66) \(^{(49)}\) score to age and display the differences among the GMFCS levels and reveal that children reach 90% of their motor function by 5 years of age. \(^{(55)}\) The system has achieved its original purpose and is used as a simple and well-recognized method to classify children with CP and has demonstrated increased use in clinical and family-centered practice. \(^{(56)}\) As mentioned earlier, the GMFCS- E&R incorporated the ICF concepts and examined the environmental and personal factors impact on a child’s functional performance. \(^{(6)}\)

2.5.2 Manual Ability Classification System

The MACS parallels the general concept of the GMFCS, in that it observes the child’s usual performance in everyday life; however, it focuses on the child’s fine motor movement, classifying what a child regularly does with his or her hands in daily life rather than an individual’s best capacity. To ensure that this concept of the child’s regular performance is captured in the classification, a parent or caregiver is involved in the classification process, as they witness the child’s hand behaviour in daily routines in natural environments. \(^{(7)}\)

The design structure of the MACS is similar to that of the GMFCS, in that there are five levels (I to V) which make up an ordinal scale. In Level I, the child easily handles objects independently with no ability restrictions. In level II, the child is able to handle most objects, but may struggle sometimes with a reduction in speed and precision and may use alternative methods. In level III, the child struggles with handling objects and requires modifications and adaptions to be made and set up in advance to allow for independent activities. In level IV, the child can handle a limited
selection of easily managed objects in adapted situations and require monitoring to ensure
continued success with adaptations. In level V, the child requires full assistance to handle an
object. Unlike the GMFCS, there are no age bands included in the classification system. Instead,
age appropriate objects and activities are taken into consideration when classifying at how a child
performs bilateral hand movements. \(^{(7)}\)

The MACS is a valid, reliable, and stable classification system for children between the ages of 4 to
18 years. \(^{(57,58)}\) Reliability for children aged 2 to 5 was found to be good in one study with a
weighted Kappa of 0.67; however, further development of the validly and reliability for using MACS
on children under the age of 4 is suggested. \(^{(59)}\) High intrarater reliability was established between
therapists with an intraclass correlation coefficient (ICC) of 0.97 and between parents and
therapists with an ICC of 0.96. \(^{(7)}\) In another study a slightly higher intrarater reliability was
observed between therapists with a Kappa coefficient of 1.0. \(^{(48)}\) The reliability of using the MACS
was reaffirmed with ICC values ranging from 0.66 to 1.0 among professionals and 0.73 to 0.85
between parents and health professionals. \(^{(57)}\) The GMFCS and the MACS focus on the child’s
gross and fine motor ability; however, it is important to look at all aspects of children’s lives,
including how they communicate with others.

2.5.3 Communication Function Classification System

The third functional classification system, the CFCS, classifies children with CP according to their
everyday communication performance. \(^{(8)}\) Five levels (I to V) form the ordinal scale for children
between the ages of 4 and 18 years. A child with level I is effective at communicating with
unfamiliar and familiar partners at a typical conversational pace. In level II, the child communicates
with unfamiliar and familiar partners with a slower pace. A child with level III communicates
effectively with people that he or she is familiar with, but not with people who are unfamiliar. A child
with level IV demonstrates inconsistent communication with familiar partners. A child with level V
rarely demonstrates effective communication with familiar partners. \(^{(8)}\) Similar to the MACS, the
level is determined by a parent or caregiver who is familiar with the child’s daily communication
abilities and a health professional and distinct age bands have not been incorporated.

Similar to the GMFCS and the MACS, the CFCS used nominal groups and the Delphi survey
consensus methods to develop this classification system. \(^{(8)}\) Inter-rater reliability was established
using a weighted Kappa. Among professionals it was 0.66 and improved to 0.77 when used on children 5 years of age and older. Interrater reliability was moderate between parents and health professionals with a weighted Kappa of 0.49 and decreased to 0.42 for children who were 5 years of age and older. (8) A strong interrater reliability between therapists was examined in children with CP and periventricular white matter injury, with a Kappa coefficient of 0.98. A possible explanation for this higher interrater reliability is due to a small sample and narrow variance between raters. (48) Test-retest reliability for professionals was strong with a weighted Kappa of 0.82. (8,48)

The GMFCS, MACS, and CFCS all have a similar parallel structure in their design concepts. All three classification systems focus on the child’s functional ability examining their everyday performance, have 5 levels on an ordinal scale, and are designed for children with CP. However, unlike the GMFCS and MACS which focus primarily on the individual’s motor function, the CFCS focuses more on the individual’s participation in communication, providing a more complete description of all aspects of the functional abilities of a child with CP.

2.6 Relationships among Functional Classification Systems

Understanding the relationship among different classification systems is receiving more attention as this understanding provides clinicians, researchers, and families with a greater appreciation of the functional abilities of children with CP. More research has been conducted on the relationships between the GMFCS and the MACS, compared to the CFCS, because the MACS was established prior to the CFCS. One study found an overall poor association between the GMFCS and the MACS with a Kappa value of 0.32. (60) However, it was noted that the relationship between the GMFCS and MACS classification systems were complementary to each other providing a more complete description of the functional abilities of a child with CP, (4,60,61) as they are constructed from the same ICF concepts and focus on the child’s usual abilities in the home, school, and community. (60,62) The GMFCS and MACS was used to assess upper limb function in individuals with spastic CP, comparing unilateral and bilateral hand movement. Common profiles were not observed in Park and colleague’s research, as 53.5% of the study exhibited different levels of GMFCS and MACS with a weighted Kappa of 0.55 between systems. Correlations between GMFCS and MACS for children with unilateral hand movement were lower ($r_s = 0.60$) compared to bilateral hand movement ($r_s = 0.72$). (63) The researchers concluded that there was a greater
variation in bimanual activities and gross motor function in children with CP and further research should be conducted on a population-based sample to support the evidence.

The GMFCS, MACS, and CFCS provide complementary systems for health professionals and researchers to describe the functional abilities of children with CP. To date, only one paper has described the functional relationships among the GMFCS, MACS, and CFCS. However, one paper observed the relationship among the CFCS, CP subtype, gross motor function, manual ability, cognitive function and neuroimaging findings. This study found that communication profiles existed and could be derived from the CFCS because it correlated to gross motor, fine motor, and cognitive functions. Although this study found functional communication profiles it did not report the relationship among all three classification systems providing an overall functional profile. It reported associations of the CFCS to the GMFCS and the CFCS to the MACS. A strong correlation with both the GMFCS and MACS was found according to Spearman’s correlation coefficient of 0.78 and 0.80, respectively. This study provided a more in-depth understanding of the communication abilities of children with CP and their association to CP subtype, gross and fine motor function, and cognitive function.

Hidecker and colleagues established functional profiles for children with CP by combining these three classification systems. In terms of the bivariate relationships, the GMFCS and the MACS were strongly correlated ($r_s = 0.69$), the MACS and the CFCS were moderately correlated ($r_s = 0.54$), and the GMFCS and the CFCS were moderately correlated ($r_s = 0.47$). Of the 125 possible cell combinations, 62 cells were filled. They found that the functional profile of all level I was most frequently observed in 10% of the sample, followed by GMFS level II, MACS level I, and CFCS level I, and of GMFCS level II, MACS level II, and CFCS level I, both profiles combined representing 5% of the sample. Limitations with the Hidecker study were the relatively small sample size (n=222) and the clinic sampling. A larger sample size is required to examine the 125 possible combinations of GMFCS, MACS, and CFCS levels to determine if similar functional profiles can be established. Health conditions and how they are associated with the functional profiles of children with CP were not taken into consideration in their study. As CP is such a diverse condition, often accompanied by co-occurring impairments and comorbidities, it is important to ascertain the frequency of various associated health conditions and their associated impact.
2.7 Associated Health Conditions

Every child with CP displays different characteristics at varying levels, making each diagnosis unique. This is due to the fact that CP is, “…often accompanied by other disturbances of sensation, perception, cognition, communication, and behaviour; by epilepsy, and by secondary musculoskeletal problems.” (1) Although CP is a non-progressive brain injury, as individuals with CP age, their quality of life is influenced by co-occurring impairments, diseases, and functional limitations. (65) It is important to understand the health conditions associated with CP, because they can potentially have impact on the individual and the family. (66)

A population-based systematic review on associated health conditions, diseases, and functional limitations found that among children with CP 3 in 4 were in pain; 1 in 2 had an intellectual disability; 1 in 3 could not walk; 1 in 3 had a hip displacement; 1 in 4 could not talk; 1 in 4 had epilepsy; 1 in 4 had a behavior disorder; 1 in 4 had bladder control problems; 1 in 5 had a sleep disorder; 1 in 5 dribbled; 1 in 10 were blind; 1 in 15 were tube-fed; and 1 in 25 were deaf. (67) This study was limited in that only articles published in English were used and the data were subject to publication biases. In contrast, a North American population-based study investigating children with CP under the age of 5 years, found that the burden of comorbidities occurred in less than 25% of the study sample. (68) The most frequently occurring comorbidities in the study sample were: non-verbal (22.2%), active afebrile seizure disorder (16.9%), severe auditory impairment (11.5%), cortical blindness (9.5%), and gavage feeding requirement (7.8%). The increased burden experienced by the child and family, with these co-occurring comorbidities, was more frequent in children with ataxic-hypotonic, spastic quadriplegic, and dykinetic CP compared to children with spastic diplegia. (68) Both of these population-based studies clearly demonstrate the wide range and extent of associated health conditions that can affect a child’s life.

Wong and colleagues supported these findings and compared the prevalence and impact of associated health conditions of pre-school children with and without CP. (69) They established that children with CP were found, on average, to have 3.4 to 6.7 health conditions for children ranging in all GMFCS levels, compared to an average of fewer than one for typically developing children. They found that the prevalence of associated health conditions increased with lower GMFCS functional levels, with the exception of teeth and gum, sleeping, and breathing problems, which did not follow this trend. The relationship between less functional GMFCS levels and increased
impact experienced by the child and family from the co-occurring comorbidities was also observed in a population-based study.\(^{(68)}\) Similar findings indicate that children with lower levels of functioning who present with more than one health condition are more likely to have a poorer overall health status.\(^{(70)}\) However in this study, the prevalence and impact of associated health conditions was experienced among children with CP in all levels of GMFCS and the correlations between gross motor function and health status as reported by parents found that health was not a valid indicator of the child’s functional abilities.\(^{(70)}\)

A multicenter population-based cross sectional study of 235 children found that children with CP required more medication than a typically developing child.\(^{(71)}\) Liptak and colleagues also found that children who required the use of feeding tubes experienced more burdens, as they were typically at a lower functional ability, had increased medication usage, and experienced respiratory problems.\(^{(71)}\) There is a wide range of behavioural issues that is five times more likely to be present in children with CP as reported by their parents in a national survey.\(^{(72)}\) Behavioural problems are seen as problematic for children with CP and affect their daily lives, specifically behaviours of dependency, being headstrong, and hyperactive.\(^{(72)}\) It should be recognized how each different combination of associated health conditions affects and reflects the child’s overall health status.

As previously mentioned in the definition of CP by Rosenbaum and colleagues,\(^{(1)}\) epilepsy is often associated with with CP, occurring in approximately 30 to 35% of children with CP.\(^{(73-75)}\) A study conducted in the United States reported the proportion of children with CP who were also diagnosed with Autism Spectrum Disorder (ASD), epilepsy, or both and found opposite relationships between the two associated health conditions. The proportion of children with CP and epilepsy increased in relationship to the child’s decreasing walking ability. Opposite to epilepsy, ASD was found to be more common among children with CP who could walk independently.\(^{(73)}\)

There are a wide range of associated health conditions which can affect the lives of individuals with CP and their families. It is important to determine the prevalence and impact of associated health conditions to aid in understanding the diagnosis and developing appropriate rehabilitation
programs. Understanding how other associated health conditions can impact a child's development will contribute to providing a more complete functional profile.

2.8 Summary of Literature Review

The literature identifies that functional classification systems focus more on the child's ability compared to their health condition according to diagnosis alone. By focusing on the child’s everyday functions, the individual, their families, and health care professionals can improve communication. There is a current gap in the literature in that holistic functional profiles have not been established and validated for all children with CP. More research is required to examine the functional relationships among the GMFCS, MACS, and CFCS to provide individualized profiles. To more fully understand how CP affects a child's life, associated health conditions must also be considered, including the role that they play in the development of the child. By classifying children with CP based on their motor ability, bilateral hand movement, and their everyday communication, as well as how associated health conditions impact their lives, a more holistic view of CP will be achievable, aiding in communication, clinical practice, and research.
Chapter 3 Objectives

The primary objective was to establish functional profiles for children with CP by examining the relationships among the GMFCS, MACS, and CFCS levels in children with CP. Specific objectives included:

1. Determining the bivariate correlations between the GMFCS and the MACS, the GMFCS and the CFCS, and the MACS and the CFCS.
2. Determining the total number of combinations that arise from the 125 possible profile cells.
3. Determining the proportion of the same level in all three classification systems.
4. Determining the most frequent combinations.

The secondary objective was to describe the prevalence and impact of associated health conditions in the most frequent functional profiles for children with CP and to determine any significant differences among the groups.

It was anticipated that there would be a relatively small proportion of frequently occurring profiles in children with CP as every child with CP is unique and presents with different variations in functional levels and associated health conditions.
Chapter 4 Methods

4.1 Study Design

This is a descriptive study to describe the possible combinations of the GMFCS, MACS, and CFCS among children with CP and the prevalence and impact of associated health conditions of the most frequently occurring clusters. This study is part of a five-year prospective cohort study, Developmental Trajectories of Impairments, Associated Health Conditions and Participation of Children with CP: The On Track Study (CHIR MOP# 119276). Ethical approval for this research was granted by The University of Western Ontario (Appendix A), as well as participating universities and sites in the United States of America and Canada.

4.2 Sample

Eligible participants in this study must have been diagnosed with CP or were suspected to have CP at the time of recruitment. Children participating in the On Track study were between the ages of 18 months and 10 years at the time of recruitment. The inclusion criteria for setting the minimum age to 18 months allows for a more complete data set to be taken from the earliest age at which it is possible to assess children in other measures in the On Track Study. Although in many parts of the world a diagnosis is not given until a much older age, eighteen months of age allows for a fairly confident diagnosis of CP to be given to children. The minimum age was also selected because by the time the study is complete the youngest children (18 months) will be older than 2 years and a firm diagnosis of CP or a significant gross motor delay can be established by a physician. This minimum inclusion age range was also chosen because GMFCS levels are valid and reliable for children starting at the age of 2 years. In this report only children over two years of age are included. The maximum age restriction of 10 years allowed data to be collected for preschool and elementary school-aged children, as the oldest child would be 12 years of age, at the end of the one-year study period for each child. Families were excluded from the study if they did not speak English, French, or Spanish.

A convenience sampling approach was taken to recruit participants for the study from clinical sites across Canada and the United States, including children from urban, rural, and suburban areas for a more representative sample. Variable methods were used to recruit participating families;
families were first approached either by mail or in person with a recruitment pamphlet followed by a letter of information. All parents provided signed consent on behalf of themselves and their children and children over 7 years provided signed assent (Appendix B). A targeted sample size of 875 children for the study aimed to achieve the goal of 175 children in each GMFCS level for the On Track study. For the purpose of this study an analysis of all of the children in the data set by April 30, 2014 who were over two years of age were included. Child participant demographics (n=222) are presented in Table 1.

Table 1: Child Demographics

<table>
<thead>
<tr>
<th>Total (n = 222)</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age - years</td>
<td>n = 218</td>
</tr>
<tr>
<td>Mean</td>
<td>6.1</td>
</tr>
<tr>
<td>Standard Deviation (SD)</td>
<td>2.6</td>
</tr>
<tr>
<td>Range (min, max)</td>
<td>9.46 (1.5, 11.0)</td>
</tr>
<tr>
<td>Gender – n (%)</td>
<td>n = 216</td>
</tr>
<tr>
<td>Boy</td>
<td>114 (53)</td>
</tr>
<tr>
<td>Girl</td>
<td>102 (47)</td>
</tr>
<tr>
<td>Limb Distribution – n (%)</td>
<td>n = 220</td>
</tr>
<tr>
<td>Monoplegia</td>
<td>5 (2)</td>
</tr>
<tr>
<td>Hemiplegia</td>
<td>62 (28)</td>
</tr>
<tr>
<td>Diplegia</td>
<td>59 (27)</td>
</tr>
<tr>
<td>Triplegia</td>
<td>13 (6)</td>
</tr>
<tr>
<td>Quadriplegia</td>
<td>81 (37)</td>
</tr>
</tbody>
</table>

*note

SD = Standard Deviation
Parent demographics are described in Table 2.

Table 2: Parent Demographics

<table>
<thead>
<tr>
<th></th>
<th>Total (n = 222)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age - years</td>
<td>n = 211</td>
</tr>
<tr>
<td>Mean</td>
<td>37.5</td>
</tr>
<tr>
<td>Standard Deviation (SD)</td>
<td>6.8</td>
</tr>
<tr>
<td>Range (min, max)</td>
<td>44 (20, 64)</td>
</tr>
<tr>
<td>Relationship to child – n (%)</td>
<td>n = 216</td>
</tr>
<tr>
<td>Mother/Adoptive Mother</td>
<td>193 (89)</td>
</tr>
<tr>
<td>Father/Adoptive</td>
<td>15 (7)</td>
</tr>
<tr>
<td>Father/Stepfather</td>
<td></td>
</tr>
<tr>
<td>Other (Aunt, Foster Mother, Grandmother, Grandfather, nurse in LTC)</td>
<td>8 (4)</td>
</tr>
<tr>
<td>Marital Status – n (%)</td>
<td>n = 215</td>
</tr>
<tr>
<td>Married or living with a partner</td>
<td>184 (86)</td>
</tr>
<tr>
<td>Never Married</td>
<td>14 (6)</td>
</tr>
<tr>
<td>Separated/Divorced</td>
<td>17 (8)</td>
</tr>
<tr>
<td>Education Level – n (%)</td>
<td>n = 213</td>
</tr>
<tr>
<td>Less than high school</td>
<td>5 (2)</td>
</tr>
<tr>
<td>High school</td>
<td>41 (19)</td>
</tr>
<tr>
<td>Community College</td>
<td>58 (27)</td>
</tr>
<tr>
<td>Bachelors Degree</td>
<td>66 (31)</td>
</tr>
<tr>
<td>Master Degree</td>
<td>26 (17)</td>
</tr>
<tr>
<td>Doctoral Degree</td>
<td>7 (4)</td>
</tr>
<tr>
<td>Total household income (before taxes) – n (%)</td>
<td>n = 222</td>
</tr>
<tr>
<td>Less than $15,000</td>
<td>3 (1)</td>
</tr>
<tr>
<td>$15,000 - $29,999</td>
<td>14 (6)</td>
</tr>
<tr>
<td>$30,000 - $44,999</td>
<td>16 (7)</td>
</tr>
<tr>
<td>$45,000 - $59,999</td>
<td>14 (6)</td>
</tr>
<tr>
<td>$60,000 - $74,999</td>
<td>21 (10)</td>
</tr>
<tr>
<td>$75,000 - $89,000</td>
<td>23 (11)</td>
</tr>
<tr>
<td>$90,000 or more</td>
<td>89 (40)</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>42 (19)</td>
</tr>
</tbody>
</table>

*note
SD = Standard Deviation
LTC = Long Term Care

4.3 Data Collection Tools

The GMFCS, (5,6) MACS, (7) and CFCS (8) classification tools were used to determine an appropriate level for each child in the three areas of motor, hand, and communication functions.
There are five distinct levels (level I to level V) in each of the three classification systems that form an ordinal scale. The GMFCS assesses a child’s self-initiated movement, from the age of 2 years to 18 years (Appendix C). \(^{(5,6)}\) The MACS tool was designed to assess how a child handles objects in daily life for children between the ages of 4 to 18 years (Appendix D). \(^{(7)}\) The CFCS observes the child’s everyday communication performances and is valid for children between the ages of 4 and 18 years (Appendix E). \(^{(8)}\) As described previously, all classification systems have evidence of reliability and validity.

Each child’s associated health conditions were measured using the Child Health Conditions Questionnaire (Appendix F). \(^{(69)}\) The questionnaire consists of 16 items pertaining to various health problems, for example seeing, digestion, breathing, skin, communication, heart, pain, and sleeping. Each item is rated on a 7-point Likert scale to determine the extent to which the problem affects the child’s daily activities, from 1 “not at all” to 7 “to a very great extent”. These 16 health items were developed based on a functioning aspect of components similar to body functions in the ICF. The Child Health Conditions Questionnaire demonstrated good test-retest reliability with an ICC of greater than 0.80 for both number and impact of associated health conditions. \(^{(69)}\) Both the number of associated health conditions and the average impact were used to describe the health status of the most frequent clusters. In addition, parents completed a demographic questionnaire (Appendix G). These data (in addition to distribution of limb involvement) were used to describe the sample.

### 4.4 Data Collection Procedures

Data collection on the classification levels was completed by the parent or caregiver and by the assessing therapist. Parents recorded what they perceived to be their child’s level using the “Questions about your child’s usual abilities at home, school and in the community” form in the Parent Booklet: Time 1 Assessment (Appendix H). During the one-hour assessment the assessor also classified the children into the level that they felt was appropriate for the GMFCS, MACS, and CFCS, using the “Classification Systems” form in the Assessor Booklet: Time 1 Assessment (Appendix I). Consensus for GMFCS, MACS, and CFCS levels must have been reached between parent or caregiver and the assessing therapist. If consensus agreement on the three classification systems was not reached initially, the therapist and primary caregiver were to discuss the classification levels together until they came to an agreement or reported that an agreement
was not met. Decision algorithms and flow charts to help with the determination of the various levels were provided in all study kits to aid in the consensus process and decisions between levels (refer to previous GMFCS (Appendix C), MACS (Appendix D), and CFCS (Appendix E) classification appendices). In the portion of the Assessor Booklet Collecting data on classification (Appendix I) there were three columns for entry data. The three columns recorded data on if initial consensus was achieved by both the parent and the assessor (first column), if either the parent or therapist revised their classification based on discussion and came to consensus on the level (second column), or if the classification remained different between the parent and the assessor (third column). For the purpose of this study, data recorded in the first two columns were used to identify each child’s level. Participants for whom consensus was not obtained were excluded.

Parents or caregivers had the option of completing a hard copy or an online version of the data collection booklet. All therapists completed a hard copy of the assessor data collection booklet. Completed hard copies of the data collection booklets were couriered to the team at Western University and entered into the Empower database for analysis.

4.5 Data Analysis

Data were analyzed using SPSS version 22 after being downloaded from the Empower Database. Spearman’s rho (with 95% confidence intervals) was calculated to determine the bivariate correlations between the GMFCS and the MACS, the GMFCS and the CFCS, and the MACS and the CFCS. A coefficient of greater than 0.75 was considered to be a good to excellent relationship, 0.50 to 0.75 to be a moderate to good relationship, 0.25 to .50 to be a fair relationship, and 0.00 to 0.25 to represent little or no relationship. Inter-relationships of classifications among children with CP were examined using nested cross-tabulation. Nested cross-tabulation tabulates the results of one data item, GMFCS, against the other two data items, MACS and CFCS, to show patterns of interaction. Nested cross-tabulation of the GMFCS, MACS, and CFCS produces 125 possible cell combinations to determine the child’s functional status. Total numbers and frequency counts were used to determine the total possible combinations out of 125 cells, to determine the proportion of children who were reported to be the same level in all three classification systems, and the frequency of the most prevalent combinations. The prevalence of each associated health condition was reported in a table format, to help distinguish the most commonly associated health conditions in the most frequently occurring functional profiles based
on the GMFCS, MACS, and the CFCS. The impact of the associated health conditions on the child was calculated by using the cumulative average of the impact. Differences among the most prevalent classifications were established for number of associated health conditions and impact of associated health conditions using a one-way ANOVA and Friedman’s one-way ANOVA for parametric and non-parametric data, respectively (with post-hoc analyses). Finally, the frequency and proportion of each health condition for the most prevalent functional profiles was established. A Chi Square test was used to determine significant differences among profiles. A p value of 0.05 was pre-set for all inferential analysis.
Chapter 5 Results

5.1 Bivariate Correlations

5.1.1 Gross Motor Function Classification System – Manual Ability Classification System

According to Portney and Watkins (75) there was a moderate to good relationship between the GMFCS and the MACS ($r_s = 0.71$, 95% confidence interval (CI) 0.64 – 0.78).

5.1.2 Manual Ability Classification System – Communication Function Classification System

The relationship between the MACS and the CFCS was considered to be moderate to good ($r_s = 0.65$, CI = 0.55-0.72).

5.1.3 Gross Motor Function Classification System – Communication Function Classification System

The GMFCS was not as strongly correlated with the CFCS as the previous two correlations. However, it was still considered to represent a moderate to a good relationship ($r_s = 0.50$, CI = 0.39-0.61).

5.2 Relationship among all Three Functional Classifications

A nested cross-tabulation of the three functional classification systems produced 125 possible cell combinations, displaying a total of 56 functional cells where one or more children was represented in each of the 56 cells. Various combinations of GMFCS, MACS, and CFCS levels of the 222 children with CP showed that fewer than 50% of the total possible combinations were established in this sample (45%). The functional cells represented by this sample are reported in Table 3.
### Table 3: Inter-relationships of all Three Functional Classifications

<table>
<thead>
<tr>
<th>GMFCS level I (n = 89)</th>
<th>CFCS level</th>
<th>Row totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I II III IV V</td>
<td></td>
</tr>
<tr>
<td>MACS level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>30 3 1 1 2</td>
<td>37</td>
</tr>
<tr>
<td>II</td>
<td>28 5 20 4 0</td>
<td>47</td>
</tr>
<tr>
<td>III</td>
<td>0 1 2 1 0</td>
<td>4</td>
</tr>
<tr>
<td>IV</td>
<td>0 0 0 1 0 1</td>
<td>1</td>
</tr>
<tr>
<td>V</td>
<td>0 0 0 0 0 0</td>
<td>0</td>
</tr>
<tr>
<td>Column totals</td>
<td>58 9 13 7 2</td>
<td>89</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GMFCS level II (n = 43)</th>
<th>CFCS level</th>
<th>Row totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I II III IV V</td>
<td></td>
</tr>
<tr>
<td>MACS level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>9 2 1 1 0</td>
<td>13</td>
</tr>
<tr>
<td>II</td>
<td>10 7 3 3 0</td>
<td>23</td>
</tr>
<tr>
<td>III</td>
<td>0 1 2 2 0</td>
<td>5</td>
</tr>
<tr>
<td>IV</td>
<td>0 1 0 1 0 2</td>
<td>2</td>
</tr>
<tr>
<td>V</td>
<td>0 0 0 0 0 0</td>
<td>0</td>
</tr>
<tr>
<td>Column totals</td>
<td>19 11 6 7 0</td>
<td>43</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GMFCS level III (n = 25)</th>
<th>CFCS level</th>
<th>Row totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I II III IV V</td>
<td></td>
</tr>
<tr>
<td>MACS level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>4 0 0 0 0</td>
<td>4</td>
</tr>
<tr>
<td>II</td>
<td>8 3 2 0 0</td>
<td>13</td>
</tr>
<tr>
<td>III</td>
<td>2 2 1 0 1</td>
<td>6</td>
</tr>
<tr>
<td>IV</td>
<td>0 0 1 1 0 2</td>
<td>2</td>
</tr>
<tr>
<td>V</td>
<td>0 0 0 0 0 0</td>
<td>0</td>
</tr>
<tr>
<td>Column totals</td>
<td>14 5 4 1 1</td>
<td>25</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GMFCS level IV (n = 35)</th>
<th>CFCS level</th>
<th>Row totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I II III IV V</td>
<td></td>
</tr>
<tr>
<td>MACS level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>1 0 0 0 0 1</td>
<td>1</td>
</tr>
<tr>
<td>II</td>
<td>3 0 1 0 0 4</td>
<td>4</td>
</tr>
<tr>
<td>III</td>
<td>2 6 4 3 1 16</td>
<td>16</td>
</tr>
<tr>
<td>IV</td>
<td>0 1 6 6 0 13</td>
<td>13</td>
</tr>
<tr>
<td>V</td>
<td>0 0 1 1 0 1</td>
<td>1</td>
</tr>
<tr>
<td>Column totals</td>
<td>6 7 11 10 1</td>
<td>35</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>GMFCS level V (n = 30)</th>
<th>CFCS level</th>
<th>Row totals</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>I II III IV V</td>
<td></td>
</tr>
<tr>
<td>MACS level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I</td>
<td>0 0 0 0 0 0</td>
<td>0</td>
</tr>
<tr>
<td>II</td>
<td>0 0 0 0 0 0</td>
<td>0</td>
</tr>
<tr>
<td>III</td>
<td>0 0 0 0 0 0</td>
<td>0</td>
</tr>
<tr>
<td>IV</td>
<td>0 1 3 6 5 15</td>
<td>15</td>
</tr>
<tr>
<td>V</td>
<td>1 0 2 2 10 15</td>
<td>15</td>
</tr>
<tr>
<td>Column totals</td>
<td>1 1 5 8 15 30</td>
<td>30</td>
</tr>
</tbody>
</table>

*note
GMFCS = Gross Motor Function Classification System
MACS = Manual Ability Classification System
CFCS = Communication Function Classification System
From Table 3 the frequency of the occurrence of the same level of classification in all three systems was determined. Of the 222 children 49 (23%) were found to be the same level in all three classification systems. The most common same level classification was GMFCS level I, MACS level I, and CFCS level I (n = 30, 14%). Sequentially all level IIs represent 3% (n = 7), all level IIIs 1% (n = 1), all level IVs 3% (n = 6), and all level Vs 2% (n = 5).

The most prevalent functional profiles were considered to be those that represented 5% or more of the 222 participants. The most prevalent functional cell combination was (I, I, I) representing 14% of the total sample, closely followed by (I, II, I) representing 13% with (II, II, I) and (I, II, III) representing 5% each. The most prevalent functional cell combinations accounted for 37% of the total sample.

### 5.3 Prevalence and Impact of Associated Health Conditions

A descriptive analysis observed the average number and standard deviation of associated health conditions and the impact that these associated health conditions had on the child’s life in the four most common functional profiles ((I,I,I), (I, II, I), (II, II, I), and (I, II, III)). As the classification level increased the average number and impact also increased. This trend can be seen in Table 4. A significant difference in number of associated health conditions was determined among the four groups (F = 6.78, df = 3, p < 0.001), with a post hoc Tukey’s test determining differences between (I, I, I) and (II, II, I) (p = 0.003) and between (I, I, I) and (I, II, III) (p = 0.004). Using a Friedman’s one-way Anova test, significant differences in the impact were determined among groups. Post hoc test using a Mann Whitney U (with Bonferroni correction of 0.0125) established differences between (I, I, I) and (II, II, I) of 0.001 and between (I, I, I) and (I, II, III) of 0.009, with a Bonferroni correction of 0.0125.
Table 4: Average Number and Impact of Prevalent Associated Health Conditions

<table>
<thead>
<tr>
<th>(GMFCS, MACS, CFCS) levels</th>
<th>Number of Associated Health Conditions - mean (SD)</th>
<th>range (min, max)</th>
<th>Impact of Associated Health Conditions – X (SD)</th>
<th>M (IQR)(25,75)</th>
</tr>
</thead>
<tbody>
<tr>
<td>(I, I, I)</td>
<td>1.6 (1.5)</td>
<td>1.0 (0.0, 1.0)</td>
<td>0.5 (0.8)</td>
<td>0.2 (0.0, 0.5)</td>
</tr>
<tr>
<td>(I, II, I)</td>
<td>2.7 (2.0)</td>
<td>1.6 (0.0, 1.6)</td>
<td>1.0 (1.2)</td>
<td>0.3 (0.1, 0.8)</td>
</tr>
<tr>
<td>(II, II, I)</td>
<td>4.5 (2.9)</td>
<td>2.6 (0.0, 2.6)</td>
<td>1.8 (1.3)</td>
<td>0.8 (0.5, 1.1)</td>
</tr>
<tr>
<td>(I, II, III)</td>
<td>4.6 (3.6)</td>
<td>2.7 (0.0, 2.7)</td>
<td>2.1 (1.4)</td>
<td>0.8 (0.3, 1.3)</td>
</tr>
</tbody>
</table>

*note
GMFCS = Gross Motor Function Classification System
MACS = Manual Ability Classification System
CFCS = Communication Function Classification System
\( \bar{X} \) = Mean
M = Median
IQR = Interquartile Range
The number and proportion of associated health conditions in each of the most prevalent functional profiles are recorded in Table 5. Chi Square tests were non-significant across groups except for ‘speaking and communicating’ and ‘seizures’, using Bonferroni’s correction of 0.003.

Table 5: Proportion of Each Associated Health Condition in the Four Most Prevalent Groups

<table>
<thead>
<tr>
<th>Health Condition – n (%)</th>
<th>Functional Groups</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>(I, I, I)</td>
</tr>
<tr>
<td>Seeing</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Hearing</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Learning/understanding</td>
<td>4 (14)</td>
</tr>
<tr>
<td>Speaking/communicating</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Emotions/behaviour</td>
<td>11 (38)</td>
</tr>
<tr>
<td>Seizures/epilepsy</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Mouth</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Teeth/gums</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Digestion</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Growth</td>
<td>2 (7)</td>
</tr>
<tr>
<td>Sleeping</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Repeated infections</td>
<td>0 (0)</td>
</tr>
<tr>
<td>Breathing problems</td>
<td>3 (10)</td>
</tr>
<tr>
<td>Skin problems</td>
<td>5 (17)</td>
</tr>
<tr>
<td>Heart problems</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Pain</td>
<td>5 (17)</td>
</tr>
</tbody>
</table>

note

*not all (GMFCS, MACS, CFCS) combinations had full associated health conditions data

(x, x, x) = (GMFCS, MACS, CFCS) classification levels I to III

GMFCS = Gross Motor Function Classification System
MACS = Manual Ability Classification System
CFCS = Communication Function Classification System

X² = Chi squared test
Chapter 6 Discussion

6.1 Summary of the Results

Although there are currently many classification systems used to classify children with CP, there is not one singular classification system that can fully describe a child’s functional abilities and overall health status. Definitions of cerebral palsy have referred to it as an umbrella term in the past (12) and recognized that CP is more than just a motor disorder because it is associated with various comorbidities. (1) The GMFCS, (5,6) the MACS, (7) and the CFCS (8) are all valid and reliable functional classification systems for children with CP, focusing on their abilities rather than their impairments. The functional profiles that are established from profiling these three classification systems together, along with the description of associated health conditions, provides a more holistic description children with CP.

Descriptive analysis demonstrated that children with CP are all unique and that there is a great deal of diversity among them. Relationships were found between the three classification systems, through bivariate correlations. The possible combinations of GMFCS, MACS, and CFCS levels that arose from the nested cross-tabulation are represented in Table 5.1. The frequency and proportions of the most common cell combinations of the 125 possible cells are described below. This study found that the most common profile combinations are (I, I, I), (I, II, I), (I, II, II), and (I, II, III) making up 37% of the total sample. This means that potentially one third of children with a diagnosis of CP could fall into one of four functional profiles that are most commonly reported. As well, the number of associated health conditions and their impact on the child’s life are described for the most prevalent functional profiles. The most common associated health condition in each of the four prevalent functional profiles is controlling emotions and behaviour in (I, I, I) and in (I, II, I). In profile (I, II, I) it was problems seeing and in profile (I, II, III) it was problems with speaking and communicating. It should be noted that controlling emotions and behaviours is in the top three most prevalent associated health conditions in each functional profile, affecting 38 to 60% of the samples in the profiles. All functional profiles had a high frequency count for each of the following associated health conditions: seeing, controlling emotions and behaviours, and digestion. The most frequent combinations were observed in more detail for any profile that represented 5% or more of the total sample.
6.2 Comparison of Results to Existing Literature

There was a moderate to good correlation between the GMFCS and MACS, the MACS and the CFCS, and the GMFCS to the CFCS. In a similar study by Hidecker and colleagues they also found relationships among the classification systems to represent a moderate to good correlation.\(^{(46)}\) They reported Spearman's correlations of 0.69 between the GMFCS and the MACS, 0.54 between the MACS and the CFCS, and 0.47 between the GMFCS and the CFCS.\(^{(46)}\) The correlation between the GMFCS and the CFCS falls outside of the boundary for “moderate to good”, but there is not a significant difference from this study’s results. Compared to the results from this study using a 95% CI, the relationship between the MACS and the CFCS is statistically significant\((p > 0.05)\). This study shows a stronger correlation between the two functional classification systems compared to Hidecker’s. One other study observed the correlation between the MACS and the CFCS, however they reported a stronger correlation than this current study and Hidecker’s\((\text{Spearman’s } 0.80, p < 0.01)\).\(^{(64)}\) A possible explanation for the stronger correlation is that Himmelmann's and colleagues study had a smaller sample size of 86.\(^{(64)}\) The correlation between just the GMFCS and the MACS has previously been reported by others and was shown to have a poor overall association\((\text{Kappa } 0.35)\); however stronger relationships were presented among various subtypes of CP.\(^{(60)}\) This finding cannot be directly interpreted with the current findings because Kappa correlations use a different analysis that controls for chance agreements. The relationships that exist between the classification systems demonstrates that together these classification systems are useful in describing children’s functional abilities and are useful when combined with each other.

When the three functional classification systems were analyzed together using a cross-tabulation method, it resulted in a total of 56 different functional profiles of 125 possibilities. In this study, the proportion of cells filled was significantly lower than that established initially by Hidecker and her group\((n = 62; \chi^2 = 16.0, \text{df} = 1 , p > 0.001)\).

The most common functional profile was all level I classifications. The only other study to establish functional profiles from observing the three functional classifications systems was Hidecker and colleagues.\(^{(46)}\) Similar to this study, with a sample of 222 Hidecker and colleagues, found that their most common profile was children in level I for the three classification systems, representing 10% of the total sample\(^{(46)}\) where this study was higher reporting 14% of the total sample. A few
key differences were noted in comparison to the Hidecker study. Hidecker’s study was more diverse when considering functional profiles. Their study filled 50% of the functional profile cells, whereas this study occupied 45% of the total cells. Due to the fact that this study was less diverse, it was expected that there would be a greater representation in specific profiles. This study had a larger recruitment number for GMFCS level I, therefore it makes sense that some of the most common functional profiles would incorporate GMFCS level I. In comparison, this study found a greater representation of the most prevalent functional profiles (37% in comparison to 20%), explainable by a less diverse sample. These results are significantly different than Hidecker’s study in that a greater representation of the most prevalent functional profiles was determined ($p < 0.001$). In both studies, two functional profiles were discovered to be the most common, (I, I, I) and (II, II, I).

A key difference in the inter-relationships among the GMFCS, the MACS, and the CFCS when establishing the functional profiles is that this study also took into consideration the second part of the definition of CP, which is that it is often associated with other health conditions. It is important when profiling to consider the health conditions that are associated and that impact the child’s life, because they are just as important as treating the motor disabilities. It has been reported that it is often the associated health conditions that have the greatest impact on children with CP and their families.

It was observed that an increase in a level, in one or more of the three functional classification systems resulted in an increase in the number of associated health conditions and their impact on the child. Of the sixteen associated health conditions that were reported on, controlling emotions and behaviours ranked in the top three most predominant associated health conditions across the four functional profiles. Controlling emotions and behaviours has been recognized as a prevalent and impactful health condition for children with CP. A report on the comparison of the prevalence and impact of associated health conditions on preschoolers found similar results in regards to associated health conditions. Wong and colleagues reported on preschoolers, therefore the average age of the participant was lower compared to this study, so it is possible that not all associated health conditions had been developed or were reported on at the younger age explaining a lower frequency and average impact at different developmental ages, different conditions might be more prevalent. Statistical significance was found across the four most
common functional profiles for children with difficulties seeing or communicating or who experience seizures. The average number and impact of associated health conditions increased from GMFCS level I to level V, supporting our findings in that as the functional level increases it can be expected that the child will experience a greater number of associated health conditions and their impact will be greater. A significant difference between the functional profile (I, I, I) and two of the lower functioning groups (II, II, I) and (I, II, III) was determined, supporting the previous notion.

6.3 Clinical Significance

The use of functional classification systems to assist in understanding the condition of CP has received greater attention and recognition among parents, children, and practitioners than other methods of classification. In particular, the GMFCS has received widespread recognition for its clinical utility and impact and is considered to be a prime classification system for describing functional ability in children with CP. However, it is important to acknowledge that CP is not solely classified by a gross motor condition as stated in the definition of CP, other functional abilities should be considered. The MACS and CFCS take into account a child’s everyday performance on their ability to manipulate objects with both hands and to communicate with familiar and unfamiliar partners. The GFMCS focuses on the child’s ability to perform gross motor activities like walking, while the MACS relies more heavily on cognitive ability and voluntary motor control to perform bimanual fine motor skills. The CFCS focuses more on cognitive tasks of exchanging information between individuals, compared to limb movements in the GMFCS and the MACS. The three classification systems place emphasis on different aspects of the human body and together give a more complete representation. The classification systems were all developed to be analogous to each other when they were established by similar methods. This allows for clinicians and researchers to easily use the three classification systems as they all focus on the child’s ability and use the same scaling system, levels I to V.

To demonstrate a better picture of how unique individuals with CP are two case studies were selected from the functional profiles (I, I, I) and (I, II, II), representing the children who reported the greatest impact in the two profiles. It should be noted that there are children in each of the four most prevalent functional profiles who reported no associated health conditions and therefore no related impact on their lives. For the purpose of this study Case 1 (I, I, I) will present Dan who is 6.3 years old and has diplegia. Case 2 (I, II, III) will present Sarah’s associated health conditions
and impact; she is 9.2 years old and has hemiplegia. The prevalence of associated health conditions and the impact on the individual's life will be discussed. Recall that when the Child Health Conditions Questionnaire was completed, the parents were asked to first report on if the child has the health condition and secondly to report on the extent of how the problem affects the child’s life, if present. The impact was recorded and coded by 1 – not at all, 2 – to a very small extent, 3 – to a small extent, 4 – to a moderate extent, 5 – to a fairly great extent, 6 – to a great extent, and 7 – to a very great extent. The formatting of this questionnaire is contained in Appendix F.

Dan’s parent reported problems of pain affecting his life to a small extent, learning and understanding and sleeping to a moderate extent, and controlling emotions or behaviours to a fairly great extent. He was also diagnosed with anxiety. Sarah who is from the functional profile (I, II, III) represented the child who reported the greatest impact of associated health conditions on her life in the sample. Sarah’s parent reported that she had problems with repeated infections but that they did not affect her daily activities in life. On the other hand problems with controlling emotions or behaviour, teeth and gums, and pain affected her life to a very small extent, problems involving the mouth a small extent, seeing, speaking or communicating in other ways, and problems with digestion affected her life to a moderate extent, learning and understanding, and problems with the heart impacted her life to a great extent, and seizures had a very great impact on her daily activities in life. After viewing examples of two children with CP it provides a greater understanding of the diversity among children and how the prevalence and impact of associated health conditions can vary even between a few differences in levels of functional classification, with Dan at GMFCS I, MACS I, and CFCS I and Sarah at GMFCS I, MACS II, and CFCS III. These differences are also highlighted in the context of some children in all four most prevalent groups reporting no associated health conditions.

Information provided by the Health Conditions Questionnaire can be used by families and practitioners to gain a better estimate of the associated health conditions to better deal with and plan to ameliorate the impact of these associated health conditions. By identifying the most prevalent associated health conditions, health practitioners can better identify what they should be screening and observing for when seeing a child with CP. As the results of this study assist in providing a more holistic profile for children with CP as a relationship among the three systems was
observed. This can help parents, practitioners and researchers to better understand the relationships and similarities among the functional systems and appreciate the fact that all children have unique profiles and needs.

6.4 Limitations

A limitation to the study is the relatively small sample size due to an early cutoff date for analyzing the data. Another potential limitation of the study is that the sample was obtained through convenience sampling and limited to participants within select regions of North America, making the results less generalizable to the CP population as a whole.

6.5 Future Research

This area of research is pertinent to contributing to a better quality of life for children with CP and their families. It provides helpful information regarding a greater understanding of what to expect with a diagnosis of CP. While the three functional classification systems in combination with data on associated health conditions provide a more holistic picture this study should be replicated with a larger sample size. This will allow for the results to be more generalizable providing a stronger predication of the most common functional profiles and what the health conditions that they are associated with. Future research should also investigate other aspects of the child’s life, like participation and services received and not received. This research collected GMFCS, MACS, and CFCS levels based on an agreement between parents and the assessor and excluded those that were not in agreement. Research should be conducted to better understand parents and assessors agreements and disagreements on perceived levels for the child, and if there is significance when an agreement cannot be determined.

6.6 Conclusions

Overall, this study reported four prevalent functional profiles for children with CP, but it should be recognized and emphasized how diverse every child with CP is. These functional profiles can only assist in understanding the diagnosis of CP. As CP is such a heterogeneous condition it will always be a challenge to classify and group children into a couple of categories, because every child presents with different functional levels and associated health conditions. These results suggest that understanding the functional profiles for children with CP and including their
associated health conditions is important for families and practitioners. They provide a more holistic picture of what to possibly expect from a child who is classified into one of the three functional classification systems. It is important to consider all functional aspects of a child as well as to observe how associated health conditions contribute to impacting not only the child’s life but the parents as well, to contribute to improving the quality of life of the child and family.
References


Appendix A: Western’s Ethics Approval

Principal Investigator: Dr. Doreen Badlutt
File Number: 160242
Review Level: Delegated
Approved Local Adult Participants: 0
Approved Local Minor Participants: 0
Protocol Title: Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay
Department & Institution: Health Sciences/Physical Therapy, Western University
Sponsor: Canadian Institutes of Health Research

Ethics Approval Date: June 12, 2012
Expiration Date: August 31, 2017

Use of Human Participants - Ethics Approval Notice

Western University Protocol

<table>
<thead>
<tr>
<th>Document Name</th>
<th>Comments</th>
<th>Version Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Western University Protocol</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Advertisement</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Letter of Information &amp; Consent</td>
<td></td>
<td>2012/06/12</td>
</tr>
<tr>
<td>Assent</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

This is to certify that the University of Western Ontario Research Ethics Board for Health Sciences Research involving Human Subjects (HSREB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans and the Health Canada/ CIHI Good Clinical Practice Practice Guidelines, and all applicable laws and regulations of Ontario has reviewed and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of this REB also complies with the membership requirements set forth in Division 5 of the Food and Drug Regulations.

The ethics approval for this study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB’s periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000440.

This is an official document. Please retain the original in your files.

The University of Western Ontario
Office of Research Ethics
Support Services Building Room 5130 • London, Ontario • CANADA • N6G 1G9
Ph: 519-661-3036 • F: 519-850-2466 • ethics@uwbo.ca • www.uwo.ca/research/ethics
Research Ethics

Principal Investigator: Dr. Deone Barnett
File Number: 105342
Review Level: Delegated
Approvers: Local Adult Participants: 0
Approvers: Local Minor Participants: 0
Protocol Title: Monitoring Development of Children with Central Poly or Gross Motor Delay
Department: Health Science/Physical Therapy, Western University
Sponsor: Canadian Institutes of Health Research

Ethics Approval Date: December 20, 2012
Expiry Date: August 31, 2017

Documents Reviewed & Approved

<table>
<thead>
<tr>
<th>Document</th>
<th>Coauthors</th>
<th>Version Date</th>
</tr>
</thead>
<tbody>
<tr>
<td>Revised protocol with new terms and revisions due to new electronic database.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revised letter of information, including details of the Firepower database, except for MMF number, inclusion of data links to family for families in the MOVE &amp; PLAY study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Invitation to participate in the previous MOVE &amp; PLAY study.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informed consent for parents in MOVE &amp; PLAY.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informed consent for new families.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Informed consent for new families.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Final formatted paper.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changes to recruitment brochures: revised location of local contact person and overall study coordinator, contact information, correct MMF number, changes to how this is tracked — with input from other ethics boards.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Revised recruitment brochure.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Corrected order of listing items 2, 14, and 15. Changed order of examples in item 9, added one example without the label.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Added clarification that “look-up” means reduces</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Preprogrammed instructions became new parent will complete instead of interview, access notes for consistency (e.g., “Yes” instead of “both” or “all”).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New classifications for EMSTC to replace “Home Visit Questionnaire.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>All references to page 9 removed without consent to page 10. Aims section A.2 changed to ensure better data quality, including a few minor changes to the “changes to the database” section.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Removed the term “last” on the cover page of parent data collection booklet. Minor changes to increase clarity and ensure consistency of terms.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New cover page for new parent data collection booklet.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New form for new parent data collection booklet.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New form for 6 Months Walk Test.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New form for 6 Months Walk Test.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Add parenthetical note: “new form due to new parent data collection booklet.”</td>
<td></td>
<td></td>
</tr>
<tr>
<td>New form for classification to include an option if the therapist agrees with the parent, or if the parent changes their classification on discussion with another, and an option if the therapist and parent disagree, with a consensus box to explain.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Western University, Support Services Bldg/Br, SS50 London, ON, Canada N6A 3K7
1. 519.656.3024 2. 519.850.2466 www.uwo.ca/ethics
This is to notify you that The University of Western Ontario Research Ethics Board for Health Sciences Research involving Human Subjects (REB) which is organized and operates according to the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans has received and granted approval to the above referenced revision(s) or amendment(s) on the approval date noted above. The membership of the REB also complies with the membership requirements for REBs as defined in Division 1 of the Food and Drug Regulations.

The ethics approval for the study shall remain valid until the expiry date noted above assuming timely and acceptable responses to the HSREB periodic requests for surveillance and monitoring information. If you require an updated approval notice prior to that time you must request it using the University of Western Ontario Updated Approval Request Form.

Members of the HSREB who are named as investigators in research studies, or declare a conflict of interest, do not participate in discussion related to, nor vote on, such studies when they are presented to the HSREB.

The Chair of the HSREB is Dr. Joseph Gilbert. The HSREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000940.

<table>
<thead>
<tr>
<th>Ethics Officer for Contact for Further Information</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
</tr>
<tr>
<td>January Schedin</td>
</tr>
<tr>
<td>John Kelly</td>
</tr>
<tr>
<td>Joseph Weber</td>
</tr>
</tbody>
</table>

This is an official document. Please retain the original in your files.
Appendix B: Consent and Assent Forms

Letter of Information
Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

Primary Investigator: Doreen Bartlett, PT PhD
School of Physical Therapy, Faculty of Health Sciences

This study is funded by CIHR (Canadian Institutes of Health Research) Operating Grant MOP #119278

This letter contains information to help you decide whether or not to participate in this research study with your child. You are being invited to participate because you are the parent of a young child, between the ages of 18 months and 10 years, with a diagnosis of cerebral palsy or delayed gross motor development, with problems with muscle tone and balance, and you either participated in the Move & PLAY study or you and your child are currently being followed through a health centre. For families who participated in the Move & PLAY study before this, we will be able to put together information collected earlier with new information from this study to get an even better picture of children’s development. For this study, we are inviting eight-hundred and seventy-five children and their parents, who speak English, French, or Spanish, who live in different regions of Canada (up to 529 families) and the United States (up to 350 families) to take part. We aim to recruit up to 50 children and families from Thames Valley Children’s Centre. In this multi-site study, we plan to describe the patterns of development of balance, range of motion, muscle strength, endurance, and health conditions for each of five levels of gross motor ability. We also plan to describe patterns of development of self-care and participation in recreation activities for children based on similarities of gross motor, hand function and communication abilities. Each participating family will be followed 2 times over a one-year period. These aspects of your child may have been assessed using different measures in the past. We are aiming to standardize methods of collecting this information, so we can learn more about different groups of children. Once the data from this study are analyzed, we will provide guidelines for rehabilitation therapists to determine if individual children are developing ‘as expected’, ‘better than expected’ or ‘not as expected’ based on their initial functional ability level. This information will help therapists help families like yours support young children with cerebral palsy or with motor delays and problems with muscle tone and balance.

If you agree to take part in this study, we (a study coordinator and an assessing therapist) will make arrangements to either come to your home or see you at a clinic visit at a mutually convenient time. Before the first home or clinic visit, you will receive a package of six questionnaires (either by mail or accessible on-line, whichever you prefer) that we are asking you to complete at a time that is convenient to you. These questionnaires ask questions about you, your child, and your family, including your daily activities and experiences and the services your child receives. We will also ask you to describe your child’s function with respect to his or her abilities to move, use his or her hands and to communicate. At the first visit, we anticipate you will be able to complete these questionnaires within one hour. At the final visit, we will give you 5 questionnaires, which should take 35 minutes or so to complete. They can be completed any time after you receive them, before your home or clinic visit, or during the visit.

Version 3: April 16, 2013

The University of Western Ontario
School of Physical Therapy
Elborn College • London, Ontario • CANADA • N6G 1H1
PH: 519-661-3360 • F: 519-661-3866 • www.uwo.ca/fhs/pt

Initials: ___
At each visit, the assessing therapist will go through these questionnaires with you, in case you have any questions. Then he or she will conduct a series of physical assessments with your child, including measures of balance, range of motion, and muscle strength, and possibly a walking test, if your child is able to walk and is older than three years of age. In general, these measures will be familiar to both you and your child. He or she will also classify your child on his or her abilities to move, use his or her hands, and to communicate, and will end by discussing these classifications with you. We anticipate that this portion will be completed within one hour. We have used all of these measures in a previous study and found that they are acceptable to both children and parents. In addition, therapists found the measures feasible to administer to children such as yours. The data that is collected from you will then be entered into an electronic database that is protected by a username and password.

Involvement in this study will not affect the care that your child normally receives. Risks to your child are similar to those to which he or she is exposed in physical therapy assessments, including falling when walking or when balance is tested. The assessors will take all normal safety precautions to appropriately guard your child from these risks. There are no known risks to your participation in this study, aside from possible distress when you are discussing your child’s level of gross motor abilities, hand function or communication abilities. If you are uncomfortable with this discussion, please contact the principal investigator using the contact information at the beginning of this letter of information.

You and your child will not benefit directly from participation in this work; however, this study has the potential to improve future monitoring and rehabilitation care for children like yours. We will, however, provide you with feedback on your child’s summary scores for endurance, health conditions, self-care and participation in recreation activities (based on information which you will provide), as well as the summary scores for balance, range of motion, and strength (as assessed by the therapist). You can discuss these with your child’s treating therapist. At each of the visits, we will reimburse you for parking and travel costs up to $25. Additionally, as a token of thanks, a $20 gift card for your child will be given at each visit.

Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study at any time while we are collecting data with no effect on you and your child’s future care. Once the data analysis is completed, we will not be able to withdraw data to protect the integrity of the research. If you are participating in another study at this time, please inform your child’s therapist to determine if it is appropriate to be involved in this study as well. You do not waive any legal rights by signing the consent form.

The information that all participants provide in this study will be widely disseminated. Your confidentiality will be respected. No information that discloses you or your child’s identity will be released. Paper copies of the data we collect will be stored in a locked filing cabinet in a secure office and will be destroyed after seven years. This electronic database will be password protected and will be accessed only by study investigators, graduate students, collaborators, and statistical analysts. Your data travels in a scrambled format to a server (storage computer) that is located in Montreal, Canada and to a backup server located in Vancouver, Canada. Your name, contact information and your date of birth are part of this database. No other personal identifiers will be entered into the database. The company that houses the database is a professional company with extremely high standards of physical and virtual security (www.netsential.ca). We want to let you know however, that even with this high level of security, there is always a remote chance that your information could be accessed or "hacked" by someone who is not supposed to have your information. If we become aware that this had happened, we would inform you immediately. Once the data are collected for this study, they will be entered into a spreadsheet and sent to Dr. Steve Hanna at CanChild Centre for Childhood Disability for analysis. In addition to the main analyses that will be conducted in this study, the data we collect may be analyzed for other purposes.

Version 3: April 16, 2013

Initials: ___
Because this project is being coordinated through the Western University, representatives of the University of Western Ontario Health Sciences Research Ethics Board may contact you or require access to your study-related records to monitor the conduct of the research.

If you have any questions about the study you may contact Doreen Bartlett by telephone at _____ extension _____ or by email at (____)_____. If you have any questions about your rights as a research participant or the conduct of the study you may contact the Office of Research Ethics at (519) 661-3036 or by email at ethics@uwo.ca.

This letter is for you to keep.
Consent Form
Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

Primary Investigator:
Doreen Bartlett, PT PhD

I have read the Letter of Information, have had the nature of the study explained to me, and I agree to participate. All questions have been answered to my satisfaction. I will receive a signed copy of this consent form.

(legal guardian’s name, please print) (legal guardian’s signature) (date)

Legal guardian of: ________________________________ (child’s name, please print)

(name of person obtaining informed consent, please print) (signature of person obtaining informed consent) (date)

Version 3: April 16, 2013

Initials: ____
Please provide the following information if you would like to receive a summary of the results of the study, in addition to the individual results for your child.

Name: ________________________________

Address: ________________________________
Street address (house or apartment number)

__________________________
City

__________________________
Province

__________________________
Postal Code

Email: ________________________________

What is your child's date of birth? ____________________ Day ____________________ Month (spell) ____________________ Year

Please check here if you give us permission to contact you about a future research project [ ]

Version 3: April 16, 2013

Initials: _____
Child Assent Form

Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

Primary Investigator: Doreen Bartlett, PT PhD
School of Physical Therapy, Faculty of Health Sciences

Why you are here

The study team wants to tell you about a project about children with cerebral palsy. This project is for children like you from across Canada and the United States. They want to see if you would like to help them by being a part of this project. Dr. Doreen Bartlett and some other rehabilitation workers are doing this study.

What is the project about?

The study team wants to understand many things about you and the other children in the project such as how strong you are, how you move around, how you move your muscles, and what daily everyday activities you do. They want to help you and other children have the best treatment so you can enjoy each day.

What will happen during your visit?

If you agree to help and be a part of this project, you will be seen by one of the therapists two-times for one-hour each time. Your first visit is today, and your next visit will be one-year from now. This is what will happen:

1. Today, for your first visit, you will go through several movement activities that look at things like your balance, strength, walking and movement. You will be asked to show us your best try at each of these activities. The therapist will identify what tests you are good at and what tests you may need some extra help with.

2. For your second visit, you will go through the same tests that you are doing today. This will help the therapist understand if you have made any changes since your first visit. Your tests will be studied to understand your patterns of development.

Version 1: May 8, 2012

The University of Western Ontario
School of Physical Therapy
Elborn College • London, Ontario • CANADA - N6G 1H1
PH: 519-661-3360 • F: 519-661-3866 • www.uwo.ca/ths/pt
Will the project hurt in any way?
This project will not hurt or cause any pain to you in any way. If at any time during a test you feel pain or are hurting, you can say no to doing it. No one will be mad at you if you say no.

Will your movement get better if you are in the project?
This project will not make you move better. By helping and being a part of the project, the therapist team might find out something that will help other children like you later.

What if you have questions?
You can ask any question at any time, now or during the tests. You can talk to the therapists, your family, or someone else about this project. No question is a bad question. We want to answer any questions you may have.

Can I change my mind about being in the study?
If you do not want to be in the project any more, you can say no. You can change your mind at any time. No one will be mad at you if you change your mind. If you do not want to be in the project, just say so. Even if you say yes today, you can say no at any time. It is up to you.

This letter is for you to keep.
Child Assent Form

Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

Primary Investigator: Doreen Bartlett, PT PhD
School of Physical Therapy, Faculty of Health Sciences

I have had the project details read to me and I want to participate.

Name of Child (please print): ________________________________

Child Signature: ________________________________

Age of Child: __________

Date: ________________________________

Signature of Person Obtaining Assent: ________________________________

Date: ________________________________

Version 1: May 8, 2012

Initials: ___
Appendix C: Gross Motor Function Classification System

GMFCS – E & R
Gross Motor Function Classification System
Expanded and Revised

GMFCS - E & R © Robert Palisano, Peter Rosenbaum, Doreen Bartlett, Michael Livingston, 2007
CanChild Centre for Childhood Disability Research, McMaster University

CanChild Centre for Childhood Disability Research, McMaster University
(Reference: Dev Med Child Neurol 1997;39:214-223)

INTRODUCTION & USER INSTRUCTIONS

The Gross Motor Function Classification System (GMFCS) for cerebral palsy is based on self-initiated movement, with emphasis on sitting, transfers, and mobility. When defining a five-level classification system, our primary criterion has been that the distinctions between levels must be meaningful in daily life. Distinctions are based on functional limitations, the need for hand-held mobility devices (such as walkers, canes, or wheelchairs) or to a lesser extent, quality of movement. The distinctions between Levels 1 and 2 are not as pronounced as the distinctions between the other levels, particularly for infants less than 2 years of age.

The expanded GMFCS (2007) includes an age band for youth 12 to 18 years of age and emphasizes the concepts inherent in the World Health Organization’s International Classification of Functioning, Disability and Health (ICF). We encourage users to be aware of the impact that environmental and personal factors may have on what children and youth are observed or reported to do. The focus of the GMFCS is on determining which level best represents the child’s or youth’s present abilities and limitations in gross motor function. Emphasis is on usual performance in home, school, and community settings (i.e., what they do), rather than what they are known to be able to do at their best (capability). It is therefore important to classify current performance in gross motor function and not to include judgments about the quality of movement or prognosis for improvement.

The title for each level is the method of mobility that is most characteristic of performance after 6 years of age. The descriptions of functional abilities and limitations for each age band are broad and are not intended to describe all aspects of the function of individual children/youth. For example, an infant with hemiplegia who is unable to crawl on his or her hands and knees, but otherwise fits the description of Level 1 (i.e., can pull to stand and walk), would be classified in Level 1. The scale is ordinal, with no intent that the distances between levels be considered equal or that children and youth with cerebral palsy are equally distributed across the five levels. A summary of the distinctions between each pair of levels is provided to assist in determining the level that most closely resembles a child’s/youth’s current gross motor function.

We recognize that the manifestations of gross motor function are dependent on age, especially during infancy and early childhood. For each level, separate descriptions are provided in several age bands. Children below age 2 should be considered at their corrected age if they were premature. The descriptions for the 6 to 12 year and 12 to 18 year age bands reflect the potential impact of environment factors (e.g., distance in school and community) and personal factors (e.g., energy demands and social preferences) on methods of mobility.

An effort has been made to emphasize abilities rather than limitations. Thus, as a general principle, the gross motor function of children and youth who are able to perform the functions described in any particular level will probably be classified at or above that level of function; in contrast, the gross motor function of children and youth who cannot perform the functions of a particular level should be classified below that level of function.
OPERATIONAL DEFINITIONS

Body support walker – A mobility device that supports the pelvis and trunk. The child/youth is physically positioned in the walker by another person.

Hand-held mobility device – Canes, crutches, and anterior and posterior walkers that do not support the trunk during walking.

Physical assistance – Another person manually assists the child/youth to move.

Powered mobility – The child/youth actively controls the joystick or electrical switch that enables independent mobility. The mobility base may be a wheelchair, scooter or other type of powered mobility device.

Self-propsels manual wheelchair – The child/youth actively uses arms and hands or feet to propel the wheels and move.

Transported – A person manually pushes a mobility device (e.g., wheelchair, stroller, or pram) to move the child/youth from one place to another.

Walks – Unless otherwise specified indicates no physical assistance from another person or any use of a hand-held mobility device. An orthosis (i.e., brace or splint) may be worn.

Wheeled mobility – Refers to any type of device with wheels that enables movement (e.g., stroller, manual wheelchair, or powered wheelchair).

GENERAL HEADINGS FOR EACH LEVEL

LEVEL I - Walks without Limitations
LEVEL II - Walks with Limitations
LEVEL III - Walks Using a Hand-Held Mobility Device
LEVEL IV - Self-Mobility with Limitations; May Use Powered Mobility
LEVEL V - Transported in a Manual Wheelchair

DISTINCTIONS BETWEEN LEVELS

Distinctions Between Levels I and II - Compared with children and youth in Level I, children and youth in Level II have limitations walking long distances and balancing; may need a hand-held mobility device when first learning to walk; may use wheeled mobility when traveling long distances outdoors and in the community; require the use of a railing to walk up and down stairs; and are not as capable of running and jumping.

Distinctions Between Levels II and III - Children and youth in Level II are capable of walking without a hand-held mobility device after age 4 (although they may choose to use one at times). Children and youth in Level III need a hand-held mobility device to walk indoors and use wheeled mobility outdoors and in the community.

Distinctions Between Levels III and IV - Children and youth in Level III sit on their own or require at most limited external support to sit, are more independent in standing transfers, and walk with a hand-held mobility device. Children and youth in Level IV function in sitting (usually supported) but self-mobility is limited. Children and youth in Level IV are more likely to be transported in a manual wheelchair or use powered mobility.

Distinctions Between Levels IV and V - Children and youth in Level V have severe limitations in head and trunk control and require extensive assisted technology and physical assistance. Self-mobility is achieved only if the child/youth can learn how to operate a powered wheelchair.
Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)

BEFORE 2ND BIRTHDAY

LEVEL I: Infants move in and out of sitting and floor sit with both hands free to manipulate objects. Infants crawl on hands and knees, pull to stand and take steps holding on to furniture. Infants walk between 18 months and 2 years of age without the need for any assistive mobility device.

LEVEL II: Infants maintain floor sitting but may need to use their hands for support to maintain balance. Infants creep on their stomach or crawl on hands and knees. Infants may pull to stand and take steps holding on to furniture.

LEVEL III: Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.

LEVEL IV: Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.

LEVEL V: Physical impairments limit voluntary control of movement. Infants are unable to maintain antigravity head and trunk postures in prone and sitting. Infants require adult assistance to roll.

BETWEEN 2ND AND 4TH BIRTHDAY

LEVEL I: Children floor sit with both hands free to manipulate objects. Movements in and out of floor sitting and standing are performed without adult assistance. Children walk as the preferred method of mobility without the need for any assistive mobility device.

LEVEL II: Children floor sit but may have difficulty with balance when both hands are free to manipulate objects. Movements in and out of sitting are performed without adult assistance. Children pull to stand on a stable surface. Children crawl on hands and knees with a reciprocal pattern, cruise holding onto furniture and walk using an assistive mobility device as preferred methods of mobility.

LEVEL III: Children maintain floor sitting often by “W-sitting” (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assure sitting. Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements) as their primary methods of self-mobility. Children may pull to stand on a stable surface and cruise short distances. Children may walk short distances indoors using a hand-held mobility device (walker) and adult assistance for steering and turning.

LEVEL IV: Children floor sit when placed, but are unable to maintain alignment and balance without use of their hands for support. Children frequently require adaptive equipment for sitting and standing. Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees without reciprocal leg movement.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.

BETWEEN 4TH AND 6TH BIRTHDAY

LEVEL I: Children get in and out of, and sit in, a chair without the need for hand support. Children move from the floor and from chair sitting to standing without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.

LEVEL II: Children sit in a chair with both hands free to manipulate objects. Children move from the floor to standing and from chair sitting to standing but often require a stable surface to push or pull up on with their arms. Children walk without the need for a hand-held mobility device indoors and for short distances on level surfaces outdoors. Children climb stairs holding onto a railing but are unable to run or jump.

LEVEL III: Children sit on a regular chair but may require pelvic or trunk support to maximize hand function. Children move in and out of chair sitting using a stable surface to push or pull up with their arms. Children walk with a hand-held mobility device on level surfaces and climb stairs with assistance from an adult. Children frequently are transported when traveling for long distances or outdoors on uneven terrain.

LEVEL IV: Children sit on a chair but need adaptive seating for trunk control and to maximize hand function. Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms. Children may at best walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces. Children are transported in the community. Children may achieve self-mobility using a powered wheelchair.

LEVEL V: Physical impairments restrict voluntary control of movement and the ability to maintain antigravity head and trunk postures. All areas of motor function are limited. Functional limitations in sitting and standing are not fully compensated for through the use of adaptive equipment and assistive technology. At Level V, children have no means of independent movement and are transported. Some children achieve self-mobility using a powered wheelchair with extensive adaptations.
### BETWEEN 6TH AND 12TH BIRTHDAY

**Level I:** Children walk at home, school, outdoors, and in the community. Children are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Children perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Children may participate in physical activities and sports depending on personal choices and environmental factors.

**Level II:** Children walk in most settings. Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects. Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing. Outdoors and in the community, children may walk with physical assistance, a hand-held mobility device, or use wheeled mobility when traveling long distances. Children have at best only minimal ability to perform gross motor skills such as running and jumping. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

**Level III:** Children walk using a hand-held mobility device in most indoor settings. When seated, children may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface. When traveling long distances, children use some form of wheeled mobility. Children may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

**Level IV:** Children use methods of mobility that require physical assistance or powered mobility in most settings. Children require adaptive seating for trunk and pelvic control and physical assistance for most transfers. At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility. When positioned, children may use a body support walker at home or school. At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

**Level V:** Children are transported in a manual wheelchair in all settings. Children are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and/or mobility but limitations are not fully compensated by equipment. Transfers require complete physical assistance of an adult. At home, children may move short distances on the floor or may be carried by an adult. Children may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.

### BETWEEN 12TH AND 18TH BIRTHDAY

**Level I:** Youth walk at home, school, outdoors, and in the community. Youth are able to walk up and down curbs without physical assistance and stairs without the use of a railing. Youth perform gross motor skills such as running and jumping but speed, balance, and coordination are limited. Youth may participate in physical activities and sports depending on personal choices and environmental factors.

**Level II:** Youth walk in most settings. Environmental factors (such as uneven terrain, inclines, long distances, time demands, weather, and peer acceptability) and personal preference influence mobility choices. At school or work, youth may walk using a hand-held mobility device for safety. Outdoors and in the community, youth may use wheeled mobility when traveling long distances. Youth walk up and down stairs holding a railing or with physical assistance if there is no railing. Limitations in performance of gross motor skills may necessitate adaptations to enable participation in physical activities and sports.

**Level III:** Youth are capable of walking using a hand-held mobility device. Compared to individuals in other levels, youth in Level III demonstrate more variability in methods of mobility depending on physical ability and environmental and personal factors. When seated, youth may require a seat belt for pelvic alignment and balance. Sit-to-stand and floor-to-stand transfers require physical assistance from a person or support surface. At school, youth may self-propel a manual wheelchair or use powered mobility. Outdoors and in the community, youth are transported in a wheelchair or use powered mobility. Youth may walk up and down stairs holding onto a railing with supervision or physical assistance. Limitations in walking may necessitate adaptations to enable participation in physical activities and sports including self-propelling a manual wheelchair or powered mobility.

**Level IV:** Youth use wheeled mobility in most settings. Youth require adaptive seating for pelvic and trunk control. Physical assistance from 1 or 2 persons is required for transfers. Youth may support weight with their legs to assist with standing transfers. Indoors, youth may walk short distances with physical assistance, use wheeled mobility, or, when positioned, use a body support walker. Youth are physically capable of operating a powered wheelchair. When a powered wheelchair is not feasible or available, youth are transported in a manual wheelchair. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports, including physical assistance and/or powered mobility.

**Level V:** Youth are transported in a manual wheelchair in all settings. Youth are limited in their ability to maintain antigravity head and trunk postures and control arm and leg movements. Assistive technology is used to improve head alignment, seating, standing, and mobility but limitations are not fully compensated by equipment. Physical assistance from 1 or 2 persons or a mechanical lift is required for transfers. Youth may achieve self-mobility using powered mobility with extensive adaptations for seating and control access. Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility.
Information for users

The Manual Ability Classification System (MACS) describes how children with cerebral palsy (CP) use their hands to handle objects in daily activities. MACS describes five levels. The levels are based on the children’s self-initiated ability to handle objects and their need for assistance or adaptation to perform manual activities in everyday life. The MACS brochure also describes differences between adjacent levels to make it easier to determine which level best corresponds with the child’s ability to handle objects.

The objects referred to are those that are relevant and age-appropriate for the children, used when they perform tasks such as eating, dressing, playing, drawing or writing. It is objects that are within the children’s personal space that is referred to, as opposed to objects that are beyond their reach. Objects used in advanced activities that require special skills, such as playing an instrument are not included in this considerations.

When establishing a child’s MACS level, choose the level that best describes the child’s overall ability to handle objects in a home, school or community setting. The child’s motivation and cognitive ability also affect the ability to handle objects and accordingly influence the MACS level. In order to obtain knowledge about how a child handles everyday objects, it is necessary to ask someone who knows the child well. MACS is intended to classify what the children usually do, not their best possible performance in a specific test situation.

MACS is a functional description that can be used in a way that is complement to the diagnosis of cerebral palsy and its subtype. MACS assesses the child’s overall ability to handle everyday objects, not the function of each hand separately. MACS does not take into account differences in function between the two hands. Rather, it addresses how the children handle age-appropriate objects. MACS does not intend to explain the underlying reasons for impaired manual abilities.

MACS can be used for children aged 4–18 years, but certain concepts must be placed in relation to the child’s age. Naturally there is a difference in which objects a four-year old should be able to handle, compared to a teenager. The same applies to independence – a young child needs more help and supervision than an older child.

MACS spans the entire spectrum of functional limitations found among children with cerebral palsy and covers all sub-diagnoses. Certain sub-diagnoses can be found at all MACS levels, such as bilateral CP, while others are found at lower levels, such as unilateral CP. Level I includes children with minor limitations, while children with severe functional limitations will usually be found at levels IV and V. Typically-developed children were to be classified according to MACS, however, a level “O” would be needed.

Moreover, each level includes children with relatively varied function. It is unlikely that MACS is sensitive to changes after an intervention; in all probability, MACS levels are stable over time.

The five levels in MACS form an ordinal scale, which means that the levels are ordered, but differences between levels are not necessarily equal, nor are children with cerebral palsy equally distributed across the five levels.

E-mail: christine.ellisson@liu.se, www.macs.ru


On Track Study - Classification Systems (version date 29-Nov-2012)
What do you need to know to use MACS?

The child's ability to handle objects in important daily activities, for example during play and leisure, eating and dressing.

In which situation is the child independent and to what extent do they need support and adaptation?

I. **Handles objects easily and successfully.** At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

II. **Handles most objects but with somewhat reduced quality and/or speed of achievement.** Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

III. **Handles objects with difficulty; needs help to prepare and/or modify activities.** The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

IV. **Handles a limited selection of easily managed objects in adapted situations.** Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

V. **Does not handle objects and has severely limited ability to perform even simple actions.** Requires total assistance.

**Distinctions between Levels I and II**

Children in Level I may have limitations in handling very small, heavy or fragile objects which demand detailed fine motor control, or efficient coordination between hands. Limitations may also involve performance in new and unfamiliar situations. Children in Level II perform almost the same activities as children in Level I but the quality of performance is decreased, or the performance is slower. Functional differences between hands can limit effectiveness of performance. Children in Level II commonly try to simplify handling of objects, for example by using a surface for support instead of handling objects with both hands.

**Distinctions between Levels II and III**

Children in Level II handle most objects, although slowly or with reduced quality of performance. Children in Level III commonly need help to prepare the activity and/or require adjustments to be made to the environment since their ability to reach or handle objects is limited. They cannot perform certain activities and their degree of independence is related to the supportiveness of the environmental context.

**Distinctions between Levels III and IV**

Children in Level III can perform selected activities if the situation is prearranged and if they get supervision and plenty of time. Children in Level IV need continuous help during the activity and can at best participate meaningfully in only parts of an activity.

**Distinctions between Levels IV and V**

Children in Level IV perform part of an activity, however, they need help continuously. Children in Level V might be able to participate in simple actions in special situations, e.g., by pushing a button or occasionally hold undemanding objects.
Supplementary MACS level identification chart
To be used together with the MACS leaflet

Does the child handle most kinds of objects independently?

Yes  No

Does the child perform even difficult manual tasks with fair speed and accuracy and does not need to use alternative ways of performance?

Yes  No

Level I
Handles objects easily and successfully. At most limitations in the ease of performing manual tasks requiring speed and accuracy.

Level II
Handles most objects but with somewhat reduced quality and/or speed of achievement. May avoid some tasks or use alternative ways of performance.

Level III
Handles objects with difficulty, needs help to prepare and/or modify activities.

Level IV
Handles a limited selection of easily manage objects in adapted situations, requires continued support.

Level V
Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.

Does the child perform a number of manual tasks which commonly need to be adapted or prepared, and help is only needed occasionally?

Yes  No

Level I
Handles objects easily and successfully. At most limitations in the ease of performing manual tasks requiring speed and accuracy.

Level II
Handles most objects but with somewhat reduced quality and/or speed of achievement. May avoid some tasks or use alternative ways of performance.

Level III
Handles objects with difficulty, needs help to prepare and/or modify activities.

Level IV
Handles a limited selection of easily manage objects in adapted situations, requires continued support.

Level V
Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.
Appendix E: Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

Purpose
The purpose of the CFCS is to classify the everyday communication performance of an individual with cerebral palsy into one of five levels. The CFCS focuses on activity and participation levels as described in the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF).

User Instructions
A parent, caregiver, and/or a professional who is familiar with the person's communication selects the level of communication performance. Adults and adolescents with cerebral palsy may also classify their communication performance. The overall effectiveness of the communication performance should be based on how they usually take part in everyday situations requiring communication, rather than their best capacity. These everyday situations may occur in home, school, and the community.

Some communication may be difficult to classify if performance falls across more than one level. In those cases, choose the level that most closely describes the person's usual performance in the most settings. Do not consider the individual's perceived capacity, cognition, and/or motivation when selecting a level.

Definitions
Communication occurs when a sender transmits a message and a receiver understands the message. An effective communicator independently alternates as a sender and a receiver regardless of the demands of a conversation, including settings (e.g., community, school, work, home), conversational partners, and topics.

All methods of communication performance are considered in determining the CFCS level. These include the use of speech, gestures, behaviors, eye gaze, facial expressions, and augmentative and alternative communication (AAC). AAC systems include (but are not limited to) manual sign, pictures, communication boards, communication books, and talking devices—sometimes called voice output communication aids (VOCA) or speech generating devices (SGD).

Distinctions between the levels are based on the performance of sender and receiver roles, the pace of communication, and the type of conversational partner. The following definitions should be kept in mind when using this classification system.

Effective senders and receivers shift quickly and easily between transmitting and understanding messages. To clarify or repair misunderstandings, the effective sender and receiver may use or request strategies such as repeating, rephrasing, simplifying, and/or expanding the message. To speed up communication exchanges, especially when using AAC, an effective sender may appropriately decide to use less grammatically correct messages by leaving out or shortening words with familiar communication partners.

A comfortable pace of communication refers to how quickly and easily the person can understand and convey messages. A comfortable pace occurs with few communication breakdowns and little wait time between communication turns.

Unfamiliar conversational partners are strangers or acquaintances who only occasionally communicate with the person. Familiar conversational partners such as relatives, caregivers, and friends may be able to communicate more effectively with the person because of previous knowledge and personal experiences.
Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

Clarifications

★ Determining the CFCS level does not require testing, nor does it replace standardized communication assessments. The CFCS is not a test.

★ The CFCS groups people by the effectiveness of current communication performance. It does not explain any underlying reasons for the degree of effectiveness such as cognitive, motivational, physical, speech, hearing, and/or language problems.

★ The CFCS does not rate the person's potential for improvement.

★ The CFCS may be useful in research and service delivery when classifying communication effectiveness is important.

Examples include:
1) describing functional communication performance using a common language among professionals and laypersons,
2) recognizing the use of all effective methods of communication including AAC,
3) comparing how different communication environments, partners, and/or communication tasks might affect the level chosen,
4) choosing goals to improve the person's communication effectiveness.

Communication Methods

Regardless of the number of communication methods used, only 1 CFCS level is assigned for the overall communication performance. The optional box below is provided to list all the communication methods used.

The following methods of communication are used by this individual: (Please check all that apply)

- Speech
- Sounds (such as an "aaaah" to get a partner's attention)
- Eye gaze, facial expressions, gesturing, and/or pointing (e.g., with a body part, stick, laser)
- Manual signs
- Communication book, boards, and/or pictures
- Voice output device or a speech-generating device
- Other

See page 3 for a description of the five levels.
See page 4 for a chart to help distinguish between levels.
Frequently asked questions can be found on the CFCS website. http://cfcs.us
Communication Function Classification System (CFCS) for Individuals with Cerebral Palsy

I. Effective Sender and Receiver with unfamiliar and familiar partners. The person independently alternates between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with both unfamiliar and familiar conversational partners. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

II. Effective but slower paced Sender and Receiver with unfamiliar and/or familiar partners. The person independently alternates between sender and receiver roles with most people in most environments, but the conversational pace is slow and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstanding are often repaired and do not interfere with the eventual effectiveness of the person's communication with both unfamiliar and familiar partners.

III. Effective Sender and Receiver with familiar partners. The person alternates between sender and receiver roles with familiar (but not unfamiliar) conversational partners in most environments. Communication is not consistently effective with most unfamiliar partners, but is usually effective with familiar partners.

IV. Inconsistent Sender and/or Receiver with familiar partners. The person does not consistently alternate sender and receiver roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is sometimes effective with familiar partners.

V. Seldom Effective Sender and Receiver even with familiar partners. The person is limited as both a sender and a receiver. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is seldom effective even with familiar partners.

Key:
P Person with CP
U Unfamiliar Partner
F Familiar Partner
----- Less effective

The difference between Levels I and II is the pace of the conversation. In Level I, the person communicates at a comfortable pace with little or no delay in order to understand, compose a message, or repair a misunderstanding. In Level II, the person needs extra time at least occasionally.

The differences between Levels II and III concern pace and the type of conversational partners. In Level II, the person is an effective sender and receiver with all conversational partners, but pace is an issue. In Level III, the person is consistently effective with familiar conversational partners, but not with most unfamiliar partners.

The difference between Levels III and IV is how consistently the person alternates between sender and receiver roles with familiar partners. In Level III, the person is generally able to communicate with familiar partners as a sender and as a receiver. In Level IV, the person does not communicate with familiar partners consistently. This difficulty may be in sending and/or receiving.

The difference between Levels IV and V is the degree of difficulty that the person has when communicating with familiar partners. In Level IV, the person has some success as an effective sender and/or an effective receiver with familiar partners. In Level V, the person is rarely able to communicate effectively, even with familiar partners.

On Track Study - Classification Systems (version date 29-Nov-2012)
CFCS Level Identification Chart

Does the person consistently and effectively alternate sender and receiver roles with familiar partners?

Does the person consistently and effectively communicate with unfamiliar partners?

Is the person an effective sender AND/OR a receiver at least some of the time?

Level I
Effective Sender and Receiver with unfamiliar and familiar partners

Level II
Effective, but slower-paced Sender and/or Receiver with unfamiliar and familiar partners

Level III
Effective Sender AND Effective Receiver with familiar partners

Level IV
Inconsistent Sender and/or Receiver with familiar partners

Level V
Seldom Effective Sender and Receiver with familiar partners

On Track Study - Classification Systems (version date 29-Nov-2012)
Children's development can be affected by the health problems that they experience. You will be asked some questions about different health problems. We want to know whether or not your child has any of these problems, and if your child has a health problem, to what extent does the health problem affect your child's daily activities.

Ch1. Does your child have problems seeing?  

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch2. Does your child have problems hearing?  

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ch3. Does your child have problems **learning and understanding**?  

To what extent does this problem affect your child's daily activities?  

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch4. Does your child have problems **speaking, or communicating in other ways** (e.g. signs, gestures, picture cards, or sounds that are not words)?  

To what extent does this problem affect your child's daily activities?  

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch5. Does your child have problems **controlling emotions or behaviour**?  

To what extent does this problem affect your child's daily activities?  

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ch6. Does your child have problems with seizures or epilepsy?  

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch7. Does your child have problems involving the mouth (e.g. swallowing, chewing, and drooling)?  

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch8. Does your child have problems with teeth and gums?  

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ch9. Does your child have problems with digestion (e.g. reflux, vomiting, or constipation)?

To what extent does this problem affect your child’s daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Ch10. Does your child have problems with growth?

To what extent does this problem affect your child’s daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

Ch11. Does your child have problems with sleeping?

To what extent does this problem affect your child’s daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>
Ch12. Does your child have problems with repeated infections?  

To what extent does this problem affect your child’s daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch13. Does your child have problems with breathing (e.g. asthma)?  

To what extent does this problem affect your child’s daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch14. Does your child have problems with skin (e.g. eczema)?  

To what extent does this problem affect your child’s daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Ch15. Does your child have problems with the heart (e.g. birth defect)? 〇 No 〇 Yes

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch16. Does your child have problems with pain? 〇 No 〇 Yes

To what extent does this problem affect your child's daily activities?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>To a very small extent</th>
<th>To a small extent</th>
<th>To a moderate extent</th>
<th>To a fairly great extent</th>
<th>To a great extent</th>
<th>To a very great extent</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Ch17. Does your child have any other health problems? 〇 No 〇 Yes

If yes, specify problem:


Appendix G: Family Information

Family Information Form

This form asks some general questions about your family and child. Some of the questions may seem personal, but we ask about this information to describe families that participate in this study.

This information will be kept completely confidential
No names are attached to the form; only a number

If you have any questions or concerns about this form, the therapist will be able to help you with this during your study appointment.

Child Information

1. What is your child's gender?  
   ○ Boy  ○ Girl

The information in the next 3 questions will tell us whether the ethnic backgrounds of families living in North America are represented among the Canadian and American participants in this study. Your responses to these questions will not be discussed individually but will be reported as a summary for the entire group. We appreciate your sharing this with us.

(These questions have been adapted to include race and ethnicity questions used in the 2010 United States Census and the 2011 Statistics Canada Census.)
2. Is your child of Hispanic, Latino, or Spanish origin?

- No, not of Hispanic, Latino, or Spanish origin
- Yes, Mexican, Mexican American, Chicano
- Yes, Puerto Rican
- Yes, Cuban
- Yes, another Hispanic, Latino, or Spanish origin - Print origin, for example, Argentinean, Columbian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on:

3. Is your child an Aboriginal person?

Note: First Nations (North American Indian) includes Status and Non-Status Indians.

- No, not an Aboriginal person
- Yes, First Nations (North American Indian)
- Yes, Métis
- Yes, Inuk (Inuit)
- Yes, Alaska native
- Yes, other:
4. Is your child:
Mark more than one or specify, if applicable.

☐ White
☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc)
☐ Chinese
☐ Black, African American, or Negro
☐ Filipino
☐ Latin American
☐ Arab
☐ Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, etc.)
☐ West Asian (e.g. Iranian, Afghan, etc.)
☐ Korean
☐ Japanese
☐ Native Hawaiian or Other Pacific Islander
☐ Other - Please specify __________________________

Parent / Caregiver Information
This section asks questions about YOU.

5. What is your relationship to this child?

☐ mother  ☐ father
☐ adoptive mother  ☐ adoptive father
☐ stepmother  ☐ stepfather
☐ foster mother  ☐ foster father
☐ grandmother  ☐ grandfather
☐ other, please specify: __________________________
6. What is your marital status?
- never married
- married or living with a partner
- separated
- divorced
- widowed

7. How old are you? □□ years

8. What is the highest level of education you FINISHED?
- less than high school
- high school or GED
- community college diploma; technical degree / associate degree
- bachelors degree
- master degree
- doctoral degree

9. Do you work full-time or part-time or not at all?
- full-time (30 hours or more per week)
- part-time (less than 30 hours per week)
- not employed at this time

The information in the next 3 questions will tell us whether the ethnic background of families living in North America are represented among the Canadian and American participants in this study. Your responses to these questions will not be discussed individually but will be reported as a summary for the entire group. We appreciate your sharing this with us.

(These questions have been adapted to include race and ethnicity questions used in the 2010 United States Census and the 2011 Statistics Canada Census.)
10. Are you of Hispanic, Latino, or Spanish origin?
   - No, not of Hispanic, Latino, or Spanish origin
   - Yes, Mexican, Mexican American, Chicano
   - Yes, Puerto Rican
   - Yes, Cuban
   - Yes, another Hispanic, Latino, or Spanish origin - *Print origin, for example, Argentinian, Columbian, Dominican, Nicaraguan, Salvadoran, Spaniard, and so on:*

11. Are you an Aboriginal person?
   *Note: First Nations (North American Indian) includes Status and Non-Status Indians.*
   - No, not an Aboriginal person
   - Yes, First Nations (North American Indian)
   - Yes, Métis
   - Yes, Inuk (Inuit)
   - Yes, Alaska native
   - Yes, other: ____________________  If yes, please specify name of enrolled or principle tribe
12. Are you:
Mark more than one or specify, if applicable.

☐ White
☐ South Asian (e.g. East Indian, Pakistani, Sri Lankan, etc)
☐ Chinese
☐ Black, African American, or Negro
☐ Filipino
☐ Latin American
☐ Arab
☐ Southeast Asian (e.g. Vietnamese, Cambodian, Malaysian, Laotian, etc.)
☐ West Asian (e.g. Iranian, Afghan, etc.)
☐ Korean
☐ Japanese
☐ Native Hawaiian or Other Pacific Islander
☐ Other - Please specify ______________________

13. We would like to ask some information about all of the people who live with you.

You have told us about yourself and your child. Now we want to know about your spouse or partner, your other children, and other relatives like grandparents or aunts, uncles and cousins who may live with you. We also want to know about people who are not relatives, but may live with you.

We just need to know each person's age. Use initials, not names. You don’t need to write anything here about yourself or your child.

For example:  BG  12 years old
                 SF  75 years old
How many people live with you (do not count yourself or your child who is participating in this study)?

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years

initials

[ ] [ ] age in years
14. What is the total household income, before taxes?
   ○ less than $15,000
   ○ $15,000 - $29,999
   ○ $30,000 - $44,999
   ○ $45,000 - $59,999
   ○ $60,000 - $74,999
   ○ $75,000 - $89,999
   ○ $90,000 or more
   ○ Prefer not to answer

15. What is your postal code or zipcode? __________________
Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

Parent Booklet
TIME 1 ASSESSMENT

SITE: __________  CHILD’S STUDYID: __________
INSTRUCTIONS FOR PARENTS

TIME 1 ASSESSMENT

Dear Parent,

You are receiving this booklet because you have agreed to participate with your child in the ON TRACK Study: Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay.

THANK YOU AGAIN FOR AGREEING TO HELP US WITH THIS STUDY.
YOUR HELP IS VERY VALUABLE TO US.

The information we are collecting will help therapists and parents monitor if a child is developing as expected in their physical development and participation. Then, the health care professionals working with children can use the results of this study, in combination with our previously completed Move & PLAY Study results, to provide the services that are most beneficial and meaningful for each child and their family members.

There are 2 visits planned, about 12 months apart, and you will be asked to do some questionnaires at both visits.

ALL INFORMATION YOU GIVE US WILL BE KEPT COMPLETELY CONFIDENTIAL. Names are not connected to the booklets, only unique identification numbers.

THIS BOOKLET IS FOR THE FIRST VISIT.

DATE COMPLETED: __________________________

Day/Month/Year

Please turn the page for some general instructions about this booklet.
INSTRUCTIONS FOR PARENTS
TIME 1 ASSESSMENT

Here are some general instructions about this booklet:

Each questionnaire is printed on a different colour paper. Each questionnaire will have some instructions about how to answer the questions for that section. Please read them carefully!

When you are done, please take a minute to check and see if you have answered every question.

Don’t worry if you have trouble answering some of the questions. The study assessor will be available to help you at the study visit.

Please make any comments on the last page of this booklet.

There may be some questions that you think don’t apply to you, your child, or your family. We ask you to choose the answer that is the best fit, even if it isn’t exactly what you want to say. Please do your best to answer all the questions.

If there are any questions you would rather not answer, please make a note that you choose not to answer it. The study assessor may ask you about any missing answers—it’s OK to tell her or him that you don’t want to answer that question.

THANK YOU FOR PARTICIPATING IN THIS STUDY!
Questions about your child’s usual abilities
at home, school and in the community

In the next section, there are three classification systems that are used for grouping the abilities of people with cerebral palsy and gross motor delay. These systems are enclosed with this data collection booklet. Each system is clinically useful to therapists and families as a way to discuss and describe:

- Movement abilities
  *Gross Motor Function Classification System or GMFCS*

- Hand abilities
  *Manual Abilities Classification System or MACS*

- Communication abilities
  *Communication Function Classification System or CFCS*

The main goal of this study is to create benchmarks, or reference curves, which can later be used to assist therapists and families when monitoring children’s development and making decisions about interventions.

Looking closely at smaller groups of children in each of the levels of a classification system will go a long way to meeting parents’ wishes to have specific information about their children, based on their child’s individual characteristics.

We believe that parents are in the best position to judge their child’s usual performance in different settings (home, school, and community). We ask that you read through the descriptions for the levels and make a classification for the GMFCS, MACS and CFCS in this booklet.

At the study visit, the study assessor will go over your classifications with you.
Gross Motor Function Classification System

Please specify your child's age band:

- [ ] Between 2nd and 4th birthday
- [ ] Between 4th and 6th birthday
- [ ] Between 6th and 12th birthday

*Please choose ONE box that best fits your child for the age band that matches his or her current age. You can discuss this with your child's assessing therapist.*
Between 2nd and 4th birthday

- **LEVEL I:**
  - Children floor sit with both hands free to manipulate objects
  - Movements in and out of floor sitting and standing are performed without adult assistance
  - Children walk without the need for canes, crutches or a walker

- **LEVEL II:**
  - Children floor sit but may have difficulty with balance when both hands are free to manipulate objects
  - Movements in and out of floor sitting and standing are performed without adult assistance
  - Children pull to stand on a stable surface
  - Children crawl on hands and knees with a reciprocal pattern
  - Children take steps holding onto furniture
  - Children walk using a cane, crutches, or a walker

- **LEVEL III:**
  - Children maintain floor sitting and may require adult assistance to assume sitting
  - Children creep on their stomach or crawl on hands and knees (often without reciprocal leg movements)
  - Children may pull to stand on a stable surface and take steps holding onto furniture
  - Children may walk short distances indoors using a walker and adult assistance for steering and turning

- **LEVEL IV:**
  - Children floor sit when placed, but are unable to maintain balance without use of their hands for support
  - Children frequently require adaptive equipment for sitting and standing
  - Self-mobility for short distances (within a room) is achieved through rolling, creeping on stomach, or crawling on hands and knees

- **LEVEL V:**
- Physical impairments restrict movement and control of head and trunk postures
- All areas of motor function are limited
- Children have no means of independent movement and are carried or transported in a stroller or wheelchair
- Some children achieve self-mobility using a powered wheelchair

**Between 4th and 6th birthday**

- **LEVEL I:**
  - Children get into and out of, and sit in, a chair without the need for hand support
  - Children move from the floor and from chair sitting to standing
  - Children walk indoors and outdoors, and climb stairs
  - Children have emerging ability to run and jump

- **LEVEL II:**
  - Children sit in a chair with both hands free to manipulate objects
  - Children move from the floor to standing and from chair to sitting to standing but often require a stable surface to push or pull up on with their arms
  - Children walk without support indoors and for short distances outdoors
  - Children climb stairs holding onto a railing

- **LEVEL III:**
  - Children sit on a regular chair but may require hip or trunk support to maximize hand function
  - Children move in and out of chair sitting using a stable surface to push on or pull up with their arms
  - Children walk with a walker on level surfaces
  - Children climb stairs with assistance from an adult
  - Children frequently are transported in a wheelchair when traveling for long distances or outdoors on uneven terrain

- **LEVEL IV:**
  - Children sit on a chair but need adaptive seating for trunk control and to maximize hand function
  - Children move in and out of chair sitting with assistance from an adult or a stable surface to push or pull up on with their arms
- Children may walk short distances with a walker and adult supervision but have difficulty turning and maintaining balance on uneven surfaces
- Children are transported in a wheelchair in the community
- Children may achieve self-mobility using a powered wheelchair

LEVEL V:
- Physical impairments restrict voluntary control of movement and the ability to maintain head and trunk postures
- All areas of motor function are limited
- Children have no means of independent movement and are transported in a wheelchair
- Some children achieve self-mobility using a powered wheelchair

Between 6th and 12th birthday

LEVEL I:
- Children walk at home, school, outdoors and in the community
- Children are able to walk up and down curbs without physical assistance
- Children are able to walk up and down stairs without the use of a railing
- Children perform gross motor skills such as running and jumping
- Children often participate in physical activities and sports

LEVEL II:
- Children walk in most settings
- Children may experience difficulty walking long distances and balancing on uneven terrain, inclines, in crowded areas, confined spaces or when carrying objects
- Children walk up and down stairs holding onto a railing or with physical assistance if there is no railing
- Outdoors and in the community, children may walk with physical assistance, cane, crutches, or walker, or use wheeled mobility when traveling long distances
- Limitations in performance of gross motor skills may necessitate adaptations for participation in physical activities and sports

LEVEL III:
- Children walk using a hand-held mobility device in most indoor settings
- When seated, children may require a seat belt for hip alignment and balance
- Sit-to-stand and floor-to-stand transfers require physical assistance of a person or support surface
- When traveling long distances, children use some form of wheeled mobility
- Children may walk up and down stairs holding onto a railing with supervision or physical assistance
- Limitations in walking may necessitate adaptations to enable participation in physical activities and sports

LEVEL IV:
- Children use methods of mobility that require physical assistance or powered mobility in most settings
- Children require adaptive seating for trunk control
- Children require physical assistance for most transfers
- At home, children use floor mobility (roll, creep, or crawl), walk short distances with physical assistance, or use powered mobility
- When positioned, children may use a body support walker at home or school
- At school, outdoors, and in the community, children are transported in a manual wheelchair or use powered mobility
- Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and/or powered mobility

LEVEL V:
- Children are transported in a manual wheelchair in all settings
- Children are limited in their ability to maintain head and trunk postures and control arm and leg movements
- Transfers require complete physical assistance of an adult
- Children may achieve self mobility using powered mobility
- Limitations in mobility necessitate adaptations to enable participation in physical activities and sports including physical assistance and using powered mobility
Manual Ability Classification System
for Children with Cerebral Palsy

Please use the attached form to mark the category that best matches your child's ability to use his or her hands in daily life. If your child is under 4 years of age, please still complete this form.

PLEASE CHECK ONLY ONE BOX

I

Handles objects easily and successfully. At most, limitations in the ease of performing manual tasks requiring speed and accuracy. However, any limitations in manual abilities do not restrict independence in daily activities.

II

Handles most objects but with somewhat reduced quality and/or speed of achievement. Certain activities may be avoided or be achieved with some difficulty; alternative ways of performance might be used but manual abilities do not usually restrict independence in daily activities.

III

Handles objects with difficulty; needs help to prepare and/or modify activities. The performance is slow and achieved with limited success regarding quality and quantity. Activities are performed independently if they have been set up or adapted.

IV

Handles a limited selection of easily managed objects in adapted situations. Performs parts of activities with effort and with limited success. Requires continuous support and assistance and/or adapted equipment, for even partial achievement of the activity.

V

Does not handle objects and has severely limited ability to perform even simple actions. Requires total assistance.
Communication Function Classification System for Individuals with Cerebral Palsy

Please use the attached form to mark the category that best describes your child's ability to communicate in daily life.

PLEASE CHECK ONLY ONE BOX

I  ☐

Effective Sender and Receiver with unfamiliar and familiar partners. The person independently alternates between sender and receiver roles with most people in most environments. The communication occurs easily and at a comfortable pace with both unfamiliar and familiar conversational partners. Communication misunderstandings are quickly repaired and do not interfere with the overall effectiveness of the person's communication.

II  ☐

Effective but slower paced Sender and/or Receiver with unfamiliar and/or familiar partners. The person independently alternates between sender and receiver roles with most people in most environments, but the conversational pace is slow and may make the communication interaction more difficult. The person may need extra time to understand messages, compose messages, and/or repair misunderstandings. Communication misunderstandings are often repaired and do not interfere with the eventual effectiveness of the person's communication with both unfamiliar and familiar partners.

III  ☐

Effective Sender and Receiver with familiar partners. The person alternates between sender and receiver roles with familiar (but not unfamiliar) conversational partners in most environments. Communication is not consistently effective with most unfamiliar partners, but is usually effective with familiar partners.
IV ○

**Inconsistent Sender and/or Receiver with familiar partners.** The person does **not** consistently alternate **sender** and **receiver** roles. This type of inconsistency might be seen in different types of communicators including: a) an occasionally effective sender and receiver; b) an effective sender but limited receiver; c) a limited sender but effective receiver. Communication is **sometimes effective** with **familiar partners**.

V ○

**Seldom Effective Sender and Receiver even with familiar partners.** The person is limited as both a **sender and a receiver**. The person's communication is difficult for most people to understand. The person appears to have limited understanding of messages from most people. Communication is **seldom effective** even with **familiar partners**.
THANK YOU FOR COMPLETING THESE QUESTIONS!

PLEASE REMEMBER YOU CAN ASK THE STUDY ASSESSOR FOR HELP IF YOU HAD ANY PROBLEMS WITH THE QUESTIONS.
Appendix I: Assessors' Classifications and Booklet Instructions

Monitoring Development of Children with Cerebral Palsy or Gross Motor Delay

Assessor Booklet
TIME 1 ASSESSMENT

SITE: __________ CHILD’S STUDYID: __________
Here are some general instructions about this booklet:

**Colour Coded Sections:** Each questionnaire in this booklet is printed on a different colour paper. Each questionnaire will have some instructions about how to answer the questions for that section. Please read them carefully!

**Corrections:** Please mark the answers clearly on the data collection pages and if corrections are made, be sure to mark the final answer clearly.

**Missed Questions:** Please mark a line through any item that is not completed, making sure to write a note to explain why it was missed. This will save time later when following up on missed information.

**Adding Comments:** Please do not write comments on the front side of each page, use this space only to check off or write-in the answers. We encourage you to write any comments or clarifications on the back side of the page. If you do write a comment or question on the back side of the page, please refer to the specific question number. For example “comment re ECAB2...”

**Conservative Scoring Rule:** If you are having trouble choosing between two hierarchical response items, it is likely because you are not fully confident of the higher order response (i.e. the more highly functional or less impaired score). Please be conservative and choose the lower order response (i.e. the less functional or more impaired score) indicating that you are fully confident that at least this much is true.

**Checking for Completion:** At the end of the appointment, please take a few minutes to check all the pages for completion. Also make sure that you have completed the checklist and comments section at the end of this booklet. These steps will help to ensure that all of the Time 1 activities are completed and will minimize the amount of missing data for us to recover later.

Thank you for your help to collect these important details!
Child's Study ID _____
Therapist's ID _____

TIME 1 ASSESSOR COVER PAGE

CP 1  Date of assessment: ________________ (day/month/year)

CP 2  Region  
☐ Canada  
☐ Philadelphia  
☐ Atlanta  
☐ Oklahoma  
☐ Seattle/ Tacoma

CP 3  Location of assessment  
☐ Clinic setting  
☐ Home  
☐ Other (specify)________________________

CP 4  Child's Date of Birth: ________________ (day/month/year)
### Classification Systems

#### GMFCS

<table>
<thead>
<tr>
<th>Indicate level in this column if you agree with the parent classification</th>
<th>Indicate level in this column if parent revised his or her classification based on discussion</th>
<th>Indicate level in this column if your classification remains different from the parent (and provide rationale in the comments box below)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>III</td>
<td>III</td>
<td>III</td>
</tr>
<tr>
<td>IV</td>
<td>IV</td>
<td>IV</td>
</tr>
<tr>
<td>V</td>
<td>V</td>
<td>V</td>
</tr>
</tbody>
</table>

#### MACS

<table>
<thead>
<tr>
<th>Indicate level in this column if you agree with the parent classification</th>
<th>Indicate level in this column if parent revised his or her classification based on discussion</th>
<th>Indicate level in this column if your classification remains different from the parent (and provide rationale in the comments box below)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>III</td>
<td>III</td>
<td>III</td>
</tr>
<tr>
<td>IV</td>
<td>IV</td>
<td>IV</td>
</tr>
<tr>
<td>V</td>
<td>V</td>
<td>V</td>
</tr>
</tbody>
</table>

#### CFCS

<table>
<thead>
<tr>
<th>Indicate level in this column if you agree with the parent classification</th>
<th>Indicate level in this column if parent revised his or her classification based on discussion</th>
<th>Indicate level in this column if your classification remains different from the parent (and provide rationale in the comments box below)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>I</td>
<td>I</td>
</tr>
<tr>
<td>II</td>
<td>II</td>
<td>II</td>
</tr>
<tr>
<td>III</td>
<td>III</td>
<td>III</td>
</tr>
<tr>
<td>IV</td>
<td>IV</td>
<td>IV</td>
</tr>
<tr>
<td>V</td>
<td>V</td>
<td>V</td>
</tr>
</tbody>
</table>
Comments:

Please indicate the child's distribution of involvement from the choices below:

Monoplegia (involvement of one limb)

Hemiplegia (involvement of one side)

Diplegia (more involvement of legs than arms)

Triplegia (involvement of three limbs)

Quadriplegia (involvement of four limbs)
Comments

Indicate if extraordinary conditions about the visit occurred. Please note that any adverse events should be reported immediately.
# Curriculum Vitae

<table>
<thead>
<tr>
<th><strong>Name:</strong></th>
<th>Emily Dyszuk</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Post-secondary Education and Degrees:</strong></td>
<td>University of Western Ontario London, Ontario, Canada 2008-2012 B.A. University of Western Ontario London, Ontario, Canada 2012-2014 M.Sc. (Pending)</td>
</tr>
<tr>
<td><strong>Honours and Awards:</strong></td>
<td>Province of Ontario Graduate Scholarship 2012-2014</td>
</tr>
<tr>
<td><strong>Related Work Experience:</strong></td>
<td>Teaching Assistant University of Western Ontario 2012-2014 Research Assistant University of Western Ontario 2012-2014</td>
</tr>
</tbody>
</table>