



Final Report to Families and Community Partners on the Participate Study Findings

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Introduction

About this report

This summary report describes the objectives, methods, and key findings of a three year study of the leisure and recreational activities of school age children and youth with physical disabilities in Ontario, Canada. A team of researchers from *CanChild* Centre for Childhood Disability Research, Thames Valley Children's Centre, and the Hospital for Sick Children worked together on this project. The purpose of the study was to examine the child, family and environmental factors that influence the leisure and recreational participation of children and youth with physical disabilities.

We begin this report by defining participation and describing its relevance to children's health, well-being and development. We then explain the study's main objectives, describe how we measured and gathered information about children's participation and share the study's primary findings. We also discuss findings from a comparative study of the leisure and recreational participation of children without physical disabilities. In the final section of the report, we discuss the meaning of key findings and offer suggestions about how families, service providers, and policy makers may use these findings to support the leisure and recreational activities of children and youth with physical disabilities.

This report is designed for use by a broad audience including families, service providers and organizations, policy makers and government agencies, planners, educators and school boards, researchers, and interested members of the public concerned with the health and well-being of children and youth with physical disabilities. Our goal in using this style of reporting is to establish common knowledge about the leisure and recreational activities of children with physical disabilities and related factors that have the potential to support the participation of these children and youth.

What is participation and why is it important?

The World Health Organization (WHO), in the new International Classification of Functioning, Disability and Health, defines participation as involvement in a life situation (2001). For children and youth, involvement in life situations includes participation in recreational and leisure activities as well as school and work activities. Recreational and leisure activities include artistic, creative, cultural, active physical, sports, play, social, and skill-based activities (Kalscheur, 1992; King et al., 2003; Sloper, Turner, Knussen, & Cunningham, 1990).

Regular participation in day-to-day activities is an important aspect of children's health, well-being and development. Participation in leisure and recreational activities has been shown to be of benefit to the development of children's skills and competencies, social relationships, and children's long-term mental and physical health (Caldwell, 1990; Forsyth & Jarvis, 2002; Larson & Verma, 1999; Lyons, 1993; Simeonsson et al., 2001; Werner, 1989).

Why is this study important?

Currently, we know very little about the leisure and recreational participation of children and youth with physical disabilities. The research that does exist has shown that children and youth with disabilities are more limited in their participation than children without disabilities (Brown & Gordon, 1987; Canadian Institute of Child Health (CICH), 1994; Stevenson, Pharoah & Stevenson, 1997). Yet, we have much to learn about how and in what ways the activities of children with physical disabilities differ from those of their peers. It is important to identify and understand factors within the child, family and environment that influence these children's participation.

Studies like this give us a better understanding of children's participation and the factors that influence their participation. This information is necessary to design effective interventions and create public policies that increase accessibility and opportunities for all children to participate in leisure and recreational activities at home and in their communities.

What were the objectives of this study?

The primary objective of the study was to describe the patterns of participation of children and youth with physical disabilities, and to examine how these patterns change over time. We also wanted to determine the child, family and environmental factors that enhance participation in formal and informal activities of childhood.

How did we describe patterns of participation?

We have described children's patterns of participation using an activity categorization scheme developed in the *Children's Assessment of Participation and Enjoyment* (CAPE; King et al., 2004), a measurement tool designed specifically for this study. Using the CAPE, we organized children's activities into two broad categories, formal and informal activities. Formal activities are structured activities that involve rules and a leader, coach or instructor (Sloper et al., 1990). Formal activities typically require advance planning, and may involve fees or require resources such as transportation. Team sports and lessons are examples of formal activities. Informal activities are more spontaneous in nature and are often initiated by the child or youth. Examples of these activities include bicycle riding, watching TV, or reading.

The CAPE was also designed to measure and describe children's involvement in five specific types of activities: recreational, active physical, social, skill-based and self-improvement. By organizing children's activities into these five activity types we were able to look at children's patterns of participation in groups of activities that share certain characteristics. As a result of these grouping schemes, we were able to describe a broad but detailed picture of children's participation. We were also able to identify factors that played a significant role in influencing the intensity of children's participation in formal and informal activities.

Methods

This study involved 427 children with physical disabilities and their families. Families were recruited through 11 publicly funded regional children's rehabilitation centres and one outpatient department of a children's hospital in Ontario. The children who participated were 6 to 14 years of age at the time of recruitment and had a range of physical functional limitations. In 2001-2003 we collected child and family data at three points in time at nine month intervals using mail-out questionnaires, followed by a home-based interview with the child. The data presented in this report come from the first of these three points of data collection.

How did we gather information about participation?

The study team designed and used two related but independent measures, the *Children's Assessment of Participation and Enjoyment (CAPE)* and the *Preferences for Activities of Children (PAC)*; King et al., 2004). These measures were used to gather information on multiple dimensions of children's participation in everyday activities outside of their mandated school activities. These two measures have recently been published by The Psychological Corporation and can be used by service providers in clinical practice or by researchers interested in the participation of children with or without disabilities.

The version of the CAPE used in this study included 49 items that provided information about five dimensions of children's participation: diversity (number of activities done), intensity (frequency of participation based on the total number of possible activities within a category), with whom and where activities take place, and children's enjoyment of the activities in which they participated. The final, published version of the CAPE includes 55 items. The PAC, which is an extension of the CAPE, measures children's preferences for the same activities contained in the CAPE. In addition to providing information about five dimensions of participation, the CAPE allows three levels of scoring: Overall Participation scores, Formal and Informal scores, and scores for each of the five Activity Types (recreational, active physical, social, skill-based and self-improvement).

As with any new tool, validation is an on-going process; preliminary assessments of the CAPE and PAC have demonstrated sufficient internal consistency, test-retest reliability and validity (King et al., 2004). Evidence suggests CAPE scores can provide reliable and valid inferences about a child's activity patterns. The CAPE and PAC manual (King et al., 2004) provides extensive information about the development and assessment of these tools.

What other information was collected?

In addition to the CAPE and PAC, families completed several standardized measures and questionnaires. These were used to gather information about child, family and environmental factors that might influence dimensions of children's participation.

How did we analyze the data?

We began our analyses by examining the demographic data to learn more about the children and families in the study. Examples of demographic data include information about how many boys and girls were in the study, their ages, what types of communities the families were from, and family income. We then looked at the participation data to see if there were any patterns that we might want to explore further. We looked at similarities and differences in participation diversity, intensity, and enjoyment for boys and girls and across the different age groups (6-8, 9-11, 12-14 years).

After this initial work was completed, we used more complex statistical methods (structural equation modeling) to construct a model of how child, family and environmental factors affected the intensity of children's formal and informal participation in leisure and recreational activities.

What is a model of factors?

A statistical model is a mathematical representation of how factors operate together to influence or predict a particular outcome. In this study, we were interested in examining how a collection of child, family and environmental factors operated together to influence the intensity of children's participation in recreational and leisure activities.

Before the study began we proposed a conceptual model of factors affecting the recreational and leisure participation of school-aged children with physical disabilities (King et al., 2003). In effect, this model was a mini-theory about how the child, family and environmental factors we measured would operate together to influence the intensity of children's participation.

Once data collection and our initial analyses were complete, we used a statistical method known as structural equation modeling to test whether our initial conceptual model of factors (King et al., 2003) was similar to the data we collected. These results, which include the factors that significantly influenced participation intensity for children with physical disabilities, are discussed later in this report.

Findings

Who were the children in the study?

The 427 children and youth in the study were 6 to 14 years old at the time of enrollment in the study. Most of the children (41%) were between 9 and 11 years old. The percentages of study participants in the 6 to 8 age range (29%) and 12 to 14 age range (30%) were similar. Slightly more boys (54%) than girls (46%) participated in the study.

The participants had a wide range of physical disabilities (see Table 1). The majority of the children and youth had cerebral palsy (51%) while the other children and youth in the study had a number of different types of health or developmental problems.

Table 1			
About the children and youth in the study			
		# of Children and Youth	% of Children and Youth
Child's age	6-8 years	125	29.3
	9-11 years	176	41.2
	12-14 years	126	29.5
Child's sex	Male	229	53.6
	Female	198	46.4
Child's health or development problem	Cerebral palsy	216	50.8
	Skeletal disorder	54	12.7
	Spina bifida	52	12.2
	Acquired brain injury	25	5.9
	Neuromuscular disorder	20	4.7
	Minor motor difficulties	18	4.2
	Developmental delay	12	2.8
	Other	30	6.7

Who were the families in the study?

The families involved in this study lived in various types of communities in Ontario. Half of the families lived in major cities, 32% lived in smaller cities, and 18% lived in small towns or rural areas. The majority of child participants (83%) lived in a two-parent family and the parent respondents were primary females (89%). Just over half (51%) of the families reported annual incomes of less than \$60,000 while 47% of families reported annual incomes over \$60,000. In 2000, the median family income for Ontario was \$61,000 (Statistics Canada, 2001).

What did we learn about the participation of children with physical disabilities?

As expected, we found differences in participation based on children's sex and age. These differences are described in the sections that follow. We also examined the effect of diagnosis on children's participation. To accomplish this we collapsed the eight diagnostic categories that appear in Table 1 into two broad categories, Central Nervous System impairments and Musculoskeletal impairments. We then tested for differences in children's participation intensity based on these two categories. We found no significant differences in participation intensity for children in these two groups after we accounted for differences in age, sex and functional ability (Law et al., 2004).

Diversity of Participation

In looking at the diversity or number of activities in which the children participated, we found that children with physical disabilities participated in a diverse range of activities, particularly informal activities. Children and youth participated in a greater number of informal activities than formal activities. The most common activities among children with physical disabilities, which were all informal in nature, included watching T.V., listening to music, playing computer/video games, and crafts/drawing. Girls tended to do more social and skill-based activities, while boys participated in more active physical activities. The range of activities was less diverse for youth 12 years or older, particularly within recreational activities.

Intensity of Participation

In terms of participation intensity, boys participated more intensely in active physical activities, whereas girls participated more intensely in both social and skill-based activities. Older children's overall participation and participation in informal activities was less intense than that of younger children. Given that some of the activities, such as pretend play, are more appropriate for younger children, it is not surprising that participation patterns among the older group of children differed from the younger age group.

Context of Participation

We also looked at the context of children's participation - with whom and where children participated in activities. Children reported they typically participated in recreational, social, and self-improvement activities either alone or with family and relatives. Active physical and skill-based activities were generally done with friends and others. In looking at where activities took place, recreational and self-improvement activities took place most often in the child's home or in a relatives' home. Active physical, social and skill-based activities took place in a variety of locations, including school, community, and other locations outside the immediate community.

Enjoyment of Participation

Children and youth rated their level of enjoyment of activities on a five-point scale ranging from "not at all" to "love it". Their ratings were then averaged to obtain scores for their overall enjoyment, their enjoyment of formal and informal activities, as well as their enjoyment of the five activity types (recreational, active physical, social, skill-based and self-improvement). Looking across this range of scores we found significant differences for boys and girls. Girls reported greater enjoyment of formal, informal, social, skill-based and self-improvement activities than did boys. There were also differences in age groups. Children and youth in the older age group showed decreased overall enjoyment of activities in which they participated.

What did we learn about the participation of children without physical disabilities?

An additional study was conducted with 354 school-aged children without physical disabilities and their families. These families, all of whom lived in the London, Ontario area were recruited through the assistance of the Thames Valley District School Board.

The purpose of the study was to gather information about the leisure and recreational participation of children without physical disabilities. This allowed us to explore whether and what ways the participation of children with and without physical disabilities differed.

Children and youth without physical disabilities participated in a broad range of activities. Like children with physical disabilities, children without physical disabilities participated in more informal activities than formal activities. The intensity of their participation was similar to children with disabilities, with both groups of children participating more intensely in informal activities than formal activities. The diversity and intensity of recreational activities for children without a physical disability declined across the three age groups (6-8, 9-11, 12-14 years). It is important to remember that these data reflect age-related differences in participation among separate groups of children, not the same children as they grow older.

How do the results compare between children with and without physical disabilities?

We found significant differences in the diversity and intensity of children's overall participation between children with and without physical disabilities. Generally, children without physical disabilities participated in a greater number of activities in their overall, formal and informal activities than did children with physical disabilities. We also found small differences in the intensity of children's participation. Children without physical disabilities participated slightly more intensely in their overall activities as well as in their formal and informal activities than did children with physical disabilities. We also found that children without physical disabilities participated more intensely in the five types of activities measured in this study than did children with physical disabilities.

What factors influence participation for children with physical disabilities?

In this study, we also collected information about environmental, family and child factors that might influence participation intensity in formal and informal activities. In our analyses, we examined the influence of these factors in two ways. We examined simple relationships between each factor and formal and informal participation intensity (pair-wise relationships). However, simple pair-wise relationships can be quite different than those observed when the factors are arranged in a model, because pair-wise relationships do not take into account the complex inter-relations among other relevant factors within a model. For this reason we used data for the 427 children and youth with physical disabilities and structural equation modeling to test a comprehensive model of recreational and leisure participation to determine the relative influence of environmental, family and child-related factors on participation intensity.

In looking at the simple pair-wise relationships between each factor and formal and informal participation intensity, we found that children participate more intensely in informal activities when social support from friends, parents, and teachers is higher.

Social support did not have a significant relationship with children's participation in formal activities. Likewise, environmental supports such as physical accessibility, resource availability and program policies were significantly related to participation in informal activities, but not formal activities.

From the perspective of family factors, children had increased levels of both formal and informal participation when families reported higher levels of family cohesion, had higher incomes, and when families reported greater participation in recreational and social activities and greater interest in political, intellectual and cultural activities.

The significant child factors that related to formal and informal participation intensity included children's formal and informal activity preferences and functional abilities. In this study, children's functional abilities included cognitive, communicative, and physical functioning, as well as their physical health status.

Within the structural equation model, child functional abilities, child preferences for formal and informal activities, and the family's orientation to activities (family participation in social and recreational activities and interest in political, intellectual and cultural activities) were significant, direct predictors of participation intensity. Children's functional abilities had the strongest direct influence on informal participation intensity, whereas children's preference for formal activities had the strongest direct influence on the intensity of children's formal participation.

In addition, several family and environmental factors had an indirect influence on participation intensity through their effects on child functioning, family orientation to activities and child activity preferences. At the level of the family, these factors were degree of family cohesion and family income. At the level of the environment, these factors were support to the child from parents, friends, and teachers and the presence of a supportive environment. By supportive environment we mean physical, social and attitudinal environments that parent respondents perceived as accessible, accommodating, socially supportive and non-discriminatory for their child.

What factors influence children's enjoyment of activities?

For children with disabilities, enjoyment of activities was found to increase with higher levels of social support from friends and classmates. Children with higher levels of physical, cognitive and communicative functioning tended to enjoy activities more. Children with high self-esteem and with parents who had fewer emotional difficulties had higher enjoyment ratings. The activities the children enjoyed the most were the ones they preferred to do.

Discussion

What do the results of the study mean?

The participation of children with physical disabilities is extensive, particularly their participation in informal activities. The findings in this study are similar to those of other studies with children with disabilities (Brown, 1987; Sloper et al., 1990) which found relatively less participation in formal and active physical activities. Children with disabilities participate in more informal activities than they do formal activities. Although there was variation in participation in informal activities, all the children in the study participated in some informal activities. In contrast, there were some children in the sample (6%) who did not participate in any formal activities. Of the children who participated in at least one formal activity (94%), only 60% participated in formal activities once a week or more.

Other research study findings from children with and without disabilities indicate that children who participate in formal activities outside of school have better outcomes (Canadian Council on Social Development (CCSD) & Canadian Policy Research Networks (CPRN), 2001). These children tend to have higher self-esteem, better social relationships, and higher academic achievement (Brown, 1987; Larson & Verma, 1999; CCSD & CPRN, 2001). Participation in extracurricular activities also promotes competence and buffers the effects of childhood adversities (Garton & Pratt, 1991; Stewart, Reid, & Mangham, 1997; Werner, 1989).

It is important to keep in mind that participation in more activities is not necessarily better (Forsyth & Jarvis, 2002; Henry, 1998). For example, a child might choose to participate in fewer activities but may have intense involvement in these activities. Another child might be involved in several activities, but participate in them very infrequently. The important consideration concerns children being unable to participate in activities in which they would like to be involved.

Our findings indicate that several factors within the child, family and environment directly and indirectly influenced the intensity of recreational and leisure participation for children with physical disabilities. The most important direct predictors of children's participation were children's functional abilities, their preferences, and family orientation to activities.

A number of other family and environmental factors had significant indirect effects on children's participation, which means that they influenced the intensity of children's participation through various pathways. These pathways indicated the importance of supportive environments, supportive child relationships, family income, and family cohesion. We found that supportive environments (i.e., environments that are accessible, accommodating, socially supportive, non-discriminatory, and resource ready) influenced participation intensity through their effects on children's functional ability. Greater social support from friends, parents, and teachers enhanced participation by affecting children's activity preferences.

With respect to the family, we found that family cohesion had a strong effect on family members participating together part in social and recreational activities, which in turn affected children's participation intensity. Family income indirectly influenced children's participation intensity through its effects on family orientation to activities. Thus, families play an important role in providing opportunities, support, and encouragement for children to take part in various activities.

This research study and its findings demonstrate the complexity of participation. Each child is different in how they participate in everyday activities and there are many factors which influence their participation patterns. Participation is best understood by examining children and families within their environments. Interventions to increase participation need to be implemented at various levels – including the community environment, the family, and the child.

How can we use these findings?

Families

The findings of this study will be useful for children and youth with disabilities and their families by providing knowledge to parents about what they can do to promote their child's participation. It is important that we recognize that children with disabilities are participating in an extensive range of activities. While results of this study indicate there are still differences in participation between children with and without disabilities, these differences are less extensive than those reported 10 to 20 years ago.

The role that families play in enabling their children's participation is vital. Families provide the context and support for children to explore participation in the activities which they prefer. Together with their child, the family can examine which activities both they and their children are interested in doing. Matching family and child activity preferences is one of the factors that will likely lead to greater participation. Families can seek assistance from service providers to help identify activities in which their children can participate and develop supports to enhance such participation.

Service Providers and Organizations

The findings provide service providers with knowledge about important factors that affect the intensity of leisure and recreational participation for children with physical disabilities. For example, knowing the major roles played by child functioning, family activity preferences, and child preferences indicates that therapists should pay attention to these – assess them formally and discuss this information with families. Use of the *Children's Assessment of Participation and Enjoyment (CAPE)* and *Preferences for Activities of Children (PAC)* provides information to facilitate matching a child's activity preferences to their participation. The results from the assessment can serve as a tool to begin a discussion about the fit between the child and activities available within their environment.

The findings of this study will also enable service providers to work with families to compare the participation of individual children with data available from the CAPE (King et al., 2004) and to identify goals and areas for intervention. For example, if the child prefers to participate in active physical activities in the neighborhood or community, the service provider and family can work together to facilitate such activity involvement. Service providers can assist families in their understanding of the importance of participation and provide support and programs to improve children's accessibility to activities.

The CAPE and PAC, which were developed for this study, can be used to evaluate the effectiveness of interventions and services designed to enhance or promote children's leisure and recreational participation.

Policy Makers

Policy makers and communities can use these findings to develop programs and supports that facilitate the participation of children with physical disabilities who are facing barriers. Findings from this study indicate there are multiple inter-related determinants of recreational and leisure participation for children with physical disabilities. The most important predictors of participation were children's functional abilities, their preferences for formal versus informal activities, family involvement in social and recreational activities, and family preferences for political, intellectual, and cultural activities. Other family and environmental factors played significant but smaller roles in influencing participation through their effects on these more direct determinants. These other factors included supportive environments, family income, family cohesion, and supportive relationships for the child. Identifying key determinants of participation and pathways to enhanced participation will assist policy makers in mobilizing the resources and supports necessary to foster the recreational and leisure participation of children with physical disabilities.

From a policy standpoint, it is important to stress that the child, family and environmental factors in this study operated together as an interdependent system. Seen from this perspective, efforts to promote children's participation must take into account the interrelationships between the child, family, and the social and physical environments in which children live, learn and play. Because there are multiple and interconnected levels of influence on children's participation (intrapersonal, social, physical environment and policy), policy interventions are likely to be most effective when they address both direct determinants and factors involved in pathways leading to enhanced participation intensity.

For example, our findings show that, through the indirect pathways we described earlier, children participate more intensely when environmental barriers are lower, family income is higher, when social supports to the child are higher, and when family members help and support one another (cohesiveness).

Policy interventions therefore need to address both the direct determinants of children's enhanced participation, and environmental and family factors that have indirect effects. The findings suggest the importance of multi-pronged approaches aimed not only at the child, but at the family and environmental levels as well. For instance, the findings suggest the importance of reducing environmental barriers because these affect children's participation by influencing the child's functional ability.

Findings of this study illustrate the fundamental role that families play in enhancing children's participation. Families who have a child with a disability experience greater stress and significantly more health problems than families whose children do not have a disability (Brehaut et al., 2004). Learning what works best to support families of children with disabilities is essential. Certainly, policies which support families' access to information and services to enhance participation in a coordinated manner are important. Policies which subsidize children's participation in after-school programs and community-based activities may be particularly important for families of lower income to ensure that their child with a disability can participate in activities of their choice (Canadian Council on Social Development, 2001; Larner, Zippiroli & Behrman, 1999).

Where do we go from here?

Through ongoing analyses, we are examining how children's participation changes over time. Using longitudinal data from this study we will be developing a comprehensive model of child, family and environmental factors affecting the leisure and recreational participation of children with physical disabilities.

We are distributing this summary report to families, children's rehabilitation centres, family organizations, parent networks, granting agencies, school boards and government agencies. This broad distribution will help to ensure that the findings are available to a wide range of stakeholders. We will also present these findings at conferences and write papers for journals to share the results with national and international health care professionals and child advocates.

The findings of the study will help to guide our thinking about future research and consultation in this area.

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We would like to thank the 427 families from across Ontario who were involved in the Participate Study. The many hours they spent filling out questionnaires and completing interviews made this study a success. The information they shared with us is invaluable and will make a difference in the lives of many children and families.

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Grandview Children's Centre, Oshawa, Ontario
Hospital for Sick Children, Toronto, Ontario
KidsAbility Centre for Child Development, Waterloo, Ontario
Ottawa Children's Treatment Centre, Ottawa, Ontario
Pathways Health Centre for Children, Sarnia, Ontario
PRISM Centre for Audiology and Children's Rehabilitation, Chatham, Ontario
Thames Valley Children's Centre, London, Ontario

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