The Power of Participation: How do children with and without complex communication needs participate at home, school and in the community?

Pammi Raghavendra, Rachael Virgo, Cathy Olsson, Alison Lane, and Tim Connell
Novita Children’s Services, SA & The Ohio State University, USA

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Aims
Participation, involvement in everyday activities, is vital for the overall development of a child.
To develop a comprehensive, multi-dimensional description of the participation of children with physical disabilities and CCN.
To examine the association of key functional abilities with aspects of participation:
- Communication and physical ability
- Time use
- Social networks (parent and school staff)
- Participation in activities
- School participation
- Level of self-determination.

ICF

Method
Design: A cross-sectional descriptive survey.
Ethics: Children, Youth & Women’s Health Services (CYWHS) University of SA Department of Education & Children’s Services (DECS).

Three groups of children aged 10-15 years:
Group I: Physical disability & CCN
Group II: Physical disability
Group III: No disability (typically developing peers).


Participants

©Dr. Pammi Raghavendra, Novita Children’s Services
Parimala.raghavendra@novita.org.au
Social Networks
(Blackstone & Hunt Berg, 2003)

Social Networks: A communication inventory for individuals with complex communication needs and their communication partners:

- Types of assistive technology
- Modes of communication
- Strategies to support communication
- Topics of conversation
- Types of communication.

Social Networks: Circles of Communication Partners (CCP)

- Circle 1 = life partners
- Circle 2 = good friends
- Circle 3 = acquaintances
- Circle 4 = paid partners
- Circle 5 = unfamiliar partners

Children’s Assessment of Participation & Enjoyment (CAPE)
King et al., 2004

Investigates what activities child has done outside of school time over the past 4 months.

55 activities:
- 40 Informal activities (eg writing a story, dancing)
- 15 Formal activities (eg learning to dance, participating in school clubs).

Five dimensions of Participation:
- Diversity
- Intensity
- Where
- With whom
- Enjoyment.

Adapted “Student’s engagement in activities at school - An observation measurement tool”
(Eriksson, 2005)

5 activity types:
- Recreational (eg puzzles, playing with pets)
- Physical (eg team sports, gardening)
- Social (eg talking on the phone, hanging out)
- Skill-based (eg swimming, music lessons)
- Self-improvement (eg writing letters, reading).

Means of response: verbal or non-verbal.

Reliability – internal consistency & test-retest values - sufficient evidence (King et al., 2004).

Validity – high content & construct validity (King et al., 2004, 2006).
Adapted “Student’s engagement in activities at school - An observation measurement tool” (Eriksson, 2005)

Results Social Networks: Average Number of Communication Partners

Reported by child/caregiver

Overall CAPE Scores

Results CAPE: Top 5 common activities that children participated in

1. Watching TV or a rented movie
2. Visiting
3. Playing computer or video games
4. Hanging out
5. Playing with pets
Results CAPE: Other popular activities that children participated in

<table>
<thead>
<tr>
<th>GROUP I</th>
<th>GROUP II</th>
<th>GROUP III</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Disability &amp; CCN</td>
<td>No Disability</td>
<td>Physical Disability &amp; CCN</td>
</tr>
<tr>
<td>Shopping (N=14)</td>
<td>Going to a party (N=13)</td>
<td>Shopping (N=13)</td>
</tr>
<tr>
<td>Talking on the phone (N=11)</td>
<td>Talking on the phone (N=7)</td>
<td>Talking on the phone (N=7)</td>
</tr>
<tr>
<td>Listening to music (N=14)</td>
<td>Entertaining others (N=7)</td>
<td>Entertaining others (N=7)</td>
</tr>
<tr>
<td>Playing board or card games (N=13)</td>
<td>Doing individual physical activities (N=7)</td>
<td>Doing individual physical activities (N=7)</td>
</tr>
<tr>
<td>Going for a walk or a hike (N=13)</td>
<td>Playing games (N=12)</td>
<td>Playing games (N=12)</td>
</tr>
</tbody>
</table>

School Observation – Adapted Eriksson’s

“How student communicates”

All 3 groups used unaided communication – facial expression, body language and gestures.

Group II and III used more speech.

Group I:
- Device only used by 9/14 participants and was limited to 17/85 activities (≈ 20%)
- Supports for use of device limited at school for use, low expectations for use and many opportunities for support missed.

Key Observations at School

Group I (Physical Disability & CCN):
- Interactions with peers extremely limited.
- Barriers observed: lack of opportunities provided by partners, seating arrangements did not facilitate communication, means to initiate communication quietly.

Group II (Physical Disability):
- Engagement with peers varied; most active socially and few isolated.

Group III (No Disability):
- TDP continuously talk with peers during school, even during activities within the class.
- Broad group of friends and a small group of close friends.

Group II & III - Frequent interactions, same opportunities as classmates to communicate, long interactions.

Summary

Limited number of Circle 3 communication partners for Group I than Group II & Group II.

Group I’s social network consists of higher number of partners from Circle 4 than family and friends.

Activity participation shows that children with CCN are participating in a range of activities and enjoy their involvement.

Intensity is low with limited social contexts and locations highlighting participation restrictions for Group I.

Reduced Physical activity for Group I & Group II is of concern.
Summary

School Participation: Included but interactions with peers limited for Group I.
Group II more similar to Group III in engagement with peers.
Role of communication in participation is highlighted.

Emerging Data - Implications

Utility of tools to measure participation.
CAPE provides a direct measure of participation in leisure and recreation.
Helps in identifying activities to target for communication intervention in functional contexts.
Social Networks - Highlights supports to develop & maintain good friendships with peers and acquaintances.
School observation - Ongoing training of partners with focus on peers.

References


