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

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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.

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ICF

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

Health condition (disorder or disease)

Body functions & structures
Social Networks
GMFCS Level

Activities
MARCA

Participation
CAPE
Eriksson's
(school observation)

Environmental factors
Social Networks

Personal factors
AIR Self-determination Scale

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).

Tools: Self-report, survey, observation.

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Participant Inclusion Criteria

Group	Physical Disability	Communication Ability	Cognitive Capacity	Recruitment
I Physical disability & CCN	CP, spina bifida, other syndromes, non-progressive conditions. GMFCS = I - V	CCN & uses AAC	Able to self-report with/without help from caregiver.	Novita Children's Services client database.
II Physical disability	CP, spina bifida, other syndromes, non-progressive conditions. GMFCS = I - V	Speech for daily communication.	Able to self-report with/without help from caregiver.	Novita Children's Services client database. Matched to Group I for GMFCS, age +/- 2 years, gender, socioeconomic status & school type.
III No Disability	None	Speech for daily communication.	Able to self-report with/without help from caregiver.	Via principal at same school as Group I or Via staff at Novita Children's Services. Matched to Group 1 for age, gender & socioeconomic status.

GMFCS = Gross Motor Functioning Classification System

Participants

GROUP	NO	MEAN AGE	GENDER	DIAGNOSIS	GMFCS	COMMUNICATION	TYPE OF SCHOOL
I Physical disability & CCN	14	12;9 years	8 boys 6 girls	CP = 12 Quadriplegia = 1 Syndrome = 1	Level I = 1 Level II = 2 Level III = 3 Level IV= 5 Level V = 3	Facial expression, gestures, vocalizations, speech, simple/complex device	Mainstream = 7 Special School = 4 Special Class = 3
II Physical disability	8	13;4 years	4 boys 4 girls	CP = 7 Spina Bifida = 1	Level II = 2 Level III = 3 Level IV= 3	Speech	Mainstream = 6 Special School = 1 Special Class = 1
III No disability	13	12;8 years	8 boys 5 girls	No disability	N/A	Speech	Mainstream = 13

GMFCS = Gross Motor Functioning Classification System

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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.

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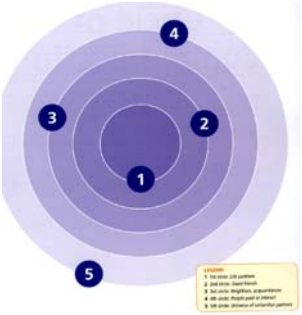
Social Networks:
Circles of Communication Partners (CCP)



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

Social Networks (Blackstone & Hunt Berg, 2003)

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.

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

Children's Assessment of Participation & Enjoyment (CAPE)
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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).

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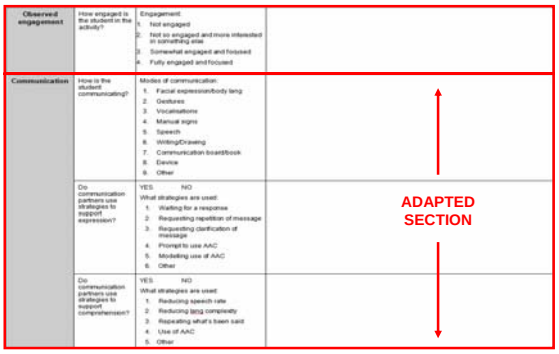
Adapted "Student's engagement in activities at school - An observation measurement tool"
(Eriksson, 2005)

	Question	Type	Description & Examples
Type of activity	What is the lesson/activity?		
Inclusion	Is the student doing the same activity as peers?	All the time Most of the time Some of the time None of the time	
	Is the student located in the same place as peers?	All the time Most of the time Some of the time None of the time	
Support	Does the student need more support than peers?	YES NO What support is provided? 1. Help starting activity 2. Help explaining activity 3. Help simplifying activity 4. Help focusing on activity 5. Help continuing activity 6. Help with behaviours 7. Help getting motivated 8. Other	

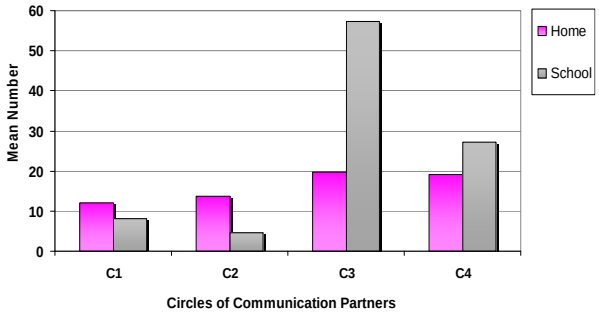
Adapted "Student's engagement in activities at school - An observation measurement tool"

(Eriksson, 2005)



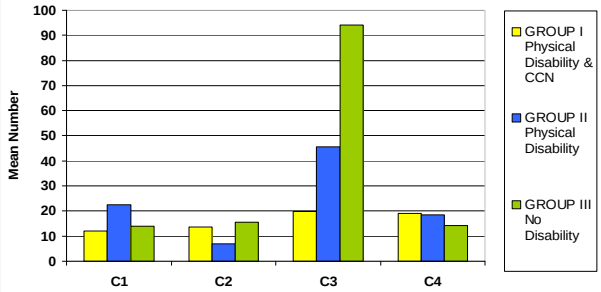
Results Social Networks: Average Number of Communication Partners

Group 1 - Home and School

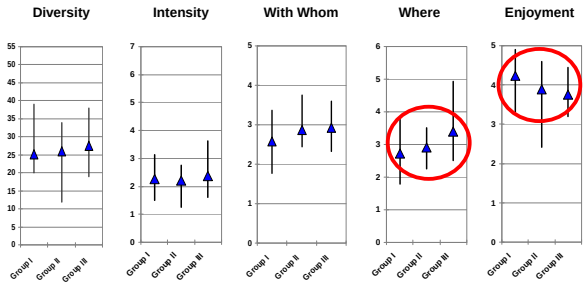


Results Social Networks: Average Number of Communication Partners

Reported by child/caregiver

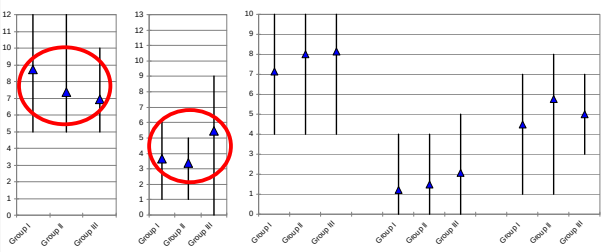


Overall CAPE Scores



Group I = Physical Disability & CCN *Group II = Physical Disability* *Group III = No Disability*

Overall CAPE Scores



Group I = Physical Disability & CCN *Group II = Physical Disability* *Group III = No Disability*

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

GROUP 1 Physical Disability & CCN	GROUP II Physical Disability	GROUP III No Disability
Shopping (N=14) Talking on the phone (N=11)	Going to a party (N=8) Talking on the phone (N=7) Doing homework (N=8)	Shopping (N=13) Going to a party (N=12) Doing homework (N=13)
Listening to music (N=14) Playing board or card games (N=13) Going for a walk or a hike (N=13)	Entertaining others (N=7) Doing individual physical activities (N=7)	Doing a chore (N=13) Playing games (N=12)

School Observation – Adapted Eriksson's

Average	GROUP I Physical Disability & CCN	GROUP II Physical Disability	GROUP III No Disability
Activities / 4hrs	9	9	7
Same activity as peers	75%	83%	93%
Same location as peers	83%	86%	94%
Level of engagement	69%	81%	85%

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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.

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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.

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Key Observations at School

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.

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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.

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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.

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