



Parent Needs & Strategies for Promoting Child Participation

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BACKGROUND

- For children, participation plays an important role in the establishment of physical and mental well-being, skill development, provision of grounds for social bonding and interpersonal skill development, improvement of peer interactions and school performance, and yielding better developmental outcomes in adulthood (Cosbey, Dunn, & Johnston, 2010; Desha & Ziviani, 2007; Law et al., 2006).
- Participation has been associated with academic success, lower rates of school dropout and reduced arrests in young adulthood; and the ability to set and obtain personal goals (Cairns, Farmer, & Mahoney, 2003; McNeil, 2009).
- Lack of participation at younger ages can lead to reduced motivation later in life (McNeil, 2009).
- In comparison to children without disabilities, participation of children with disabilities is often of lesser quality and frequency. Among children with physical disabilities, there is greater restriction in participation, more time spent in passive activities, less variation, and fewer social engagements (Law et al., 2006).
- Children with disabilities are more frequently isolated from participating in social activities, due to the nature of their disabilities or limited opportunities to engage with typically developing peers (Cosbey, Dunn, & Johnston, 2010; Elksnin & Elksnin, 1995; Panacek & Dunlap, 2003)

OBJECTIVES

- Primary Purpose:** To examine parent needs and strategies for promoting participation of their children in the contexts of home, school, and community based on data collected from a new measure: The Participation and Environment Measure for Children & Youth (PEM-CY).
- Secondary Purpose:** To compare open-ended responses about parent needs and strategies between parents of children with and without disabilities.

METHODS

Data Collection: This study examined existing data that were collected for the larger study that developed and tested the PEM-CY (Coster, et al., in press). Data collection for the larger study occurred from May 2010 to October 2010. Recruitment occurred through collaboration with various agencies and colleagues. Participants completed the web-based version of the PEM-CY and a demographic questionnaire.

Participants were parents/guardians of children with and without disabilities across the U.S. and Canada (n=576) who met the following selection criteria: (1) were the legal guardian of a child who was the focus of the survey, (2) could read English, and (3) the child who was the focus of the survey was between 5-17 years of age.

Data Analyses: Data from open-ended questions regarding parent strategies and needs were analyzed through use of content analysis and thematic coding. Codes were generated through identification of recurring patterns identified in data. Results were compared for children with disabilities and children without disabilities.

SAMPLE DEMOGRAPHICS (n=576)

Demographic Category	*Percent of Respondents
Child's disability status	Disability (49%); No Disability (51%)
Type of disability (Parent could report up to three conditions)	Multiple physical, cognitive and psychosocial conditions often reported. The most frequent conditions were: Orthopedic Impairment (36%); Developmental Delay (26%); Speech or Language Impairment (21%); Health impairment (18%); Autism Spectrum Disorder (17%)
Country of Residence	USA (37%); Canada (63%)
Language Spoken at Home	English: (97%); Other (3%)
Community Type	Major Urban (46%); Suburban (34%); Small Town (16%); Rural (4%)
Respondent	Mother (90%); Father (8%); Other (2%)
Respondent Education	High School or less (5%); Some College/ Technical training (14%); College Graduate (49%); Graduate Degree (33%)
Annual Income Before Taxes	\$80,000 or more (62%); Less than \$80,000 (35%); Not reported (3%)
Child Gender	Male (54%) Female (46%)
Child Race/Ethnicity	Caucasian-non-Hispanic (81%); Black (3%); Latin American/Hispanic (2%); South Asian (2%); Chinese (2%); Other or not reported (10%)
Type of School Class	Regular Classroom (72%); Both Regular & Special Education (14%); Special Education (12%); Not in School (2%)
Child Age (in years)	Range (5-17 years); Mean (11.16); Standard Deviation (3.08)

* Percent (%) rounded to nearest whole number in all tables

KEY FINDINGS

PARENT IDENTIFIED NEEDS

IDENTIFIED NEED	CHILDREN WITH DISABILITIES Total Responses: 232			TYPICALLY DEVELOPING CHILDREN Total Responses: 67		
	94 Responses HOME	70 Responses SCHOOL	68 Responses COMMUNITY	26 Responses HOME	26 Responses SCHOOL	15 Responses COMMUNITY
1:1 Support	31%	19%	21%	12%	8%	7%
Additional Staff	~	4%	~	~	8%	~
Childcare	4%	~	2%	4%	~	13%
Equipment/Structure/Modification	21%	29%	16%	8%	8%	~
Funding	14%	7%	13%	27%	8%	8%
Inclusion	~	6%	13%	~	~	~
Information/Communication	1%	~	~	8%	~	~
More Programs	3%	10%	22%	19%	35%	40%
Other	3%	6%	4%	8%	8%	13%
Parent Coaching	2%	~	~	8%	~	~
Parent Communication	~	3%	~	~	4%	~
Social Opportunities	4%	~	~	~	~	~
Specialist	14%	4%	3%	~	8%	~
Teacher/staff training	~	10%	~	~	8%	~
Time	2%	~	~	8%	~	~
Transportation	~	3%	6%	~	8%	20%

PARENT IDENTIFIED STRATEGIES

STRATEGY	CHILDREN WITH DISABILITIES Total Responses: 562	TYPICALLY DEVELOPING CHILDREN Total Responses: 644
Accessibility, Equipment & Modification	32 (6%)	11 (2%)
Parent involvement	113 (20%)	132 (21%)
Activity planning	36 (6%)	60 (9%)
Provide transportation	37 (7%)	67 (10%)
Encouragement & Support	91 (16%)	137 (21%)
Seeking activity	125 (22%)	110 (17%)
Advocate	11 (2%)	1 (<1%)
Educate child	36 (6%)	20 (3%)
Educate self	6 (1%)	1 (<1%)
Educate others	16 (3%)	3 (<1%)
Participation with peers	37 (7%)	56 (9%)
Financial	8 (1%)	29 (5%)
Other	14 (2%)	17 (3%)

DEFINITIONS OF STRATEGIES

- Accessibility, equipment, & modification:** Changes to the environment or utilization of a specific object to promote participation. This excludes the mentions of purchasing specific objects, which were categorized under "Financial."
- Parent involvement:** Parent identifies partaking in an activity with the child, supervising the child, or engaging in dialogue with school or community environments where participation takes place.
- Activity planning:** Parent identifies coordinating participation, prepping the child and/or environment for participation, or having a strategy to prevent crisis. This is differentiated from instances in which venues for participation are sought out, which were categorized under "Seeking activity."
- Provide transportation:** Parents driving children to activities, or providing other means of transportation (ex. Taxi). This was distinguished from general accompaniment to activities.
- Encouragement and support:** Parents identify conversation, positive reinforcement, making participation "fun," or attending a child's events (i.e. recital, sports game).
- Seeking activity:** Parents noted actively looking for ways their child could participate in the home, school, or community.
- Advocate** includes instances in which parents specifically indicated they advocate for their child, or otherwise engage in discussions with institutions to obtain objects or circumstances that suit their child's needs.
- Educate Child** Parents express desire to have their child learn about ways to engage in participation and its benefits.
- Educate Self:** Parents express desire to learn about ways to increase their child's participation.
- Educate Others:** Parents express desire to teach others, such as a family member or educator, about ways to engage their child in activities.
- Participation with Peers:** Parents express desire to get their child involved in activities with peer groups.
- Financial:** Any instance in which a response reflects a parent's desire to have the economic support to pay for their child to participate in activities.
- Other:** Did not fit into other categories. Examples include specific therapy and chores.

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SUMMARY OF KEY FINDINGS

NEEDS

- Parents of children with disabilities identified over three times as many needs as parents with typically developing children (232:67).
- Most needs occurred in the home environment. The most needs were in the categories of 1:1 support, equipment and home modification, funding, and access to specialists.
- Parents of children with and without disabilities identified the following need categories across all three settings: 1:1 support, equipment and structure modification, funding, and access to more programs.
- Parents of typically developing children identified access to more programs as their greatest need.

STRATEGIES

- Parent strategies to support child participation are fundamentally similar between populations. The most commonly identified strategies were parent involvement, seeking activity, and encouragement and support. 58% of responses from parents of children with disabilities and 58% of responses from parents of typically developing children fell into these 3 categories.
- Although responses frequently presented similarly in nature, responses also often alluded to being disability-specific:
 - "Physically assist her to do activities" (*Parent involvement*)
 - "Investigate programs within the community that would suit her and her disability" (*Seeking activity*)
 - "Treat him like an equal member of the family" (*Encouragement and support*)
- Strategies more common among parents of children with disabilities were advocate, educate child, educate others, and accessibility, equipment, and modification.

DISCUSSION

The higher number of needs in the home setting may have occurred because questions about the home were asked about first OR because this is where parents might be most aware of their child's participation (given this is where parent-child interactions most often occur). Parents might need more explicit instructions in the PEM-CY to obtain information from others (e.g., their child, teachers, activity leaders/instructors).

Parents of typically developing children identified a high need for "more programs." There was a high need for after school programs, perhaps due to the fact that parents are working.

"1:1 support" identified as major need category at home for families of children with disabilities: 13 of 29 responses included the word "respite," while others used words like "24/7 care" or "Personal Care Attendants." This indicates that these families may have critical needs during night hours.

The identified needs represent a variety of physical and social barriers associated with disability that have been reported in other studies. (Law, et al., 1999; Pivik, McComas & Laflamme, 2002)

Contrary to findings in the literature, few needs were reported in the area of social skill development.

Findings about parent strategies were similar to those found in other studies (Bedell, Cohn & Dumas, 2004; Bedell, Khetani, Cousins, Coster & Law, 2011).

Financial supports were identified more frequently by parents of children without disabilities – possibly because "extra" finances were more limited (due to disability associated expenses) or other needs were of greater priority for families of children with disabilities.

Similar to findings from Davison, et al. (2003), provision of transportation was identified more frequently by parents of typically developing children (Davison et al., 2003). This finding might be explained by the fact that children with disabilities are often reported as more restricted in their participation than typically developing children (also found in the larger PEM-CY study, Coster et al., in press) and thus parents of children with disabilities might have placed greater priority on other strategies to promote their children's participation.

Further research is needed with a more diverse sample in terms of race/ethnicity, income/educational level, and geographic location.

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