

THESIS

PARTICIPATION IN EARLY CHILDHOOD EDUCATIONAL ENVIRONMENTS FOR
YOUNG CHILDREN WITH AND WITHOUT DEVELOPMENTAL DELAYS: A MIXED
METHODS STUDY

Submitted by

Tanya Elizabeth Benjamin

Department of Occupational Therapy

In partial fulfillment of the requirements

For the Degree of Master of Science

Colorado State University

Fort Collins, Colorado

Fall 2014

Master's Committee

Advisor: Mary Khetani

Patricia Davies
Rachel Lucas-Thompson

Copyright by Tanya Elizabeth Benjamin 2014

All Rights Reserved

ABSTRACT

PARTICIPATION IN EARLY CHILDHOOD EDUCATIONAL ENVIRONMENTS FOR YOUNG CHILDREN WITH AND WITHOUT DEVELOPMENTAL DELAYS: A MIXED METHODS STUDY

Children's participation in school-based activities is an important indicator of their inclusion. Prior studies have shown disparities in school participation between children with and without disabilities, but there is limited knowledge about whether these disparities are present during the early childhood period. The purpose of this concurrent transformative mixed methods study is three-fold: 1) to generate new knowledge about similarities and differences in how young children with and without developmental delays participate in daycare/preschool activities (in terms of their participation frequency, level of involvement, and parental desire for change), 2) to examine similarities and differences in perceived environmental supports for participation in daycare/preschool activities, and 3) to identify patterns in the strategies used by parents who want their child's participation to change. This study leverages the newly developed Young Children's Participation and Environment Measure (YC-PEM) to build new knowledge about young children's participation in a daycare/preschool environment.

Study results suggest moderate to large disability group differences in young children's daycare/preschool participation and perceived environmental support for participation, even after controlling for the confounding effects of child gender, child age, and family income. Parents of young children with developmental delays, on average, report their children as less involved in daycare/preschool activities and perceive fewer supports for participation in their child's daycare/preschool environment. At the item level, significant disability group differences were

found with respect to the child's *frequency* and *level of involvement* in daycare/preschool activities across all three daycare/preschool activities (i.e., group learning, socializing with friends, field trips and events). Significant disability group differences were also found in *percent desire change* for two of three activities (i.e., group learning, socializing with friends). Lastly, significant group differences on *perceived environmental support* for daycare/preschool participation were found for all but one environmental item (programs and services).

Among parents who desired change in their child's participation in daycare/preschool activities, a desire for change was reported across multiple dimensions (frequency, level of involvement, broader variety). The most commonly reported parental strategies to improve participation in daycare/preschool activities pertained to *childcare tasks* and *child peer groups*, and these strategies were used irrespective of the type(s) of change that parents desired.

In conclusion, the study findings suggest that 1) discrepancies in school participation between children with and without disabilities can be detected in the early childhood period and along multiple dimensions (frequency, level of involvement, parental desire for change); 2) there are wide range of perceived environmental barriers that may be appropriate intervention targets to minimize disparities in school participation for young children with developmental delays; 3) some, but not all, of the ten family accommodations that have been reported in prior literature are commonly used by parents to improve their young child's participation in a daycare/preschool setting. These study results, in turn, support the utility of the YC-PEM for use by stakeholders to 1) identify young children with participation restriction in an early childhood educational setting, 2) identify specific environmental barriers and supports impacting participation in this setting, and 3) anticipate the types of parental strategies that could be expanded upon by stakeholders to improve participation outcomes for young children experiencing participation restriction.

ACKNOWLEDGEMENTS

First and foremost, I would like to express my gratitude to my parents who gave me the opportunity to travel across continents to be a part of CSU and CPERL. I am also extremely grateful for such amazing siblings, my older sister Anisha and my twin brother Rohan for their constant support, encouragement, and love. I would also like to shout out a huge thank you to my past and present roommates, Jewel, Gloria & Hallie and, also to all my other friends here in Fort Collins, for being like family to me. I have also got to acknowledge my fellow CPERL team members Jiang, Molly, Kristen and Lauren for their constructive feedback on my writing and presentations for the proposal hearing and defense, also for making the lab environment such a fun place to be amidst all of the work.

I would like to thank all my committee members: Dr. Rachel Lucas-Thompson, Dr. Patricia Davies and Dr. Lauren Little, for their thoughtful insights that helped me view my study through an interdisciplinary lens, and also for all the valuable feedback on my work which has helped me in completing this study and also in disseminating it.

Most importantly, I am blessed to have had the opportunity to be mentored by Dr. Mary Khetani. I am extremely grateful for the time that Dr. Mary has spent in developing me as a scholar, giving me opportunities that I never expected to have and, most importantly playing a key role in further developing my professional story, to guide my future vision of bringing about a change in the lives of children with disabilities in the developing regions of the world.

Last but not the least, I would like to thank God almighty, for every good and perfect gift is from above, coming down from the father of heavenly lights, who does not change like shifting shadows (James 1:17).

TABLE OF CONTENTS

ABSTRACT.....	ii
ACKNOWLEDGEMENTS.....	iv
TABLE OF CONTENTS.....	v
Introduction.....	1
Importance of Universal Education and Related Disparities	2
Promoting Universal Education by Addressing Stakeholder Needs	3
Assessing Children's School Participation to Address Stakeholder Needs.....	4
Development of Children’s Participation Measures.....	6
Strengths and Limitations of the Participation and Environment Measure for Children and Youth (PEM-CY) in Meeting Educational Stakeholder Needs.....	9
Applying the PEM Approach to Improve Knowledge about Participation in Younger Children.....	12
Purpose.....	16
Relevance of Thesis Topic to Occupation and Rehabilitation Science.....	19
Method.....	21
Study Design.....	21
Participants.....	24
Data Collection	25
Measures.....	26
Data Analysis.....	28
Results.....	37
Participant Characteristics.....	37

Quantitative Findings.....	40
Mixed Method Findings.....	45
Discussion.....	47
Conclusion.....	55
References.....	56
APPENDIX A: Daycare/Preschool Section of the YC-PEM.....	69
APPENDIX B: The ICF Framework.....	72
APPENDIX C: Coding of Parent Strategies into Ten Family Accommodations.....	73
APPENDIX D: Relationship between Types of Change Desired and Types of Strategies Used.....	79

Introduction

Children with disabilities participate less in a school setting when compared to children without disabilities. These discrepancies seen in school participation between children with and without disabilities have been documented in literature. In contrast to the knowledge that is available on participation of school going children with disabilities (5-17 years), there is limited knowledge on the participation of young children (0-5 years) with and without developmental delays in daycare/preschool settings. We do not know if these discrepancies in school participation between children with and without disabilities arise during the early childhood period. Moreover, parents of school-aged children with disabilities perceive the environment to be less supportive to their child's school participation when compared to parent's of children without disabilities, but again, we do not know if these differences in the perceived environmental impact on school participation are seen between parents of young children with and without developmental delays. Through this study we hope to generate new knowledge on the similarities and differences in daycare/preschool participation between young children with and without developmental delays.

To get a comprehensive understanding of the participation of young children in daycare/preschool settings, we will also examine strategies used by parents of young children to promote their child's participation in specific daycare/preschool activities in which they desire change. Previous literature has identified ten accommodations that parents of children with disabilities commonly use to promote their child's participation across different settings, and in this study, we will be examining the most common types of strategies that parents have used from the ten accommodations to promote their child's participation in the daycare/preschool setting. This information will add to the literature base on family accommodations.

Importance of Universal Education and Related Disparities

Nearly 93 million children (0-14 years) worldwide live with some form of disability and are at a risk for experiencing societal exclusion (UNICEF, 2013a; WHO & World Bank, 2011). According to article 7 of the United Nations Enable Convention on the Rights of the Child (2008), children should have equal opportunity for full enjoyment of all human rights and fundamental freedoms, regardless of differences in their ages, backgrounds, abilities, and interests. Universal education, or the opportunity for children with and without disabilities to fully function in the school environment, is an important part of this international mandate and is further reinforced by national policies like Parts B and C of the Individuals with Disabilities Education Act (IDEA) of 1997 (Individuals with Disabilities Education Act, 1997) in the United States of America, the India's Persons With Disability Act (PWD) of 1995 (Government of India, 1995, section 5) and the Swedish "One School for All" policy (Lgr 80, 1980). These national educational policies mandate that children with and without disabilities benefit equally from their school environment by engagement in activities that provide opportunities to learn new skills and form positive relationships with their peers and teachers (Kohama, 2012; Pivik, McComas & Laflamme, 2002; Simeonsson, Carlson, Huntington, McMillen & Brent, 2001).

The enactment of national educational policies has resulted in a vast increase in the number of children with disabilities enrolling in school in both developed and developing regions of the world. As of 2001, approximately 6.2 million children with disabilities in the United States were enrolled in special education services, of which 600,000 were preschool-aged children (U.S. Department of Education, 2001). Similarly, the Ministry of National Education in Turkey recently reported a five-fold increase in school enrollment of children with disabilities,

from 40,050 students enrolled for the 2004-2005 school year to 92,355 students enrolled for the 2010-2011 school year (Cakiroglu & Melekoglu, 2013).

Despite positive trends in school enrollment of children with disabilities, there are still many children with disabilities who lack access to educational opportunities. According to UNICEF (2013b), children with disabilities continue to account for one third of all school-aged children worldwide who do not attend school (p. 13). Furthermore, UNESCO (2009) reports that only 56% of young children (0-5 years) with disabilities worldwide have access to any form of early education (p. 2). These data suggest that the educational access needs of some, but not all, children with disabilities are being addressed by nations in order to fully achieve the goal of universal education (United Nations, 2008).

Disparities in school enrollment may be related to the quality in educational programming. UNESCO (2009) reports that 80% of all young children with disabilities live in developing countries where the provision of pre-primary education services are insufficient. Among other factors, Boocock (1995) highlights economic barriers such as inadequate oversight and resources (trained staff, equipment and supplies for quality assessment and intervention) for the provision of quality education for children with disabilities in developing countries.

Promoting Universal Education by Addressing Stakeholder Needs

Multiple stakeholders (e.g., teachers, school officials, parents) can benefit from access to information and resources to improve the quality of educational programming for students with disabilities. These stakeholders need to be able to collaborate in order to 1) effectively and efficiently identify children with inclusion needs (i.e. children who have difficulty participating in school activities), 2) specify the types of inclusion needs with which children present (i.e., difficulties in participation these children present with: frequency or involvement), and 3)

identify the types of modifiable environmental factors impacting school exclusion (i.e. factors hindering or supporting their participation in the school). In more developed regions of the world, the provision of school-based services typically relies on interdisciplinary collaboration involving health and educational professionals (Barnes & Turner, 2001; Campbell, Missiuna, Rivard, & Pollock, 2012; Deloitte & Touche, 2010; Guralnick, 1998; Villeneuve, 2009). For example, collaborative team practices between teachers and occupational therapists when developing goals and reviewing student progress are standard aspects of intervention planning in school-based practice within the United States (Barnes & Turner, 2001; Casillas, 2010; Villa, Thousand, Nevin & Malgeri, 1996).

In addition to interdisciplinary collaboration, parent expertise and involvement in the planning and delivery of services is also critical for enacting client-centered services for children with disabilities beginning in early childhood (Hanna & Rodger, 2002; Meisels & Fenichel, 1996). This type of professional-parent partnership involving providers (e.g., governmental and non governmental service), community volunteers, and the larger community (e.g., people with disabilities, their families and other community members) is often used for needs assessment and group level intervention planning, particularly in developing regions of the world where a community-based rehabilitation (CBR) service approach is used (Cameron, Nixon, Parnes & Pidsadny, 2005; Miles, 1996; WHO, UNESCO & ILO, 2004). Hence, interprofessional and parent-provider collaboration are essential for addressing the inclusion needs of children with disabilities in both developed and developing regions of the world.

Assessing Children's School Participation to Address Stakeholder Needs

In order to understand the inclusion needs of children with and without disabilities, stakeholders can gather information about how children participate in school-based activities,

ranging from classroom activities to school-sponsored sports and creative activities (e.g., art, music, games) for children and youth (Simeonsson, et al., 2001) and classroom activities such as meal time, circle time, and recess for younger children (Leung, Chan, Chung & Pang, 2011). Current U.S. educational policy emphasizes participation as a key indicator of full inclusion for infants and toddlers with disabilities (Individuals with Disabilities Education Act, 1997, pp.1431-1444) and for school-aged children with disabilities (Individuals with Disabilities Education Act, 1997, pp. 1411-1419). Greater participation is hypothesized as being linked to positive health and developmental outcomes (Dunst, 2001) such as increased physical, cognitive, and social skills (Larson & Verma, 1999; Mahoney, Larson & Eccles, 2005), positive self-identity and belonging (Coatsworth, Palen & Sharp, 2006; Finn, 1989; Odom, Buysse & Soukakou, 2011; Simeonsson, et al., 2001), and better physical and mental health (Masse, Miller, Shen, Schiariti & Roxborough, 2012; Sandler, Ayers, Suter, Schultz & Twohey-Jacobs, 2004). A school is often considered to be a microcosmic representation of larger society, so skills learned by participating at school may help children with disabilities to prepare for healthy independent living upon their transition to adulthood (Booth & Samdal, 1997; Masse, et al., 2012). For younger children with disabilities, participation in early childhood educational environments (e.g., center-based daycare, preschool, kindergarten) may facilitate their positive transition to elementary school (Anderson et al., 2003; Conn-Powers, Ross-Allen, & Holburn, 1990; Wong, 2002).

The International Classification of Functioning, Disability and Health for Children and Youth (ICF-CY) offers a biopsychosocial framework to guide international educational research, policy, and practice efforts that explicitly focus on participation outcomes for children with disabilities (Simeonsson, et al., 2003). Instead of focusing on the classification of childhood diseases and health conditions as covered by ICD codes, the ICF-CY models the impact of the

childhood disease or health condition on everyday functioning. According to the ICF-CY, participation is one way of describing functional outcomes of concern for pediatric health, rehabilitation, and educational providers (WHO, 2007).

The authors of the ICF-CY define participation as “involvement in life situations” and depict it as being influenced by personal and environmental factors. However, Coster and Khetani (2008) suggest that the ICF definition and modeling of participation does not adequately guide measurement development work in this area (p. 640). Specifically, no agreement could be reached on the difference between the ICF-CY domains of activity and participation (McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006), so there is one set of classification codes for both concepts along with a set of four options for how to apply these codes. As a result, instrument developers cannot rely solely on the ICF-CY to provide clear and consistent direction to measurement developers about the domains and dimensions to include in a new participation measure. Rather, multiple interpretations of how the concept of ICF participation should be operationalized are possible (Coster & Khetani, 2008). Multiple conceptualizations, in turn, decrease the likelihood that participation instruments will afford for harmonized and internationally comparable data for building knowledge about disparities in participation (Simeonsson, et al., 2003).

Development of Children’s Participation Measures

Ambiguity about the concept of ICF participation has led to the use of an alternative approach to instrument development in this area within the past decade whereby researchers 1) propose a working definition of the participation concept for children, based on prior literature (Hammel, Magasi, Heinemann, Whiteneck, Bogner & Rodriguez, 2008), and/or stakeholder input (Coster et al. 2012; Khetani et al., 2013), in order to inform the initial design of a new

measure (Coster & Khetani, 2008; Khetani & Coster, 2008; McConachie et al., 2006), and then 2) clearly communicate the decisions that they made during the measure development process (Coster et al., 2012). Following the measure development process and its initial validation, researchers are encouraged to retrospectively map items from developed measures back to the ICF-CY to compare content coverage across measures, because this information can foster common dialogue when multiple measures are used for building knowledge on the topic (Coster & Khetani, 2008; Simeonsson, et al., 2003).

Coster and colleagues (2012) used this alternative approach for the development of the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, Law, & Bedell, 2010). First, Coster & Khetani (2008) proposed the following working definition of children's participation: "involvement in sets and sequences of organized activities directed towards a personally or socially meaningful goal" (p. 643). Their research team then gathered parent perspectives about the concept of children's participation to inform the initial design of the instrument. Parent input helped them to 1) identify relevant sets and sequences of activities and environmental factors to include in the measure and the relevant dimensions to include in the measure, 2) try and design an instrument to reflect the inextricable link between the concepts of participation and environment (i.e. the environment playing a significant role in defining the extent to which a child maybe able to participate across different settings) as described by parents (Bedell, Khetani, Cousins, Coster & Law, 2011) to increase the face validity of the instrument (Coster, et al., 2012).

Chien and colleagues (2014) recently compared the items of 16 self-report or proxy surveys about children's participation in terms of their fit with the nine ICF-CY chapter codes and using established linking rules (Adolffson, et al., 2011; Cieza, et al., 2005). They identified

four measures with high ICF-CY content density (i.e., those measures with the highest percentage of items linked to the ICF-CY): 1) the School Function Assessment (SFA) (Coster, Deeney, Haltiwanger & Haley, 1998) had 100% ICF-CY item fit; 2) the Assistance to Participation Scale (APS) (Bourke-Taylor, Law, Howie & Pallant, 2009) displayed a 75% ICF-CY item fit; 3) the Child and Adolescent Scale of Participation (CASP) (Bedell, 2009) also demonstrated a 75% ICF-CY item fit; 4) the Participation and Environment Measure for Children and Youth (PEM-CY) (Coster, Law & Bedell, 2010) with 88% ICF-CY item fit.

Among the four measures found to have high content density, the SFA, CASP and PEM-CY explicitly assess for school participation as shown in Table 1 below.

Table 1. Key Features of Children’s Participation Measures with High ICF-CY Content Density

Name	Age (Years)	Purpose	Perspective	Content	Dimensions	Psychometrics	Environmental Impact
APS	5-18	Research & Intervention planning	Caregiver	Home & community	<u>Objective:</u> Degree of assistance required	Cronbach α : 0.88	Not Addressed
SFA	Grade : K-6	Intervention planning	Teacher or other school-based provider	School	<u>Objective:</u> Involvement	Cronbach α : 0.92-0.98 ICC: 0.82-0.99	Addressed specific to school only
CASP	5 and older	Research & Intervention planning	Caregiver	Home, school & community	<u>Objective:</u> Degree of restriction	Cronbach α : 0.98 ICC: 0.94	Addressed broadly and separately through a companion instrument, the Child and Adolescent Scale of Environment (CASE)
PEM-CY	5-17	Research	Caregiver	Home, school & community	<u>Objective:</u> Frequency, involvement <u>Subjective:</u> Desire for change	Cronbach α : ≥ 0.80 (except for school resources: 0.73) ICC: 0.73- 0.99	Addressed specific to home, school, and community settings

The SFA, CASP and PEM-CY differ in their content coverage, respondent type, dimension(s) addressed, evaluation of environmental impact, and primary purpose. These additional features of measures reflect important considerations for stakeholders when selecting a measure to use and are therefore summarized in Table 2 below.

Table 2. Similarities and Differences among the CASP, SFA and PEM-CY

Name	Participation	Environmental Impact
CASP	<p><u>Assesses 1 dimension</u>, i.e., current level of participation in various activities in terms of:</p> <ul style="list-style-type: none"> • Age Expected - Full participation • Somewhat Restricted • Very Restricted • Unable • Not Applicable 	<p>Addressed broadly across all settings through open ended questions, specifically for each child:</p> <ul style="list-style-type: none"> • Effective strategies • Supports • Barriers <p>That affect participation</p>
SFA	<p><u>Assesses 1 dimension</u></p> <ul style="list-style-type: none"> • Participation extremely limited • Participation in a few activities • Participation in all aspects with constant supervision • Participation in all aspects with occasional assistance • Modified full participation • Full participation 	<p>Addressed specifically for a school setting</p> <p><u>Measures Task Supports:</u></p> <ul style="list-style-type: none"> • Physical Task Assistance • Cognitive/Behavioral Task Assistance • Physical Task Adaptations • Cognitive/Behavioral Task Adaptations
PEM-CY	<p><u>Assesses 3 dimensions</u></p> <ul style="list-style-type: none"> • Frequency (e.g. once in the last 4 months) • Involvement (e.g., very involved) • Desire for change (e.g., no change desired; yes, do more often) 	<p>Addressed specifically for a school setting</p> <p><u>Measures Supports and Barriers:</u></p> <ul style="list-style-type: none"> • Environmental Features (e.g., physical layout, demands of activities, sensory qualities, relationship with peers, attitudes of teachers, directors) • Environmental Resources (e.g., time, money, policies and procedures)

Strengths and Limitations of the PEM-CY in Meeting Educational Stakeholder Needs

The PEM-CY was initially designed for research applications though may hold utility in meeting the baseline assessment needs of school professionals. A unique feature of the PEM-CY

is that it combines comprehensive assessment of children's school participation with an assessment of the physical, social, attitudinal, and institutional features of the school environment that may support or challenge the child's participation in that setting. This combined assessment approach was informed by parent input about the inextricable link between the concepts of participation and the environment (Bedell, Khetani, Cousins, Coster & Law, 2011) and may help stakeholders obtain a more detailed assessment about the perceived impact of the school environment on a child's participation specific to activities within that setting. This detailed assessment of environmental impact may be an important asset to the PEM-CY given that environments are important but often underemphasized when intervening to promote children's participation (Anaby et al., 2013; Anaby et al., 2014). Information about environmental impact may provide valuable information to stakeholders (e.g., school principals, service providers) who have the authority to modify or guide decision-making about when and how to modify environments to promote school participation outcomes.

Another key feature of the PEM-CY is that it gives parents the opportunity to describe up to three strategies that they have used to promote their child's participation in a specific setting. Information about parent strategies may help service providers build on PEM-CY results to engage in collaborative intervention planning to meet best practice standards for client-centered practice. In CBR, information about parenting practices is commonly gathered via interview as part of assessing for client needs (Hartley et al., 2005). Ecocultural theorists argue that an in-depth understanding of parenting practices, including their strategies to promote family functioning, provides a window into parental beliefs and expectations about their child and therefore can help providers plan for interventions that are culturally relevant and sustainable (Weisner, 2002). Hence, information from the PEM-CY about parenting strategies may help

stakeholders leverage parental expertise to expand upon their understanding of clients' perceptions of how to intervene.

In addition to providing stakeholders with comprehensive and detailed information about school participation, supports and barriers in the school environment, and parent strategies to promote school participation for an individual student, the PEM-CY also meets stakeholder need to differentiate the participation patterns of groups of children with and without disabilities in an educational setting. Recent studies suggest that the PEM-CY can detect significant participation differences between children and youth with and without disabilities in the home (Law et al., 2013), school (Coster et al., 2013) and community (Bedell et al., 2013). In the school setting, Coster and colleagues (2013) found that children with disabilities participate less often and are less involved in school-based activities, and a significantly higher percentage of parents of children with disabilities desired change in their child's participation for all five school activities as compared to parents of children without disabilities, even after controlling for child factors (e.g., age, diagnosis, gender), family-related factors (e.g., respondent education, family income), and environmental factors (e.g., classroom placement) that might confound these results. These findings were consistent with other studies that have also reported on participation disparities among children with and without disabilities in structured and unstructured school-based activities (Ericksson, Welander & Granlund, 2007; Hemmingson & Borell, 2002; Simeonsson, et al., 2001). For the school environment, Coster and colleagues (2013) found that parents of children with disabilities were more likely than parents of children without disabilities to report on the physical layout, sensory qualities, and physical, cognitive, and social demands of school-based activities as making it harder for their children to participate in school-based activities.

Similarly, Hemmingson & Borell (2002) reported on the impact of these features of the school environment on children's participation.

There are several limitations that may prevent uptake of the PEM-CY in school-based practice. One potential drawback to the PEM-CY is that it evaluates the child's participation in broader types of activities (e.g., classroom activities) rather than discrete school-based activities (e.g., group work, classroom discussions, tests) because it was initially designed for use in large sample research. This level of specificity may be needed to inform the design of tailored interventions that address the participation needs of an individual child with disability in relationship to a specific school activity. This is one way in which the PEM-CY may be insufficiently developed to systematically guide intervention planning with individual families (Khetani, Cliff, Schelly, Daunhauer & Anaby, 2014). Secondly, there are no published studies that report on the validation of the PEM-CY in different cultural contexts to support its utility for meeting the baseline assessment needs of stakeholders who are situated in schools that are located in both developed and developing regions of the world. However, the PEM-CY has been translated into four languages (French, Spanish, Portuguese & Korean) and six more translations are underway (Chinese, Dutch, Hebrew, Icelandic, Slovene & Turkish).

Applying the PEM Approach to Improve Knowledge about Participation in Younger Children

In contrast to recent advancements in the development and validation of participation measures for children and youth, fewer participation measures have been developed that are suitable for use with parents of younger children. As a result, there is less knowledge about disparities in young children's participation and perceived environmental supports and barriers to participation in early childhood educational settings. We have descriptive knowledge about the

types of activities in which young children with developmental delays participate (Dunst et al., 2002), and we also have an understanding of the broad types of family accommodations made by parents of young children to manage everyday life when raising a young child with a disability (Bernheimer & Keogh, 1995). New assessments of young children's participation may afford for opportunities to understand 1) if there are disparities in participation between young children with and without delays, 2) how environments are perceived to impact participation restriction, and 3) what strategies parents of young children with delays have used to improve their child's participation in activities. This knowledge might help stakeholders decide when and how to intervene in promoting young children's participation in daycare/preschool activities.

The Young Children's Participation and Environment Measure (YC-PEM) (Khetani, Coster, Law, & Bedell, 2013) is a newly developed measure that is modeled after the PEM-CY (Coster et al., 2010) but for younger children (0-5 years). Similar to the development of the PEM-CY, to develop the YC-PEM, Khetani & Coster (2008) first drew on existing interdisciplinary literature about the important activities (Dunst et al., 2002), environmental factors (King et al., 2003), and ten types of family accommodations that are used by families of young children with developmental delays to promote their participation in activities (Bernheimer & Keogh, 1995). They then proposed the following working definition of young children's participation:

For infants and young children, participation as outcome is characterized by involvement in organized sets and sequences of activities that typically involve the presence and engagement of others. These life situations are setting-specific (i.e., home, community) and, in addition to promoting the learning and development of skills and capacities, may serve an overarching goal of achieving health and sustenance and enjoyment and well-being. (Khetani & Coster, 2008).

As discussed by Khetani (in preparation), initial decisions about content, scaling, and layout of the YC-PEM were largely informed by qualitative work undertaken to identify parents'

perspectives about 1) the relevant settings and types of activities in which young children participate, 2) key ways of appraising young children's participation, 3) environmental factors and parents strategies in promoting young children's participation, and 4) whether to combine assessment of participation and environment (Khetani, Cohn et al., 2013). Data from a national, longitudinal study of preschoolers with disabilities were used to further validate the decision about whether to assess for environmental impact at the setting level (Khetani, Graham, & Alvord, 2013) and to identify the types of child, family, and environmental factors that are most commonly associated with participation restriction (Khetani, Graham, & Alvord, 2013; Khetani, Orsmond, Cohn, Law, & Coster, 2012). The YC-PEM then underwent several rounds of cognitive testing (i.e., where respondents have been asked a series of follow-up probes, asking them to explain how each question was understood and how they arrived at the answers they gave) as preparation for field-testing. The YC-PEM has undergone psychometric evaluation and has been found to be a valid and reliable instrument for measuring participation and environment among young children (0-5 years) in home, school and community settings (Jiang & Khetani, 2014; Khetani, Graham, Davies, Law, & Simeonsson, 2014).

Although the PEM-CY and the YC-PEM both assess for participation and environment in the same instrument, there are several differences in the content and layout of the YC-PEM. Differences between the PEM-CY and YC-PEM include the use of: 1) age-appropriate activities (e.g., group learning in the YC-PEM versus classroom activities in the PEM-CY); 2) age-relevant environmental factors (e.g., emphasis on temperature and texture of objects under sensory qualities in the YC-PEM versus noise, crowds and lighting in the PEM-CY); 3) age-appropriate response options to appraise the child's participation (e.g., frequency responses range from 'never' to 'once or more each day' in the YC-PEM versus 'never' to 'daily' in the PEM-

CY); 4) specificity of reporting on parent strategies to promote participation (e.g., in the YC-PEM, parents are asked to provide specific strategies used for each activity type for which they desire change versus general strategies used to promote participation in a specific setting in the PEM-CY). In these four ways, the YC-PEM is similar to the PEM-CY but changes have been incorporated so that the instrument is applicable to younger children. The YC-PEM has recently undergone initial psychometric validation but has not yet been used to build knowledge about participation patterns of young children with and without delays. This type of descriptive knowledge is needed to inform decision-making about its utility for baseline assessment in early childhood education research and practice contexts.

Purpose

The purpose of this study is to generate new knowledge about the participation patterns of young children with and without developmental delay(s) within early childhood educational contexts, using the newly validated Young children's Participation and Environment Measure (YC-PEM). I will approach my study purpose by addressing the following five aims:

Aim 1. Examine similarities and differences among young children with and without developmental delay(s) in terms of their *frequency* of participation in early childhood educational activities using the YC-PEM (QUAN).

Aim 2. Examine similarities and differences among young children with and without developmental delay(s) in terms of their *level of involvement* in early childhood educational activities using the YC-PEM (QUAN).

Aim 3. Examine similarities and differences among parents of young children with and without developmental delay(s) in terms of their *desire for change* in their child's participation in early childhood educational activities using the YC-PEM (QUAN).

Aim 4. Examine the relationship between *types of change desired* and *parent strategies* employed to promote young children's participation in early childhood educational settings using the YC-PEM (qual → QUAN).

- a. For parents who desire change in their child's participation in early childhood educational activities, examine the types of change that are most commonly desired (quan).
- b. For parents who desire change in their child's participation in early childhood educational activities, examine types of parent strategies most commonly employed (qual).

- c. For parents who desire change in their child's participation in early childhood educational activities, examine the relationship between types of parent strategies employed and types of change desired (qual →QUAN).

Aim 5. Examine similarities and differences in parent perceptions of *environmental factors* that support and hinder participation in early childhood educational settings for young children with and without developmental delay(s) using the YC-PEM (QUAN).

Findings from prior studies about school-aged children's participation (Coster et al., 2013) as well as descriptive studies of young children's community participation (Khetani, Graham, & Alvord, 2013) and validation studies of other young children's participation measures (Law, King, Petrenchik, Kertoy & Anaby, 2012; Rosenberg, Jarus & Bart, 2010) informed my hypotheses for each of the proposed study aims. Specifically, I hypothesized that 1) young children with developmental delays participate in activities less often when compared to their same aged peers without developmental delay(s) (*Aim 1*); young children with developmental delays are less involved in activities when compared to their same aged peers without developmental delay(s) (*Aim 2*); and 3) parents of young children with developmental delays are more likely to report a desire for change in their child's participation when compared to parents of same aged peers without developmental delay(s) (*Aim 3*); 4) parents of young children with developmental delays report a greater number of environmental barriers and a fewer number of environmental supports when compare to their similar aged peers without delay(s) (*Aim 5*). I do not have a hypothesis for *Aim 4* because the purpose of this aim is to extend current knowledge about parent strategies by exploring whether there are patterns in the types of strategies that parents employ relative to the types of change they desire.

By addressing these five study aims, I will generate new knowledge about discrepancies in participation between young children with and without developmental delay(s) in early childhood educational programs using the YC-PEM. This, in turn, will also help establish the utility of the YC-PEM for meeting stakeholder needs when conducting a client-centered baseline needs assessment in early childhood educational programs. As shown in Figure 1 below, study results will also support stakeholder informational needs in terms of 1) identifying children with participation restriction, as informed by knowledge about similarities and differences in participation patterns (Aims 1-3), 2) specifying the types of intervention needs with which children present, according to knowledge about common types of change desired (Aim 4a), and 3) identifying how to promote participation, as informed by knowledge about parent strategies and perceived environmental supports to participation (Aims 4 b-c and 5).

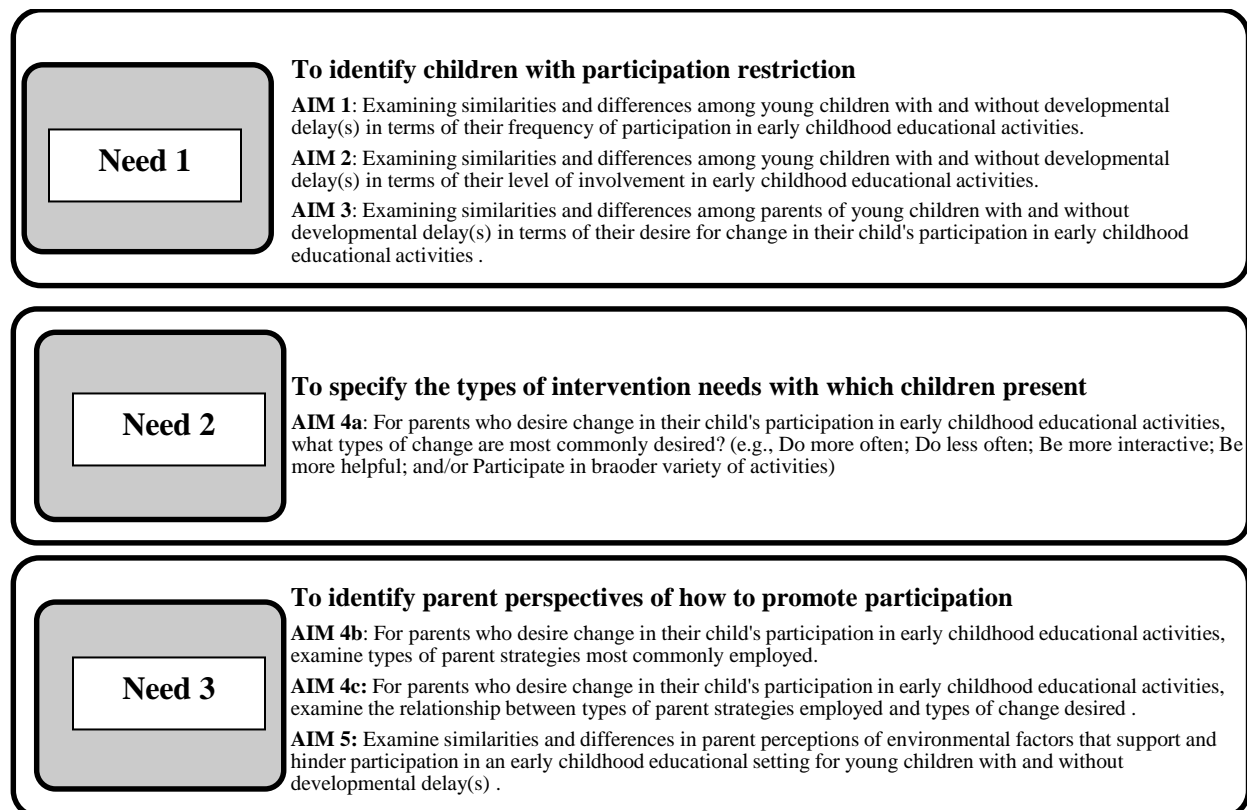


Figure 1: Study Aims as Mapped to Stakeholder Need.

Relevance of Thesis Topic to Occupation and Rehabilitation Science

Each student pursuing research training in the Department of Occupational Therapy at Colorado State University is asked to communicate how their research addresses the goal of occupational therapy, which is to promote human performance and participation in everyday life. Towards this end, each student is asked to consider how his or her proposed study is influenced by scholarship in occupational science and rehabilitation science and how their study would be situated in the Occupation and Rehabilitation Science (OARS) model (see Figure 2 below). In this section, I describe how my progress on my research has been influenced by these two scientific disciplines and how I think my work currently maps to the OARS model.

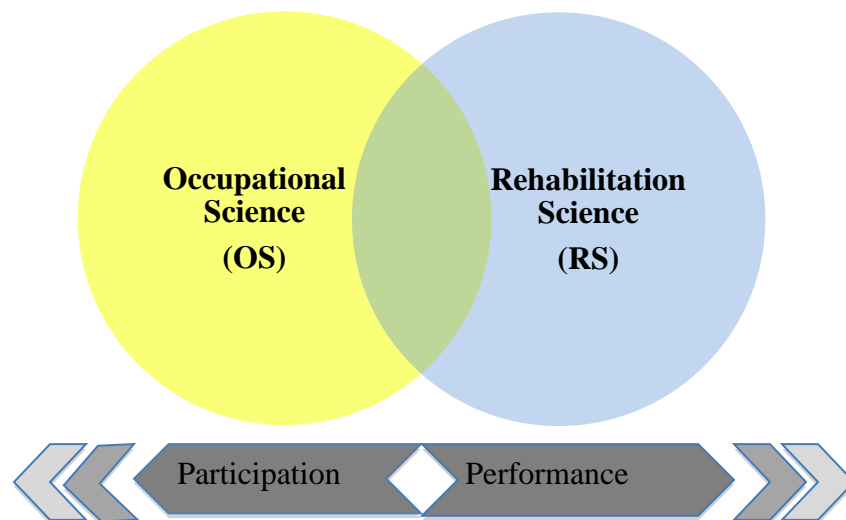


Figure 2: The Occupation and Rehabilitation Science (OARS) Graphic.

My thesis focuses on using a newly developed instrument called the Young Children's Participation and Environment Measure (YC-PEM) to characterize young children's participation patterns in early childhood education programs, environmental supports to participation in this setting, and parent strategies to promote change in participation. The YC-PEM is a tool that measures both the subjective and the objective aspects of children's

participation. Specifically, the YC-PEM assesses dimensions of frequency and involvement in participation (i.e., objective) and the desire for change (i.e., subjective) in young children's daycare/preschool participation. I have also leveraged data about parental strategies to promote their child's participation. These data were derived from open-ended questions on the survey, and are intended to help expand assessment of the subjective qualities of children's participation.

The OARS graphic (see Figure 2 above) suggests that occupational science has a stronger tradition of emphasizing scholarship on the outcome of participation when compared to the discipline of rehabilitation science. However, most of the research literature that has informed the design of my thesis had been published in rehabilitation science. My understanding is that since the introduction of the ICF and ICF-CY, there has been a significant increase in the number of publications by rehabilitation scientists on the topic of children's participation. Hence, I drew heavily on the rehabilitation science literature in the introduction of my thesis and had anticipated that I would have the opportunity to integrate some occupational science literature while interpreting my mixed methods study results on parental desire for change in their child's daycare/preschool participation. I am not sure if I can map my work to the area of overlap between both sciences in the shorter-term as I carry out my thesis as much as I can in the longer-term should I continue to pursue research on this topic.

Method

Study Design

I propose to address my five study aims using a concurrent transformative mixed methods study design. In this section, I describe my rationale for using a mixed methods study approach to best address the purpose of this study and then provide my rationale for using a concurrent transformative study design.

A mixed methods study design is typically employed when one type of research methodology is insufficient for addressing the research problem under investigation (Creswell, 2009). This main objective of this study is to fill important knowledge gaps about similarities and differences in school participation, perceived environmental supports and barriers to school participation, and parent-reported strategies to promote participation for young children with and without developmental delays. To achieve this main study objective, I will use a newly developed caregiver report instrument, the YC-PEM, in order to 1) differentiate the participation patterns of young children with and without disabilities, 2) meaningfully describe the types of participation needs with which young children present, and 3) closely examine parent perceptions of environmental supports to participation and strategies to improve participation in this setting. This knowledge can help stakeholders focus their interventions to promote participation-level outcomes. Data from closed-ended and open-ended questions of the YC-PEM need to be leveraged to fill these important knowledge gaps.

A common feature of all mixed methods research is an explicit integration, or mixing, of both qualitative and quantitative methods in one or more phases of the research process (Tashakkori & Teddlie, 1998). In this study, mixing of qualitative and quantitative methods happened at both the data collection (i.e., concurrent) and data analytic (i.e., transformative)

phases of study. Concurrent designs are often used to expand on one form of data using the other (Creswell & Clark, 2011). In this study, quantitative and qualitative methods were combined to afford parents with an opportunity to thoroughly appraise their child's participation in early childhood educational programs. As shown in Figure 3, parents first answered closed-ended questions about their child's participation (frequency, involvement, and desire for change). If parents selected 'yes, desire change', they were prompted to report on the type(s) of change that they desire (e.g., change in frequency, level of involvement, and/or broader variety of activities of that type) and were also asked to describe up to three strategies that they have tried to help their child participate in that specific type of activity. In this way, the mixing of closed-ended and open-ended items during data collection helped gather a greater depth of knowledge about parents' participation goals for their child and their prior attempts to reach those goals.

A transformative design involves changing data from one form to another (e.g., open-ended narrative data is transformed to numerical counts) to help answer a research question. In this study, a transformative study design is appropriate for achieving Aim 4c. For Aim 4c, we attempt to explore links between parent strategies and types of change desired. My rationale for pursuing this aim is that prior studies have yielded a broad set of ten strategies commonly employed by parents of young children with disabilities (Bernheimer & Keogh, 1995) that may be less useful for guiding intervention planning that is specific to improving the child's participation in a particular activity or setting, or in a particular manner (e.g., do more often vs. be more involved). Specific information about patterns in parental strategy use could help practitioners anticipate the types of strategies that are commonly employed by parents, as a starting point to meeting parents where they are at in order to begin intervention planning. In this study, responses to the open-ended questions on the YC-PEM about parent strategies to promote

daycare/preschool participation were sorted into the 10 family accommodations that have been reported on in the literature (Bernheimer & Keogh, 1995), and then the responses were transformed into quantitative data (i.e., number counts) and linked back to parental responses about type(s) of change desired. This process of quantifying narrative data enabled me to explore the most commonly reported parent strategies relative to the type(s) of change desired (Creswell & Clark, 2011).

Limitations of this particular study design include: 1) the depth and flexibility of the qualitative information can be lost when quantifying the qualitative data, and 2) the process of analyzing, coding, and relating unstructured with structured data to each other is complex and time intensive (Driscoll, Appiah-Yeboah, Salib & Rupert, 2007). Despite these limitations, this study design would be best suited to address my study purpose.

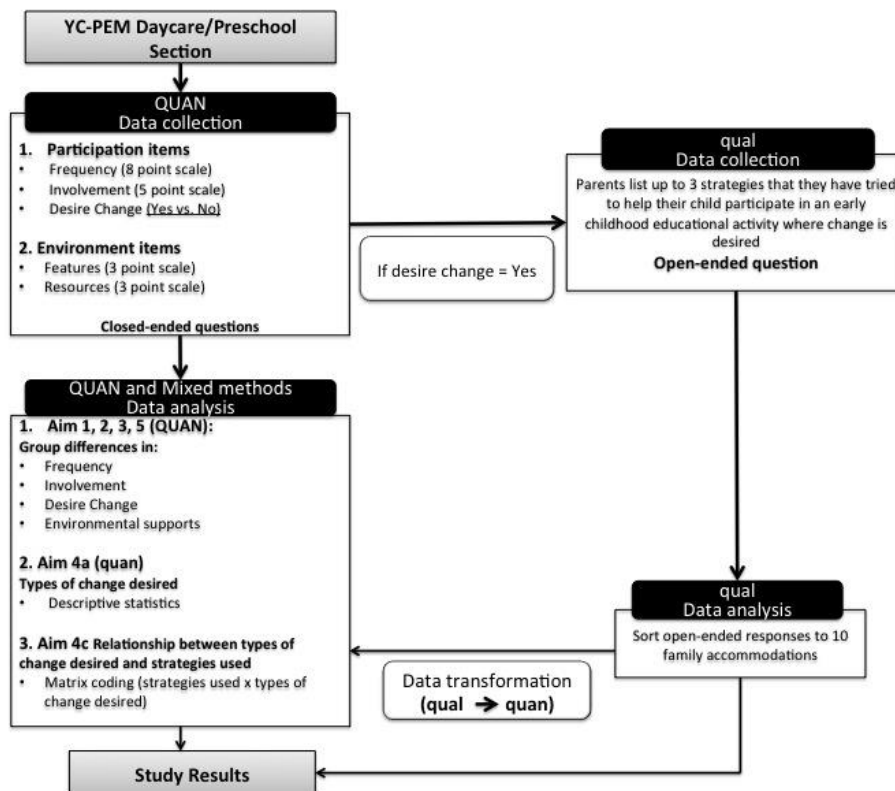


Figure 3: Concurrent Transformative Mixed Methods Design

Participants

Data for this cross-sectional study (n=129) are drawn from a larger validation study of the YC-PEM (June-October 2013), which was conducted using a web-based format that involved 395 caregivers of young children with and without developmental delays residing in the USA and Canada. Convenience and snowball sampling methods were used to recruit diverse study participants in terms of their geographic location, socioeconomic status, and their child's age and service enrollment. Research staff first approached program directors of early intervention agencies and early childhood centers in the Colorado Front Range and Wyoming communities and provided them with study flyers and talking points to use when distributing flyers to families. Notices about the study and enrollment updates were also posted via agency-sponsored electronic newsletters and social media sites (i.e., newsfeeds from our Facebook page were liked and shared by agencies on their Facebook pages). Staff also attended community-sponsored events (e.g., universal playground design workshop) to solicit for additional recruitment help and to directly enroll families who were in attendance at the event. Research staff then built on one or more of these three sampling methods to expand recruitment via established contacts at early intervention programs, early childhood centers, summer camps, and medical and dental clinics in diverse regions within North America (US and Canada). Each participant who agreed to help with participant recruitment was issued two study flyers along with their mailed payment.

Caregivers were deemed eligible to participate if they met the following criteria: 1) they were 18 years or older; 2) they identified themselves as a parent or a legal guardian of a child aged between 0-5 years; 3) they were able to speak and read English; 4) they had access to the internet; and, 5) they resided in North America (United States and Canada). For this study, we employed an additional inclusion criterion: 1) the participant self-identified as having a child

enrolled in an early childhood educational program (i.e., center-based daycare, preschool, or kindergarten). Sample characteristics are summarized in Tables 4 – 7.

Data Collection

Approval was obtained from the Institutional Review Board prior to participant recruitment and data collection. A secure web-based platform was used for data collection and data management during the enrollment period (June-October 2013).

Each eligible and interested participant was directed to enroll in the study via a web link located on the project flyer. Participants were first asked to review the inclusion criteria and confirm their eligibility and then were guided through the process of creating a user account and then logging in with their username and password to gain access to the study site. Upon entering the study site, each participant was asked to select a captioned video or text-only version of the online consent to review and enroll to complete the study online.

Data for this study were collected as part of a larger online validation of the YC-PEM instrument. The larger study involved three parts: Part 1) Demographic questionnaire, YC-PEM Time 1, and Craig Hospital Inventory of Environmental Factors (CHIEF-CP) (completion time: 45-50 minutes); Part 2) Pediatric Evaluation of Disability Inventory – Computer Adaptive Device (PEDI-CAT) phone interview (completion time: 15-20 minutes); Part 3) YC-PEM Time 2 (completion time: 25-30 minutes). A subset of data from Part 1 (YC-PEM and Demographic questionnaire) of the larger validation study was used for this study. Therefore, data collection for this study involved consented participants completing the demographic questionnaire and YC-PEM daycare/preschool section. Participants could take a 5-10 minute break after completion of the demographic questionnaire and each section of the YC-PEM. Upon survey completion, participants were asked to provide their mailing address to receive payment. Each

study participant was issued a \$10 US cash or gift card payment for completing Part 1 of the study online. Each of the twelve recruitment sites were invited to enter into a prize drawing for a refurbished iPad at the end of the study enrollment period, and occupational therapy providers who helped with recruitment were eligible to earn up to two professional development units (PDU) towards recertification.

Measures

Demographic Questionnaire. Caregivers reported on 1) family factors (e.g., respondent type, education, employment status and, marital status), 2) household factors (e.g., annual income), 3) child factors (e.g., age, gender, race/ethnicity, childcare arrangement, early childhood intervention/special education service enrollment) and, 4) their child's functioning in 12 areas (e.g., mobility, vision, hearing, communication, self-feeding, paying attention, controlling behavior) as (no problem vs. little problem/big problem). This questionnaire took approximately five minutes to complete.

Young Children's Participation and Environment Measure (YC-PEM). This questionnaire assessed caregiver perceptions on their young child's participation in broad types of activities that take place in the home (13 items, e.g., mealtime, cleaning up, indoor play and games, celebrations at home), daycare/preschool (3 items, e.g., group learning, socializing with friends, field trips and events), and community (12 items, e.g., dining out, classes and lessons, community attractions, overnight visits or trips) settings. Data from the daycare/preschool section of the YC-PEM were used to achieve study aims for this study.

The daycare/preschool section asks the caregiver to assess their child's participation in 3 broader types of activities: a) group learning (e.g., circle time, story time, music and movement, art projects), b) socializing with friends (e.g., mealtime, snack time, outdoor play), and c) field

trips and events (e.g., parent night out, going to the library, school concert or fundraiser). For each type of activity, the caregiver assessed three dimensions of their child's participation 1) frequency (8-point scale, from never [0] to once or more each day [7]), 2) level of involvement (5-point scale, from not very involved [1] to very involved [5]; participants skipped this step if they selected "never" for frequency), and 3) parental desire for change in the child's participation (yes [1] vs. no [0]). If yes, the caregiver was asked to clarify if change was desired in terms of frequency (i.e., more or less often), level of involvement (i.e., more interactive and/or more helpful) and/or participation in a broader variety of activities of that type. When the caregiver desired change in their child's participation for one or more activities in the daycare/preschool category, he/she was prompted to describe up to three strategies that have been employed to promote their child's participation in activities of that type, using an open-ended response format.

After completing the participation items for the daycare/preschool section, caregivers evaluated the impact of environmental features and resources on the child's participation in that setting by answering 16 questions. Impact of environmental features (e.g., physical layout, sensory qualities) on participation was assessed on a 3-point scale (no impact/usually helps [3] to usually makes harder [1]). The perceived impact of environmental resources (e.g., school related policies and procedures, access to personal transportation) on participation was assessed on a 3-point scale (not needed/usually yes [3] to usually no [1]). Before proceeding to the next section, caregivers described up to three strategies for promoting their child's participation in that setting.

The YC-PEM has 3 participation scales and 1 environment scale. For this study, four YC-PEM Daycare/Preschool setting summary scores were calculated: 1) *Frequency* was calculated as the average of all ratings (range = 0 - 7); 2) *Involvement* was calculated as the average of all ratings (range = 1 - 5); 3) *Percent Desire Change* was calculated by summing the number of

items scored as 'yes, desire change', divided by the total number of items, and multiplied by 100 (range = 0 - 100); 4) *Environmental Support* was calculated by summing responses across all environmental features and resources items and dividing the sum by the maximum possible score, and multiplying the score by 100 (range = 0 - 100).

The YC-PEM daycare/preschool section has moderate to high internal consistency for the following scales: frequency ($\alpha = 0.72$); level of involvement ($\alpha = 0.80$); desire for change ($\alpha = 0.67$); environmental support ($\alpha = 0.92$) (Jiang & Khetani, 2014). Test-retest reliability over a 2-4 week period ranged from moderate to high: frequency (ICC = 0.31); involvement (ICC = 0.78); environmental supportiveness (ICC = 0.92); and desire for change ($\kappa = 0.59$) (Khetani, Graham, Davies, Law, & Simeonsson, 2014). The internal consistency for *desire change* in daycare/preschool activities was slightly below the threshold of adequate reliability (ICC < 0.70) and the test-retest reliability for *frequency* of participation in daycare/preschool activities was also below the threshold of adequate reliability ($\kappa < 0.40$) (Khetani, Graham, Davies, Law, & Simeonsson, 2014).

Data Analysis

Data collected online were automatically pushed to a central data repository and exported via Microsoft Excel to IBM SPSS 21.0 (SPSS, Inc., Chicago, IL, USA) for Aims 1, 2, 3, 4a and 5 analyses, and from IBM SPSS 21.0 (SPSS, Inc., Chicago, IL, USA) to NVivo 10.0 (NVivo, QSR International Pty Ltd. Version 10, 2012) for Aims 4b analyses.

The YC-PEM daycare/preschool section contains closed and open-ended questions. Closed-ended questions were first analyzed using a quantitative analytic approach (QUAN) to examine disability-related differences in frequency, level of involvement, parental desire for change, and perceived environmental support for daycare/preschool participation. The open-

ended items about parental strategy use were first analyzed using qualitative methods (qual) to describe common types of strategies used. These responses were then transformed (qual > quan) to further examine patterns in strategy use relative to types of change desired. In the remainder of this section, I describe details for carrying out the quantitative analysis (QUAN) and the mixed method analyses (qual, and qual > quan).

Quantitative data analyses (QUAN).

Identifying the participation needs of young children and perceived environmental supports for participation in daycare/preschool activities (Aims 1-3 and 5). Data were first screened via visual inspection (histogram) and normality statistics (absolute values of > 2 for skewness and > 7 for kurtosis) to ensure that data met assumptions of normality (Field, 2009). Five YC-PEM items (4 environment items and 1 desire change item) did not meet the criteria for normality, resulting in nonparametric tests for analyses involving those items (Osborne, 2013).

For Aim 1, independent samples *t*-tests were used to compare children with and without developmental delays in terms of how frequently they are reported to participate in specific daycare/preschool activities. I did not compute summary-level comparisons for the YC-PEM *frequency* scale because the test-retest reliability for the frequency scale in the daycare/preschool section of the YC-PEM was below the threshold of adequate reliability ($\alpha < 0.40$) (Khetani, Graham, Davies, Law, & Simeonsson, 2014).

Independent samples *t*-tests were also used to perform summary-level and item-level analyses comparing young children with and without developmental delays in terms of their *level of involvement* (**Aim 2**) because *frequency* and *level of involvement* are continuous variables and all data in these scales met the criteria for normality. Absolute values of Cohen's *d* were

computed to estimate effect size, where $d \geq 0.2$ denotes a small effect, $d \geq 0.5$ is medium and $d \geq 0.8$ is large (Cohen, 1988).

For Aim 3, chi-square tests were used to compare children with and without developmental delays in terms of parental *desire for change* (Aim 3) at the item-level, because this outcome was based on categorical data, and an odd's ratio was used to report on effect size. I did not compute summary level comparisons for desire change because the internal consistency for the *desire change* scale in daycare/preschool section of the YC-PEM was slightly below the threshold of adequate reliability ($ICC < 0.70$).

For Aim 5, Mann-Whitney *U* tests were performed to examine similarities and differences in parent perceptions of *environmental support* for their child's daycare/preschool participation. We initially performed these analyses because, 1) 4 of the 16 environmental items did not fit the criteria for normality, 2) these outcomes are continuous variables, and 3) missing data in the environmental scores (1 missing value (0.77%) for 11 items, 2 missing values (1.5%) for 4 items, and 14 missing values (10.8%) for the outside weather conditions item). Although *t*-tests are robust to violations of the assumptions that conclusions may not be warranted, these item-level analyses were re-run using independent samples *t*-tests. We reported on the independent samples *t*-test results because these results were similar to the Mann Whitney *U* test results and, central limit theorem reassures us that with sufficiently large sample sizes, sampling distributions of means are normally distributed regardless of the distributions of variables (Tabachnick & Fidell, 2013).

Missing data for this study pertained to responses in the YC-PEM environmental section. One participant had missing data on all 16 environment items, resulting in case deletion for summary-level comparisons of *perceived environmental support*, but all other missing data were

treated using mean substitution for summary-level disability group comparisons. Item-level comparisons were conducted using pairwise deletion for all missing data.

If significant summary and item-level group differences were found in Aims 1-3 and 5 analyses, these differences were confirmed while controlling for potential confounders. Chi-square tests were first used to identify potential confounders. Significant group differences between children with and without developmental delays were found only with respect to child gender. Although no significant group differences were found based on child age or family income, these variables were also entered as covariates because prior studies have identified these demographic factors to have a confounding effect on the participation of children and youth in activities (Bedell et al., 2013; Law et al., 2006). ANCOVA and ANOVA analyses were used to control for the three confounders (child age, child gender, family income) on group differences in daycare/preschool participation and perceived environmental support to participation. We used a general linear model to control for these confounders in between-group item-level comparisons involving continuous variables (i.e., responses on items within the YC-PEM *frequency*, *involvement*, and *environmental support* scales) and the generalized linear model to control for confounders in between-group item-level comparisons involving categorical variables (i.e., responses on items within the YC-PEM *desire change* scale).

Due to multiple comparisons, Bonferroni corrections were made to reduce Type 1 error rate by dividing 0.05 by the number of comparison tests conducted for each set of group comparisons. This resulted in a significance level of .025 for participation item-level group comparisons, and a significance level of .003 for environment item-level group comparisons.

Mixed- method data analysis.

Specify the types of intervention needs with which children present (Aim 4a).

Descriptive statistics (frequencies and percentages) were used to describe the most common types of change desired by parents of young children (quan).

Examining how parents promote their child's participation (Aims 4b-c). Responses to the open-ended items about parent strategy use were content coded using Nvivo 10.0. We examined the type(s) of parents strategies most commonly employed by parents who desired change in their child's participation in the daycare/preschool activities (Aim 4b) by coding our YC-PEM data on parent-reported strategies to the ten family accommodations (See Table 3). Two coders independently coded parent-reported strategies (N = 126) into the ten types of family accommodations reported in literature. Before coding for this study began, the second coder was oriented to the general topic of this thesis, the research questions being pursued, and the ten types of family accommodations, each with examples, to understand the coding scheme for Aim 4 analyses (Gallimore et al., 1996). Then, a pilot test was run in which both coders (the second coder and myself) content coded 30 parent-reported strategies from the YC-PEM home section to the ten types of family accommodations. The final coding began only when both coders reached 80% consensus after independently coding the home strategies to the ten types of family accommodations. The coding process is further elaborated in *Figure 4* as shown below.

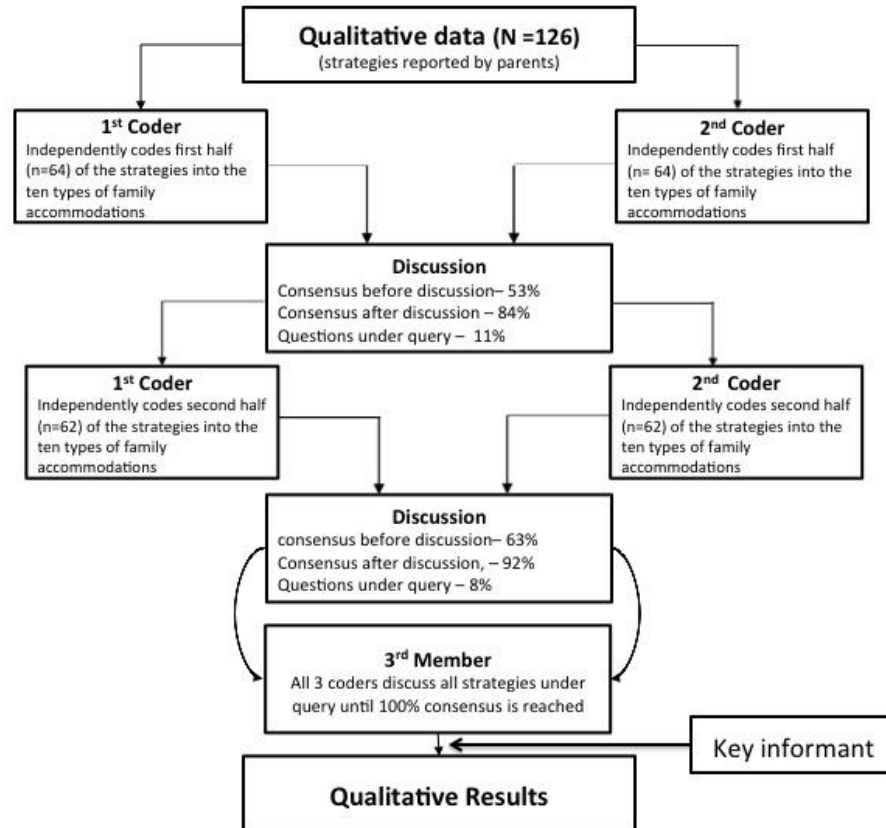


Figure 4. The Coding Process

Once the narrative data on parent-reported strategies had been coded to the ten family accommodations, I transformed the open-ended coded responses into numerical data. Transformation of narrative data into numerical counts was pursued in order to better examine the relationship between types of change desired by parents and the strategies commonly used by parents to improve their child's participation (Aim 4c). This relationship between type(s) of change desired and parent strategies employed was examined using a matrix coding approach as outlined in Table 3 below.

Table 3. Commonly reported parent strategies relative to type(s) of change desired (Aim 4c)

Family Accommodations	Type(s) of change desired			
		Involvement		
	Frequency	Be more interactive	Be more helpful	Participate in broader variety of activities
Family subsistence (e.g., hours worked; flexibility of work schedule)	n (%)			
Services (e.g., availability of services; sources of transportation)				
Home/neighborhood safety and convenience (e.g., safety and accessibility of play area; alterations in home)				
Domestic workload (e.g., amount of work that needs to be done; persons available to do it)				
Childcare tasks (e.g., complexity of child care tasks; presence of extraordinary childcare demands)				
Child peer groups (e.g., child's play groups: children with disabilities vs typically developing children; amount of parent supervision needed)				
Marital roles (e.g., amount of shared decision making regarding child with delays; degree to which childcare and household tasks are shared)				
Instrumental/emotional support (e.g., availability and use of formal and informal sources of support; costs of using support)				
Father/spouse role (e.g., amount of involvement with child with delays; amount of emotional support provided)				
Parent information (e.g., reliance on professional vs. nonprofessional sources of information)				

To establish trustworthiness and rigor for the Aim 4b analysis, I ensured reliability by having two separate coders, transferability by having a key informant, and to ensure authenticity

I used self-reflexivity. Self-reflexivity includes acknowledgement of the researchers' prior experiences that can impact his or her hypotheses and approach to data collection and/or analysis. Self-reflexivity further adds to the trustworthiness of study results.

Prior to beginning graduate study, I worked as an occupational therapist in the community health department of a mission hospital in Bangalore, India for a period of two years. I primarily worked with children with disabilities and their families in rural villages and the urban slums of the city. Most parents of children with disabilities that I worked with focused on intervening to fix their child and less often intervened on their child's environment. Secondly, most parents of children with disabilities that I worked with desired a change in their child's frequency in school participation. Since most of the children with disabilities that I worked with had been denied admission into school, parents often framed their desire for change in terms of their child gaining admission to school. Hence, I expected that the strategies most commonly used by parents will primarily focus on the child and also, that parents will more often desire a change in their child's frequency of participation.

My experiences in practice have also shaped how I conducted Aim 4 analyses. The two coders for this study had different levels of knowledge on the topic of young children's participation. A member of our research team at CPERL served as a second coder. She independently content coded parent-reported strategies on the YC-PEM to the ten types of family accommodations that have been previously reported in the literature (Bernheimer & Keogh, 1995) (see Table 3). A third member was recruited from the research team to weigh in on decisions in cases where there was discrepancy in the coding of parental strategies to the family accommodations. I ensured transferability by having a key informant who served as a content expert. The key informant viewed the qualitative results at completion (*See figure 4*) with a new

set of eyes to determine the accuracy of the qualitative findings based on the specific descriptions of the codes. The two coders, the third member who helped establish consensus, and the key informant are all members of the same research team. Although this decision was made based on my comfort level in seeking support as an international student and for feasibility, employing team members in Aim 4 analyses could have potentially contributed to higher consensus rates (see Figure 4) because the team members were invested in my ability to successfully complete this study just as much, if not more, than they were in ensuring study rigor.

Results

In this section, I will first report on participant characteristics. This will then be followed by a summary of the quantitative (QUAN) findings where I report on similarities and differences between young children with and without developmental delays in terms of participation frequency (Aim 1), level of involvement (Aim 2), desire for change (Aim 3), and perceived environmental support (Aim 5). Finally, I will report the findings of my mixed methods study aim (Aim 4), including a) the types of change most commonly desired by parents (quan), b) the strategies most commonly used by parents to improve their young child's participation in daycare/preschool activities (qual), and c) the relationship between type(s) of change desired and parent-reported strategies to improve daycare/preschool participation (qual > quan).

Participant Characteristics

The YC-PEM daycare/preschool section was completed by 129 caregivers of young children with and without disabilities (37 children with developmental delays and 92 children without developmental delays) between 3 and 71 months ($M = 49.3$, $SD = 16.5$). Most respondents were mothers (94.6%), married (89.9%), and resided in the United States (92.1%). At least two-thirds of the study participants held a college degree (69.7%), were employed outside of the home (66.6%), and had their child enrolled in a center-based program (76.0%).

There were fewer children with developmental delays ($n = 37$) as compared to children without developmental delays ($n = 92$). Both groups (children with developmental delays, and children without developmental delays) were similar in demographic characteristics except that there were more boys in the subsample of children with developmental delays. More than 50% of children with developmental delays reported functional problems for 9 out of 12 areas assessed.

Children were reported to be receiving a variety of services to address these areas of functional difficulty, with the most common service being speech and language therapy (83.8%) followed by occupational therapy (62.2%). Most children receiving services carried a diagnosis (77.4%), followed by developmental delay (no diagnosis) (16.1%), and at risk for delay (6.4%). Additional sample characteristics are summarized in Table 4 below.

Table 4. Participant Characteristics

		Total	Delays	No Delays	χ^2	<i>p</i>
		n=129 (%)	n=37 (%)	n=92 (%)		
Respondent Type					.73	ns
	Father/Male legal guardian	7 (5.42)	3 (8.10)	4 (4.34)		
	Mother/Female legal guardian	122 (94.6)	34 (91.9)	88 (95.7)		
Marital Status					.53	ns
	Married	116 (89.9)	33 (89.2)	83 (90.2)		
	Single, Never Married	5 (3.87)	2 (5.40)	3 (3.26)		
	Domestic Partner	5 (3.87)	1 (2.70)	4 (4.34)		
	Separated	3 (2.32)	1 (2.70)	2 (2.17)		
Respondent Education					5.45	ns
	High school	5 (3.87)	3 (8.10)	2 (2.17)		
	Some college/university	18 (14.0)	7 (18.91)	11(11.9)		
	Associate degree	7 (5.42)	3 (8.10)	4 (4.34)		
	College/University graduate	47 (36.4)	10 (27.0)	37 (40.2)		
	Some graduate coursework	9 (6.97)	2 (5.40)	7 (7.60)		
	Graduate degree	43 (33.3)	12 (32.4)	31 (33.7)		
Employment					2.59	ns
	Yes	86 (66.6)	22 (59.4)	64 (69.5)		
	No	43 (33.3)	15 (40.5)	28 (30.4)		
Educational enrollment**						
	Parent/Legal guardian/Extended	76 (58.9)	21 (56.8)	55 (59.8)	.10	ns

	Family					
	Center-Based Program	98 (76.0)	27 (73.0)	71 (77.2)	.25	ns
	Family Daycare	7(5.42)	1 (2.70)	6 (6.52)	.75	ns
	Parent Cooperative Nursery School	0 (0.00)	0 (0.00)	0 (0.00)		
	In home Provider	8 (6.20)	4 (10.81)	4 (4.34)	1.89	ns
	Kindergarten	33(25.6)	10 (27.0)	23 (25.0)	.57	ns
	Other	3 (2.32)	1 (2.70)	2 (2.17)	.32	ns
	Family Income*				18.64	ns
	< 30,000	11 (8.5)	6 (16.21)	5 (5.43)		
	30,001-50,000	14 (10.8)	3 (8.10)	11 (11.9)		
	50,001-70,000	26(20.1)	8 (21.62)	18 (19.5)		
	70,001-100,000	33 (25.5)	10 (27.0)	23 (25.0)		
	> 100,000	45(34.8)	10 (27.0)	35 (38.0)		
	Child Gender				5.87	.01
	Male	69 (53.5)	26 (70.3)	43 (46.7)		
	Female	60 (46.5)	11 (29.7)	49 (53.3)		
	Child Age (months) *				52.33	ns
	< 24	12 (9.30)	3 (8.10)	9 (9.78)		
	24 - 48	36 (27.9)	12 (32.4)	24 (26.0)		
	49 - 71	81 (62.7)	22 (59.4)	59 (64.1)		
	Child Race/Ethnicity				5.26	ns
	American Indian/ Alaskan Native	1 (0.77)	0 (0.00)	1 (1.08)		
	Asian	3 (2.32)	2 (5.40)	1 (1.08)		
	Native Hawaiian/Pacific Islander	0 (0.0)	0 (0.00)	0 (0.0)		
	Black/African American	2 (1.55)	1 (2.70)	1 (1.08)		
	Multiracial	21(16.3)	4 (10.81)	17 (18.5)		
	Other	6 (4.65)	3 (8.10)	3 (3.26)		
	White	96(74.4)	27 (73.0)	69 (75.0)		
	Functional Difficulties**					
	Mobility	20 (15.5)	17 (45.9)	3 (3.26)	34.66	< .001

	Processing information	30 (23.2)	25 (67.6)	5 (5.43)	55.89	< .001
	Seeing	12 (9.3)	12 (32.4)	0 (0.0)	31.90	< .001
	Sensations	36 (27.9)	28 (75.7)	8 (8.69)	57.58	< .001
	Managing emotions	62 (48.0)	29 (78.4)	33 (35.9)	18.26	< .001
	Communication	36 (27.9)	27 (73.0)	9 (9.78)	51.19	< .001
	Hearing	11 (8.52)	8 (21.6)	3 (3.26)	11.25	< .01
	Controlling Behavior	51 (39.5)	29 (78.4)	22 (23.9)	31.74	< .001
	Self-feeding	25 (19.3)	21 (56.8)	4 (4.34)	45.39	< .001
	Safety Awareness	44 (34.1)	28 (75.7)	16 (17.4)	38.82	< .001
	Paying Attention	44 (34.1)	23 (62.2)	21 (22.8)	17.46	< .001
	Bladder & Bowel control	24 (18.6)	19 (51.4)	5 (5.4)	35.88	< .001
	Services**				N/A	N/A
	Speech and language therapy	N/A	31 (83.8)	N/A		
	Occupational Therapy	N/A	23 (62.2)	N/A		
	Physical Therapy	N/A	9 (24.32)	N/A		
	Medical/Private specialized preschool program	N/A	1 (2.70)	N/A		
	Public special education preschool	N/A	12 (32.4)	N/A		
	Other therapy/services	N/A	13 (35.1)	N/A		

*Analyses were performed on cases with complete data only. Family Income for 1 participant is 0.00, resulting in case deletion.

** Participants could select more than one response.

Quantitative Findings (QUAN)

A post-hoc power analysis was performed using the GPower (Faul & Erdfelder, 1992). The sample size of 129 was used for the statistical power analysis. The alpha level used for this analysis was $p < .05$. The post hoc analysis revealed that the statistical power of this study was .72 (i.e., moderate effect).

The next section summarizes similarities and differences in daycare/preschool participation and perceived environmental impact on participation among young children with and without developmental delays. Results are based on responses to items in two YC-PEM scales (i.e., *involvement* and *environmental support*) for summary-level disability group comparisons and all four YC-PEM scales for item-level disability group comparisons. Summary-level disability group differences were analyzed for two of four YC-PEM scales with adequate internal consistency and test-retest reliability (*level of involvement* and *environment support scales*) (Khetani, Graham, Davies, Law, & Simeonsson, 2014).

Summary-level group differences in daycare/preschool participation and environment. Parents of young children with developmental delays, on average, reported their child as being less involved in daycare/preschool activities as compared to children without developmental delays. Significant and large mean group differences were observed even after adjusting for the potential confounding effects of child age, child gender, and family income. Similarly, parents of young children with developmental delays perceived their child’s daycare/preschool environment as being less supportive for participation as compared to the perceptions of parents raising young children without developmental delays. Differences in perceived environmental support were statistically significant with moderate effect size (See Table 5).

Table 5. Differences in daycare/preschool participation and environment for young children with and without developmental delays

YC-PEM Scores	Delays Mean (SD)	No delays Mean (SD)	<i>t/U</i>	<i>p</i>	<i>d/r</i>	<i>F</i>	<i>p</i>
Involvement	3.13 (.76)	4.17 (.71)	-6.470	< .001	1.41	39.62	< .001
Environmental Support	76.01 (13.0)	95.10 (5.96)	6.876	< .001	0.68	N/A	N/A

Note: *F* value controlled for child gender, child age and family income.

Item-level group differences in daycare/preschool participation and environment.

Frequency. Parents of young children with developmental delays on average reported their child as participating less often in all three daycare/preschool activities, before and after controlling for potential confounding effects of child age, child gender, and family income. As shown in Table 6 below, item-level mean group differences in child’s frequency of participation were found for all three activities: 1) socializing with friends; 2) field trips and events, and; 3) group learning.

Table 6. Item level group differences in frequency (Aim 1)

YC-PEM Items	Frequency						
	Delays Mean (SD)	No delays Mean (SD)	<i>t</i>	<i>p</i>	<i>d</i>	<i>F</i>	<i>p</i>
Group learning	5.21 (1.35)	5.95 (.82)	-3.10	< .01	.66	12.05	< .01
Socializing with friends	5.21 (1.39)	6.06 (.75)	-3.50	< .01	.76	17.48	< .001
Field trips and events	1.94 (1.61)	3.02 (1.56)	-3.49	< .01	.68	8.82	< .01

Note: Scale points (0 – never participates; 1 – once in the last 4 months; 2 – few times in the last 4 months; 3 – once in the last month; 4 – few times in the last month; 5 – once each week; 6 – few times each week; 7 – once or more each day); F value controlled for child gender, child age and family income.

Involvement. Parents of young children with developmental delays, on average, reported their child as being less involved in daycare/preschool activities when compared to parents of young children without developmental delays. As shown in Table 7, item-level mean group differences in the child’s level of involvement were found for all three activities: 1) group learning; 2) socializing with friends; and 3) field trips and events.

Table 7. Item-level group differences in involvement (Aim 2)

YC-PEM Items	Involvement						
	Delays Mean (SD)	No delays Mean (SD)	<i>t</i>	<i>p</i>	<i>d</i>	<i>F</i>	<i>p</i>
Group learning	3.00 (0.74)	4.20 (0.84)	-7.792	< .001	1.51	54.16	< .001
Socializing with friends	2.89 (1.04)	4.14 (0.87)	-6.936	< .001	1.30	40.89	< .001
Field trips and events	2.96 (0.93)	4.10 (1.01)	-5.178	< .001	1.17	25.64	< .001

Note: Scale points (1- Not very involved; 3 - somewhat involved; 5 – very involved); F value controlled for child gender, child age and family income.

Desire change. A significantly higher percentage of parents raising young children with developmental delays reported a desire for change in their child’s participation in two of the three daycare/preschool activities, even after controlling for potential confounding effects of child age, child gender, and family income. As shown in Table 8 below, item-level mean group differences in percent desire change were found for two activities 1) group learning, and 2) socializing with friends. Statistically significant differences were not seen when comparing groups based on responses to the field trip and events item. The effect sizes (i.e., measured using Odd’s ratio) for group learning and, socializing with friends were ≥ 4.30 , indicating a large effect, that is, an increase in odds in parents of children with developmental delays experiencing a greater desire for change compared to parents of children without developmental delays.

Table 8. Item level group differences in percent change desired (Aim 3)

YC-PEM Items	Percent Change Desired						
	Delays N (%)	No Delays N (%)	χ^2	<i>p</i>	Odds Ratio	Wald χ^2	<i>p</i>
Group learning	29 (78.37)	17 (18.47)	41.26	< .001	15.99	29.79	< .001
Socializing with Friends	28 (75.67)	16 (17.39)	39.88	< .001	14.77	30.12	< .001
Field Trips and events	18 (48.64)	36 (39.13)	.55	ns	1.33	.18	ns

Note: Wald χ^2 value controlled for child gender, child age and family income.

Perceived environmental support. As shown in Table 9 below, parents of young children with developmental delays perceived features and resources within the daycare/preschool environment to be less supportive in its impact on their child’s participation. Moderate to large item-level group differences were found for 15 out of the 16 items, both before and after adjusting for confounders, and no significant group difference on perceived environmental support was found for the remaining 1 environment item (See Table 9).

Table 9. Item-level group differences in perceived environmental support to daycare/preschool participation (Aim 5)

	Environmental Features						
YC-PEM Items	Delays, Mean (SD)	No delays, Mean (SD)	<i>t</i>	<i>p</i>	<i>d</i>	<i>F</i>	<i>p</i>
Physical Layout	2.24 (.54)	2.9 (.14)	- 8.03	< .001	-1.67	125.10	< .001
Sensory Qualities	2.18 (.51)	2.91 (.32)	-7.88	< .001	-1.71	80.55	< .001
Outside weather conditions	2.34 (.59)	2.70 (.48)	-3.12	< .01	-0.66	11.99	< .01
Physical demands of activities	2.13 (.71)	2.79 (.50)	-5.09	< .001	-1.07	38.15	< .001
Cognitive demands of activities	1.83 (.72)	2.75 (.47)	-7.09	< .001	-1.51	67.33	< .001
Social demands of activities	1.75 (.76)	2.70 (.58)	-6.79	< .001	-1.40	52.97	< .001
Child’s relationship with peers	1.97 (.72)	2.81 (.46)	-6.50	< .001	-1.39	54.95	< .001
Attitudes and actions of directors, teachers, therapists and other staff	2.21 (.62)	2.89 (.31)	-6.20	< .001	-1.38	61.01	< .001
	Environmental Resources						
YC-PEM Items	Delays, Mean (SD)	No delays, Mean (SD)	<i>t</i>	<i>p</i>	<i>d</i>	<i>F</i>	<i>p</i>
School related policies and procedures	2.00 (.84)	2.90 (.33)	-6.25	< .001	-1.41	66.05	< .001
Personal transportation	2.54 (.55)	2.97 (.14)	-4.70	< .001	-1.07	46.98	< .001
Public transportation	2.51 (.65)	2.95 (.25)	-4.01	< .001	-.89	27.20	< .001
Programs and services	2.75 (.43)	2.92 (.30)	-2.12	< .05	-.45	4.98	ns
Supplies	2.51 (.65)	2.90 (.30)	-3.47	< .01	-.77	19.43	< .001
Information	2.61 (.54)	2.91 (.28)	-3.12	< .01	-.69	12.24	< .01
Time	2.61 (.49)	2.85 (.35)	-2.72	< .01	-.56	8.87	< .01
Money	2.22 (.68)	2.67 (.51)	-4.00	< .001	-.74	13.71	< .001

Note: Response options for environmental features (1 –no impact/usually helps; 2 – sometimes helps/sometimes makes it harder; 3 –usually makes harder) and environmental resources (1 –not needed/usually yes; 1- sometimes yes/sometimes no; 3 – usually no); *F* value controlled for child gender, child age and family income.

Mixed-Method Findings

Types of change most commonly desired (Aim 4a: quan). Parents most often desired change across multiple dimensions (change in frequency, change in involvement (be more interactive, be more helpful), and/or change in terms of participating in a broader variety of activities of that type).

Table 10. Types of change most commonly desired by parents (Aim 4a)

YC-PEM Items	Total N	Frequency (%)	Type(s) of change desired		
			Involvement (%)		Variety (%)
			Be more interactive	Be more helpful	
Group Learning	46	32 (69.56)	29 (63.0)	27 (58.6)	26 (56.5)
Socializing with friends	44	21(47.72)	24 (54.5)	23 (52.2)	19 (43.1)
Field Trips and Events	54	41 (75.92)	12 (22.2)	4 (7.40)	26 (48.1)

Strategies most commonly used by parents (Aim 4b: qual). Parents who desired a change in their child’s daycare/preschool participation reported up to three strategies that they had used to promote their child’s participation. As summarized in Table 11, parents most often reported on strategies pertaining to *child care tasks* (41.26 %) and *child peer groups* (18.25%).

We also identified some new strategies (e.g., training staff of her needs/limitations; introducing her to new people and places; put in calendar so we all remember when the events are), as well as some responses that were not framed as strategies (e.g., he is also self-conscious so he doesn't like doing things that draw attention to him self; music and art should be more encouraged at preschool). See Appendix C for more detail on coding of strategies.

Table 11. Strategies Most Commonly Used by Parents (Aim 4b)

Strategies	N (%)
Child Care Tasks	52 (42.9%)
Child Peer Groups	24 (19.8)
Family Subsistence	7 (5.78%)
Services	4 (3.30%)
Home/neighborhood Safety	2 (1.65%)
Domestic Workload	2 (1.65%)
Parent information	2 (1.65%)
Instrumental /Emotional Support	1 (.82%)
Father or Spouse Role	1 (.82%)
Other Accommodations	5 (4.13%)
Total	121

Note: 15 strategies reported by parents were reported in future tense and therefore omitted

Relationship between types of change desired and parent-reported strategies

(Aim 4c qual → quan). Parents most often desired a change across multiple dimensions, and the most commonly reported parental strategies pertained to *child care tasks* and *child peer groups*. These strategies were used irrespective of the type(s) of change that parents desired. (See Table 12).

Table 12. Relationship between types of change desired and common strategies used.

Family Accommodation	Types of change desired			
	Frequency	Involvement		Participate in broader variety of activities
		Be more interactive	Be more helpful	
Family Subsistence	3	3	6	5
Services	2	1	3	4
Home/neighborhood Safety	1	1	2	2
Domestic Workload	1	0	1	1
Child Care Tasks*	9	18	33	26
Child Peer Groups*	11	10	17	16
Instrumental or Emotional Support	0	0	1	0
Other Strategies	3	2	5	3

* Strategies most commonly reported

Discussion

Despite the establishment of national and international inclusion policies (Government of India, 1995, section 5; IDEA, 1997; Lgr 80, 1980) discrepancies exist in school enrollment (UNESCO, 2009; UNICEF, 2013b) and participation (Coster et al., 2013; Ericksson, Welander & Granlund, 2007; Hemmingson & Borell, 2002; Simeonsson, et al., 2001) between children with and without disabilities. Although disparities in school enrollment have been documented for younger children (UNESCO, 2009; UNICEF 2013b), prior studies about disparities in children's participation have primarily focused on school-aged children and youth. Therefore, it is unclear if disparities in participation are present during the early childhood period (0-5 years). This knowledge about disparities in school participation for younger children could help key stakeholders (teachers, therapists, parents, and school administrators) decide when and how to intervene in promoting children's participation in activities that take place within an educational setting.

The YC-PEM is a newly validated caregiver report instrument (Khetani et al., 2014) that affords a new opportunity to closely examine similarities and differences in young children's participation within an early childhood educational setting. The YC-PEM includes an assessment of young children's participation in early childhood educational activities, perceived impact of the child's educational environment on participation, and parent-reported strategies for improving participation in this setting. To our knowledge, this is the first study to apply the YC-PEM in order to examine discrepancies in participation between young children with and without developmental delays that is specific to early childhood educational settings.

Results of the present study confirm all study hypotheses that children with developmental delays participate less frequently (Aim 1), are less involved (Aim 2), and have

fewer environmental supports to promote participation in daycare/preschool activities (Aim 5), and also that parents of children with developmental delays are more likely to want their child's participation to change (Aim 3), when compared to children without developmental delays. Study results are consistent with previous research studies that also reported: 1) lower participation rates for children with disabilities in a school setting when compared to children without disabilities (Coster et al., 2013; Eriksson et al., 2007; Eriksson & Granlund, 2004; Simeonsson et al., 2001) and; 2) an increased likelihood for the environment to serve as a barrier rather than a support to participation for children with disabilities in a school setting when compared to children without disabilities (Hemmingson & Borrell, 2002; Law, Haight, Milroy, Willms, Stewart & Rosenbaum, 1999). In the remainder of this section, I discuss each of these study findings in greater detail.

Differences in the Frequency of Participation between Groups (Aim 1)

Young children with developmental delays were reported to participate less often in all three types of daycare/preschool activities (group learning, socializing with friends and field trips and events). Young children with developmental delays, on average, were reported to participate once each week in group learning and socializing with friends, as compared to a few times each week among young children without developmental delays. Although both groups of children have reduced participation in field trips and events, young children with developmental delays were reported to participate, on average, less than once each month as compared to young children without developmental delays who were reported to participate in this type of activity on a monthly basis.

There are several ways to interpret these findings. First, these disability group differences in participation frequency could be attributed to the lack of services that are available for

children with developmental delays within daycare/preschool programs. In our study sample, children with developmental delays most commonly received speech and language therapy (83.8%), followed by occupational therapy services (62.2%). However, these data do not specify whether services are being provided to the child in the school setting as compared to the home or clinic. Therefore, young children with developmental delays may be participating less often in daycare/preschool activities because of a lack of service availability within the school setting to enable the child with a developmental delay to participate in daycare/preschool activities with typically developing peers. This interpretation of Aim 1 findings is further supported by the data pertaining to significant group differences in the perceived impact of programs and services on daycare/preschool participation, where parents of children with and without developmental delays reported programs and services as ‘sometimes yes/sometimes no’ with respect to supporting their young child’s participation in daycare/preschool activities (See Table 9).

Alternatively, young children with developmental delays who receive therapy services in a clinic or at home may not attend early childhood educational programs as often as young children without developmental delays, thereby limiting how often they will have chances to participate in daycare/preschool activities. Another consideration is that data collection for this study was undertaken during the summer season, so it is possible that group differences in participation frequency reflect seasonal differences in daycare/preschool enrollment.

Among the three types of daycare/preschool activities, field trips and events (e.g., going to the library, school concert) was the most infrequent type of activity pursued by young children with and without developmental delays. In comparison to group learning and socializing with friends, field trips and events typically involve additional planning and resources for children to

participate, regardless of their abilities (e.g., parent volunteers may be needed to decrease student-to-adult ratios; the field trip or event might require public transportation).

Differences in the Level of Involvement between Groups (Aim 2)

Inclusion is often described as more than the physical presence of the child in a school setting (Eriksson et al., 2007; Simeonsson et al., 2001). In this study, disability group differences in daycare/preschool participation were examined along multiple dimensions, including how often the child participates as well as the child's level of engagement in the activity. Young children with developmental delays were significantly less involved in all three daycare/preschool activities as compared to young children without developmental delays. These results are consistent with and extend prior research on the effect of disability on the extent to which children and youth are involved in school-based activities (Coster et al., 2013) and the extent to which young children with developmental delays participate in community activities (Khetani et al., 2013).

Characteristics of the children sampled in this study may help to explain these findings. A vast majority of the young children with developmental delays in this study were reported to have behavioral problems ($n = 29, 78.4\%$). Prior studies have suggested the impact of young children's functional abilities on out-of-home participation, where the young child's behavior was reported as being a predictive factor for positive adaptation in the school setting (McIntyre et al., 2006). Moreover, parents of children with disabilities with behavioral problems reported more barriers to their child's participation compared to children with disabilities with no behavioral problems (Law et al., 2007) and this link between behavior problems and participation difficulty has been examined by researchers specifically for community activities and, they have reported problems with managing behavior as the strongest predictor of

community participation outcomes among young children with developmental delays (Khetani, Orsmond, et al., 2013). Therefore, a higher percentage of children with developmental delays who were reported to have behavior problems in our study sample could help to explain the magnitude of group differences that were found in this study.

Differences in Parent's Desire for Change between Groups (Aim 3)

The subjective assessment of participation is important for ensuring occupational therapy best practice because it reflects the client's perspective of whether the current level of participation is problematic and something that they want to intervene on. Study results suggest that more parents of young children with developmental delays desire a change in their child's daycare/preschool participation as compared to parents of young children without developmental delays, specifically in two of three daycare/preschool activities (*group learning* and *socializing with friends*). In contrast, parents of children without developmental delays more frequently desired a change in *field trips and events* compared to parents of children with developmental delays. This contrasts with findings of Coster and colleagues (2013), where parents of children with disabilities more frequently desired a change in their child's participation in *field trips and events* in comparison with parents of children without developmental delays. This type of activity may not be deemed as problematic for parents of young children with developmental delays given that it happens less often as compared to other daycare/preschool activities like group learning and socializing with friends.

Differences in Perceived Environmental Supports between Groups (Aim 5)

Study results suggest that parents of young children with developmental delays perceive the daycare/preschool environment to be less supportive of their child's participation when compared to parents of young children without developmental delays. These results are

consistent with previous research findings where environmental factors have been reported more often by parents as barriers than supports for children with disabilities when compared to children without disabilities in school settings (Bedell et al., 2011; Eriksson, 2005; Law et al., 2007; Pivik et al., 2002; Rosenberg, Ratzon, Jarus & Bart, 2012). Furthermore, study results are consistent with Hemmingson and Borell (2002) who found that the majority of the barriers faced by children with disabilities were related to how the school activities were organized. Similarly, results of this study show that disability group differences in perceived support of physical, social and cognitive demands of daycare/preschool activities. These results are particularly relevant for occupational therapists whose training is focused on improving the child's engagement in activities. This level of specificity in identifying supports and barriers across all 16 environmental items is necessary for stakeholders to be able to intervene for promoting a young child's participation.

Mixed Method Findings (Aims 4a-c)

There was no hypothesis driving the main analyses for Aims 4a-c, as this was the first study to examine the relationship between types of change desired relative to the types of strategies most commonly used by parents of young children who desire a change in their child's participation. Parents in this study most commonly used strategies that corresponded to two specific types of family accommodations, 'child care tasks' (e.g., behavior management - reinforcing positive behavior, correcting as missteps occur) and 'child peer groups' (participation with groups of children – finding age appropriate peer groups, plan park play dates). These results suggest that some, but not all, family accommodations are relevant to improving participation-level outcomes in the daycare/preschool setting.

Study results differ from previous studies that suggested 1) all ten family accommodations to be equally relevant to promoting young children's participation (Gallimore et al., 1996); 2) strategies commonly used by parents and grandparents are focused less on the child and more on family subsistence (e.g., the family as a team, the family adapts time) (Maul & Singer, 2009); and 3) strategies used by parents of young children to promote home and community participation include a balance of strategies that focus on the child (e.g., managing behavior, rest and respite) and on other family accommodations (e.g., planning and preparing) (Khetani et al., 2013). These differences in our study results could be due to the small sample size of 126 strategies that were incorporated from one setting, in this study.

It is interesting that in our study results the most commonly reported strategies were directed towards the child and less on the child's environment. Although early interventions for young children with developmental delays are typically geared towards fixing the problems within the child, there is emerging evidence of the efficacy of compensatory approaches to intervention to improve functional performance and participation outcomes. For example, Law and colleagues (2011) recently conducted a pediatric trial in which they established equal efficacy of context-focused and child-focused approaches to intervening with young children with cerebral palsy to improve functional performance and out-of-home participation outcomes.

Parental views on disability and normalcy could potentially influence decisions made by parents with respect to their child's intervention strategies. The early identification of a problem coupled with no specific diagnosis might cause parents to first try and fix their child and later change their approach to a needs and strength based approach as the child ages (King et al., 2006). This is partially reflected in our study sample where approximately twenty five percent of children with developmental delays did not have a specific diagnosis.

Moreover, these commonly used strategies (i.e., child care tasks; child peer groups) were used irrespective of the type(s) of change that parents desired. This may be attributed to the use of data on strategies that are specific to the school setting. Future research could incorporate strategies used by parents from three different settings (home, school and community) to 1) examine if patterns among family accommodations do exist between or across settings, and 2) to explicitly define these ten family accommodations that were reported in literature.

Study Limitations

Results of this study should be considered in light of some limitations that could have potentially impacted the interpretability of our findings, some of which may afford for future research opportunities using the YC-PEM. First, the use of convenience and snowball sampling strategies limit the generalizability of these findings to the larger American and Canadian populations and to parents whose children are not enrolled in a center-based early childhood program. Secondly, data were obtained online from parents and the results could have potentially been different if the data were collected through face-to-face interviews with parents or via observation of the child in the daycare/preschool environment. Similarly, data were obtained from parents who are typically not present during the school day. Future studies involving teacher input could gather a different perspective on young children's participation in the daycare/preschool setting.

Conclusion

This study extends prior knowledge about the presence of discrepancies in school participation between young children with and without developmental disabilities during the early childhood period. Additionally, study results draw attention to intervention targets that focus on changes to the child's environment and/or leveraging parental expertise about strategies that could be expanded upon to promote participation in daycare/preschool activities. In these ways, the study findings support the utility of the YC-PEM for use by educational stakeholders in daycare/preschool settings to identify children with inclusion needs and to gain insight about possible mechanisms for intervening in partnership with parents. Future research is needed to see whether similar types of discrepancies in participation between young children with and without developmental delays are present in other settings like the home and the community.

References

- Adolfsson, M., Malmqvist, J., Pless, M., & Granlund, M. (2011). Identifying child functioning from an ICF-CY perspective: Everyday life situations explored in measures of participation. *Disability & Rehabilitation*, *33*(13-14), 1230-1244.
- Anaby, D., Hand, C., Bradley, L., DiRezze, B., Forhan, M., DiGiacomo, A., & Law, M. (2013). The effect of the environment on participation of children and youth with disabilities: A scoping review. *Disability & Rehabilitation*, (0), 1-10
- Anaby, D., Law, M., Coster, W., Bedell, G., Khetani, M. A., Avery, L., & Teplicky, R. (2014). The mediating role of the environment in explaining participation of youth with and without disabilities across home, school and community. *Archives of Physical Medicine and Rehabilitation*. doi: 10.1016/j.apmr.2014.01.005.
- Anderson, L. M., Shinn, C., Fullilove, M. T., Scrimshaw, S. C., Fielding, J. E., Normand, J., & Carande-Kulis, V. G. (2003). The effectiveness of early childhood development programs: A systematic review. *American Journal of Preventive Medicine*, *24*(3), 32-46.
- Barnes, K. J., & Turner, K. D. (2001). Team collaborative practices between teachers and occupational therapists. *American Journal of Occupational Therapy*, *55*(1), 83-89.
- Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y. C., Teplicky, R., ... & Khetani, M. A. (2013). Community participation, supports and barriers of school age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation*, *94*(2), 315-323.
- Bedell, G. M. (2009). Further validation of the Child and Adolescent Scale of Participation (CASP). *Developmental Neurorehabilitation*, *12*(5), 342-351.

- Bedell, G. M., Khetani, M. A., Cousins, M. A., Coster, W. J., & Law, M. C. (2011). Parent perspectives to inform development of measures of children's participation and environment. *Archives of Physical Medicine and Rehabilitation, 92*(5), 765-773.
- Bernheimer, L. P., & Keogh, B. K. (1995). Weaving interventions into the fabric of everyday life an approach to family assessment. *Topics in Early Childhood Special Education, 15*(4), 415-433.
- Boocock, S. S. (1995). Early childhood programs in other nations: Goals and outcomes. *Future of Children, 5*, 94-114.
- Booth, M. L., & Samdal, O. (1997). Health-promoting schools in Australia: models and measurement. *Australian and New Zealand Journal of Public Health, 21*(4), 365-370.
- Bourke-Taylor, H. M., Law, M., Howie, L., & Pallant, J. F. (2009). Development of the Assistance to Participate Scale (APS) for children's play and leisure activities. *Child: Care, Health and Development, 35*(5), 738-745.
- Cakiroglu, O., & Melekoglu, M. A. (in press). Statistical trends and developments within inclusive education in Turkey. *International Journal of Inclusive Education*.
- Cameron, D. L., Nixon, S., Parnes, P., & Pidsadny, M. (2005). Children with disabilities in low-income countries. *Paediatrics & Child Health, 10*(5), 269.
- Campbell, W. N., Missiuna, C. A., Rivard, L. M., & Pollock, N. A. (2012). Support for Everyone: Experiences of occupational therapists delivering a new model of school-based service. *Canadian Journal of Occupational Therapy, 79*(1), 51-59.
- Casillas, D. (2010). Teachers' perceptions of school-based occupational therapy consultation: Part 2. *Early Intervention & School, 17*, 1-4.

- Chien, C. W., Rodger, S., Copley, J., & Skorka, K. (2014). Comparative content review of children's participation measures using the International Classification of Functioning, Disability and Health-Children and Youth. *Archives of Physical Medicine and Rehabilitation, 95*(1), 141- 152.
- Cieza, A., Geyh, S., Chatterji, S., Kostanjsek, N., Ustun, B., & Stucki, G. (2005). ICF linking rules: An update based on lessons learned. *Journal of Rehabilitation Medicine, 37*, 212-218.
- Coatsworth, J. D., Palen, L. A., Sharp, E. H., & Ferrer-Wreder, L. (2006). Self-defining activities, expressive identity, and adolescent wellness. *Applied Developmental Science, 10*(3), 157-170.
- Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences*. 2nd ed. Hillsdale (NJ): Lawrence Erlbaum Associates, Inc.
- Conn-Powers, M. C., Ross-Allen, J., & Holburn, S. (1990). Transition of young children into the elementary education mainstream. *Topics in Early Childhood Special Education, 9*(4), 91-105.
- Coster, W., Bedell, G., Law, M., Khetani, M. A., Teplicky, R., Liljenquist, K., ... & Kao, Y. C. (2011). Psychometric evaluation of the participation and environment measure for children and youth. *Developmental Medicine & Child Neurology, 53*(11), 1030-1037.
- Coster, W. J., Deeney, T., Haltiwanger, J., & Haley, S. M. (1998). *School Function Assessment*. San Antonio, TX: PsychCorp.
- Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability & Rehabilitation, 30*(8), 639-648.

- Coster, W., Law, M., Bedell, G., Khetani, M., Cousins, M., & Teplicky, R. (2012). Development of the participation and environment measure for children and youth: conceptual basis. *Disability & Rehabilitation, 34*(3), 238-246.
- Coster, W. J., Law, M., & Bedell, G. M. (2010). *Participation and Environment Measure for Children and Youth* (PEM-CY). Boston, MA: Boston University.
- Coster, W., Law, M., Bedell, G., Liljenquist, K., Kao, Y. C., Khetani, M., & Teplicky, R. (2013). School participation, supports and barriers of students with and without disabilities. *Child: Care, Health and Development, 39*(4), 535-543.
- Creswell, J. (2009). Mixed methods procedures, In *Research Design Qualitative, Quantitative, and Mixed Methods Approaches* (3rd ed, pp. 203-227).
- Creswell, J. W., & Clark, V. L. P. (2011). *Designing and conducting mixed methods research* (2 ed). Thousand Oaks, CA: SAGE Publications, Inc.
- Deloitte & Touchee. (2010). *Review of school health support services: Final report*. Delloitte & Touche LLP and Affiliated Entities. Retrieved from:
http://www.health.gov.on.ca/en/public/contact/ccac/docs/deloitte_shss_review_report.pdf
- Driscoll, D. L., Appiah-Yeboah, A., Salib, P., & Rupert, D. J. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology, 18*. Retrieved from:
<http://digitalcommons.unl.edu/cgi/viewcontent.cgi?article=1012&context=icwdmeea>
- Dunst, C. J. (2001). Participation of young children with disabilities in community learning activities. In Guralnick M. J (Eds), *Early Childhood Education* (pp. 307-336).

- Dunst, C. J., Hamby, D., Trivette, C. M., Raab, M., & Bruder, M. B. (2002). Young children's participation in everyday family and community activity. *Psychological Reports, 91*, 875-897.
- Eriksson, L. (2005). The relationship between school environment and participation for students with disabilities. *Developmental Neurorehabilitation, 8*(2), 130-139.
- Eriksson, L., & Granlund, M. (2004). Perceived participation. A comparison of students with disabilities and students without disabilities. *Scandinavian Journal of Disability Research, 6*(3), 206-224.
- Eriksson, L., Welander, J., & Granlund, M. (2007). Participation in everyday school activities for children with and without disabilities. *Journal of Developmental and Physical Disabilities, 19*(5), 485-502.
- Faul, F., Erdfelder, E., Lang, A-G., & Buchner, A. (2007). G*Power 3: A flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods, 39*, 175-191.
- Field, A. (2009). *Discovering statistics using SPSS*. Thousand Oaks, California: Sage Publications Ltd.
- Finn, J. D. (1989). Withdrawing from school. *Review of Educational Research, 59*(2), 117-142.
- Gallimore, R., Coots, J., Weisner, T., Garnier, H., & Guthrie, D. (1996). Family responses to children with early developmental delays II: Accommodation intensity and activity in early and middle childhood. *American Journal on Mental Retardation, 11*(3), 215-232.
- Government of India. *The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act*. (1995). Retrieved from:
<http://socialjustice.nic.in/pwdact1995.php>

- Guralnick, M. J. (1998). Effectiveness of early intervention for vulnerable children: A developmental perspective. *American Journal on Mental Retardation*, 102(4), 319-345.
- Hammel, J., Magasi, S., Heinemann, A., Whiteneck, G., Bogner, J., & Rodriguez, E. (2008). What does participation mean? An insider perspective from people with disabilities. *Disability and Rehabilitation*, 30(19), pp. 1445-1460.
- Hanna, K., & Rodger, S. (2002). Towards family- centred practice in paediatric occupational therapy: A review of the literature on parent–therapist collaboration. *Australian Occupational Therapy Journal*, 49(1), 14-24.
- Harkness, S., Zylicz, P. O., Super, C. M., Welles-Nyström, B., Bermúdez, M. R., Bonichini, S., Moscardino, U., & Mavridis, C. J. (2011). Children's activities and their meanings for parents: A mixed-methods study in six western cultures. *Journal of Family Psychology*, 25(6), 799.
- Hartley, S. O. V. P., Ojwang, P., Baguwemu, A., Ddamulira, M., & Chavuta, A. (2005). How do carers of disabled children cope? The Ugandan perspective. *Child: Care, Health and Development*, 31(2), 167-180.
- Hemmingson, H., & Borell, L. (2002). Environmental barriers in mainstream schools. *Child: Care, Health and Development*, 28(1), 57-63.
- Individuals with Disabilities Education Act, 20 U.S.C. § 1400 *et seq.* Retrieved 3 January 2014 from the LexisNexis Academic database.
- Jiang, X., & Khetani, M. A. (2014). Relationship between child age and reliability of the Young Children's Participation and Environment Measure (YC-PEM). Poster presented at the CURC Showcase, Colorado State University , Fort Collins, Colorado.

- Khetani, M. A. (in preparation). Development of the Young Children's Participation and Environment Measure (YC-PEM).
- Khetani, M. A., Cliff, A. B., Schelly, C., Daunhauer, L., Anaby, D. (2014). Decisional support algorithm for collaborative care planning using the Participation and Environment Measure for Children and Youth (PEM-CY): A mixed methods Study. *Physical and Occupational Therapy in Pediatrics*.
- Khetani, M. A., Cohn, E. S., Orsmond, G. I., Law, M. C., & Coster, W. J. (2013). Parent perspectives of participation in home and community activities when receiving part C early intervention services. *Topics in Early Childhood Special Education, 32*(4), 234-245.
- Khetani, M. A., & Coster, W. (2008). Clarifying the construct of ICF participation to support measurement. *Occupational Therapy Journal of Research, 27*(1), 83S.
- Khetani, M. A., Coster, W., Law, M. & Bedell, G. M. (2013). *Young Children's Participation and Environment Measure (YC-PEM)*. Fort Collins, CO.
- Khetani, M., Graham, J. E., & Alvord, C. (2013). Community participation patterns among preschool- aged children who have received Part C early intervention services. *Child: Care, Health and Development, 39*(4), 490-499.
- Khetani, M. A., Graham, J. E., Davies, P., Law, M., & Simeonsson, R. (2014). Psychometric properties of the Young Children's Participation and Environment Measure (YC-PEM). *Archives of Physical Medicine and Rehabilitation*.
- Khetani, M., Orsmond, G., Cohn, E., Law, M., & Coster, W. (2012). Correlates of community participation among families transitioning from Part C early intervention services. *OTJR: Occupation, Participation, and Health, 32*, 61-72.

- King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., & Petrenchik, T. (2006). Predictors of the leisure and recreation participation of children with physical disabilities: A structural equation modeling analysis. *Children's Health Care, 35*(3), 209-234.
- King, G., Law, M., King, S., Rosenbaum, P., Kertoy, M. K., & Young, N. L. (2003). A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Physical & Occupational Therapy in Pediatrics, 23*(1), 63-90.
- Kohama, A. (2012). *Inclusive Education in India: A Country in Transition* (Undergraduate honors thesis). Retrieved from: <http://intldept.uoregon.edu/wp-content/uploads/2012/12/INTL-UG-Thesis-Kohama.pdf>
- Larson, R. W. & Verma, S. (1999). How children and adolescents spend time across the world: work, play and developmental opportunities. *Psychological Bulletin, 125* (6), 701– 736.
- Law, M., Anaby, D., Teplicky, R., Khetani, M. A., Coster, W., & Bedell, G. (2013). Participation in the home environment among children and youth with and without disabilities. *British Journal of Occupational Therapy, 76*(2), 58-66.
- Law, M. C., Darrah, J., Pollock, N., Wilson, B., Russell, D. J., Walter, S. D., ... & Galuppi, B. (2011). Focus on function: a cluster, randomized controlled trial comparing child- versus context- focused intervention for young children with cerebral palsy. *Developmental Medicine & Child Neurology, 53*(7), 621-629.
- Law, M., Haight, M., Milroy, B., Willms, D., Stewart, D., & Rosenbaum, P. (1999). Environmental factors affecting the occupations of children with physical disabilities. *Journal of Occupational Science, 6*(3), 102-110.
- Law, M., King, G., King, S., Kertoy, M., Hurley, P., Rosenbaum, P., Young, N., & Hanna, S. (2006). Patterns of participation in recreational and leisure activities among children with

- complex physical disabilities. *Developmental Medicine & Child Neurology*, 48(05), 337-342.
- Law, M., King, G., Petrenchik, T., Kertoy, M., & Anaby, D. (2012). The assessment of preschool children's participation: Internal consistency and construct validity. *Physical & Occupational Therapy in Pediatrics*, 32(3), 272-287.
- Law, M., Petrenchik, T., King, G., & Hurley, P. (2007). Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Archives of Physical Medicine and Rehabilitation*, 88(12), 1636-1642.
- Leung, G. P., Chan, C. C., Chung, R. C., & Pang, M. Y. (2011). Determinants of activity and participation in preschoolers with developmental delay. *Research in Developmental Disabilities*, 32(1), 289-296.
- Lgr 80. (1980). *Läroplan för grundskolan*, [Curriculum for the compulsory school 1980]. Stockholm: Liber.
- Mahoney, J. L., Larson, R. W., & Eccles, J. S. (Eds.). (2005). *Organized activities as contexts of development: Extracurricular activities, after school and community programs*. Mahwah, NJ. Inc., Publishers.
- Mâsse, L. C., Miller, A. R., Shen, J., Schiariti, V., & Roxborough, L. (2012). Comparing participation in activities among children with disabilities. *Research in Developmental Disabilities*, 33(6), 2245-2254.
- Maul, C. A., & Singer, G. H. (2009). "Just good different things": Specific accommodations families make to positively adapt to their children with developmental disabilities. *Topics in Early Childhood Special Education*.

- McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., & Parkinson, K. N. (2006). Participation of disabled children: how should it be characterized and measured? *Disability & Rehabilitation*, 28(18), 1157-1164.
- McIntyre, L. L., Blacher, J., & Baker, B. L. (2006). The transition to school: Adaptation in young children with and without intellectual disability. *Journal of Intellectual Disability Research*, 50(5), 349-361.
- Meisels, S. J., & Fenichel, E. S. (Eds). (1996). *New visions for the developmental assessment of infants and young children*. Washington DC: Zero to Three/National Center for Infants, Toddlers, and Families.
- Miles, S. (1996). Engaging with the Disability Rights Movement: the experience of community-based rehabilitation in southern Africa. *Disability & Society*, 11(4), 501-518.
- Odom, S. L., Buysse, V., & Soukakou, E. (2011). Inclusion for young children with disabilities: A quarter century of research perspectives. *Journal of Early Intervention*, 33(4), 344-355.
- Osborne, J. W. (2013). *Best practices in data cleaning*. Sage Publishers. Thousand Oaks, California.
- Park, J., Turnbull, A. P., & Turnbull, H. R. (2002). Impacts of poverty on quality of life in families of children with disabilities. *Exceptional children*, 68(2), 151-170.
- Pivik, J., McComas, J., & Laflamme, M. (2002). Barriers and facilitators to inclusive education. *Exceptional Children*, 69(1), 97-107.
- Rosenberg, L., Jarus, T., & Bart, O. (2010). Development and initial validation of the Children Participation Questionnaire (CPQ). *Disability & Rehabilitation*, 32(20), 1633-1644.

- Rosenberg, L., Ratzon, N. Z., Jarus, T., & Bart, O. (2012). Perceived environmental restrictions for the participation of children with mild developmental disabilities. *Child: care, health and development*, 38(6), 836-843.
- Sandler, I. N., Ayers, T. S., Suter, J. C., Schultz, A., & Twohey-Jacobs, J. (Eds). (2004). *Adversities, strengths, and public policy*. Washington, DC: American Psychological Association. doi: [10.1037/10660-003](https://doi.org/10.1037/10660-003)
- Simeonsson, R. J., Carlson, D., Huntington, G. S., McMillen, J. S., & Brent, J. L. (2001). Students with disabilities: A national survey of participation in school activities. *Disability & Rehabilitation*, 23(2), 49-63.
- Simeonsson, R. J., Leonardi, M., Lollar, D., Bjorck-Akesson, E., Hollenweger, J. & Martinuzzi, A. (2003). Applying the International Classification of Functioning, Disability and Health (ICF) to measure childhood disability. *Disability & Rehabilitation*, 25(11-12), 602–610.
- Tabacchnick, B. G., & Fidell, L. S. (2013). *Using Multivariate Statistics*. Upper Saddle River, New Jersey: Pearson Education Inc.
- Tashakkori, A., & Teddlie, C. (1998). *Mixed methodology: Combining qualitative and quantitative approaches*. Thousand Oaks, CA: Sage.
- The United Nations Children’s Fund (UNICEF) (2013a). *The state of the world’s children*. Retrieved from:
http://www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf
- The United Nations Children’s Fund (UNICEF) (2013b). *Education equity now! Global initiative on out of school children*. Geneva, Switzerland. Retrieved from:
http://www.unicef.org/education/files/Unicef_Global-Initiative-on-Out-of-School-Children_Summary_En_FINAL.pdf

- United Nations Educational Scientific and Cultural Organization (UNESCO) (2009). *Inclusion of children with disabilities: The early childhood imperative*. Retrieved from:
<http://unesdoc.unesco.org/images/0018/001831/183156e.pdf>
- United Nations (2008). *Convention on the Rights of the Child*. Retrieved from:
<http://www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC.C.GBR.CO.4.pdf>
- U.S Department of Education. (2001). *To assure the free appropriate public education of all children with disabilities: Twenty-third annual report to congress on the implementation of the Individuals with Disabilities Education Act*. Washington DC, United States: Department of Education.
- Villa, R. A., Thousand, J. S., Nevin, A. I., & Malgeri, C. (1996). Instilling collaboration for inclusive schooling as a way of doing business in public schools. *Remedial and Special Education, 17*(3), 169-181.
- Villeneuve, M. (2009). A critical examination of school-based occupational therapy collaborative consultation. *Canadian Journal of Occupational Therapy, 76, Supplement 1 to Issue 3, 206*(218), 13.
- Weisner, T. S. (2002). Ecocultural understanding of children's developmental pathways. *Human Development, 45*(4), 275-281.
- Whiteneck, G., & Dijkers, M. P. (2009). Difficult to measure constructs: conceptual and methodological issues concerning participation and environmental factors. *Archives of Physical Medicine and Rehabilitation, 90*(11), 22-35.
- Wong, D. K. P. (2002). Struggling in the mainstream: The case of Hong Kong. *International Journal of Disability, Development and Education, 49*, 79-94.

World Health Organization, United Nations Educational Scientific and Cultural Organization & International Labour Office. (2004). *CBR: A strategy for rehabilitation, equalization of opportunities, poverty reduction and, social inclusion of people with disabilities*. WHO

Library Cataloguing-in-Publication Data. Retrieved from:

http://digitalcommons.ilr.cornell.edu/gladnetcollect/167?utm_source=digitalcommons.ilr.cornell.edu%2Fgladnetcollect%2F167&utm_medium=PDF&utm_campaign=PDFCoverPages

World Health Organization & The World Bank. (2011). *World Report on Disability*. WHO

Library Cataloguing-in-Publication Data. Retrieved from:

http://whqlibdoc.who.int/publications/2011/9789240685215_eng.pdf

WHO. (2007). *International Classification of Functioning, Disability and Health: Children and Youth version (icf-cy)*. Geneva, Switzerland: World Health Organization Press, WHO

APPENDIX A: Daycare/Preschool Section of the YC-PEM



DAYCARE/PRESCHOOL PARTICIPATION



A Educational Programming: This type of activity involves planned activities within an organized early childhood education program or preschool that helps the child learn new skills.

	A. Typically, how often does your child participate in this type of educational activity? CHECK ONE RESPONSE <input type="checkbox"/>	B. Think about 1 or 2 activities of this type that your child does most often. Typically, how involved is your child when doing this type of educational activity? CHECK ONE RESPONSE <input type="checkbox"/>	C. Would you like your child's participation to change in this type of educational activity? IF YES, CHECK ALL THAT APPLY <input type="checkbox"/>
	Never (skip to Question C) Once in the last four months Few times in the last four months Once in the last month Few times in the last month Once each week Few times each week Once or more each day Not very involved Somewhat involved Very involved	No change desired Yes, do more often Yes, do less often Yes, be more interactive Yes, be more helpful Yes, participate in a broader variety of activities	
A1. Group learning (e.g., circle time, story time, music and movement, art projects)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
A2. Socializing with friends (e.g., mealtime, snack time, outdoor play)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
A3. Field trips and events (e.g., parent night out, going to the library, school concert or fundraiser)	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>	<input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>

If you selected **YES** to Question C, please describe up to three strategies that you have tried to help your child participate successfully in this type of activity. If you responded 'no change desired' to all of the questions above, please proceed to the next page.

1. _____

2. _____

3. _____

A1. Group learning (e.g., circle time, story time, music and movement, art projects)

A2. Socializing with friends (mealtime, snack time, outdoor play)

A3. Field trips and events (e.g., parent night out, going to the library, school concert or fundraiser)

A. Typically, how often does your child have the chance to participate in this type of educational activity?

CHECK ONE RESPONSE

- Never (skip to Question C)
- Once in the last four months
- Few times in the last four months
- Once in the last month
- Few times in the last month
- Once each week
- Few times a week
- Once or more each day
- Not very involved

B. Think about 1 or 2 activities of this type that your child does most often. Typically, how involved is your child when doing this type of educational activity?

CHECK ONE RESPONSE

- Somewhat involved
- Very involved
- No change desired
- Yes, do more often
- Yes, do less often
- Yes, be more interactive
- Yes, be more helpful
- Yes, participate in a broader variety of activities

C. Would you like your child's participation to change in this type of educational activity?

IF YES, CHECK ALL THAT APPLY

If you selected YES to Question C, please describe up to three strategies that you have tried to help your child participate successfully in this type of activity. If you responded 'no change desired' to all of the questions above, please proceed to the next page.

1. _____

2. _____

3. _____

DAYCARE/PRESCHOOL ENVIRONMENT

Do the following things in the organized daycare/preschool environment help or make it harder for your child to participate in activities?

	No impact	Usually helps	Sometimes helps; sometimes makes harder	Usually makes harder
1. The physical layout (having organized, open, clean, safe space in the classroom; having ramps, stairs and elevators in the school building)				
2. Sensory qualities of the organized daycare or preschool (e.g., amount and/or type of sound, light, smell, temperature, texture of objects)				
3. Outside weather conditions (e.g., temperature, climate)				
4. The physical demands of typical activities (e.g., strength, endurance, coordination)				
5. The cognitive demands of typical activities (e.g., concentration, attention, problem-solving)				
6. The social demands of typical activities (e.g., communication, interacting with others)				
7. Your child's relationships with peers				
8. The attitudes and actions of directors, teachers, therapists, and other staff who care for your child at daycare or preschool				

Are the following available and/or adequate to support your child's participation at organized daycare/preschool?

	Not needed	Usually, yes	Sometimes yes, sometimes no	Usually, no
9. School-related policies and procedures (e.g., enrollment and attendance policies; check-in procedures and incident reporting to ensure safety; rules for behavior)				
10. Access to personal transportation to get to daycare/preschool (e.g., personal car)				
11. Access to public transportation to get to daycare/preschool (e.g., bus, train, subway)				
12. Programs and services at the organized daycare or preschool (e.g., educational assistant, special resources, etc.)				
13. Supplies (e.g., assistive devices, adapted toys, craft supplies, organic food choices, modular furniture, accessible bathrooms, classrooms and playgrounds, access to internet and technology to support learning)	N/A			
14. Information (e.g., about activities, services, programs)	N/A			
15. Do you (and your family) have enough time to support your child's participation at daycare/preschool (e.g., transporting your child, preparing for the school day, keeping current about your child's learning at school)?	N/A			
16. Do you (and your family) have enough money to support your child's participation at daycare or preschool (e.g., paying tuition, purchasing supplies, participating in fundraisers)?	N/A			

What are some things that help your child participate successfully in activities at organized daycare/preschool? PLEASE LIST UP TO 3 STRATEGIES.

1. _____
2. _____
3. _____

APPENDIX B: ICF Framework

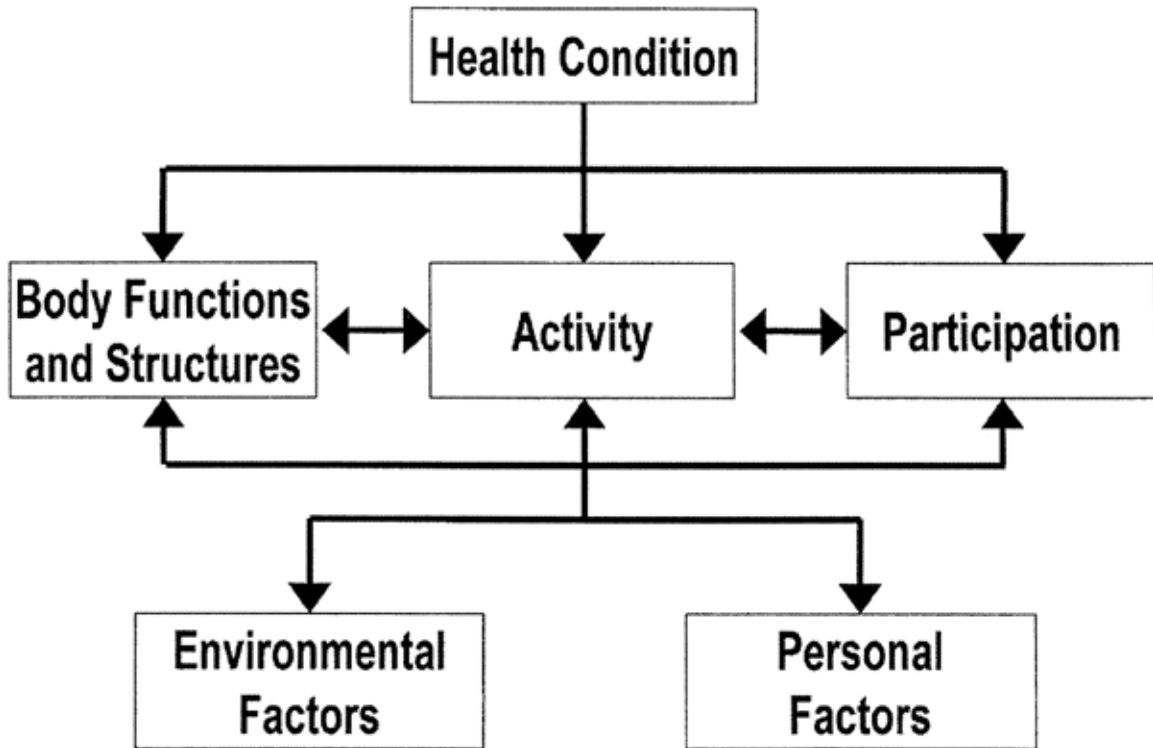


Figure 3: ICF Framework

APPENDIX C: Coding of Parent Strategies into Ten Family Accommodations

1. Family subsistence

(e.g., hours worked; flexibility of work schedule)

- **Mother arranges for flexibility in work or works at home**
- **Father arranges for flexibility in work or works at home**
- **Mother is not working or reduces hours for child**
 - Schedule work off to participate in activities
- **Father is not working or reduces hours for child**
 - Schedule work off to participate in activities
- **Mother works to support services or insurance**
- **Father works to support services or insurance**
- **Mother has less desirable job for services or insurance**
- **Father has less desirable job for services or insurance**
- **Mother is in school or training program**
- **Family makes other types of subsistence accommodation**
 - We demonstrate group time at home as a family with other siblings daily.
 - We have 4 kids, so if we go out, we usually take kids with
 - Have enough time/energy to do activities outside the home
 - The biggest thing is just scheduling these events. Once we schedule them he's pretty happy to participate.
 - Plan and go on more free and cheap outings around town. He really likes music, so more of those types of events.
 - Ensuring that we have plenty of time so no one is rushed as that makes her behavior issues worse
 - Ensuring that we have plenty of time so no one is rushed as that makes her behavior issues worse

2. Services

(e.g., availability of services; sources of transportation)

- **Mother drives to services with choice not to**
- **Family moves for services**
- **Family makes much effort to access services**
 - Finding appropriate sensitive caregivers
 - Find out what's available to do in the community
 - Expose her to a variety of activities and keep trying to bring them back even if the first time she does not like them
- **Less convenient or more expensive services are chosen**
- **The family switches or compromises services for accessibility**
- **Father or relatives drive child to some or all services**
- **Family has no car so they use the bus or walk**
- **Family makes other types of accommodation in accessing services**
 - Increase daycare time - planned for next term

3. Home/neighborhood safety and convenience

(e.g., safety and accessibility of play area; alterations in home)

- **The family's home is altered for convenience or safety of child**
- **The location of family's home is selected for child's benefit**
- **The location of family's home is selected for another family member's benefit**

- **The child is kept in locked areas for his or her own safety**
- **Family makes other types of accommodation in home/ neighborhood**
 - When we go on trips outside of the home we make sure there is a place for our son to run and have sensory input.
 - Managing the stimuli of the event is extremely important, such as moving away from loud, over stimulating activities and seeking out quiet respite spaces.

4. Domestic workload

(e.g., amount of work that needs to be done; persons available to do it)

- **Parents decide to have no more children due to the workload created by child**
- **Mother's workload has increased due to the child**
- **Father gives additional assistance with domestic workload due to child**
- **Help is hired to assist because of the workload due to child**
 - Save money to hire a babysitter for parent night out.
 - Nanny needs to take him to classes.
- **Siblings give additional assistance with domestic workload due to child**
- **Parent changes or eases up on domestic tasks due to child**
- **Family makes other types of accommodation in domestic workload**

5. Childcare tasks

(e.g., complexity of child care tasks; presence of extraordinary childcare demands)

- **Physical care (e.g., lifting, using braces)**
 - With the help of his compression vest and his communication book, we've been able to come back to school for activities with minimal tantrums from Dexter.
- **Behavior management**
 - Our son is very shy so giving him time to warm up to the group is helpful.
 - Encourage her to talk more
 - Talk before going to an activity so she knows what to expect and what is expected of her.
 - He can either be right up in front, blocking everyone's view or lose interest quickly and want to wander away from the group at times. His teachers remind him gently to be courteous to his friends or be more attentive, which works for the most part. If he's really just not into it, they let him play quietly by himself.
 - Reinforce positive behavior
 - Cue him before event
 - Set expectations ahead of time
 - Correct as missteps occur
 - Focus on one activity at a time Consistency
 - Keep the pace up. He gets bored and distracted during long wait times.
 - Take her to more story time events so she will be used to another adult telling her to sit with other kids.
 - Having activities be consistent and regular
 - Preparing him for what he has to do and what is going to happen
 - Since our 16-month daughter has recently started fulltime daycare, we are working closely to help her begin socializing with classmates. This includes enforcing personal space of others and basic sharing for now.
 - Role-play and remind him how to behave.
 - Talk to him about his school friends while at home and encourage him to play with them.
 - Discuss the expectations that he has for his day and 'pump' him up about how great his day will be
 - Give him self confidence
 - Explain to him what he can and should expect ie: pick up time, lunch menu ect

- Discuss the issue with her
- Keeping him in the front, where he is less likely to be distracted
- GIVE BACKGROUND KNOWLEDGE BEFORE GOING SO SHE CAN PAY CLOSER ATTENTION TO SPECIFICS.
- Positive Encouragement leading up to preschool days
- Lots of loving affirmation when returning home from preschool
- Reminding him to wait his turn to talk during circle time.
- Have clear expectations
- Preview what is coming up
- Have rewards and praise for participation
- Praising after successfully participating in an activity.
- Reminding beforehand of what she needs to do at the activity.
- Familiarize the child with different activities, he is VERY routine oriented and doesn't like to break from that
- **Constant monitoring**
 - Timing the event for when she is well rested and fed
 - Engaging him one on one is helpful.
 - Making sure she is well rested and happy
 - ASK QUESTIONS THROUGHOUT TO ENCOURAGE COMMUNICATION.
 - Needs to change activities often to keep his attention
- **Therapies/medical appointments**
- **Transportation**
- **Educational tasks (e.g., computers, educational games)**
 - She will be going to pre-school 5 days instead of 3 days in the fall
- **Other Strategies**
 - Have options to write or color - he focuses well on writing or drawing
 - Have more field trips planned
 - Prepare ahead of time
 - Participate in activities designed for my child's age rather than those designed for children her brother's age
 - Provide her with this opportunity more often
 - Appropriate Rest & Food/Water to be happy for functions
 - Offering new suggestions for outside games.
 - Same as above. Keeping it fun and interesting. Familiar but still coming up with new activities.
 - To provide her opportunities for these kinds of interactions
 - Expose her to activities on her own terms.
 - Give space/freedom to explore
 - Let him think it was his idea
 - To reinforce what they are doing at school at home
 - Making sure he feels safe in the environment
 - Making sure she is well rested and happy

6. Child peer groups

(e.g., child's play groups: children with disabilities vs typically developing Children; amount of parent supervision needed)

- **Participate in groups of children with mixed status**
- **Participate in groups of children with handicaps only**
- **Participate in groups of typical children only**
- **Parent supervises child's play groups (e.g., doesn't let child play outside alone)**
- **Mother cares for children in the home to have playmates for child**
- **Family makes other types of play group accommodations**

- Introducing her to new people and places
- Spending time with my son while he is interacting with friends- he doesn't have much opportunity though outside of preschool.
- **Participate with Groups of Children**
 - Finding age appropriate peers with similar interests
 - Making sure he can 'practice' his social skills by joining groups/other kids every day
 - Redirecting him to interact with peers instead of adults
 - She needs to be encouraged to participate and play with others.
 - ENCOURAGE PLAY WITH OTHER CHILDREN
 - Aside from lots of prompting from parents and caretakers, there isn't much we've found that makes Dexter interested in socializing with peers. He has a few friends he will follow around but he mostly prefers being by himself. At school he is forced to interact with peers and I assume with time it will be more normal for him to interact with peers.
 - Allow her to sit near friends so she is comfortable
 - Do these more often so he gets the interaction with other peers he needs.
 - Encourage him to interact with his peers
 - Utilizing smaller groups is helpful.
 - Plan park play dates
 - Increase frequency of exposure to group learning
 - Place my child within her peer group rather than with parents in social settings
 - Provide greater opportunity for social play
 - Try again with friends
 - Our son is most often shy in-group learning scenarios with strangers. We are letting him come into his own and not forcing the activity. He is happy and comfortable in more familiar surroundings like his preschool. We are trying a new swim lesson with friends he already knows.
 - Making new friends (the nanny does this)
 - Keeping the group smaller
 - SETUP GROUP EVENTS FOR CHILD
 - Having other kids participate and asking a child to copy them

7. Instrumental/emotional support

(e.g., availability and use of formal and informal sources of support; costs of using support)

- **Grandparents**
 - Get grandparents to get her out.
- **Parent support groups**
- **Church/religious group or orientation**
- **Professional parental therapy**
- **Friends**
- **Other family members**
- **Multiple sources of support**
- **Family makes other types of support accommodations**
-

8. Father/spouse role

(e.g., amount of involvement with child with delays; amount of emotional support provided)

- **Father's contribution is an equal or primary role in childcare**
- **Father makes contribution on evenings/weekends only**
- **Father provides emotional support for mother**
- **Father assists with childcare**

- Get daddy to get her out.
- **Father assists with domestic workload**
- **Father assists with transportation**
- **Father plays with child**
- **Father contributes nonspecific or other instrumental support**
- **Father avoids contributing to shared workload, has low participation**
- **Family makes other types of accommodations in father participation**

9. Parent information

(e.g., reliance on professional vs. nonprofessional sources of information)

- **Attending lectures, taking courses**
- **Professionals**
 - To be in contact with the preschool teachers about how we can support these activities in the home
- **Researching and reading**
- **Family and friends**
- **Parents/ parent groups**
- **Programs or organizations**
 - The school I feel knows more about my child's understanding then I do I am so grateful for the program and ask many questions
- **Family makes other types of accommodations for information**
 - The teachers and staff make the children feel welcome, a great reason why the kids like going to school.
 - We are new to this area, so we don't know a lot of people with kids his age. It's been difficult to find kids his age with parents we like to hang out with, too!
 - Usually participates in these activities at school
 - I love the he has play dates and would love him to have more.
 - Have more programs available.
 - More activities at no extra cost.
 - Our Mommy and Me class is limited to just once a week, and can not afford to pay for another day a week... but would like to plan to attend story time in the library more often.
 - Recently increase activities at local sport centre and seen an increase in cooperation

10. Other Strategies

1. Training staff on her needs/limitations
2. Introducing her to new people and places
3. Put in calendar so we all remember when events are
4. Find more opportunities in the community to participate.
5. Relationship with care providers

11. Not Applicable

1. He is also self-conscious so he doesn't like doing things that draw attention to himself
2. Music and art should be more encouraged at preschool
3. Access to music and art projects should be more plentiful
4. We need to do more of this in the home as well

5. I have a newborn -- too busy, so I guess more help.
6. It would be nice if child was more helpful during mealtime. perhaps more routine?
7. I would like child to be more interested in activity at hand... perhaps make activity shorter but demand more involvement?
8. Would like her to participate more consistently Would like her to participate more consistently
9. More exposure to socializing will help her to become more comfortable with other people
10. His daycare teachers do a variety of activities with the children each day to keep them engaged. One strategy would be to continue to offer the same at home and on the weekends.
11. SHE NEEDS TO TALK LESS WITH HER FRIENDS AND LISTEN MORE TO HER TEACHERS
12. Needs supportive staff at school to help him transition
13. Other environments where non-family members are in charge and giving instructions
14. He needs more adult help to learn how to socialize with other kids. The desire is there, but the communication skills are not.
15. Attend frequent learning program
16. Understands that he is a big boy now and that going to school for a couple of hours a week will help him in being able to play with other children.
17. Understands that he should not hit other children.
18. The teachers and staff make the children feel welcome, a great reason why the kids like going to school.
19. We are new to this area, so we don't know a lot of people with kids his age. It's been difficult to find kids his age with parents we like to hang out with, too!
20. Usually participates in these activities at school
21. I love the he has play dates and would love him to have more.
22. Have more programs available.
23. More activities at no extra cost.
24. Our Mommy and Me class is limited to just once a week, and can not afford to pay for another day a week... but would like to plan to attend story time in the library more often.
25. Recently increase activities at local sport centre and seen an increase in cooperation
26. With school starting, my son will have more opportunities to interact with peers.

APPENDIX D: Relationship between Types of Change Desired and Types of Strategies Used

Family accommodations	Strategies used by parents	Types of change desired				
		Do more often	Do less often	Be more interactive	Be more helpful	Participate in broader variety of activities
Child care tasks						
	1. Our son is very shy so giving him time to warm up to the group is helpful.					
	2. Encourage her to talk more			x	x	x
	3. Talk before going to an activity so she knows what to expect and what is expected of her.			x	x	x
	4. He can either be right up in front, blocking everyone's view or lose interest quickly and want to wander away from the group at times. His teachers remind him gently to be courteous to his friends or be more attentive, which works for the most part. If he's really just not into it, they let him play quietly by himself.	x			x	
	5. Timing the event for when she is well rested and fed	x		x	x	x
	6. Needs to change activities often to keep his attention				x	
	7. Have options to write or color - he focuses well on writing or drawing				x	
	8. Have more field trips planned			x	x	
	9. Engaging him one on one is helpful.				x	x
	10. Reinforce positive behavior				x	x
	11. Prepare ahead of time				x	x
	12. Give space/freedom to explore				x	x
	13. She will be going to pre-school 5 days instead of 3 days in the fall	x		x		x
	14. Cue him before event					x
	15. Set expectations ahead of time					x
	16. Correct as missteps occur					x
	17. Making sure she is well rested and happy				x	x
	18. Keep the pace up. He gets bored and distracted during long wait times.	x		x	x	x
	19. Familiarize the child with different activities, he is VERY routine oriented and doesn't like to break from that				x	x
	20. Having activities be consistent and regular				x	
	21. Preparing him for what he has to do and what is going to happen				x	
	22. Participate in activities designed for my child's age rather than those designed for children her brother's age	x			x	

	23. Since our 16-month daughter has recently started fulltime daycare, we are working closely to help her begin socializing with classmates. This includes enforcing personal space of others and basic sharing for now.				x	
	24. Role-play and remind him how to behave.				x	x
	25. Talk to him about his school friends while at home and encourage him to play with them.				x	x
	26. Give him self confidence	x				
	27. Explain to him what he can and should expect ie: pick up time, lunch menu ect	x				
	28. Discuss the issue with her				x	x
	29. Provide her with this opportunity more often				x	
	30. To reinforce what they are doing at school at home			x	x	x
	31. Keeping him in the front, where he is less likely to be distracted			x	x	x
	32. Offering new suggestions for outside games.			x	x	
	33. Focus on one activity at a time			x		
	34. Reminding him to wait his turn to talk during circle time.			x	x	
	35. Making sure he feels safe in the environment					x
	36. Have clear expectations			x	x	x
	37. Preview what is coming up			x	x	x
	38. Have rewards and praise for participation			x	x	x
	39. Praising after successfully participating in an activity.				x	
	40. Reminding beforehand of what she needs to do at the activity.				x	
	41. With the help of his compression vest and his communication book, we've been able to come back to school for activities with minimal tantrums from Dexter.			x		x
	42. Same as above. Keeping it fun and interesting. Familiar but still coming up with new activities.			x		
	43. To provide her opportunities for these kinds of interactions			x	x	x
	44. Expose her to activities on her own terms.	x		x	x	x
	45. Discuss the expectations that he has for his day and 'pump' him up about how great his day will be	x				
Total		9		18	33	26
Child Peer Groups	1. Allow her to sit near friends so she is comfortable			x	x	x
	2. Finding age appropriate peers with similar interests			x	x	x
	3. Do these more often so he gets the interaction with other peers he needs.	x		x		
	4. Encourage him to interact with his peers				x	x
	5. Utilizing smaller groups is helpful.				x	x
	6. Introducing her to new people and places				x	x

	7. With school starting, my son will have more opportunities to interact with peers.			x	x	x
	8. Plan park play dates	x			x	x
	9. Making sure he can 'practice' his social skills by joining groups/other kids every day	x			x	
	10. Increase frequency of exposure to group learning	x			x	
	11. Place my child within her peer group rather than with parents in social settings	x			x	
	12. Provide greater opportunity for social play	x			x	x
	13. Try again with friends	x		x	x	x
	14. Our son is most often shy in-group learning scenarios with strangers. We are letting him come into his own and not forcing the activity. He is happy and comfortable in more familiar surroundings like his preschool. We are trying a new swim lesson with friends he already knows.	x		x	x	x
	15. Redirecting him to interact with peers instead of adults			x	x	x
	16. She needs to be encouraged to participate and play with others.	x		x	x	x
	17. Keeping the group smaller					x
	18. SETUP GROUP EVENTS FOR CHILD	x			x	x
	19. ENCOURAGE PLAY WITH OTHER CHILDREN	x			x	x
	20. Aside from lots of prompting from parents and caretakers, there isn't much we've found that makes Dexter interested in socializing with peers. He has a few friends he will follow around but he mostly prefers being by himself. At school he is forced to interact with peers and I assume with time it will be more normal for him to interact with peers.			x		x
	21. Having other kids participate and asking a child to copy them			x		
Total		11		10	17	16
Family Subsistence	1. Ensuring that we have plenty of time so no one is rushed as that makes her behavior issues worse	x		x	x	x
	2. We demonstrate group time at home as a family with other siblings daily.	x		x	x	x
	3. Schedule work off to participate in activities	x			x	
	4. We have 4 kids, so if we go out, we usually take kids with.			x		
	5. Have enough time/energy to do activities outside the home				x	x
	6. The biggest thing is just scheduling these events. Once we schedule them he's pretty happy to participate.			x	x	x
	7. Plan and go on more free and cheap outings around town. He really likes music, so more of those types of events.				x	x
Total		3		3	6	5
Services	1. Finding appropriate sensitive caregivers			x	x	x
	2. Find out what's available to do in the community	x				x
	3. Increase daycare time - planned for next term				x	x
	4. Expose her to a variety of activities and keep trying to bring them back even if the first time she does not like them.	x			x	x
Total		2		1	3	4
Home/neighborhood safety	1. When we go on trips outside of the home we make sure there is a place for our son to run and have sensory input.	x		x	x	x

	2. Managing the stimuli of the event is extremely important, such as moving away from loud, over stimulating activities and seeking out quiet respite spaces.				x	x
Total		1		1	2	2
Domestic Workload	1. Save money to hire a babysitter for parent night out.	x			x	x
Total		1			1	1
Parent Information	1. The school I feel knows more about my child's understanding then I do I am so grateful for the program and ask many questions	x		x	x	x
	2. To be in contact with the preschool teachers about how we can support these activities in the home			x	x	x
Total		1		2	2	2
Instrumental/Emotional Support	1. Get grandparents to get her out.				x	
Total		0		0	1	0
Father/Spouse Role	1. Get daddy to get her out.				x	
Total					1	
Marital role	N/A					
Other	1. Training staff on her needs/limitations			x	x	x
	2. Introducing her to new people and places				x	x
	3. Put in calendar so we all remember when events are	x			x	
	4. Find more opportunities in the community to participate.	x			x	
	5. When we go on trips outside of the home we make sure there is a place for our son to run and have sensory input.	x		x	x	x
Total		3		2	5	3