Social Participation of Youth with Cerebral Palsy: Determinants and Effects of Self-perceived Competence

A Dissertation

Submitted to the Faculty

of

Drexel University

by

Lin-Ju Kang

in partial fulfillment of the

requirements for the degree

of

Doctor of Philosophy

May 2010

DEDICATION

I dedicate this dissertation to my beloved parents, Tien Kang and Jean-Yun Liang, who have unconditionally supported my pursuit of a PhD far away from home. My accomplishments are built upon their love, trust, and encouragement.

ACKNOWLEDGEMENTS

Upon the completion of my dissertation, I am pleased and thankful to many people who have supported me throughout my PhD life. Dr. Robert J. Palisano is the best supervisor I ever have. He guided my research direction but also allowed me the freedom to learn and think independently. I have learned advanced skills and competencies as to “how” to do research other than “what” to do. Dr. Margo N. Orlin is my co-supervisor who has provided me many experiences in teaching and practice. Both of them are also wonderful life mentors. I could share every moment of happiness and sadness in my life with them and their care was a driving force to keep me going. Dr. Lisa A. Chiarello has always supported my achievement in academics by providing positive and constructive feedback. Working with her for the CAPS and Move & Play studies are valuable experiences that will benefit my future carrier. Dr. Marcia Polansky is a knowledgeable statistician and has guided me to solve many statistical issues. Last but not the least; I want to give special thanks to Dr. Gillian A. King. It was amazing that her feedback and comments always advanced my studies and writing skills to a next level. I was very lucky to have these phenomenal professors to be on my advisory committee.

The funding provided by Shriners Hospitals for Children (Clinical Outcomes Study No. 9197) and the co-investigators, site coordinators, youth and families who participated in the CAPS study are greatly appreciated. I couldn’t use the database for my dissertation without their time and efforts.

Peer support is defiantly relevant during my PhD life. I would like to thank the company of my dear friends: Nihad Almasri, Hui-Ju Chang, Sirinart Laibsirinon, Denise Begnoche, and Mi-hee An…etc. Particularly, Nihad started and finished the PhD and me

and undoubtedly we spent every important moment together. I’ve known Hui-Ju for over 10 years and she was the most important source of support during the down time of my life. My boyfriend, Yueh-Ting Yang, is the source of my happiness. He has perfected my life. We attained our PhD and MS degrees at the same day and will continue a brand new and better life together.

I met two amazing persons, Elizabeth Wang-Hsu and Robert Hsu, when I first came to Philadelphia. They are more like families to me than just friends. They took care of me since the first minute I came here and continuously supported my study and daily life. Spending time with them and their lovely daughter and son, Sharon and Ian, greatly reduced my homesickness. It is never enough to say thanks for what they’ve done for me.

The unconditional support and encouragement from my family is the strongest driving force for attaining my PhD. During the past 4 years we only spent few months together. I appreciate my parents’ trust to allow me to study alone in a foreign country. Even just through a phone call or web-camera, I could feel their love and care. In memory of the couple of my uncle who passed away while I’m studying here, I want to say thank you and sorry to them. I wish they would be happy to see my achievement and forgive me for missing their funerals. Also I hope to spend more time with my grandmother, aunt, brother, sister in law, and two younger cousins after going home, to make up the family time we missed. I realized that “no pain, no gain” and certainly became strong-minded given these sacrifices and loss. Upon graduation, I am ready to move on to the next stage of my life and carrier.

TABLE OF CONTENTS

ABSTRACT

Social Participation of Youth with Cerebral Palsy:
Determinants and Effects of Self-perceived Competence
Lin-Ju Kang, PT, PhD

Social participation fosters the development of meaningful relationships, perceived competence and psychosocial well-being. The aim of this dissertation was to expand knowledge of the multi-dimensional and interactive nature of social participation of youth with cerebral palsy (CP) by identifying: 1) determinants of social participation and 2) whether participation with friends differs based on self-perceived competence as a friend.

The participants were 209 youth 13-21 years old with cerebral palsy (52% males) and their parents. Participants were part of a larger study on Activity and Participation of Children with Cerebral Palsy and were recruited from six Shriners Hospitals for Children and one Children's Rehabilitation Center. The measures included the Children's Assessment of Participation and Enjoyment, Fulfillment in Social Roles, Gross Motor Function Classification System, Coping Inventory, Pediatric Outcomes Data Collection Instrument, Family Environment Scale, Measure of Processes of Care, and Service Questionnaire. Sequential multiple regression analysis was used to determine the youth, family and service determinants of social participation with friends and other non-family members. Kruskal-Wallis One-Way Analyses of Variance was used to examine the differences in the number, total frequency, and enjoyment of activities done with friends among youth with high, middle, low self-perceived competence as a friend.

Youth and service characteristics were determinants of participation with friends but not other non-family members. Higher sports and physical function (β=.25), communication/speech ability (β=.18), inclusive education program (β=.21), and the higher extent to which desired community recreational activities were obtained (β=.22) explained 46% of the variance in number of activities done with friends. Higher parental education (β=.25) explained 6% of variance in number of activities done with other non-family members and was the sole determinant.

The number (χ^2=17.07, df=2, p<.001) and total frequency (χ^2=18.35, df=2, p<.001) of activities done with friends, but not enjoyment of activities (χ^2=1.86, df=2, p>.05), differed based on youth's self-perceived competence as a friend. Youth with higher self-perceived competence did more activities with friends and participated with them more often.

Services and supports that promote youth's mobility, communication, and social skills, and enable access to community opportunities and real-life experiences with friends and other non-family members may help to optimize social participation and competence of youth with CP.

CHAPTER 1: RESEARCH PROPOSAL

1.1. Specific Aims

Restrictions in social participation among youth with cerebral palsy (CP) may increase the difficulties associated with successful transition to adult life. In adolescence and young adulthood, participation with persons outside the family is a context to form social relationships, learn and apply social skills. A sense of belonging and being trusted by others is meaningful for adolescents with CP to achieve life success (G. King, Cathers, Polgar, MacKinnon, & Havens, 2000). Children and youth with physical disabilities have been reported to be less socially active, participate in fewer social activities, and often experience social isolation and loneliness (Brown & Gordon, 1987; Poulsen, Ziviani, Cuskelly, & Smith, 2007; Stevenson, Pharoah, & Stevenson, 1997). Youth with CP have been found to have limited social contacts with persons outside the families and were concerned about not having many friends their age (Adamson, 2003). Lack of social experiences may have negative impacts on the development of social skills and competencies (Brown & Gordon, 1987; Larson & Verma, 1999). Knowledge of factors that are facilitators or barriers to social participation of youth with CP is limited.

Social participation is defined as *a person's active engagement in activities that are performed formally and informally with their friends, instructors / teachers, coworkers, or other non-family members*. Factors that have been identified as potential determinants of leisure and recreational participation include: child age and sex, activity preferences, and functional abilities; family relationships and participation in cultural and recreational activities; and the physical, social, and attitudinal environment (Brown & Gordon, 1987; Donkervoort et al., 2007; G. King, Law, Hanna, et al., 2006; Law, Petrenchik, King, & Hurley, 2007). Health care professionals play a vital role in providing services and supports that optimize activity and participation of youth with CP. Knowledge of factors that are facilitators or barriers of social participation has implications for clinical decision making in planning health care services, allocating community resources, and minimizing environmental barriers to encourage social participation of youth with CP.

Self-perceived social competence is an important aspect of youth's psychosocial well-being, which may be associated with social participation (McGee, Williams, Howden-Chapman, Martin, & Kawachi, 2006). Self-perceived social competence as a friend is defined as a youth's judgment of how well they are able to make friends, interact with friends, and help friends out. Participation in extracurricular activities and peer interactions may be associated with a youth's social competence (Marsh, 1992). Participation in team sports and social recreational activities of adolescents with typical development significantly predicted their attachment to peers and self-perceived strengths (McGee, et al., 2006). Relations between self-perceived social competence and social participation have not been determined in youth with CP. Knowledge of social competence in relation to participation will facilitate families and health care professionals to support the psychosocial well-being of youth with CP including the development of social skills.

The overall aim of this proposed research is to expand knowledge of the multi-dimensional and interactive nature of social participation of youth with CP by identifying determinants of social participation and whether participation with friends differs based on self-perceived competence as a friend. The overall aim will be accomplished by the following specific aims.

Aim 1: Determinants of Social Participation

To identify youth, family, and service determinants of social participation in recreational and leisure activities with: 1) *friends*, and 2) *non-family members* for youth with CP.

Hypotheses: The following characteristics are hypothesized as determinants of higher social participation of youth with CP:

1. Youth characteristics: 13-16 years-old, female, higher adaptive behavior, higher gross motor, physical, cognitive, and communicative function.

2. Family characteristics: higher family cohesion, social integration in community activities and lower family conflict.
3. Service characteristics: higher availability of school-based therapy services and community services, general information provided to a higher extent, coordinated and comprehensive care provided to a higher extent, and higher parental perception of services meeting their child's needs for participation.
4. Educational placement: attend special school or special program in regular school.

Similar youth and family factors are hypothesized as determinants of participation with friends and with other non-family members. A role of health care professionals is to provide information about community activities and programs and consult on adaptations and accommodations. Services, therefore, are hypothesized to have a greater impact on participation with other non-family members such as instructors/coaches or paid tutors than participation with friends.

Aim 2: Social Participation and Self-perceived Competence as a Friend

To identify whether participation with friends in recreational and leisure activities differs between youth with CP who have the highest, middle and lowest self-perceived competence as a friend.

Hypotheses:

1. Youth who have the highest self-perceived competence as a friend, compared with youth with middle and lowest competence, will:
    a) Participate in more activities with friends
    b) Perform these activities more often
    c) Have a higher level of enjoyment
2. Youth with middle self-perceived competence as a friend, compared with youth who have the lowest competence, will:
    a) Participate in more activities with friends
    b) Perform these activities more often
    c) Have a higher level of enjoyment

The results will have implications for physical therapists and other health care providers serving youth with CP who identify goals for social participation and competence. Knowledge of determinants of social participation will help to identify focuses of health care services and interventions. Knowledge of whether participation with friends differs based on self-perceived competence as a friend will highlight the need for services and supports that enhance social skills and competence.

1.2. Background and Significance

Cerebral palsy describes a group of disorders of movement and posture, causing activity limitation, attributed to non-progressive disturbances in the developing fetal or infant brain (Rosenbaum et al., 2007). Although the neurologic disturbance is non-progressive, physical abilities and priorities for participation of individuals with CP change over time. Physical therapy is a frequent service received by people with cerebral palsy across their lifespan. A focus of physical therapy services for children with CP is on minimizing impairments and improving motor functioning and fitness in daily activities. Current perspectives recognize the importance of participation for health and well-being and identification of personal and environmental factors that are determinants of participation (Majnemer & Mazer, 2004; Palisano, Snider, & Orlin, 2004). Successful participation in home, school and community life is an ultimate goal in rehabilitation services (Goldstein, Cohn, & Coster, 2004). For youth with CP who experience challenges transitioning to adulthood, therapists have a role to support their meaningful engagement in adult lives including independent living, postsecondary education, employment and leisure.

Social Participation of Youth with Cerebral Palsy

Participation is broadly defined as “the involvement in life situations” in the International Classification of Functioning, Disability and Health (ICF) (World Health Organization, 2001). The ICF model (Figure 1) provides a conceptual framework for understanding and studying health and health-related states, outcomes, and determinants. The ICF model highlights the process of enabling a person’s active choice and engagement in meaningful daily activities. The ICF framework includes three components of health (body functions and structures, activities, and participation) and two contextual factors (environmental and personal). Participation is a result of dynamic interactions between a person and the environments relevant to the person (Forsyth & Jarvis, 2002). The complexity of participation can be understood by a person’s objective and subjective experiences when engaging in a variety of activities, as well as the contexts in which the person participates (Chen & Cohen, 2003; Coster, 1998; Law, 2002). The dissertation proposal focuses on participation in recreational and leisure activities within social contexts among youth with CP.

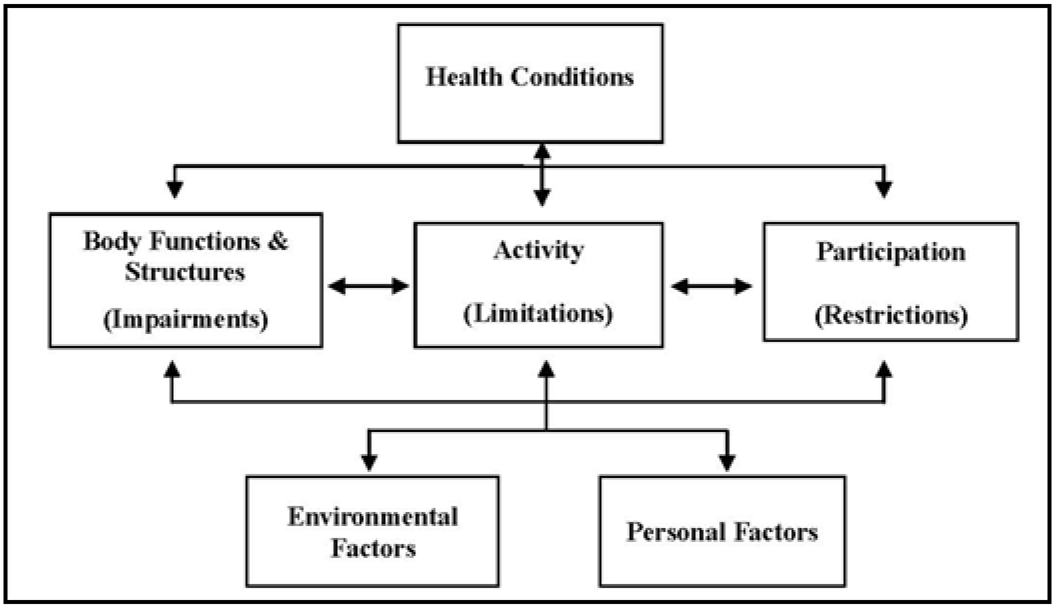


Figure 1. The International Classification of Functioning, Disability and Health (ICF) (WHO, 2001)

Social participation is defined as active engagement in activities that are performed with persons outside the family such as friends, instructors / teachers, coworkers, or others. Chen and Cohn (2003) conceptualized social participation as "the extent to which a child is able to engage in a context that is growth-enhancing, personally satisfying, and acceptable to the adults or peers in their lives" (p. 63). Social participation involves forming and maintaining social relationships through interactions with other people during daily activities (Chen & Cohen, 2003; Herzog, Ofstedal, & Wheeler, 2002). The interactions may occur in various forms such as joint participation in activities, providing support to others, visiting or phone calls within the contexts of socialization, leisure, productive, and educational activities (Herzog, et al., 2002). Through participating in meaningful and intrinsically-motivating activities with others, people with disabilities reported positive gains in mental and physical health, opportunity to form social networks, and development of social competencies and self-concept (Barletta & Loy, 2006; Specht, King, Brown, & Foris, 2002). Establishment of social networks outside the family is a particular desire of adolescents with physical disabilities (McGavin, 1998). Peer relationships in adolescence are important in supporting the transition to adult life including independent living, work, and marriage.

Children and youth with CP demonstrated a solitary and passive pattern of participation in leisure activities (Richardson, 2003). Children and youth 6-19 years with physical disabilities, mostly CP and spina bifida, spent more time on quiet recreation and in the home environment than their peers without disabilities (Brown & Gordon, 1987). Adolescents with CP 11-17 years were less active in physical activity than their age-matched peers without physical disabilities (Maher, Williams, Olds, & Lane, 2007).

Children and youth with physical disabilities participated in fewer social activities, were less socially active and skilled when interacting with others compared with peers without disabilities (Poulsen, et al., 2007; Stevenson, et al., 1997), and they often experienced loneliness and social isolation (Poulsen, et al., 2007; Stevenson, et al., 1997).

The pattern of more home-based sedentary activities and less socialization was more obvious in adolescents (Poulsen, et al., 2007; Stevenson, et al., 1997). Among 60 youth with CP 12-22 years-old , more than half indicated that their best friends also had disabilities, and their participation with friends was mostly passive (e.g. watching TV) or active immobile recreation (e.g. playing chess) (Blum, Resnick, Nelson, & St Germaine, 1991).

Factors Influencing Social Participation

Participation is a multi-determined construct that can be influenced by various personal and environmental factors (G. King, Law, Hanna, et al., 2006; G. King et al., 2003). King and associates (2003) published the model of determinants of the leisure and recreational participation of children with physical disabilities. This model adopts a strength-based approach in which participation is facilitated by supportive factors related to the *child*, *family*, and community *environment*. Child and family factors are proximal factors that are more closely related to the child's participation while the environmental factors are more distal factors that may influence participation indirectly through the effects on more proximal factors. A structural equation model (SEM) analysis was employed to test the model on the outcomes of the intensity of participation in formal and informal activities (G. King, Law, Hanna, et al., 2006). The sample included 427 children and adolescents 6 to 15 years old with a variety of physical disabilities (50.8% had cerebral palsy). Results revealed that child cognitive, communicative and physical functions, child activity preferences, and family recreational preference and participation had direct impact on the child's participation. In addition, family cohesion, perceived environmental barriers, and a supportive relationship for the child were indirect predictors of participation (G. King, Law, Hanna, et al., 2006).

Using the model of determinants of the leisure and recreational participation of children with physical disabilities as a framework (G. King, et al., 2003), potential child, family, and environmental determinants of recreational and leisure participation of children and youth with disabilities will be appraised.

Child factors: Personal factors including age and sex, impairments in body functions and structures, and activity limitations are factors that have been identified as influencing leisure participation of children and adolescents with CP. Adolescents with physical disabilities 12-15 years had lower level of recreation participation than children 6-12 years (G. King, Law, King, et al., 2006; Law et al., 2006); however, among children and youth with disabilities 6-19 years of age, socialization activities such as visiting or making phone calls and time spent outside home were higher based on age (Brown & Gordon, 1987). In youth without disabilities, participation in sport and recreational activities declined from early to late adolescence (McGee, et al., 2006). Among children with physical disabilities, females participated more intensively in social, skill-based and self-improvement activities; while males participated more intensively in active physical activities (G. King, Law, King, et al., 2006; Law, et al., 2006).

Children with CP 10-12 years in Level V of the Gross Motor Functional Classification System (limited motor function) had a lower level of participation than children in levels I to IV (Imms, Reilly, Carlin, & Dodd, 2008). Child cognitive, communicative and physical functioning were identified to be associated with the preferences and patterns of participation in daily formal and informal activities (Brown & Gordon, 1987; Donkervoort, et al., 2007; G. King, Law, Hanna, et al., 2006; Majnemer et al., 2008). A review of studies involving adolescents and young adults with CP of normal intelligence concluded that age, sex, and child's self-efficacy are related to development of peer relationship; physical functioning and communication problems were related to accessing and engaging in social activities (Wiegerink, Roebroeck, Donkervoort, Stam, & Cohen-Kettenis, 2006).

Adaptive behavior may be an important determinant of social participation and social behaviors. Adaptive behavior is employed to respond to personal and environmental needs and interact with physical and social environment (Zeitlin &

Williamson, 1994). Children who use active adaptive behaviors, such as seeking solutions to improve negative situations, are more likely to cope with peer rejection effectively (Reijntjes, Stegge, & Terwogt, 2006). In the model of determinants of participation of children with physical disabilities, King et al. (2003) proposed that higher emotional and behavioral function was related to higher intensity of leisure and recreational participation but more evidence is needed to support this relationship. Higher emotional and behavioral function has also been reported to predict supportive social behaviors of children 6 to 11 years old (G. King et al., 2005).

Research supports the hypotheses that age, sex, gross motor function classification, physical functioning, adaptive behaviors, cognitive and communicative problems are determinants of social participation in recreational and leisure activities for youth with CP.

Family factors: Family functioning and family relationships may have a great impact on child's social participation and peer relationships. Family socioeconomic status such as higher family income, married status of parents, and higher educational levels have been documented to positively affect participation and social life of children with physical disabilities (Law, et al., 2006; Sloper, Turner, Knussen, & Cunningham, 1990). Family cohesion and family preferences and participation in cultural recreational activities are associated with child's participation in social leisure activities (G. King, Law, Hanna, et al., 2006; McGee, et al., 2006). Particularly, families with higher emotional bonds and open communication among family members had a strong positive influence on social skills of their children with disabilities measured in school contexts (Bennett & Hay, 2007).

Based on previous research, the family environment appears to provide an important foundation on which children build social competence and initiate exploring their social environment. Therefore, family relationships and family preferences and participation in community activities are hypothesized determinants although the outcome examined in the present research will focus on youth's social participation excluding the family members.

Environmental factors: The ICF model conceptualizes five aspects of environment that may influence participation: 1) Products and technology; 2) Natural and built environment; 3) Support and relationships; 4) Attitudes, values, and beliefs; and 5) Services, systems and policies (WHO, 2001). Previous studies have investigated supports and barriers of the physical, social, attitudinal and service environments on social and recreational participation of children with disabilities (Law et al., 1999; Lawlor, Mihaylov, Welsh, Jarvis, & Colver, 2006; Mihaylov, Jarvis, Colver, & Beresford, 2004). One should keep in mind that the perceived impact of environmental factors may vary depending on the unique needs and characteristics of each child and family, such as child age, physical functioning or other associated behavioral problems (Law, et al., 2007).

Physical environment: Two qualitative studies with families of children with physical disabilities identified that limited mobility, lack of transportation, and problems with accessibility of playground, building and community organizations are potential barriers to social leisure activities (Law, et al., 1999; Lawlor, et al., 2006). Similarly, barriers of environmental inaccessibility were also identified in a survey of providers of community activities for children with physical disabilities (Rosenberg, 2000).

Social and attitudinal environment: Social and attitudinal supports and barriers may have a major impact on social participation; this is especially important for adolescents with disabilities who experience social isolation (Law, et al., 1999; Lawlor, et al., 2006). Concerns were expressed by parents toward the competitive nature of sport and leisure activities that limit their child's participation (Law, et al., 1999). The emphasis on better performance and winning, as well as the safety concerns in competitive activities may hinder active engagement of children with disabilities. Formal and informal social supports to the child and parents are proposed to influence child's level of participation (G. King, Law, Hanna, et al., 2006; G. King, et al., 2003).

Health Care and Community Services: Lack of knowledge, availability and coordination of services has been identified as barriers to social participation in the community for children with disabilities. Parents expressed needs for knowing, locating and coordinating the health care, school and community services for their child (Law, et al., 1999). A review article suggested that limited information of available resources, lack of consultation, as well as uncoordinated services restricted opportunities for participation of children with CP (Mihaylov, et al., 2004). The lack of personnel who are knowledgeable about managing the needs of children with disabilities was identified by service providers as a barrier to providing effective community programs (Rosenberg, 2000). Youth with CP in Canada reported lower satisfaction with recreational services than their peers without disabilities (J. E. Magill-Evans & Restall, 1991). This finding suggests that barriers for successful recreational participation may exist even when community services are available.

Youth and family-centered services may enhance social participation by sharing information and coordinating services that address the identified needs of youth with cerebral palsy. Youth and family-centered services build on the unique strengths of each youth and family. Youth are actively engaged in identifying goals and needs. Services providers collaborate with youth and family to determine the plan of care (S. King, Teplicky, King, & Rosenbaum, 2004; Law et al., 1998; P. Rosenbaum, King, Law, King, & Evans, 1998). Research is needed to identify the structures and processes of heath care services and community programs that promote social skills and enhance successful participation.

School Environment: School is a primary environment for education and peer interaction. Inclusion of students with disabilities in the general education program is supported by the Individuals with Disabilities Education Act (IDEA) (PL 105-17). Students with intellectual, physical, behavioral, communication disabilities, however, demonstrated limited social experiences and lower perception of social integration compared with peers in the general educational program (Baker & Donelly, 2001; Stanovich, Jordan, & Perot, 1998). Children with physical disabilities were reported to have lower social acceptance compared with their peers without disabilities in ordinary school (O'Moore, 1980). Students with mild learning disabilities had more positive perception of educational and academic abilities in special school compared with those students in general school (Meadan & Halle, 2004). Research has focused primarily on social experiences of students with intellectual or learning disabilities; the influence of school and educational program placement on social participation of youth with CP has not been determined.

Based on the identified barriers to social participation and principles of youth and family-centered services, social participation of youth with CP was hypothesized to be related to availability of medical and community services, and parental perceptions of the extent services meet their child's needs for participation, meet information needs, and are coordinated and comprehensive. Educational placement is a special case of service factors that is proposed to be related to youths' social networks. The influence of physical, social and attitudinal environments will not be examined in the proposed study.

Self-perceived Social Competence in Youth with CP

Self-perceived competence refers to a person's judgment of his/her ability to perform activities successfully (Kimiecik, Horn, & Shurin, 1996). Harter (1978) conceptualized that self-perceived competence comprises multiple domains such as athletic, social, and academic performance (Harter, 1985b). Self-perceived social competence can be understood by the youth's feelings about the way they make friends and get along with friends (Harter, 1985a), reflecting their perceptions of peer relationships and performance in a friend's role.

Youth with CP may be at risk of having a lower self-perceived social competence than their peers without disabilities given their functional limitations and socialization difficulties (Shields, Loy, Murdoch, Taylor, & Dodd, 2007). Children and youth with CP aged 8 to 16 years were reported to have lower perception of social acceptance than their peers without disabilities (Shields, et al., 2007; Shields, Murdoch, Loy, Dodd, & Taylor, 2006). Sex seems to be an important mediator of the effect of disability on the self-perceived social competence. Adolescent females under 18 years of age with physical disabilities, including CP and spina bifida, had lower perceived social acceptance compared with females without disabilities; while males with physical disabilities did not differ from males without disabilities (G. King, Shultz, Steel, Gilpin, & Cathers, 1993; J. E. Magill-Evans & Restall, 1991).

Self-perceived Social Competence in Relation to Social Participation

A hypothesis of the proposed research is that youth with higher self-perceived social competence have higher social participation and a higher level of enjoyment in activities that are performed with friends. The proposed relationship between social competence and social participation is based on the perspective that children with disabilities prefer, participate, and enjoy the activities with which they feel competent (G. King, Law, King, et al., 2006). Participation in social and physical activities has been reported to be associated with perceived social and athletic competence for children and adolescents with and without physical disabilities (Kimiecik, et al., 1996; G. King, Law, King, et al., 2006). Anxiety or limited confidence in social situations may contribute to child's difficulties in peer interactions and consequent lack of friends (Doll, 1996; Lightfoot, Wright, & Sloper, 1999). Adolescents and adults without disabilities reported that lack of confidence and skills limited their desire to participate in physical activities (Allender, Cowburn, & Foster, 2006).

Experiences in social interactions may help to build self competence, but knowledge of how self-perceived competence relates to social participation of youth with CP is limited. Harter (1978) suggested that perceived competence is partly the result of feedback obtained from a person's functioning in a particular domain. Youth's social competence, therefore, may be influenced by attitudes of peers when engaging in social activities. Youth with CP reported that experiences in participation in leisure, education or work in general, were reasons for an increase in their overall self-perception as they transitioned from adolescence to adulthood (J. E. Magill-Evans & Restall, 1991). Adamson (2003) studied adolescents with CP 12-17 years of age and found that they have a positive view of themselves overall, including their relationships with others. However, adolescents with CP still reported difficulties when getting along with peers without disabilities and lack of close friends to be with or to talk with (Adamson, 2003).

A positive relationship has been reported between sport participation and social competence in adolescents without disabilities (Donaldson & Ronan, 2006; Gaskin &

Morris, 2008). In youth 18-21 years of age, participation in sports, clubs or groups as well as cultural, recreational and social activities significantly predicted their attachment to peers and self-perceived social competency (McGee, et al., 2006). Children with developmental coordination disorder (DCD) who perceived themselves as less physically competent participated in fewer community-based recreational and physical activities than their peers who had higher perceived competence (Hay & Missiuna, 1998). Participation in physical activities with friends and others may provide a socialization environment in which children and youth learn cooperation skills and develop appropriate behaviors to “fit in” a peer group. The needs of social acceptance, a sense of belonging and trusting relationship with others are meaningful for adolescents with CP to achieve success in life (King, et al., 2000). Therefore, studies on youth with CP are needed to understand their self-perceived competence and participation in social situations outside of the family.

Significance

Transition to adulthood is an exciting but challenging period during which youth prepare for adult life such as living away from parents, work, community integration and social relationships including marriage. Social participation during adolescence may facilitate readiness for adult social roles as a spouse, coworker or neighbor (Richardson, 2003). Youth with CP experience increased challenges transitioning to adult life given their difficulties in mobility, communication and socialization (Wiegerink, et al., 2006). Adolescents with physical disabilities are more dependent on family members for self-care activities, participate less with friends or persons outside the family, and tend to perform more solitary and sedentary activities at home (McGavin, 1998). An important role of physical therapists and other health care providers is to support the wishes of youth to engage in community social life and contribute to society. Knowledge of determinants of social participation (Aim1) will help to better understand youth, family and service factors associated with higher social participation. The findings will have implications for providing youth- and family-centered services that support youth in achieving their goals for social participation and community integration.

Social competence is fundamental to a youth's psychosocial well-being and may be associated with participation and enjoyment of activities. Youth with CP have been reported to have less social competence than their peers without disabilities (Shields, et al., 2007; Shields, et al., 2006). Knowledge of whether social participation differs based on youth's self-perceived competence as a friend (Aim 2) will have implications for planning services that promote physical, social and psychological health. The findings may provide insights on enhancing social self-perception through optimizing peer engagement for youth who are less competent in role as a friend.

1.3. Preliminary Research

Conceptual Model of Successful Participation in Recreation and Leisure Activities

During my Independent study in Summer 2007 with Dr. Palisano, I formulated a conceptual model of successful participation on the basis of theories, models and research. Participation focuses on recreational and leisure activities in the context of entertainment, socialization, physical activities, and skill enhancement. My motive for development of a model was to provide a framework for investigating the relationship between participation and relevant determinants of successful participation among children and youth with cerebral palsy. The model serves as a conceptual framework for my dissertation proposal.

A person who has *successful participation* is defined as actively engaged in activities physically, socially, and psychologically and experiencing enjoyment and a feeling of competence toward their participation. Successful participation is conceptualized as being supported by child, family, and environment characteristics. Ongoing experiences of successful participation may contribute to positive health outcomes and wellness that affect quality of life.

Participation is a *multi-dimensional* construct involving objective and subjective experiences (Coster, 1998; Eriksson & Granlund, 2004; Law, 2002; Passmore, 2003). “More is better” does not characterize successful participation; the degree of social engagement and personal enjoyment and satisfaction are also important attributes. Participation is influenced by various personal and environmental factors (G. King, Law, Hanna, et al., 2006; G. King, et al., 2003). The interactive nature of participation is represented by the ICF model (WHO, 2001). The conceptual model of participation for children with physical disabilities developed by King and associates (2003) delimits and articulates the key supporting factors and outlines the complex relationships among factors.

Description of the Model

The conceptual model of successful participation is illustrated in Figure 2. The model conceptualized that *successful participation* occurs when a dynamic balance is achieved between the interaction of *personal participation* and *contextual determinants*. The interaction is an ongoing and changing (i.e. dynamic) process; the experiences of a person’s participation and supports from the contextual factors may vary across various time and situations. Therefore, successful participation is a dynamic process that involves continuous balancing between personal values and expectations, activity requirements, and environmental changes.

Personal participation encompasses three dimensions: (1) physical, (2) social, and (3) psychological. Success in physical participation refers to children who actively chose activities they like, are physically engaged in the activity, and gain skills through participation (Barletta & Loy, 2006; Eriksson & Granlund, 2004; Passmore, 2003). Success in social participation refers to children establishing and maintaining social relationships and acquiring social skills by interacting with others appropriately and working with others in group activities (Heah, Case, McGuire, & Law, 2007; Yuen, Pedlar, & Mannell, 2005). Positive psychological experience of participation refers to children demonstrating interest and enjoyment (Heah, et al., 2007), and developing a sense of achievement, self-competence or self-esteem. The positive feedback will motivate children to keep engaging in the activities (Barletta & Loy, 2006; Brooks & Magnusson, 2007).

Contextual determinants contain three domains: (1) child, (2) family, and (3) environmental. Each domain represents characteristics that are unique but interrelated. To elaborate, child characteristics are different from family characteristics, but child characteristics are influenced by the family system. Family characteristics are different from community environmental characteristics, but family characteristics are influenced by the context of community environment.

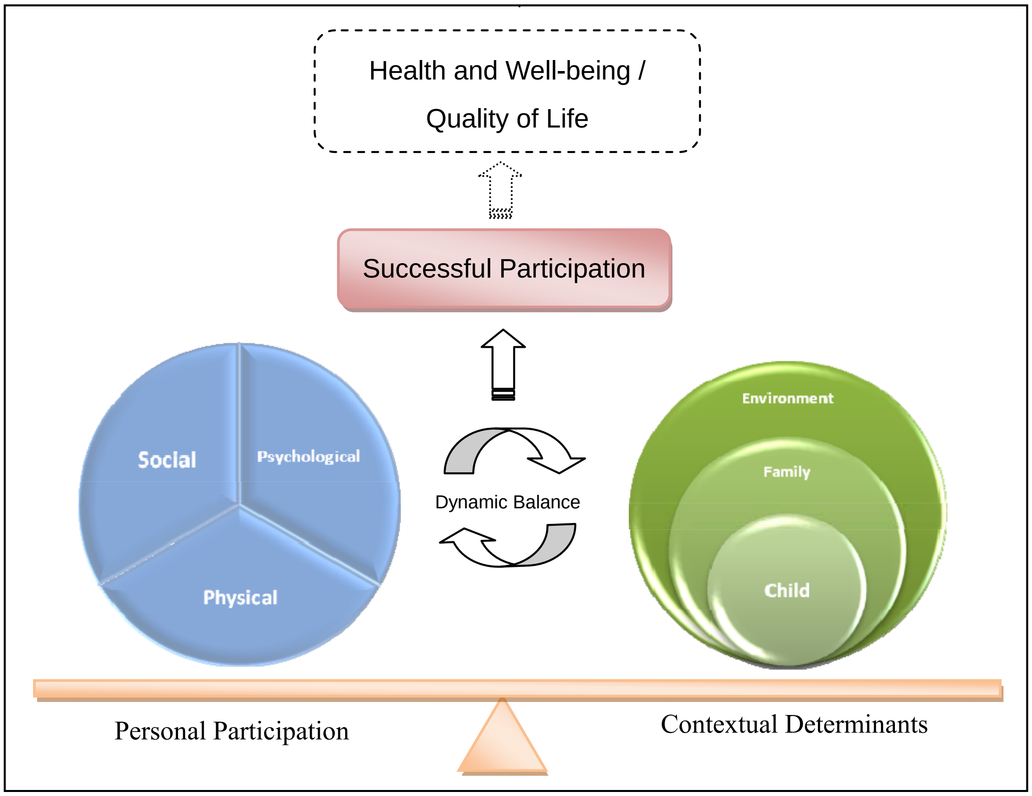


Figure 2. Conceptual Model of Successful Participation

Study of Participation in Home, Extracurricular, and Community Activities among Children and Youth with Cerebral Palsy

Beginning in Summer 2007, I participated in conceptualization, literature review, data analysis, interpretation of results, and writing the manuscript "Participation in Home, Extracurricular, and Community Activities among Children and Youth with Cerebral Palsy". The manuscript targeted the journal *Developmental Medicine and Child Neurology* and is in process of revision and resubmission. The purpose relates to the second aim of the CAPS study which was to examine the effect of age and gross motor function on diversity and intensity of participation among children and youth with CP. The sample included 271 children and youth with CP, 160 were between 6 and 12 years-old and 111 youth were between 13 and 21 years-old. The number of participants in each GMFCS level varied from 36 to 64. The data of the Children's Assessment of Participation and Enjoyment (CAPE) were analyzed.

Two-way ANOVAs revealed that diversity and intensity of participation varied based on age and GMFCS level but effects varied depending on activity domain and type. The effect of age was significant for Overall participation, Informal activities and Recreational activities, in which children consistently had higher diversity and intensity than youth. The effect of GMFCS level was significant for Overall participation, both Formal and Informal activities, and Recreational, Physical, and Self-improvement activities. Children and youth in Levels I and II/III had higher diversity and intensity of Overall participation, both Formal and Informal activities, Recreational, and Self-improvement activities than children and youth in Levels IV/V. Uniquely, children and youth in Level I had significantly higher diversity and intensity of participation in Physical activities, but children and youth in Levels II/III and Levels IV/V did not differ from each other. The effect of age and GMFCS Level was not significant for Social and Skill-based activities.

Study of Social and Community Participation of Children and Youth with Cerebral Palsy

The second project that I participated in is “Social and Community Participation of Children and Youth with Cerebral Palsy”. We operationally define “social participation” as a child’s engagement in activities that are performed with their friends, instructors / teachers, coworkers, or other non-family members; and “community participation” as a child’s involvement in activities that are performed outside the home environments, including the neighborhood, extracurricular activities at school environment, within and beyond the community where the child lives. The purpose of this study was to identify the: 1) activity domains and types that children and youth with CP are more likely to perform with non-family members and in the neighborhood, community or beyond, 2) activity domains and types that children and youth with CP have higher diversity and enjoyment of participation; and 3) differences between females and males in social engagement, community participation, diversity and enjoyment of participation. The sample included 386 children and youth with cerebral palsy between 6 to 21 years-old (210 males and 170 females). Data from the Children’s Assessment of Participation and Enjoyment (CAPE) measure were analyzed.

Activity Domains: The paired t-tests indicated that children and youth performed proportionately more Formal activities with friends and others (p<.001) and in the neighborhood, community or beyond (p<.001) compared with Informal activities. Over half (50.5%) of the Formal activities were performed with friends and non-family members and 79.1% were performed outside the home or indoor environment compared with 18.8% and 33.8% respectively for the Informal domain. Children and youth, however, participated in proportionately fewer activities in the Formal domain (18.1%) compared with the Informal domain (52.4%) (p<.001). On average, children and youth reported a mean level of enjoyment of 3.9 for both domains, indicating they liked doing the activities ‘very much’.

Activity Types: The repeated measures ANOVAs and post-hoc paired t-tests indicated that the percentage of activities performed with friends and others was highest for Physical (38.1%) and Skill-based (38.3%) activities, followed by Social activities (26.4%), and lowest for Recreational (14.7%) and Self-improvement (14.3%) activities (p<.001). The percentage of activities performed in the neighborhood, community or beyond was highest for Physical (55.8%) and Skill-based (55.9%) activities, followed by Self-improvement (46.9%), Social activities (42.6%), and lowest for Recreational (21.4%) activities (p<.001).

Children and youth participated in proportionally more Social (68.4%) than Recreational (63.1%) and Self-improvement (46.5%) activities, and had the lowest diversity scores for Physical (20.5%) and Skill-based (20.0%) activities (*p*<.001). Children and youth also reported a higher level of enjoyment for Social activities (4.3) than Recreational activities (4.1), Physical activities (4.0), and Self-improvement activities (3.3); the difference in level of enjoyment between Social and Skill-based (4.2) was not significant. Level of enjoyment was lowest for Self-improvement activities (*p*<.001).

Sex Differences: Females participated in proportionately more Skill-based (23.3%) and Self-improvement (50.2%) activities than males (17.3% and 43.5%, respectively) (p=.001). Males performed more Physical activities in the neighborhood, community or beyond (60.8%) than females (49.8%) (*p*<.001). Differences in participation between females and males for Recreational, Social, Formal domain and Informal domain activities were not significant (*p*>.01).

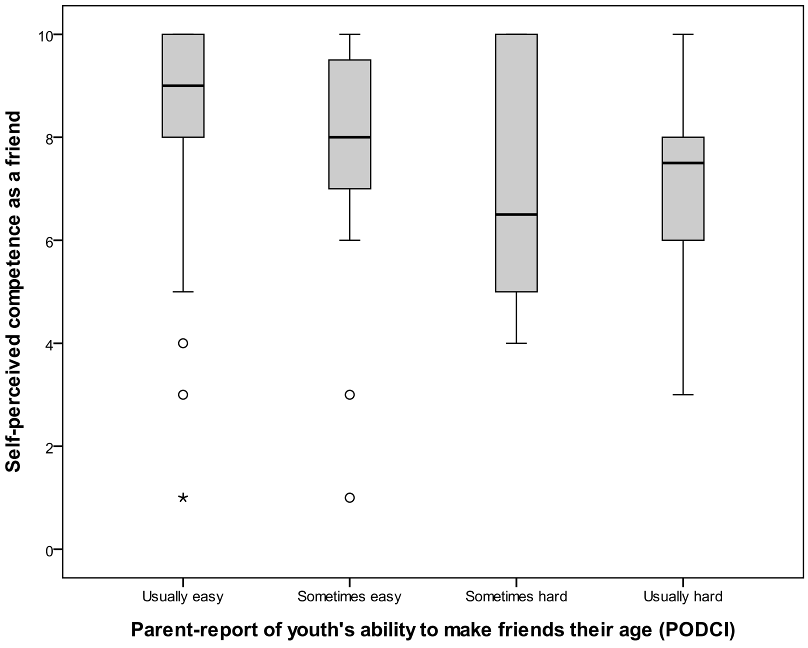
Examination of Concurrent Validity of Self-perceived Competence as a Friend

The independent variable for Aim 2 is the "youth-rated performance level as a friend" measured by the Fulfillment in Social Roles (FSR) questionnaire developed for the CAPS study. The measure is completed by children and youth. I examined concurrent validity for the question "How would you rate the way you are able to have friends, help your friends out, and hang out with your friends now?" rated on a 10-point scale. Ratings of youth 13-21 years of age were correlated with two parent-reported ratings on the Pediatric Outcomes Data Collection Instrument (PODCI). The items selected were:

1) "Is it easy or hard for your child to make friends with children their own age?" (rated on a 4-point scale ranges from '1=usually easy' to '4=usually hard')
2) "How often in the last week did your child get together and do things with friends?" (rated on a 3-point scale ranges from '1=often' to '3=never or rarely').

The relationships between the youth-rated performance level as a friend and the two parent-reported ratings were examined by Spearman rank Correlation coefficients (r_s). Youth-rated performance level as a friend significantly correlated with parental perception of their child's ability in making friends (r_s=-.277, p=.001) and parental report of the frequency of their child to "get together and do things with friends" in the past week (r_s=-.326, p<.001). Figure 3 presents the box plots for each analysis.

The magnitudes of the correlations were judged as acceptable because the performance in role as a friend involves more issues that are not asked in the selected parent-report questions. For question one, helping friends out and cooperation with others are also important in addition to making friends. For question two, frequency of getting together with friends in only the past week is too short to accurately represent the bigger picture of how often the child has been with friends. The results provide some evidence of concurrent validity for the data on the youth-rated performance level as a friend.



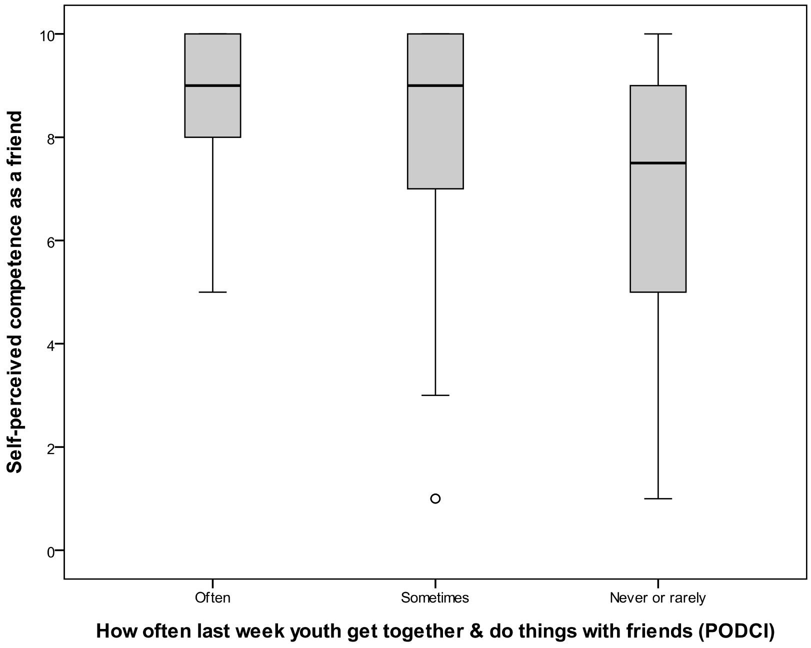


Figure 3. Box plots of child performance as a friend versus each parent-report question

1.4. Research Design and Methods

Participants

The participants were selected from a sample of convenience of 219 youth (adolescents and young adults) with CP 13-21 years of age and their parents or guardians. The participants were part of a larger study of activity and participation of children with cerebral palsy [children's activity and participation study (CAPS)]. Participants were recruited from six Shriners Hospitals for Children [Chicago, Illinois; Erie, Pennsylvania; Lexington, Kentucky; Northern California (Sacramento); Philadelphia, Pennsylvania; Springfield, Massachusetts] and Kluge Children's Rehabilitation Center, Charlottesville, Virginia. Ethical approval was provided by the Institutional Review Board of each hospital. Youth were included in the CAPS study if they had a primary diagnosis of cerebral palsy made by a physician. Adolescents and youth were excluded from the study if they had associated health conditions that might influence participation such as cystic fibrosis, cancer, or a mental health disorder such as clinical depression. Informed consent was provided by parents or guardians and youth greater than 16 years of age and informed assent was provided by adolescents 13 to 15 years of age.

For Aim1, the participants will include the 209 youth who completed the Children's Assessment of Participation and Enjoyment (CAPE) independently, with adult-assistance or through parent proxy. For Aim 2, the participants will include the 130 youth who completed the Fulfillment in Social Roles (FSR) questionnaire independently or with adult-assistance. Youth who had a diagnosis of intellectual disability based on parent report will be excluded because their abilities to understand the concept of role as a friend might be limited. The descriptive information of participant in Aim 1 and 2 will be reported accordingly.

Measures

Social Participation

Children's Assessment of Participation and Enjoyment (CAPE)

The CAPE (G. King et al., 2004) is a 55-item measure of participation in formal and informal daily activities outside of mandated school curriculum over the past four months. The CAPE was designed to be completed by children and youth 6-21 years of age. Each item is categorized by activity domain (Formal and Informal) and activity type (Recreational, Physical, Social, Skill-based, and Self-Improvement). Table 1 provides examples of items for each activity domain and type. For each of the 55 activities, five dimensions of participation are measured: *Diversity* (whether each activity was performed during the past 4 months), *Intensity* (how often the activity was performed), *With Whom* and *Where* the activity was performed, and level of *Enjoyment* for the activity. Table 2 provides the scoring system of each dimension of participation. In this study, the Diversity, Frequency and Enjoyment scores for activities performed with friends and others will be analyzed (Aim 1 & 2). The Diversity score is the number of activities a youth performed and higher scores indicate greater variety of participation. The Frequency score is the average frequency of activities performed (Imms, 2008). The Enjoyment score is the average level of enjoyment for activities performed.

The CAPE has been reported to have acceptable internal consistency, test-retest reliability, content validity, construct validity, and convergent and discriminate validity (G. King, Law, King, et al., 2006; G. King, et al., 2004). Scores on the CAPE will be used as the outcome variables for both study aims, representing the concept of social participation. The score calculation and item selection will be described in the data analysis section.

Table 1. Examples of items under each typology of activities for the CAPE (King et al., 2004)

Types	**Formal Domain (15 items)**	**Informal Domain (40 items)**
Recreational (12 items)		Playing board or card games Doing crafts, drawing or coloring Playing computer or video games
Physical (13 items)	Doing martial arts Racing or track and field Doing team sports Participating in school clubs	Bicycling, in-line skating or skateboarding Doing water sports Playing non-team sports
Social (10 items)		Hanging out Going to a party Going on a full-day outing
Skill-based (10 items)	Swimming Taking art (or music) lessons Participating in community organizations	Dancing
Self-improvement (10 items)	Doing a religious activities	Reading Going to the public library Doing a chore Doing volunteer work

Table 2. Scoring system of each dimension of participation for the CAPE (King et al., 2004)

Dimensions	**Questions**	**Scoring**	
Diversity	In the past 4 months, have you done this activity?	**0**	No
		1	Yes
Intensity	If yes, how often have you done this activity in the past 4 months?	**1**	Once/4 months
		2	Twice/4 months
		3	Once/week
		4	Two to three times/week
		5	Once/week
		6	Two to three times/week
		7	Once/day
With Whom	With whom do you do this activity most often?	**1**	Alone
		2	With family
		3	With other relatives
		4	With friends
		5	With others
Where	Where do you do this activity most often?	**1**	Home
		2	Relative’s home
		3	In your neighborhood
		4	At school
		5	In your community
		6	Beyond your community
Enjoyment	How much do you like or enjoy doing this activity?	**1**	Not at all
		2	Somewhat; sort of
		3	Pretty much
		4	Very much
		5	Love it

Self-perceived Competence as a Friend

The Fulfillment of Social Roles (FSR)

The FSR is a 12-item questionnaire that was developed by the investigators of the CAPS study. The questions include the child's rating of importance, performance level, and satisfaction as a family member, friend, student, and group member of a club, sports team, or youth organization. The FSR was designed to be completed by children and youth 6-21 years of age. For each of the four social roles, the children rate: a) the *importance* of these roles on a 10-point scale ("1=not important at all" to "10=extremely important"), b) *performance* in these roles on a 10-point scale ("1=not able to do at all" to "10=able to do extremely well"), and c) *satisfaction* with these roles on a 10-point scale ("1=not satisfied at all" to "10 extremely satisfied"). The psychometric properties of the FSR have not been examined. Performance as a friend will be used as an independent variable in Aim 2. The results for concurrent validity are presented in preliminary studies section.

Youth Characteristics

Gross Motor Functional Classification System (GMFCS)

The Gross Motor Function Classification System (GMFCS) is a five-level classifying system that provides description of age-specific gross motor function for children with cerebral palsy ≤ 12 years of age (Palisano, Rosenbaum, & Walter, 1997). A classification is made based on present functional abilities and limitations and needs for mobility devices in daily activities with emphasis on sitting, transfer and mobility. The preliminary version of the expanded and revised GMFCS (Palisano, Rosenbaum, Bartlett, & Livingston, 2008) includes a 12-18 year old age band that was used to classify youth with CP over 12 years of age. The evidence of good content, construct, and discriminative validity, and inter-rater reliability has been published (Palisano, et al., 1997). The inter-rater reliability of research assistants was examined using a criterion videotape. Each research assistant classified at least 11 children and achieved an agreement of greater than 80% with the criterion rating.

Family Demographic Information (FDI)

The FDI form was developed for the CAPS study to obtain the caregiver and child information. In the caregiver section, basic information such as language, occupation, education and family income are collected. In the child section, child's associated diagnosis, developmental conditions, school placement, and amount and type of health care services are collected. These child characteristics are hypothesized to be predictors to social participation (Aim 1).

Coping Inventory (CI)

The CI (S. Zeitlin, 1985) is a 48-item self-report measure of child's adaptive behavior. This measure was developed for children ages 3 to 16 years old. Each item is rated on a 5-point scale with responses ranging from 1 (a behavior is not effective) to 5 (a behavior is consistently effective across situations). The inventory measures coping in two domains: Self (meeting personal needs) and Environment (responding to and interacting with the social environment). Three coping styles are assessed within each domain: 1) Productivity, the degree to which behaviors are socially responsible, enhance self-esteem, and produce desired results; 2) Active, the degree of task persistence; and 3) Flexible, the degree of adaptability. In the CAPS study, the internal consistency of 6 subscales for youth (13-21 years) with cerebral palsy varied from .78 to .91 and the overall internal consistency was .94. The subscale scores provide standardized scores for Self and Environment domains and an Adaptive Behavior Index (ABI). The ABI will be included in data analysis in Aim 1 given the high correlations across all items and is hypothesized to predict social participation.

Pediatric Outcomes Data Collection Instrument (PODCI)

The PODCI assesses physical functioning for upper extremity, transfers and mobility, and sports; comfort, happiness and satisfaction; and expectations for treatment

(Daltroy, Liang, Fossel, & Goldberg, 1998). The measure was designed for children 2-18 years of age and the parent form was used. Good internal consistency of the measure and moderate to good test-retest reliability were reported. Scoring algorithms are used to compute scores for each dimension on a scale of 0-100. The mean scores of upper extremity & physical function and transfers & basic mobility scales (highly correlated among youth in the CAPS study, r=.86) and the scale score of sports and physical function (moderate correlation with upper extremity and transfers & mobility scale scores among youth in the CAPS study, r=.71-.83) will be used in this study. The two measures of physical functioning are hypothesized predictors of social participation (Aim 1).

Family Characteristics

Family Environment Scale (FES)

The FES (Moos & Moos, 2002) is a 90-item questionnaire to measure family functioning. Items reflect 10 subscales of family functioning: Cohesion, Expressiveness, and Conflict, Independence, Achievement orientation, Intellectual-cultural orientation, Active-recreational orientation, Moral-religious orientation, Organization and Control. Each of the subscales comprises nine true–false items. Research showed that the internal consistency ranged from .61 to .78 and the test-retest reliability ranged from .54 to .91 (Moos & Moos, 1994).

Two summary indices were reported to have good internal consistency and construct validity in the manual: 1) Family Relationship Index, a 27-item index representing the quality of family relationship, is the sum of Cohesion, Expressiveness and reverse Conflict subscales; 2) Family Social Integration Index, a 27-item index that measure the extent to which a family is socially engaged into the community, is the sum of Intellectual-cultural orientation, and Active-recreational orientation, and Moral-religious emphasis subscales. The Cronbach's alpha for each index and subscale used for age group 13-21years in the CAPS study are as following: Family relationship index=.56 (Cohesion=.63 , Expressiveness= .38 and Conflict=.73); Family social integration index=.73 (Intellectual-cultural orientation=.64, Active-recreational orientation=.67, and Moral-religious emphasis=.68). Given the low internal consistency of Family relationship index and Expressiveness, two subscales of the family relationship index (Cohesion and Conflict) and the Family Social Integration Index will be used as predictors of social participation (Aim 1).

Services Characteristics

Service Questionnaire

The Service Questionnaire is a 13-item measure developed for the CAPS study to assess the accessibility / availability and coordination of medical care, educational, and community services. Parents were asked to rate the extent that their child received services based on their perceived needs and indicate how well the services were coordinated with each other and with the family. A single question asks about the extent that received services meet their child's needs for activity and participation in daily life. Responses are rated on an ordinal scale. The parent rating of availability of school-based therapy and community recreational services, and the extent services meeting their child's needs are hypothesized to be predictors of social participation (Aim 1).

Measure of Processes of Care (MPOC)

The MPOC (S. King, Rosenbaum, & G. King, 1995) is a self-report measure to assess parent's perception about how the care services are delivered. The shorter and refined 20 item version was used (S. King, G. King, & Rosenbaum, 2004). The measure includes five scales: 1) Enabling and Partnership, 2) Providing General Information; 3) Providing Specific Information; 4) Coordinated and Comprehensive Care, and 5) Respectful and Supportive Care. Items are rated on a 7-point scale (1= 'not at all'; 4= 'to a moderate extent'; 7= 'to a very great extent') and 'not applicable' (0). Excellent reliability and validity have been reported (G. King, Law, King, & Rosenbaum, 1998; S. M. King, et al., 1995). The scaled scores of Providing General Information (behaviors to meet the family needs for general information) and Coordinated and Comprehensive Care (behaviors to provide holistic and consistent care) are hypothesized to be predictors of social participation (Aim 1). These two subscales were selected because: 1) Services that provide the family with information of available and appropriate community programs may enhance their child's opportunities for participation in organized activities with others. 2) Services that are coordinated and comprehensive may indicate that service providers look at youth's needs as a whole (including social needs) and coordinate with each other to form an intervention plan that best addresses the youth's needs for social participation.

Procedures

At each hospital, data were collected by one to three research assistants. Research assistants were health professionals who had experiences in serving children and families with cerebral palsy in the disciplines of physical therapy, occupational therapy, nursing, psychology, and social work. Prior to data collection, the research assistants received a procedural manual and were trained in a two-day workshop to learn the procedures. To insure the fidelity of data, teleconferences were scheduled at 3 month intervals and a second workshop was held at the mid-point of data collection to enable communication between study investigators and research assistants. After the end of data collection, a teleconference was held to discuss the research assistants' insights about the measures used in the study.

Each data collection session took 2-3 hours. For all measures, a custom designed display of each question was shown on a computer monitor. The parent or youth completed the questions using mouse clicking, thus enabling direct entry of scores into a backend database. The CAPE was completed by interviewing the youth using either the computer display or the standardized picture cards and coding sheets. Parent assistance or parent proxy was used as necessary except for the enjoyment score for which parent proxy was not permitted. Assistance was provided to youth or parents who had difficulty with reading or marking responses. Among the 209 youth who completed the CAPE, 116 (55.5%) were completed by child alone, 48 (23%) were completed with assistance, and 45 (21.5%) were completed by parent proxy.

The FSR was completed using the computer display. Adult assistance was employed as needed to explain the concepts or scale when the youth could not understand the questions, not to answer for them. Parent proxy was used only when the youth had no means of understanding the questions, thus will be excluded in this proposed study. Among 130 youth who completed the FSR, 111(85.4%) were completed by child alone and 19 (14.6%) were completed with assistance.

The Family Demographic Information form, Coping Inventory, Pediatric Outcomes Data Collection Instrument, Family Environment Scale, Service Questionnaire and Measure of Processes of Care were completed by the parents or other primary caregivers.

Data Analysis

Aim 1: Determinants of Social Participation

The analyses will focus on identifying the significant predictors of child, family, and services that explain social participation with friends and non-family members among youth with cerebral palsy. The sample will include 209 youth with CP between 13 to 21 years old.

Dependent Variable (Outcome Variable)

Two outcome variables will be calculated using the *Diversity* and *With Whom* dimensions for the 55 activities in the CAPE. The outcome variables will be analyzed in two separate regression models using the same sets of potential predictor variables:

1. ***Diversity of activities performed with friends:*** For items that *With Whom* dimension scored as ‘With friends’, the sum of the number of activities (0-55) will be calculated.
2. ***Diversity of activities performed with others:*** For items that the *With Whom* dimension scored as ‘With others (instructors, other individuals, or multiple types of people)’, the sum of the number of activities (0-55) will be calculated.

Independent Variable (Predictor Variables)

The hypothesized predictors are categorized as child, family, and services. Educational placement is included as a special case of services. In multiple regression a ratio of 15 - 20 observations to each predictor variable is desired to ensure the generalizability of the results (Hair, Anderson, Tatham, & Black, 1998). Based on the sample size of 209 youth, a maximum of 13 predictors will be selected to enter into the regression analysis.

YOUTH FACTORS

Age. Youth will be divided into two age groups: 13-16 years and 17-21 years. The age groups are dichotomous data.

Sex. Youth will be divided into female and male. The sex is dichotomous data.

GMFCS level. Youth's gross motor function was classified by the Gross Motor Function Classification System with five levels: I to V. Youth with higher levels (i.e. Levels IV or V) have lower functional abilities. The GMFCS levels are ordinal data.

Physical function. Two summary scale scores measured by the Pediatric Outcomes Data Collection Instrument (PODCI) are used to represent physical function: 1) the mean score of the Upper Extremity & Physical Function and Transfers and Basic Mobility Scales (because they are highly correlated r=.86, p<.001), and 2) the score for the Sports and Physical Function scale. Scores range from 0 to 100 with higher scores representing higher physical functioning in daily activities. The scores for the two scales are continuous data.

Adaptive behavior index (ABI). The ABI was measured by the Coping Inventory with scores ranging from 1.0 to 5.0. ABI scores are continuous data.

Learning/Understanding problems. The information is obtained from the Family Demographic Form. Parents reported whether their child has learning and understanding problems in two separate questions, and if yes, to what extent this problem affects their daily life ('1=Have problem but not at all affect daily life' to '5=To a great extent affect daily life'). For youth with both problems, the average score for the extent the problems affect daily life will be calculated. For youth who have only one problem, the score for that problem will be used. For youth with no problems, a zero will be assigned. The scores are ordinal data.

Communication/Speech problems. The information is obtained from the Family Demographic Form. Parents reported whether their child has communication and speech problems in two questions, if yes, to what extent this problem affects their daily life (‘1=Have problem but not at all affect daily life’ to ‘5=To a great extent affect daily life’). For youth with both problems, the average score for the extent the problems affect daily life will be calculated. For youth who have only one problem, the score for that problem will be used. For youth with no problems, a zero will be assigned. The scores are ordinal data.

FAMILY FACTORS

Family Cohesion and Conflict subscales. The two subscales are derived from items on the Family Environmental Scale. Each subscale contains 9 items. Scores range from 0 to 9. The scores for the two subscales are continuous data.

Family social integration index. The Family social integration index is derived from items on the Family Environmental Scale. This is a 27-item index representing the sum of Intellectual-cultural orientation, Active-recreational orientation, and Moral-religious emphasis subscales, the scores range from 0 to 27. The Family social integration index scores are continuous data.

SERVICE FACTORS

Availability of school-based therapy and community services. Two scores measured by the Service Questionnaire will be used: parents indicated the extent they received 1) school-based therapy services of a physical, occupational, or speech therapist, 2) community recreational and/or religious activities that parents needed for their child. The scores range from 1 to 4 ('1=None of the services' to '4=All of the services'). Before answering the two questions, parents first answered if they had needs for the services. Parents who indicated no needs for the services did not answer to what extent they received the services; therefore, sensitivity tests will be performed to determine how to impute missing data. The scores representing availability of services are ordinal data.

Providing General Information. Providing General Information (5 items) is a scale of the Measure of Processes of Care (MPOC). Each item is scored on a 1 to 7 scale ('1= not at all' to '7= to a very great extent') and the scale score is an average score of valid items. If at least 4 items are not scored, a scale score is not calculated. The scores for the scale are continuous data.

Coordinated and Comprehensive Care. Coordinated and Comprehensive Care (4 items) is a scale of the Measure of Processes of Care (MPOC). Each item is scored on a 1 to 7 scale ('1= not at all' to '7= to a very great extent') and the scale score is an average score of valid items. If at least 3 items are not scored, a scale score is not calculated. The scores for the scale are continuous data.

Services meeting needs in participation. The score is measured by the Service Questionnaire. It is a single question that parents indicated the extent their needs related to supporting their child's participation in daily activities met by all the services received. The scores range from 1 to 5 ('1=Not at all' to '5=Completely') and are ordinal data.

Educational Placement. Youth will be divided into four groups: regular high school / regular program, regular high school / special program, special high school, and other (including did not attend school, home school, and post-secondary school such as technical school, college or other post-secondary program). The educational placements are nominal data with 4 categories.

Statistical Analysis

Statistical analyses will be performed using the SPSS for Windows software program (version 16.0). Descriptive statistics will be computed for all variables. Bivariate correlations will be calculated to examine the relationships between each potential predictor variable and the outcome variables. Person product-moment correlation coefficients (*r*) will be used for continuous variables, Spearman rank correlation coefficients (r_s) will be used for ordinal variables, and simple linear regression analysis will be used for nominal variables. Predictor variables that are significantly correlated with the outcome variables and have coefficients >.20 will be included in the initial regression model. Bivariate correlations will also be calculated to examine inter-correlations among predictor variables.

The following assumptions of multiple linear regression will be examined (Tabachnick & Fidell 2007):

1. Normality, Linearity, and Homoscedasticity of Residuals: The assumptions of normality, linearity and homoscedasticity between predicted outcome variable scores and residuals (errors of prediction) will be examined by a *Residual Scatterplot*. Residuals are differences between obtained and predicted outcome variable scores. The assumptions are met if the residuals are normally distributed about the predicted scores (normality), the residuals have a linear relationship with predicted scores (linearity), and the variance of the residuals about the predicted scores are approximately the same for all predicted scores (homoscedasticity).

2. Absence of univariate and multivariate outliers: Univariate outliers are cases with an extreme value on one variable; multivariate outliers are cases with an unusual combination of scores on two or more variables. Outliers can be identified for both predictor variables and outcome variables. *Histograms* of each outcome variable and predictor variable will be used to examine the distribution of scores and identify univariate outliers that are unattached to the rest of distribution, and then to determine whether there is a need for transformation. *Transformation*, if appropriate, will be performed both to improve the normality of data distributions and to reduce the influence of univariate outliers by pulling them close to the center of distribution, which should be undertaken prior to identifying multivariate outliers. Multivariate outliers among the predictor variables will be identified by the *Mahalanobis Distance* method at $p<.001$ using the X^2 distribution. Mahalanobis distance is "the distance of a case from centroid of the remaining cases, the centroid is the point created at the intersection of the means of all the variables"(Tabachnick & Fidell, 2007). Cases with multivariate outliers will be removed from the database.
3. Absence of multicollinearity and singularity: Multicollinearity is a problem when predictor variables are highly correlated (>.90). Multicollinearity will be assessed by computing the *Squared Multiple Correlations (SMCs)* among predictor variables. The

SPSS program converts SMC to tolerance (1-SMC), predictor variables with tolerances approach zero (.01-.0001) will be excluded from the regression analysis.

Educational placement will be entered into the regression as three dummy variables. Dummy variables are a set of dichotomous variables that act as replacement predictor variables; each dummy variable represents one category in the predictor variable (Hair, et al., 1998). Three dummy codes of “regular high school / special program’, ‘special high school’, ‘other (including did not attend school, home school, and post-secondary school)’ will be constructed to provide comparisons to the ‘regular high school / regular program’ (reference group).

Sequential multiple regression analysis will be performed on the two outcome variables, diversity of activities performed with friends and diversity of activities performed with others. For each regression analysis, predictor variables are entered in blocks based on theoretical importance: child variables first, followed by family variables, educational placement and service variables (Figure 4). The sequence is based on the model that child and family factors are more proximal determinants while environmental factors (including services) are more distal determinants to participation (G. King, et al., 2003). After entry of all predictor variables, the unstandardized and standardized regression coefficients of each variable, multiple correlation (R), coefficient of determination (R^2), and adjusted R^2 of the regression model will be obtained. The significance of increased explained variances (R^2 change) will be used to determine the best prediction model. A significance level of $p<.05$ will be used. The adjusted R^2 value will indicate the amount of variability in participation diversity with friends and participation diversity with others that are predicted by the variables of child, family and service.

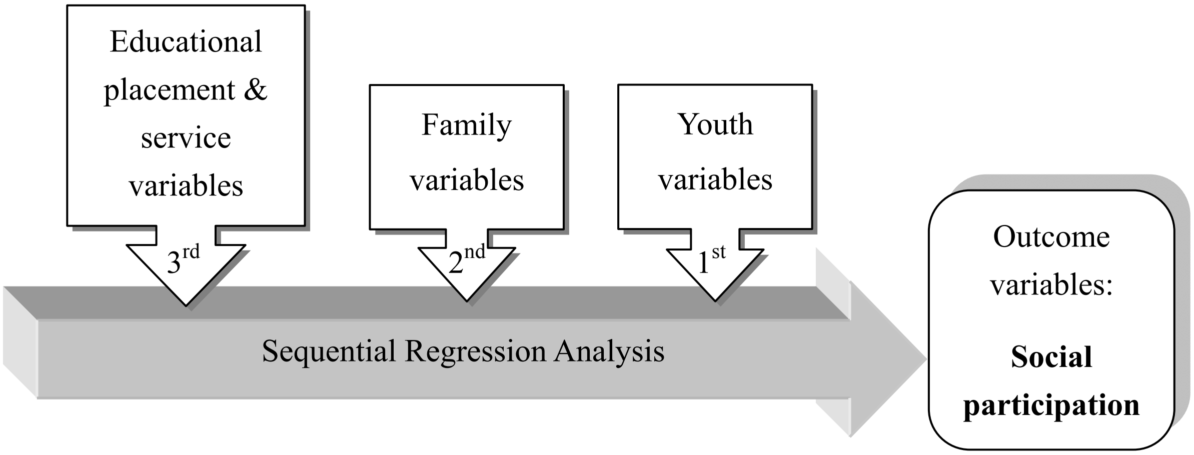


Figure 4. The proposed steps of sequential regression analysis

Aim 2: Social Participation and Self-perceived Competence as a Friend

The analyses will focus on examining whether participation with friends in recreational and leisure activities differ among youth with CP who have highest, middle and lowest levels of self-perceived competence as a friend. The sample will include 135 youth between 13 to 21 years old.

Independent variable:

The youth-rated performance level as a friend measured by the FSR is the independent variable. The question asks about “for your role as friend, how would you rate the way you are able to have friends, help your friends out, and hang out with your friends now?” Response options are on a 10-point scale from ‘1’=not able to do at all to ‘10’=able to do extremely well. The data distribution was negatively skewed (skewness = -1.31), with many youth reporting they were able to perform extremely well in a friend’s role. The youth will be divided into three groups: 1) youth in the highest competence group with a rating of 10 (n=49, 36.3%), 2) youth in the middle competence group with ratings 8 to 9 (n=45, 33.3%) and 3) youth in the lowest competence group with ratings 1 to 7 (n=41, 30.4%).

Dependent variables:

Three variables representing social participation will be calculated for the 55 activities in the CAPE:

1. ***Diversity of activities performed with friends:*** For items that *With Whom* dimension scored as ‘With friends’, the sum of the number of activities (0-55) will be calculated.

2. ***Frequency of activities performed with friends:*** For items that *With Whom* dimension scored as ‘With friends’, the mean of item frequency (1-7) will be calculated.
3. ***Enjoyment of the activities performed with friends:*** For items that *With Whom* dimension scored as ‘With friends’, the mean of Enjoyment scores (1-5) will be calculated. The CAPE completed by parent proxy does not provide Enjoyment scores.

Statistical Analysis

Statistical analyses will be performed using the SPSS for windows software program (version 16.0). Descriptive statistics will be computed on the characteristics of youth with highest, middle, and lowest self-perceived competence as a friend. The characteristics include age, sex, GMFCS levels, educational placement, coping behaviors (ABI), and physical functioning. For each characteristic, a one-way analysis of Variance (ANOVA) will be performed followed by Tukey’s HSD post hoc tests to examine group differences in continuous variables, the Chi-square tests will be used for group differences in nominal variables. A significance level of $p<.05$ will be used for all of the analyses.

Descriptive statistics will be computed on the three dependent variables for each group: diversity, frequency and enjoyment of activities performed with friends. To identify differences in social participation among the three groups, the multivariate analysis of covariance (MANCOVA) will be performed, while controlling for age, sex and GMFCS level. A general rule of thumb for choosing covariates is to select a very small number of covariates, all correlated with the dependent variables and not correlated with each other. The correlation analysis for Aim 1 will help to re-specify covariates that should be controlled. A significance level of $p<.05$ will be used for the MANCOVA. The following assumptions of MANCOVA (Tabachnick & Fidell, 2007) will be examined:

1. Multivariate normality: This assumption refers to the distributions of means of the various dependent variables in each cell and all linear combinations of them are normally distributed. In this study, robustness to violation of multivariate normality can be ensured with a large sample size of 130 (>20 in each group).
2. Absence of univariate and multivariate outliers: Outliers will be identified for each of the three groups. The methods of examining univariate and multivariate outliers are provided in Aim 1.
3. Linearity: This assumption refers to linear relationships among all pairs of dependent variables, all pairs of covariates, and all pairs of dependent variables-covariates in

each group. This assumption is less important when the dependent variables in each group are reasonably balanced distribution.

4. Homogeneity of variance-covariance matrices: This assumption refers to variance-covariance matrices with each group are sampled from the same population variance-covariance matrices. In this study, robustness to violation of homogeneity can be ensured given the sample size are approximately equal for each group.
5. Absence of multicollinearity and singularity: the multicollinearity and singularity of dependent variables will be examined by computing within-group tolerance (1-SMC) for each dependent variable.

If a significant main effect is found by MANCOVA, two methods may be used to identify which of the dependent variables differ based on the group effect. If the three dependent variables are uncorrelated, univariate ANCOVA will be performed for each dependent variable. If the three dependent variables are correlated, Roy-Bargmann stepdown analysis will be used to assess the importance of dependent variables. To perform the stepdown analysis, the highest-priority dependent variable is examined by univariate ANCOVA with adjustment for specified covariates. The remainder of the dependent variables is examined in a series of ANCOVAs with adjustment for higher-priority dependent variables and covariates. If the three dependent variables are correlated, the priority order of entry of the dependent variables will be enjoyment, percentage, and frequency of activities performed with friends and others. The psychological experiences (i.e. enjoyment of the activities) are assumed to be more important variable associated with self-perceived social competence compared with objective experiences (i.e. how many and how often the activities were performed) while participating with friends or others. An adjusted significance level of $p<.016$ (0.05/3) will be used to prevent from inflated Type I error due to multiple testing.

For variables with significant group effects, pairwise comparisons with Bonferroni adjustment will be used to identify differences between youth with highest, middle, and lowest competence as a friend. An adjusted significance level of $p<.016$ (0.05/3) will be used to prevent from inflated Type I error due to multiple comparisons.

1.5. Limitations

A secondary analysis will be used for this study. Limitations inherent to secondary analysis may impact on analysis and interpretation of the results. Some constructs of interest such as social supports received by the youth and family cannot be tested. Analysis of determinants of social participation is restricted to the measures or questionnaires selected for the specific aims of the CAPS study. For example, adult-form of the Coping Inventory is preferred to measure adaptive behaviors from the youths' perspectives instead of parent-form. Fulfillment in Social Roles was not developed to measure self-perceived social competence. The Service Questionnaire does not provide information on focuses of services. Moreover, social participation is value-based and may vary based on intrinsic characteristics. Activity preferences and social orientation were not measured in this study. Some youth may have desired a high level of social participation while others may have preferred more solitary activities. For youth who had lower level of social participation, we do not know whether they chose not to participate in activities with their friends and others or were unable to participate because of limited abilities or opportunities. Given these limitations, the results will be interpreted carefully.

Summary of Data Analysis

In Aim 1, two sequential multiple regression analyses will be performed to identify the significant child, family, and service factors that determine social participation with friends and with non-family members among youth with cerebral palsy. The dependent variables are: 1) diversity of activities performed with friends, and 2) diversity of activities performed with others. The predictor variables will be entered in blocks by the order of child variables, family variables, dummy variables for educational placement, and service variables. A significance level of $p<.05$ will be used.

In Aim 2, the multivariate analysis of covariance (MANCOVA) will be performed to identify differences in participation with friends among youth with CP who have highest, middle and lowest levels of self-perceived competence as a friend, while controlling for age, sex and GMFCS level. A significance level of $p<.05$ will be used. The independent variable is the youth-rated performance level as a friend; the dependent variables are diversity, frequency and enjoyment of activities performed with friends. If there is a significant main effect, univariate ANCOVA or Roy-Bargmann stepdown analysis will be used to assess the importance of dependent variables. Pairwise comparisons with Bonferroni adjustment will be used to identify differences between youth groups. An adjusted significance level of $p<.016$ (0.05/3) will be used for univariate ANCOVA or stepdown analysis and pairwise comparisons.

Time Line

Jan. 2009	Complete the dissertation proposal
	Take the qualifying examination
March 2009	Get data set ready for analysis, including data clean-up and recoding and computing new variables
June 2009	Aim#1: Complete data analysis and submit the chapter for feedback
Sept. 2009	Aim#2: Complete data analysis and submit the chapter for feedback
Dec. 2009	Defend dissertation
Jan. 2010	Submit dissertation to library

1.6. References

Adamson, L. (2003). Self-image, adolescence, and disability. *American Journal of Occupational Therapy, 57*(5), 578-581.

Allender, S., Cowburn, G., & Foster, C. (2006). Understanding participation in sport and physical activity among children and adults: a review of qualitative studies. *Health Education Research, 21*(6), 826-835.

Baker, K., & Donelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society, 16*(1), 71-85.

Barletta, A., & Loy, D. P. (2006). The experience of participation in challenger little league through the eyes of a child with physical disability. *American Journal of Recreation Therapy, 5*(3), 6-12.

Bennett, K. S., & Hay, D. A. (2007). The role of family in the development of social skills in children with physical disabilities. *International Journal of Disability, Development and Education, 54*(4), 381-397.

Blum, R. W., Resnick, M. D., Nelson, R., & St Germaine, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics, 88*(2), 280-285.

Brooks, F., & Magnusson, J. (2007). Physical activity as leisure: the meaning of physical activity for the health and well-being of adolescent women. *Health Care for Women International, 28*(1), 69-87.

Brown, M., & Gordon, W. A. (1987). Impact of impairment on activity patterns of children. *Archives of Physical Medicine & Rehabilitation, 68*(12), 828-832.

Chen, H.-F., & Cohen, E. S. (2003). Social participation for children with developmental coordination disorder: conceptual, evaluation and intervention considerations. *Physical & Occupational Therapy in Pediatrics, 23*(4), 61-78.

Coster, W. (1998). Occupation-centered assessment of children. *American Journal of Occupational Therapy, 52*(5), 337-344.

Daltroy, L. H., Liang, M. H., Fossel, A. H., & Goldberg, M. J. (1998). The POSNA Pediatric Musculoskeletal Functional Health Questionnaire: Report on reliability, validity, and sensitivity to change. *Journal of Pediatric Orthopeadics, 18*(5), 561-571.

Doll, B. (1996). Children without friends: Implications for practice and policy. *School Psychology Review, 25*(2), 165-183.

Donaldson, S. J., & Ronan, K. R. (2006). The effects of sports participation on young adolescents' emotional well-being. *Adolescence, 41*(162), 369-389.

Donkervoort, M., Roebroeck, M., Wiegerink, D., van der Heijden-Maessen, H., Stam, H., & The Transition Research Group South West, N. (2007). Determinants of functioning of adolescents and young adults with cerebral palsy. *Disability & Rehabilitation, 29*(6), 453-463.

Eriksson, L., & Granlund, M. (2004). Conceptions of Participation in Students With Disabilities and Persons in Their Close Environment. *Journal of Developmental and Physical Disabilities, 16*(3), 229-245.

Forsyth, R., & Jarvis, S. (2002). Participation in childhood. *Child: Care, Health & Development, 28*(4), 277-279.

Gaskin, C. J., & Morris, T. (2008). Physical activity, health-related quality of life, and psychosocial functioning of adults with cerebral palsy. *Journal of Physical Activity & Health, 5*(1), 146-157.

Goldstein, D. N., Cohn, E., & Coster, W. (2004). Enhancing participation for children with disabilities: application of the ICF enablement framework to pediatric physical therapist practice. *Pediatric Physical Therapy, 16*(2), 114-120.

Hair, J. F., Anderson, R. E., Tatham, R. L., & Black, W. C. (1998). *Multivariate Data Analysis* (5th ed.). New Jersey: Upper Saddle River.

Harter, S. (1985a). *Manual for the self-perceptions profile for children*. Denver: University of Denver Press.

Harter, S. (1985b). *Social Support Scale for Children*. Denver, CO: Department of Psychology, University of Denver.

Hay, J., & Missiuna, C. (1998). Motor proficiency in children reporting low levels of participation in physical activity. *Canadian Journal of Occupational Therapy, 65*(2), 64-71.

Heah, T., Case, T., McGuire, B., & Law, M. (2007). Successful participation: the lived experience among children with disabilities. *Canadian Journal of Occupational Therapy - Revue Canadienne d Ergotherapie, 74*(1), 38-47.

Herzog, A. R., Ofstedal, M. B., & Wheeler, L. M. (2002). Social engagement and its relationship to health. *Clinics in Geriatric Medicine, 18*(3), 593-609.

Imms, C. (2008). Review of the Children's Assessment of Participation and Enjoyment and the Preferences for Activity of Children. *Physical & Occupational Therapy in Pediatrics, 28*(4), 389-404.

Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2008). Diversity of participation in children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(5), 363-369.

Kimiecik, J. C., Horn, T. S., & Shurin, C. S. (1996). Relationships among children's beliefs, perceptions of their parents' beliefs, and their moderate-to-vigorous physical activity. *Research Quarterly for Exercise & Sport, 67*(3), 324-336.

King, G., Cathers, T., Polgar, J. M., MacKinnon, E., & Havens, L. (2000). Success in life for older adolescents with cerebral palsy. *Qualitative Health Research, 10*(6), 734-749.

King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., et al. (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., Hurley, P., Hanna, S., Kertoy, M., et al. (2006). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39.

King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al. (2004). *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC).* San Antonio, TX: Harcourt Assessment, Inc.

King, G., Law, M., King, S., & Rosenbaum, P. (1998). Parents' and service providers' perceptions of the family-centredness of children's rehabilitation services. *Physical and Occupational Therapy in Pediatrics, 18*, 21-40.

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.

King, G., McDougall, J., DeWit, D., Hong, S., Miller, L., Offord, D. R., et al. (2005). Pathways to children's academic performance and prosocial behaviour: Roles of physical health status, environmental, family, and child factors. *International Journal of Disability, Development and Education, 52*(4), 313-344.

King, G., Shultz, I., Steel, K., Gilpin, M., & Cathers, T. (1993). Self-evaluation and self-concept of adolescents with physical disabilities. *American Journal of Occupational Therapy, 47*(2), 132-140.

King, S., King, G., & Rosenbaum, P. (2004). Evaluating health service delivery to children with chronic conditions and their families: development of a refined Measure of Processes of Care (MPOC-20). *Children's Health Care, 33*(1), 35-57.

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: a review of the literature. *Seminars in Pediatric Neurology, 11*(1), 78-86.

King, S., Rosenbaum, P. L., & King, G. (1995). *The Measures of Processes of Care*. Hamilton, Ont., Canada: CanChild Centre for Childhood Disability Research, McMaster University.

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. (2002). Participation in the occupations of everyday life. *American Journal of Occupational Therapy, 56*, 640-649.

Law, M., Darrah, J., Pollock, N., King, G., Rosenbaum, P., Russell, D., et al. (1998). Family-centred functional therapy for children with cerebral palsy: an emerging practice model. *Physical and Occupational Therapy in Pediatrics, 18*(1), 83-102.

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., et al. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology, 48*(5), 337-342.

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.

Lawlor, K., Mihaylov, S., Welsh, B., Jarvis, S., & Colver, A. (2006). A qualitative study of the physical, social and attitudinal environments influencing the participation of children with cerebral palsy in northeast England. *Pediatric rehabilitation, 9*(3), 219-228.

Lightfoot, J., Wright, S., & Sloper, P. (1999). Supporting pupils in mainstream school with an illness or disability: young people's views. *Child: Care, Health & Development, 25*(4), 267-283.

Magill-Evans, J. E., & Restall, G. (1991). Self-esteem of persons with cerebral palsy: from adolescence to adulthood. *American Journal of Occupational Therapy, 45*(9), 819-825.

Maher, C. A., Williams, M. T., Olds, T., & Lane, A. E. (2007). Physical and sedentary activity in adolescents with cerebral palsy. *Developmental Medicine & Child Neurology, 49*(6), 450-457.

Majnemer, A., & Mazer, B. (2004). New directions in the outcome evaluation of children with cerebral palsy. *Seminars in pediatric neurology, 11*(1), 11-17.

Majnemer, A., Shevell, M., Law, M., Birnbaum, R., Chilingaryan, G., Rosenbaum, P., et al. (2008). Participation and enjoyment of leisure activities in school-aged children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(10), 751-758.

Marsh, H. W. (1992). Extracurricular activities: Beneficial extension of the traditional curriculum or subversion of academic goals? *Journal of Educational Psychology, 84*(4), 553-562.

McGavin, H. (1998). Planning Rehabilitation: A Comparison of Issues for Parents and Adolescents. *Physical & Occupational Therapy in Pediatrics, 18*(1), 69-82.

McGee, R., Williams, S., Howden-Chapman, P., Martin, J., & Kawachi, I. (2006). Participation in clubs and groups from childhood to adolescence and its effects on attachment and self-esteem. *Journal of Adolescence, 29*(1), 1-17.

Meadan, H., & Halle, J. W. (2004). Social Perceptions of Students with Learning Disabilities Who Differ in Social Status. *Learning Disabilities Research & Practice, 19*(2), 71-82.

Mihaylov, S. I., Jarvis, S. N., Colver, A. F., & Beresford, B. (2004). Identification and description of environmental factors that influence participation of children with cerebral palsy. *Developmental Medicine & Child Neurology, 46*(5), 299-304.

Moos, R. H., & Moos, B. S. (1994). *Family Environmental Scale manual* (3rd ed.). Palo Alto, CA: Consulting Psychologists Press.

Moos, R. H., & Moos, B. S. (2002). *A Social Climate Scale: Family Environment Scale Manual – Development, Applications, Research* (3rd ed.). Palo Alto, CA: Mindgarden Inc.

O'Moore, M. (1980). Social acceptance of the physically handicapped child in the ordinary school. *Child: Care, Health & Development, 6*(6), 317-338.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology, 50*(10), 744-750.

Palisano, R. J., Rosenbaum, P. L., & Walter, S. (1997). Development and validation of a gross motor function classification system for children with cerebral palsy. *Developmental Medicine & Child Neurology, 39*, 214-223.

Palisano, R. J., Snider, L. M., & Orlin, M. N. (2004). Recent advances in physical and occupational therapy for children with cerebral palsy. *Seminars in pediatric neurology, 11*(1), 66-77.

Passmore, A. (2003). The occupation of leisure: Three typologies and their influence on mental health in adolescence. *OTJR: Occupation, Participation and Health, 23*(2), 76-83.

Poulsen, A. A., Ziviani, J. M., Cuskelly, M., & Smith, R. (2007). Boys with developmental coordination disorder: loneliness and team sports participation. *American Journal of Occupational Therapy, 61*(4), 451-462.

Reijntjes, A., Stegge, H., & Terwogt, M. M. (2006). Children's coping with peer rejection: the role of depressive symptoms, social competence, and gender. *Infant & Child Development, 15*(1), 89-107.

Richardson, P. (2003). From roots to wings: social participation for children with physical disabilities. *Developmental Disabilities Special Interest Section Quarterly, 26*(1), 1-4.

Rosenbaum, P., King, S., Law, M., King, G., & Evans, J. (1998). Family-centred service: a conceptual framework and research review. *Physical and Occupational Therapy in Pediatrics, 18*(1), 1-20.

Rosenbaum, P., Paneth, N., Leviton, A., Goldstein, M., Bax, M., Damiano, D., et al. (2007). A report: the definition and classification of cerebral palsy April 2006. *Developmental Medicine & Child Neurology Supplement, 109*, 8-14.

Rosenberg, A. E. (2000). Conducting an inventory of informal community-based resources for children with physical disabilities: enhancing access and creating professional linkages. *Physical & Occupational Therapy in Pediatrics, 20*(1), 59-79.

Shields, N., Loy, Y., Murdoch, A., Taylor, N. F., & Dodd, K. J. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine & Child Neurology, 49*(5), 350-354.

Shields, N., Murdoch, A., Loy, Y., Dodd, K. J., & Taylor, N. F. (2006). A systematic review of the self-concept of children with cerebral palsy compared with children without disability. *Developmental Medicine & Child Neurology, 48*, 151-157.

Sloper, P., Turner, S., Knussen, C., & Cunningham, C. (1990). Social life of school children with Down's syndrome. *Child: Care, Health & Development, 16*(4), 235-251.

Specht, J., King, G., Brown, E., & Foris, C. (2002). The importance of leisure in the lives of persons with congenital physical disabilities. *American Journal of Occupational Therapy, 56*(4), 436-445.

Stanovich, P. J., Jordan, A., & Perot, J. (1998). Relative differences in academic self-concept and peer acceptance among students in inclusive classrooms. *Remedial and Special Education, 19*(2), 120-126.

Stevenson, C. J., Pharoah, P. O., & Stevenson, R. (1997). Cerebral palsy- the transition from youth to adulthood. *Developmental Medicine & Child Neurology, 39*(5), 336-342.

Tabachnick, B. G., & Fidell, L. S. (2007). *Using Multivariate Statistics* (5th ed.). Boston, MA: Allyn & Bacon.

Wiegerink, D. J., Roebroeck, M. E., Donkervoort, M., Stam, H. J., & Cohen-Kettenis, P. T. (2006). Social and sexual relationships of adolescents and young adults with cerebral palsy: a review. *Clinical Rehabilitation, 20*(12), 1023-1031.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization.

Yuen, F. C., Pedlar, A., & Mannell, R. C. (2005). Building Community and Social Capital through Children's Leisure in the Context of an International Camp. *Journal of Leisure Research, 37*(4), 494-518.

Zeitlin, S. (1985). *Coping Inventory: A Measure of Adaptive Behavior* Bensenville, Illinois: Scholastic Testing Service.

Zeitlin, S., & Williamson, G. G. (1994). *Coping in young children: Early intervention practices to enhance adaptive behavior and resilience*. Baltimore, MD: Paul H Brookes Publishing.

CHAPTER 2: DETERMINANTS OF SOCIAL PARTICIPATION WITH FRIENDS AND OTHER NON-FAMILY MEMBERS FOR YOUTH WITH CEREBRAL PALSY

Accepted for publication in *Physical Therapy*, April 2010

2.1. Abstract

Background. Social participation provides youth opportunities to develop friendships, self-concept, and a sense of meaning in life. Youth with cerebral palsy (CP) have been reported to participate more in home-based leisure activities and have fewer social experiences with friends and others compared with youth without disabilities.

Objective. To identify youth, family, and service determinants of participation in leisure activities with friends and with other non-family members for youth with CP.

Design. A cross-sectional analytic design.

Methods. The participants were 209 youth with CP 13-21 years-old (51.7% males) and their parents recruited from seven children's hospitals in six different states. Youth completed the Children's Assessment of Participation and Enjoyment by structured interview. Parents completed the Coping Inventory, Pediatric Outcomes Data Collection Instrument, Family Environment Scale, Measure of Processes of Care, Demographic and Service Questionnaires. Researchers determined Gross Motor Function Classification System level. Sequential multiple regression analysis was used to determine the youth, family and service variables that predict participation with friends and with other non-family members.

Results. Higher sports and physical functioning, higher communication/speech abilities, inclusive educational settings, and the higher extent to which desired community recreational activities were obtained explained 45.8% of the variance in the number of activities done with friends ($p<.001$). Higher parental education explained 6.3% of the variance in the number of activities done with other non-family members ($p=.001$).

Limitations. Youth's activity preferences and intensity of participation were not examined.

Conclusions. Youth and service characteristics were determinants of participation with friends but not other non-family members. The findings have implications for physical therapists to promote sports, physical, and communication abilities and enhance community opportunities that optimize social participation of youth with CP.

Keywords: Cerebral Palsy, Youth, Social Participation, Determinants, Leisure, Recreation

2.2. Introduction

Participation creates avenues to form friendships, develop self-concept, and determine a sense of meaning in life (Barletta & Loy, 2006; Specht, et al., 2002). Participation is defined as involvement in life situations and represents an interaction between an individual and the physical, social, and attitudinal environments (Colver & Sparcle, 2006; World Health Organization, 2001). Social participation involves forming and maintaining social relationships and is supported by accessible environments and positive interactions (Chen & Cohen, 2003). In adolescence, social participation facilitates readiness for adult life including work, marriage, and recreation (Richardson, 2003). Participation in social and leisure activities enable youth to expand social networks with persons not involved in their home or school routines. This real-world experience is important for youth's development of life skills and fulfillment of adult roles (Bandura, 1986; Brollier, Shepherd, & Markley, 1994).

Youth with physical disabilities have been reported to have limited social opportunities outside the family (Brown & Gordon, 1987; Poulsen, et al., 2007; Stevenson, et al., 1997). Adolescents with CP reported being worried about lack of friends their age and limited opportunities to interact with non-family members (Adamson, 2003). Previously we found that social participation of children and youth with CP differed based on age and gross motor function (Palisano et al., 2009). Although diversity and intensity of participation declined in youth with CP compared with children with CP (Orlin et al., 2009), youth did a higher proportion of activities with friends/others than children. Children and youth who walk without restrictions did a higher proportion of activities with friends/others than those who walk with restrictions or are unable to walk (Palisano, et al., 2009). Other personal and environmental factors associated with social participation with persons outside the family for children and youth with CP have not been examined.

Contemporary conceptual frameworks and empirical data (Bronfenbrenner & Ceci, 1994; G. King, Law, Hanna, et al., 2006; G. King, et al., 2003) suggest that social participation of youth with CP is influenced by youth, family, and service characteristics. The ecological perspective views youth and family factors as more proximal while the community environment (including services) are more distal factors influencing participation (G. King, et al., 2003). Research suggests that age, sex, adaptive behavior, physical and sports ability, cognition and communication are personal characteristics that influence social participation of youth with CP. With respect to age, participation in sports groups and recreational activities declined in young adults 18-21 years compared with adolescents 13-15 years (McGee, et al., 2006). Girls with physical disabilities participated in more social, skill-based and self-improvement activities; while boys participated in more active physical activities (G. King, Law, Hurley, Petrenchik, & Schwellnus, 2010; Law, et al., 2006). Effective adaptive behavior enables children and youth to respond to personal and environmental needs, and to interact with peers (Reijntjes, et al., 2006; Zeitlin & Williamson, 1994). Moreover, children and youth with CP who have higher physical, cognitive and communicative functioning showed higher intensity of leisure participation and fewer restrictions in accessing and engaging in social activities (Imms, et al., 2008).

Family relationships, involvement in community activities, and youth and family centered services are family and service factors that are thought to influence social participation of youth with CP. Higher family socioeconomic status, cohesion, open communication, and family preferences for social leisure activities were associated with higher participation and social skills of children with physical disabilities (Bennett & Hay, 2007; Law, et al., 2006; Sloper, et al., 1990). Services that are accessible, coordinated, and responsive to individualized needs of youth and family may enhance participation (Susanne King, et al., 2004). Program information, transportation, accessible facilities, and coordinated services were frequently identified needs for social and community participation of children with disabilities (Mihaylov, et al., 2004).

Educational placement is an environmental variable which may influence social interactions with peers (Baker & Donelly, 2001). Students with disabilities in regular classrooms reported more peer interactions than students in special classrooms (Kennedy, Shukla, & Fryxell, 1997; Miller, Fullmer, & Walls, 1996). Nonetheless, students with disabilities within regular classrooms were less socially integrated than their peers without disabilities (Stanovich, et al., 1998). The influence of educational placement on social participation has not been studied for youth with CP.

The purposes of this study were to identify youth, family, and service determinants of social participation in leisure activities with: 1) friends, and 2) other non-family members for youth with CP. Social participation is operationally defined as activities done with persons outside the family such as friends, instructors, coaches or tutors. We hypothesized that there are different determinants for participation with friends compared with participation with other non-family members. This is based on the assumption that doing things with friends requires better mobility, communication, and social skills compared with activities supervised by instructors and coaches who may be a source of formal support for making adaptations and accommodations. The results should assist physical therapists and other health professionals to identify services and supports that promote social participation desired by youth with CP.

2.3. Methods

Participants

The participants were 209 youth with CP 13-21 years old and their parents. The participants were part of a larger study of activity and participation of children and youth with CP. Participants were recruited from six Shriners Hospitals for Children [Chicago, Illinois; Erie, Pennsylvania; Lexington, Kentucky; Northern California (Sacramento); Philadelphia, Pennsylvania; Springfield, Massachusetts] and Kluge Children's Rehabilitation Center, Charlottesville, Virginia. Youth were excluded if they had associated health conditions that might influence participation such as cystic fibrosis, cancer, or mental health disorders. Ethical approval was provided by the Institutional Review Board of each hospital. Informed consent was provided by parents and youth ≥ 16 years old. Informed assent was provided by youth 13 to 15 years old.

Youth and Family demographics are provided in Tables 1 and 2. Participants were 137 adolescents (13-16 years) and 72 young adults (17-21years). Youth had a mean age of 16.2 years (SD=2.3 years), 52% were males, and 68% were Caucasian. The number of youth in each of the five levels of the Gross Motor Function Classification System varied from 26 to 57. Caregivers were primarily mothers (78%) and fathers (13%); thus are referred to as parents throughout the paper. Parents had a mean age of 44.6 (SD=9.2) years, 50.5% had received higher than high school education, and 64% were employed. The median for family income was \$45,000 - \$59,999 per year.

Table 1. Youth Demographics and Scores for Youth Variables

Youth Characteristics / Variables	**n**	**%**
Age group (n=209)		
Adolescent (13-16y)	137	65.6%
Young adult (17-21y)	72	34.4%
Sex (n=209)		
Male	108	51.7%
Female	101	48.3%
Race (n=209)		
Caucasian	142	68.0%
African American	21	10.0%
Hispanic/Latino	21	10.0%
Other	25	12.0%
GMFCS level (n=209)		
I- Walk without restrictions	54	25.8%
II- Walk with restrictions	57	27.3%
III- Walk with assistive devices	33	15.8%
IV- Limited self-mobility	26	12.4%
V- Severely limited posture/self-mobility	39	18.7%
Learning/Understanding Problems (n=195)		
No Problem	89	45.6%
Problem	106	54.4%
If a problem, extent affected daily activities, *Mdn*	3	
Communication/Speech Problems (n=195)		
No Problem	113	57.9%
Problem	82	42.1%
If a problem, extent affected daily activities, *Mdn*	3	
Subscales for the PODCI (n=191), *M (SD)*		
Upper Extremity Function and Transfers/Mobility	58.5	34.4
Sports and Physical Function	35.7	27.7
Adaptive Behavior Index (n=181), *M (SD)*	3.93	0.75

M: Mean; *SD*: Standard deviation; *Mdn*: Median

Table 2. Family Demographics and Subscales for Family Environment Scale (FES)

Family Characteristics / Variables	**n**	**%**
Caregiver respondents (n=194)		
Mother	151	77.8%
Father	25	12.9%
Grandmother	12	6.2%
Other	6	3.1%
Parental education (n=192)		
Less than high school	11	5.7%
High school	84	43.8%
Some college/Associates degree	57	29.7%
Bachelors degree	29	15.1%
Graduate degree	11	5.7%
Employment (n=189)		
Full-time	82	43.4%
Part-time	39	20.6%
Not employed	68	36.0%
Family income (n=176)		
Less than $29,999	50	28.4%
$30,000 - $59,999	52	29.5%
$60,000 - $99,999	46	26.2%
$100,000 and over	28	15.9%
Number of children in the household (n=189)		
1	64	33.9%
2	64	33.9%
3	40	21.2%
4 and above	21	11.0%
Subscales for FES (n=183), *M (SD)*		
Cohesion	7.3	1.8
Conflict	2.6	2.1
Organization	6.4	1.9
Family Social Integration Index	19.6	4.2

M: Mean; *SD*: Standard deviation

Measure of Participation

Children's Assessment of Participation and Enjoyment (CAPE). The CAPE is a 55-item measure of participation in leisure and recreational activities excluding the mandated school curriculum (G. King, et al., 2004). Each item is categorized by domain (Formal and Informal) and activity type (Recreational, Physical, Social, Skill-based, and Self-Improvement). Formal activities refer to activities involving rules or goals and are often structured by adults, while Informal activities refer to activities involving little or no prior planning and are often initiated by the child. Examples of activities are provided in Table 3. For each activity, five dimensions of participation are measured: Whether the activity was done during the past 4 months, and, if done, How Often, With Whom, Where, and Enjoyment for the activity (Table 4). The number of activities done and the With Whom scores were analyzed in this study. Good reliability and validity of the CAPE have been documented (G. King, Law, King, et al., 2006; G. King, et al., 2004).

Table 3. Examples of items under each typology of activities for the CAPE (King et al., 2004)

Types	**Formal Domain (15 items)**	**Informal Domain (40 items)**
Recreational (12 items)		Playing board or card games Doing crafts, drawing or coloring Playing computer or video games
Physical (13 items)	Doing martial arts Racing or track and field Doing team sports Participating in school clubs	Bicycling, in-line skating or skateboarding Doing water sports Playing non-team sports
Social (10 items)		Hanging out Going to a party Going on a full-day outing
Skill-based (10 items)	Swimming Taking art (or music) lessons Participating in community organizations	Dancing
Self-improvement (10 items)	Doing a religious activities	Reading Going to the public library Doing a chore Doing volunteer work

Table 4. Scoring system of each dimension of participation for the CAPE (King et al., 2004)

Dimensions	Questions	Scoring	
Diversity	In the past 4 months, have you done this activity?	**0**	No
		1	Yes
Intensity	If yes, how often have you done this activity in the past 4 months?	**1**	Once/4 months
		2	Twice/4 months
		3	Once/week
		4	Two to three times/week
		5	Once/week
		6	Two to three times/week
		7	Once/day
With Whom	With whom do you do this activity most often?	**1**	Alone
		2	With family
		3	With other relatives
		4	With friends
		5	With others
Where	Where do you do this activity most often?	**1**	Home
		2	Relative's home
		3	In your neighborhood
		4	At school
		5	In your community
		6	Beyond your community
Enjoyment	How much do you like or enjoy doing this activity?	**1**	Not at all
		2	Somewhat; sort of
		3	Pretty much
		4	Very much
		5	Love it

Measures of Youth, Family, and Services Variables

Gross Motor Function Classification System (GMFCS). The GMFCS is a five-level system for classifying children with CP based on functional abilities and limitations (Palisano, et al., 1997). The preliminary version of 12-18 year age band of the expanded and revised GMFCS (Palisano, et al., 2008) was used. The GMFCS has evidence of content, construct, and discriminative validity, and inter-rater reliability (Palisano, et al., 2008; Palisano, et al., 1997). Inter-rater reliability of research assistants was examined for this study and each achieved an agreement of > 80% with the criterion rating.

Demographic Questionnaire. The questionnaire was developed for the activity and participation study to obtain parent and youth information. Questions on youth's developmental problems and educational placement were analyzed. Parents reported whether their child had problems in learning, understanding, communication, and speech and if the response was "yes", indicated the extent to which the problem affected daily activities (1='Not at all' to 5='To a great extent'). These four questions were used to calculate two scores (learning/understanding problems and communication/speech problems), as follows: youth with no problems received a score of 0; youth with one problem, received a score of 1 to 5, reflecting the extent to which the problem affected their daily activities; youth with both problems received the average of the two scores (Appendix 1). Parents also indicated whether their children attended: regular high school / regular program, regular high school / special program, special high school, home school, post-secondary education, or did not attend school.

Coping Inventory. The Coping Inventory is a 48-item measure of adaptive behavior in meeting personal needs and interacting with social environments (S. Zeitlin, 1985). Three dimensions are measured: 1) Productivity, the degree to which behaviors are socially responsible; 2) Active, the degree of task persistence; and 3) Flexible, the degree of adaptability. Each behavior is rated on a 5-point scale (1= 'Not effective' to 5= 'Consistently effective across situations'). The full scale Adaptive Behavior Index was used for analysis. Internal consistency for all items was .94 based on scores for the youth in the study.

The Pediatric Outcomes Data Collection Instrument (PODCI). The PODCI is a parent-report measure of health, physical and mental functions (Daltroy, et al., 1998). The scores for each subscale range from 0 to 100. Three subscales were analyzed: Upper Extremity Function, Transfers/Mobility, and Sports and Physical Function. Upper Extremity Function and Transfers/Mobility subscale scores of youth in the study had a high correlation (r=.86) and, therefore, were combined into a single mean score.

The Family Environment Scale (FES). The FES is a 90-item measure of family functioning (Moos & Moos, 2002). Parents indicated if each statement is true or false for their families. Items are evenly divided among 10 subscales: Cohesion, Expressiveness, Conflict, Independence, Achievement Orientation, Intellectual-Cultural Orientation, Active-Recreational Orientation, Moral-Religious Emphasis, Organization, and Control. Items can be further grouped into two summary indices, Family Relationship Index and Family Social Integration Index. Internal consistency was examined for subscales and summary indices using our data. Two subscales, Cohesion and Conflict, and Family Social Integration Index were selected for analysis using the criteria of Cronbach's alpha >.60 for scores of the youth in the study.

Service Questionnaire. The questionnaire was developed for the activity and participation study to measure the accessibility and coordination of health, educational, and community services. Questions on community recreational activities and school-based therapy services were analyzed. Parents first indicated whether they had needs for the activities / services and if the response was 'yes', indicated the extent to which they obtained desired activities / services (1= 'None' to 4= 'All' of the activities / services') (Appendix 2).

The Measure of Processes of Care (MPOC). The MOPC, 20 item version (S. King, King, & Rosenbaum, 2004) was used to measure parental perceptions of services delivered by health care professionals and organizations. Two scales, Providing General Information and Coordinated and Comprehensive Care, were selected for analysis. Parents were instructed to provide an overall rating of services for each item using a 7-point scale (1= ‘Not at all’ to 7= ‘To a very great extent’) or Not applicable (0). Good reliability and validity have been reported (S. King, et al., 2004).

Procedure

Data were collected by one to three research assistants in each hospital and each session took 2 to 3 hours. Research assistants were mostly health professionals experienced in serving children and families with CP. Research assistants determined youth’s GMFCS levels. Youth completed the CAPE by structured interview; parent assistance or proxy was used as necessary. Among the 209 youth, 116 (55.5%) completed the CAPE independently, 48 (23%) received some assistance, and 45 (21.5%) parents completed as a proxy. Parents completed the remaining measures either by computer or by paper/pencil.

Data Analysis

Statistical analyses were performed using the Predictive Analytics Software version 17 (SPSS, Chicago, IL). Descriptive statistics were performed for all measures. The number of activities on the CAPE done with friends was the sum of number of activities done in which the With Whom dimension score was “4= With friends”. The number of activities on the CAPE done with other non-family members was the sum of number of activities done in which the With Whom dimension score was “5= With others (instructors, other individuals, or multiple types of people)” (Table 4).

Bivariate correlations were calculated to examine the association between each predictor variable and the number of activities done with: 1) friends and 2) other non-family members. Predictor variables that were significantly correlated with the outcome variables ($p<.05$) and of a magnitude of $\geq.20$ were included in the regression analyses. Data for the outcome variables were skewed, therefore, non-parametric statistics were used. Spearman’s rank correlation coefficients (r_s) were calculated for continuous and ordinal predictor variables and Point-biseral correlation coefficients (r_{pb}) were calculated for dichotomous predictor variables (Field, 2005).

For the model of determinants of participation with friends, a sequential multiple regression analysis was performed to determine the best predictive combination of youth, family and service variables. Data were missing for one or more predictor variables for 36 (17%) youth. Regression analyses were performed using scores for the 173 youth with complete data. There were no differences in age, sex, and GMFCS level between youth with and without complete data. Natural logarithmic transformation was performed for three variables for which the data were substantially skewed: “number of activities done with friends”, “learning/understanding problems” and “communication/speech problems”. There was a high correlation between GMFCS level and Upper Extremity Function and Transfer/Mobility (r=.88), therefore, GMFCS level was excluded from the regression analysis.

To perform the sequential multiple regression analysis, youth variables were entered in the first block and service variables were entered in the second block. None of the correlations for family variables met the inclusion criteria for inclusion in regression analysis. Educational placement was coded as ‘Regular high school/special program’, ‘Special high school’, and ‘Other’ with ‘Regular high school/regular program’ as the referent for the analysis. ‘Other’ includes *Home school* and *No school.* Since the number of youth who either did not attend school or received home schooling was small, the two categories were combined. Questions pertaining to community recreational activities and school-based therapies were entered as two variables: need for the activities / services (yes/no) and extent desired activities / services were obtained. To form a parsimonious model, a predictor variable was retained in the model if the probability level of the *t*-test associated with a beta coefficient was p <.05.

For the model of determinants of participation with other non-family members, none of the correlations for predictor variables met the criteria for inclusion in regression analysis. Predictor variables, therefore, were re-specified to include family organization, education, income, employment status, and number of children in the household. Family organization was measured by the Organization subscale of the Family Environment Scale, which indicates structure in planning family activities and responsibilities. The re-specification was based on the hypothesis that youth's participation involving non-family members is related to the issues represented by these variables, such as family efforts and time demands for arranging community activities (Mactavish, Schleien, & Tabourne, 1997; Van Naarden Braun, Yeargin-Allsopp, & Lollar, 2006).

Spearman's rank correlation coefficients (r_s) were calculated for re-specified variables. Data were missing for one or more predictor variables for 21 (10%) youth. A simple linear regression analyses was performed for scores of the 188 youth with complete data. There were no differences in age, sex, and GMFCS level between youth with and without complete data.

2.4. Results

During the past 4 months, youth performed an average of 4.4 leisure activities with friends (SD=4.7, min.-max.= 0-26), and 1.9 leisure activities with other non-family members (SD=2.3, min.-max.= 0-14). Forty-six (22%) youth did not perform any activities with friends and 62 (30%) did not perform any activities with other non-family members during the past 4 months. The descriptive statistics for youth, family, and service variables are presented in Table 1, 2, and 5, respectively.

Table 5. Educational Placement and Scores for Service Variables

Service Variables	n	%
Educational placement (n=193)		
Regular high school / regular program [a]	79	41.0%
Regular high school / special program	68	35.2%
Special high school	23	11.9%
Other [b]	23	11.9%
Community recreational activities (n=192)		
No needs	71	37.0%
Have needs	121	63.0%
If a need, extent the activities were obtained, *Mdn*	2.0	
School-based therapy services (n=193)		
No needs	62	32.1%
Have needs	131	67.9%
If a need, extent the services were obtained, *Mdn*	3.0	
Scales for the Measure of Process of Care, *M (SD)*		
Providing General Information (n=187)	3.9	2.0
Coordinated and Comprehensive Care (n=183)	5.1	1.5

M: Mean; *SD*: Standard deviation; *Mdn*: Median

[a] Regular high school / regular program includes post-secondary school (n=12)

[b] Other includes youth who did not attend school (n=11) and attended home school (n=12)

Relationships between Predictor and Outcome Variables

The bivariate correlations are presented in Table 6. For the activities done with friends, lower GMFCS level, higher upper extremity function and transfer/mobility, sports and physical function, and adaptive behaviors, fewer communication/speech and learning/understanding problems were associated with doing more activities with friends.

The magnitude of these correlations ranged from .33 to .56 (*p*<.001). Family conflict was correlated with doing more activities with friends (r= .17, *p*=.02) but the magnitude of the correlation did not meet the criteria for inclusion in regression analysis. A higher extent to which desired community recreational activities and school-based therapy services were obtained and a more inclusive educational setting were associated with doing more activities with friends. The magnitude of these correlations ranged from .30 to .38 (*p*<.001).

For the activities done with other non-family members, higher parental education (r=.25, *p*<.01) and family organization (r=.18, *p*=.01) were associated with doing more activities with others. The magnitude of the correlation for family organization did not meet the criteria for inclusion in regression analysis.

Table 6. Correlations between the predictor variables and the number of activities done with friends and with other non-family members (others)

Outcomes Predictor Variables	Number of activities w/ Friends	Number of activities w/ Others
YOUTH FACTORS		
Age (r_{pb})	.07	.08
Sex (r_{pb})	- .01	.11
GMFCS level (r_{s})	- .45 [a]	.12
Upper Extremity Function and Transfer/Mobility (r_{s})	.55 [ab]	- .12
Sports Physical Function (r_{s})	.56 [ab]	- .06
Adaptive behavior (r_{s})	.33 [ab]	- .10
Learning/Understanding problems (r_{s})	- .52 [ab]	.02
Communication/Speech problems (r_{s})	- .37 [ab]	- .03
FAMILY FACTORS		
Family Cohesion (r_{s})	- .01	- .02
Family Conflict (r_{s})	.17 [a]	.03
Family Social Integration Index (r_{s})	.05	.04
Family Organization (r_{s})	N/A	.18 [a]
Parental education (r_{s})	N/A	.25 [ab]
Family income (r_{s})	N/A	.10
Employment status (r_{s})	N/A	-.01
Number of children in household (r_{s})	N/A	.01
SERVICE FACTORS		
Extent community recreational activities were obtained (r_{s})	.30 [ab]	- .03
Extent school-based therapy services were obtained (r_{s})	.34 [ab]	- .03
Coordinated and Comprehensive Care (r_{s})	.11	- .16 [a]
Providing General Information (r_{s})	.02	- .03
Educational Placement (r_{s})	.38 [ab]	- .07

r_{s}: Spearman's rank correlation coefficients; r_{pb}: Point-biseral correlation coefficients

[a] p<.05; [b] Predictor variable included in the regression analysis

Determinants of Activities Done with Friends

The results of the multiple regression analysis are presented in Table 7. The full model of youth and service variables explained 45.8% of the variance in number of activities done with friends, *F* (12, 160) = 11.26, *p*< .001. Youth variables were entered first and explained 40.2% of the variance, *F* (5, 167) = 22.47, *p*< .001. Service variables explained an additional 5.6% of the variance, *F change* (7, 160) = 2.35, *p*=.03. Youth with higher sports and physical function (β=.25), fewer communication/speech problems (β=−.18), and who obtained a higher extent of desired community recreational activities (β=.22) did more activities with friends. Youth in 'Regular school/regular program' were more likely to do activities with friends than youth in 'Regular school/special program' (β=−.21) and 'Other' (β=−.16).

Determinants of Activities Done with Other Non-family Members

The simple regression analysis revealed that parental education explained a small but significant amount (6.3%) of the variance in the number of activities done with other non-family members, F(1,186)=12.50, *p*=.001. Higher parental education (β=.25, *p*=.001) was the sole determinant of doing more activities with other non-family members.

Table 7. Sequential Multiple Regression Analysis for Diversity of Activities done with Friends (n=173)

Model	Predictor Variables	β	T	*p*
Youth	Upper Extremity Function and Transfer/Mobility	.11	.89	.38
	Sports and Physical Function	.25	2.39	.02
	Adaptive Behavior Index	.03	.42	.68
	Communication/speech problem	-.18	-2.1	.04
	Learning/understanding problem	-.06	-.76	.47
Services	Needs for community recreational activities	.16	1.56	.12
	Extent community recreational activities were obtained	.22	2.02	.04
	Needs for school-based therapy services	-.08	-.79	.43
	Extent school-based therapy services were obtained	-.05	-.53	.60
	Educational placement			
	Regular high school/Regular program (Referent)			
	Regular high school/special program	-.21	-2.59	.01
	Special high school	-.04	-.51	.61
	Other	-.16	-2.44	.02

β: Standardized beta values

2.5. Discussion

Youth with CP participated in a small proportion of activities on the CAPE with persons outside the family. Previously we reported that this cohort did a mean of 18.5 to 24.5 of the 55 activities on the CAPE (Orlin, et al., 2009); of which a mean of 4.4 and 1.9 activities were done with friends and other non-family members. Within the framework of the International Classification of Functioning Disability and Health (World Health Organization, 2001), the desire for social participation is a personal construct. Consequently, doing more activities on the CAPE should not be assumed to a desired outcome for all youth. For some youth with CP, participation in a small number of activities with friends and others may reflect their choices to focus on specific activities they like, or their preferences for family and solitary activities.

Several limitations for the study should be considered while interpreting the results. The operational definition of social participation only reflects how many activities were participated in and with whom. Time did not allow youth to complete the Preferences for Activities of Children (G. King, et al., 2004), a companion measure to the CAPE. Doing so would have enabled analysis of the types of activities they preferred. Furthermore, we do not know the extent youth were actively engaged in a contextually appropriate manner in the activities they did with friends and others, and their quality of interactions.

The results suggest that youth who are more competent in recreation and sports, and communication are able to do a greater variety of activities with friends. Previous studies have indicated that higher mobility, functional abilities, and communication skills might enhance choices and opportunities for social activities among adolescents and young adults with CP (Shikako-Thomas, Majnemer, Law, & Lach, 2008; Wiegerink, et al., 2006). Our previous study also suggests that self-sufficient mobility and some ability to run and jump might enable social participation in recreational and leisure activities for children and youth with CP (Palisano, et al., 2009).

The extent to which youth obtained desired community recreational activities was associated with their social participation with friends, over and above the influence of youth characteristics. Community recreation and leisure programs provide youth with opportunities to establish friendships and social networks. Participation in group activities enables adolescents to experience team cooperation and develop peer attachment (McGee, et al., 2006). Further research is recommended to understand the types, formats, and structure of community activities that optimize social interactions of youth with CP.

The finding that youth in regular educational programs were more likely to do activities with their friends compared with those in special educational programs most likely can be attributed to several factors. One factor is related to the youth characteristics. For our sample, youth in regular educational programs had higher physical, cognitive, and communicative functioning, which might be related to doing more activities with friends. Another factor is the support of classmates and friends that might also influence social participation (G. King, Law, King, et al., 2006). Though inclusion is thought to facilitate social interactions (Kennedy, et al., 1997; Miller, et al., 1996), youth with disabilities have reported mixed feelings regarding social experiences in inclusive settings (Lightfoot, et al., 1999). Among 33 adolescents 11-16 years with illnesses or disabilities in regular schools, more than half reported difficulties in interacting with their peers without disabilities, whereas five reported positive experiences as being helped by their peers (Lightfoot, et al., 1999).

Our findings that family characteristics were not associated with social participation of youth with CP may reflect a developmental perspective. Youth may be more independent in arranging activities with friends than children and the family may be less influential for their peer participation. Our findings are not consistent with other studies in which family cohesion, communication, activity preferences, and income were predictors of leisure participation (G. King, Law, Hanna, et al., 2006; Law, et al., 2006). The discrepancy might reflect our particular focus on number of activities that the youth take part with their friends, while other studies (G. King, Law, Hanna, et al., 2006; Law, et al., 2006) focused on intensity of participation in formal and informal activities for children with disabilities. Furthermore, whether or not to participate with friends may not simply depend on personal choice or family preferences. Although not examined in the study, social participation may be influenced by the social and attitudinal factors that are beyond the control of individual youth and family, such as attitudes, values, and supports of people in the community (Law, et al., 1999).

Social participation with other non-family members was associated with parental education, but not youth and service characteristics. This finding may reflect parental knowledge of and ability to access organized recreational activities (Antle, Mills, Steele, Kalnins, & Rossen, 2007) regardless of their children's abilities and resource barriers. Compared with activities done with friends, activities involving adult instructors or coaches such as dance or swimming lessons often require more planning and assistances by the family members. Higher parental education has been reported to be associated with higher participation in organized activities for children with Down Syndrome (Sloper, et al., 1990). In addition, educational attainment may be related to parental competencies in using electronic and print media to locate and utilize community resources. Higher parental knowledge regarding leisure-time activity has been found to positively affect adolescent's experiences and interests in leisure activities (Sharp, Caldwell, Graham, & Ridenour, 2006).

Youth and service characteristics were determinants of social participation with friends but not other non-family members. The finding may reflect a difference in the type of activities done with friends versus non-family members. Informal activities refer to voluntary activities involving little or no plan that are often initiated by the youth, while formal activities refer to structured activities involving rules or goals that are often organized by adults. In our study, among the informal activities done with friends and others, 75% were done with friends and 25% were done with others. Among the formal activities done with friends and others, 32% were done with friends and 68% were done with others. This suggests that physical, communication, and social skills may be especially important for participation in informal activities with friends where formal support and assistance are not provided. In comparison, formal activities were more often done by youth with others. During formal activities, adults such as instructors and coaches may be a source of support that enables participation by accommodating and adapting activities based on the youth's abilities. Physical, cognitive, and communication functioning was found to predict informal participation more strongly than formal participation for children with disabilities (G. King, Law, Hanna, et al., 2006). Similarly, child sex, manual ability, and gross motor function was found to predict diversity of participation in informal activities while none of the child characteristics was found to predict formal activities for children with CP (Imms, Reilly, Carlin, & Dodd, 2009).

2.6. Implications for Practice

For adolescents and young adults with CP, services and interventions that promote sports, physical, and communication abilities might enhance opportunities for social participation with friends. Physical therapists are encouraged to actively involve youth with CP in planning and engaging in recreational and sport activity based on their interests. Organized sports and physical activities provide a social context in which youth experience team cooperation and build supportive networks (Allender, et al., 2006; Poulsen, et al., 2007). Therapists can involve youth in identifying goals, analyzing skills needed for the activity, and developing instructions and interventions. With appropriate instruction and practice, youth may improve their sports and physical activity skills, enabling active participation. Therapists can also involve youth and families in problem-solving barriers to participation. Strategies may involve sharing information, consulting and coordinating with the program instructors, coaches and team members.

Physical therapists are encouraged to address communication skills needed for successful social participation in desired activities. Effective communication enables youth to express themselves and interact with others. Moreover, youth with CP may have special needs to communicate with others regarding physical management and activity adaptation during sports, clubs, or group activities. Physical therapists can assist with identifying difficulties in communication specific to their desired activities, and then collaborate with speech therapists to provide interventions (Pennington, Goldbart, & Marshall, 2004). Physical therapists can also provide information about augmentative and alternative communication systems and training programs that help the youth to achieve an independent role during social interaction (Pennington, et al., 2004).

Health care professionals, including physical therapists, have an important role as advocates for social and community participation of youth with CP and their families. Thomas and Rosenberg (Thomas & Rosenberg, 2003) suggest that the skills and knowledge required for community-based pediatric physical and occupational therapists to successfully promote community participation involves assessment, ongoing consultation/assistance, intervention, and continued education. Therapists are encouraged to identify physical, social/attitudinal, and service barriers to participation, by using standard measures or individual in-depth interviews. Therapists should be aware that lack of information and nearby facilities, availability and accessibility of programs, high cost and time demands were frequently cited barriers to community participation (Law, et al., 1999; Statistics Canada, 1995). Effective strategies to promote community opportunity could be developed based on a comprehensive assessment for the strengths, abilities, and challenges of individual youth and family.

Therapists are encouraged to apply knowledge and expertise to develop consultation and intervention plans that are feasible and helpful. Strategies to promote community inclusion include providing recommendations for meaningful activities and resources that fit individual abilities and interests, interventions for skills development and use of assistive technology, consultation on activity accommodations and environmental modifications, suggestions for transportation, and education for staff of community facilities (J. Magill-Evans, Darrah, & Adkins, 2003/2004; Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004; Thomas & Rosenberg, 2003).

Further research is recommended to identify structures and processes of physical therapy services that promote successful social participation desired by youth with CP. We perceive successful social participation as a person's physical (doing), social (belonging), and psychological (being) engagement in desired roles. Therapists have a unique role in providing supports and services that optimize sport activity and physical abilities, communication skills, and community opportunities. Clinical trials are needed to determine the effectiveness of participation-based interventions in optimizing social and community participation of youth with CP.

2.7. References

Adamson, L. (2003). Self-image, adolescence, and disability. *American Journal of Occupational Therapy, 57*(5), 578-581.

Allender, S., Cowburn, G., & Foster, C. (2006). Understanding participation in sport and physical activity among children and adults: a review of qualitative studies. *Health Education Research, 21*(6), 826-835.

Antle, B. J., Mills, W., Steele, C., Kalnins, I., & Rossen, B. (2007). An exploratory study of parents' approaches to health promotion in families of adolescents with disabilities. *Child: Care Health Development, 34*, 185-193.

Baker, K., & Donelly, M. (2001). The social experiences of children with disability and the influence of environment: A framework for intervention. *Disability & Society, 16*(1), 71-85.

Bandura, A. (1986). *Social foundations of thought and action: A social cognitive theory*. Englewood Cliffs: Prentice Hall.

Barletta, A., & Loy, D. P. (2006). The experience of participation in challenger little league through the eyes of a child with physical disability. *American Journal of Recreation Therapy, 5*(3), 6-12.

Bennett, K. S., & Hay, D. A. (2007). The role of family in the development of social skills in children with physical disabilities. *International Journal of Disability, Development and Education, 54*(4), 381-397.

Brollier, C., Shepherd, J., & Markley, K. F. (1994). Transition from school to community living. *American Journal of Occupational Therapy, 48*(4), 346-353.

Bronfenbrenner, U., & Ceci, S. J. (1994). Nature-nurture reconceptualized in developmental perspective: A bioecological model. *Psychological Review, 101*, 568-586.

Brown, M., & Gordon, W. A. (1987). Impact of impairment on activity patterns of children. *Archives of Physical Medicine & Rehabilitation, 68*(12), 828-832.

Chen, H.-F., & Cohen, E. S. (2003). Social participation for children with developmental coordination disorder: conceptual, evaluation and intervention considerations. *Physical & Occupational Therapy in Pediatrics, 23*(4), 61-78.

Colver, A., & Sparcle, G. (2006). Study protocol: SPARCLE--a multi-centre European study of the relationship of environment to participation and quality of life in children with cerebral palsy. *BMC Public Health, 6*, 105.

Daltroy, L. H., Liang, M. H., Fossel, A. H., & Goldberg, M. J. (1998). The POSNA Pediatric Musculoskeletal Functional Health Questionnaire: Report on reliability, validity, and sensitivity to change. *Journal of Pediatric Orthopeadics, 18*(5), 561-571.

Field, A. (2005). *Discovering Statistics Using SPSS* (2nd ed.). London: SAGE Publications Ltd.

Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2008). Diversity of participation in children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(5), 363-369.

Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2009). Characteristics influencing participation of Australian children with cerebral palsy. *Disability & Rehabilitation, 31*(26), 2204-2215.

Kennedy, C. H., Shukla, S., & Fryxell, D. (1997). Comparing the effects of educational placement on the social relationships of intermediate school students with severe disabilities. *Exceptional Children, 64*, 31-47.

King, G., Law, M., Hanna, S., King, S., Hurley, P., Rosenbaum, P., et al. (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., Hurley, P., Petrenchik, T., & Schwellnus, H. (2010). A developmental comparison of the out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. *International Journal of Disability, Development and Education, 57*(1), 77-107.

King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al. (2006). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39.

King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al. (2004). *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)*. San Antonio, TX: Harcourt Assessment, Inc.

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.

King, S., King, G., & Rosenbaum, P. (2004). Evaluating health service delivery to children with chronic conditions and their families: development of a refined Measure of Processes of Care (MPOC-20). *Children's Health Care, 33*(1), 35-57.

King, S., Teplicky, R., King, G., & Rosenbaum, P. (2004). Family-centered service for children with cerebral palsy and their families: a review of the literature. *Seminars in Pediatric Neurology, 11*(1), 78-86.

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., et al. (2006). Patterns of participation in recreational and leisure activities among children with complex physical disabilities. *Developmental Medicine & Child Neurology, 48*(5), 337-342.

Lightfoot, J., Wright, S., & Sloper, P. (1999). Supporting pupils in mainstream school with an illness or disability: young people's views. *Child: Care, Health & Development, 25*(4), 267-283.

Mactavish, J., Schleien, S., & Tabourne, C. (1997). Pattern of family recreation in families that include children with a developmental disability. *Journal of Leisure Research, 29*(1), 21-46.

Magill-Evans, J., Darrah, J., & Adkins, R. (2003/2004). Youths with cerebral palsy and their satisfaction with recreational services: Implications for inclusion. *Leisure, 28*(1-2), 71-86.

McGee, R., Williams, S., Howden-Chapman, P., Martin, J., & Kawachi, I. (2006). Participation in clubs and groups from childhood to adolescence and its effects on attachment and self-esteem. *Journal of Adolescence, 29*(1), 1-17.

Mihaylov, S. I., Jarvis, S. N., Colver, A. F., & Beresford, B. (2004). Identification and description of environmental factors that influence participation of children with cerebral palsy. *Developmental Medicine & Child Neurology, 46*(5), 299-304.

Miller, K. J., Fullmer, S. L., & Walls, R. T. (1996). A dozen years of mainstreaming literature: a content analysis *Exceptionality, 6*, 99-109.

Moos, R. H., & Moos, B. S. (2002). *A Social Climate Scale: Family Environment Scale Manual – Development, Applications, Research* (3rd ed.). Palo Alto, CA: Mindgarden Inc.

Orlin, M. N., Palisano, R. J., Chiarello, L. A., Kang, L.-J., Polansky, M., Almasri, N., et al. (2010). Participation in home, extracurricular, and community children and youth with cerebral palsy. *Developmental Medicine & Child Neurology, 52*, 160-166.

Palisano, R. J., Kang, L.-J., Chiarello, L. A., Orlin, M. N., Oeffinger, D., & Maggs, J. (2009). Social and community participation of children and youth with cerebral palsy is associated with age and gross motor funtion classification. *Physical Therapy, 89*, 1304-1314.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology, 50*(10), 744-750.

Palisano, R. J., Rosenbaum, P. L., & Walter, S. (1997). Development and validation of a gross motor function classification system for children with cerebral palsy. *Developmental Medicine & Child Neurology, 39*, 214-223.

Pennington, L., Goldbart, J., & Marshall, J. (2004). Speech and language therapy to improve the communication skills of children with cerebral palsy. *Cochrane Database of Systematic Reviews*(2), CD003466.

Poulsen, A. A., Ziviani, J. M., Cuskelly, M., & Smith, R. (2007). Boys with developmental coordination disorder: loneliness and team sports participation. *American Journal of Occupational Therapy, 61*(4), 451-462.

Reijntjes, A., Stegge, H., & Terwogt, M. M. (2006). Children's coping with peer rejection: the role of depressive symptoms, social competence, and gender. *Infant & Child Development, 15*(1), 89-107.

Richardson, P. (2003). From roots to wings: social participation for children with physical disabilities. *Developmental Disabilities Special Interest Section Quarterly, 26*(1), 1-4.

Rimmer, J. H., Riley, B., Wang, E., Rauworth, A., & Jurkowski, J. (2004). Physical activity participation among persons with disabilities: Barriers and facilitators. *American Journal of Preventive Medicine, 26*(5), 419-425.

Sharp, E. H., Caldwell, L. L., Graham, J. W., & Ridenour, T. A. (2006). Individual motivation and parental influence on adolescents' experiences of interest in free time: A longitudinal examination. *Journal of Youth and Adolescence, 35*(3), 359-372.

Shikako-Thomas, K., Majnemer, A., Law, M., & Lach, L. (2008). Determinants of participation in leisure activities in children and youth with cerebral palsy: systematic review. *Physical & Occupational Therapy in Pediatrics, 28*(2), 155-169.

Sloper, P., Turner, S., Knussen, C., & Cunningham, C. (1990). Social life of school children with Down's syndrome. *Child: Care, Health & Development, 16*(4), 235-251.

Specht, J., King, G., Brown, E., & Foris, C. (2002). The importance of leisure in the lives of persons with congenital physical disabilities. *American Journal of Occupational Therapy, 56*(4), 436-445.

Stanovich, P. J., Jordan, A., & Perot, J. (1998). Relative differences in academic self-concept and peer acceptance among students in inclusive classrooms. *Remedial and Special Education, 19*(2), 120-126.

Statistics Canada. (1995). *A portrait of persons with disabilities*. Ottawa, ON: Statistics Canada.

Stevenson, C. J., Pharoah, P. O., & Stevenson, R. (1997). Cerebral palsy-the transition from youth to adulthood. *Developmental Medicine & Child Neurology, 39*(5), 336-342.

Thomas, A. D., & Rosenberg, A. (2003). Promoting community recreation and leisure. *Pediatric Physical Therapy, 15*, 232-246.

Van Naarden Braun, K., Yeargin-Allsopp, M., & Lollar, D. (2006). Factors associated with leisure activity among young adults with developmental disabilities. *Research in Developmental Disabilities, 27*(5), 567-583.

Wiegerink, D. J., Roebroeck, M. E., Donkervoort, M., Stam, H. J., & Cohen-Kettenis, P. T. (2006). Social and sexual relationships of adolescents and young adults with cerebral palsy: a review. *Clinical Rehabilitation, 20*(12), 1023-1031.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health*. Geneva, Switzerland: World Health Organization.

Zeitlin, S. (1985). *Coping Inventory: A Measure of Adaptive Behavior* Bensenville, Illinois: Scholastic Testing Service.

Zeitlin, S., & Williamson, G. G. (1994). *Coping in young children: Early intervention practices to enhance adaptive behavior and resilience*. Baltimore, MD: Paul H Brookes Publishing.

2.8. Appendices

Appendix 1. Questions Analyzed on Demographic Questionnaire.

	Does your child have problems with this area?	**Does your child's problem affect his/her daily activities?**				
		Not at all	To a small extent	To a moderate extent	To a fairly great extent	To a great extent
Problems with Communication	☐ NO ☐ YES	1	2	3	4	5
Problems with Speech	☐ NO ☐ YES	1	2	3	4	5
Problems with Understanding	☐ NO ☐ YES	1	2	3	4	5
Problems with Learning	☐ NO ☐ YES	1	2	3	4	5

Calculation of scores – example for communication/speech problems:

- If a parent reports no problems for both communication and speech, the score is 0.
- If a parent reports a problem for speech which affects their child's daily activities to a small extent, and reports no problems for communication, the score is 2.
- If a parent reports a problem for communication which affect their child's daily activities to a small extent, and a problem for speech which affect their child's daily activities to a fairly great extent, the average score is 3.

Appendix 2. Questions Analyzed on the Service Questionnaire

1a. In the past 12 months, did you (and / or your child) want any community recreational and / or religious activities (such as play groups, dance / swim sessions, camps, clubs, sports, and church activities)?

☐ 1= Yes (answer 1b) ☐ 0= No (go onto question 2a)

1b. To what extent have you received the community recreational and / or religious activities that you or your child wanted:

☐ 4= All of the activities
☐ 3= Most of the activities
☐ 2= Some of the activities
☐ 1= None of the activities

2a. In the past 12 months, did your child have therapy needs at school requiring the services of a physical, occupational, or speech therapist?

☐ 1= Yes (answer 1b) ☐ 0= No (go onto question 3a)

2b. To what extent have you received the school-based therapy services that your child needed:

☐ 4= All of the services
☐ 3= Most of the services
☐ 2= Some of the services
☐ 1= None of the services

CHAPTER 3: YOUTH WITH CEREBRAL PALSY'S SOCIAL PARTICIPATION AND SELF-PERCEIVED COMPETENCE AS A FRIEND

Submitted to *Child: Care, Health, and Development*, May 2010

3.1. Abstract

Background. Social participation with friends fosters development of meaningful relationships, life skills, and psychosocial well-being. Youth with cerebral palsy (CP) face challenges to establishing social relationships with friends. The aim of this study was to explore whether social participation with friends differs among youth with CP based on their self-perceived competence as a friend.

Methods. A total of 135 youth with CP, 13-21 years old, completed the measures Fulfillment in Social Roles and Children's Assessment of Participation and Enjoyment. Youth were assigned to high, middle, and low groups defined by their self-perceived competence as a friend. Kruskal-Wallis One-Way Analyses of Variance was used to examine differences in the number, total frequency, and enjoyment of activities done with friends among the three groups. Post-hoc analysis of significant group effects was performed using a Mann-Whitney U test or Kolmogorov-Smirnov test.

Results. Youth participated in a median of 4 leisure activities with friends in the past 4 months. On average, they performed every activity 'two to three times per month' and enjoyed these activities 'very much'. Youth with high self-perceived competence as a friend did the greatest number of activities and participated most often with friends. Youth with low self-perceived competence did the fewest activities and participated least often with friends. No differences were found in the enjoyment of activities done with friends among the three groups.

Conclusions. For youth with CP, the number and frequency of activities done with friends differed based on self-perceived competence as a friend, but not enjoyment. The results suggest a positive link between social participation and self-perceived social competence. Health care providers have a role to support youths' efforts to engage with friends by enhancing community opportunities, developing and providing interventions in natural social environments, and incorporating peer support into service delivery.

Keywords: Social Participation, Competence, Friend, Cerebral Palsy, Youth

3.2. Introduction

Social participation with friends fosters the development of meaningful relationships, social competence and psychosocial well-being (Collins, 1997; King et al., 2003). Adolescents with cerebral palsy (CP) view a sense of belonging and being believed in by others as key factors associated with success in life (King et al., 2000). Youth with CP face unique challenges to establishing social networks and fulfillment of adult social roles as a spouse, coworker or neighbor (Poulsen et al., 2007; Stevenson et al., 1997). Difficulties in mobility, communication, and socialization, and dependency on family members for self-care and transportation often limit the social opportunities of youth with physical disabilities (Blum et al., 1991; McGavin, 1998). For youth with CP, sports and physical function, communication ability, inclusive education program, and access to desired community recreational activities have been found to be associated with higher participation with friends (Kang et al., in press).

Self-perceived social competence is an essential aspect of psychosocial health that may be facilitated through social participation (De Winter et al., 2002). Self-perceived social competence refers to a person's judgment of his/her ability to successfully establish and maintain positive social relationships, and to support and help others (Anderson-Butcher et al., 2008; Harter, 1985). Children and adolescents with CP might be at risk of having low self-perceived social competence (Shields et al., 2006). Adolescent females with physical disabilities have reported lower social acceptance compared with females without disabilities; while males with physical disabilities did not differ from males without disabilities (King et al., 1993; Magill-Evans & Restall, 1991; Shields et al., 2007). It is noteworthy that children and adolescents with CP do not report lower overall self-worth compared with peers with typically development (Lavigne & Faier-Routman, 1992; Shields, et al., 2007; Shields, et al., 2006).

Research suggests a positive relation between self-perceived competence and participation experiences. Adolescents' social competence has been linked to higher participation in sports and extracurricular activities (Donaldson & Ronan, 2006; Marsh, 1992). Participation in groups and social activities predicts adolescents' peer attachment and self-perceived strengths, such as 'friendly', 'humorous', and 'outgoing' (McGee et al., 2006). Children with developmental coordination disorder who perceive themselves as more physically competent have been found to participate in more community recreational and physical activities than those who are less competent (Hay & Missiuna, 1998). Children with physical disabilities who reported higher perceived social competence have been found to report higher preferences for social activities, participate in these activities more intensively, and have more enjoyment (King et al., 2006).

Whether social participation differs based on self-perceived social competence has not been determined for youth with CP.

The aim of this study was to explore whether participation with friends in leisure and recreational activities differs among youth (adolescents and young adults) with CP based on their self-perceived competence as a friend (high, middle, low), operationally defined as youths' judgment of how well they are able to make friends, interact with friends, and help friends out. We hypothesized that 1) Youth with CP with high self-perceived competence as a friend participate in the greatest number of activities with friends, did activities with friends most frequently, and have the highest enjoyment and 2) Youth with CP with low self-perceived competence as a friend participate in the fewest activities, did activities with friends least frequently, and have the lowest enjoyment.

3.3. Methods

Participants

The participants were 135 youth with CP, 13-21 years old, and their parents. Youth had a mean age of 16.2 years (SD=2.2 years), 50% were males, and 65% were Caucasian. The number of youth in each level of the Gross Motor Function Classification System (Palisano et al., 2008) varied from 11 to 47. The participants were part of a larger study on Activity and Participation of Children with Cerebral Palsy that included 219 youth. Among the 151 youth who completed the measure Fulfillment in Social Roles (FSR) independently or with adult-assistance, 16 who had a diagnosis of intellectual disability based on parent report were excluded from the analysis as they might have difficulty in understanding the concepts measured by the FSR, resulting in a sample size of 135.

Participants were recruited from six Shriners Hospitals for Children [Chicago, Illinois; Erie, Pennsylvania; Lexington, Kentucky; Northern California (Sacramento); Philadelphia, Pennsylvania; Springfield, Massachusetts] and Kluge Children's Rehabilitation Center, Charlottesville, Virginia. Youth with a diagnosis of cerebral palsy and no other medical or mental health diagnosis that may influence participation were included. Ethical approval was provided by the Institutional Review Board of each hospital. Informed consent was provided by parents and youth ≥ 16 years of age. Informed assent was provided by youth 13 to 15 years of age. Table 1 presents the youths' demographic characteristics.

Table 1. Demographic information and prevalence of developmental problems for the youth grouped by self-perceived competence as a friend

Characteristics	Self-perceived competence as a friend					
	High (n=94)		Middle (n=31)		Low (n=10)	
	n	%	n	%	n	%
Age, Mean; SD	16.1	2.2	16.9	2.2	15.2	1.3
Sex						
Male	50	53.2%	13	41.9%	5	50.0%
Female	44	46.8%	18	58.1%	5	50.0%
GMFCS level						
I. Walk without restrictions	33	35.1%	11	35.5%	3	30.0%
II. Walk with restrictions	23	24.5%	9	29.0%	3	30.0%
III. Walk with assistive devices	20	21.3%	6	19.4%	1	10.0%
IV. Limited self-mobility	13	13.8%	1	3.2%	1	10.0%
V. Severely imitated posture/self-mobility	5	5.3%	4	12.9%	2	20.0%
Race						
Caucasian	67	71.3%	23	74.2%	6	60.0%
African American	10	10.6%	2	6.5%	0	0.0%
Hispanic/Latino	6	6.4%	4	12.9%	2	20.0%
Other	11	11.7%	2	6.5%	2	20.0%
Developmental Problems [a]						
Communication	5	5.7%	3	9.7%	2	22.2%
Speech	18	20.5%	7	22.6%	4	44.4%
Understanding	15	17.0%	9	29.0%	1	11.1%
Learning	34	38.6%	15	48.4%	1	11.1%
Behavioral/emotional	15	17.0%	8	25.8%	1	11.1%
Attention	20	22.7%	9	29.0%	1	11.1%

[a] Number (%) of youth who had each of the developmental problems by parent report is presented. Subject numbers for the high, middle, and low groups are 88, 31, and 9.

Measures

Fulfillment in Social Roles (FSR)

The FSR is a 12-item questionnaire developed by the study investigators for use with youth 13-21 years of age (Appendix), based on the view that "participation" can be measured not only by involvement in activities but also in life roles that are meaningful to children and youth. The items were developed based on reviewing the literature, examining related measures, feedback from the participants during pilot testing, and personal practice knowledge. The FSR measures perceptions of importance, performance, and satisfaction in role as a family, friend, student, and member of a group. Self-perceived competence as a friend was measured by the question "How would you rate the way you are able to have friends, help your friends out, and hang out with your friends?" Youth provided their ratings on a 10-point scale ("1=not able to do at all" to "10=able to do extremely well").

Concurrent validity was examined by correlations between scores for self-perceived competence as a friend and two parent-reported questions on the Pediatric Outcomes Data Collection Instrument (AAOS/POSNA, 1994). Higher youth-perceived competence as a friend (1=low, 2=middle, 3=high) was significantly correlated (r_s=.31, p<.001) with higher parental perception of their child's ability to make friends their own age (1=usually hard to 4=usually easy) and also significantly correlated (r_s=.26, p<.01) with how often their child did things with friends in the past week (1=never or rarely, 2=sometimes, 3=often). We did not anticipate a high magnitude of correlation as parents and youth might have different perceptions (Dunn et al., 2007), and self-perceived competence as a friend is a broader construct than that examined by the two parent-report questions.

Children's Assessment of Participation and Enjoyment (CAPE)

The CAPE is a 55-activity measure of participation in leisure and recreational activities excluding mandated school curriculum designed for use with children and youth 6-21 years of age (King et al., 2004). Each activity is categorized by domain (Formal and Informal) and type (Recreational, Physical, Social, Skill-based, and Self-Improvement). Formal activities refer to activities involving rules or goals (e.g., organized sports or art lessons). Informal activities refer to activities that involve little or no prior planning and are often self-initiated (e.g., playing or hanging out). For each activity, five dimensions of participation are measured: Whether the activity was done during the past 4 months, and, if done, How Often, With Whom, Where, and Enjoyment of the activity. Whether the activity was done, How Often, With Whom and Enjoyment were the dimensions analyzed in this study (Table 2). Adequate reliability and validity for the CAPE has been documented. The test-retest reliability for the overall diversity (total numbers of activities done) and enjoyment was .75 and .65 (King, et al., 2004). The construct validity has been demonstrated by that the CAPE scores were correlated with environmental, family, and child variables (King, et al., 2006).

Table 2. The scoring for the dimensions of participation on the CAPE (King et al. 2004)

Dimensions	**Scoring**	
Activity done?	**0**	No
	1	Yes
How Often?	**1**	Once/4 months
	2	Twice/4 months
	3	Once/week
	4	Two to three times/month
	5	Once/week
	6	Two to three times/week
	7	Once/day
With Whom?	**1**	Alone
	2	With family
	3	With other relatives
	4	With friends
	5	With others (instructors, other individuals, or multiple types of people)
Enjoyment?	**1**	Not at all
	2	Somewhat; sort of
	3	Pretty much
	4	Very much
	5	Love it

Gross Motor Function Classification System (GMFCS)

The GMFCS is a five-level system for classifying children with CP based on functional abilities and limitations (Palisano et al., 1997). The preliminary version of the 12-18-year age band of the expanded and revised GMFCS (Palisano, et al., 2008) was used. For the larger study, inter-rater reliability was examined. Each of the 19 research assistants achieved a percent agreement of >80% with the criterion rating.

Procedure

As part of the larger study, data were collected by one to three research assistants at each hospital. Research assistants included nurses, occupational therapists, physical therapists, psychologists and social workers who were experienced in serving individuals with CP. Parents provided youth and family information by completing a demographic questionnaire. Research assistants observe youth's functional abilities and determined their GMFCS levels. Prior to data collection, research assistants made their best judgment about each youth's ability to complete the FSR and CAPE by asking screening questions and through interactions. Youth completed the FSR independently or with adult assistance when they had difficulty with reading, understanding, or marking responses. Youth completed the CAPE by structured interview with the research assistant; parental assistance for recalling whether an activity was done in the past four months was provided as necessary.

Data Analysis

Scores for self-perceived competence as a friend were negatively skewed (skewness = -1.3), with 70% of the youth rated 8 or above (Mean = 8.1, SD =2.2). This presented a challenge to assigning youth into three groups. Based on our interpretation of the response options ("1=not able to do at all" to "10=able to do extremely well"), youth with scores of 8 to 10 were assigned to the high self-perceived competence group (n=94, 69.6%), youth with scores of 5 to 7 were assigned to the middle self-perceived competence group (n=31, 22.9%), and youth with scores of 1 to 4 were assigned to the low self-perceived competence group (n=10, 7.4%). Table 3 presents the distribution of ratings for each group. Chi-square tests and Analysis of Variance were used to examine the differences in demographic characteristics of youth among the three groups, the significance level was $p<.05$.

Three dependent variables were calculated. The *number* of activities done with friends is the sum of the number of activities done where the With Whom dimension was 'With friends'. The *total frequency* of activities done with friends is the sum of the How Often scores for activities done where the With Whom dimension was 'With friends'. The *enjoyment* of activities done with friends is a mean level of enjoyment calculated by the sum of Enjoyment scores for activities done where the With Whom dimension was 'With friends' divided by the number of activities done with friends.

Statistical analyses were performed using the Predictive Analytics Software version 18.0 (SPSS, Chicago, IL). Kruskal-Wallis One-Way Analyses of Variance, a non-parametric statistic, was used to examine group differences in the number, total frequency, and enjoyment of activities done with friends. The significance level was $p<.05$. Post-hoc analysis of significant effects was performed using a Mann-Whitney U test or Kolmogorov-Smirnov test. The Mann-Whitney U test was used for comparison between the high and middle self-perceived competence groups. Due to a small number of participants in the low self-perceived competence group, the Kolmogorov-Smirnov test was used for comparisons with the other two groups because this test is more powerful than a Mann-Whitney U test when a group has a sample size < 25 (Field, 2009). The significance level was $p<.016$ using the Bonferroni adjustment (0.05/3).

Table 3. Distribution of scores for self-perceived competence as a friend for the youth grouped by self-perceived competence as a friend

Self-perceived competence as a friend								
High (n=94)			Middle (n=31)			Low (n=10)		
score	n	%	score	n	%	score	n	%
8	19	14.1	5	9	6.7	1	3	2.2
9	26	19.2	6	8	5.9	2	0	0.0
10	49	36.3	7	14	10.4	3	3	2.2
						4	4	3.0

3.4. Results

Analyses comparing demographic characteristics of youth among the three groups were performed to rule out possible grouping bias. No significant difference was found in age, number of males and females, gross motor function level and prevalence of developmental problems among the three groups (*p values* >.05).

Table 4 presents the descriptive statistics for the number, total frequency, and enjoyment of activities done with friends. For the entire sample, youth participated in a median of 4 leisure activities (IQR=2-9) with friends in the past 4 months. On average, youth performed each activity ‘two to three times per month’ with friends and had a median total frequency score of 18 (IQR=8-40). Only youth who participated in at least one activity with friends (n=127) provided enjoyment scores, and they enjoyed the activities ‘very much’ (Median=4.1, IQR=3.6-4.6). Table 5 presents examples of activities that youth are more likely to do with friends. These activities were majorly informal social activities including hanging out and entertaining others.

The number of activities done with friends differed based on youth’s self-perceived competence as a friend (χ^2=17.07, df=2, p<.001) (Figure 1). Table 6 presents the Z scores for post hoc analyses of significant effects. Youth with high self-perceived competence did more activities with friends than did youth with middle (p<.01) and low (p<.001) self-perceived competence. Youth with middle self-perceived competence did more activities with friends than did youth with low self-perceived competence (p=.01).

The total frequency that activities were done with friends differed based on youth’s self-perceived competence as a friend (χ^2=18.35, df=2, p<.001) (Figure 2). Youth with high self-perceived competence did activities with friends more frequently than did youth with middle (p<.01) and low (p<.001) self-perceived competence. Youth with middle self-perceived competence did activities with friends more frequently than did youth with low self-perceived competence (p=.01) (Table 6). No group differences were found in the enjoyment of activities done with friends (χ^2=1.86, df=2, p>.05).

Table 4. Descriptive statistics for the number, total frequency, and enjoyment of activities done with friends for the youth grouped by self-perceived competence as a friend

Activities done with friends	Self-perceived competence as a friend									
	High			Middle			Low			
	n	Mdn	IQR	n	Mdn	IQR	n	Mdn	IQR	Sig.*
Number	94	6	2-9	31	3	2-6	10	2	1-2	p<.001
Total Frequency	94	25.0	12.0-45.5	31	14.0	5.0-21.0	10	8.5	5.0-10.0	p<.001
Enjoyment	89	4.1	3.6-4.6	28	4.2	3.5-4.7	10	4.0	3.0-4.5	NS

Mdn = Median; IQR = Inter-quartile range; NS = not significant

* Kruskal-Wallis One-Way Analyses of Variance

Number of activities done with friends is the sum of the number of activities done where the With Whom dimension was scored as ‘With friends’.

Total frequency of activities done with friends is the sum of the How Often scores where the With Whom dimension was scored as ‘With friends’.

Enjoyment of activities done with friends is a mean level of enjoyment calculated by the sum of Enjoyment scores where the With Whom dimension was scored as ‘With friends’ divided by the number of activities done with friends.

Table 5. Examples of activities participated with friends by the highest number of youth for each group

Activity	Domain / Type [a]	No. (%) of youth did with friends
High self-perceived competence (n=94)		
Hanging out	Informal / Social	66 (70%)
Talking on the phone	Informal / Social	55 (59%)
Entertaining others	Informal / Social	48 (51%)
Playing games	Informal / Physical	38 (40%)
Going to the movies	Informal / Social	34 (36%)
Middle self-perceived competence (n=31)		
Talking on the phone	Informal / Social	14 (45%)
Hanging out	Informal / Social	12 (39%)
Entertaining others	Informal / Social	9 (29%)
Going to a party	Informal / Social	7 (23%)
Low self-perceived competence (n=10)		
Hanging out	Informal / Social	3 (30%)
Bicycling/skating/skateboarding	Informal / Physical	2 (20%)
Playing games	Informal / Physical	2 (20%)
Entertaining others	Informal / Social	2 (20%)

[a] Activity domain and type based on the CAPE typology (King et al., 2004)

Table 6. Differences among the high, middle, and low self-perceived competence groups

Groups	Z scores for post hoc analyses of significant effects		
	Number	Total Frequency	Enjoyment
High & Middle [a]	-2.62 (p<.01)	-3.14 (p<.01)	NS
High & Low [b]	1.98 (p<.001)	2.30 (p<.001)	NS
Middle & Low [b]	1.32 (p=.01)	1.42 (p=.01)	NS

NS = not significant

[a] Group comparison was performed using the Mann-Whitney U test

[b] Group comparison was performed using the Kolmogorov-Smirnov test

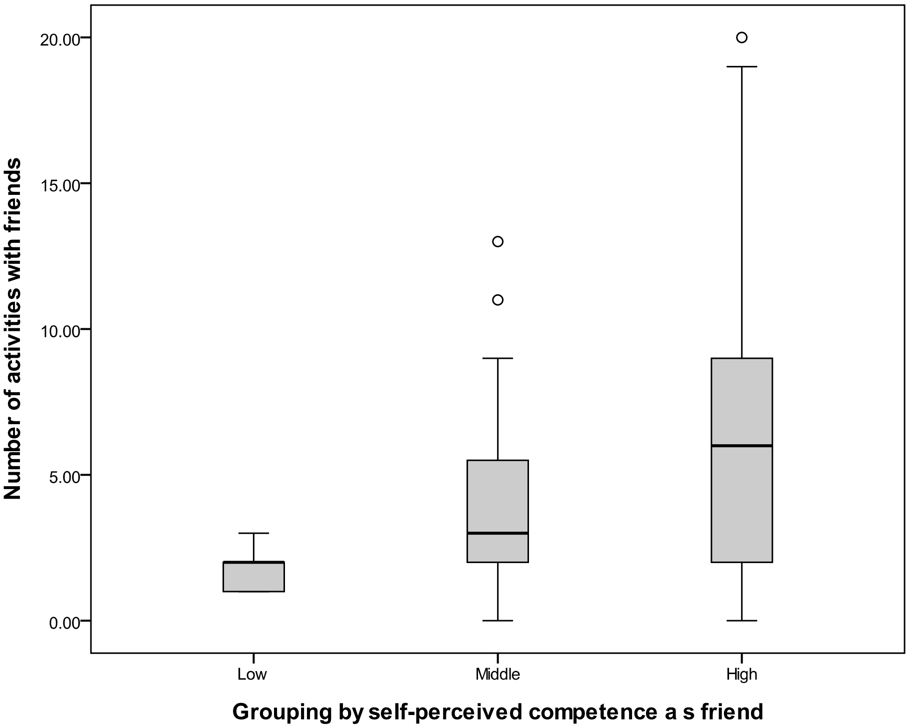


Figure 1. Box plots for the number of activities done with friends of the youth in the three groups

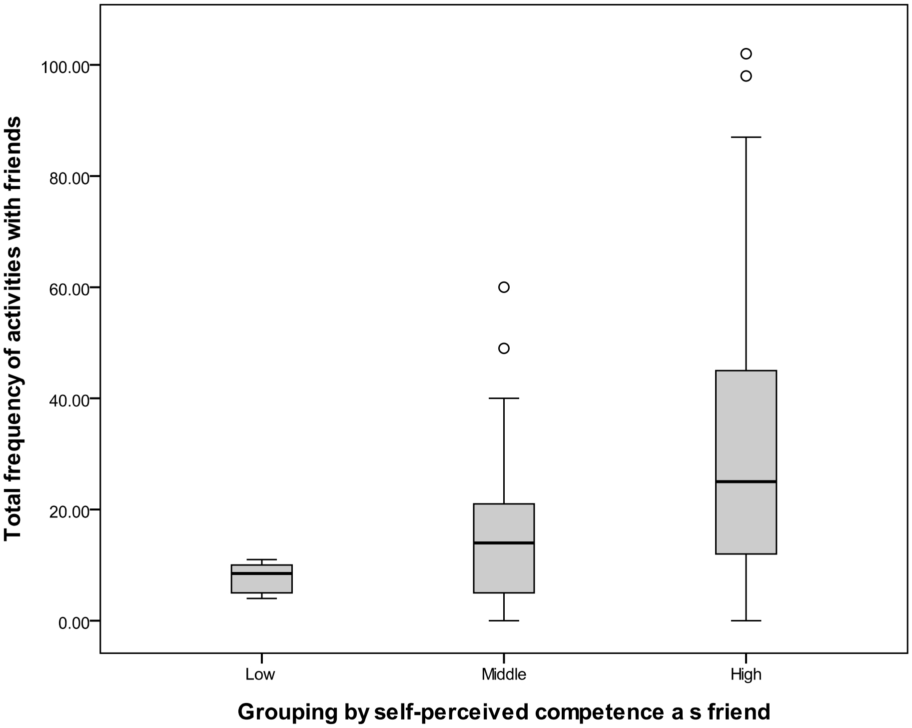


Figure 2. Box plots for the total frequency of activities done with friends of the youth in the three groups

3.5. Discussion

Among youth with CP, those with high self-perceived competence as a friend did the greatest number of activities and had the highest frequency of participation with friends; while youth with low self-perceived competence did the fewest activities and had the lowest frequency of participation with friends. The hypothesis that enjoyment of activities done with friends differs based on youth-perceived competence was not supported. No differences were found in age, sex, gross motor function, and prevalence of developmental problems among youth with high, middle, and low self-perceived competence. Consequently these factors do not appear to mediate differences in the number of activities and frequency of participation with friends. A challenge to interpretation of the results is that the psychometric properties of the measure Fulfillment in Social Roles have not been determined. In addition, self-perceived competence as a friend was measured by a single question that encompasses several constructs related to establishing and maintaining friendships, and helping behaviors.

Our finding that many youth with CP reported high competence as a friend is supported by related studies involving youth with and without disabilities. Anderson-Butcher and colleagues (Anderson-Butcher, et al., 2008) reported that scores for the Perceived Social Competence Scale among 424 children and youth were negatively skewed; most participants reported high competence (means of 3.9 to 4.2 on a 5-point scale). Gaskin and Morris (Gaskin & Morris, 2008) found that scores for psychosocial functioning and perceived social support among 51 adults with CP were negatively skewed; participants reported high levels of social functioning and experienced high levels of social support. A possible explanation is that these youth have developed effective strategies to cope with their limitations during social interaction (Miyahara & Piek, 2006). Receiving emotional and physical support from friends might have been considered as positive interactions (Lightfoot et al., 1999). Another explanation is that youth might have selectively provided ratings for things they were good at for social interaction (Crocker & Major, 1989), or based on their experiences with best friends, the ones they usually spent time together and felt confident to interact with.

Youth with CP who were more competent in being a friend had higher diversity and frequency of participation with friends, which suggests a positive relation between experiences of participation and a sense of competence in role as a friend. Youth who have higher perception of social competence might be more motivated and confident to participate with their friends. In turn, persistent participation with friends provides youth with more experiences in doing things and interacting with friends, thus facilitating social skill development and a sense of competence. This is consistent with the tenet of an ecological/experiential approach, namely that real-life experiences and learning opportunities in daily living optimize the development of life skills, a sense of competence and self-efficacy (Graham et al., 2009; King et al., 2005).

The enjoyment of activities done with friends did not differ based on self-perceived competence as a friend. This may reflect the relatively high enjoyment reported by all participants. Our findings are similar to those of Imms and colleagues (Imms et al., 2008) who reported a mean of 4.0 for overall enjoyment for children with CP. King and colleagues (King et al., 2009) reported a mean of 3.9 for enjoyment of formal and informal activities for children with physical disability.

The findings suggest that a role of health care providers is to support youth with CP to have more opportunities of participation and sustained engagement with friends. Community recreational activities often provide opportunities for establishing friendships. Health professionals may assist youth to access community recreational activities by providing information, transportation, and consultation on activity accommodations and environmental modifications (Thomas & Rosenberg, 2003). For youth in need of better skills to interact with friends, social skills training has been found to increase youths' interpersonal adaptation and problem-solving to manage peer conflict or rejection

(Spence, 2003). Health care providers may also incorporate peer support into service delivery. Peers and friends often provide more emotional support, companionship and exposure to community experiences than family or health professionals (La Greca et al., 1995).

Mentoring, an intervention approach involving peer support, has been shown to positively impact the self-efficacy and community knowledge of individuals with physical disabilities (Hibbard et al., 2002; Powers et al., 1995). Mentors who have similar disabilities may guide youth with CP to gain life skills and competence by sharing experiences, discussing problems, and providing social support. Some mentors may benefit from education and instruction to enhance communication, listening, and advocacy skills, and knowledge of disability and community resources (Hibbard, et al., 2002).

Further study is recommended to examine the effects of peer support and participation with friends on promoting social self-efficacy and psychosocial well-being of youth with CP. In addition, no standardized scale measures the perceptions of competence in roles as a friend. Future work is needed to design a scale that measures constructs related to establishing friendships, maintaining relationships, and helping behaviors, in order to provide a more in-depth understanding of role competence as a friend.

3.6. Conclusions

For youth with CP, the number of activities done and frequency of participation with friends differed based on their self-perceived competence as a friend. The results highlight the need for health care services that enrich social experiences, skills and competence. Services and supports that enhance opportunities for participation in a variety of social leisure activities and encourage sustained engagement with friends may foster a sense of social competence and psychosocial well-being of youth with CP.

3.7. Key Messages

- Youth with CP who perceived themselves as more competent in being a friend participated in more activities with friends in the past 4 months and did these activities more frequently, but did not have more enjoyment.
- Age, sex, gross motor function, and developmental problems did not differ among youth with CP with high and low self-perceived competence as a friend
- There may be a reciprocal relationship between participation with friends and self-perceived competence as a friend. Youth with higher competence might prefer to engage with friends; social experiences with friends might in turn facilitate a sense of competence.
- Participation experiences with friends and peer supports may help to enhance social competence and psychosocial well-being of youth with CP, although further study is needed.

3.8. References

Anderson-Butcher, D., Iachini, A., & Amorose, A. (2008). Initial reliability and validity of the perceived social competence scale. *Research on Social Work Practice, 18*(1), 47-54.

Blum, R. W., Resnick, M. D., Nelson, R., & St Germaine, A. (1991). Family and peer issues among adolescents with spina bifida and cerebral palsy. *Pediatrics, 88*(2), 280-285.

Collins, W. (1997). Relationships and development during adolescence: Interpersonal adaptation to individual change. *Personal Relationships, 4*(1), 1-14.

Crocker, J., & Major, B. (1989). Social stigma and self-esteem: The self-protective properties of stigma. *Psychological Review, 96*(4), 608-630.

De Winter, M., Baerveldt, C., & Kooistra, J. (2002). Enabling children: participation as a new perspective on child health promotion. *Child: Care, Health and Development, 25*(1), 15-23.

Donaldson, S. J., & Ronan, K. R. (2006). The effects of sports participation on young adolescents' emotional well-being. *Adolescence, 41*(162), 369-389.

Dunn, N., Shields, N., Taylor, N. F., & Dodd, K. J. (2007). A systematic review of the self-concept of children with cerebral palsy and perceptions of parents and teachers. *Physical & Occupational Therapy in Pediatrics, 27*(3), 55-71.

Field, A. (2009). *Discovering statistics using SPSS*. London, England: SAGE.

Gaskin, C. J., & Morris, T. (2008). Physical activity, health-related quality of life, and psychosocial functioning of adults with cerebral palsy. *Journal of Physical Activity & Health, 5*(1), 146-157.

Graham, F., Rodger, S., & Ziviani, J. (2009). Coaching parents to enable children's participation: An approach for working with parents and their children. *Australian Occupational Therapy Journal, 56*(1), 16-23.

Harter, S. (1985). *Manual for the self-perceptions profile for children*. Denver: University of Denver Press.

Hay, J., & Missiuna, C. (1998). Motor proficiency in children reporting low levels of participation in physical activity. *Canadian Journal of Occupational Therapy, 65*(2), 64-71.

Hibbard, M., Cantor, J., Charatz, H., Rosenthal, R., Ashman, T., Gundersen, N., et al. (2002). Peer support in the community: Initial findings of a mentoring program for individuals with traumatic brain injury and their families. *The Journal of head trauma rehabilitation, 17*(2), 112-131.

Imms, C., Reilly, S., Carlin, J., & Dodd, K. (2008). Diversity of participation in children with cerebral palsy. *Developmental Medicine & Child Neurology, 50*(5), 363-369.

Kang, L.-J., Palisano, R. J., Orlin, M. N., Chiarello, L. A., King, G., & Polansky, M. (in press). Determinants of Social Participation with Friends and Other Non-Family Members for Youth with Cerebral Palsy. *Physical Therapy*.

King, G., Baldwin, P. J., Currie, M., & Evans, J. (2005). Planning successful transitions from school to adult roles for youth with disabilities. *Children's Health Care, 34*(3), 193-216.

King, G., Cathers, T., Polgar, J. M., MacKinnon, E., & Havens, L. (2000). Success in life for older adolescents with cerebral palsy. *Qualitative Health Research, 10*(6), 734-749.

King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al. (2006). Measuring children's participation in recreation and leisure activities: Construct validation of the CAPE and PAC. *Child: Care, Health and Development, 33*(1), 28-39.

King, G., Law, M., King, S., Hurley, P., Hanna, S., Kertoy, M., et al. (2004). *Children's Assessment of Participation and Enjoyment (CAPE) and Preferences for Activities of Children (PAC)*. San Antonio, TX: Harcourt Assessment, Inc.

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.

King, G., Petrenchik, T., Law, M., & Hurley, P. (2009). The Enjoyment of Formal and Informal Recreation and Leisure Activities: A comparison of school-aged children with and without physical disabilities. *International Journal of Disability, Development and Education, 56*(2), 109 - 130.

King, G., Shultz, I., Steel, K., Gilpin, M., & Cathers, T. (1993). Self-evaluation and self-concept of adolescents with physical disabilities. *American Journal of Occupational Therapy, 47*(2), 132-140.

La Greca, A., Auslander, W., Greco, P., Spetter, D., Fisher Jr, E., & Santiago, J. (1995). I get by with a little help from my family and friends: Adolescents' support for diabetes care. *Journal of Pediatric Psychology, 20*(4), 449-476.

Lavigne, J., & Faier-Routman, J. (1992). Psychological adjustment to pediatric physical disorders: A meta-analytic review. *Journal of Pediatric Psychology, 17*(2), 133-157.

Lightfoot, J., Wright, S., & Sloper, P. (1999). Supporting pupils in mainstream school with an illness or disability: young people's views. *Child: Care, Health & Development, 25*(4), 267-283.

Magill-Evans, J. E., & Restall, G. (1991). Self-esteem of persons with cerebral palsy: from adolescence to adulthood. *American Journal of Occupational Therapy, 45*(9), 819-825.

Marsh, H. W. (1992). Extracurricular activities: Beneficial extension of the traditional curriculum or subversion of academic goals? *Journal of Educational Psychology, 84*(4), 553-562.

McGavin, H. (1998). Planning Rehabilitation: A Comparison of Issues for Parents and Adolescents. *Physical & Occupational Therapy in Pediatrics, 18*(1), 69-82.

McGee, R., Williams, S., Howden-Chapman, P., Martin, J., & Kawachi, I. (2006). Participation in clubs and groups from childhood to adolescence and its effects on attachment and self-esteem. *Journal of Adolescence, 29*(1), 1-17.

Miyahara, M., & Piek, J. (2006). Self-esteem of children and adolescents with physical disabilities: Quantitative evidence from meta-analysis. *Journal of Developmental and Physical Disabilities, 18*(3), 219-234.

Palisano, R. J., Rosenbaum, P., Bartlett, D., & Livingston, M. H. (2008). Content validity of the expanded and revised Gross Motor Function Classification System. *Developmental Medicine & Child Neurology, 50*(10), 744-750.

Palisano, R. J., Rosenbaum, P. L., & Walter, S. (1997). Development and validation of a gross motor function classification system for children with cerebral palsy. *Developmental Medicine & Child Neurology, 39*, 214-223.

Poulsen, A. A., Ziviani, J. M., Cuskelly, M., & Smith, R. (2007). Boys with developmental coordination disorder: loneliness and team sports participation. *American Journal of Occupational Therapy, 61*(4), 451-462.

Powers, L., Sowers, J., & Stevens, T. (1995). An Exploratory, Randomized Study of the Impact of Mentoring on the Self-Efficacy and Community-Based Knowledge of Adolescents with Severe Physical Challenges. *The Journal of Rehabilitation, 61*(1), 33-41.

Shields, N., Loy, Y., Murdoch, A., Taylor, N. F., & Dodd, K. J. (2007). Self-concept of children with cerebral palsy compared with that of children without impairment. *Developmental Medicine & Child Neurology, 49*(5), 350-354.

Shields, N., Murdoch, A., Loy, Y., Dodd, K. J., & Taylor, N. F. (2006). A systematic review of the self-concept of children with cerebral palsy compared with children without disability. *Developmental Medicine & Child Neurology, 48*, 151-157.

Spence, S. (2003). Social skills training with children and young people: Theory, evidence and practice. *Child and Adolescent Mental Health, 8*(2), 84-96.

Stevenson, C. J., Pharoah, P. O., & Stevenson, R. (1997). Cerebral palsy- the transition from youth to adulthood. *Developmental Medicine & Child Neurology, 39*(5), 336-342.

Thomas, A. D., & Rosenberg, A. (2003). Promoting community recreation and leisure. *Pediatric Physical Therapy, 15*, 232-246.

3.9. Appendix

Fulfillment in Social Roles

For adolescents 13 and Older

We would like to learn about what teenagers and young adults think is important in their daily lives. We are interested in 1) what you think is important, 2) your rating of your performance level, and 3) your satisfaction as a family member, friend, student, and member of a group, club, sport's team, or organization. For each question please rate importance, performance and satisfaction on a scale of 1 to 10.

MY ROLE AS A MEMBER OF MY FAMILY

How important is it to you to be able to have responsibilities in your family, spend some time with your family, and hang out with your sisters and brothers?

1	2	3	4	5	6	7	8	9	10
not important at all									extremely important

How would you rate the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not able to do at all									extremely well

How satisfied are you with the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not satisfied at all									extremely satisfied

MY ROLE AS FRIEND

How important is it to you to be able to have friends, help your friends out, and hang out with your friends?

1	2	3	4	5	6	7	8	9	10
not important									extremely
at all									important

How would you rate the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not able to do									extremely
at all									well

How satisfied are you with the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not satisfied									extremely
at all									satisfied

MY ROLE AS A STUDENT AT SCHOOL

How important is it to you to be able to do things at school, participate in group projects, and join in during school events?

1	2	3	4	5	6	7	8	9	10
not important									extremely
at all									important

How would you rate the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not able to do									extremely
at all									well

How satisfied are you with the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not satisfied									extremely
at all									satisfied

MY ROLE AS A MEMBER OF A GROUP, CLUB, SPORTS TEAM, OR ORGANIZATION

How important is it to you to be able to be part of a team or club?

1	2	3	4	5	6	7	8	9	10
not important at all									extremely important

How would you rate the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not able to do at all									extremely well

How satisfied are you with the way you are able to do this now?

1	2	3	4	5	6	7	8	9	10
not satisfied at all									extremely satisfied

CHAPTER 4: SUMMARY

Social participation provides youth opportunities to form meaningful relationships and develop self-identity and has been linked to a sense of competence and meaning in life. The aims of this dissertation were to increase knowledge of the multi-dimensional and interactive nature of social participation in leisure activities of youth with cerebral palsy (CP). This knowledge is important for identifying the structure and processes of service delivery that support social participation of youth with CP.

The aim of Study 1 (Chapter 2) was to identify youth, family, and service determinants of participation with friends and with other non-family members. The aim of Study 2 (Chapter 3) was to explore whether participation with friends differs among youth based on their self-perceived competence as a friend.

The participants included 209 youth 13-21 years old with cerebral palsy (52% males) and their parents. Participants were part of a larger study on Activity and Participation of Children with Cerebral Palsy and were recruited from six Shriners Hospitals for Children and one Children's Rehabilitation Center. The measures included the Children's Assessment of Participation and Enjoyment, Fulfillment in Social Roles, Gross Motor Function Classification System, Coping Inventory, Pediatric Outcomes Data Collection Instrument, Family Environment Scale, Measure of Processes of Care, and Service Questionnaire.

Three modifications to the research proposal were made: re-specification of predictors of participation with other non-family members, the criteria for grouping youth based on their self-perceived competence, and use of non-parametric analyses. In Study 1, none of the correlations between potential predictor variables and number of activities done with non-family members met the criteria for inclusion in the regression model. Predictor variables, therefore, were re-specified to include variables that represent family structure and resources for arranging community activities, such as family organization, education, and income. Among the re-specified variables, however, only parental education met the criteria for inclusion in regression analysis. Consequently, a simple regression analysis was performed for the model of participation with other non-family members.

In Study 2, scores for self-perceived competence as a friend were negatively skewed, which presented a challenge to assigning youth into three groups. The criteria for assigning youth to groups in the proposal were intended to create three groups with similar numbers of participants. Youth were assigned to the highest (rating of 10, n=49, 36.3%), middle (ratings of 8 to 9, n=45, 33.3%), and lowest (ratings of 1 to 7, n=41, 30.4%) ratings of self-perceived competence as a friend. Subsequently, the criteria were modified to better reflect differences in ratings of self-perceived competence regardless of the number of participants in each group. Youth then were assigned to three groups based on operational definitions of ratings that represent low (ratings of 1 to 4, n=10, 7.4%), middle (ratings of 5 to 7, n=31, 22.9%), and high (ratings of 8 to 10, n=94, 69.6%) self-perceived competence as a friend. A parametric analysis, multivariate analysis of covariance, was no longer appropriate to examine the differences in the number, total frequency, and enjoyment of activities done with friends among the three groups. Therefore, non-parametric analyses, including Kruskal-Wallis One-Way Analyses of Variance, Mann-Whitney U tests or Kolmogorov-Smirnov tests were performed.

The Figure illustrates summary findings of the two studies. Youth with CP were more likely to participate with friends in informal social and physical activities. Better sports and physical functioning, communication ability, inclusive education program, and opportunities for desired community recreational activities were associated with participation in more activities with friends. Furthermore, participation in more activities and doing these activities more often with friends was found to be positively affected by self-perceived competence as a friend, an important aspect of psychosocial well being.

Higher parental education, but not youth and service characteristics, was associated with participation in more activities with other non-family members. Activities done with others, including coaches and instructors, were more likely to be formal activities. Perhaps parental education is associated with knowledge of and ability to utilize community resources to enable youth's participation in formal or organized leisure activities.

The findings suggest an expanding role of health care providers and educators to support the efforts of youth with CP to engage with friends and enhance social competence. Physical, occupational, and speech therapy services that promote sports, physical, and communication abilities may enhance social opportunities for participation with friends. Therapists can assist youth to access community recreations by providing information, consultation on transportation, activity accommodations and environmental modifications.

Educators have an important role in facilitating social participation of youth with disabilities as school is a major environment for peer interactions. Peers and friends provide emotional support, companionship, modeling and exposure to community experiences that are desired by youth with CP. Some youth may benefit from guidance by school personnel on initiating and sustaining interactions with peers. In addition, school-based therapies that are integrated into the student's education program and encourage peer support may facilitate social competence.

There were several limitations to my dissertation research. The operational definition did not cover all aspects of social participation, reflecting only the activities youth participated with friends and others. For instance, the extent to which youth were actively engaged in a contextually appropriate manner during the activities and their quality of interactions with friends and others is not known. Additionally, activity preferences were not measured; doing so would have enabled analysis of whether youth preferred certain activities and whether they actually participated in preferred activities.

A challenge to interpreting the scores of self-perceived competence as a friend is that the psychometric properties of the measure Fulfillment in Social Roles have not been determined. Research is needed to determine the reliability and validity of this measure. In addition, self-perceived competence as a friend was measured by a single question involving constructs related to establishing friendships, maintaining relationships, and helping behaviors. Research is recommended to measure these constructs separately, in order to provide a more in-depth understanding of role competence in being a friend.

Further research is needed to identify the structure and processes of health care services that promote successful social participation of youth with CP. Health professionals can offer multiple approaches of service delivery, such as education, direct intervention, and consultation. An intervention program that incorporates peer support may be effective in promoting social participation and emotional well being. Clinical trials are recommended to determine the effectiveness of participation-focused interventions on fulfilling life roles that are essential and meaningful to youth with CP.

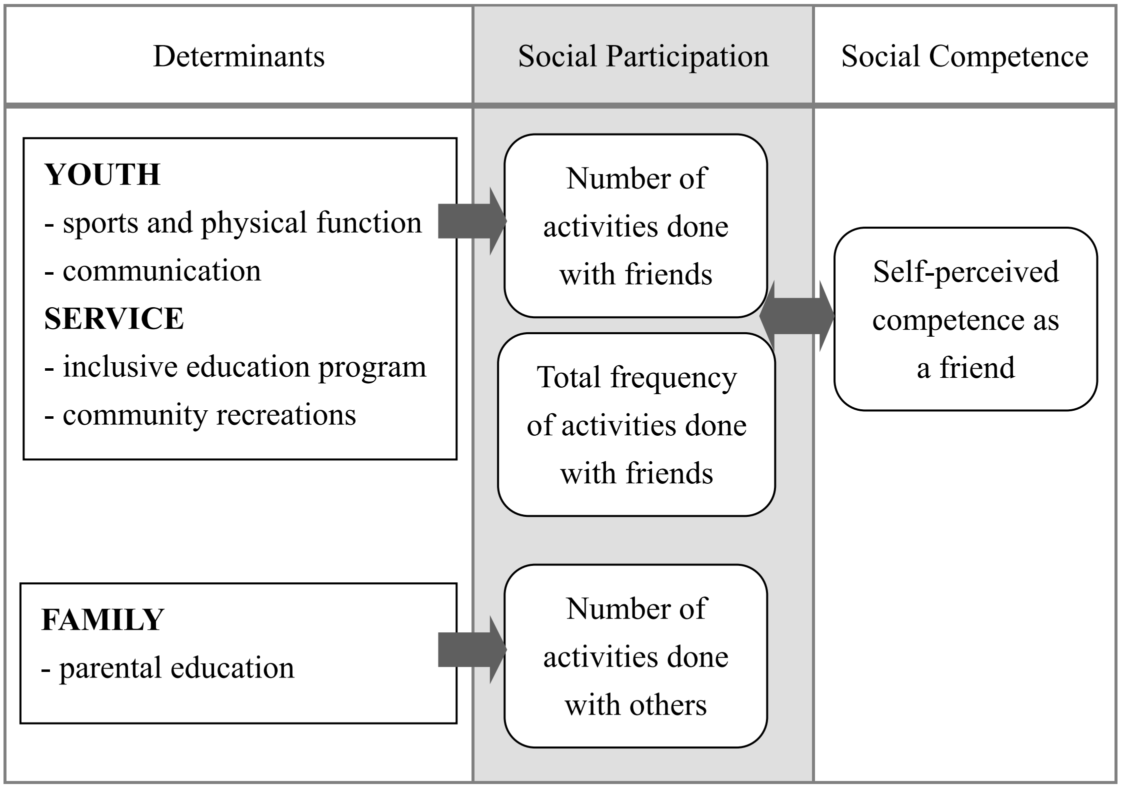


Figure. Summary findings of the two dissertation studies

VITA

BIOGRAPHICAL SKETCH

NAME Lin-Ju Kang

EDUCATION/TRAINING

INSTITUTION AND LOCATION	DEGREE	MM/YY	FIELD OF STUDY
Chang Gung University, Tao-Yuan, Taiwan	B.S.	06/2003	Physical Therapy
National Yang-Ming University, Taipei, Taiwan	M.S.	06/2005	Physical Therapy (Pediatrics)
Drexel University, Philadelphia, PA, USA	Ph.D.	06/2010	Physical Therapy (Pediatrics)

A. Personal Statement

My goal is to apply knowledge and skills to attain academic and clinical positions in pediatric physical therapy, and to achieve excellence in research and practice.

B. Positions and Honors

Positions and Employment

2003 - 2005	Graduate Research Assistant, Dept. of Physical Therapy and Assistive Technology, National Yang-Ming University, Taipei, Taiwan.
2005 - 2006	Research Assistant/Project manager, School and Graduate Institute of Physical Therapy, National Taiwan University, Taipei, Taiwan.
2006 - 2010	Graduate Research Assistant, Department of Physical Therapy & Rehabilitation Sciences, Drexel University, Philadelphia, PA, USA.

Other Experience and Professional Memberships

2003-present	Honorary member of The Phi-Tau-Phi Scholastic Society of R.O.C
2003-2005	Member, Physical Therapy Association of Taiwan
2007-2009	Member, American Physical Therapy Association

Honors

2003 - 2004	Academic scholarships for master’s students, National Yang-Ming University, Taipei, Taiwan.
2006 - 2008	Drexel University Provost Fellowship, Philadelphia, PA
2008 - 2010	Drexel University Travel Awards, Philadelphia, PA
2010	Highly Commended for Best Dissertation, Drexel University Graduate School Excellence Committee, Philadelphia, PA

C. Selected Peer-reviewed Publications

Published Journal Articles

1. **Kang LJ**, Chen YP, Sung WH, Chuang TY, Lee SJ, Tsai MW, Jeng SF, Doong JL. Training Effects of Virtual Reality on Reaching Behavior in Children with Cerebral Palsy: Case Report. *Formosan Journal of Physical Therapy,* 30: 339-47, 2005.
2. Chen YP, **Kang LJ**, Chuang TY, Doong JL, Lee SJ, Tsai MW, Jeng SF, Sung WH. The Use of Virtual Reality to Improve Upper-Extremity Control in Children with Cerebral Palsy: A Single-Subject Design. *Physical Therapy,* 87: 1441-1457, 2007.
3. Palisano RJ, **Kang LJ**, Chiarello L, Orlin M, Oeffinger D, Maggs J. Social and Community Participation of Children and Youth with Cerebral Palsy is Associated with Age and Gross Motor Function Classification. *Physical Therapy*, 89: 1304-1314, 2009.
4. Orlin M, Palisano RJ, Chiarello L, **Kang LJ**, Polanky M, Almasri N, Maggs J. Participation in Home, Extracurricular, and Community Activities among Children and Youth with Cerebral Palsy. *Developmental Medicine and Child Neurology*, 52: 160-166, 2010.
5. Chiarello L, Palisano RJ, Maggs J, Orlin M, Almasri N, **Kang LJ**, Chang H. Family Priorities for Activity and Participation of Children and Youth with Cerebral Palsy. *Physical Therapy*, in press.
6. **Kang LJ**, Palisano RJ, Orlin M, Chiarello L, King G, Polansky M. Determinants of Social Participation with Friends and Other Non-Family Members for Youth with Cerebral Palsy. *Physical Therapy*, accepted for publication.

Published Abstracts

1. **Kang LJ**, Palisano RJ, Orlin M, Chiarello L, Polansky M, Maggs J. Social and Community Particpation Among Children and Youth with Cerebral Palsy. *Developmental Medicine and Child Neurology,* 51(suppl 5): 82-83, 2009.
2. **Kang LJ**, Polansky M, Palisano R, Orlin M, Chiarello L, Maggs J. Social Engagement and Community Participation Among Children and Youth with Cerebral Palsy. *Pediatric Physical Therapy*, 21(1): 92, 2009.
3. Orlin MN, Chiarello LA, **Kang LJ**, Palisano RJ, Polansky M, Almasri N, Maggs J. Participation Among Children with Cerebral Palsy. *Developmental Medicine and Child Neurology,* 51 (suppl 5): 70, 2009.
4. **Kang LJ**, Palisano RJ, Orlin M, Chiarello L, Polansky M, King G. Determinants of social participation with friends and other non-family members among youth with Cerebral palsy. *Pediatric Physical Therapy*, 22(1): 98, 2010.