

**Effects of Increased Parental Knowledge of Development of Children  
with Disabilities**

BY

LOUISA SUSMAN

B.A., Barnard College N.Y., 1985

M.S., Columbia College of Physicians and Surgeons N.Y., 1987

THESIS

Submitted as partial fulfillment of the requirements  
for the degree of Doctor of Philosophy in Disability Studies  
in the Graduate College of the  
University of Illinois at Chicago, 2012

Chicago, Illinois

Defense Committee:

Tamar Heller, Chair and Advisor  
Thubi Kolobe, University of Oklahoma  
Suzann Campbell  
Donald Hedeker, School of Public Health  
Mark Gelula, School of Medical Education

## ACKNOWLEDGEMENTS

I would like to thank my committee members- Dr. Tamar Heller (Chair), Dr. Thubi Kolobe, Dr. Suzann Campbell, Dr. Don Hedeker and Dr. Mark Gelula- for their continuous support, assistance and encouragement. I could not have finished this dissertation without them.

I would like to thank profusely the parents and children who participated in this study. I learned so much from them and continue to learn from all of the parents, children and families with whom I have been fortunate enough to encounter during my career.

I would like to thank the many friends and professionals that have assisted me on the path to complete this dissertation.

- To Vardit Kindler- my partner in crime- from whom I learned so much in presenting and implementing these groups, was always there with me and was there for me whenever I needed any advice.
- To Orpah Fuchs-Bar, Malka Haimy and Rina Chamudot for their advice, knowledge and assistance in translating and reviewing the content of the intervention and measures.
- To my research assistant Avigail Noble-Kleiman without whom I would not have been able to complete this endeavor.

Lastly and most importantly I dedicate this dissertation to my dear husband Yehuda, my children- Dvoranit, Joshie, Baruchi, Shani, Noam, Ro'i, Aviyah and Hadar and to my mother and my late father, OB" M. Without their love, support and patience I could not have completed this dissertation.

LFS

## TABLE OF CONTENTS

<u>CHAPTER</u>	<u>PAGE</u>
I. INTRODUCTION.....	1
A. Background.....	1
B. Theoretical Framework.....	5
C. Research Questions.....	10
II. LITERATURE REVIEW.....	11
A. Child Development.....	11
(a) Conceptual Framework.....	11
(b) Context and environment: Its influences on developmental Processes.....	13
1. Physical home environment.....	14
2. Parent-Child Interaction.....	17
(c) Maternal characteristics.....	21
1. Influences of mental health on child developmental outcomes .....	21
i. Stress and family functioning.....	22
ii. Maternal mental health.....	25
2. Maternal age, SES, level of education.....	28
3. Parental knowledge of development and developmental expectations.....	29
4. Maternal Beliefs and Practices.....	33
(d) Summary.....	36
B. Methodological Issues of Research on children with disabilities.....	36
C. Cerebral Palsy.....	39
(a) Definition and Classification.....	40
(b) Impairments in CP .....	41
(c) Cerebral Palsy through the life cycle.....	48
(d) Effects of impairments on functional independence and their relationship to participation.....	50
(e) Summary .....	56
D. Adult Learning.....	57
(a) Bandura's social learning theory.....	57
(b) Knowles' andragogical model .....	63
(c) Specific strategies fostering behavioral change.....	68
(d) Summary.....	70
E. Outcome measures .....	70
F. Conceptual Model.....	71

## TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
III. METHODS.....	75
A. Design.....	75
B. Study sample.....	75
(a) Recruitment Methods.....	75
(b) Participants .....	76
C. Measures.....	77
(a) Child characteristics.....	78
1. Child health Characteristics.....	78
2. GMFCS.....	78
(b) Parental Characteristics.....	78
1. Demographic Variables.....	78
2. Measures of Parental Self-Efficacy.....	79
3. Knowledge of Development of Children with Disabilities Inventory...79	79
(c) Home Observation Measurement of the Environment Inventory.....	80
(d) Checklist of child Participation in Age-Appropriate Activities.....	81
(e) Post-Intervention Survey.....	82
(f) Reliability.....	82
D. Procedures.....	83
(a) Measurement sessions.....	83
(b) Piloting testing.....	84
(c) Timeframe and location of the completed research project.....	84
(d) Educational Intervention Package.....	84
1. Unit One: Session One.....	87
2. Unit Two: Session Two through Four.....	88
3. Unit Three: Session Five.....	96
E. Data Analysis.....	99
(a) Demographic Information.....	99
(b) Missing Data .....	101
(c) Differences between the Pre and Post-tests.....	101
(d) Correlation of the outcome measures and group membership.....	103
(e) Group effect on post-test.....	107
(f) Relationship between self-efficacy and knowledge.....	111
(g) Mediational Model.....	112
IV. DISCUSSION.....	113
A. Overall Study Model: Changes in parental behaviors.....	113
B. Demographic Information.....	114
C. Outcome measures.....	115
(a) Knowledge.....	115
(b) Participation.....	117
(c) Home environment.....	119

## TABLE OF CONTENTS (continued)

<u>CHAPTER</u>	<u>PAGE</u>
(d) Self-efficacy.....	120
(e) Group feedback.....	122
V. CONCLUSION.....	125
CITED LITERATURE.....	130
APPENDICIES.....	140
Appendix A.....	141
Appendix B.....	148
Appendix C.....	149
Appendix D.....	152
Appendix E.....	153
Appendix F.....	154
Appendix G.....	159
Appendix H.....	161
Appendix I.....	164
Appendix J.....	165
Appendix K.....	166
Appendix L.....	176
Appendix M.....	188
VITA.....	189

## LIST OF TABLES

<u>TABLE</u>	<u>PAGE</u>
I. DEMOGRAPHIC INFORMATION.....	100
II. DIFFERENCES PRE AND POST-TEST FOR ALL MEASURES.....	103
III. CORRELATIONS.....	105
IV. SELF-EFFICACY.....	108
V. KNOWLEDGE.....	109
VI. HOME.....	110
VII. PARTICIPATION.....	111
VIII. CORRELATION BETWEEN THE CHANGE SCORES OF PRE-TEST AND POST-TEST SELF-EFFICACY AND KNOWLEDGE.....	112

**LIST OF FIGURES**

<u>FIGURE</u>	<u>PAGE</u>
1. THE CONCEPTUAL MODEL.....	74

## **LIST OF ABBREVIATIONS**

WHO	World Health Organization
ICF	International Classification of Function
CP	Cerebral Palsy
HOME	Home Observation of Measurement of the Environment Inventory
SES	Socioeconomic Status
NICU	Neonatal Intensive Care Unit
GMFCS	Gross Motor Function Classification System
IHDP	Infant Health and Development Project
ICIDH	International Classification of Functioning Disability and Health
PI	Principal Investigator
IT- HOME	Infant and Toddler Home Observation Measure of the Environment
EC-HOME	Early Childhood Home Observation Measure of the Environment
MC-HOME	Middle Childhood Home Observation Measure of the Environment
ADL	Activities of Daily Living



## SUMMARY

This research addresses the link between parental competence, specifically the characteristic of parental knowledge, and its influence on their child's with a disability's participation in age-appropriate activities through their influence on the physical and social home environment. This study examined pathways through which parents mediate change in children with cerebral palsy (CP). Parental and child characteristics were considered as they contribute to parental level of competence and this in turn may influence the home environment influencing child participation in age-appropriate activities. Moderating effects related to the degree of impairment and capacities of the child are considered in this model. Additionally, the relationship of level of knowledge of their child with a disability's development on parental sense of self-efficacy was examined.

This research design of this study was a pre/post-test design with random assignment into two groups, an intervention group and a control group. A sample of convenience consisted of a total of 31 parents and their children recruited for this study. The goal of the content of the educational intervention package was to increase parental knowledge about CP, the child's development, home and play activities.

The results of this study demonstrated a significant increase in parental knowledge pertaining to CP as a result of an educational intervention in five meetings over the course of a ten week period. There were no significant measurable changes the home environment or child participation in age-appropriate activities that may be attributed to increased parental knowledge. There was no significant difference between groups in all demographic information examined other than parents' ages. The difference in mothers' age appeared to serve as a negative

## **SUMMARY (continued)**

influence on the knowledge measure but had no significant influence on the other measures; however when the influence of group membership was considered the influence of mother's age no longer remained significant. There was no significant difference in all child characteristics. There were some overall increases as evident in overall mean increases in the participation measure for all groups. The small increases evident in these post-test results which may be attributed to some ideas parents received from exposure to the pre-test questions providing them with suggestions of some aspects being observed and considered central in the home environment and suggestions of areas of importance for their child's development.

The measures of the home environment and participation appeared to have lacked sensitivity to capture change in behaviors and were a major limitation for this study. The participation measure was developed for too wide a variety of child ages weakening the ability of the measures to capture change. Additionally the HOME is typically used as a screening tool which appeared to have a mild ceiling effect pre-testing.

Parental feedback as examined in the post-test survey unanimously reported that they would recommend participating in such a group in the future and they unanimously would recommend participation to others families and offered to field calls from future potential parents. Moreover, they requested that we continue the meetings in the future and wanted to exchange emails and phone numbers to maintain contact with the other parents in the group. Parents' self-reports in this study describes the importance of participation in the life of the community.

## **SUMMARY (continued)**

Reconsidering and redesigning measurement tools focusing on outcomes such as participation might improve the ability to gauge the influence of programs targeting parental knowledge as part of early intervention services.

## I. INTRODUCTION

### A. **Background**

Predicting child developmental outcomes is a major focus in current research. Biological influences have been demonstrated to be the strongest predictors of child developmental outcomes (Nelson, 2000). Research has further demonstrated the importance of the context, the physical and social home environment, as influencing child developmental outcomes (Bradley et al 1993). Sameroff (Shonkoff et al, 1992) in his commentary on the Early Intervention Collaborative Study emphasized that analyses of child development should not be restricted to the child but extended to the family and the social institutions of which the child is a part. Changes in US public law reflect this understanding. Early intervention programs do not necessarily focus on the child's home environment within the formal development and structure of their early intervention packages (Brooks-Gunn et al, 2000).

Early intervention programs have been demonstrated to be most effective when families are intimately involved in decision-making regarding entry of their child into the system, goal determination and continued implementation of goals from the intervention and into the home setting (Brooks-Gunn, 2000). The recognition of the knowledge and understanding parents have of their child and his/her abilities and the importance of the child's home environment on developmental processes has evolved over the last forty years. Johnson (1990) describes the evolution in the healthcare system regarding the changing roles of the families. In the past active family involvement in decision making regarding their child's healthcare was discouraged by the healthcare systems. The Association for the Care of Children's health was founded in 1965 with the goal of encouraging and fostering a multidisciplinary and collaborative approach designed to

encourage the support and care of children by their families by supporting the caring role of families. Oddly enough families were invited to participate in the conferences only in the mid 1980's. This inconsistency was evident in much of the practice then and still is evident in many settings today. Recognizing the increasing level of involvement of parents both by their own insistence and because of the recognition by interventionists as to the benefits to children and their families has encouraged the development of intervention programs incorporating parent involvement in all aspects of planning their child's intervention and incorporating parent education programs into intervention plans (Bailey & McWilliams, 1993; Simeonsson & Bailey, 1990).

Early intervention has gained recognition as an important component of service provision to children with disabilities and their families (Ramey & Ramey, 1998). Legislative action in the United States reflects increasing recognition of the importance of early intervention in the population of children at risk and diagnosed with an array of developmental disabilities. Equal opportunity for education for individuals with disabilities was first legislated in the PL 94-142 in 1975. The Individuals with Disabilities Education Act (IDEA) was legislated in 1997 authorizing intervention for children aged 3-6 years old and in Part C for children aged 0-3 years old.

The impact of parents on their child's developmental outcomes is theorized to occur through their influence on the structure and content of their child's social and physical home environment (Bradley et al, 1993). Parents of typically developing children are exposed to knowledge regarding typical development through observation of other families, and additional sources of knowledge readily available to them. The availability of knowledge regarding typical development allows parents of children without disabilities to develop expectations regarding

their child's development and their interaction with family members and later on with same age peers, play activities, and methods to structure a fostering environment for their child during everyday age-appropriate activities. Parents of children with disabilities are frequently not exposed to the development of children with disabilities through observation of other children and families and information is not easily available in typical child rearing books and other sources of knowledge. Parents of children with disabilities might have difficulty assessing their child's abilities, and gaining knowledge regarding expectations and methods to assist their child interact and maximize their participation.

Parental competence is theorized to be the mechanism of parental influence on their child's physical and social home environment. Parental competence can be described as comprised of a number of parental characteristics. Parental characteristics include socioeconomic status, maternal education, knowledge of development relating to their child and his/ her development and abilities, parental self-efficacy and maternal beliefs and child rearing practices. Child and family characteristics moderate the amount of parental competence necessary to influence the home environment and in turn influence child developmental outcomes. Identifying the characteristics of parental competence amenable to change and effective methods that may be employed to influence and increase the overall level of parental competence may increase the efficacy of early intervention programs and influence child developmental outcomes and participation in age-appropriate activities, particularly with children with disabilities.

This research theorizes that of all the characteristics comprising parental competence, parental knowledge of development is one of the components more amenable and accessible to change. This belief reflects the importance early intervention frameworks place on parent education components as an integral part of the early intervention framework. Early intervention

frameworks, however, often address typical development and provide parents of children with disabilities minimal knowledge specifically relating to their child's disability and their capacity and the mechanisms to assist their child achieve maximum participation in age-appropriate activities. This research focuses on examining the influence of parental knowledge of development of children with disabilities on the individual with a disability's environment. Secondly, it examines the impact of this change in environment on the level of participation of children in age-appropriate activities. Understanding the pathways by which parental knowledge influences their beliefs and behaviors and in turn influences child developmental outcomes and their level of participation in age-appropriate activities may increase the effectiveness of early intervention programs.

The International Classification of Function, Disability and Health (ICF) developed by the World Health Organization (WHO), (World Health Organization, 2001) used a framework incorporating both degree of participation of the individual in age-appropriate activities and environmental and societal influences on individuals with impairments that restrict or limit their physical and social participation in the world around them. The ICF examines personal capability within the framework of environmental demands and the restrictions and limitations imposed by the environment on the individual with varying impairments. Societal limitations and/or the resulting handicap involve socially imposed barriers preventing or limiting individuals with disabilities from functioning at the highest level according to their capabilities. Understanding the source of limitation, decreased participation or handicap is important in assessing and providing interventions to enable individuals with disabilities maximum participation according to their own personal capabilities.

## B. **Theoretical Framework**

The basic principles of normative development seem to guide changes in developmental processes of children with disabilities. Environmental (Bronfenbrennar, 1986) and transactional models (Sameroff & Fiese, 2000) emphasize the importance of transactions between the child and his/her caregivers, the physical home environment (Bronfenbrennar, 1986) as well as the interaction and assets of the child influencing parental well-being (Hauser-Cram et al, 2001).

The child's home environment is comprised of quality and quantity of positive stimulation in a child's home environment, the contents and type of physical environment and quality of the parent-child interaction. The influences of the home environment on a child's cognitive and social developmental processes have been demonstrated extensively in the literature (Bradley et al, 1994; Bradley et al, 1993; Morrisset et al, 1990). Parent-child interaction at varying ages has been shown to be influenced by both child and parent through variations in responsiveness of the parent and child and the quality and quantity of the interaction (Barnard et al, 1997). Recently the home environment has been shown to also influence motor development (Kolobe et al, unpublished; Zahr, 1999).

Parents of typically developing children are usually knowledgeable regarding typical child development. They are exposed to knowledge regarding child development through many channels and sources of information throughout their life experiences prior to and throughout parenthood. Sources of information vary for all parents. Sources of information include access to books, information from relatives, daily observations and contact with other families of typically developing children and general knowledge of the typical child development obtained throughout their life course. These parents typically provide positive environments, social



encounters and influence child developmental outcomes because they can accurately assess their child's abilities and age-related developmental expectations.

Parents of children with disabilities are rarely exposed to parenting of children with disabilities until they have their own child with a disability. These parents may lack basic knowledge regarding development of children with disabilities relating to limited access to sources of information regarding their child's development and information that may assist them learn and model behaviors that may foster a positive environment improving their child's developmental outcomes and participation. Parents of children with disabilities may have more difficulty providing positive social encounters for their child with a disability, providing toys and environments that are commensurate with their abilities, fostering academic and social development and increasing their child's overall independence. As a result children with disabilities might face increased limitations in participation in age-appropriate activities related to limited parental knowledge regarding the development of children with disabilities and the child's physical impairment. It is proposed that parents of children with disabilities need access to sources of information to increase the positive environment and developmental outcomes of their child.

Current intervention programs for parents of children with disabilities tend to focus on remediation of the child's disability (Sameroff & Fiese, 2000). The educational aspect of early intervention programs typically focus on teaching parents of children with disabilities typical child development and through this knowledge the disability may be remediated (Sameroff and Fiese, 2000). In fact children with disabilities develop differently and often demonstrate different patterns of development, and interactions than typically developing children (Sigman & Ruskin, 1999). Understanding typical development is not sufficient to improve parental understanding of

the development of children with disabilities, the constraints imposed upon their child and how they as parents may foster increased participation of their child in age-appropriate activities. Often overlooked in early intervention are the constraints imposed upon the child by the environment and social interactions with caregivers and peers.

Given the evidence demonstrating the influence of environmental factors on development (Bradley et al, 1994) perhaps programs should focus on decreasing the constraints faced by the child with a disability and developing and fostering strategies by their caregivers to decrease the constraints their children might face. Professionals involved in early intervention generally have increased knowledge of development of children with disabilities, improved access to information regarding development of children with disabilities and are exposed to a broader spectrum of children with disabilities across various ages. Professionals may be able to better assess and determine current and anticipate future constraints facing the child with a disability than parents because of their increased knowledge. This knowledge is important to convey to parents of children with disabilities. Providing parents with knowledge of their child with a disability's development may enable parents to more accurately anticipate their child's abilities and enable parents to better assist their child to overcome current and future environmental constraints. The result may be an improved home environment for the child with a disability and increased participation of the child in age-appropriate activities.

Research examining the effectiveness over time of early intervention programs indicates that programs focusing primarily on the child and minimally addressing the child's context may produce short term gains in child developmental outcomes as compared with a control group (McCarton et al, 1997; Sameroff & Fiese, 2000), but that these results are often not maintained after the intervention concludes. Other programs that addressed the family context of the child

offered services to participating families but had limited effects on families because the participating families did not always use the services (Brooks-Gunn et al, 2000) or the services did not properly target the family's needs and produced negative effects (Brinker, Seifer & Sameroff, 1984). Programs addressing the families through parent education have demonstrated more lasting change in child developmental outcomes (Hanson, 1985; Moxley-Haegert & Serbin, 1983; Brooks-Gunn et al, 2000). Much of this large scale research has focused on children at risk. Only a few limited small scale studies have examined the influence of the environment on developmental outcomes of children with disabilities (Mihaylov et al, 2004; King G et al, 2003; O'Brien P, 2002).

A common assumption of many early intervention programs is that providing knowledge of development to parents will influence their beliefs and behaviors producing positive effects on their child's development. Currently research examining parental beliefs, practices and cultural differences among parents indicates this is not the case (Gutierrez et al, 1988; Wood, 2001; Goodnow, 1988). Parents may not be receptive or interested in the information provided. It is important for research to determine the factors that encourage adaptation and changes in behaviors beneficial to child developmental outcomes especially among parents of children with disabilities. Knowledge of adult education and learning, family interactions and dynamics is needed in designing programs to improve the effectiveness of an educational package. Bandura's social learning theory (1977) provides a framework for understanding adult behavioral change. Fostering change in behaviors requires an individual to access and change the beliefs underlying the practices and recognize the need to change behaviors. Hence, specific behaviors should be targeted in intervention packages to increase their success. A program

targeting behavioral change should be designed incorporating methods and techniques to assist parents of children with disabilities in altering entrenched behaviors.

Overall there is relatively limited research available with strong research designs targeting children with disabilities as opposed to other populations such as infants and children at high risk for developmental disabilities in part due to the heterogeneity of the population and samples available. This research will address specifically the population of children with cerebral palsy (CP) limiting the diagnosis to decrease heterogeneity. It is important to select one type of disability to focus the educational information provided in this intervention to reflect knowledge important to parents of children with CP and knowledge that may be applied in their everyday lives.

This research addresses the link between parental competence, specifically the characteristic of parental knowledge, and its influence on their child's with a disability's participation in age-appropriate activities through their impact on the physical and social home environment (Benasich & Brooks-Gunn, 1996) and decreasing constraints imposed on their child with a disability. This study examined pathways through which parents mediate change in children with CP. The conceptual model for this study is that increased knowledge of parents about their child's disability and their child's abilities influences their child's physical and social and home environment and influences their child's participation in age-appropriate activities. Parental, family and child characteristics may contribute to parental level of competence and this in turn may influence the home environment influencing child participation in age-appropriate activities. Moderating effects related to the degree of impairment and capacities of the child are considered in this model. Additionally, the relationship of level of knowledge of their child with a disability's development on parental sense of self-efficacy is examined.

### C. **Research Questions**

The research questions include the following:

- 1, Does a psycho-educational intervention increase knowledge of parents regarding their child's disability?
2. Through what mechanisms does parental competence influence child developmental outcomes?

More specifically:

- Does change in parental knowledge of their child's disability influence parenting behaviors as evidenced in changes in the physical and social home environment?
- Are changes in the child's physical and social home environment linked to the child's level of participation in age-appropriate activities?
- Does level of knowledge relating to their child's development affect parental sense of self-efficacy?

## **II. LITERATURE REVIEW**

### **A. Child Development**

#### **(a) Conceptual Frameworks**

Numerous models explain factors that influence child development. Explanations of child development are complex and as yet poorly understood. Child development outcomes are described in terms of expectations in motor, language and cognitive domains which ultimately are reflected through the child's daily functioning and participation in age-appropriate activities in a variety of life situations. Understanding the expected function of children in the various settings and factors influencing this function should assist in determining variables most amenable to intervention. Sameroff's transactional model, Bronfenbrenner's ecological framework, neuromaturational theory and dynamical systems approach are some of the conceptual models describing the influences on child development. Each of these models will be discussed in further depth with an emphasis on the models' consideration regarding environmental influences on the child's function and participation in age-appropriate activities.

The neuromaturational model views development as a hierarchical predetermined progression of maturation intrinsic to the organism preparing the infant to achieve a higher form of behavior. The stages of motor development are influenced by the maturation occurring within the central nervous system. Certain predictable changes occurring during neural maturation are the causal determinants of behavioral change. As the organism matures functional behavior appears as a result of the development and maturation of the nervous system. Development is supported by but not changed by environmental factors. The neuromaturational model

emphasizes neuroanatomic changes without consideration of additional variables contributing to the change (Daly, 2004; Campbell, 2000).

Smith and Thelen (2003) introduced the dynamical systems model to describe motor development in response to the inability of neuromaturational theories to adequately explain the full range and complexity of motor development. Thelen describes development as emerging from a confluence of subsystems in a task-specific context (Thelen, 1991) and the importance of the process, the combined effects and interactions of all the subsystems guiding the outcome, rather than the product or developmental achievement. The systems involved in the dynamical systems model may be divided into internal and external subsystems. The internal subsystems include musculoskeletal, neurological, sensory, perception, motivation and arousal among others. The external subsystems refer to the environmental context and the immediate surroundings influencing the specific demands of the task to be performed by the child (Thelen, 1991; Campbell, 2000).

Sameroff's transactional model (Sameroff & Fiese, 2000) views developmental outcomes as the mutual effects of the context on child and child on context, the transactions between the child and his environment (Sameroff & Fiese, 2000). Developmental outcomes are neither the result of the individual or the experiential context alone but the product of the individual and their experiences. This model stresses the characteristics that the child brings to the transactions and the effects the child elicits from the environment.

Bronfenbrenner (1986) provides a broader definition of the influences on the developing child than the transactional model. The ecological framework for understanding child development looks beyond the immediate family network and considers the additional influences affecting the child and family. Bronfenbrenner (1986) describes this conceptual framework of

child development as a series of concentric circles embedded one within the other. The child is central to this system defined as the microsystem. Surrounding the child is the mesosystem exerting the strongest influence on the child and his/her development. The mesosystem includes the child's parents and immediate family, with the extended family contributing and influencing the child. The family is the central context in which development occurs. The mesosystem varies among families and is influenced by the family's socioeconomic status (SES), level of education of the primary caregivers, family functioning, and many other variables and exerts the strongest influence on the child's development. The ecological model considers the influences beyond the immediate family influencing the child's family and their functioning. Beyond the micro and mesosystem is the exosystem which includes the parents' workplace, friends and school. Society, legislation, societal attitudes and ideologies comprise the macrosystem. Bronfenbrenner's ecological model of understanding child development is one of the few conceptual frameworks that consider society's influence on a child's development (Bronfenbrenner, 1986).

(b) **Context and Environment in Research: Its Influences on Developmental Processes**

The environment referred to in early intervention research examining child developmental outcomes are typically the environment referred to by Sameroff (Sameroff & Fiese, 2000) in the transactional model and the micro and mesosystems referred to by Bronfenbrenner (1986) in the ecological model. Parents are considered the primary force shaping the child's environment through parental influence in the home. The influence of the home environment on child development outcomes has been demonstrated in the literature (McCarton et al, 1997; Brooks-Gunn et al, 2000; Klitzman et al, 1997; Olds & Klitzman, 1994). As a result of significant



findings indicating the influences of the home environment on child development outcomes early intervention programs often target parents as part of the intervention to effect change in their child's developmental outcomes through influencing the child's home environment.

Programs targeting parents assumes that interventions targeting change in parental behaviors influence parental behaviors resulting in change in the child's home environment and influence child developmental outcomes. This describes a mediational model of intervention. The mechanisms and specific changes within the parents have been described as the mysterious "black box" (Brooks-Gunn et al, 2000). The mechanism and changes in this black box were rarely specified let alone measured by researchers (Brooks-Gunn et al, 2000).

Different aspects in the home environment have been demonstrated to influence child developmental outcomes. The factors comprising the home environment include the physical aspects of the home environment, parent-child interactions, cultural influences and the influences of parental beliefs and practices, demographic characteristics of the primary caregivers and mental health of the caregivers, typically the mother (Seltzer & Heller, 1997). Research examining these factors regarding the population of infants and children at risk and with known disabilities will be described.

### 1. **Physical Home Environment**

One of the components identified as strongly influencing child development is the physical home environment. The physical home environment may be defined as the quality and quantity of stimulation provided in the home environment (Bradley et al, 1994a; Bradley et al, 1993). The physical home environment has been demonstrated to impact cognitive, language and motor development (Morrisset, Barnard, Greenberg, Booth & Spieker, 1990; Zahr, 1999; Kolobe et al, unpublished).

Zahr (1999) in a prospective study examined the factors influencing mental and motor development in 123 African-American and Hispanic infants at eight months of age. The African-American infants' motor development was observed to be correlated with mother's education and the number of days the infant spent in the hospital after birth and their mental development was predicted by the physical home environment. In Hispanic infants the physical home environment predicted motor scores while the mother-infant interaction was correlated with the mental scores on the Bayley Scales of Infant Development II.

Bradley et al (1993) in a collaborative investigation found a consistent relationship between the home environment and child cognitive outcomes. The participants in this study were 931 children and their families pooled from six different longitudinal studies conducted in North American early intervention settings. The environmental variables were divided into two types: process and status variables. Process variables were experienced directly by the child, for example objects, persons, events, transactions. Status variables were those experienced more indirectly by the child, for example social class or neighborhood. Moderate correlations between the process variables and cognitive development were found. Status variables and cognitive development had moderate relations to scores between age one and three. This study also used the Home Observation for Measurement of the Environment (HOME) (Caldwell & Bradley, 1984) to measure the home environment, and found that the scores on the HOME inventory predicted a greater amount of variance over and above the influences of socioeconomic status (SES) as measured by the Hollingshead index (a composite measure of various SES factors).

Two longitudinal studies examined characteristics within the home environment influencing developmental outcomes through adolescence (Sameroff & Fiese, 2000). The Philadelphia study (Furstenberg, et al, 1999) based on the findings of the Rochester study

(Sameroff et al, 1987) examined the number of risk factors and organized them within six ecological domains with levels within each domain. These ecological levels were organized based on their degree of influence on the child. In the Rochester and Philadelphia studies findings indicated the influence of the sum of the risk factors in the home environment and not the quality of each of the specific factors was predictive of child developmental outcomes.

Bradley et al (1994) found similar findings to the Rochester and Philadelphia studies regarding the influence of the home environment on the development of low birth weight infants. Bradley et al (1994) examined child and environmental factors related to resilience in the low birth weight infants in the Infant Health and Development Project. This project examined at risk infants for developmental disabilities but excluded participants with known disabilities. Protective factors were the presence of a male partner, number of family members in the living space, whether the family moved less than twice in the last year, safe play area, acceptance of child by family members, variety of learning materials, types of learning material present and responsivity of the caregiver to the child. It was found that three or more protective factors produced resilient children and two or less produced non-resilient children. The only child factors contributing to resilience were child health factors.

Bradley et al (1993) introduced the idea of "double advantage - double disadvantage". Children with both biological and environmental risk were found to have a statistically greater chance of having disabilities or developmental delays. Children with both an enriched environment and no biological risks had a statistically better chance of developing without any negative consequences. Total number of risk factors has proved effective in predicting the developmental trajectory of infants. Studies have found the degree of developmental problems increases with increasing numbers of risk factors necessitating interventions in later school years

(Sameroff & Fiese, 2000). These studies demonstrate the importance of examining and intervening in a child's environment to influence and increase developmental outcomes.

This study examines the influence of the environment on child participation in age-appropriate activities. The participants in this research study have diagnosed disabilities placing them at greater risk for poor developmental outcomes, hence placing greater importance of the environment on influencing the outcomes.

## 2. **Parent-child Interaction**

The conceptual framework guiding parent-child interaction is the transactional model proposed by Sameroff (Sameroff & Fiese, 2000). The developmental outcomes are neither a function of the individual or the context alone but are a combination of the individual and their experience and the interaction of one with the other. The biological makeup of the child and his/her individual characteristics and the characteristics of the caregiver and their unique interaction serve to influence the child's development.

Parent-child interaction is the early context in which an infant interacts with his/her environment (Barnard, 1997). Both partners in the interaction, parent and child, contribute to the interaction. Studies examining parent-child interactions within high-risk populations of infants have identified sets of characteristics and behaviors associated with the caregiver and infant that appear to influence child development (Barnard, 1997).

In an overview of parent-focused home programs providing intervention to infant and families at high risk for poor developmental outcomes Brooks-Gunn et al (2000) found that 13 of these studies measured parent-child interaction. Of these interventions all but two found improvements in parent-child interactions and attributed some improvement in child

developmental outcomes to the improvements in parent-child interaction. Some of these studies will be discussed in more detail below.

The Vermont Intervention Program for Low Birthweight Infants (Sameroff & Fiese, 2000; Meisels et al, 1993) enhanced the parent-child interaction by redefining the mother's definition of the infant's behavior enabling her to better understand her infant's cues. Of the 91 children and families in the studies 24 received the intervention comprised of hospital and home visits in which a nurse helped mothers adapt to their low birth weight babies. At three years of age there were significant differences between the low birth weight intervention children and control children with increased improvements in the experimental group. At nine years of age there was no difference in cognitive and achievement score between the normal birth weight children and low birth weight children receiving the intervention. This is one of the few interventions in infancy finding significant changes in child development at school age (Achenbach et al, 1990).

Affleck et al (1989) provided a home support program for families of children post neonatal intensive care discharge. The mothers in this study were divided into two groups based on the type of support they had available in their daily lives. They found positive effects of the intervention in parent-child interaction and child development outcomes only in the mothers needing support. Negative effects were found for mothers not requiring support.

The Infant Health and Development Project (IHDP) study too found impressive short term results in parent-child interaction in addition to other important findings though examining parent-child interaction was not the major focus of this study (McCarton, Wallace & Bennett, 1995). This program was a multisite randomized clinical trial involving eight sites and 985 low birth weight infants. All infants received the same medical intervention and periodic infant developmental follow-up. The intervention began at discharge from the hospital and continued

until the child was 36 months old (age corrected for prematurity). The Infant Health and Development Project program's home component focused on enhancing development through the home program focused on educating the parents on child development, family support for problems and instruction in age-appropriate games. Effects on improved cognitive changes, child behavior and parent-child interaction were found. It is unclear if the parent-child interaction contributed to the benefits to the child's developmental outcomes. Long-term results from the IHDP study do not report long term parent-child interaction effects (McCarton et al, 1997).

The Charlotte Circle Project (Rose & Calhoun, 1990) was one study that examined parent-child interaction in a developmental program targeting infants with severe mental disabilities and their caregivers. It focused on increasing the interaction between the caregiver and infant through a program improving the quality, frequency, and period of the interactions. This program demonstrated effects on parent-child interaction and on child development outcomes. The mediational relationship of parent-child interaction on child developmental outcomes was hypothesized but not examined. In a study by Mahoney et al (2004) the influence of the parental style of interaction on rate of development was demonstrated. In this study 71 children in 40 special education classroom settings participated in three types of classroom instruction. The developmental outcomes of these children were found to be related to the type of interaction between parent and child and not the teaching or other aspects within the classroom.

The Early Intervention Collaborative Study (Hauser-Cram et al, 2001) is one of the few large-scale longitudinal studies examining the cognitive and adaptive behavior development of children with developmental disabilities through middle childhood. This research study highlights the importance in considering a developmental-contextual systems perspective to

better understand and predict child developmental processes (Hauser-Cram et al, 2001). Its sample consisted of 183 children diagnosed with Down syndrome, motor impairment or developmental delay and their families. They were recruited at the time of enrollment from early intervention programs in the Northeast United States. This study examined long-term results on both parents' well-being and child developmental outcomes while at the same time examining family climate. Family climate was a variable combining parent-child interaction, parental well-being and stress and its effects on child developmental outcomes. This study found that children's types of disability predicted trajectories of development in social skills, activities of daily living and cognition. Beyond these trajectories parent-child interaction, parental well-being and stress were important predictors in the developmental outcome of these children with disabilities. These findings are similar to those of Bradley et al (1993) demonstrating the effects of "double advantage" and "double disadvantage". Child development outcomes were influenced by their biological impairments; however, the environment served to further influence their developmental outcomes beyond those predicted by their biological impairments.

The research examining parent-child interactions often measures this relationship in conjunction with child development outcomes. The mediational effects of parent-child interactions on child development are assumed though not empirically demonstrated in much research. Additionally, the relationship between parent-child interactions and biological causation is unclear. The risk of poor parent-child interactions is often increased in children with biological problems. It is unclear if the parent-child interactions are the result of the biological impairments or both the biological impairments and poorer parent-child interactions result simultaneously because the children belong to a population at risk (Barnard, 1997).

(c) **Maternal characteristics**

Parental competence as described in the conceptual model for this research is influenced by parental characteristics in addition to family and child characteristics. The mechanism of influence of parental characteristics on child development is theorized to occur through their influence on the home environment. This study will examine the influence of a parent educational intervention in influencing parental characteristics, the relationship of parental characteristics on their child's home environment and resulting influence on their child's participation in age- appropriate activities.

Characteristics comprising parental competence include SES, maternal education, maternal age, maternal knowledge of development, and maternal mental health (Lytton, 2000; Garrett et al, 1994; Brooks-Gunn et al, 2000). Research has recognized the importance of examining the influence of culture, parental beliefs and practices and their effects on child developmental outcomes through shaping the child rearing environment (Coll, 1998; Evans & Myers, 2001; Sameroff & Fiese, 2000; Wood, 2001; Goodnow, 1988). This review focuses on maternal characteristics because of their prominence in research while however acknowledging the importance of paternal influence on the child. Paternal influence on child development has been largely ignored in many of the larger studies (Brooks-Gunn et al, 2000).

1. **Influences of mental health on child developmental outcomes**

This section discusses the literature describing the effect of the presence of a family member with a disability, resulting stress placed on family functioning and the influences of this stress on mental health. The following section discusses the findings of intervention studies targeting reduction of stress and improved maternal mental health.



i. **Stress and family functioning**

Stress may be defined as conditions or events that increase the degree of difficulty experienced by an individual in fulfilling a required task and may diminish their capacity to complete the required tasks and adapt to a new situation. Coping is the caregivers' reaction to the stressful event or psychological stress perceived by the caregiver. Burden is the caregivers' perceptions of the demands required by the caregiving task. Burden can be categorized into objective or subjective burden. Objective burden is real changes in demands of the caregiving task requiring more effort or expense. Subjective burden is the caregivers' negative reaction to subjective burden.

Theorists and researchers have developed complex models in an attempt to explain differences in family functioning under stressful situations. The majority of families with a family member with a disability demonstrate successful and adaptive functioning. There are however families that do not demonstrate adaptive behaviors allowing for effective family functioning. Numerous theories examine the characteristics, resources, functioning, and reactions to caregiving stress and burden experienced by families. Examinations of these factors explain some of the variations in coping behaviors demonstrated by families when experiencing stress. Coping behaviors vary from successfully coping with the needs and challenges of a child with a disability and fostering growth and positive family functioning to a family's inability to sufficiently cope in the presence of a member with a disability resulting in negative effects on the child and on family functioning.

Previously held assumption underpinning the earlier studies assumed that the presence of a family member with a developmental or physical disability, mental illness or intellectual disability negatively affected family members and family functioning. Olshansky's concept of

chronic sorrow (Marshak et al, 1999) and the ABCX model (Wikler, 1986) which both depict the presence of a family member with a disability as primarily negatively impacting family functioning were some of the models used to describe family functioning. Current research reveals that families of children with disabilities are typically adaptive and cohesive with satisfying relationships among the family members (Summers et al, 1989). Dysfunction as a result of the presence of a child with a disability is currently described as the exception rather than the rule. Theoretical frameworks developed to examine these factors include family systems theory stress theories using well known models like the ABCX, double ABCX (Wikler, 1986), Lawton's two-factor model (Lawton et al, 1991) and Rolland's model of the relationship and typical life course within a family in the presence of illness (Rolland, 1987).

Hill's ABCX model is often described as the roller coaster model. ABCX describes four variables used to describe the factors in this stress model. A is the initial stressor event. B and C are two buffering variables that impact on the effects of the stressor. B is the family's resources. The resources include personal supports, marital satisfaction, family interactional variables like adaptability, cohesion, history of managing transitional and non-normative stressors, structure of their interaction, sharing of affect, autonomy of family members, congruence of their mythology and efficiency of task negotiation and formal support networks. C is the meaning and definition that the families give to the stressor event. X is the resulting family adaptation or outcome. Built into this model is a deficit aspect - a crisis results because of the presence of a family member with a disability. A period of disorganization follows as a result of the stressor event as the family attempts to restructure and reestablish equilibrium.

McCubbin and Patterson (Wikler, 1986) elaborated on Hill's ABCX model. They developed the double ABCX model which focuses on the family's efforts over time to recover

from a crisis situation. This model describes the concurrent stressors affecting family recovery from the original crisis, the new and previously existing resources, the family's evaluation and perception of their post crisis situation and family outcome and adaptation. The ABCX and double ABCX model allow for positive family adaptive benefits from the introduction of the stressor. The family resources, B, allows families to gain access to perceptions and meanings, C, that reduce feelings of stress or threat from a stressful event. An example would be that the quality of a marriage, family resource (B), can affect the ability of the family to cope successfully with the demands of a child with a disability (A) and result in positive family adaptation (X).

Typical family functioning has been shown to minimize negative effects resulting from stress and caregiving burden does not necessarily increase caregiving stress proportionately (Owens & Quall, 1997; Aneshensel et al, 1995). Stress and burden have been shown to operate somewhat independently and promote family functioning even in the presence of increased demands of caregiving burden.

Missing from the two stress models described above is society's influence on both the individual and their family. The importance of society and its influences on the family is becoming increasingly evident. Bronfenbrenner's model (1986) describes the influence of society on the individual and their family. This bi-directional influence is evident in examination of both legislation (Turnbull et al, 2001; Turnbull & Stowe, 2001b; Turnbull & Stowe, 2001a; Turnbull & Stowe, 2001; Turnbull et al, 2001) and historical changes in attitudes and perceptions regarding disability and the ability of individuals with disabilities to integrate into society based on society's influences and accepted norms (Ferguson, 2001).

Currently the World Health Organization has adopted a model for disability, ICF. The ICF was developed because of recognition of the influence of contextual factors on the degree of disability of an individual. Disability according to the ICF can be viewed as the effects of society and the environment on restricting an individual with impairment's functional abilities and participation in daily life activities.

Raising a child with a disability may increase stress on parents from numerous sources. Sources of stress may include family and child characteristics, service providers and the type of services and support system provided to families. All these factors may contribute to the amount of stress experienced by caregivers affecting their mental and physical health. Assessing the stressors, knowing how to assist parents to decrease the stressors and their impact on family functioning can help increase parental competence and provide a more positive fostering environment for their child resulting in improved family functioning and child participation in age- appropriate activities.

ii. **Maternal mental health**

Maternal mental health has been demonstrated to affect child developmental outcomes. Maternal mental health is affected by stress which is influenced by perceptions of coping, satisfaction, burden and self-efficacy and may result in psychological symptoms for example depression. Research has linked maternal depressive symptoms and child outcomes but few programs report measures of maternal depressive symptoms (Brooks-Gunn et al, 2000) and other measures of caregiver health and well-being.

Research reporting on the Parent Child Development Centers found increased rates of depression in mothers participating in the program (Walker et al, 1995). High rates of depression were also reported in the in the Even Start program (St. Pierre et al, 1996). Even

Start was a two-generation program with early childhood, parent education and adult literacy components. Lower depressive symptoms by mothers were reported from the Infant Health and Development cohort not receiving the intervention (McCarton et al, 1997). Differences in the cohorts and services between the interventions may explain some of the differences reported regarding the relationship between intervention and rates of depression in mothers. In the Parent Child Development Center mothers experienced pervasive problems of poverty for which the assistance provided by the interventions was not sufficient and often increased their level of depression; the interventions did not target the family's primary concerns. These findings might explain those previously discussed regarding Project Care (Ramey et al, 1990) and the study examining support to mothers of neonates discharged from the neonatal intensive care unit (Affleck et al, 1989) that interventions must be targeted to the needs of mothers or negative effects may result.

The Abecedarian program (McCarton et al, 1995) was a center-based intervention begun at infancy through three years. This program provided center based care for 111 infants from infancy through three years of age. The subjects and their families were randomly assigned to control and intervention groups. Study findings demonstrated a relationship between intervention and cognitive test scores in the participants. These findings were short term and lasted for a short period beyond the intervention in the study. Project Care (Ramey et al, 1990) was a second generation Abecedarian Project which provided both center based and home care to different cohorts. Sixty-three infants and their families participated in this study. The children and families receiving the home intervention package did not do as well as the group receiving center-based care plus the home intervention component or the control group. The family education component worsened the situation of the families. Perhaps the problems faced by the

families were so intractable that the intervention component served to highlight the problems and gave the families feelings of hopelessness and desperation (Ramey et al, 1990). The need to address social and economic difficulties faced by the family to enable them to be open and amenable to other interventions is increasingly becoming evident. The authors suggested that programs should address the difficulties faced by families and not overwhelm and increase feelings of inadequacy. Based on the results of Project Care (Ramey & Ramey, 1998) and the research by Affleck et al (1989) not all interventions are appropriate for all families.

Interventions should be provided based on families' needs because negative outcomes may result from even well planned and implemented interventions if the intervention is not appropriate for the recipients.

Brinker, Seifer & Sameroff (1994) examined the relationship between maternal stress, intervention and development of infants with disabilities over time. Maternal stress was predicted by a relationship between the infant characteristics, initial stress, number of agencies involved in the intervention and a complex interaction between infant characteristics, level of SES and attendance. Maternal stress was found to relate to child development outcomes but was moderated by SES and degree of attendance at the early intervention program.

In a prospective study of 400 mothers randomly assigned to nurse visitation and comparison condition groups in the Prenatal and Early Infancy Project increased coping ability as a result of intervention was reported (Olds et al, 1994). In an extension of this program, Project STEEP found treatment mothers showed fewer depressive symptoms and anxiety than did control group mothers.

Incorporating the findings from research examining maternal mental health is important in designing interventions. It is especially important to consider mental health in interventions

targeting populations of children with disabilities. Under certain conditions mothers of children with disabilities are at increased risk for poor maternal health as a result of intervention.

Interventions not targeting changes in this psychosocial characteristic place the mother at greater risk for poor maternal health are evident in the literature. Interventions could prove less effective in improving child outcomes. When considering a model of child development family functioning, particularly the mothers' ability to cope with stress and provide a positive fostering environment for the child is paramount. The ability of the interventionist to provide support to decrease as much as possible the stress and assist the parents in their ability to provide a positive fostering environment for their child. Additionally the ability of interventionists to identify families at risk based on family and child characteristics and family functioning and refer the families to appropriate service providers and support systems may assist parents in increasing parental competence thus providing a more positive fostering environment and improve child developmental outcomes. Parental perceptions of self-efficacy will be measured to examine the relationship between self-efficacy and parental knowledge of development of children with disabilities.

## 2. **Maternal age, SES, level of education**

Research has linked maternal age at birth, SES and level of education to poorer child developmental outcomes (Sameroff et al, 1987). These three factors are some of the factors listed as characteristics affecting child resilience as described by Bradley (1994). The Rochester and Philadelphia studies previously described delineate these factors, SES, maternal age and education as some of the environmental variables included in the risk variables associated with poor developmental outcomes. A very important finding from this study was that as the number of risk factors increased the degree of risk to developmental outcomes increased. These factors

are ascertained at the outset of the study and their relationship to changes in parental knowledge of development and the effect of level of knowledge of development to child participation in age-appropriate activities will be examined.

Garrett et al (1994) examined the determinants of the developmental status of young children in survey data of 1742 children from the National Longitudinal Survey of Youth. The findings indicated a number of variables influencing child development. They found that a child's developmental status is strongly and positively related to the quality of the home environment. Demographic and socioeconomic variables were found to be directly related to the quality of the home environment; having an indirect effect on the child's developmental status. Characteristics of the mother, child and household influenced the quality of the home environment mediating the influences of SES and demographic variables on child developmental outcomes. This study strongly supports the need to consider the environment and the influences affecting the child's environment including family demographic variables in predicting child developmental outcomes.

### 3. **Parental knowledge of development**

Many research studies target increased parental knowledge as the means to achieving improved child developmental outcomes. However, for the most part these studies assumed increased knowledge in parents occurred without measuring change in level of knowledge and measured changes in child development. Studies using a mediational model examining changes in parental knowledge and effects of increased parental knowledge on their child were not used. Many of the studies examining interventions designed to improve child developmental outcomes through increasing parental knowledge examined the effects of increased parental knowledge relating to infants discharged from the NICU and children at risk for poor developmental



outcomes though not diagnosed with a disability. Other parent education programs have focused on providing information regarding specific diseases such as asthma (Stevens et al, 2002), diabetes (Van Der Ven et al, 2003), and parents of children with critical illnesses (Melnik et al, 2004). No studies were found examining the effects of interventions targeting parental knowledge of children with motor disabilities and the effects of increased knowledge on the level of participation of children with motor disabilities in age- appropriate activities.

Garrett et al (2001) used a structural model of the developmental status of young children to examine the various factors influencing child developmental outcomes. Maternal and household characteristics, family income, child's health status, quality of the home environment were the factors found to influence child developmental outcomes. This model did not specify parental or maternal knowledge among the factors. This model presupposed the influence of parental knowledge on the quality of the home environment.

Parental knowledge influences child developmental outcomes through their impact on their child's environment. Research has demonstrated both the relationship between parental knowledge of influences fostering child development on child developmental outcomes and the impact of interventions focusing on parent education of positive child development and related changes in parental knowledge. Both these premises serve as the foundation for this proposed intervention in this study.

Interventions focusing on infants during and at discharge from the neonatal intensive care unit (NICU) typically have not described the focus of their research as increased knowledge but rather, identifying infant cues influencing parent child interactions, handling of high risk infants, detailing care for high risk infants and providing support programs for parents in transition from

NICU to home care were the focuses of the interventions (Loo et al, 2003; Barrerra et al, 1986). Change in levels of knowledge was assumed though not measured in most of these studies.

Loo et al (2003) demonstrated the effectiveness of a parent education program focusing on parental knowledge of identifying and understanding their infant's needs on levels of parental stress and coping. Barrera et al (1986) studied 83 infants, 59 preterm and 24 full term infants, for the first year of life. The preterm and full term infants were matched based on corrected age. Using blocked random assignment they were divided into two treatment and one control group. The treatment consisted of home visits between one and two hours duration weekly for the first four months and biweekly for the following eight months. The focus of the two groups were understanding developmental level of functioning using the Education for Multihandicapped Infants and an intervention focused on improving parent child interaction skills by enhancing parent observational skills as well as their sensitivity and mutual responsivity during parent-child interactions. Both interventions were found to influence the home, parent child interaction and child behavior but the parent-interaction intervention was found to be more effective than the developmental function intervention.

Differential effects were found in a program designed to support mothers during the transition from NICU to home. Ninety-four mothers were randomly assigned to control or intervention group which received a formal support program assigned to aid in their adaptation of the transition from hospital to home care of high risk infants. Positive effects were found for mother's sense of competence, perceived control, and responsiveness toward their infant. Program effects were moderated by maternal need for support and severity of infant's pre-discharge medical status. Mothers with a high level need for support experienced positive

program effects; negative program effects were found with mothers with low level needs for support (Affleck et al, 1989).

The effects of a pediatric physical therapy program were examined on the development of infants at high risk (Blauw-Hospers et al, 2011). The “Coping with and Caring for Infants with Special Needs” (COPCA) program compared the effects of typical physical therapy intervention with one combining coaching and physical therapy intervention encouraging variability of movement. Forty-six infants and their parents participated in this study. The randomized trial demonstrated minor difference between the typical physical therapy group and the COPCA group. They examined both developmental and process variables. However, because process variables were examined it was apparent that there was a lot of heterogeneity in both intervention groups and this might possibly explain the lack of significant difference between the two groups. Additionally there were two interesting findings. Infants whose mothers had lower level of maternal education did better when the coaching component was included. However, infants whose mothers had a high level of maternal education did better with only physical therapy and no coaching element in the intervention. The authors also suggest that child characteristics including degree of impairment might also play role in influencing outcomes or even to the extent of selecting type of physical therapy actions in the interventions.

The literature demonstrates the recognition of the importance of the family and their knowledge regarding their child and factors relating to their child. More clearly defined programs examining the changes in level of knowledge, type of knowledge and the mechanism of influence of knowledge on child development will assist interventionists to more effectively develop programs targeting family needs and those of the child and changes in child developmental outcomes. This study examines the influence of a parent education program on

level of parental knowledge, the influences of this knowledge on the home environment and effects of the home environment on child developmental outcomes within the framework of participation of the child with a disability in age-appropriate activities.

#### 4. **Maternal beliefs and practices**

Parental beliefs and practices are part of the child's environment. Over the last twenty years researchers have acknowledged the importance in understanding childrearing practice, patterns and beliefs which are based on a culturally-bound understanding of child needs and future expectations. These practices, patterns and beliefs are embedded in culture and determine to a large extent the behaviors and expectations surrounding a child's birth, infancy and throughout their childhood. Caregivers have a set of practices available to them which are grounded in cultural patterns and beliefs. These practices are based on beliefs from their own childhood experiences and information conveyed to them from their elders and other members of their culture.

Cultural influences have been demonstrated in levels of stress and readiness of parents to incorporate new information in to current practices and assessments. Marshak et al (1999) discuss the cultural differences present in research, assessment and examination on the efficacy of interventions. Differences not accounted for include social structure, sociolinguistic, and motivation variables. Culturally diverse parents display more difficulty in participating in decision-making; barriers often exist to proactive participation and collaboration.

Cultural factors have been demonstrated to influence the amount of stress experienced by families. Less stress was found among African-American caregivers as compared with non-African-American counterparts. Additionally African-Americans are less likely to institutionalize their family members and fewer experienced emotional distress as compared with

white caregiving counterparts. These findings are despite the fact that African-Americans had fewer available resources, lower SES, increased barriers and access to support services and women were more likely to be single or widowed mothers at an earlier age (Dilworth-Anderson & Williams, 1999; Pruchno & Patrick, 1997). Possible explanations might include less noticeable impairments and restrictions in function in the presence of milder disabilities because of differing levels of demands placed on the individual as a result of differing cultural expectations. Additionally primary stressors faced by families with a member with a disability might not be the presence of a family member with a disability but rather poverty, violence or other stressors typically found in families in low SES levels (Dilworth-Anderson & Williams, 1999; Biegel & Johnson 1997).

Benasich and Brooks-Gunn (1996) is one of the few studies examining the link between the parenting beliefs, the home environment and child outcomes. They examined the cohort from the IHDP study. They found a causal link between parenting beliefs and home environment to child cognitive and behavioral outcomes in the high risk population. Measures of maternal knowledge at 12 months were found to be significantly related the quality of the home environment, the number of child behavior problems and to a smaller extent child cognitive outcomes as measured on the Stanford-Binet IQ at 36 months.

Caldwell & Bradley found differences in the home environment, and timing of parental practices within certain cultural groups. They used the HOME to measure the environment. They found different practices among different cultural groups. These differences resulted in the delay in provision of certain stimulation in the home environment important for fostering infant development and differences in types and quantity of demands placed on children by their parents (Bradley et al, 1994a).

Gutierrez et al (1988) found differences in type of parenting related to degree of acculturation in Mexican-American parents. They found a wide range in concepts of development in these Mexican-American mothers related to both the degree of acculturation and SES. The more acculturated mothers used a more perspectivistic and complex reasoning than less acculturated Mexican-American mothers and Anglo-American mothers from the same SES. The differences in level acculturation were expected. However the increase in perspectivistic concepts of development relative to the Anglo-American mothers was not expected. The authors theorize perhaps biculturalism of the Mexican-American mothers improved their ability to be more flexible in their reactions to their children and assist and encourage them to support adaptive functioning (Gutierrez et al, 1989).

Accessing and influencing beliefs and attitudes should be considered to achieve behavioral change (Wood, 2001; Goodnow, 1988). Goodnow (1988) demonstrated the perseverance of beliefs despite attempts to alter parental beliefs regarding their child's behavior in varying intervention settings. Parental behaviors are based on their belief or ideas and changing behaviors requires altering beliefs. Providing information contradictory to current beliefs in an attempt to change practices will not necessarily change them. New information might be altered by parents to fit their current beliefs and not necessarily change behaviors to fit the newfound knowledge. Goodnow (1988) suggests that the belief that parent education targeting changing specific behaviors should be adopted and integrated into current parental behavior repertoires is erroneous. Incorporating knowledge on parenting practices and beliefs into program development has been slower and as yet not integrated into many intervention settings. Intervention programs should carefully consider paths to access parental beliefs and facilitate change in their current beliefs to alter behaviors and improve child developmental outcomes

(Evans & Myers, 2001; Goodnow, 1988). Professionals involved in intervention should be sensitive to the family's cultural background and consider the broader context of the family and society to the influences on a child's development and to effectively plan interventions sensitive to a family's cultural background (Coll, 1998; Evans & Myers, 2001; Goodnow, 1988).

(d) **Summary**

The recognition of the influence of the environment and context on the developing child has increased over the last 20 years. Varying conceptual frameworks provide different definitions of the environment and their relative contribution to explaining variations in developmental processes (Thelen & Ulrich, 1991; Bronfenbrenner, 1986; Sameroff & Fiese, 2000). The mechanism of parental influence on child developmental outcomes is theorized to occur through parental influence on their child's home environment. Identifying the components of the environment impacting on child developmental outcomes that are fairly accessible to change remains subject to debate and requires further research. Parental competence is comprised of maternal health, SES, age, education, cultural influences and parental knowledge of development. It is necessary for individuals and agencies involved in intervention to understand how families function, the importance and influence of the context in child development and the relative contribution of these variables to child developmental outcomes.

B. **Methodological Issues of Research with Children with Disabilities**

Few large scale studies have examined subjects with disabilities and typically most small studies examine efficacy of interventions rather than overall developmental outcomes. This lack of research can be attributed to methodological issues related to examining populations with disabilities. Moreover, a disproportionately large part of the research has focused on disabilities

related to language and milder developmental disabilities. Few studies examine populations of children with motor disabilities.

Large scale research examining the efficacy of intervention with the population of children with disabilities is relatively sparse when compared with research examining the at risk population of children. This lack of research is due largely to the difficulty in designing methodologically strong research on a large scale using the population of children with disabilities. Much research regarding children with disabilities examines the efficaciousness of certain treatment interventions or interventions with limited populations of children with disabilities (Shonkoff et al, 1992; Meisels et al, 1993). The broader question of overall efficacy of intervention in the population of children with disabilities is not addressed especially in the population of children with motor disabilities.

Methodological problems in research examining children with disabilities include determining the effects of intervention on development beyond the effects of maturation, the inherent heterogeneity of the population of children with disabilities even within the same diagnosis category and measurement difficulties. Ethical considerations limit the use of randomized research designs. Additionally, determining the population of children at an early age who will most likely develop disabilities limits the ability to examine interventions. Heterogeneous populations and small sample sizes limit the statistical analyses and ability to determine effects from interventions. Little specificity is provided regarding sample differences in the researched population. The descriptive statistics reported in research typically describe the disability, but often do not specify the family characteristics, SES and family structure, which may affect receptivity to and influence of the early intervention program.



Decreased power in research with children with disabilities is another limitation in determining programmatic benefits from interventions. In the Infant Health and Development Project all children diagnosed with CP were excluded at three years. Exclusion of the children with CP enhanced group differences between the intervention and control group. This increase in effects might indicate that the intervention provided in this program was less effective on the children diagnosed with CP and excluding them from the statistical analysis resulted in overall increases in the benefits received from the intervention (Pakula & Palmer, 1997).

The measurements and tools selected in research for outcome measurement often do not reflect the focus of the interventions examined and measure aspects of child development less relevant to family and child functioning. Moreover, measures used in research are typically not normed on the population of children with disabilities. Measurement should be clinically and ecologically relevant to the family and child's setting. Measurements that are broader-based with greater sensitivity to family outcomes are necessary. All these factors affect the power that will be generated from an intervention study possibly decreasing the ability to achieve power to demonstrate efficacy of interventions resulting in Type II errors.

In addition to all of the methodological difficulties involved with research in the population of children with disabilities, determining the criteria that will determine improvement- not only the measures but which of the aspects of child development will indicate an intervention's "success" is not clear from the literature. It is not clear whether intervention outcomes should be measured based on traditional developmental assessments or on a child's participation in age-appropriate activities. An additional issue is whether positive family members also indicate success even in the absence of measurable improvements in the child with a disability.

This research addresses the methodological issues presented through limiting the participants to one type of diagnosis, CP. The age of the participants is restricted to those prior to formal grade school age to further increase the homogeneity of the participants participating in this research study. Furthermore this study focuses on the child's participation as one of the outcome measures rather than developmental outcomes. Selecting participation as the measure over a three-month time period limits the effects of maturation and reflects changes in parental knowledge of their child's disability and the way in which the parents structure their home environment. The hypothesized increases in knowledge of their child's disability and increased ability of parents to shape their child's environment are hypothesized to increase their child's participation in age-appropriate activities.

### C. **Cerebral Palsy**

The purpose of this study was to develop an educational program for families regarding their child's development and examine the effects of this program on parental knowledge regarding their child's disability, its effects on the home environment and influences on their child's participation in age-appropriate activities. Limiting participants to the diagnosis of CP increases the homogeneity in the sample and the specificity of the parental education program allowing for improved research design with a larger effect size of the intervention.

Understanding the effects of the impairments of CP on function and participation in age-appropriate situations are important in both designing the contents of the educational program in this study and clearly and concisely conveying this knowledge to the participating parents. CP does not manifest purely in the areas of motor functioning. The difficulties in motor functioning may affect an individual's ability to participate in age-appropriate activities, social interactions

with both peers and family and occupations. Other areas that may be affected as a result of the brain damage include learning disabilities, attention deficits, seizures, mental retardation, and visual, auditory and other sensory disorders. In this study I am examining motor limitations and its effects on daily functioning and participation in life situations and an educational program to decrease the limitations of children diagnosed with CP on participation as a result of the motor impairments or as described by the ICF impairments in body structure and function.

(a) **Definition and Classification**

CP is a general term used to describe a non-progressive lesion resulting in disorders of posture and movement related to damage to the developing brain during the prenatal, perinatal or postnatal period (Brouwer et al, 1996). The incidence of infants diagnosed with CP is 2.3 per 1000 live births (Meberg & Broch, 2004). Although the lesion is by definition non-progressive the effects of the lesion and resulting complications on function vary through the individual's life cycle. CP affects an individual's ability to control posture and movement and affects all functional activities including activities of daily living, leisure activities and functional mobility. The overall effect of CP may result in limitations in participation in age- appropriate activities.

Classification of the types and severity of CP has not been uniform in the past. In the past the classification of CP was based on the severity of impairment (mild, moderate, severe), the affected body limbs (upper and lower extremities and right versus left side) and type of movement abnormality (spasticity, dyskinesia, ataxia) (Bax, 1964). The more limbs involved and increasing severity of the impairment typically resulted in increased limitations in functional abilities. Currently the predominant classification system in use is the Gross Motor Functional Classification System (GMFCS) which assigns levels based on the individual's functional abilities to quantify the severity of the motor impairment and its effects on functional ability of

the individual with CP (Palisano et al, 2000). In addition to describing the current level of function of the child the GMFCS was also found to validly predict future motor function based on developmental trajectories developed by the authors (Wood & Rosenbaum, 2000). This finding is important in the prediction of outcome and function of young children diagnosed with CP.

The GMFCS is a 5-level classification system focused on functional limitations, the need for assistive technology, wheeled mobility, and quality of movement. This system describes the motor level that describes the child's current gross motor function. The five levels described in this classification system are: I – walks without restriction; II – walks without assistive devices but with limitations walking outdoors and in the community; III – walks with assistive mobility device; IV – self-mobility with limitations and V – self-mobility severely limited even with the use of assistive technology.

Objective methods for predicting motor development for children diagnosed with CP has only recently been developed. Palisano et al (2002) developed functional curves that can be used to predict motor function in children with CP. Five distinct developmental curves were identified. These curves describe important and significant differences in the rates and development among children diagnosed with CP. There is significant variation within each of the five curves. These curves enable prediction of the functional development of children with CP.

(b) **Impairments in CP**

The restrictions and pathologies in motor function in children with CP can be divided into neurological and non-neurological components that result in the atypical movement evident in children with CP (Crenna et al, 1992). Understanding the nature of the impairments underlying

movement dysfunction and their effects on disorders of posture and movement can influence the understanding of the effects of CP on functioning and increased understanding can assist caregivers and interventionist in selecting more effective strategies and intervention approaches to increase functioning and participation in age-appropriate settings.

The impairments influencing motor function in children diagnosed with CP include spasticity, lack of reciprocal inhibition, coactivation of antagonists, irradiation of muscle activity of the prime mover to surrounding muscles, hypoextensibility of muscles, abnormal sensory processing, inappropriate force production and control, lack of or inappropriate anticipatory postural reactions and abnormal involuntary movements. The total effect of these impairments is that movement in children with CP occurs in abnormal synergistic patterns. The abnormal synergistic patterns produce resistance to selective control of movement at single joints resulting in difficulty in producing and completing motor tasks, overall decreases in endurance, increases in energy cost in motor activities and increases in fatigue levels throughout daily activities. Over time decreases in joint range of movement may result in muscle contractures and other orthopedic conditions in joints.

Spasticity is the presence of a velocity-sensitive increase in resistance to passive stretch and clonus. Spasticity is characterized by increased tonic stretch reflexes (increased muscle tone) with exaggerated tendon jerks, resulting from hyperexcitability of the stretch reflex, as one component of the upper motor neuron syndrome (Feldman et al, 1980). Varying degrees of reflex activity are evident in children with CP (Barolot et al, 1980). Normally stimulation of the monosynaptic reflex arc demonstrates suppression with repeated activation. The vast majority of patients examined with spinal cord injury demonstrated little or no suppression of monosynaptic reflex activity with repeated stimulation (Barolot et al, 1980). However increased use of

pharmacological interventions for the reduction of spasticity did not produce significant change in abnormal muscle synergies suggesting additional mechanisms underlying the motor impairments in children with CP (Damiano et al, 2001).

Underlying the impairment of spasticity in children diagnosed with CP is an abnormal reciprocal relationship between agonists and antagonists during voluntary movement (Dietz & Berger, 1983) and agonist-antagonist coactivation during passive movement (Mykelburst et al, 1982; Brouwer & Smits, 1996). Reciprocal inhibition contributes to preventing simultaneous agonist and antagonist activation during motor activities in the neurologically intact brain. During movement activation of agonist muscle will result in a decrease in the firing of neurons in the antagonist muscle allowing for smooth joint movement. Children with CP excessively coactivate antagonist muscles during movement because of a lack of reciprocal inhibition at the spinal level. A supraspinal component in addition to the impairment on the spinal level contributes to the lack of reciprocal inhibition in children with neurological damage (Leonard et al, 1990). Leonard et al (1990) demonstrated that children with CP lack reciprocal inhibition of the gastrocnemius-soleus H reflex before activation of the tibialis anterior muscle indicating damage to the supraspinal pathways of the agonist and the interneurons of reciprocal inhibition of the antagonists. This early dynamic phase inhibition appears to be of a supraspinal origin because of the short latency involved in the inhibition response.

Reciprocal excitation, activation of both the agonist and antagonist muscles, evident in CP, is theorized to result from a proliferation of neonatal neuronal projections or exuberances and aberrant corticospinal projections (Brouwer et al, 1996; Leonard et al, 1991). These exuberances remain in the neurologically damaged infant brain past the period when typical reductions in projections are evident in the brain with no neurological damage (Leonard et al, 1991). The

reflex overflow typical in small infants without neurological damage decreases as they develop. Infants with neurological damage do not demonstrate decreases in neonatal neuronal exuberances resulting in continuation of reciprocal excitation past infancy. Brouwer et al (1996) examined input in the soleus and tibialis anterior muscles in a sample of 13 subjects, six diagnosed with CP. Short-term discharge synchrony in the tibialis anterior and soleus muscles reflecting abnormal supraspinal modulations and abnormal spinal interneurons and abnormal axonal branching was demonstrated contributing to the abnormal reciprocal excitation and resulting abnormal muscle synergies evident in CP.

Reflex irradiation, the activation of additional muscles in addition to the involved agonist and antagonist has been demonstrated. Reciprocal excitation alone cannot explain this additional muscle activity beyond the agonist-antagonist complex. The proliferation of Ia projections to motor neurons enervating additional muscles and/or supraspinally mediated transmission changes are thought to cause the irradiation evident in muscle activity in children diagnosed with CP (Leonard et al, 1991).

Hypoextensibility of muscle in the past has been solely attributed to neuronal factors relating to spasticity when in fact mechanical changes in the properties of the muscle fibers are evident. Trophic changes and imbalance between the agonist and antagonist muscles can produce hypoextensibility (Tardieu et al, 1982a; Tardieu et al, 1982b; Dietz et al, 1983). Dietz et al (1983) demonstrated that muscle hypertonia in the lower extremity during ambulation was not attributable to an increase in electromyographic activity but rather due to muscle stiffness as a result of changes in mechanical properties of the muscle fiber. The changes in the mechanical properties of the muscle result from changes in the muscle fiber because of abnormal development. Lack of muscle growth in the presence of bone growth will result in shortened

muscles (Tardieu et al, 1982; Tardieu et al, 1979). Berger et al (1984) demonstrated that biomechanical change in muscle properties contributed to impairments in gait in children with CP and not pathological reflex activities (Berger et al, 1982). Examining EMG changes in the presence of increased muscle tension in the triceps surae Berger et al (1984) found that the changes in muscle activity was not consistent with increased muscle activity but rather a sudden mechanical stretch placed on the muscle.

Children with CP demonstrate difficulties in motor patterns resulting from decreases in force production. Timing and extent of motor activity are the involved components resulting in the impaired force production (Damiano et al, 1995; Berger et al, 1982). Decreased EMG activity was present in children with CP compared to children with no neurological deficit. Additional decreases in stereotypical activity in antagonist muscles was absent in the EMG activity of children with CP. These factors are very important contributors to overall decreased force production during gait. The increased use of selective dorsal rhizotomies to decrease abnormal muscle tone has further revealed an underlying impairment of decreased force production in children with CP (reference).

Berger et al (1984) studied the activity and functional significant of monosynaptic and polysynaptic reflexes during normal and disturbed gait. In normal gait the monosynaptic reflex activity is inhibited and a strong polysynaptic response is evident. The polysynaptic activity allows for increased force production in the required muscles for normal gait activity. In subjects with impaired motor function of supraspinal motor centers the monosynaptic responses dominate preventing adequate force production in the required muscles. Apparently there exists a reciprocal modulation between monosynaptic and polysynaptic responses. The electromyographic (EMG) output demonstrated that the decrease in force output was not



attributable to reflex activity and this reflex activity did not contribute to tension development. Polysynaptic activity to guard against perturbation could not be activated because of the presence of the monosynaptic responses in subjects with neurological deficits.

Abnormal sensory processing contributes to decreased force production during motor activities of children with CP. A sensory organization component determines the onset, timing, direction and amplitude of postural reactions from somatosensory, postural and visual stimuli (Nashner, Shumway-Cook & Marin, 1983). Impaired tactile sensation has increasingly become evident and used as a tool to aid in diagnosis during posterior dorsal rhizotomies (Barlolut & David, 1980). Impaired anticipatory control of grip force demonstrates the influences of sensory information in motor planning (Eliasson et al, 1995). Impaired sensory information does not allow children with neurological deficits to store sensory information in memory representations to be used to program movements (Eliasson et al, 1992). In grasping internal representations of the object including weight, size and friction affect the effectiveness of the anticipatory control before and during the execution of the motor task. By age two it has been shown that typically developing children begin to learn to adjust the force level in their grip (Eliasson et al, 1992). The force regulation is dependent on cutaneous input. This force is anticipated prior to and adjusted during the loading phase. Abnormal muscle coordination affects the temporal and spatial sequencing of muscle contractions to produce effective movements (Nashner et al, 1983). Temporal disturbances in postural responses and gait in children with CP consisted of incorrect sequencing and delays in onset of the required muscle activity necessary for execution of these tasks. Children and adults with CP are known to have deficits in motor control with disturbed temporal coordination and amplitude of muscle activity.

Overall stiffness evident clinically is referred to as increased tone. Alterations in tone in different parts of the body result from all of the neurological impairments discussed above. In each child they contribute in different degrees to the difficulties in motor function. Phasic and tonic muscle contractions are described in the literature. Phasic muscle contraction is muscles contracting and relaxing as needed and shifting from a contraction to a relaxing state quickly (Crenna et al, 1992). A tonic muscle contraction is a constant contraction resulting in the stiffness seen clinically in children with CP and is the typical type of muscle contraction that is evident in motor movement (Knutson & Martenson, 1980). Tonic muscle contractions require increased energy expenditure and because individuals with CP perform tonic muscle contractions over an extended period of time, increased energy expenditure and decreases in endurance are evident.

In most of the research involving the study of the underlying impairments in CP small sample sizes and comparison groups were used raising the possibility that the subjects studied were not representative of the population of subjects with CP. However, the overwhelming convergence of opinion and findings regarding the impairments provides strong convergent validity of the findings previously described.

The impairments in CP affect the ability to control posture and movement and as a result all functional activities have increased energy cost and result in decreased endurance. Decreased endurance as a result of increased energy cost and resulting increases in fatigue may affect the participation of an individual in age-appropriate functions and activities. As the GMFCS level increases, further increases in energy costs are evident because of increases in the severity of the impairments and effects on postural control and motor function and may decrease the functional abilities of individuals with CP in age-appropriate activities. Postural control is the body's

position in space for the purposes of stability and orientation and supports the primary movement which the individual attempts to perform (Woollacott & Burtner, 1996).

Increased energy costs in motor tasks and functional activities in children have been found (Olney et al, 1987). Olney et al (1987) examined the transfer of energy during gait from potential to kinetic energy. Children with hemiplegia type CP had poor transference of energy with resulting increases in energy expenditures during gait activities. Significant increases in oxygen uptake have been measured in children with CP (Rose et al, 1989). Anaerobic muscle power and endurance are decreased (Parker et al, 1992). Increase in energy expenditure during daily tasks occurs with increasing severity of motor impairment (Campbell & Ball, 1978).

The prolonged delay between muscle activation and sensory input for feedback regulation can result in impairments in sensory processing and/or muscle organization. This occurs because in typical development anticipatory control emerges early in normal development and is highly purposeful. Disturbed and delayed equilibrium reactions and postural control mechanisms are evident in individuals diagnosed with CP due to the overall effect of the impairments previously described. Deficits in postural control and motor function may affect an individual's overall participation in their daily age-appropriate activities.

(c) **CP through the life cycle**

Decreases in life expectancy, increased need for surgical intervention, physical changes and decreases in function are complications and changes through the life cycle experienced by individuals diagnosed with CP. Many factors may contribute to changes over time, such as body weight, body weight/strength ratio, contracture, changes in tone and spasticity (Bell et al, 2002). For example Bell et al (2002) examined 28 children and two gait analyses 4.4 years apart. They

found changes in gait patterns over time specifically decreases in temporal/stride parameters and kinematics overtime.

Changes in skeletal maturation and mineralization are found in children with CP (Inkkan & Yalcin, 2000) Sixty nine children (28 females and 41 males) with spastic CP and 26 typical children (13 females and 13 males) were compared. The children diagnosed with CP were further divided into three groups based on affected limbs, quadriplegia, diplegia and hemiplegia. Mineralization was adversely affected and maturation delayed in all three groups of children with CP. Group differences between children who were mobile and non-mobile were statistically significant with decreased maturation and bone density in the non-mobile group of children. The authors suggest this delayed mineralization and maturation might be a result of disrupted embryologic skeletal development due to hypoxic attack which also causes the disease.

Ando & Ueda (2000) examined a group of 163 subjects from a sample of 686 subjects answering a survey working in community workshops in Japan. They examined the subjects at the onset of the study over a six month period and approximately two years later again over a six month period. They found 35% of those examined had some functional deterioration. However they also found some of the deterioration in function could be attributed to environmental factors. Environmental factors included an inadequate work environment, poor posture and neck pain and unsuitable desks and chairs.

Santiago and Coyle (2004) examined leisure time participation in 170 women with physical disabilities ranging in ages between 21-65 years. The physical disabilities included multiple sclerosis, CP, polio, arthritis, traumatic brain injury and cardiovascular accident. They reported secondary conditions of physical deconditioning and isolation and found these conditions to be inversely related to the ability of moderately impaired women with physical

disabilities to participate in leisure time participation when functional status was controlled.

Efforts should be made to increase involvement in this health promoting behavior.

Hutton et al (1994) examined 1258 children diagnosed with CP born during 1966-84 to mothers living in the Mersey region in England. They examined the 20 year survival rate. Life expectancy of this cohort of children with CP was greater than has been suggested in some previous studies. They examined many predictors including sex, birth weight, functional ability (ambulation, manual dexterity, and mental ability). Gestational weight and age were not as predictive of survival rate as was the number of severe functional disabilities.

Katz (2003) reviewed the literature related to the survival rates of children diagnosed with CP. Certain key disabilities can be used to accurately predict life expectancy in children with CP and intellectual disabilities. These include: (1) presence and severity of mental retardation, (2) inability to speak intelligible words, (3) inability to recognize voices, (4) inability to interact with peers, (4) severity of physical disability, (5) use of tube feeding, (6) incontinence, and (7) presence and severity of seizures. The literature indicates that children with CP and developmental disability have a diminished life expectancy, which can be assessed based on simple clinical examination findings. However because of conflicting reports regarding decreases in life expectancy of people diagnosed with CP the reasons for the diminished life expectancy should be more carefully examined for other influences.

(d). **Effects of impairments on functional independence and their relationship to participation**

Understanding impairments and their effects on function can be viewed from two opposing perspectives. One perspective is the disablement framework. The disablement framework is the basis of the Guide to Physical Therapy (Rothstein, 2001). It proposes to examine an individual

based on the effects of disease, injury or congenital abnormalities on functioning which is affected by both the environment and personal factors. The ICF is an alternative model with which to view disability (WHO, 2001). This framework can be described as the enablement framework. This classification system stresses health and ability to function in the presence of disability. Health is viewed as a series of interactions between personal, environmental and societal factors and activity, environment and participation demands on age- appropriate activities for the individual. The ICF allows for a multilevel multifactor consideration of the effects of limitations on participation (Goldstein et al, 2004).

The ICF is a part of international classifications developed by the WHO (2001) to provide a framework to code information regarding health and to provide a standardized common language to communicate information about health and health care needs. The ICF is the updated version adapted from the first International Classification of Impairments and Disabilities (1980) and the second version of this classification, ICIDH-2 (WHO, 1999). The ICF is the third revision of this classification (World Health Organization, 2001). Recently a child and youth version has been developed (WHO, 2011). The ICF recognizes three important dimensions affecting disability: body function and structure, activity and participation. The ICF also recognizes the influence of contextual factors on the degree of disability of an individual. Disability as a result of CP within the enablement framework, the ICF, can be viewed as the sum total of the effects of society and the environment on restricting an individual's functional abilities. The ICF model along with current legislation in the United States focuses on inclusion of children with disabilities in their natural environments. Interventionists using this approach have an imperative to find the ways to include children in natural environments where they will participate in all activities in these environments. Currently this is difficult for children with

motor impairments especially with same age peers at a young age without physical impairments or other disabilities.

There are a number of issues relating to participation and children with disabilities that remain unclear in the literature. The first issue is a definition and measurement of participation in general for children and youth. The concept of participation between the different age groups among children between preschool, elementary school and high school children vary widely. This factor makes its measurement particularly complex. The complexity of understanding participation among children is emphasized by the numerous models developed to understand this concept. King et al (2003) developed a conceptual model of the factors affecting participation that categorized the factors into three main influences: child factors, family and environmental factors. Understanding the numerous factors and the influences are paramount to developing responsive and effective interventions to increase child participation.

Participation can be examined and understood from a variety of perspectives. Within the framework of the ICF and the adult perspective it is defined as involvement in life situations. From the perspective of children the definition of participation within the framework of the ICF includes the domains of learning and applying knowledge, communication, home and school life, relationships, and leisure and recreation. Sometimes inconsistencies are evident in what the child does in a variety of situations and are explained by including two additional aspects, capacity and performance, what the child can do and what they do in a variety of situations and is thought to be influenced by the of the activity performed, environment and personal factors (WHO,2001).

Participation can be understood within another framework, namely the capability approach. This considers beings and doings. The ICF only considers what the child does but the capability approach considers “being”, such as being happy, and more consistent with the subjective quality

of life. Within this approach what the individual achieves is affected by the person's capacity, choice and opportunity that are usually afforded by environmental factors. For example if the child has the capacity to use the computer, but none is available, or the child chooses not to use a computer then the capacity will not accurately reflect participation but capability will more accurately determine the child's participation in life situations (Morris, 2009; Nussbaum, 2000; Sen, 1992).

Coster (1998) defined participation of preschool and school age children uniquely. Participation is involved uniquely as energetic engagement in the typical activities as expected of same age peers in the same setting (Coster, 1998). In the very young child play, interactions with peers and family members, toileting, and playground activities are the central activities defining participation. Participation for older children should include school function, community activities and social relationships with their peers. Whiteneck (2006) suggested that participation can be defined by the organization of a series of activities in life situations. However, a clear definition of life situations and activities that may be used is lacking.

Mancini & Coster (2004) examined functional predictors of school participation by children with disabilities. A sample of 266 school children in United States elementary schools with a variety of disabilities was examined. They examined numerous domains: transportation, bathroom, playground, mealtime, transitions and their regular and special classroom setting. Successful participation in elementary school was associated with performance on cognitive, behavioral and physical activities. Each area examined had a unique combination of variables predicting performance. These findings highlight the influence of cognitive, behavioral and physical function on participation and the limitations in participation that can result in children with CP because of their impairments.



Physical performance was found to partly account for differences in participation with school-aged children with different types of CP and different levels of motor impairment. Schenker et al (2005) examined 148 children diagnosed with CP mainstreamed in inclusive school settings. They found that the degree of communication disorders influenced the children's degree of participation of children in the mainstreamed setting. Participation scores of children with learning disability and additional speech and language disorders were significantly more limited than those of children without additional neuroimpairments.

The finding that limitations on participation are not necessarily related to motor impairment or body structure and function are further highlighted in current research with children diagnosed with CP. Tieman et al (2004) found in a study of 307 children aged 6 to 12 years diagnosed with CP that functional performance differed depending on the environment in which the function was performed. The children in the study were divided into three groups based on the highest three items they could complete on the Gross Motor Function Measure. Performance was measured based on a parent-completed questionnaire on usual mobility methods in the home, school, outdoors and community. There were significant differences in performance in all settings for all capability groups. Children who were capable of crawling performed crawling more at home than at school or in the outdoors or community. Children who were capable of walking with support performed walking with support more at school than in the outdoors or community. Children who were capable of walking alone performed walking alone more at home than at school or in the outdoors or community, and more at school than in the outdoors or community. This study highlights the importance of examining environments and constraints on function imposed on the child because of environmental settings.

Forsyth et al (2007) found that participation of severely disabled children was influenced both by their intrinsic impairments and their environment. They measured the amount of medical and social influences and found that both significantly affected participation.

Constructing accurate measures used to assess child participation in life situations are dependent on three key concerns. They include inherent variations on how the operational concept of participation is defined, lack of consensus as to whether participation should include both subjective and objective aspects of participation or possibly both, and the ability for the literature to arrive at a consensus in defining participation and the factors that influence it (Coster & Khetani, 2008). In fact Coster and Khetani (2006) discuss the problem in determining a profile of participation not specific to the environment. For instance the CAPE was developed for an elementary school profile. The variety and range in definitions of life situations has tremendous cultural and age related variability that limits the ability to develop a wide ranging measure to cover a few years in the child population.

This study was developed and proposed prior to these discussions and questions arising in the literature suggesting that prior to measuring participation it must be more clearly defined and perhaps qualified to specific age ranges in the pediatric population due to the influences of development on the child's life situation and intricate relationship to the age, environment and family. A scale measuring participation should capture activities that are meaningful in people's daily lives. The item elected in any scale must be selected using consistent guidelines or the scale will not be meaningful. Another important consideration is that currently most measures examine participation only from the perspective of physical disabilities but the literature suggests that other disabilities should be included in any measure to address participation from a broader perspective.

In summary participation needs to be more clearly defined within the framework of life situations and from the perspective of the child and his/her family. Items used to measure participation need to reflect this conceptual framework to ensure validity of the measure.

(f) **Summary**

Though a decrease in life expectancy is demonstrated, many of the restrictions and limitations appear to be attributable to participation and environmental factors. Knowledge of the contributions of these factors and decreasing their consequences may serve to increase health and participation of individuals with CP. Increased barriers will affect a child's ability to participate and as a result increased disability may result. Determining barriers faced by children with CP and methods to decrease these barriers are essential to increase participation and decrease disability. Knowledge and methods to decrease barriers for children with CP will be discussed and will comprise a large extent of the information taught in the educational program in this research project.

Parents have an essential and pivotal role in fostering their child's development. This parental role may be more influential with children with CP because of the physical limitations caused by their impairment. Increasing their child's participation by fostering their independence by adapting and structuring the environment of their children increasing their child's participation in age-appropriate activities may decrease their child's disability. This study focuses on providing parents with the knowledge and strategies which they can implement to assist their child to increase their function and participation in age-appropriate activities.

#### D. **Adult Learning**

Current approaches in designing early intervention recognize parental influence in the home and the developing child and consequently emphasize incorporating parental involvement into program design. The influence of educational programs on the knowledge and behaviors of parents is assumed but has not been carefully examined. In this study I examine the impact of a parent education program on parental knowledge, the influence of this knowledge on parenting practices through examining the home environment and the influence of any changes in the home environment on child participation in age-appropriate activities. This section will review the literature in the field of adult education and their findings regarding effective methods for developing program structure and content to be applied to the parental education program in this study.

##### (a) **Bandura's social learning theory**

Human behavior, according to Bandura, is controlled and determined by an individual's actions and beliefs. Individuals have the ability to exert control over their lives and are producers and products of their social systems. An individual should perceive agency, the ability to exert control over their lives, to alter their behaviors. Cognitive processes may influence behavioral change. The inclusion of consciousness within this theory differentiates social cognitive theory from others because thought/mental/conscious processes influence behavior. Consciousness enables an individual to select, shape and mold events.

Bandura's social learning theory, an outgrowth of social cognitive theory, stresses the importance of personal, environmental, situational and behavioral factors influencing learning. Individuals are influenced by social situations. Social situations may be used as learning tools employing imitation and modeling, important learning strategies in social learning theory.

Bandura uses modeling and imitation as a tool in adult education for learning and reinforcing new behaviors and altering existing ones.

Behavioral change is further influenced by experiences of mastery due to successful performance. Successful experiences in specific actions may foster increased self-efficacy encouraging and reinforcing continuation of the desirable behaviors.

Self-efficacy is defined as a person's judgment and belief in their own capabilities to organize and execute courses of action necessary to attain designated levels of performances or behaviors (Eccles & Wigfield, 2002). Self-efficacy in social learning is situation specific. The level of self-efficacy is related to the context of the situation and task requirements. Higher perceived levels of self-efficacy may reduce anticipatory fears and inhibitions regarding a situation or task and influence expectations of eventual success and coping efforts. Level of self-efficacy and belief in one's ability to successfully accomplish behaviors is related to its reinforcing outcomes based on the overall consequences of the behavior and not solely on the immediate response consequences.

Efficacy expectations vary on three dimensions: magnitude, strength and generality. Magnitude describes efficacy levels required based on the perception of the level of difficulty of the specific task to the person. Generality refers to the ability to refer experiences and behaviors from one to another. The ability to generalize experiences will vary according to specific behaviors and an individual's perceived ability. Some tasks may be generalized beyond the specific actions and can serve to increase an individual's sense of efficacy beyond the specific task. The strength of self-efficacy is used to describe the sense an individual has of their abilities. Weaker expectancies are more easily extinguished by negative or disconfirming experiences. Stronger expectations of mastery will encourage an individual to persevere in their efforts

despite unsuccessful or disconfirming experiences and encourage perseverance in coping efforts despite disconfirming experiences.

Sources for efficacy expectations are performance accomplishments (value-expectancy theory), participant modeling, vicarious experience, verbal persuasion and emotional arousal (Bandura, 1977). Performance experience is an important source of efficacy information. Individuals may incorrectly attribute success to external factors rather than their own abilities depending on the methods employed for success. Individuals with higher levels of self-efficacy are more likely to mobilize greater effort and master difficult situations when provided with provisional aids than the use of performance aids. Increased use of situational aids for task performance increases the chance of attributing success to external factors and not an individual's own abilities. Discrepancies between efficacy expectations and performance are most likely to arise under conditions in which situational and task factors are ambiguous.

Bandura stresses the difference between performance efficacy and outcome efficacy. An individual might believe they know all necessary behaviors to achieve successful performance - outcome efficacy, but are not efficacious in their beliefs about their own ability to successfully complete the behavior. If an individual believes they can produce a behavior but is experiencing difficulty, performance aids will serve to encourage repeated attempts at successful completion of that behavior.

Bandura stresses the reality that the majority of learning occurs through observing other people's behavior, vicarious experiences, and their consequences. The capacity to learn by observation enables individuals to acquire large, integrated patterns of behavior without having to form them gradually by trial and error. Learning would be very time consuming and often dangerous if learning occurred only as the behaviorists describe. Bandura emphasized modeling as a tool for

teaching. Bandura describes the necessity for individuals to learn through modeling, observation of others, and the necessary influence of cognitive thoughts as part of the learning process.

Modeling in social learning can occur through observational processes not necessarily requiring immediate reinforcement. Reinforcement is defined uniquely in social learning theory. Reinforcement may be an antecedent or consequence of behavior. The predictive value of an event and possible future consequences are represented symbolically and serve as motivating influences. Behavior generally is most persistent when it is reinforced at a low and variable level and is related to its reinforcing outcomes on a cumulative level rather than momentary consequences (Bandura, 1977).

Peer group discussion and role modeling are some of a teacher's fundamental techniques used to change behaviors. Three basic effects result from role modeling. The effects include modeling effect, inhibitory/disinhibitory effect and an eliciting effect. The modeling effect exposes the learner to a new model and new response patterns. Inhibitory/disinhibitory effect increases or decreases the frequency, latency or intensity of previously acquired responses in the learner. The eliciting effect enables the learner to receive a cue from the model for releasing an existing behavior. Responsiveness to modeling cues are affected by the characteristics of models, the attributes of observers and the response consequences associated with matching behavior (Bandura, 1977).

Symbolic representations of modeled behaviors are governed by four processes: attention, retention, motor reproduction and motivational processes. People can learn through observation if they attend and understand the modeled behavior. Attention processes determine the behaviors on which the learners focus. The attitudes, interest, motivation and the model affect the degree of attention an individual provides towards any given behavior. Retention is crucial for

reproducing a modeled behavior and is retained in symbolic form. Imagery and verbal symbols assist retention of behaviors. Motor reproduction involves converting the symbolic representations into actions. Behavior is organized on both a spatial and temporal dimension. Behavioral actions can be divided into cognitive organization of the responses, initiating the responses and monitoring and reinforcing the responses through feedback. Motivational processes are linked and influenced by other factors affecting the learning of new behaviors including self-reflection, self-awareness, locus of control and self-efficacy among others (Bandura, 1977).

Modeling approaches to decrease or eliminate unwanted behaviors may also serve to increase an individual's self-efficacy (Bandura, 1977). Effective coping skills can demonstrate to individual effective methods for handling threatening situations and increase an individual's ability or belief in their ability to manage aversive aspects of the environment. These self-efficacy beliefs can affect how the individual overall perceives their environment. Social learning theory regards anxiety and defensive behavior as co-effects rather than causally linked. Perceived threats activate defensive behavior because of their predictive value rather than their aversive quality. People's knowledge of the environment and not the aversive stimuli are changed by experience and affect an individual's sense of self-efficacy in their ability to change their environment.

Self-regulation affects performance mainly through its motivational function. Motivational processes are integral to modeling in social learning theory and affect learning of behaviors at every stage. An individual's own ability at self-regulation influences the degree of persistence in performing a behavior and is more likely in the presence of increased motivation and increased value in the consequences of the specific behavior. Many complex constructs are involved in



self-regulation. Level of self-efficacy, locus of control, self-awareness, and self-reflectiveness are other factors influencing an individual's behavior and self-regulation.

Self-assessment and reflection in action influence attitudes and motivation to produce behavioral change. The relationship among these factors is bi-directional and explains some of the variability in individual motivation to change. Perceptions should be rooted in reality and based on accurate self-assessment regarding abilities to produce behavior. Poor self-assessment will influence motivation, self-reflection and the individual's perception for the need for behavioral change and the necessary skills to affect change. Participation and success of educational programs are often based on these perceptions and will influence their success.

Motivation and self-efficacy are two important concepts to be considered in program development in addition to the stage of change of the program participants. Motivation and self-efficacy are interdependent concepts that influence one another and impact on the success of educational programs (Bandura, 1977). Motivation is defined as the "process by which man is compelled to seek some goal" (Wong et al, p.111, 1983) and is primarily concerned with the activation and persistence of behaviors. It is a strong facilitator in the achievement of behavioral change. Motivation to gain new knowledge or skills is based on a drive to satisfy an individual's perceived need. Motivating factors have been described as emanating both intrinsically and extrinsically. Determination of motivation source and type can be used to indicate the stage of change of an individual and aid in matching the process to elicit behavioral change.

Self-efficacy influences motivation. Individuals with high levels of self-efficacy are more motivated to pursue and persevere in changing behaviors because of their beliefs that they may effect change. Individuals with low levels of self-efficacy may be more prone to failure because

of their beliefs in their inability to influence outcomes. Motivation is also based on cognitive processes influencing the occurrence and persistence of behaviors (Eccles & Wigfield, 2002).

(b) **Knowles' andragogical model and application in adult learning situations.**

Knowles (Knowles et al, 1998) elaborates on many of the points discussed by Bandura. Knowles discusses the different processes involved in learning situations and educating adults as compared with children and adolescents. Knowles described his theory of adult learning as andragogy. Andragogy was the term used by Knowles to describe adult learning in contrast to the term pedagogy which is used to describe the methods with which children learned. The andragogical model developed by Knowles discusses important principles developed specifically for adult education. Andragogy discusses the importance of experience and the needs of the adult to include past experiences within the context of their learning and be active participants in the learning process.

Knowles specific principles of adult education are:

- The need to know: Adults need to know why they need to learn something before beginning to learn. This can be accomplished by telling the learner why or realize the need themselves.
- The learners' self-concept: Adults want to be responsible for directing their knowledge. This transitions adults from dependent to self-directed learners.
- The role of the learners' experience: Learning and teaching strategies should be individualized.
- Use techniques that tap into the experience of the learners: Help adults examine their habits and biases so they are more open to change.

- Readiness to learn: This can occur naturally or readiness can be induced through exposure to alternative models of behaviors demonstrating increased success.
- Adults are life-centered in their orientation to learning: Adults are motivated to learn if they perceive that the learning will help them perform tasks or deal with problems relevant to their daily lives.
- Motivation: The most potent motivators are internal pressures and desires.
- Andragogical model includes pedagogical assumptions but not visa versa.

Shared control and knowledge of the educational information is reflected in Knowles' principles. Self-directed learning can be encouraged and fostered by the type of learning environment provided. Developing a democratic learning environment in determining the learning content and activities will encourage self-directed learning. This environment should be based on the real needs of the adult participants. The policies should be determined by the participants themselves whenever possible or by a representative group of the participants.

Value-expectancy theory is discussed by both Knowles and Bandura (Knowles et al, 1998; Bandura, 1977). The expectancy of successfully completing a task and the importance or value an individual places on the task to be completed serve as a strong intrinsic motivator to attempt and persist in a behavior. Many of Knowles' adult learning principles reflect the need for intrinsic motivation based on the value and importance of a task in developing the content of adult education programs and in encouraging participation.

Expectancy theory (Fox et al, 1999; Howard, 1989) can be used to understand the development of motivation of individuals and the differing levels of motivation between individuals to achieve a particular goal. The expectancy model can be used to explain the

individual variations in motivation. This model views people as purposive who interact proactively with their environments based on their expectancies about the likelihood that their efforts will result in outcomes that they value. People choose to behave in ways that will benefit them. Differing degrees of readiness of individuals for change and ability to produce change are explained by the interaction of the variables in the expectancy model. This model emphasizes the influences of the perceptions of individuals of their ability to change, self-efficacy, and the role this perception plays in motivation. The implementation of educational strategies matched to the abilities and type of motivation of the individual can greatly influence the ability of the learner to complete the program successfully (Wong, et al, 1983).

Critical reflectivity is discussed by Knowles and is one of Bandura's core features of human agency. This emphasizes the use of educational content and learning environments based on experience as a tool to invoke critical thinking, increased self-awareness, self-reflection and learning in adults. This is an outcome of the experience and social context that adults in particular bring to the learning environment.

Two types of reflection are described in the literature: knowing-in-action and reflection-in-action. Knowing-in-action is a somewhat automatic response based on our existing mental schema that enables us to perform efficiently in daily actions. Reflection-in-action is the process of reflecting while performing to understand existing schema, determining when existing schema are no longer appropriate and changing those schema when necessary (Schon, 1987; Smith, 1998). Self-reflection can be viewed as an intrinsic motivator and can be considered a form of discrepancy or gap analysis. Reflection can be used to achieve the action stage of change allowing for behavioral change to occur. Moreover, reflection-in-action can help foster increased levels of self-efficacy in an individual.

Behavioral change is often one of the goals of educational programming. Providing sources of information and increases in knowledge to the recipients of educational programs is insufficient to ensure behavioral change. Changes in underlying attitudes and beliefs should be accessed and altered to produce behavioral change. Behavioral change occurs when underlying attitudes are accessed, considered and adapted according to new beliefs of the individual (Ajzen, 2001). To this end consideration of the process of an educational program and its ability to access an individual's beliefs is equally as important as the content to achieve program success. Developing an educational program's process is often overlooked during its development. As a result many programs fail to produce behavioral change from its participants and fail to achieve its goals.

The stage of change is determined by the attitudes and beliefs held by parents and influence the readiness of the learner to attend the program and expend the effort to produce behavioral change. Participants in a behavioral program should recognize the existence of a gap in knowledge, abilities or both. Awareness of this gap allows participants to access and reconsider their attitudes, which is important to encourage behavioral change.

Prochaska (1997) describes a model of behavioral change consisting of a series of six stages through which an individual progresses along a temporal dimension. The stage of change of the participants and their readiness to change existing behaviors or learn new behaviors is an important consideration and directly affects the design and strategies implemented. The action stage of change is the point in this progression in which an individual actively engages in learning that could elicit behavioral change. The following five stages described in this model are necessary to prepare an individual for change and to enable maintenance of the behavioral changes. Targeting educational programming content for behavioral change in an individual who

has not recognized the need may result in higher rates of program failure. The first stage of change is pre-contemplation. People in this stage are either demoralized from failed attempts at change or are unaware of the necessity for change. The second stage of change is contemplation. An individual has recognized the need to change and is in the process of intending to change over the next 6 months. The third stage of change as described by Prochaska is preparation. In this stage of change an individual is intending to take action in the near future. Individuals in this stage of change have usually taken some action over the last year and typically have a plan of action. Action is the fourth stage of change described by Prochaska and occurs when individuals have made some overt modification in their lifestyles and is the targeted stage for the individuals participating in the intervention in this study. Maintenance is the fifth stage of change and is important to maintain change that occurred in the action stage. The last stage of change is described as termination. This stage is the final stage and occurs when an individual has no temptation to return and has 100% self-efficacy. The maintenance stage can last a lifetime and never have termination depending on the risk habit or behavior that is changed. Less than 20% of smokers and alcoholics attain this stage in their lifetime.

Multiple factors serve to interact and influence the ability and readiness of an individual to change. The process implemented in an educational program should serve to alert individuals as to the necessity for change, motivate individuals to change, foster the ability of an individual to perceive the ability to influence the targeted situation and reinforce this change using multiple methods. Program development is a complicated process; however, to successfully change adult behaviors all of these factors must be targeted in the development of an education program targeting behavioral change.

(c) **Specific strategies fostering behavioral change**

Group learning processes should be considered in the design of an educational program. The intent of the use of this process is encouraging collaborative learning within the group. Collaborative learning may increase support and empowerment (Panitz, 1999; Imel, 1999, Michaelson, 1997). In group learning situations the individual's learning process may occur through peer groups using discussion and role-playing. Often recommended are small learning groups. The intent of the use of small groups is for individuals to form cohesive smaller groups allowing all participants to assume equal responsibility in the learning process. The use of groups can serve to increase individuals' self-efficacy by providing vicarious experiences in which to practice. These experiences can then be applied to specific situations beyond the specific educational experience.

Learning contracts are suggested as an intrinsic motivator for the adult participants in educational programs by highlighting absent or deficient behaviors, in effect functioning as a discrepancy analysis or needs gap. Contracts foster a mutual understanding between the learner and the educator of the goals and program content to be provided. Additionally the learner develops a sense of ownership and commitment to the educational program. Methods of designing and implementing learning contracts fostering commitment to change as discussed extensively by Mazmanian et al (1997, 1998, 1999) as well as by Knowles. Knowles discusses in depth the content and application of learning contracts (Knowles et al, 1998). Learning contracts should specify the objectives, resources and strategies; as well as methods for demonstrating competence and accomplishment of the educational program. It is important to review the contract prior to its implementation and at the completion of the program to examine the success of the educational program.

Learning contracts is one method of commitment to change and can be used to facilitate behavioral change. Commitment to change including specific goals and objectives, resources and strategies to incorporate new knowledge with existing knowledge is facilitated with learning contracts (Knowles, Holton & Swanson, 1998; Mazmanian et al, 1999). Commitment to change can increase rate of success change from continuing medical education as examined in a group of physicians (Mazmanian, Dalton et al, 1998).

Learning contracts provide a framework for the whole-part-whole educational model described by Knowles et al (1998). The learner can be provided with an overview of the entire educational content through the contract. After the learner has the whole understanding of the program the contents can be broken down into components to help the learner master the parts. At the conclusion of the educational program the learning contract can be used to bring all of the parts together for participants.

Consideration of the process should not only consider the theoretical background relating to behavioral change but should consider additional criteria that can contribute to the effectiveness of learning situations. Harden and Laidlaw (1992) developed the CRISIS set of educational criteria that can be used to contribute to the effectiveness of educational situations. CRISIS is an acronym for seven factors that increase the effectiveness of adult learning situations. The factors include convenience, relevance, individualization, self-assessment, interest, speculation and systematic presentation of the material. This framework was developed for use in continuing medical education but can readily be applied to many adult learning situations.



(d) **Summary**

This study examined the influence of parental competence, specifically parental knowledge, and its influence on the home environment and effects on the child's participation in age-appropriate activities. Influencing and changing currently held beliefs and changing existing behaviors is challenging. However, incorporating researched educational principles and strategies into parent education programs was theorized to improve the effects of early intervention programs and increase their influence on child developmental outcomes.

E. **Outcome Measures**

The outcome measures used in this study examine the influence of the educational intervention on parental knowledge, the child's physical and social home environment, his/her participation in age-appropriate activities and parental self-efficacy. Significant changes in knowledge must first be demonstrated to attribute any changes in this study to the educational intervention. Parental knowledge is described as the factual knowledge of parental practices, child developmental processes specific to children with CP, including their social and physical needs, and methods of modifying the environment to meet the needs of preschool age children with CP.

Changes in the child's environment are hypothesized to result from increased parental knowledge. The home environment needs to be examined through measurement of the physical and social aspects of the home environment. The physical home environment is defined as the quality and quantity of stimulation present in the home environment from the child's perspective.

The WHO has recognized the importance of participation in individuals with disabilities. Based on the model developed by the WHO increases in child participation in age appropriate activities is an important result of this educational intervention.

Hypothesized to result from increased parental knowledge is improved parental self-efficacy. Levels of parental self-efficacy have been examined in previous studies using a scale developed by Heller et al (1999) This is a short scale that has been found to be valid and reliable to measure levels of self-efficacy (Heller, Miller & Hsieh, 1999).

#### F. **Conceptual Model**

The literature previously discussed describes multiple influences on child developmental outcomes and participation in age-appropriate activities. Hypothesized in this model is that an educational intervention would be effective in increasing parental knowledge of development of children with disabilities which would then influence the home environment and in turn increase the level of participation of children with disabilities in age-appropriate activities. In addition, increased knowledge of their child with a disability's development would positively influence parental level of self-efficacy

The conceptual model in this study hypothesizes a mediational relationship between levels of parental knowledge of development of children with disabilities and their child's degree of participation through parental structuring of the home environment. A mediator describes the pathway through which a variable "A" influences variable "C" through variable "B". In the conceptual model for this study variable "A" is parental knowledge. Parental knowledge is theorized to influence variable "B", the home environment, comprised of the physical and social

environment in a child's home. Variable "B" is the mediating variable to variable "C" which is the level of participation of a child with a disability's in age-appropriate activities.

Parental knowledge of development of disability, home environment and child participation in age-appropriate activities is examined in this study pre and post intervention. Parental knowledge of development of children with disabilities is theorized to influence child participation in age-appropriate activities through parental influence on the home environment. Parents shape the home environment through their influences on the physical and social home environment. Parental influence on the physical home environment occurs through the materials, content, structure and type of interactions taking place in their home. The social home environment is shaped through parent-child interactions.

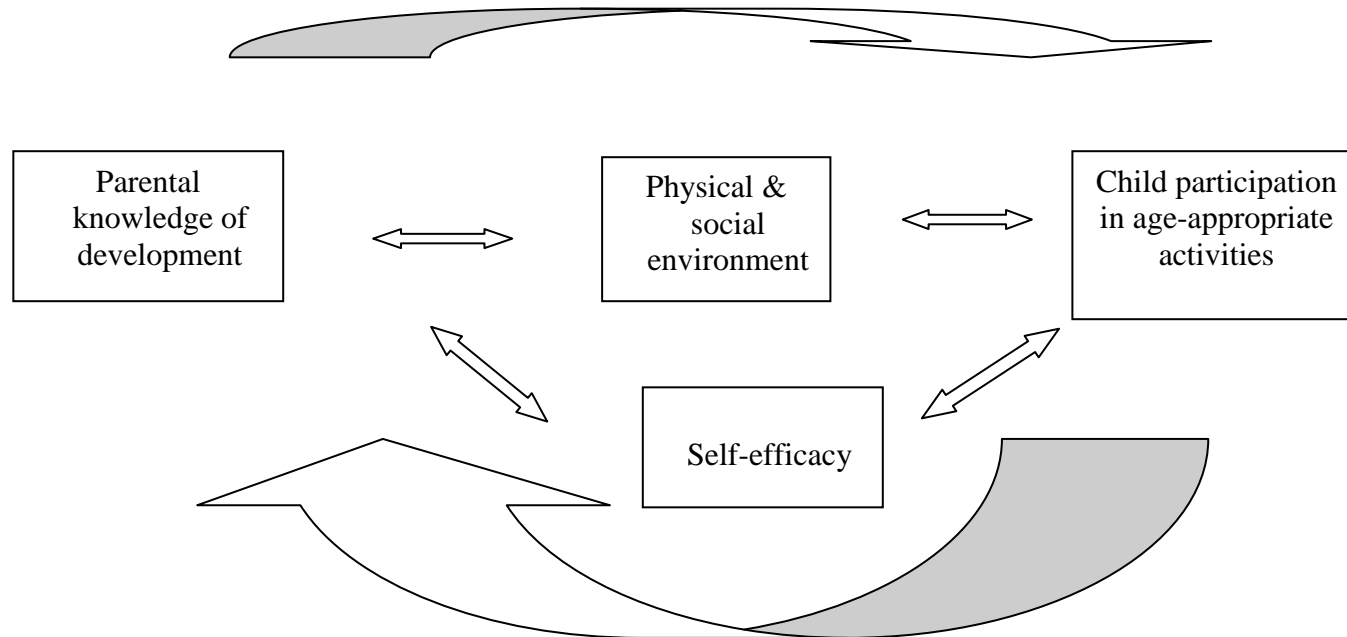
Additionally as in many models describing interactions among individuals and various systems there are additional circular influences. Increases in participation would encourage parents to continue in their positive influences, increase their knowledge to gain additional incites and may influence their self-efficacy further encouraging parents to learn more and do more to increase the positive aspects in their child's environment and increase their child's participation.

This conceptual model hypothesizes that providing an intervention to parents of children with disabilities focusing on the knowledge of development of children with disabilities can positively shape their child's home environment in ways that facilitate an increase in their child's participation in age-appropriate activities. The level of impairments is the child characteristic hypothesized to influence level of participation in age-appropriate activities.

This model hypothesizes that a positive relationship exists between the level of parental knowledge of their child's disability and parental sense of self-efficacy. Parental self-efficacy

has been shown to affect an individual's reaction to challenges and influence parental involvement, strategies, activities and methods selected in teaching and educating their child. Level of self-efficacy may influence the ability of parents to actively apply their knowledge in daily activities in the home.

**Figure 1: Conceptual Model**



### III. METHODS

#### A. **Design**

This study included a pre/post-test design with two groups was used, an intervention group and a control group. A sample of convenience consisted of a total of 31 parents and their children recruited for this study. Of the 31 participants tested, one parent and child dyad dropped out of this study because they moved overseas. Randomly assigned into two equal groups, one group received all pre and posttest measures only and the second group received all pre and posttest measures and participated in the educational intervention described in this study. This design allowed comparison of the mediating effects of a parent education program on increasing parents' level of knowledge and self-efficacy, and the effects of this knowledge on their child's participation in age-appropriate activities through influencing their child's home environment. Using t-tests, correlation and regression analyses I examined the linkage among the variables parental knowledge, physical and social home environment and level of child participation and the relationship between parental knowledge and parental self-efficacy.

#### B. **Study Sample**

##### (a) **Recruitment methods**

Participants were recruited from special education daycare, preschool and early intervention centers providing intervention to children with CP in major city centers and their suburbs in Israel (Tel Aviv and Jerusalem). The following strategies were used to recruit parents: The principle investigator (PI) disseminated information regarding this study through study information posted at child developmental centers, telephone contacts with healthcare workers in early intervention programs in the city centers mentioned above, seminars related to pediatric

care, continuing education programs relating to pediatric topics, and through parent support and information centers.

Physical and occupational therapists employed at the various centers recruited participants for this study and obtained informed consent from parents. Parents signed the consent form written in Hebrew, translated into English and translated back into Hebrew. The versions were compared for accuracy by another individual based on the requirements of the institutional review board and accepted by the University of Illinois at Chicago (UIC). Additionally, consent was obtained from the Ministry of Education in Israel and both UIC and the Ministry of Education reached an agreement on the content of the consent form (Appendix A). After obtaining written informed consent the recruiter provided the PI with parental contact information. They were contacted by the PI and a home visit was scheduled. All parents agreed to conduct the visits in their home. At the initial home visit, the PI, a bilingual pediatric physical therapist, explained and administered all testing measures in the preferred language of the parents, Hebrew or English.

(b) **Participants**

The sample represented all social classes in Israel. Israeli health services are based on socialized medicine and are easily accessible to all its citizens.

A sample of convenience of 31 parents and their children who met the following inclusion criteria participated in this study:

- Children between 1½ and 6 years of age, attending daycare, preschool or early intervention centers and diagnosed with CP by a pediatric neurologist.
- Children diagnosed with CP at all impairment levels I and V based on the GMFCS.
- Children were able to understand and follow simple spoken directions.

- At least one parent was fluent in written and spoken Hebrew and was the designated parent participating in this study.

Exclusion criteria:

Children with any major medical conditions other than the diagnosis of CP were excluded from this study. The focus of the intervention package was increasing knowledge related to children with motor impairments. Children diagnosed with blindness (excluding cortical visual impairment), unresolved feeding disorders requiring ongoing medical intervention or any medical conditions necessitating regular medical intervention were excluded from this study. This was determined based on parent interview, recommendations of the referring body, observation by the PI during the initial home visit, and examination of the forms completed by parents at the initial home visit detailing their child's current health status and medical needs.

Participation in this intervention was contingent on parent agreement to attend all sessions. Missing up to one session was acceptable. The influence of dosage or levels of participation in early intervention programs is discussed extensively in the literature (Brooks-Gunn et al, 2000). Attendance at 80% of the sessions is considered a high level of participation. The intervention was provided on a bi-weekly basis for 10 weeks. There was no financial compensation for participation in this study. Confidentiality was maintained and data was stored by the PI in a password protected computer and locked file cabinet.

### C. **Measures**

The present study used instruments determining the GMFCS, and measures examining parental self-efficacy and knowledge, the child's physical and social home environment and the degree of participation of the child in age- appropriate activities. These areas selected for



measurement reflected the major components described in my conceptual model. When available, standardized instruments with good psychometric properties were used. The tools selected to measure the social and physical environment, parental self-efficacy and GMFCS are used in research and clinical practice. The instrument measuring parental knowledge and child participation were developed specifically for this study because no comparable measures were available.

(a) **Child characteristics**

1. **Child's medical information.**

Information regarding the child's current health status and medical needs were gathered using the form described in Appendix B. This form was used to ensure that any children with any major medical conditions other than the diagnosis of CP were excluded from this study according to the exclusion criteria previously discussed.

2. **GMFCS**

The level of impairment was determined based on the criteria of the GMFCS described by Palisano et al (2000) and is widely used in both research and clinical practice (see Appendix C). This information was used to assess any influences of the child's level of impairment on the intervention effects. The information was obtained from the referring center. If the information was unavailable this researcher assessed the level of impairment at the initial home visit.

(b) **Parental Characteristics**

1. **Demographic variables**

An interview form developed for this study was used to gather demographic data believed to contribute and influence child outcomes; marital status, number of members in the household, family income, level of parents' education, occupation, and household structure including

support system information. The demographic variables were compared between the control and intervention group to test for any statistical differences between the two groups. (see Appendix D).

## **2. Measures of parental self-efficacy**

The measure used to examine self-efficacy is a brief scale based on Bandura's concept of self-efficacy and modified to reflect self-efficacy relating to members of families of individuals with a disability (Heller, Miller & Hsieh, 1999). This scale consists of six statements. Examples of items include: "I would make a fine model for a parent of a child with a disability" and "I honestly believe I have the skills necessary to be a good caregiver of my relative". The items are rated by using a four point Likert scale from 1 as strongly disagrees to 4 which is strongly agrees. The higher scores reflect higher levels of parental self-efficacy. Heller et al (1999) found differences in level of self-efficacy between the intervention and control groups at follow-up validating this scale for use in measurement of self-efficacy. The level of self-efficacy is measured based on the total score on the scale. Its alpha reliability on the pre-test was .72 and on the post-test .635. (see Appendix E).

## **3. Knowledge of Development and Capabilities of Children with Disabilities Inventory.**

A 45-item scale examining parental knowledge of development and capabilities of children with disabilities was developed for this research study. This inventory is modeled on the Knowledge of Infant Development Inventory developed by MacPhee (1981) that examines knowledge of development of typically developing infants. Five expert pediatric physical and occupational therapists reviewed the contents of this measure and assisted in its development. The checklist is comprised of 45 items rated for agree, disagree and unsure. The questions

examined parental knowledge of the development and capabilities of children with disabilities and are based on the knowledge covered in this educational package. It was pre-tested on 10 parents not participating in this study for clarity and brevity. Questions relate to parental knowledge of play, motor, feeding and toileting abilities of children with disabilities. The last three questions, 43-45 were added early on in the study. The reason for the addition of three more items was that though this measure was examined by five therapists prior to study commencement the PI felt after examining it once more that an important concept relating to participation and the ICF, the central theme of the first session, was not addressed in the knowledge measure in the original version (see Appendix F).

The alpha reliability of the pre-test knowledge measure was .736 and for the post-test it was .734.

(c) **Home Observation Measurement of the Environment Inventory**

The Home Observation of the Environment was used to measure the quantity and quality of stimulation in the home environment (Caldwell & Bradley, 1984). The focus of this measure is on the child in their environment. The HOME is a standardized inventory developed for three age ranges of children with three corresponding inventories developed to measure their environment. The Infant Toddler HOME (IT-HOME) was developed for children 0-3 years old, the Early Childhood HOME (EC-HOME) was developed for children 3-6 years old and the Middle Childhood HOME Inventory (MC-HOME) was developed for children aged 6 years and above. In this study either the IT- or EC-Home was used in this study depending on the age of the child with a disability.

The 45 binary items on the IT- HOME (Caldwell & Bradley, 1984) are organized into six subscales and scored using semi-structured interviews and observations of mother-child

interactions during a home visit. The aspects assessed on the IT-HOME include the amount of vocal stimulation, available play materials, frequency and stability of adult contact, avoidance of restriction of motor and exploratory behaviors, and other home characteristics indicative of parental concern with achievement. The subscales were based on factor analyses. The point biserial correlation coefficients between the items and subscales were greater than .25. Cronbach alpha reliabilities ranged from .49 to .78. Correlations between the HOME and other socioeconomic factors ranged from .24 and .50 (see Appendix G).

The 55 binary items on the EC-HOME (Caldwell & Bradley, 1984) are arranged into eight subscales and scored using semi-structured interviews and observations of mother-child interactions during a home visit. The characteristics assessed by the HOME include development, amount of academic and language stimulation, child's physical environment, parent's responsiveness to the child, available play materials, discipline and other home characteristics indicative of parental concern with achievement (see Appendix H). The EC-HOME has been widely used in planning interventions and in research (Bradley et al, 1993). It has sound psychometric properties and has been described in research (Bradley et al, 1994). The EC-HOME test-retest reliability is .7 as reported by the authors on the total score. Internal consistency on the EC-HOME is .7 with a range of .53 to .93 for each of the subscales. The EC-HOME has been found to correlate highly with children's scores on language and IQ tests (Bradley et al, 1993). The authors report that completion of either the IT or EC-HOME requires approximately 60 minutes.

(d) **Checklist of child participation in age-appropriate activities**

Parents completed a checklist of 15 activities in which children ages one and a half to six years old typically participate and the frequency of their occurrence. Parents were asked to

complete this checklist based on memory for activities occurring over the four-week period prior to the pre and post measurement sessions. The total was taken of these activities pre and post intervention and was compared. The checklist items include questions asking whether their child participates in games or play activities with at least one family member once a day, visits a playground, participates in a play date with a friend at the child's house, visits a friend in their house and participates in a trip to the supermarket or shopping trip. Cronbach's alpha reliabilities for pre-test and post-test were .826 and .834 respectively (see Appendix I).

(e) **Post-intervention survey.**

Parents participating in the intervention were requested to complete an open-ended intervention survey. It consisted of five questions surveying the parents' opinion of the relevance of the content of the meetings (see Appendix J).

(f) **Reliability**

The PI recruited and trained five testers to implement all data collection at the conclusion of the study to ensure that at the time of post intervention the testers were blind to group membership. The testers were recruited from physical therapy programs from one of the major universities in Israel. The testers were fluent in both Hebrew and English to ensure that they were able to complete all test measures (one is currently not available in Hebrew). They were provided with pre-coded packets for each participant to complete and a separate form with corresponding coding with all participant contact information.

No special reliability training for the self-efficacy, participation and knowledge assessments was provided since participants complete them independently. Instructions were given to not assist the parents in completion of the assessments in any way. The HOME assessment required special training. The training was conducted as follows. All testers were

required to read the manual prior to meeting and note any questions. At the reliability meeting all items were reviewed individually after which all testers and the PI reviewed a tape of the IT-HOME and scored it. All responses were reviewed and any discrepancies were discussed and resolved. At the following meeting a similar procedure was followed to obtain good reliability for the EC-HOME.

#### D. **Procedures**

##### (a) **Measurement sessions**

Testing measures were completed at the scheduled home visits. The PI conducted all pre-test visits prior to group assignment. In all 31 home visits were conducted and all measures were completed in one visit. During the home visit parents first completed the consent forms, demographic and child medical forms, Knowledge of Development and Capabilities of Children with Disabilities Inventory, checklist of child participation in age-appropriate activities, the HOME and the checklist measuring parental efficacy. The time required to complete these measures was less than anticipated and were completed within 80 minutes.

Five additional testers blind to group membership administered post-test measures to the participants. Other than the participants only the PI was knowledgeable of group membership. Participants in both the intervention and control group were asked not to reveal group membership during post-test measurements. Post-test administration followed the same order as described above for the pre-testing. Each of the post-intervention visits took approximately 60 minutes for all data collection.

(b) **Pilot testing of intervention**

The intervention package was reviewed with five pediatric physical and occupational therapists prior to study commencement. This pilot allowed the PI to practice and receive input from experienced therapists as to the intervention content and structure. No major suggested revisions were received. Additionally the content of the educational intervention sessions were reviewed with a group parents of children with CP ten years of age or older for their assessment of the relevance of the content to parents of younger children with CP based on their experiences. No major revisions were suggested. The input from these parents is described in additional detail in the description of the intervention package (see Appendix K).

(c) **Timeframe and location of the completed research project**

Two series of educational interventions were conducted. Prior to each intervention 15 parent- child groups were pre-tested. After pre-testing, participants were randomly assigned into intervention or control groups within each cohort. Each intervention group met bi-weekly over a ten week period. There were approximately eight participants in each intervention group. Testers were recruited and trained while conducting the first intervention for post-testing. The duration of this study including recruitment, pre-testing, intervention and post-testing was ten months.

The sessions were held in Jerusalem, Israel and convenient and accessible to the participants. Each session was approximately two hours in duration, though some were longer because parents didn't want to end them.

(d) **Educational intervention package**

This intervention package was based on the educational framework described by Bandura (2001, 1977) and Knowles (1998). The information for the adult learner should be important and

meaningful to them. The knowledge provided in this educational package was important and applicable to the participants and their children's daily lives. Bandura emphasized modeling as a tool for teaching and the importance of personal, environmental, situational and behavioral factors in fostering adult learning. Peer group discussion and role modeling are some of a teacher's fundamental techniques as described by Bandura and were used extensively in this educational package.

The workshop series content was developed in consultation with parents of children with CP as previously discussed. A meeting was held between a senior pediatric physical therapist, a senior pediatric occupational therapist who is also a specialist in adapting computer and mobilized wheelchairs for this population along with two parents of children diagnosed with cerebral palsy, one female aged 17 years old and one eight year old male, both with major physical impairments and the female also has severe cognitive impairments. A discussion was held reviewing their needs as parents of children with CP as they remembered it as parents of young children with CP. They volunteered to participate in the groups as the parents of older children and volunteered to serve as consultants on an ongoing basis if necessary. We reviewed the content, handout materials and organization of the meetings. The major issue that they raised was their need as parents of young children to meet with other parents of children with CP and their need to increase their knowledge through articles, the internet and any other source of information.

The overall goals for this educational intervention were fourfold. The first goal was to create parental awareness of the importance of their child's participation in age-appropriate activities through knowledge of the effects of the proximal and distal environments on their child's development and abilities. The second goal was to increase parental knowledge of the



development and capabilities of children with disabilities, specifically CP, across the life span. Some of the major points of emphasis include increasing the knowledge of the relationship between motor skills and the environment, physical and social barriers faced by children with disabilities in daily interactions with siblings and peers and the importance of their child's participation in age-appropriate activities. The third goal was to provide a framework and methods for parents to apply their knowledge and provide their child with a positive and fostering environment (physical and social home environment), age-appropriate social and play situations to increase cognitive development, minimizing limitations due to motor limitations and increasing independence and participation in daily age-appropriate activities. The fourth goal was to increase parental self-efficacy through increased knowledge of their child's disability encouraging parents to find solutions independently to barriers faced by their child's ability to participate in age-appropriate activities. This last goal was not specifically addressed in any one session but rather the benefits to parental sense of self-efficacy were hypothesized to occur as a result of their increases in knowledge and practical experience throughout all the sessions in application of their knowledge.

The educational package was divided into three units. Unit one consisted of one session, unit two three sessions and unit three one session. Each session followed a similar structure. The class began with a discussion of the previous session's assignment for example an observation or log, except for the first session which began with introductions of themselves and their child. In this first session parents introduced their child through the selection of an object or thought they felt described or represented their child and their unique relationship with their child. A didactic section followed after which an experiential strategy was used to reinforce, practice and model the information discussed in the didactic session. A home assignment was presented and used to

reinforce the new information learned at the session. Parents were provided with packets at the beginning of each session which included information relating to that specific session and any necessary forms such as the observation form which was used to assist them with observations for their home assignments (Appendix M). A detailed description of the goals, lessons plans and strategies used in this package is provided in Appendix L.

Some of the videotapes of various interactions and situations between the participating parents and their child in their home setting were viewed during the educational meetings. In addition some additional videotapes and pictures of other children not participating were also used in the power point presentations during each session. All appropriate consent forms used in the preschool settings were signed and are on record. Parents signed consent forms for all videotapes and pictures for use solely for the purposes of this study.

#### 1. **Unit one: Session one.**

Unit one consisted of one session. The focus of this unit was to alert the participants to the importance and influence the content of this program can have on their everyday lives and assess and ensure that the learners are ready to learn as described by Prochaska (1997). There were two goals for this session. The first goal was to create an awareness of the importance of participation through knowledge of the effects of the proximal and distal environment on their child. The second goal was to increase parental knowledge of the physical and social barriers faced by preschool children with disabilities in daily interactions with siblings and peers. This session additionally explained to parents their rights under Israeli law both in terms of education and obligations of the health providers (Israeli law has a form of socialized medicine with basic coverage to all its citizens). Additional objectives addressed the importance of participation and

the limitations that may be imposed on their child's participation in age-appropriate activities because of environmental constraints.

The session began with basic introductions of all the participants. Participants were asked to bring a snapshot of their child and/or present an object or thought that they felt best described their child. Parents were given small loose leaf binders to use over the course of this intervention for storing handouts, note taking, and recording observations and activities asked to do at home. Introductions were followed by a discussion of knowledge and skills parents anticipate gaining from participating in this intervention. The didactic session included describing the topics for each of the meetings, defining participation and discussion of its importance, and a brief review of Israeli law and family rights as pertains to them and their needs as a parent of a child with a disability. The lecture also included a very brief overview of the ICF framework, the barriers restricting their child's participation in a variety of environments (home, school, and playground) and how current Israeli law can be used to decrease barriers and increase their child's participation. An experiential section allowed parents to frame these concepts within their own personal lives. A specific picture of a 10 year old girl at the beach diagnosed with CP was displayed and issues were raised such as identifying the restrictions and barriers in the pictures and parents suggested some possible solutions that the parents of the child in the picture might have taken to encourage and impact on the level of the child's participation. Over the next two weeks parents were asked to observe their child in their home environment and a public setting and list three barriers encountered by their child in each situation.

## 2. **Unit Two: Sessions two through four**

Unit two consists of three sessions. These units focused on increasing parental knowledge of life span development of their child with a disability, parental ability to problem solve relating

to barriers that may be limiting their child's participation and methods and strategies parents can use to increase their child's social and physical independence. Topics covered included emotional development of the child with a disability, influence of a child with a disability on siblings and activities of daily living. Topics in activities of daily living included: dressing, feeding, toileting and bathing, play both in the home and outside in the garden or playground, adaptive toys and the importance and methods of fostering participation of their child in age-appropriate activities with peers. This unit discussed day to day situations and application of the information provided in this package into their daily lives. The intent was to provide examples of specific behaviors and increase the relevance of the material to the parents' daily lives.

Session	Goal	Objective
Two	<ul style="list-style-type: none"> <li>• Increase parental knowledge of the development of children with disabilities, specifically CP, across the life span.</li> <li>• Increase parental knowledge of the physical and social barriers faced by preschool children with disabilities in daily interactions with siblings and peers.</li> <li>• Increase parental knowledge of the importance of their child's participation in age-appropriate activities.</li> <li>• Provide a framework and methods for parents to apply their knowledge and provide their child with increases in independence and participation in daily activities.</li> <li>• Increase in parental self-efficacy.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents should explain limitations in body structure and function associated with CP and its influences on their child's participation in age appropriate activities.</li> <li>• Parents should explain the diversity in development of children with disabilities.</li> <li>• Parents will explain the GMFCS.</li> <li>• Parents should explain the development and capabilities of children with CP through the GMFCS trajectories of development.</li> <li>• Parents will determine their child's developmental trajectory according to the GMFCS.</li> <li>• Parents should understand the differences between capacity and performance of a task and the relationship to the environmental setting.</li> <li>• Parents will list 2 changes that can be made to increase their child's participation in the playground. Included in changes will be environmental changes either through parental intervention or the use of assistive devices.</li> </ul>
Three	<ul style="list-style-type: none"> <li>• Increase parental knowledge of the development and capabilities of children with disabilities specifically CP across the life span.</li> <li>• Increase parental knowledge of the relationship between motor skills and the environment and their influence on their child's participation in play activities.</li> <li>• Provide a framework and methods for parents to apply their knowledge in play and provide their child with a positive and fostering environment for their child with a disability.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents should be able to explain 3 different types of play.</li> <li>• Parents should identify 3 different play environments and suggest 1 method for adapting each environment to increase their child's participation.</li> <li>• Parents should identify one method to encourage their child to initiate play activities in their home.</li> <li>• Parents should be able to identify 4 toys and 3 activities that are age and disability appropriate for their child.</li> <li>• Parents should be able to identify 2 strategies they can utilize to adapt an</li> </ul>

	<ul style="list-style-type: none"> <li>• Provide a framework and methods for parents to apply their knowledge and provide their child with age-appropriate social and play situations to improve their child's cognitive development minimizing limitations due to motor limitations.</li> <li>• Provide a framework and methods for parents to apply their knowledge and provide their child with increases in independence and participation in play activities.</li> <li>• Increase parental self-efficacy.</li> </ul>	<p>activity or toy for their child with a disability.</p> <ul style="list-style-type: none"> <li>• Parents should recognize the importance of fostering child initiation throughout all activities and specifically methods to increase interaction of their child with CP with other children in the family.</li> <li>• Parents should identify issues that might arise in siblings and the various roles their other children in the family might assume resulting from presence of a child with a disability in the family.</li> </ul>
Four	<ul style="list-style-type: none"> <li>• Increase parental knowledge of the importance of their child's participation in activities of daily living (ADL's).</li> <li>• Provide methods for parents to apply their knowledge and provide their child with increases in independence and participation in ADL's.</li> <li>• The importance of fostering child initiation throughout all activities.</li> <li>• Parents should understand the influence of physical impairments on their child's emotional developmental and specifically relating to the concept of learned helplessness.</li> <li>• Increase in parental self-efficacy.</li> </ul>	<ul style="list-style-type: none"> <li>• Parents should identify 3 methods to foster increased assistance and participation of their child in dressing and toileting activities.</li> <li>• Parents should list 2 aspects of dressing that their child can currently complete independently.</li> <li>• Parents should identify 2 changes in type of clothing their child wears to increase their child's independence in dressing.</li> <li>• Parents should identify 2 adaptations in food, utensils or the environment to increase their child's independence.</li> <li>• Parents should explain the concept of learned helplessness.</li> <li>• Parents should explain the influence of increasing their child's participation in daily activities can minimize the development of learned helplessness and increase their sense of feelings of control in his/her daily life.</li> </ul>

## Session Two

The goal for this session was to increase parental knowledge of the development and capabilities of children with disabilities specifically CP across the life span, the importance of

participation in age-appropriate activities and the physical and social barriers faced by preschool children with disabilities in interactions with siblings and peers and increase in parental self-efficacy. The objectives for this session were for parents to be able to explain limitations in body structure and function associated with CP, the influences of these restrictions on their child's participation in age-appropriate activities and the diversity in development of children with disabilities. The concept and use of assistive devices was introduced in this session to provide parents with additional strategies to help their child and decrease possible feelings of hopelessness related to understanding the developmental trajectory of their child and the realization of the limitations faced by their child. Parents were presented with the predicted gross motor developmental trajectory of their child through understanding the growth curves that can be used to predict gross motor function. This enabled parents to develop a prognosis of their child's future physical functioning. Parents were presented with the concepts of capacity and performance and the effects of the environment on their child's performance and influence on participation. This session provided parents with a framework and specific methods to apply their knowledge and decrease barriers and increase their child's independence and participation in age-appropriate activities.

The session began with a discussion among parents describing some of the barriers their child encountered both in and out of the home (proximal and distal environment) over the past two weeks. Following was an experiential class activity. Parents were asked to pair up and attempt to prepare for their partner coffee or a snack while experiencing restriction of movement (their arms were taped to their sides and they were unable to reach horizontally). A didactic section followed explaining to parents the limitations in body structure and function relating to CP, the effects on sensory systems, motor functioning, compensations and adaptations used by

their children to increase their functioning and the interaction of these limitations and the environment on their child's participation, the GMFCS, developmental trajectories, differences between capacity and performance, and strategies to decrease barriers faced by their child in a variety of environments and increase their child's participation. The parents observed a variety of pictures and a video clip demonstrating the effects of limitations of posture and mobility in a variety of environments. Following were pictures and a video clip illustrating some possible solutions to decreasing barriers and their impact on functioning and participation and highlight to the parents the effect they can have on their child's functioning and participation. They were provided with examples of assistive devices including seating, standers and other items that may be used to help their child accomplish and participate in age-appropriate activities.

The home observation for this session was for parents to list three situations in which limitations in body structure and function affected their child's ability to participate in an age-appropriate activity and to list two changes made in any of the above situations that increased their child's participation.

### Session Three

The goals of the third session were to increase parental knowledge of the interaction of motor and social-emotional development, physical and social barriers faced by children with disabilities, the importance of their child's participation in age-appropriate activities and contemplation of the effects of the presence of a sibling with a disability on the other siblings. This provided a framework and methods for parents to apply their knowledge and provide their child with a positive and fostering environment (physical and social home environment), age-appropriate social and play situations to increase cognitive development minimizing limitations due to motor limitations and increases in independence and participation in daily age-appropriate



activities. Additionally as parents were provided with frameworks in which to apply their knowledge increases in parental self-efficacy were hypothesized to result from these changes. The objectives focused on parental knowledge, relating to types of play, effects on siblings within the family, identifying play environments and activities appropriate for their child and methods to adapt the activities and environments for their child and encourage their child to initiate play activities at home.

The session began with a review of their home assignment, limitations in function experienced by their child related to mobility and modifications made by parents to decrease the limitations and increase their child's function. The experiential activity for the current session was an assignment to modify a play activity. Parents paired off and were assigned a task and diagnosis of type of CP and asked to come up with some suggestions for modifications and present their solutions to the other pairs. The play activities included: ball playing for a child with hemiplegia, dressing a doll with hemiplegia, ball playing with a child with quadriplegia who was unable to sit independently and a child with diplegia playing soccer. This highlighted to parents the limitations in motor functioning their child experiences and possible solutions for them to implement in their daily lives and the increased frustration and decreased enjoyment their child might experience as a result of their limitations. A didactic section described the purpose, types, materials and framework relating to play. The importance of reading, child initiation, participation and the interactive experience with others was discussed. A second part to the didactic session included a discussion of current research examining the effects of a sibling with a disability on other siblings. This material was presented by a social worker specializing in siblings of children with disabilities. For the home assignment parents were asked to go to a playground, gymboree or public play area and describe what they did to increase their child's

participation. Parents were also asked to select two toys and adapt them for their child's use and describe their experience, amount of time child played, any friends or siblings and overall feelings during the activity.

#### Session Four

The goals of this session were to increase parental knowledge of the importance of their child's participation in ADL's, to provide methods for parents to apply their knowledge and provide their child with increases in independence and participation in ADL's. This provided parents with practical experience in which they were able to apply their knowledge relating to their child's disability and increase their sense of self-efficacy. The objectives for this session were for parents to identify their child's current abilities, different methods to foster increased assistance and participation of their child in ADL activities, and adaptations they made to the environment to increase their child's independence in these types of activities.

The session began with a review of the play activities parents did at home and their experiences. As part of the class experiential activity parents were given a large shirt to button over their clothing, put on shoes or socks while sitting on a very unstable surface. A didactic section followed explaining to parents about ADL's, age-appropriate expectations across the life span, modifications and strategies they can employ to increase their child's participation and independence in these activities. An educational specialist was a guest speaker and provided insight into the emotional development of children with disabilities and its influence on the possible increased level of frustration and learned helplessness a child with a disability could experience and importance to increase the sense of control experienced by a child with a disability. A video clip of a child dressing was shown for illustrative purposes. Parents were asked to provide suggestions for modifications to increase the independence and participation of

these children during dressing. Afterwards another video clip of one child eating was viewed in two different situations. This was used to illustrate the influences the environment can have on function and participation. Parents were asked to provide additional suggestions for modifications to increase the independence and participation of this child. The primary objective for this segment was for parents to understand different ways in which they could break down an activity into manageable parts to enable their child with a disability to succeed in some aspect of the activity. At home parents were asked to select one aspect of dressing (removing shoes, jacket, socks, or putting on a shirt) and practice with their child. They were asked to record the difficulties and adaptations made to decrease the level of difficulty for their child. Parents were asked to report on two articles of clothing changed or two other types of changes they implemented to decrease the level of difficulty in dressing and log two changes made during mealtime to increase their child's independence. Additionally parents prepared a short, 10 minute, presentation about their child and discuss changes made in their home as a result of this educational package and plans for the future.

### 3. **Unit Three: Session five**

This unit consisted of one session which revisited and reviewed critical information covered in previous sessions and further served to integrate this information into the everyday lives of the participants. This unit consisted of one session divided into three segments.

#### Session Five

The goals to be reviewed in this session were to further emphasize an awareness of the importance of participation through knowledge of the effects of the proximal and distal environments on their child, increase parental knowledge of the development and capabilities of children with CP, physical and social barriers faced by children with disabilities, their influence

on their child's participation in age-appropriate activities and further increase their sense of self-efficacy. Additionally this session reinforced the framework and methods for parents to apply their knowledge in age-appropriate social and play situations to increase cognitive development, minimizing limitations due to motor limitations and increases in independence and participation in daily age-appropriate activities. The objectives for this session were to reinforce the concepts of participation, limitations relating to barriers and their impact on their child's participation in age-appropriate activities. This session reviewed with parents life-span related health issues and the topic of inclusion by inviting a parent of an older child diagnosed with cerebral palsy to share in her life experiences.

This session was divided into three segments. The first segment began with a short report from parents on the effectiveness of the suggestions provided by the other parents for dressing and eating reporting on their previous home assignment. Following was a review of the GMFCS and growth trajectories, definitions of terms they might encounter during interactions with the health care professions, an overview of life span health-related issues and potential health complications associated with CP. The second segment focused on strengthening the newly learned behaviors. This helped reinforce the adaptation of behavioral changes into the daily lives of the participating families. Parents prepared a short presentation, an informal learning contract, to help reinforce and practice the newly learned behaviors into their day to day lives. Some parents provided pictures or presented a short video or discussed some aspect of change in their child's and their family's life they felt resulted from their participation in this educational intervention. The third segment was a meeting with a parent of an older child (13 years of age) diagnosed with CP. This mother related her own experiences raising her daughter and her

encounters with the public school and health care systems. Time was allocated for questions by the participants to this parent.

## E. **Data Analysis and Results:**

### (a) **Demographic Information**

Thirty-one parent-child dyads were initially enrolled in this study. Of these thirty-one families one was initially enrolled in the first round of this study but due to personal reasons joined in the second round of intervention groups three months later. One family dropped out because they moved overseas after the initial home visit but prior to the randomization for groups. Thirty parent-child or primary caregiver-child dyads in total participated in this study and were included in the data analysis. All the data was analyzed using SPSS version 16.

The demographic information, parental ages, years of education, work hours, and number of siblings were examined using an independent samples t-test comparing group means. Table 1 provides a summary of the analysis of the demographic data. There was a significant difference in the ages of the mothers and fathers. The fathers and mothers were older in the control group than in the intervention group (mean age of 40.06 and 38.0 years respectively versus 34.21 years and 32.46), ( $p = .032$ ). There were no significant differences between groups on hours each parent worked, level of education of either parent, number of siblings in the family and child age. Marital status between groups was examined using Pearson chi square. There was no significant difference between groups ( $p = .483$ ). The influence of significant differences between groups for mothers' age was examined in the statistical analyses of the dependent measures using hierarchical regression with mothers' age entered as a covariate (Table IV through VII).

The GMFCS was examined using an independent samples t-test comparing group means. Though the measure was ordinal this analysis for the GMFCS was selected because the data was approximately normally distributed. There was no significant difference in the levels of severity

of CP between groups as measured using the GMFCS. However the statistical analysis appears to show a group difference trending towards significance ( $p=.080$ ) with the parents of children with more severe CP participating in the intervention groups. A possible explanation is that due to the small sample size the group difference did not reach a level of significance. See table I. The influence of the trend towards increased severity in the intervention group was examined in the statistical analyses of the measures using hierarchical regression with the GMFCS entered as a covariate (Table IV through VII).

**TABLE I**  
**DEMOGRAPHIC INFORMATION**

Demographic variable	Control Group Mean (SD)	Intervention group Mean (SD)	P=
Mother's age	38.0 (7.34)	32.46 (5.97)	0.032
Father's age	40.0 (6.52)	34.21 (7.44)	0.032
Years of education of mother	15.07 (1.77)	14.8 (1.97)	0.701
Years of education of father	15.53 (2.36)	14.92 (3.42)	0.598
Number of siblings	2.66 (2.25)	2.06 (2.05)	0.502
Age of child in months	47.866 (18.25)	40.33	0.453
GMFCS (level of severity of CP)	2.467 (1.35)	3.4 (1.45)	0.080

$p=.05$

(b) **Missing Data**

There was a small percentage of missing data in the data collected for all measures in this study. Missing data was coded as 99. Data assessments with different numbers of items depending on child age and the two versions of the knowledge assessment used were coded 98 to account for the different number of total items. Values for missing data were imputed based on the average of the completed data for the specific measure for each participant.

There were four outcome measures and the data was collected both pre-intervention and post-intervention. The percentages of missing data per pre-test measure ranged from .007 to 1 1/2 %. The percentages of missing data per post-test measure ranged from .006 to 2%. No one measure was missing more than four items. Overall there was a small percentage of completely missing data for any measure and there was no significant difference between the amount of missing data pre and post-testing and between groups.

(c) **Differences between the pre and post-tests**

Mean scores for the pre and post-tests for the knowledge and HOME assessments were computed. Total participation and self-efficacy scores were obtained by computing a total of the responses provided. Pre-test and post-test results were compared between groups for the HOME, knowledge, participation and self-efficacy using independent samples t-test (see table II).

There were no significant differences in pre-test scores between groups on the HOME ( $p = .813$ ) and knowledge assessments ( $p = .815$ ). There was a statistically significant difference on pre-test scores between the intervention and control groups in the participation and



self-efficacy measures. The control group had statistically significantly higher scores than the intervention group on the participation pre-test scores ( $p = .020$ ). The control group participants tended to do more age appropriate activities and more often than the intervention group. There was a significant difference in pre-test scores in the self-efficacy measure with the intervention group scoring higher than the control group ( $p = .045$ ).

Post-test results were compared between groups for the HOME, knowledge, participation and self-efficacy using independent samples t-test (see table II). There was a significant difference between groups in the knowledge measure. The intervention group demonstrated a higher increase in level of knowledge when compared with the control group ( $p = .029$ ). There was a significant between group differences in the participation assessment with the control group scoring higher than the intervention group ( $p = .026$ ). Similar findings were found between groups in the pre-test participation assessment. No significant differences were found in the post test scores of the HOME ( $p = .622$ ) or in the self-efficacy measure ( $p = .293$ ).

**TABLE II**  
**DIFFERENCES PRE AND POST-TEST FOR ALL MEASURES**

Assessment	Pre-test Mean (SD)		p =	Post-test Mean (SD)		p =
	Control	Intervention		Control	Intervention	
Knowledge	29.74 (5.77)	29.27 (5.20)	0.815	29.92 (4.97)	33.97 (4.61)	0.029
HOME	45.328 (4.10)	45.76 (4.71)	0.813	46.44 (4.49)	47.25 (4.40)	0.622
Participation	56.45 (12.22)	46.26 (10.32)	0.020	59.10 (12.35)	49.58 (9.61)	0.026
Self-efficacy	18.49 (3.19)	20.53 (1.99)	0.045	19.42 (2.61)	20.4 (2.35)	0.293

p=.05

(d) **Correlation of the outcome measures and group membership**

The Pearson Product Moment Correlation coefficient was used to examine the relationship of the four outcome measures using the pre and post intervention scores of the self-efficacy, HOME, knowledge, and participation outcome measures and group membership. The correlations of the outcome measures and group membership reveal similar findings as was seen in the independent samples t-tests and hierarchical regression described later. The pre-test and post-test measures have a significant relationship as expected. There is a relationship between group membership and participation. The control group as a whole had significantly higher levels of participation in both the pre-test participation scores (p=.023) and post-test participation scores (p=.022) than the intervention group with similar increases in their mean score. The post-test knowledge measure was significantly related to group membership (p=.030).

Similar findings were evident in the hierarchical regression described in the following section, in that, intervention increased knowledge. A relationship between group membership and pre-test self-efficacy was found ( $p=.042$ ). Some additional significant correlations were evident between the participation, knowledge and HOME measures. These relationships are possibly related to similarities between overlapping concepts in the constructs of the assessments. The pre-test knowledge measure was significantly related to both the pre-test participation ( $p=.032$ ) and the post-test participation ( $p=.023$ ) (see Table III).

**TABLE III**  
**CORRELATIONS**

	Pre-test HOME	Post-test HOME	Pre-test self- efficacy	Post-test Self- efficacy	Pre-test participation	Post-test participation	Pre-test knowledge	Post-test knowledge	Group membership
Pre-test HOME	1 .30	.714** .000 30	-.158 .403 30	-.220 .242 30	.227 .328 30	.357 .052 30	.211 .262 30	.270 .148 30	.045 .815 30
Post-test HOME	.714** .000 30	1 .30	-.197 .297 30	-.282 .131 30	.159 .402 30	.315 .090 30	.129 .498 30	.299 .109 30	.094 .609 30
Pre-test self- efficacy	-.158 .403 30	-.197 .297 30	1.000 .30	.670** .000 30	-.071 .710 30	-.231 .220 30	-.148 .436 30	.181 .337 30	.374* .042 30
Post-test Self- efficacy	-.220 .242 30	-.282 .131 30	.670** .000 30	1.000 .30	-.059 .758 30	-.304 .102 30	-.201 .286 30	-.010 .959 30	.197 .298 30
Pre-test participation	.227 .228 30	.159 .402 30	-.071 .710 30	-.059 .758 30	1.000 .30	.814** .000 30	.392* .032 30	.091 .634 30	-.413* .023 30

\* correlation is significant at the .05 level (2-tailed).

\*\*correlation is significant at the .01 level (2-tailed)

**TABLE III (continued)**  
**CORRELATIONS**

---

Post-test participation	.357 .052 30	.315 .090 30	-.231 .220 30	-.304 .102 30	.814** .032 30	1.000 . 30	.415* .023 30	.088 .644 30	-.418* .022 30
Pre-test knowledge	.211 .262 30	.129 .498 30	-.148 .436 30	-.201 .286 30	.392* .032 30	.415** .023 30	1.000 . 30	.666** .000 30	-.028 .884 30
Post-test knowledge	.270 .148 30	.299 .109 30	.181 .337 30	-.010 .959 30	.091 .634 30	.088 .644 30	.666** .000 30	1.000 . 30	.397* .030 30
Group membership	.045 .815 30	.097 .6 30	.374* .042 30	.197 .298 30	-.413* .023 30	-.418* .022 30	-.028 .884 30	.397* .030 30	1.000 . 30

\* correlation is significant at the .05 level (2-tailed).

\*\*correlation is significant at the .01 level (2-tailed)

(e) **Group effect on post-test controlling for pretest results, GMFCS and mothers' age**

Group effects were examined for each of the outcome measures, post-test self-efficacy, HOME, knowledge and participation while controlling for the covariates of mothers' age and GMFCS. A hierarchical regression was used to analyze the outcomes. Three blocks of independent variables were entered to examine their effects on the dependent variable. In all cases the dependent variable was the post-test outcome measure. The first block was the pre-test score of the outcome measure that was examined. The second block of data entered was the covariates of mothers' age and GMFCS to control for any influence of the group difference in these variables. The third block entered into the regression was the group membership variable (intervention versus control).

The results for self-efficacy, knowledge, HOME and participation are presented in tables IV through VII. No group effects were found in the HOME, participation and self-efficacy outcome measures. There was a significant group effect in the knowledge outcome measure ( $p = .018$ ).

Table IV shows the impact of the intervention on post-test self-efficacy with pre-test self-efficacy mothers' age and GMFCS as covariates in the hierarchical regression. This model shows no significant differences in self-efficacy attributable to group membership ( $p = .992$ ) and no significant influence of mothers' age and GMFCS.

**TABLE IV**  
**SELF-EFFICACY**

<b>Variable</b>	<b>Sig.</b>	<b>B</b>	<b>R</b>	<b>R square</b>	<b>Adj. R Square</b>	<b>F</b>	<b>DF</b>
Pre-test self-efficacy	.000	.607	.685	.469	.450	24.751	1
Pre-test self-efficacy	.000	.649	.705	.497	.439	8.572	3
Mothers' age	.609	2.968E-02					
GMFCS	.241	-.320					
Pre-test self-efficacy	.000	.649	.705	.497	.417	6.182	4
Mothers' age	.642	2.992E-02					
GMFCS	.278	-.321					
Group effect	.992	7.994E-03					

Dependent variable: Post-test self-efficacy  
P=.05

Table V indicates the influence of the group effect on parental knowledge with pre-test knowledge, mothers' age and GMFCS as covariates in the hierarchical regression. There was a positive group effect on post-test knowledge scores while controlling for pretest scores, mothers'

age and GMFCS. The GMFCS did not significantly influence the knowledge measure. There was a significant negative influence of mother's age on the knowledge scores ( $p=.033$ ); however when the influence of group membership is entered into the regression the significance disappears of mother's age disappears and only group membership on knowledge remains.

**TABLE V**  
**KNOWLEDGE**

Variable	Sig.	$\beta$	R	R square	Adj.R Square	F	DF
Pre-test knowledge	.000	.652	.652	.425	.404	20.683	1,28
Pre-test knowledge	.000	.655	.724	.525	.470	9.562	3,26
Mothers' age	.033	-.319					
GMFCS	.220	.178					
Pre-test knowledge	.000	.669	.789	.622	.561	10.279	4,25
Mothers' age	.372	-.134					
GMFCS	.758	.043					
Group Effect	.018	.367					

Dependent variable: Post-test knowledge  
 $p=.05$



Table VI describes the results of the hierarchical regression examining the group effect on the post-test HOME using pre-test HOME, mothers' age and GMFCS as covariates. There were no significant effects in the HOME scores as a result of a group effect ( $p = .912$ ) and no influence of mothers' age and GMFCS on the outcome measures.

Table VII presents the influence of group membership on the post-test participation scores while controlling for the pre-test scores, mothers' age and GMFCS. There was no significant change in participation scores as a result of group membership ( $p=.457$ ) and no significant influence of mothers' age and GMFCS.

**TABLE VI**  
**HOME**

Variable	Sig.	$\beta$	R	R square	Adj. R Square	F	DF
Pre-test HOME	.000	.726	.726	.528	.511	31.267	1,28
Pre-test HOME	.000	.670	.753	.567	.517	11.366	3,26
Mothers' age	.154	-.202					
GMFCS	.912	-.015					
Pre-test HOME	.000	.671	.753	.568	.498	8.204	4,29
Mothers' age	.200	-.211					
GMFCS	.954	-.009					
Group Effect	.912	-.017					

Dependent Variable: Post-test HOME scores  
P=.05

**TABLE VII**  
**PARTICIPATION**

Variable	Sig.	$\beta$	R	R square	Adj. R Square	F	DF
Pre-test participation	.000	.813	.813	.661	.649	54.701	1,28
Pre-test participation	.000	.817	.814	.662	.623	16.963	3,26
Mothers' age	.865	-.021					
GMFCS	.982	.003					
Pre-test participation	.000	.789	.818	.669	.617	12.655	4,29
Mothers' age	.635	-.067					
GMFCS	.831	.030					
Group Effect	.457	-.107					

Dependent Variable: Post-test Participation  
P=.05

(f) **Relationship between self-efficacy and knowledge**

It was hypothesized that the level of knowledge would affect parental sense of self-efficacy. The difference between the pre-test and post-test scores for both self-efficacy and knowledge were computed. These differences were then examined using the Pearson Product Moment Correlation. No correlation was found between knowledge and parental self-efficacy as illustrated in table VIII.

**TABLE VIII**

**CORRELATION BETWEEN THE CHANGE SCORES OF PRE-TEST AND POST-TEST  
SELF-EFFICACY AND KNOWLEDGE**

		<b>Change score Self- efficacy</b>	<b>Change score knowledge</b>
<b>Change score Self- efficacy</b>	Pearson Correlation	1.000	-.254
	Sig. (2-tailed)	-	.175
	N	30	30
<b>Change score knowledge</b>	Correlation	-.254	1.000
	Sig. (2-tailed)	.175	-
	N	30	30
P =.05			

(f) **Mediational Model**

Hypothesized in the conceptual model was the influence of parental knowledge on the home environment and on participation. There were no significant changes in the home environment and participation and therefore the data would not allow the model to be tested; nor did it provide support for this model.

## IV. DISCUSSION

### A. **Overall Study Model: Changes in Parental Behaviors**

This study demonstrated a significant increase in parental knowledge pertaining to CP as a result of an educational intervention in five meetings over the course of a ten week period. There were no significant measurable changes in parental behaviors as reflected by the lack of significant changes in the measures used to assess the home environment or child participation in age-appropriate activities that may be attributed to increased parental knowledge. A number of reasons are suggested that may explain the lack of measurable change in parental behaviors.

In any intervention the question relating to dosage is raised. The optimal dosage or minimal number of meetings required to achieve change in behaviors is unclear. This research indicated that five sessions was sufficient to produce significant increases in parental knowledge of CP but apparently insufficient to produce measurable changes in parental behaviors. As discussed extensively in the literature review change in behaviors is extremely difficult to achieve and requires a lot of commitment, time and energy from the individual targeted for behavioral change. Perhaps the dosage of five sessions was insufficient to change behaviors and additional meetings were necessary to foster behavioral change. This intervention attempted to incorporate numerous methods to assist parents to integrate newly learned behaviors in their daily routines. Perhaps if the space between the meetings was longer or additional sessions were included to enable more time to internalize and practice newly learned behaviors significant changes in behaviors may have resulted. Additionally, it is possible that there were behavioral changes but was only applied to parenting practices at a longer interval past the time period when the post-intervention measurements were collected. Furthermore perhaps other moderating

factors such as severity of CP of the child may influence the amount of dosage needed in order to adapt newly acquired information into families' particular life situation and behavioral practices and necessitate increased sessions and time to implement any behavioral changes.

Another possible reason for lack of change in parental behaviors may be explained as a result of the lack of sensitivity of the specific measures and difficulty in developing measures of the behaviors that are valid and reliable. This will be further discussed in the following sections detailing each of the specific measures.

#### **B. Demographic Information**

There was no significant difference between groups in all demographic information examined other than parents' ages. The difference in mothers' age appeared to serve as a negative influence on the knowledge measure but had no significant influence on the other measures; however when the influence of group membership was considered the influence of mother's age no longer remained significant. There are number of ideas that might explain this influence. Perhaps as a parent ages and are challenged with a different type of experience than they had previously they are more aware of the importance of increasing their knowledge and being exposed to new ideas. Additionally it is possible that the younger parents had younger children at home, less help from older children in household tasks and were therefore less open to the intervention. In considering the influence of mothers' age there appears to have been a stronger effect of the educational intervention on the knowledge measure which was negatively influenced by the significant differences between groups in regards to others' age.

There was no significant difference in all child characteristics. However there appeared to be a trend for an increased level of severity of cerebral palsy in the intervention group. The increased level of severity in the intervention group might have decreased the effect size of the

educational intervention. Increasing severity of the children in the intervention group might have made it more difficult for the parents to change their behaviors. This could be supported by the findings that participation of severely disabled children was influenced both by their intrinsic impairments and their environment and behavioral change in the population of children with severe physical impairments might be much more difficult to influence (Forsyth, 2007).

Cultural and religious demographic aspects were not collected in this study. However, several of the participants identified themselves as members of the ultra-religious Jewish segment of the Israeli population. The parents that participated in the intervention groups that were identified themselves as ultra-orthodox expressed the importance of their beliefs in providing a source of strength. Beliefs according to the parents themselves provide a source of strength and guidance. Additionally they consulted with and received guidance from their Rabbi or spiritual guide as well as medical professionals prior to medical interventions or courses of treatment. This is an aspect that should be considered in future studies.

### C. **Outcome Measures**

#### (a) **Knowledge**

There was a statistically significant increase in parental knowledge. This demonstrated that in five sessions parents can significantly increase their knowledge of their child's disability. Parents expressed both verbally and in post-intervention questionnaires enjoyment regarding the learning experience and were actively involved. There was a lot of spontaneous sharing of information pre and post the meetings. Sharing information and knowledge about their experiences with raising their child, encounters with the various government offices, equipment and their experiences with the system and assistance to other parents to navigate the system was

discussed extensively throughout all of the meetings. This was expressed in the surveys collected from parents at the conclusion of the fifth meeting.

The knowledge they gained was aimed at helping them change the environment faced by their child with a disability. The questions examined their knowledge of participation and the importance of their role in assisting their child with a disability to decrease the barriers they might face. Basic knowledge of CP was gained in this study to assist them in their navigation of the health system in a friendly and supportive environment in an easily accessible format.

In examining the items of the knowledge measure certain questions appeared to have a high rate of correct scores pre-intervention with no change post intervention among the two groups. The questions appeared to have a commonality among them. Questions pertaining to understanding the importance of the environment were answered by most parents correctly.

Questions such as:

- It is important to for a child with CP to participate in activities with same age peers.
- The home environment is a very important influence on a child's development.
- It is important to encourage a child with CP to initiate and develop independence as much as the child can.
- Encouragement and providing opportunities to participate in activities that are age-appropriate can help improve the cognitive abilities of a child with CP.

It appeared that they understood the importance and influence of the environment on their child's development. However the questions related to the specific implementation regarding changing and developing a more positive environment were answered incorrectly by a majority of the parents and appeared to improve in the intervention group in the post-testing. Questions such as:

- According to the World Health Organization, the term "participation" refers to age appropriate functions, such as communication and dressing that a child can complete independently.

- The term “barrier” or impairment refers to limitations imposed by the physical impairment of a child with CP
- The current functional abilities of the CP child cannot predict future abilities. There is a need to wait for his maturation for this to be known.
- The use of augmentative communication accessories can delay the speech development of a child.
- Children with CP do not need to participate in sports activities.
- A child with CP needs to receive maximal help to prevent frustration It is important for a child with CP to walk in any way possible to enable future mainstreaming in school

These questions focus on more specific ideas to apply the theoretical knowledge. These questions pre-testing were answered by the majority of parents incorrectly and there was marked improvement in responses in the intervention group post-intervention.

It is however unclear how this increase in knowledge can influence their child’s care in the long term. It is possible that the trend of greater severity of CP in the intervention group might have influenced the impact of the increase in knowledge on the other outcome measures. It is possible that the trend towards increased severity of CP in the intervention group might have made it more difficult for parents to change their behaviors as reflected in the measure of the environment and produce changes in child behaviors as measured by participation. A child diagnosed with CP at the GMFCS level V for example is unable to sit independently, unable to assist in transfers and is unlikely to succeed in using wheelchair mobility for any type of independent movement. Influencing changes in parental behaviors with children with severe CP is probably more difficult and would possibly require more time and practice to realize change.

This relationship and influence of child characteristics is also posited in the “COPCA” study (Blauw-Hospers et al (2011). The authors also suggest that child characteristics including



degree of impairment might also play role in influencing outcomes or even to the extent of selecting type of physical therapy actions in the interventions.

Increasing knowledge is one step in changing behaviors. This intervention attempted to access and influence parental beliefs enabling changes in behavior. However, as is often the case perseverance of beliefs despite attempts to alter parental beliefs and influence behaviors may often occur (Goodnow, 1988) and is the challenge of any intervention attempting to alter behaviors. Professionals involved in intervention should be sensitive to the family's cultural background and consider the broader context of the family and society to the influences on a child's development and to effectively plan interventions sensitive to a family's cultural background (Coll, 1998; Evans & Myers, 2001; Goodnow, 1988). Cultural considerations were not taken into account in this intervention and because of problems in sample size is difficult to implement in the population of children and their families with disabilities. In the future perhaps considering it the study a multicultural approach would be important.

(b) **Participation**

There were some overall increases as evident in overall mean increases in the participation measure for all groups. The small increases evident in these post-test results which may be attributed to some ideas parents received from exposure to the pre-test questions providing them with suggestions of some aspects being observed and considered central in the home environment and suggestions of areas of importance for their child's development. Additionally there might have been a small maturation effect as their children got older over the course of the study.

There has been an increase in research examining the concept of participation. The concept remains difficult to define and its measurement elusive as discussed in the literature

review. Participation within the framework of the ICF is defined as involvement in a life situation (WHO, 2000). Coster (1998) defined participation as energetic engagement in the typical activities as expected of same age peers in the same setting. Whiteneck (2006) suggests that life situations can be considered the organization of a series of activities as determining and defining participation. In fact the definition of participation at the preschool level was not discussed at all in the research literature at the time of inception of this study. Moreover, the severity of CP influences the degree of participation (Forsyth, 2007). The literature discusses that the limitations on participation are related to motor impairment, function and the child's environment (Tieman et al, 2004; Forsyth et al, 2007). Over the last few years there has been a tremendous increase in the amount of research and definition of participation in the literature. The typical activities that may be used to operationalize the definition of CP in the age range of approximately one and a half years to six years old remain unclear.

At the time the study proposal was accepted no measures with sound psychometric properties were available to examine participation in this age range. The lack of measures with tested psychometric properties might have significantly hindered the ability to measure change in child participation. Additionally behavioral change might be subtle further hindering the ability to measure such change. In retrospect the assessment developed was not sufficiently sensitive to measure change in the construct of participation.

In examining the items on the assessment and after examining the assessment over time in the pre and post measures certain issues became apparent which were not clear in the pretesting of the measures. Items 7-14 might have been influenced by the time of year. Inclement weather in Israel is primarily in the winter months with little or no rain from April through October. The

study was carried out during those months and the weather might have affected when and how often parents went out with their child.

The likert scale developed for the participation measure may not have been sensitive enough to capture change. The intervals differentiating between frequencies of occurrences of each of the activities may have covered too large a time period and therefore might not have been sensitive enough to capture changes in levels of participation. Any increases in change in participation pre and post-intervention might have fallen within the same interval despite some increases in participation. It is possible that had the intervals covered shorter time periods the measure might have been able to capture more subtle changes in frequencies of activities and perhaps have demonstrated measurable changes in levels of participation.

The measurement tool appears to not be specific enough in the age ranges, toddler and preschoolers, to reflect and measure the degree of participation. The study restricted the age of the participating children between the range of approximately 1.5 and 6 years of age and at the time this study was proposed it was felt that this would be sufficient to facilitate homogeneity and allow measurement of participation in typical daily activities in the age range. The items in the participation measure reflected the many activities experienced by children in the age range from approximately 1.5 years old to 6 years. In effect there was too broad an age range included in this study. There exists too much variety in types of activities that are appropriate within this age range necessitating too large a variety of activities included and an insufficient number of items to sufficiently capture change within this age range.

(c) **Home environment**

There were no significant changes in the HOME scores pre and post-testing. There was an overall increase in the mean HOME scores in both groups post-testing. This may be attributed to

the questions in the interview pre-testing which might have alerted the control group as well to some important aspects in the home environment that influence child participation.

The available measure for the home environment, the HOME, is typically used as a screening tool to identify environments lacking in the necessary stimulation in the home. This measure is not typically used to identify increases in home environments that are relatively high functioning. Though SES levels were not collected, very few of the families participating in this study appeared to be living in poverty. Most families owned their own homes and had easy access to good medical care as a result of socialized medical care system in Israel. The measure might not have been sensitive enough to measure change in middle class families. There were limited areas in which change could occur in this measure post-intervention. There are 45 or 55 items in this measure depending on the age of the child. The mean of the HOME scores was above 45. Most of the homes scored 80% or above, hence indicating somewhat of a ceiling effect.

(d) **Self-efficacy**

Self-efficacy was hypothesized to increase as a result of increases in parental knowledge. Though increased parental knowledge occurred there was no significant increase in self-efficacy. In fact the intervention group had statistically significant higher scores in self-efficacy pre-testing which disappeared in the post-testing. In examination of the raw scores the intervention group had a slight decrease in raw scores post intervention and the control group had a slight increase. This slight increase was enough for the significant difference between groups to disappear. This apparent decrease in self-efficacy for the intervention group may be related to the fact that this group was more likely to have children with more severe CP and after participating in the intervention were more likely to rethink or reappraise their actions. Perhaps

they were more realistic, more able to recognize and confront difficulties they faced in their lives and the intervention served as an alerting effect. Perhaps down the road in a few months there might be an increase in self-efficacy after they were able to digest and implement some of the newly acquired knowledge. The increases in knowledge might have somewhat negatively affected the self-efficacy of the parents participating in the intervention, possibly, by increasing awareness of challenges facing them in providing care for their child and the importance of their day to day influence on their child.

Two studies report differential results as a result of parental needs at the time of providing the interventions. The “COPCA” study found that mothers had a high level of maternal education did better with only physical therapy and no coaching element in the intervention (Blauw-Hospers et al, 2011). As previously discussed perceived need for support also served to modify the effects of an intervention designed to assist mothers in transitioning their infant from NICU to home. Mothers with a high level need for support experienced positive program effects; negative program effects were found with mothers with low level needs for support (Affleck et al, 1989).

Bandura presents self-efficacy in a somewhat different light from the way the scale was developed for use in this study. Perhaps rewording the questions using the language “How certain are you that you are the best parent” reflecting Bandura’s key concept of human agency would have allowed parents to more critically examine the questions and might have used the scale differently.

Perhaps the self-efficacy scale needed additional items reflecting a wider variety of items reflecting knowledge of the system that would assist parents of children with disabilities with their day to day needs. This might have allowed the measure to better reflect any changes in

parental self-efficacy. Additionally the overall sense of self-efficacy in the two groups appeared to be relatively high despite the significant difference between groups in the pre-test. The maximum score per participant that could be measured was 24. The parents of the children in this study appeared overall to have high self-efficacy prior to the study as reflected in their pre-test scores.

(e) **Group feedback**

Parents were asked to complete post-intervention surveys. In addition many of the comments and interchanges during the meetings were recorded.

The participants in the intervention groups expressed enjoyment throughout the meetings. At the conclusion of all five meetings during the two rounds of interventions it was necessary to remind parents of the timeframe of the meetings and that it was time to go home. In the post-intervention surveys completed by parents they requested additional meetings and suggested supplementary topics for the meetings.

Many of the comments in the course of the meetings were very interesting. There was a lot of interaction among the parents. I found myself at times playing the role of observer and the parents themselves guided the evenings. There were obviously some that were more vocal than others but as the meetings progressed all had what to say and gave each other suggestions with their difficulties. Specific comments in the survey included:

“I thought I knew a lot about CP but some much of the information in the meetings was new to me”.

“I totally identified with the idea of learned helplessness with my child. It made me rethink how I approach him”.

“I would love to have more meetings such as these and would especially also like ones with my child attending as well”.

“I enjoyed the meetings very much. I would like to go into more detail on the practical side of caring for child with CP- like how to help him dress and eat with more independence”.

At the conclusion of each meeting parents were asked to sum up the meaning of the meeting to them. Some of the comments were specific practical ideas they learned wither from the presentation or comments from other parents. These ideas included solutions to equipment problems, seating, bureaucratic issues. Other comments related to their feelings such as how the meeting was very powerful to them, empowering, and how they felt about the power of togetherness - of meeting with other parents. Other comments expressed by parents included, sense of frustration and helplessness, the importance to try and increase their child's sense of self-confidence. At the last meeting parents sat mesmerized listening to stories from the mother of a 14 year old girl diagnosed with CP and her fight to integrate, and then move her to a special class and a description of her Bat Mitzvah celebration, a religious celebration of coming of age for females. Especially moving was her sense of fear of not knowing if her daughter will marry and live on her own and her feeling of making an extra special celebration for her Bat Mitzvah almost as if it was her wedding. Many of the fears of the future for the children of the participants came to the surface at that point.

After the intervention was concluded I know that quite a few people exchanged emails and phone numbers with the intent of keeping in touch. Some were in touch regarding technical bureaucratic issues to learn from others that have gone learned how best navigate the system. All

participants at the conclusion requested additional meetings and hoped they could continue at a future date.

The parents completing the post-test survey unanimously reported that they would recommend participating in such a group in the future and they unanimously would recommend participation to others families and offered to field calls from future potential parents. It is known to this researcher that some of the parents did maintain contact among the group and consulted one another regarding information about construction to enable accessibility in their apartment and partial financial support that is provided from public funding. A longer-term follow-up on concrete actions taken and support maintained may be useful in future research.



## V. CONCLUSION

The ability to increase parental knowledge through a series of educational meetings was demonstrated; however, the influence of increased knowledge on the home environment and participation was not demonstrated. The pathways of parental influence were theorized to occur through parental influence on structuring their child's environment resulting from increases in parental knowledge from an educational program that focused on increasing parental knowledge of the development of children with disabilities, constraints in the environment and methods of fostering increased participation of their child in age-appropriate activities.

There was an increase in parental knowledge of their child's disability as a result of the educational intervention. This is an important finding. Parents of children with disabilities do not typically take the time for a more formal learning situation for their children. Perhaps it is important within the structure of early interventions to include educational sessions for parents to take the time for them to learn and invest in themselves and the importance this might have on their child's development. The mechanism and effect of increased knowledge on child development needs to be further examined.

Refocusing the impact of interventions from one measuring child development to one measuring changes in child participation might measure outcomes that have a bigger impact on functioning in the population of children with disabilities. Parents' self-reports in this study describes the importance of participation in the life of the community. Refocusing measurement outcomes and improved findings might influence the ability to integrate programs targeting parental knowledge as part of early intervention services.

It is unclear what and if there were any additional effects as a result of the educational intervention that were not measured. The positive feedback from the parents participating in the intervention is important to consider. Navigating the medical, educational and any bureaucratic system can be very frustrating and difficult for parents. Parents self-reports described increases in confidence as a result of the knowledge discussed in the interventions and felt they would feel less intimidated and hesitant to deal with the necessary bureaucratic organizations. Possibly the measure of self-efficacy used in the study did not reflect this aspect of self-efficacy. The influence of this knowledge and how it impacts on the family dynamics is unclear and will need to be further examined. It is unclear how this increase in parental knowledge can be effectively utilized to change aspects in the environment and reflect this change in increased child participation. In addition to examining self-efficacy future studies should consider examining parental support and mental health aspects of parental characteristics. Based on the feedback received it is very possible that the intervention influenced these aspects which were not examined in this study.

The importance of the parent education components in intervention programs is widely recognized. It is important to continue examining the influence of parental knowledge as a mechanism to foster long term change and provide a supportive environment when the interventionist is not around. At the time of the development of this study it was thought that five sessions would be sufficient to impact on parental behaviors. Changing behaviors as extensively discussed in the literature review is a daunting task and it remains unclear the duration and frequency necessary to influence behaviors. Developing and designing the topics and structure of interventions, considering the number of hours, meetings, how often meetings are held and the number of meetings necessary to effect change is unclear.

The group feedback was very positive. Perhaps in the future it is important to allow for more flexibility in topics, allowing the parents to determine and provide input for the topics and discussions to be held in ensuing weeks would allow parents to be more active participants as described by Bandura (1977).

Often when examining such interventions it is quite possible as discussed in the discussion section that parents required more time to digest the material and implement changes in their home. A retrospective study perhaps six months later might indeed find some changes in levels of participation of parental self-efficacy that were not captured one month after the conclusion of the intervention.

Another important aspect that should be considered in future research is including parents as peer trainers. They could conduct some of the meetings as was done to a very small extent in the last meeting in this intervention which was extremely well received by the participating parents.

Few child characteristics were examined. The primary focus was examining the changes and influences parents had on the child's environment and the mediating aspect this had on the child's participation. Perhaps more child characteristics should be considered. Influences of cognitive abilities, communication influencing the child's sense of learned helplessness is equally important to the level of motor impairment as classified using the GMFCS.

The present study is one of few examining the influences of a parent education program on parental knowledge and the influences of this knowledge on the child with a disability. Although an attempt was made to limit heterogeneity in the participant population there is still a great deal of variability in abilities, function and resulting levels of participation inherent within the diagnosis of CP. Heterogeneity might have decreased the impact of the intervention,

resulting in fewer measurable changes. Additionally the power in this study was low due to the relatively small sample size necessitating a very strong effect size of approximately 80% which is very high. This is an inherent difficulty in a study of this nature when examining the population of children with diagnosed impairments such as CP. Parents are often hesitant to participate because they are still accepting their child's limitations and are focused on remediating the impairment as opposed to finding ways for their child to adapt to their impairments.

The participants in this study resided primarily in major city centers rather than in outlying development towns, hence limiting the demographic variability. However, there are strong cultural differences within the sample that reflect Israeli society including families from non-Jewish populations such as Arab and Bedouin communities, Christian and Muslim religions and Jewish communities including ultra-Orthodox, traditional and secular populations. Though this information can be extrapolated from the data, the sample size was not large enough to examine the data from this perspective.

Pre-testing the measures appears to serve as a tool alerting parents to aspects of development that were examined in this study possibly influencing parental behaviors towards their child with a disability and increasing awareness as to the importance of participation of their child in age-appropriate activities whether or not they participated in the intervention. As discussed previously some of the measures lacked sensitivity to capture change in behaviors. The participation measure was developed for too wide a variety of child ages weakening the ability of the measures to capture change. The HOME was in fact a screening tool which appeared to have a mild ceiling effect pre-testing.

Further research is necessary to examine the effects of increased parental knowledge on the child's environment. Improving and more clearly defining the definition of participation is important. In addition the recognition of the importance of changing the measurement outcomes of children with disabilities from a developmental perspective to measurement of participation as a research outcome is gaining in acceptance. This will enable refocusing of the research and the measurement outcomes of interventions to target the environment of the child rather than specific functional developmental changes.

## CITED LITERATURE

- Achenbach TM, Phares V, Howell CT, Rauh VA, Nurcombe B. (1990). Seven-year outcome of the Vermont Intervention Program for Low-Birthweight Infants. *Child Dev.*, 61(6), 1672-1681.
- Affleck G, Tennen H, Rowe J, Roscher B, Walker L (1989). Effects of formal support on mothers' adaptation to the hospital-to-home transition of high risk infants: the benefits and costs of helping. *Child Dev.*, 60, 488-501.
- Ajzen I (2001). Nature and operation of attitudes. *Annu. Rev. Psychol.*, 52, 27-58.
- Ando N, Ueda S (2000). Functional deterioration in adults with CP. *Clin Rehabil.*, 14(3), 300-6.
- Aneshensel CS, Pearlin LI, Mullan JT, Zarit SH, Whitlatch CJ (1995). Profiles in Caregiving: The unexpected career, NY: Academic Press.
- Bailey DB, McWilliam PJ (1993). The search for quality indicators. In P.J. McWilliam & D.B. Bailey (Eds.), *Working together with children and families* (pp. 3-20). MD: Paul H. Brookes.
- Bandura A (1977). Self-efficacy: Toward a unifying theory of behavior change, *Psychological Review*, 84, 191-215.
- Bandura, A. (1977). *Social Learning Theory*, Englewood Cliffs NJ: Prentice Hall.
- Barnard K (1997). Influencing parent-child interactions for children at risk. In M. Guralnick (Ed.), *The effectiveness of early intervention* (pp. 249-270). MD: Paul H. Brookes.
- Barolot-Romana G, David R (1980). Neurophysiological mechanisms in abnormal reflex activities in CP and spinal spasticity, *J Neurol Neurosurg Psychiatr*, 43, 333-342.
- Baron RM, Kenny DA (1986). The moderator-mediator variable distinction in social psychological research: conceptual, strategic, and statistical considerations. *Journal of Personality and Social Psychology*, 51, 1173-1182.
- Barrerra ME, Rosenbaum PL, Cunningham CE (1986). Early home intervention with low birth-weight infants and their parents. *Child Development*, 57, 20-33.
- Bax M. (1964). Terminology and classification of CP. *Developmental Medicine and Child Neurology*, 6, 295.

- Bell KJ, Ounpu SM, DeLuca, Peter A, Romness M (2002). Natural progression of gait in children with CP. *Journal of Orthopedics*, 22 (5), 677-682.
- Benasich AA, Brooks-Gunn J (1996). Maternal attitudes and knowledge of child-rearing: Associations with family and child outcomes. *Child Development* 67(3), 1186-1205.
- Berger W, Horstmann G, Dietz V (1982). Pathophysiology of gait in children with cerebral palsy. *Electoencephelogram Clin Neurophysiol*, 53, 538-548.
- Berger W, Horstmann G, Dietz V (1984). Tension development and muscle activation in the leg during gait in spastic hemiparesis: Independence of muscle hypotonia and exaggerated stretch reflexes. *J Neurol Neurosurg Psychiat*, 47, 1029-1033.
- Biegel DE, Johnson JA (1997). Overcoming barriers faced by African-American families with a family member with mental illness. *Family Relations*, 46 (2), 163-171.
- Bradley, RH (1993). Children's home environments, health, behavior, and intervention efforts: A review using the HOME inventory as a marker measure. *Genetic Soc Gen Psychol*, 19(4), 437-490.
- Bradley RH, Whiteside L, Mundfrom DJ, Casey PH, Kelleher KJ, Pope SK (1994). Early indications of resilience and their relation to experiences in the home environments of low birthweight, premature children living in poverty. *Child Dev*, 65 (2), 346-360.
- Bradley RH, Mundfrom DJ, Whiteside L, Casey PH, Barrett K (1994a). A factor analytic study of the Infant Toddler and early childhood versions of the HOME inventory administered to white, black, and Hispanic American parents of children born preterm. *Child Development*, 65, 880-888.
- Brinker R, Seifer R, Sameroff A (1994). Relations among maternal stress, cognitive development and early intervention in middle- and low-SES infants with developmental disabilities. *American Journal of Mental Retardation*, 98, 463-80.
- Bronfenbrennar U (1986). Ecology of the family as a context for human development: research perspectives. *Developmental Psychology*, 6, 723-742.
- Brooks-Gunn J, Berlin LJ, Fuligni AS (2000). Early childhood intervention programs: What about the family? In JP Shonkoff , SJ Meisels (Eds), *Handbook of Early Childhood Intervention* (pp. 549-588). NY:Cambridge University Press.
- Brouwer B, Smits E (1996). Corticospinal input onto motor neurons projecting to ankle muscles in individuals with CP. *Dev Med Child Neurol*, 38, 787-796.

- Caldwell BM, Bradley RH (1984). Home Observation for Measurement of the Environment. Ark: Center for Research on Teaching and Learning at the University of Arkansas.
- Campbell J, Ball J (1978). Energetics of walking in CP. *Orthop Clin North Am*, 9, 374-376.
- Campbell SK (2000). In SK Campbell, DW VanderLinden, RJ Palisano (Ed), Physical therapy for children (pp. 1-22). PA: Saunders, 2000, 2nd ed.
- Coll CG, Magnuson K (1999). Cultural influences on child development: Are we ready for a paradigm shift. In AS Masten (Ed). Cultural processes in child development (pp. 1-24). NJ: Lawrence Erlbaum Assoc.
- Coster W (1998). Occupation-centered assessment of children. *Am J Occup Ther*, 52(5), 337-44.
- Crenna P, Inverno M, Frigo C, Palmieri R, Fedrizzi E (1992). Pathophysiological profile of gait in children with CP. In H Forssberg H, H Hirschfeld (Eds). Movement Disorders in Children (pp. 186-198). Basel.
- Daly WC (2004). Gesell's infant growth orientation: a composite. *Journal of Instructional Psychology*, 31 (4), 321-324.
- Damiano DL, Quinlivan J, Owen BF, Shaffrey M, Abel MF (2001). Spasticity versus strength in cerebral palsy: Relationships among involuntary resistance, voluntary torque, and motor function. *Eur J Neuro*, 5, 40-49.
- Damiano DL, Kelly LE, Vaughn CL (1995). Effects of quadriceps femoris muscle strengthening on crouch gait in children with spastic diplegia. *Phy Therapy*, 75,658-671.
- Dietz V, Berger W (1983). Normal and impaired regulation of muscle stiffness in gait: A new hypothesis about muscle hypertonia. *Exper Neurol*, 79, 680-687.
- Dilworth-Anderson P, Williams SW (1999). The contexts of experiencing emotional distress among family caregivers to elderly African Americans. *Family Relations*, 48 (4), 391-395.
- Eliasson AC, Gordon AM (2000). Impaired force coordination during object release in children with hemiplegic CP. *Dev Med Child Neurol*, 42, 228-234.
- Eliasson AC, Gordon Am, Forssberg H (1995). Tactile control of isometric fingertip forces during grasping in children with CP. *Dev Med Child Neurol*, 37, 72-84.



- Evans JL, Myers RG (2001). Childrearing practices: Creating programs where traditions and modern practices meet. <http://www.ecdgroup.com/cn/cn151lead.html>
- Ferguson PM (2001). Mapping the family: Disability studies and the exploration of parental response to disability. In GL Albrecht, KD Seelman, M Bury (Eds). *Handbook of Disability Studies* (pp.373-395). CA: Thousand Oaks Sage Press.
- Forsyth R, Colver A, Alvanides S, Wooley M, Lowe M (2007). Participation of young severely disabled children is influenced by their intrinsic impairments and environment. *Developmental Medicine and Child Neurology*, 49, 345-349.
- Fox, RD, Miner C (1999). Motivation and the facilitation of change, learning, and participation in educational programs for health professionals. *JCEHP*, 19(1), 132-141.
- Furstenberg FF, Cook T, Eccles J, Elder GH, Sameroff AJ (1999). *Urban Families and Adolescent success*. Chicago: University of Chicago Press.
- Garrett P, Ferron J, Ng'andu N, Bryant D, Harbin G (1994). A structural model for the developmental status of young children. *Journal of Marriage and the Family*, 56, 147-163.
- Goldstein DN, Cohn E, Coster W (2004). Enhancing participation for children with disabilities: Application of the ICF enablement framework to pediatric physical therapists practice. *Phys Ther*, 16, 114-120.
- Goodnow JJ (1988). Parents' ideas, actions and feelings: Models and methods from developmental and social psychology. *Child Development*, 59, 286-320.
- Gutierrez J, Sameroff AJ, Karrer BM (1988). Acculturation and SES effects on Mexican-American parents' concept of development, *Child Dev*, 59, 250-255.
- Harden RM, Laidlaw JM (1992). Effective continuing education: the CRISIS criteria. *Medical Education*, 26(5), 408-422.
- Hauser-Cram P, Warfield ME, Shonkoff JP, Krauss MW, Sayer A, Upshur CC (2001). Children with disabilities: a longitudinal study of child development and parent well-being. *Monogr Soc Res Child Dev*, 66 (3), 1-114; discussion 115-126.
- Heller, T., Miller, A.B., & Hsieh, K. (1999). Impact of a consumer-directed family support program on adults with disabilities. *Family Relations*, 48, 419-427.
- Howard, 1989 Howard, K. W. (1989). A comprehensive Expectancy Motivation Model: Implications for adult education and training. *Adult Education Quarterly*, 39(4), 199-210.

Individuals with Disabilities Education Act Amendments of 1997. 37-157.

Hutton JL, Cooke T, Pharoah PO (1994). Life expectancy in children with CP. *BMJ*, 309(6952):431-5.

Katz RT (2003). Life expectancy for children with CP and mental retardation: implications for life care planning. *Neurorehabilitation*. 18(3), 261-70.

King G, Law M, King S, Rosenbaum P, Kertoy MK, Young NL.(2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Phys Occup Ther Pediatr*. 23(1), 63-90.

Imel S (1999). Using groups in adult learning: theory and practice. *JCEHP*, 19(1), 54-61.

Ihkan DY, Yalcin E (2000). Changes in skeletal maturation and mineralization in children with CP and evaluation of related factors. *Journal of Child Neurology*, 16 (6), 425-430.

Klitzman H, Olds D, Henderson C, Hanks C, Cole R, Tatelbaum R, McConnochie KM, Sidora K, Luckey DW, Shaver D, Engelhardt K, James D, Barnard K (1997). Effect of prenatal and infancy home visitation by nurses on pregnancy outcomes, childhood injuries and repeated childbearing. *JAMA*, 278(8), 644-652.

Knowles MS, Holton EF, Swanson RA (1998). *The Adult Learner: The Definitive Classic in adult education and human resource development*. MA: Butterworth Heineman.

Knutsson E, Martensson A (1980). Dynamic motor capacity in spastic paresis and its relation to prime mover dysfunction, spastic reflexes and antagonist co-activation. *Scand J Rehab Med*, 12, 93-106.

Kolobe TK, Susman L, Bulanda M, presented at APTA combined sections conference, 2002.

Johnson 1990 Johnson, B.H. (1990). The changing role of families in health care. *Children's Health Care*, 19(4), 234-41.

Lawton et al, 1991 Lawton MO, Moss M, Kleban MH, Glicksman A, Rovine M (1991). A two-factor model of caregiving appraisal and psychological well-being. *Journal of Gerontology*, 46 (4), 181-189.

Leonard CT, Hirschfeld H, Morkitani T, Forssberg H (1990). Deficits in reciprocal inhibition of children with CP as revealed by H reflex testing. *Dev Med Child Neuro*, 32, 374-384.

- Leonard CT, Hirschfeld H, Moritani T, Forssberg H (1991). Myotatic reflex development in normal children with cerebral palsy. *Exp Neurol*, 111 (3), 379-382.
- Loo KK, Espinosa M, Tyler R, Howard J (2003). Using knowledge to cope with stress in the NICU: how parents integrate learning to read the physiologic and behavioral cues of the infant. *Neonatal Network*, 22 (1), 31-37.
- Lytton H (2000). Toward a model of family-environmental and child-biological influences on development. *Developmental Review*, 20, 150-179.
- Mahoney G, Wheeden CA, Perales F (2004). Relationship of preschool special education outcomes to instructional practices and parent-child interaction. *Research in Developmental Disabilities*, 25, 539-558.
- Mancini MC, Coster WJ (2004). Functional predictors of school participation by children with disabilities. *Occup Ther Int.*, 11(1),12-25
- Marshak, LE, Seligman M, Prezant F (1999). Disability and the family life cycle: Recognizing and treating challenges. Chapter 3: School age years (pp. 66-121). NY: Basic Books.
- MacPhee D (1981). Manual for Knowledge of Infant Development Inventory (KIDI), unpublished data available through ETS Test Collection.
- Mazmanian PE, Mazmanian PM (1999). Commitment to Change: theoretical foundations, methods and outcomes. *JCEHP* 19(4), 200-207.
- McCarton C, Brook-Gunn J, Wallace I, Bauer C, Bennett E, Bernbaum J, Broyles S, Casey P, McCormick M, Scott D, Tyson J, Tonascia J, Meinert C (1997). Results at 8 years of early intervention for low-birth-weight premature infants. *JAMA*, 277, 126-32.
- McCarton CM, Wallace IF, Bennett FC (1995). Preventive interventions with LBW premature infants: an evaluation of their success. *Seminars in Perinatology*, 19(4), 330-340.
- Meberg A, Broch H (2004). Etiology of CP. *J Perinat Med*, 32(5),434-9.
- Meisels SJ, Dichtelmiller M, Liaw FR (1993). A multidimensional analysis of early childhood intervention program. In CH Zeanah (Ed.) Handbook of infant mental health (pp.361-85). NY: Guilford Press.
- Melnyk BM, Small L, Carno MA (2004). The effectiveness of parent-focused interventions in improving coping/mental health outcomes of critically ill children and their parents: an evidence base to guide clinical practice. *Pediatr Nurs* 30(2),143-8.

- Michaelsen LK, Fink LD(1997). Designing Effective Group Activities: Lessons for Classroom Teaching and Faculty Development. *To Improve the Academy*, 16, 373-398.
- Mihaylov SI, Jarvis SN, Colver AF, Beresford B (2004). Identification and description of environmental factors that influence participation of children with CP. *Dev Med Child Neurol*, 46(5), 299-304.
- Morrisett CE, Brand KE, Greenberg MT, Booth CL, Spieker SJ (1990). Environmental influences on early language development: The context of social risk. *Development and Psychopathology*, 2, 127-149.
- Moxley-Haegert L, Serbin LA (1983). Developmental education for parents of delayed infants: Effects on parental motivation and children's development. *Child Dev*, 54 (5), 1324-1331.
- Myklebust BM, Gottlieb GL, Penn RD, Agarwal GC (1982). Reciprocal excitation of antagonistic muscles as a differentiating feature in spasticity. *Ann Neurol*, 12, 367.
- Nashner LM, Shumway-Cook A, Marin O (1983). Stance posture control in select groups of children with cerebral palsy: deficits in sensory organization and muscular coordination. *Exp Brain Res*, 49, 393-409.
- Nelson CA (2000) The neurological bases of early interventions. In Shonkoff JP, Meisels SJ (Eds). *Handbook of Early Childhood Intervention* (pp. 204-230). NY: Cambridge University Press
- O'Brien P, Dyck I, Caron S, Mortenson P (2002). Environmental analysis: insights from sociological and geographical perspectives. *Can J Occup Ther*, 69(4),229-38.
- Olds DL, Henderson CR, Kitzman H (1994). Does prenatal and infancy nurse home visitation have enduring effects on qualities of parental caregiving and child health at 25 to 50 months of life? *Pediatrics*, 93 (1), 89-98.
- Olney SJ, et al (1987). Mechanical energy patterns in gait of cerebral palsied children with hemiplegia. *Physical Therapy*, 67, 1348-1354.
- Owens SJ, Qualls SH (1997). Family stress at the time of a geropsychiatric hospitalization. *Family Relations*, 46 (2), 179-166.
- Pakula, A, Palmer F (1997). Early intervention for children at risk for neuromotor problems. In M. Guralnick (Ed.). *The effectiveness of early intervention* (pp. 99 – 108), MD: Paul H. Brookes.

- Palisano RJ, Tieman BL, Walter SD, Bartlett DJ, Rosenbaum PL, Russell D, Hanna SE (2003). Effect of environmental setting on mobility methods of children with cerebral palsy. *Dev Med Child Neurol*, 45(2), 113-20.
- Palisano RJ, Hanna SE, Rosenbaum PL, Russell DJ, Walter SD, Wood EP, Raina PS, Galuppi BE (2000). Validation of a model of gross motor function for children with cerebral palsy. *Phys Ther*, 80(10), 974-85.
- Panitz T (1999). The Motivational Benefits of Cooperative Learning. *New Directions for Teaching & Learning*, 78, 59-67.
- Parker DF, Carriere L, Hebestreit H, Bar-Or O (1992). Anaerobic endurance and peak muscle power in children with spastic CP. *Amer J Dis Child*, 146, 1069-1073.
- Portney, L. G., & Watkins, M. P. (2000). Foundations of clinical research. Applications to practice. (2<sup>nd</sup> ed.). NJ: Prentice-Hall.
- Prochaska JO, Velicer WF(1997). The transtheoretical model of health behavior change. *American Journal of Health Promotion*, 12, 38-48.
- Pruchno R, Patrick JH (1997). African American and white others of adults with chronic disabilities: Caregiving burden and satisfaction. *Family Relations*, 46 (4), 335-336.
- Qualls SH (1997). Transitions in autonomy: The essential caregiving challenge. *Family Relations*, 46 (1), 41-46.
- Ramey CT, Ramey SL (1998). Prevention of intellectual disabilities: early interventions to improve cognitive development. *Preventative Medicine*, 27, 224-232
- Rolland JS (1987). Chronic illness and the life cycle: A conceptual framework. *Family Process*, 26(2), 203-21.
- Rose J, Gamble JG, Medeiros J, Burgos A, Haskell WL (1989). Energy cost of walking in normal children and in those with CP: Comparison of heart rate and oxygen uptake. *J Ped Ortho*, 9, 276-279.
- Rose TL, Calhoun ML (1990). The Charlotte circle project: A program for infants and toddlers with severe/profound disabilities. *Journal of Early Intervention*, 14, 175-185.
- Rothstein JM (2001). On the second edition of the Guide to Physical Therapist Practice. *PhysTher*, 81(1),6-8.
- Sameroff AJ (1986). Environmental context of child development. *J of Pediatrics*, 109 (1), 192-199.

- Sameroff AJ, Fiese BH, (2000). Transactional regulation: The developmental ecology of early intervention. In Shonkoff JP, Meisels SJ (Eds), *Handbook of Early Childhood Intervention* (pp135-159). NY: Cambridge University Press.
- Santiago M, Coyle C (2004). Leisure-time physical activity and secondary conditions in women with physical disabilities. *Disabil Rehabil*, 26(8),485-94.
- Schon DA (1987). *Educating the reflective practitioner*. CA: Josey-Bass.
- Seltzer MM, Heller T (1997). Introduction: Families and caregiving across the life course: Research advances on the influence of context. *Family Relations*, 46 (4), 321-323.
- Shonkoff, J.P., Hauser-Cram, P., Krauss, M., & Upshur, C. (1992). Development of infants with disabilities and their families. *Monographs of the Society for Research in child Development*, 57 (6, Serial No. 230).
- Sigman M, Ruskin E, Arbeile S, Corona R, Dissanayake C, Espinosa M, Kim N, Lopez A, Zierhut C (1999). Continuity and change in the social competence of children with autism, down syndrome and developmental delays. *Monogr Soc Res Child Dev*, 64 (1), 115-130; discussion 131-139.
- Simeonsson RJ, Bailey DB (1990). Family dimensions in early intervention. In SJ Meisels, JP Shonkoff (Eds.), *Handbook of Early Childhood Intervention* (p. 428). NY:Cambridge University Press.
- Smith A (1998). Learning about reflection. *J of Advanced Nursing*, 28(4), 891-898.
- Smith LB, Thelen E (2003). Development as a dynamic system, trends in cognitive sciences, 7(8), 343-348.
- St. Pierre R, Swartz J, Murray S, Deck D (1996). Improving family literacy: Findings from the national Even Start evaluation. Cambridge MBT Assoc, Inc.
- Stevens CA, Wesseldine LJ, Couriel JM, Dyer AJ, Osman LM, Silverman M (2002). Parental education and guided self-management of asthma and wheezing in the pre-school child: a randomized controlled trial. *Thorax*, 57, 39-44.
- Summers JA, Behr SK, Turnbull AP (1989). Positive adaptation and coping strengths of families who have children with disabilities. In Singer GHS & Irvin LK (Eds), *Support for Caregiving Families: Enabling positive Adaptation to Disability*.
- Tardieu C, Tardieu G, Colbeau-Justin D(1979). Trophic muscle regulation in children with congenital cerebral lesions. *J Neurol Sci*, 42, 357-364.

- Tardieu C, Huet de la Tour E, Bret MD et al (1982). Muscle hypoextensibility. *Arch Phys Med Rehab*, 63, 97-107.
- Thoman EB, Acebo C, Dreyer CA, Becker PT, Freese MP (1979). Individuality in the interactive process. In EB Thoman (Ed), *Origins of the infant's social responsiveness* (pp. 305-338). NJ: Erlbaum.
- Tieman B, Palisano RJ, Graceley EJ, Rosenbaum P, Chiarello LA, O'Neil M (2004). Changes in mobility of children with CP over time and across environmental settings. *Phys Occup Ther Pediatr*, 24(1-2),109-28.
- Turk MA, Scandale J, Rosenbaum PF, Weber RJ (2001). The health of women with cerebral palsy. *Phys Med Rehabil Clin N Am*,12(1),153-68.
- Turnbull AP, Turbiville V, Turnbull HR (2000). Evolution of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In JP. Shonkoff & SJ. Meisels (Eds), *Handbook of Early Childhood Intervention* (pp.630-650).NY: Cambridge University Press.
- Van Der Ven NC, Weinger K, Yi J, Pouwer F, Ader H, Van Der Ploeg HM, Snoek FJ (2003). The confidence in diabetes self-care scale: psychometric properties of a new measure of diabetes-specific self-efficacy in Dutch and US patients with type 1 diabetes. *Diabetes Care*. 26(3),713-8.
- Walker T, Rodriguez G, Johnson D, Cortez C (1995). AVANCE Parent-child education program. In S. Smith, I Sigel (Eds). *Two generation programs for families in poverty: A new intervention strategy* (pp.67-90). NJ: Ablex.
- International Classification of Functioning, Disability and Health - Children and Youth Version.
- Wikler LD(1986). Family stress theory and research on families of children with mental retardation. In JJ Gallagher and PM Vietze (Eds.) *Families of handicapped persons: research, programs, and policy issues* (pp. 167-196) MD:Brookes.
- Wong J, Wong S, Mensah LL (1983). A conceptual approach to the development of motivational strategies. *Journal of Advanced Nursing*, 8, 111-116.
- Wood W (2000). Attitude change: Persuasion and social influence. *Annu. Rev. Psychol*, 51, 539-570.
- Woollacott MH, Burtner P (1996). Neural and musculoskeletal contributions to the development of stance balance control in typical children and in children with cerebral palsy. *Acta Paediatr Suppl*, 416, 58-62.

- World Health Organization, 2001 World Health Organization. (1980). International Classification of Impairments, Disabilities, and Handicaps. Geneva: World Health Organization.
- World Health Organization. (2001). The International Classification of Functioning, Disability and Health - ICF. Geneva: World Health Organization.
- Zahr LK (1999). Predictors of development in premature infants from low-income families: African Americans and Hispanics. *Journal of Perinatology*, 19 (4), 284-289.



## **APPENDICIES**

## APPENDIX A

### UNIVERSITY OF ILLINOIS AT CHICAGO

Office for the Protection of Research Subjects (OPRS)  
Office of the Vice Chancellor for Research (MC 672)  
203 Administrative Office Building  
1737 West Polk Street  
Chicago, Illinois 60612-7227

### Approval Notice Continuing Review

February 18, 2011

Louisa Susman, MS  
Disability and Human Development  
1640 W Roosevelt Road  
M/C 626  
Chicago, IL 60612  
Phone: (201) 645-4147 / Fax: (312) 416-1430

RE: **Protocol # 2006-0536**  
**“Mediating Effect of Increased Parental Knowledge on Participation of Children with Disabilities through Influence on the Home Environment”**

Dear Ms. Susman:

Your Continuing Review was reviewed and approved by the Expedited review process on February 17, 2011. You may now continue your research.  
Please note the following information about your approved research protocol:

<b><u>Protocol Approval Period:</u></b>	February 23, 2011 - February 22, 2012
<b><u>Approved Subject Enrollment #:</u></b>	120 (Limited to data analysis of 62 subjects)

Additional Determinations for Research Involving Minors: The Board determined that this research satisfies 45CFR46.404', research not involving greater than minimal risk. Therefore, in accordance with 45CFR46.408', the IRB determined that only one parent's/legal guardian's permission/signature is needed. Wards of the State may not be enrolled unless the IRB grants specific approval and assures inclusion of additional protections in the research required under 45CFR46.409'. If you wish to enroll Wards of the State contact OPRS and refer to the tip sheet.

<b><u>Performance Sites:</u></b>	UIC
<b><u>Sponsor:</u></b>	None
<b><u>Research Protocol(s):</u></b>	

## APPENDIX A (continued)

a) Mediating Effects of Increased Parental Knowledge of Development of Children with Disabilities on their Participation in Age-Appropriate Activities through Influence on the Home Environment

Your research meets the criteria for expedited review as defined in 45 CFR 46.110(b)(1) under the following specific categories:

(6) Collection of data from voice, video, digital, or image recordings made for research purposes., (7) Research on individual or group characteristics or behavior (including but not limited to research on perception, cognition, motivation, identity, language, communication, cultural beliefs or practices and social behavior) or research employing survey, interview, oral history, focus group, program evaluation, human factors evaluation, or quality assurance methodologies.

**Please note the Review History of this submission:**

Receipt Date	Submission Type	Review Process	Review Date	Review Action
02/15/2011	Continuing Review	Expedited	02/17/2011	Approved

Please remember to:

☐ Use your **research protocol number** (2006-0536) on any documents or correspondence with the IRB concerning your research protocol.

☐ Review and comply with all requirements on the enclosure,  
**"UIC Investigator Responsibilities, Protection of Human Research Subjects"**

**Please note that the UIC IRB has the prerogative and authority to ask further questions, seek additional information, require further modifications, or monitor the conduct of your research and the consent process.**

**Please be aware that if the scope of work in the grant/project changes, the protocol must be amended and approved by the UIC IRB before the initiation of the change.**

We wish you the best as you conduct your research. If you have any questions or need further help, please contact OPRS at (312) 996-1711 or me at (312) 996-0548. Please send any correspondence about this protocol to OPRS at 203 AOB, M/C 672.

Sincerely,  
 Brandi L. Drumgole, B.S.  
 IRB Coordinator, IRB # 2

**APPENDIX A (continued)****Office for the Protection of Research Subjects**

Enclosure(s):

- 1. UIC Investigator Responsibilities, Protection of Human Research Subjects
- cc: Tamar Heller, Disability and Human Development, M/C 626  
Tamar Heller, Disability and Human Development, M/C 62

## APPENDIX A (continued)

22-OCT-2009 15:48 FROM LISHKAT HAMADAN

TO 90732955533

P.01/07

מדינת ישראל  
משרד החינוך  
לשכת המדען הראשי

ד' חשוון, תש"ע  
22 אוקטובר, 2009

אל: מנהלי מחוזות

שלום רב,

מצ"ב העתק ההיתר הסופי לאיסוף מידע לצורכי המחקר בנושא:  
"השפעה של שיפור ידע החורים ובנוגע להתפתחות של ילדים עם מוגבלות על  
תפקודי הילדים בחיי היום יום"  
בביצוע גב' לואיזה זוסמן.

בברכה,  
דקלה אליאס  
דקלה אליאס  
רכזת לשכה בכירה

## APPENDIX A (continued)

## נספח III

בקשה להשתתפות במחקר הכרוך בהתערבות חינוכית להורים לילדים עם שיתוק מוחין

נושא המחקר: "השפעת הידע של הורים לגבי התפתחות ילדים עם מוגבלויות על פעילותם של הילדים"

הורים יקרים שלום,

שמי לואיזה זוסמן, סטודנטית לתואר שלישי באוניברסיטת אילינוי בשיקאגו שבארצות הברית. במסגרת עבודת הדוקטורט שלי אני מעוניינת לבדוק את השפעת הידע של הורים לילדים עם מוגבלויות על התפתחות הילד ועל השתתפותו בפעילויות יום-יומיות טיפוסיות.

ההשתתפות שלכם ושל ילדיכם במחקר זה הינה בהתנדבות: החלטתכם להשתתף או לא, לא תשפיע על קשריכם העכשוויים או העתידיים עם האוניברסיטה או המרכז שבו ילדכם מקבל שירותי התערבות. כמו כן, גם אם תחליטו להשתתף, הנכם זכאים להפסיק את השתתפותכם כל עת שתמצאו מבלי שתהיה לכך השפעה על הקשר עם הגורמים שצוינו.

מטרתו העיקרית של המחקר היא לבדוק האם קורס להורים בנושא עידוד התפקוד בקרב ילדים עם שיתוק מוחין יעזור להורים לדעת ולהבין יותר טוב על אודות תהליך ההתפתחות של ילדים עם שיתוק מוחין, והאם ידע זה יגרום לשינוי הסביבה הביתית וישפר את השתתפותו של הילד בתפקודים יום-יומיים. אם תסכימו להשתתף במחקר זה נבקש מכם את הדברים הבאים:

1. להרשות לחוקר להיכנס לבתיכם כדי:

א. לצפות ולצלם באמצעות וידאו את האינטראקציה היום-יומית ביניכם לבין ילדיכם למשך שעה עד שעתיים.

ב. לראיין אתכם על אודות פעולות שונות שאתם עושים עם ילדיכם בבית.

ג. למלא כמה שאלונים לגבי:

- המצב הרפואי של ילדיכם
- תחומתכם לגבי הקשר שלכם עם ילדיכם
- הידע שלכם לגבי התפתחות ילדיכם
- מידע על עיסוקיכם: העבודה שלכם, חינוך וכו'

## APPENDIX A (continued)

משך התצפית באינטראקציות היום-יומיות ביניכם וילדיכם ומילוי השאלונים יארכו בין 2 עד 3 שעות וניתן יהיה לחלקן לשתי פגישות, בהתאם לרצונכם.

2. מחלק מההורים נבקש, בנוסף לפעולות איסוף המידע הנ"ל, להשתתף בקורס ההורים. הקורס יכול להימשך פגישות שיתפרסו על עשרה שבועות, קרוב לאזור מגוריהם. הבחירה של המשתתפים בקורס זה תיעשה באקראי. הקורס יתקיים בבתים פרטיים. כל פגישה תיערך בין שעה וחצי עד שתיים. הקורס יאפשר לכם ללמוד דברים רבים שייתנו לכם ידע לגבי ילדיכם ודברים שאתם יכולים לעשות בבית ובמקומות אחרים בכדי לעזור לה/לו להשתתף באופן מלא יותר בחיי המשפחה ובסביבתו הטבעית. יתר ההורים שייטלו חלק במחקר יהוו את קבוצת הביקורת (כלומר, לא ישתתפו בקורס). עם זאת, יוצע להורים אלה להשתתף בפגישה אחת שבה יתוארו התכנים שהועברו להורים שהשתתפו בקורס.

בסוף הקורס יערכו שוב ראיונות, תצפיות, ומילוי שאלונים לכלל ההורים.

האנשים היחידים שידעו על השתתפותכם במחקר יהיו האנשים שהם חלק מצוות המחקר, אנשים מהמרכז שבו גייסו אתכם למחקר והורים שנמצאים אתכם בקבוצה. אנו נקפיד לשמור על חסיון מלא של כל המידע שייאסף במהלך המחקר, אשר ישמש אך ורק לצורכי מחקר זה ולא יועבר לאף גורם, פרט לצוות המחקר. עוד יודגש כי הממצאים יפורסמו באופן שלא יאפשר לזהות את המשתתפים במחקר. כמו כן, כל מידע מזוהה שייאסף יושמד מייד עם תום עיבוד הנתונים או עד לתאריך 31.12.2008, המועד המוקדם מבין השניים. זאת, למעט קלטות הוידאו שעל פי בקשת האוניברסיטה לא יושמדו, אך יטושטשו בהן פני הנבדקים באופן שלא ניתן יהיה לזהותם.

יצוין כי אין תגמול כספי עבור ההשתתפות במחקר זה או ההוצאות האישיות הכרוכות בהשתתפות (נסיעות, שמרטף וכו').

אם יתעוררו שאלות, ניתן לפנות אלי בכל שאלה הקשורה למחקר במספר טלפון 054-582-0265. כמו כן ניתן להתקשר אל המנחה תמר הלר בארה"ב בטלפון 011-312-413-1647.

אם אתם מסכימים להשתתף במחקר, אנא חתמו על כתב ההסכמה בעמוד הבא, והעבירו אותו בהקדם האפשרי אל המרכז שבו מטופל ילדיכם.

## APPENDIX A (continued)

לכבוד

לואיזה זוסמן,

ג"נ

הנדון: כתב הסכמה לאיסוף נתונים מזוהים

הואיל ואת עורכת מחקר ותכנית התערבות בנושא "השפעת ידע ההורים על התנהגויותיהם של ילדים עם שיתוק מוחין" והואיל וביקשת את הסכמתי לכך שתאספי במסגרת המחקר והתכנית נתונים מזוהים (להלן "הנתונים") אודותי ואדות בני/בתי \_\_\_\_\_ (שם הבן/בת)

לפיכך הריני מצהיר בזאת כדלקמן:

1. כי מסרת והסברת לי את מטרות המחקר והתכנית ואת הנושאים ואת הסוגיות שייבדקו במסגרתם

2. כי מסרת והסברת לי את כל הפעולות, על תוכנן, הכרוכות בהשתתפות במסגרת מחקר זה והתכנית הנלווית אליו

3. כי ציינת בפניי את המועד שבו יושמד הזיהוי מהנתונים שייאספו

4. כי תיארת בפניי את כל האמצעים שתנקוט כדי להבטיח את סודיות הנתונים המזוהים עד אשר יושמד זיהויים

5. כי מסרת לי את אופן פרסומם של הנתונים

6. לאחר שהבנתי את כל האמור לעיל, הריני נותן בזה את הסכמתי לאיסוף הנתונים על ידך. ולראיה באתי על החתום

חתימה

שם האב/האם

תאריך



## **APPENDIX B**

### **Child's Current Medical Status**

**Name of child:**

**Diagnosis:**

**Please answer briefly:**

**How is your child's overall health?**

**Please describe any complications concerning your child's current overall health.**

**Please list the visits to your child's primary medical provider and reasons for these visits over the last six months.**

**Medications:**

**Surgeries:**

**Hospitalizations:**

## APPENDIX C

### GMFCS



CanChild Centre for Childhood Disability Research  
Institute for Applied Health Sciences, McMaster University,  
1400 Main Street West, Room 408, Hamilton, ON, Canada L8S 1C7  
Tel: 905-525-9140 ext. 27850 Fax: 905-522-6095  
E-mail: [canchild@mcmaster.ca](mailto:canchild@mcmaster.ca) Website: [www.canchild.ca](http://www.canchild.ca)

### 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*

GMFCS © Robert Palisano, Peter Rosenbaum, Stephen Walter, Dianne Russell, Ellen Wood, Barbara Galuppi, 1997  
*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, crutches, or canes) or wheeled mobility, and to a much lesser extent, quality of movement. The distinctions between Levels I and II 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 I (i.e., can pull to stand and walk), would be classified in Level I. 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., distances 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.

## APPENDIX C (continued)

### 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-propels 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

- |                  |   |  |
|------------------|---|--|
| <b>LEVEL I</b>   | - | Walks without Limitations                                |
| <b>LEVEL II</b>  | - | Walks with Limitations                                   |
| <b>LEVEL III</b> | - | Walks Using a Hand-Held Mobility Device                  |
| <b>LEVEL IV</b>  | - | Self-Mobility with Limitations; May Use Powered Mobility |
| <b>LEVEL V</b>   | - | 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.

## APPENDIX C (continued)

Gross Motor Function Classification System – Expanded and Revised (GMFCS – E & R)	
BEFORE 2 <sup>ND</sup> BIRTHDAY	
<b>LEVEL I:</b> 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.	
<b>LEVEL II:</b> 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.	
<b>LEVEL III:</b> Infants maintain floor sitting when the low back is supported. Infants roll and creep forward on their stomachs.	
<b>LEVEL IV:</b> Infants have head control but trunk support is required for floor sitting. Infants can roll to supine and may roll to prone.	
<b>LEVEL V:</b> 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 2 <sup>ND</sup> AND 4 <sup>TH</sup> BIRTHDAY	
<b>LEVEL I:</b> 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.	
<b>LEVEL II:</b> 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.	
<b>LEVEL III:</b> Children maintain floor sitting often by "W-sitting" (sitting between flexed and internally rotated hips and knees) and may require adult assistance to assume 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.	
<b>LEVEL IV:</b> 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.	
<b>LEVEL V:</b> 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 4 <sup>TH</sup> AND 6 <sup>TH</sup> BIRTHDAY	
<b>LEVEL I:</b> 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 without the need for objects for support. Children walk indoors and outdoors, and climb stairs. Emerging ability to run and jump.	
<b>LEVEL II:</b> 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.	
<b>LEVEL III:</b> 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 on 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.	
<b>LEVEL IV:</b> 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.	
<b>LEVEL V:</b> 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.	

## APPENDIX D

### Family Demographic Form

**Name of child:**

**Name of Father:**

**Name of Mother:**

**Address:**

**Phone numbers: Home:**

**Work:**

**Cell phone:**

**Age of parents:**

**Father:**

**Mother:**

**Parents' education in years:**

**Father:**

**Mother:**

**Marital Status: (Please circle)**

**Father: Single**

**Married**

**Divorced**

**Mother: Single**

**Married**

**Divorced**

**Occupation and place of employment:**

**Father:**

**Mother:**

**Hours of work per week:**

**Father:**

**Mother:**

**Siblings: (please list year of birth and gender)**

**1.**

**2.**

**3.**

**4.**

**5.**

**6.**

**7.**

**8.**

**Additional family members living at home:**

**School child is currently attending:**

## APPENDIX E

### Parental Self-Efficacy Checklist

Please indicate how much you agree with the following statements about your child's current effect on your life.

For each item write the best response from the code.

<u>Strongly Disagree</u>	<u>Disagree</u>	<u>Agree</u>	<u>Strongly Agree</u>
1	2	3	4

I would make a fine model for a parent of a child with a disability \_\_\_\_\_

I feel I can manage my child's behavior \_\_\_\_\_

If anyone can find the answer to what is troubling my child I can \_\_\_\_\_

I honestly believe I have the skills necessary to be a good caregiver to my child \_\_\_\_\_

Taking responsibility for my child gives my self-esteem a boost \_\_\_\_\_

I feel that what I do can help improve my child's situation \_\_\_\_\_

## APPENDIX F

**Knowledge of Development and Capabilities of Child with Cerebral Palsy (CP) Inventory**  
Please circle next to each statement if you agree, disagree or are unsure

<b>1. The motor patterns of development of a child with CP are similar to a child with normal development, but their development is slower.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>2. It is important to for a child with CP to participate in activities with same age peers.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>3. The home environment is a very important influence on a child's development.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>4. It is important to encourage a child with CP to initiate and develop independence as much as the child can.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>5. Encouragement and providing opportunities to participate in activities that are age- appropriate can help improve the cognitive abilities of a child with CP.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>6. According to the World Health Organization, the term "participation" refers to age appropriate functions, such as communication and dressing that a child can complete independently.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>7. The term “barrier” or impairment refers to limitations imposed by the physical impairment of a child with CP.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>8. Coping with “barriers” is dealt with only by the child with CP and his/her family.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>9. The current functional abilities of the CP child cannot predict future abilities. There is a need to wait for his maturation for this to be known.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>



**APPENDIX F (continued)**

<b>10. If a child with CP can complete an activity in a specific environment for example his home, he will be able to do the same activity anywhere.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>11. A child with CP cannot play with toys/games that are age appropriate for him/her, because of his impairment.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>12. The term play refers only to an activity with toys or objects.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>13. It is critical to provide therapeutic intervention prior to two years of age because you may miss the critical stage of the development of the brain which occurs by two years of age.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>14. The number and types of interventions provided to children are the critical factor determining whether a child will walk or talk.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>15. The play of a child with CP will always be restricted and he/she will not be able to play at a level matching their cognitive abilities.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>16. It is most likely that adaptive equipment will not significantly improve the daily functions of a child with CP.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>17. Because a child with CP has such difficulty with daily activities maximal help must be provided to them in all activities.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>18. The use of augmentative communication accessories can delay the speech development of a child.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>



**APPENDIX F (continued)**

<b>19. The abilities of a child with CP in any specific environment, like at home, indicate his abilities in all other environments like preschool/school.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>20. Children with CP do not need to participate in sports activities.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>21. A child who does not walk by 18 months will not walk independently.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>22. Sitting in a chair with support before acquiring independent sitting, might cause orthopedic problems.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>23. It is preferable to wait and start treatment intervention only after the child's diagnosis is determined.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>24. A child should stand only after he can stand up alone.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>25. A child should sit alone only after he can come to sit independently.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>26. Because a lot of activities are very difficult for a child with CP, a lack of motivation is the most significant reason for an inability to succeed in many things.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>27. A child has to lie on his stomach as much as possible in order to learn to crawl.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>28. Adapted equipment should be used to improve function in a child with CP.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>29. A child with CP needs to receive maximal help to prevent frustration.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>30. There is no need to use augmentative communication devices if the family understands the child.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>

**APPENDIX F (continued)**

<b>31. A child with CP should not sit in a regular bath until they are able to sit independently.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>32. A child with CP must walk in order to be able to be integrated in a regular school.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>33. It is not worthwhile for a young child with CP to move with the help of accessory devices for locomotion, in order to prevent a decrease in his activity and motivation for walking in the long term.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>34. It is not advisable for a child with CP to play in the playground because he/she may get hurt.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>35. The most important thing for a child with CP is to learn is to walk so that he/she can be like other kids their age.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>36. When parents of a child with CP understand what their child wants to say and understand his needs, it isn't so important if others find it hard to understand him.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>37. When a child with CP invites a child home to play, it is preferable for the child to be younger in age.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>38. Participation and function are the same thing.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>39. A child with CP may get tired faster than a child without CP because daily activities require him/her to use more effort and energy.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>40. The emotional and behavioral development of a child with CP is similar to that of a child without CP.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>

**APPENDIX F (continued)**

<b>41. It is not worthwhile to set limits for a child with CP because everything is hard for them.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>42. Toys that are a lot higher than a child with CP's current cognitive abilities are best to help a child develop more quickly intellectually.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>43. Due to the difficulties of a child with CP –he/she do not have to help out around the house.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>44. A child with CP should perform most of his activities on the floor.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>
<b>45. A child with CP needs to receive maximal help to prevent frustration.</b>	<b>Agree</b>	<b>Disagree</b>	<b>Unsure</b>

## APPENDIX G

### Home Observation Measurement of the Environment: Infant and Toddler (IT-HOME)

**INFANT/TODDLER HOME INVENTORY**  
Bettye M. Caldwell and Robert H. Bradley

Family name \_\_\_\_\_ Date \_\_\_\_\_ Visitor \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Child's name \_\_\_\_\_ Birthdate \_\_\_\_\_ Age \_\_\_\_\_ Sex \_\_\_\_\_

Parent present \_\_\_\_\_ If other than parent, relationship to child \_\_\_\_\_

Family composition \_\_\_\_\_  
(persons living in household, including sex and age of children)

Family ethnicity \_\_\_\_\_ Language spoken \_\_\_\_\_ Maternal education \_\_\_\_\_ Paternal education \_\_\_\_\_

Is mother employed? \_\_\_\_\_ Type of work when employed \_\_\_\_\_

Is father employed? \_\_\_\_\_ Type of work when employed \_\_\_\_\_

Current child care arrangements \_\_\_\_\_

Summarize past year's arrangements \_\_\_\_\_

Other persons present during visit \_\_\_\_\_

Comments \_\_\_\_\_

**SUMMARY**

Subscale	Score	Lowest Fourth	Middle Half	Upper Fourth
I. RESPONSIVITY		0 - 6	7 - 9	10 - 11
II. ACCEPTANCE		0 - 4	5 - 6	7 - 8
III. ORGANIZATION		0 - 3	4 - 5	6
IV. LEARNING MATERIALS		0 - 4	5 - 7	8 - 9
V. INVOLVEMENT		0 - 2	3 - 4	5 - 6
VI. VARIETY		0 - 1	2 - 3	4 - 5
TOTAL SCORE		0 - 25	26 - 36	37 - 45

For rapid profiling of a family, place an X in the box that corresponds to the raw score on each subscale and the total score.

## APPENDIX G (continued)

Infant/Toddler HOME		
Place a plus (+) or minus (-) in the box alongside each item if the behavior is observed during the visit or if the parent reports that the conditions or events are characteristic of the home environment. Enter the subtotal and the total on the front side of the Record Sheet.		
<b>I. RESPONSIVITY</b>		24. Child has a special place for toys and treasures.
1. Parent spontaneously vocalizes to child at least at least twice.		25. Child's play environment is safe.
2. Parent responds verbally to child's vocalizations or verbalizations.		<b>IV. LEARNING MATERIALS</b>
3. Parent tells child name of object or person during visit.		26. Muscle activity toys or equipment.
4. Parent's speech is distinct, clear and audible.		27. Push or pull toy.
5. Parent initiates verbal interchanges with Visitor.		28. Stroller or walker, kiddie car, scooter, or tricycle.
6. Parent converses freely and easily.		29. Parent provides toys for child to play with during visit.
7. Parent permits child to engage in "messy" play.		30. Cuddly toy or role-playing toys.
8. Parent spontaneously praises child at least twice.		31. Learning facilitators—mobile, table and chair, high chair, play pen.
9. Parent's voice conveys positive feelings toward child.		32. Simple eye-hand coordination toys.
10. Parent caresses or kisses child at least once.		33. Complex eye-hand coordination toys.
11. Parent responds positively to praise of child offered by Visitor.		34. Toys for literature and music.
<b>II. ACCEPTANCE</b>		<b>V. INVOLVEMENT</b>
12. Parent does not shout at child.		35. Parent keeps child in visual range, looks at often.
13. Parent does not express overt annoyance with or hostility to child.		36. Parent talks to child while doing household work.
14. Parent neither slaps nor spansks child during visit.		37. Parent consciously encourages developmental advance.
15. No more than 1 instance of physical punishment during past week.		38. Parent invests maturing toys with value via personal attention.
16. Parent does not scold or criticize child during visit.		39. Parent structures child's play periods.
17. Parent does not interfere with or restrict child 3 times during visit.		40. Parent provides toys that challenge child to develop new skills.
18. At least 10 books are present and visible.		<b>VI. VARIETY</b>
19. Family has a pet.		41. Father provides some care daily.
<b>III. ORGANIZATION</b>		42. Parent reads stories to child at least 3 times weekly.
20. Child care, if used, is provided by one of three regular substitutes.		43. Child eats at least one meal a day with mother and father.
21. Child is taken to grocery store at least once a week.		44. Family visits relatives or receives visits once a month or so.
22. Child gets out of house at least 4 times a week.		45. Child has 3 or more books of his/her own.
23. Child is taken regularly to doctor's office or clinic.		
<b>TOTALS:</b> I _____ II _____ III _____ IV _____ V _____ VI _____ <b>TOTAL</b> _____		

## APPENDIX H

## Home Observation Measurement of the Environment: Early Childhood (EC-HOME)

25

**EARLY CHILDHOOD HOME INVENTORY**  
 Bettye M. Caldwell and Robert H. Bradley

Family name \_\_\_\_\_ Date \_\_\_\_\_ Visitor \_\_\_\_\_

Child's name \_\_\_\_\_ Birthdate \_\_\_\_\_ Age \_\_\_\_\_ Sex \_\_\_\_\_

Caregiver for visit \_\_\_\_\_ Relationship to child \_\_\_\_\_

Other persons present during visit \_\_\_\_\_

Family composition \_\_\_\_\_  
(persons living in household, including sex and age of children)

Family ethnicity \_\_\_\_\_ Language spoken \_\_\_\_\_ Maternal education \_\_\_\_\_ Paternal education \_\_\_\_\_

Is mother employed? \_\_\_\_\_ Type of work when employed \_\_\_\_\_

Is father employed? \_\_\_\_\_ Type of work when employed \_\_\_\_\_

Address \_\_\_\_\_ Phone \_\_\_\_\_

Current child care arrangements \_\_\_\_\_

Summarize past year's arrangements \_\_\_\_\_

## SUMMARY

Subscale	Score	Lowest Fourth	Middle Half	Upper Fourth
I. LEARNING MATERIAL		0 - 2	3 - 9	10 - 11
II. LANGUAGE STIMULATION		0 - 4	5 - 6	7
III. PHYSICAL ENVIRONMENT		0 - 3	4 - 6	7
IV. RESPONSIVITY		0 - 3	4 - 5	6 - 7
V. ACADEMIC STIMULATION		0 - 2	3 - 4	5
VI. MODELING		0 - 1	2 - 3	4 - 5
VII. VARIETY		0 - 4	5 - 7	8 - 9
VIII. ACCEPTANCE		0 - 2	3	4
<b>TOTAL SCORE</b>		<b>0 - 29</b>	<b>30 - 45</b>	<b>46 - 55</b>

For rapid profiling of a family, place an X in the box that corresponds to the raw score.



## APPENDIX H (continued)

### Home Observation Measurement of the Environment: Early Childhood (EC-HOME)

#### Early Childhood HOME

Place a plus (+) or minus (-) in the box alongside each item if the behavior is observed during the visit or if the parent reports that the conditions or events are characteristic of the home environment. Enter the subtotal and the total on the front side of the Record Sheet.

<b>I. LEARNING MATERIALS</b>	24. Rooms are not overcrowded with furniture.	
1. Child has toys which teach colors, sizes, and shapes.	25. House is reasonably clean and minimally cluttered.	
2. Child has three or more puzzles.	<b>IV. RESPONSIVITY</b>	
3. Child has record player or tape recorder and at least 5 children's records or tapes.	26. Parent holds child close 10-15 minutes per day.	
4. Child has toys or games permitting free expression.	27. Parent converses with child at least twice during visit.	
5. Child has toys or games requiring refined movements.	28. Parent answers child's questions or requests verbally.	
6. Child has toys or games which help teach numbers.	29. Parent usually responds verbally to child's speech.	
7. Child has at least 10 children's books.	30. Parent praises child's qualities twice during visit.	
8. At least 10 books are visible in the apartment or home.	31. Parent caresses, kisses, or cuddles child during visit.	
9. Family buys and reads a daily newspaper.	32. Parent helps child demonstrate some achievement during visit.	
10. Family subscribes to at least one magazine.	<b>V. ACADEMIC STIMULATION</b>	
11. Child is encouraged to learn shapes.	33. Child is encouraged to learn colors.	
<b>II. LANGUAGE STIMULATION</b>	34. Child is encouraged to learn patterned speech.	
12. Child has toys that help teach the names of animals.	35. Child is encouraged to learn spatial relationships.	
13. Child is encouraged to learn the alphabet.	36. Child is encouraged to learn numbers.	
14. Parent teaches child simple verbal manners (please, thank you, I'm sorry).	37. Child is encouraged to learn to read a few words.	
15. Parent uses correct grammar and pronunciation.	<b>VI. MODELING</b>	
16. Parent encourages child to talk and takes time to listen.	38. Some delay of food gratification is expected.	
17. Parent's voice conveys positive feelings about child.	39. TV is used judiciously.	
18. Child is permitted choice in breakfast or lunch menu.	40. Parent introduces Visitor to child.	
<b>III. PHYSICAL ENVIRONMENT</b>	41. Child can express negative feelings without harsh reprisal.	
19. Building appears safe and free of hazards.	42. Child can hit parent without harsh reprisal.	
20. Outside play environment appears safe.	<b>VII. VARIETY</b>	
21. Interior of apartment is not dark or perceptually monotonous.	43. Child has real or toy musical instrument.	
22. Neighborhood is aesthetically pleasing.	44. Child is taken on outing by a family member at least every other week.	
23. House has 100 square feet of living space per person.	45. Child has been on trip more than 50 miles during last year.	

## APPENDIX H (continued)

46. Child has been taken to a museum during past year.	VIII. ACCEPTANCE
47. Parent encourages child to put away toys without help.	52. Parent does not scold or yell at or derogate child more than once.
48. Parent uses complex sentence structure and vocabulary.	53. Parent does not use physical restraint during visit.
49. Child's art work is displayed some place in house.	54. Parent neither slaps nor spans child during visit.
50. Child eats at least one meal per day with mother (or mother figure) and father (or father figure).	55. No more than one instance of physical punishment occurred during the past week.
51. Parent lets child choose certain favorite food products or brands at grocery store.	

**TOTALS:**

I \_\_\_\_\_ II \_\_\_\_\_ III \_\_\_\_\_ IV \_\_\_\_\_ V \_\_\_\_\_ VI \_\_\_\_\_ VII \_\_\_\_\_ VIII \_\_\_\_\_

**TOTAL** \_\_\_\_\_

Comments \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_



## APPENDIX I

### Checklist of Child Participation in Age-Appropriate Activities

**In the last month, approximately how often did your child engage in the following activities?**

**For each item, write in the most appropriate number from the code.**

Not at all 1	Once a month 2	2-3 Times a month 3	Once A week 4	2-3 Times a week 5	Daily 6
-----------------	----------------------	---------------------------	---------------------	--------------------------	------------

1. How often does your child play an activity or game with a family member? (parent, sibling, grandparent) \_\_\_\_\_
2. How often does your child select a toy or game during play activities? \_\_\_\_\_
3. How often does your child select a book for you to read? \_\_\_\_\_
4. How often does your child select his/her outfit? \_\_\_\_\_
5. How often does your child select a favorite food item to eat during mealtimes? \_\_\_\_\_
6. How often does your child help in everyday activities such as food preparation, setting the table, straightening up their toys? \_\_\_\_\_
7. How often does your child play in the playground? \_\_\_\_\_
8. How often does your child choose the activity in the playground? \_\_\_\_\_
9. How often does your child play/interact with a peer in the playground? \_\_\_\_\_
10. How often does your child participate in an after school activity such as gymboree, visit to the library, or storytelling hour? \_\_\_\_\_
11. How often does your child invite a child to play at their house? \_\_\_\_\_
12. How often does your child go to a friend for a play date? \_\_\_\_\_
13. How often does your child participate in a trip to the supermarket or shopping mall? \_\_\_\_\_
14. How often does your child participate in family trips or outings? This may include attending a local religious service. \_\_\_\_\_
15. How often does your child attend appropriate family celebrations (celebrations in which other young children in the immediate or extended family are present)? \_\_\_\_\_

## **APPENDIX J**

### **Post Intervention Survey**

- 1. Have you participated in similar meetings in the past, please explain.**
- 2. Were there any additional topics that would have been important to include, please describe.**
- 3. Which topics I any would you have liked to discussed further.**
- 4. Was any of the information included unimportant?**
- 5. Would you recommend these groups to other parents and would you participate in similar groups in the future?**

## APPENDIX K

### Hebrew Translations

Child's Current Medical Status      מצב רפואי של ילדכם

שם הילד:

אבחנה:

נא לענות בקצרה על השאלות הבאות:

מה מצב בריאותי הכללי של ילדיכם:

תיאור סיבוכים בנוגע לבריאות הכללי של ילדיכם:

רשימת הביקורים לרופא המשפחה וסיבות הביקורים במשך החצי שנה האחרונה:

תרופות:

ניתוחים:

אשפוזים:

## APPENDIX K (continued)

## Family Demographic Form. מידע משפחתי

שם הילד:			
שם האב:		שם האם:	
כתובת:			
טלפון בבית:	בעבודה:	סלולרי:	
גיל ההורים:	אב:	אם:	
שנות לימוד:	אב:	אם:	
מצב משפחתי: (נא לעקוף בעיגול)			
האב:	נשוי	רווק	גרש
האם:	נשוי	רווק	גרש
מקום עבודה ושעות עבודה שבועיות:		אב:	
אם:		שעות:	
אם:		שעות:	
אחים: (נא לצרף שנת לידה ומין)			
1.	5.		
2.	6.		
3.	7.		
4.	8.		
בני משפחה נוספים שגרים בבית:			
מסגרת לימודית הנוכחית של ילדיכם:			

## APPENDIX K (continued)

## Parental Self-Efficacy Checklist שאלון הערכה עצמי של ההורה

נא לרשום באיזה מידה אתם מסכימים עם המשפטים הבאים לגבי השפעתכם על אורך החיים של ילדיכם .  
לכל משפט נא לציין התשובה הכי טובה

<u>לא מסכים בכלל</u>	<u>לא מסכים</u>	<u>מסכים</u>	<u>מאד מסכים</u>
1	2	3	4

1. אני מהווה דוגמא טובה של הורה לילד עם לקות  
\_\_\_\_\_
2. אני מרגיש שאני יכול להתנהל מול התנהגות ילדי  
\_\_\_\_\_
3. אם מישהו יכול להבין מה מפריע לילדי זה אני  
\_\_\_\_\_
4. אני מאמין שיש לי את הכישורים הנדרשים להיות מטפל/מטפלת טובה לילד שלי  
\_\_\_\_\_
5. לקיחת אחריות על ילדי מגבירה את הדימוי העצמי שלי  
\_\_\_\_\_
6. אני מרגיש שבמעשי אני יכול לשפר את מצב ילדי  
\_\_\_\_\_

## APPENDIX K (continued)

## Checklist of Child Participation in Age Appropriate Activities

שאלון על השתתפות ילדיכם היום-יומי

במהלך החודש האחרון כמה פעמים ילדיכם השתתף בפעילויות הבאות:  
לכל פריט נא לציין המספר המתאים ביותר לפי התיאור הבא .

1. באיזה תדירות ילדך לקח חלק במשחק או בפעילות עם בני משפחה?  
(כולל הורים, אחים, סבים)  
\_\_\_\_\_
2. באיזה תדירות ילדך בחר בסוג משחק בזמן פעילותיו?  
\_\_\_\_\_
3. באיזה תדירות ילדך בחר את הספר שתקראו לו?  
\_\_\_\_\_
4. באיזה תדירות ילדך בחר את בגדיו?  
\_\_\_\_\_
5. באיזה תדירות ילדך בחר את האוכל בשעת ארוחה?  
\_\_\_\_\_
6. כמה פעמים ילדך עזר בעבודות הבית כגון: הכנת אוכל, עריכת שולחן, סידור משחקיו?  
\_\_\_\_\_
7. באיזה תדירות ילדך שיחק בגן שעשועים?  
\_\_\_\_\_
8. באיזה תדירות ילדך בחר במתקנים או פעילויות בגן השעשועים?  
\_\_\_\_\_
9. באיזה תדירות ילדך שיחק או קיים אינטראקציה עם ילד בן גילו בגן השעשועים ?  
\_\_\_\_\_
10. באיזה תדירות ילדך השתתף בפעילות מחוץ למסגרת הלימודית של הגן לדוגמא: נופש פעיל, ביקור בספריה, שעת סיפור או חוג?  
\_\_\_\_\_
11. באיזה תדירות ילדך הזמין חבר לשחק אצלו בבית?  
\_\_\_\_\_
12. באיזה תדירות ילדך ביקר אצל חבר בביתו?  
\_\_\_\_\_
13. באיזה תדירות ילדך השתתף ביציאה לסופרמרקט/מכולת או לקניון?  
\_\_\_\_\_
14. באיזה תדירות ילדך השתתף בטיול משפחתי? (כולל ביקור בבית הכנסת)  
\_\_\_\_\_
15. באיזה תדירות ילדך השתתף באירועים משפחתיים? (אירועים מתאימים לילדים צעירים מהמשפחה)  
\_\_\_\_\_

(הקרובה)

**APPENDIX K (continued)****שאלון הורים Post Intervention Survey**

1. האם המידע שהועבר במפגשים התאים לצרכיכן? הסברנה למה.
2. האם היו נושאים נוספים לדעתכן שחשוב לכלול.
3. האם לדעתכן נושאים שהייתם רוצות להאריך בהם?
4. האם הועבר מידע שהיה פחות חשוב לכן להתמקד בו?
5. האם הייתם ממליצות להורים אחרים להשתתף בסנה זו? למה?

## APPENDIX K (continued)

### Parent Observation Checklist    טופס להסתכלות של ההורים

תאריך: שעה: אורך זמן של ההסתכלות:

אנשים נמצאים:

מקום: (לדוגמא: בבית בסלון, מטבח, גן שעשועים, מכלת)

משימה:

כמה פעמים ילדיכם יזם את התפקוד:

איך הוא יזם את התפקוד? (שפת גוף, דיבור, מגע, ג'סטה)

תיאור המקרה:

הגבלות: (אספקטים של הסביבה שתרמו או הגבילו את ילדיכם)

פתרונות האפשריים



## APPENDIX K (continued)

אנא היקף ליד כל משפט האם אתה מסכים, לא מסכים, לא יודע

ידע על ידע התפתחות של ילד עם שיתוק מוחין

מסכים	לא מסכים	לא יודע	1. דגמי ההתפתחות מוטוריים של ילד עם שיתוק מוחין דומים לאלה של ילד עם התפתחות תקינה, אך התפתחותם איטית יותר.
מסכים	לא מסכים	לא יודע	2. חשוב לילדים עם שיתוק מוחין להשתתף בפעילויות עם ילדים בני גילו.
מסכים	לא מסכים	לא יודע	3. הסביבה הביתית חשובה מאוד בהשפעתה על התפתחות הילד.
מסכים	לא מסכים	לא יודע	4. חשוב לעודד ילד עם שיתוק מוחין ליזום ולפתח עצמאות ככל הניתן.
מסכים	לא מסכים	לא יודע	5. עידוד ומתן הזדמנויות להשתתף בפעילויות תואמות גיל, עשוי לשפר את יכולותיו הקוגניטיביות של הילד עם שיתוק המוחין.
מסכים	לא מסכים	לא יודע	6. עפ"י ארגון הבריאות העולמי, המונח "השתתפות" מתייחס לתפקודים תואמי גיל שילד יכול לבצע באופן עצמאי לחלוטין, כגון: תקשורת, התלבשות.
מסכים	לא מסכים	לא יודע	7. תפקוד המוטורי הנוכחי של ילד עם שיתוק מוחין אינו יכול לנבא את יכולותיו העתידיות. יש צורך לחכות עד להתבגרותו.
מסכים	לא מסכים	לא יודע	8. ילד שלא הולך עד גיל 18 חודש, לא יוכל ללכת עצמאי.
מסכים	לא מסכים	לא יודע	9. אם ילד עם שיתוק מוחין מסוגל לבצע פעילות בסביבה מסוימת כגון בבית, הוא מסוגל לעשות אותה הפעילות בכל מקום.
מסכים	לא מסכים	לא יודע	10. הצבת גבולות לילד עם שיתוק מוחין גורמת לתסכול הפוגע בתפקודו הרגשי/ בבריאותו הנפשית.
מסכים	לא מסכים	לא יודע	11. המונח "משחק" מתייחס רק לפעילות עם צעצועים או חפצים.

## APPENDIX K (continued)

לא יודע	לא מסכים	מסכים	12. מספר הטיפולים וריבוי סוגי הטיפולים הם לא הדבר העיקרי שיקבע האם ילדיכם ילך ו/או ידבר.
לא יודע	לא מסכים	מסכים	13. השחק של ילד עם שיתוק מוחין תמיד יהיה מוגבל והוא אף פעם לא יוכל לשחק באופן התואם את יכולותיו הקוגניטיביות.
לא יודע	לא מסכים	מסכים	14. סביר להניח שהתאמות ציוד לא יעזרו לשפר באופן משמעותי את תפקודי היומיום של הילד עם שיתוק המוחין.
לא יודע	לא מסכים	מסכים	15. מכוון שלילד עם שיתוק מוחין קשה מידי בתפקודי יום יום צריך להגיש לו עזרה מקסימאלית בכל התפקודים.
לא יודע	לא מסכים	מסכים	16. עדיף לילדים עם שיתוק מוחין לשחק עם צעצועים על הרצפה כי ככה ירגיש יותר בטוח.
לא יודע	לא מסכים	מסכים	17. שימוש בעזרי תקשורת תומכת עלול לעכב את התפתחות הדיבור של הילד.
לא יודע	לא מסכים	מסכים	18. היכולות של הילד עם שיתוק מוחין בסביבה מסוימת, כגון הבית, מעידות על יכולותיו בכל הסביבות האחרות, כגון גן/בי"ס.
לא יודע	לא מסכים	מסכים	19. עדיף שילד עם שיתוק מוחין לא ישתתף בפעילויות ספורט.
לא יודע	לא מסכים	מסכים	20. המונח "מחסום" או מוגבלות מתייחס להגבלות הנובעות מהלקות הפיזית של הילד עם שיתוק מוחין.
לא יודע	לא מסכים	מסכים	21. ישיבה בכסא עם תמיכה לפני רכישת ישיבה עצמאית, עלולה לגרום לבעיות אורתופדיות.
לא יודע	לא מסכים	מסכים	22. בגלל הקשיים של ילד עם שיתוק מוחין אסור להציב לו גבולות כמו לילדים אחרים במשפחה.

## APPENDIX K (continued)

לא יודע	לא מסכים	מסכים	. ילד עם שיתוק מוחין אמור לעמוד רק לאחר שהוא יכול להיעמד לבד.
לא יודע	לא מסכים	מסכים	24. הדבר החשוב ביותר לילד עם שיתוק מוחין הוא לרכוש הליכה בכדי לשחק עם ילדים בני גילו.
לא יודע	לא מסכים	מסכים	25. חוסר מוטיבציה היא אחת הסיבות הכי משמעותית לאי יכולת להצליח בדברים רבים.
לא יודע	לא מסכים	מסכים	26. ילד עם שיתוק מוחין חייב לשכב כמה שיותר על הבטן כדי ללמוד לזחול.
לא יודע	לא מסכים	מסכים	27. יש להשתמש בציוד מותאם כדי לשפר תפקוד בחיי היום יום של הילד .
לא יודע	לא מסכים	מסכים	28. ילד עם שיתוק מוחין צריך לקבל עזרה מקסימאלית על מנת למנוע תסכול.
לא יודע	לא מסכים	מסכים	29. אין צורך להשתמש בעזרי תקשורת תומכת, אם המשפחה מבינה את הילד.
לא יודע	לא מסכים	מסכים	30. על מנת שלא תהיה ירידה ביכולות ובמוטיבציה של הילד עם שיתוק מוחין להליכה יש להימנע ממתן אביזרי עזר לניידות כגון: כסא ממונע, כסא גלגלים.
לא יודע	לא מסכים	מסכים	31. הצבת גבולות לילד עם שיתוק מוחין תורמת לבריאותו הנפשית של הילד .
לא יודע	לא מסכים	מסכים	32. לא רצוי שילד עם שיתוק מוחין ישחק בגן שעשועים מכוון שהוא עלול להיפגע.
לא יודע	לא מסכים	מסכים	33. כאשר ההורים של ילד עם שיתוק מוחין מבינים מה ילדם רוצה להגיד ומבינים את צרכיו, זה לא כל-כך חשוב אם אחרים מתקשים להבינו.
לא יודע	לא מסכים	מסכים	34. ילד עם שיתוק מוחין לא אמור לשבת באמבטיה רגילה עד שהוא מסוגל לשבת באופן עצמאי.

## APPENDIX K (continued)

לא יודע	לא מסכים	מסכים	36. ילד עם שיתוק מוחין עלול להתעייף מהר יותר מילד ללא שיתוק מוחין, בגלל שפעולות היום יום דורשות ממנו מאמץ ואנרגיה רבים יותר.
לא יודע	לא מסכים	מסכים	37. כדי להבטיח הצלחה יותר חשוב שילד עם שיתוק מוחין ידע ללכת בכל דרך שהיא כולל אביזרי עזר.
לא יודע	לא מסכים	מסכים	38. בדרך כלל ההתפתחות הרגשית וההתנהגותית של ילד עם שיתוק מוחין דומה לזו של ילד ללא שיתוק מוחין.
לא יודע	לא מסכים	מסכים	39. משחקים, כגון לוטו, עם דרישות קוגניטיביות הגבוהה ליכולות הילד עדיפים ממשחק ברמתו על מנת לעודד חשיבה גבוהה יותר.
לא יודע	לא מסכים	מסכים	40. בגלל הקשיים של ילד עם שיתוק מוחין עדיף לא לדרוש ממנו לעזור בעבודות בית כמו אחריו.
לא יודע	לא מסכים	מסכים	41. חשוב לאפשר לילד עם שיתוק מוחין הצלחות בכדי להפחית תחושה של חוסר אונים.
לא יודע	לא מסכים	מסכים	42. ילד עם שיתוק מוחין לא יכול לשחק במשחקים/צעצועים תואמי גיל עקב לקותו.
לא יודע	לא מסכים	מסכים	43. עדיף לילד עם שיתוק מוחין לבצע את רוב פעילויותיו על הרצפה.
לא יודע	לא מסכים	מסכים	44. חשוב שילד עם שיתוק מוחין ילך בכל דרך שהוא על מנת לאפשר לו להשתלב בעתיד בבית הספר.
לא יודע	לא מסכים	מסכים	45. עדיף לילדים עם שיתוק מוחין להתלבש על הרצפה כי ככה הכי קל להם.

## APPENDIX L

### Educational Intervention

**Overall goals:**

1. Create parental awareness of the importance of their child's participation in age-appropriate activities through increased knowledge of the effects of the proximal and distal environments on their child's development and abilities.
2. Increase parental knowledge of:
  - 2.1. Development and capabilities of children with disabilities specifically CP across the life span
  - 2.2. The relationship between motor skills and the environment
  - 2.3. Physical and social barriers faced by children with disabilities in daily interactions siblings and peers.
  - 2.4. The importance of their child's participation in age-appropriate activities.
  - 2.5. The importance of fostering child initiation throughout all activities.
3. Provide a framework and methods for parents to apply their knowledge and provide their child with:
  - 3.1. A positive and fostering environment (physical and social home environment).
  - 3.2. Age-appropriate social and play situations to increase cognitive development minimizing limitations due to motor limitations.
  - 3.3. Increases in independence and participation in daily age-appropriate activities.
4. Increase parental self-efficacy

The structure of this intervention package is based on Bandura's concepts of adult learning. Bandura's adult learning model stresses the importance of educationally based interventions to be applicable to participants and the importance of providing opportunities for modeling and imitation of behaviors that will be fostering and increase their child's participation in age-appropriate activities. The sequence developed for this intervention focuses on demonstrating to parents a knowledge gap, and demonstrates the information they can learn to narrow the gap and provide them with specific ideas and knowledge they can apply in their everyday lives. I focus on behaviors that are likely to be changes and influenced as opposed to beliefs (Goodnow, )

Initially each session demonstrates to parents the existence of a knowledge gap intending to increase their readiness to learn. The next part in this intervention package provides parents with new or a review of existing knowledge based on the topic of the session. Lastly numerous opportunities are provided to parents to apply the knowledge, observe the new behaviors increasing opportunities for modeling during the intervention session and provide parents with the methods and apply the newly learned information at home. The knowledge and behaviors modeled is based on everyday activities experienced by the parents and children in their home.

## **APPENDIX L (continued)**

**All video clips and scenarios will be developed for this intervention and will be based on the children and parents participating in the intervention. This will enable all parents participating in this study to benefit from feedback and group problem solving from the other parent participants and increase the applicability of this intervention to their everyday lives.**

### **Unit One: Session One:**

#### **Goal:**

- 1. Create parental awareness of the importance of their child's participation in age-appropriate activities through increased knowledge of the effects of the proximal and distal environments on their child's developmental outcomes and participation in daily activities.**
- 2. Increase parental knowledge of the physical and social barriers faced by preschool children with disabilities in daily interactions with siblings and same age peers.**

#### **Objectives:**

- 1. Parents will explain the laws relating to the rights of their child in healthcare, school and public environments.**
- 2. Parents will explain the differences between the distal and proximal environments.**
- 3. Parents will define participation according to the ICF framework.**
- 4. Parents will define participation according to their child's developmental level.**
- 5. Parents will list one situation faced by their child with a disability that limited their child's ability to function age-appropriately.**
- 6. Parents will identify 2 barriers restricting their child's inclusion in age-appropriate activities.**

#### **Strategies:**

##### **Class Activity:**

**Introductions: I will introduce myself and parents will also introduce themselves and their child by telling a brief story about their child. Briefly review the schedule of the education intervention. Participants will introduce themselves and a brief description of their child. They will be asked to bring a picture of their family.**

##### **Lecture:**

- 1. Current rights under Israeli law regarding: Mandatory education**
  - 1.1. Their rights regarding child placement**
  - 1.2. Participation in determining the intervention program**
  - 1.3. Their rights regarding their involvement in determining their child's educational plan**
  - 1.4. School age vs. preschool age children**
  - 1.5. Provider**
- 2. International Classification of Function responsibility as related to service provision and child age.**

## APPENDIX L (continued)

### 2.1. Definition

- 2.2. Application
- 2.3. How can you affect the level of participation of your child?
- 2.4. Environmental modification and accessibility
- 2.5. Define distal and proximal environments
- 2.6. Definition of barriers
- 2.7. How do barriers affect their child's functioning and participation in age-appropriate activities?
- 2.8. Laws relating to modification and accessibility

### Group discussion:

Observe a video clip of one of their children in a playground with other peers.

Parents will discuss the video clip in two smaller groups and join together and share their observations. Guidelines for discussion are as follows:

- 1. Define participation for the individual in the clip.
- 2. List two barriers faced by the child with a disability in the video.
- 3. Suggest three strategies that can be used to decrease the barriers and increase participation- modifications or adaptations.

Specific strategies parents may employ to decrease barriers are discussed in lesson 3. Bringing in the issue of methods to decrease barriers and alert parents to additional knowledge to be gained in subsequent lessons may serve to heighten their awareness and interest in the program and the importance of the contents of this educational package.

### Homework:

- 1. Observe your child in a public environment: list 3 barriers your child encountered.
- 2. Observe your child in your home environment: list 2 barriers your child encountered.

## Unit Two: Session Two

### Goal:

- 1. Increase parental knowledge of the development and capabilities of children with disabilities specifically CP across the life span.
- 2. Increase parental knowledge of the physical and social barriers faced by preschool children with disabilities in daily interactions with siblings and peers.
- 3. Increase parental knowledge of the importance of their child's participation in age-appropriate activities.
- 4. The importance of fostering child initiation throughout all activities

## APPENDIX L (continued)

**5. Provide a framework and methods for parents to apply their knowledge and provide their child with increases in independence and participation in daily age-appropriate activities.**

**6. Increase parental self-efficacy**

### Objectives:

- 1. Parents should explain limitations in body structure and function associated with CP and its influences on their child's participation in age-appropriate activities**
  - 2. Parents should explain the diversity in development of children with disabilities.**
  - 3. Parents will explain the GMFCS.**
  - 4. Parents should explain the development of children with CP through the GMFCS trajectories of development.**
  - 5. Parents will determine their child's developmental trajectory according to the GMFCS.**
- 
- 6. Parents should understand the differences between capacity and performance of a task and the relationship to the environmental setting.**
  - 7. Parents will list 2 changes that can be made to increase their child's participation in the playground.**

### Strategies:

#### Class activity:

- 1. Home observation: Parents will discuss of the barriers their children encountered limiting their child's participation.**
- 2. Parents will each perform 1 functional activity (writing, throwing a ball, catching a ball) in which they are sitting on the floor with poor posture, on an unstable surface and constrained in one body part. Discuss the performance of this task in relationship to performance over an extended length of time and the effects their child might experience.**
- 3. Parents will discuss their observations of their child over the last 2 weeks. Describe the limitations they found most significantly restricting their child's participation.**

### Lecture:

- 1. CP**
  - 1.1. Definition**
  - 1.2. Limitations in body structure and functions associated with CP**
  - 1.3. Describe the effects of limitations of posture and mobility on functioning.**
  - 1.4. Sensory-motor limitations associated with CP**



## APPENDIX L (continued)

- 1.5. Define compensations and adaptations and how they may affect function
- 1.6. Discuss the variety in development and capabilities experienced by the children of the participants.
- 2. Developmental trajectories
  - 2.1. Define and explain GMFCS
  - 2.2. Present and explain the developmental trajectories and their use to predict gross motor function
  - 2.3. Provide parents with the information to apply the trajectories to their own children.
- 3. Capacity vs. performance
  - 3.1. Definition
  - 3.2. Discuss 3 examples of capacity vs. performance
  - 3.3. Influence of the environment and strategies to decrease limitations from the environment
  - 3.4. ICF participation
- 4. Methods to decrease limitations of posture and mobility
  - 4.1. Understanding the source: Barriers in the environment limiting their child's participation
  - 4.2. Home
  - 4.3. Playground
  - 4.4. Mall or other public area
- 5. Adaptations to minimize barriers resulting from limitations in posture and mobility
  - 5.1. Adaptive equipment
  - 5.2. Types of equipment
  - 5.3. Benefits of use of various adaptive equipment for activities
  - 5.4. Handling
  - 5.5. Environment
  - 5.6. Demonstrate with slides the effects of adaptive equipment, environment, handling on participation of children in a variety of settings.

### Group discussion:

Three video clips will demonstrate the effects of limitations on posture and mobility in three different environments. After viewing each video clip a discussion will follow about the effects of the limitations of posture and mobility on participation resulting from environmental influences.

Observe 2 video demonstrating limitations in participation resulting from environmental barriers. Separate into 2 groups and discuss possible solutions to decrease barriers. Regroup and share discussions. Observe the same 2 videos with some adaptations and environmental changes resulting in increased participation.

## **APPENDIX L (continued)**

**Highlight the similarities in suggestions made by parents evident in the video clips and discuss new ones.**

### **Homework:**

- 1. List 3 situations in which limitations in body structure and function affected your child's ability to participate in an age-appropriate activity.**
- 2. At home and in another environment (cousin, grandparent, mall)**
  - a. Parents should log 2 activities in which decreased mobility limited their child's participation.**
  - b. Parents should list 2 methods they utilized to remove barriers and decrease the impact of their child's limitations.**

### **Unit Two: Session Three:**

#### **Goal:**

- 1. Increase parental knowledge of the development and capabilities of children with disabilities specifically CP across the life span.**
- 2. Increase parental knowledge of the relationship between motor skills and the environment and their influence on their child's participation in play activities.**
- 3. Provide a framework and methods for parents to apply their knowledge in play and provide their child with a positive and fostering environment for their child with a disability (physical and social home environment).**
- 4. Provide a framework and methods for parents to apply their knowledge and provide their child with age-appropriate social and play situations to improve their child's cognitive development minimizing limitations due to motor limitations.**
- 5. Provide a framework and methods for parents to apply their knowledge and provide their child with increases in independence and participation in play activities.**
- 6. Increase parental self-efficacy**

#### **Objectives:**

- 1. Parents should be able to explain 3 different types of play.**
- 2. Parents should identify 3 different play environments and suggest 1 method for adapting each environment to increase their child's participation**
- 3. Parents should identify one method to encourage their child to initiate play activities in their home.**
- 4. Parents should be able to identify 4 toys and 3 activities that are age and disability appropriate for their child**
- 5. Parents should be able to identify 2 strategies they can utilize to adapt an activity or toy for their child with a disability.**

## APPENDIX L (continued)

### Strategies:

#### Class activity:

1. Parents will share their experiences in decreasing barriers during their child's activities and its effects on their child's level of participation in that activity.
2. Parents will then experience playing with a ball when one body part is constrained. This will highlight to them the limitations in motor functioning their child might experience. It should also highlight the increased frustration and decreased enjoyment their child might experience as a result of their limitations.

### Lecture:

#### 1. Play

##### 1.1 Purpose of play

- 1.1.1 Enjoyment
- 1.1.2 Social interactions and friendships
- 1.1.3 Learning and cognitive goals
- 1.1.4 Importance of fostering child initiated activities and providing opportunities for children to initiate and lead during playtime.

##### 1.2. Types of play

- 1.2.1 imaginative
- 1.2.2 concrete
- 1.2.3 toys and games

##### 1.3 Play: Framework of playfulness

- 1.3.1 Intrinsic motivation
- 1.3.2. Internal control
- 1.3.3. suspension of reality
- 1.3.4. framing

##### 1.4. Expectations across the life span

##### 1.5. Play materials

- 1.5.1 Reading
- 1.5.2 Importance of reading
- 1.5.3. Interaction during reading.
- 1.5.4 Adapting a book for their child's use

#### 2. Play and participation: Framework of play and the ICF

- 2.1. Child initiated
- 2.2. Play as a positive experience for both learning and enjoyment
- 2.3. Play as an opportunity for social interactions

#### 3. Environment and play

- 3.1. Limitations resulting from restrictions in body structure and function
- 3.2. Methods and strategies to decrease limitations
  - 3.2.1. Environmental changes
  - 3.2.2. Adaptive toys
  - 3.2.3. Positioning

## APPENDIX L (continued)

**3.2.4. Demonstrate and discuss various assistive devices and adaptive toys.**

**4. Siblings and play**

**4.1 relationship and effects of disability in the family**

**4.2 Sibling placement**

**4.3 Discussion of healthy emotional development in families**

**Group discussion:**

- 1. Problem solving scenario: parents should divide into 3 groups. Three environments and play scenarios: suggestions to increase participation. (One scenario will be a playground, one play at home with sibling and sibling's friend with toy or game, one in preschool setting).**
- 2. Select one type of toy or game and adapt it for use by a child with a disability. Parents will be provided with a selection of modification suggestions, switches etc. they can use in this scenario. Possible solutions include: modify activity, positioning, switches, and environmental demands.**

**Homework:**

- 1. Go to a playground, gymboeree or public play area: what did you do to increase your child's participation.**
- 2. Select 2 toys and adapt it for your child's use. Log your experience amount of time your child played, any friends or siblings and overall feelings during the activity.**
- 3. Select a toy that you expect your child to play with independently and report on the amount of time your child played and level of enjoyment of your child.**
- 4. Parents whose children were discussed as part of the scenario will report the following session on the experience of playing with the toy adapted in this session.**

**Unit Two: Session Four: ADL's**

**Goals:**

- |           |   |
|-----------|---|
| <b>in</b> | <ol style="list-style-type: none"> <li><b>1. Increase parental knowledge of the importance of their child's participation ADL's.</b></li> <li><b>2. The importance of fostering child initiation throughout all activities</b></li> <li><b>3. Provide methods for parents to apply their knowledge and provide their child with increases in independence and participation in ADL's.</b></li> <li><b>4. Increase parental self-efficacy</b></li> </ol> |
|-----------|---|

## APPENDIX L (continued)

### Objectives:

1. Parents should identify 3 methods to foster increased assistance and participation of their child in dressing and toileting activities.
2. Parents should list 2 aspects of dressing that their child can currently complete independently.
3. Parents should identify 2 components of the activities that they can encourage their child to either initiate or complete independently.
4. Parents should identify 2 changes in type of clothing their child wears to increase their child's independence in dressing.
5. Parents should identify 2 adaptations in food, utensils or the environment to enable their child to eat more independently.

### Strategies:

#### Class activity:

1. Discuss their experiences at playground etc.
2. Discuss their experiences at home with adaptations in toys and activities for their children.
3. Parents will be given a large shirt to put over their clothing. They will then be given 2 socks to place over their hands. They will then be asked to button their shirt and remove their shoes and socks.

### Lecture:

1. ADL's
  - 1.1. Definition
  - 1.2. Types
    - 1.2.1. Feeding
    - 1.2.2. Toileting (will mention and not elaborate on in the other sections below)
    - 1.2.3. Dressing
    - 1.2.4. Bathing
  - 1.3. Age-appropriate expectations
  - 1.4 Fostering child initiated activities with a look forward towards achieving increased independence in ADL's.
  - 1.5 Discuss for each ADL what is expected
2. Modifications addressing limitations from body structure and function and environmental constraints.
  - 2.1. Strategies to decrease limitations due to the environment
  - 2.2. Dressing
    - 2.2.1. change clothing
    - 2.2.2. positioning
    - 2.2.3. alter the activity: break it down into smaller components, shorter time frame, change articles involved
  - 2.3. Feeding
    - 2.3.1. Undernourishment and food consistencies

## APPENDIX L (continued)

**2.3.2. equipment**

**2.3.3. positioning**

### **3. Emotional development**

**3.1 Learned helplessness**

**3.2 Volition and initiation**

#### **Group discussion:**

- 1. View a video clip of 2 children dressing. Discuss in 2 groups possible modifications (including timing, breaking down the activity in smaller components, positioning, modifying the clothing, etc.). Regroup and discuss their suggestions.**
- 2. View a video clip of 2 children during eating. Discuss in 2 groups modification (food textures, equipment, positioning, etc.). Regroup and discuss their findings.**

#### **Homework:**

- 1. Select one aspect of dressing (removing shoes, jacket, socks, or putting on a shirt) practice with your child and record the difficulties and how you adapt the situation to decrease the level of difficulty for your child and increase their success.**
- 2. Describe 2 articles of clothing changed or methods implemented to decrease the level of difficulty in dressing.**
- 3. Describe 2 changes made during mealtime to increase your child's independence.**

### **Unit Three: Session Five:**

#### **Goals:**

- 1. Create parental awareness of the importance of their child's participation in age-appropriate activities through increased knowledge of the effects of the proximal and distal environments on their child's development and abilities**
- 2. Increase parental knowledge of:**
  - 2.1 Development and capabilities of children with disabilities specifically CP across the life span**
  - 2.2 The relationship between motor skills and the environment**
  - 2.3 Physical and social barriers faced by children with disabilities in daily interactions with siblings and peers.**
  - 2.4 The importance of their child's participation in age-appropriate activities**
  - 2.5 The importance of fostering child initiation throughout all activities**

## APPENDIX L (continued)

3. Provide a framework and methods for parents to apply their knowledge and provide their child with:
  - 3.1 A positive and fostering environment (physical and social home environment).
  - 3.2 Age-appropriate social and play situations to increase cognitive development minimizing limitations due to motor limitations.
  - 3.3 Increases in independence and participation in daily age-appropriate activities.
4. Increase parental self-efficacy

### Part One

#### Objectives:

1. Parents should explain the concept of participation within the framework of their child's activities.
2. Parents should list 4 barriers in the distal environment influencing their child's participation in 2 age-appropriate activities.
3. Parents should explain their effect on increasing the level of independence of their child.
4. Given a scenario: Parents should be able to describe 2 ways in which they can intercede to decrease the limitations related to their child's impairment.
5. Parents should explain the importance of understanding the future barriers their child might encounter and methods they can employ to increase their child's current and future participation.

#### Strategies:

##### Class activity:

Review experiences at home with dressing and mealtimes. Did your child participate more, demonstrate more enjoyment and did it take longer (probably- discuss importance of timing of activities).

##### Lecture:

1. Review the concepts of participation
2. GMFCS and developmental trajectories.
3. Important terms parents encounter related to their child's disability
4. A look towards the future
  - 4.1. Potential medical problems
  - 4.2. Preventative health care
  - 4.3. Effects on participation

**APPENDIX L (continued)****Group discussion:**

- 1. Parents will split into 2 groups. Develop a scenario of one of their children in the 2nd grade. List barriers their child might encounter. List solutions to those barriers to increase participation. Larger group discussion: each group will present their scenario, barriers and solutions.**
- 2. Parents of an older child with CP (10 years of age or older) will join the group and discuss their own experiences.**

**Part Two: Each parent will prepare a 10 minute discussion about their child. I will ask them to discuss, demonstrate if possible with pictures or short (2 minute) video clip changes they have implemented over the last 12 weeks. This will highlight to the parents the important changes that have occurred in their home over the course of and resulting from this intervention package. It will serve as an informal learning contract to reinforce changes with the goal of continuing these changes beyond the conclusion of this intervention.**



**APPENDIX M****Parent Observation Checklist**

<b>Date:</b>	<b>Time:</b>	<b>Length of time spent</b>
<b>on activity:</b>		
<b>Individuals present:</b>		
<b>Location:</b>		
<b>Activity:</b>		

**How many times did your child initiate interaction?**

**How? (i.e. body language, speech, touch, gesture)**

**Description of occurrence:**

**Limitations: (aspects of the environment that assisted or restricted their child)**

**Possible solutions:**

## VITA

NAME: Louisa Freyer Susman

EDUCATION: B.A., History, Barnard College, Columbia University, New York, 1985  
 M.S. Physical Therapy, College of Physicians and Surgeons, Columbia University, New York, 1987  
 Ph.D., Disability Studies, University of Illinois at Chicago (UIC), Chicago, Illinois, 2012

PROFESSIONAL EXPERIENCE: Department Head: Child Development Center, Beitar, Israel  
 2005 to the Present  
 Department Head: Child Development Center, Beit Shemesh, Israel  
 2009 to the Present  
 Department Head: Special Education Preschool, Beit Shemesh, Israel, 2010 to the Present  
 Consultant to Physical Therapy Staff, Aleh, Jerusalem, Israel, 2009 to the present  
 Meuchedet Health Services: Senior Physical Therapist, Efrat and Kiryat Arba, Israel, 2008 to the Present  
 Senior staff physical therapist, Gan Hashikumi, Jerusalem Israel, 1990-2010  
 Staff Physical Therapist, Child Development Center, Kiryat Arba, Israel  
 Staff Physical Therapist, Alyn Hospital, Jerusalem, Israel, 1987-1990

AWARDS AND LICENSURE: License: Physical Therapy, New York State (1987)  
 License: Physical Therapy, Israel (1987)

PUBLICATIONS AND PRESENTATIONS: The influence of the Home Environment on Motor Development, Presentation at the Pediatric Section, APTA Convention, 2003  
 Predicting motor outcome at preschool age for infants tested at 7, 30, 60, and 90 days after term age using the Test of Infant Motor Performance.  
 Kolobe TH, Bulanda M, Susman L. Phys Ther. 2004 Dec;84(12):1144-56.