Parent Strategies and Disability Effects on Childhood Participation

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Background

- Participation is "involvement in life situations."[1] It is essential for learning, skill development, self-efficacy, quality of life, health, and well-being.[2,3]
- Research suggests that children with disabilities experience significant participation restriction, resulting in decreased quality of life and poor health and well-being.[2,4,5]
- School, home, and community settings present unique challenges and demand different skills from children. To fully understand child participation, it must be explored within each of these environments.
- Parental strategies can also have a direct effect on child participation.[3,5] Strategies that are a good fit with the child's needs can promote participation across settings, while poorly matched strategies may be ineffectual or hinder participation.

Purpose

- To compare and describe home, school, and community participation between children with and without disabilities
- To describe parent strategies, equipment, and modifications used to facilitate child participation

Participants

- 363 total participants: 310 children with disability (226 Acquired Brain Injury, 61 Developmental Disability, 23 Learning/Attention/Sensory Disorders), 53 with no disability; 199 males, 157 females; 31 aged 2.4-6 years, 98 aged 6.001-12 years, 163 aged 12.001-18 years, 63 18.001-27 years; 167 white, 21 Black, 1 Asian, 6 Hispanic, 6 Other; 116 Suburban, 24 Urban, 35 Rural

Measure

- The Child and Adolescent Scale of Participation (CASP)[4]
  - Parent report measure
  - 20 item-level questions, 4-point Likert, 4 subcategories: home participation, school participation, community participation, home and community living activities
  - 3 open-ended questions addressing parent strategies, assistive devices, and environmental modifications
- Good test-retest reliability (intra-class correlation coefficient = .94), internal consistency ($\alpha \geq 0.96$), construct validity, and discriminant validity.

Methods

- De-identified data were collected from colleagues in the USA, Canada, Australia and Israel.
- Parents/guardians of children with and without disabilities completed CASP alone or within the larger Child and Family Follow-up Survey (CFFS).
- Item-level data were analyzed through independent sample t-tests and descriptive statistics.
- Cohen's d was calculated for effect size: ≥ .20 (small), ≥ .50 (moderate), ≥ .80 (large), ≥ 1.00 (very large).
- Open-ended data were content analyzed and re-coded.

Results

Item-Level Categories	No Disability		Disability		p	d
	n	Mean (SD)	n	Mean (SD)		
Home Participation						
Social / play / leisure with family	53	3.94 (.23)	308	3.55 (.62)	<.001	.92
Social / play / leisure with friends	53	3.94 (.23)	303	3.33 (.82)	<.001	1.16
Family chores / responsibilities / decisions	53	3.68 (.58)	307	3.30 (.85)	<.001	.53
Self-care	53	3.96 (.19)	309	3.54 (.71)	<.001	.93
Moving in / around the home	53	4.00 (.00)	309	3.80 (.49)	<.001	.82
Communication with other children/adults	53	3.89 (.42)	309	3.61 (.61)	<.001	.54
Neighborhood and Community Participation						
Social / play / leisure with friends	52	3.90 (.30)	302	3.13 (.93)	<.001	1.25
Structured events / activities	52	3.85 (.41)	291	3.08 (.93)	<.001	1.15
Moving around the neighborhood / community	52	3.94 (.24)	305	3.46 (.79)	<.001	.93
Communicating with other children / adults	53	3.85 (.41)	309	3.39 (.80)	<.001	.76
School Participation						
Educational activities with children	53	3.94 (.30)	279	3.33 (.79)	<.001	1.12
Social / play / recreational activities with children	53	3.89 (.32)	280	3.31 (.77)	<.001	1.06
Moving around at school	53	4.00 (.00)	283	3.67 (.60)	<.001	1.10
Use of available / modified educational materials / equipment	53	4.00 (.00)	280	3.57 (.63)	<.001	1.37
Communicating with children / adults	53	3.94 (.23)	284	3.51 (.66)	<.001	.97
Home and Community Living Activities						
Household activities	49	3.65 (.56)	273	3.29 (.90)	<.001	.49
Shopping / managing money	48	3.88 (.39)	252	3.14 (1.04)	<.001	1.03
Managing daily schedule	52	3.63 (.66)	266	2.99 (.97)	<.001	.79
Using transportation to move about community	34	3.79 (.59)	235	3.19 (1.12)	<.001	.70
Work activities and responsibilities	37	3.76 (.64)	190	3.24 (.96)	<.001	.65

Open-Ended Categories	Frequency	
	No Disability	Disability
Promote Stability / Positioning / Safety *(e.g., slant boards, gait-belt, grab bar, positioning chair)*	0	48
Academic / Educational Support *(e.g., note-taker, study guides, mentors)*	3	39
Environmental Modifications / Promote Physical Access *(e.g., lighting, moving furniture)*	3	36
Electronics / Technology *(e.g., computer, keyboard, palm pilot)*	1	36
Mobility *(e.g., wheelchair, walker, cane)*	0	16
Self-care / Feeding *(e.g., toilet seat, modified utensils)*	0	12
Bodily Devices *(e.g., splints, braces, cochlear implants)*	0	6
Communication *(e.g., switches, picture symbols/pictures)*	0	3
Activity Planning / Organizational Support *(e.g., calendar, schedule, homework log)*	8	49
Utilization of Other Services *(e.g., aides, PT, OT)*	0	46
Family Involvement *(e.g., changing work schedules, taking interest in successes and failures, actively working on skills)*	11	31
Motivation and Support *(e.g., praise, encouragement)*	11	19
Facilitating Transportation *(e.g., bus, family member drives)*	3	11
Socialization *(e.g., organized sports, youth organizations)*	7	6

Results

- Those with disabilities scored statistically significantly lower on all home participation, community participation, school participation, and home and community living activity items than those without.
  - Items related to school participation showed the greatest magnitude of difference between groups.
  - Items related to home activities showed the least magnitude of difference between groups.
- Environmental modifications, technology, academic support, and adaptations for stability, positioning, and safety were the most commonly utilized strategies among parents of children with disabilities.
- Family involvement and motivation were the most commonly utilized strategies among parents of children without disabilities.

Discussion and Implications

- Children with disabilities showed significant participation restriction.
- The greatest differences were found in academic settings despite numerous strategies utilized to address these limitations.
  - Decreased parental control in this context may contribute to the lack of strategy success.
  - Clinical practice should foster open communication between school and home, and support strategy selection and implementation.
- Across all settings, participation in social activities with peers was significantly reduced for children with disabilities. Yet, few parents reported strategies aimed to address this issue.
  - Given the negative effects of social isolation, examination of how parents prioritize areas of need and select strategies is essential.
- Home activities yielded the smallest differences between the two groups.
  - Participation may be less restricted due to real-time feedback regarding strategy success, increased opportunities for strategy adjustment, and availability of parental support.

Limitations

- Sampling methods resulted in unequal group sizes.
- Heterogeneity of disability types within the disability group and over representation of acquired brain injury limit our ability to generalize results.
- Grouping children with various diagnoses together within a diagnostic category may mask important differences between them.
- Parent responses to open-ended questions may have been influenced by the semi-structured nature and data collection methods.
- Open-ended questions were subjectively coded by our research team; different categorization may have produced different results.

References

1 World Health Organization. (2001). International classification of functioning, disability and health (ICF; Final version). Geneva: World Health Organization.
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