

A world map in shades of blue, with a small yellow dot marking the location of Jönköping, Sweden, in the northern part of Europe.

Jönköping University

Participation in Family Activities for Children with Multiple Disabilities

Mats Granlund, PhD in Psychology, Professor of Disability Research, School of Health Sciences

Jenny Wilder, PhD in Psychology, Jönköping University, School of Health Sciences

Anna Karin Axelsson, PhD Student in Disability Research, Jönköping University, School of Health Sciences

Background

- "A mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community", and in the family. (Child Convention Article 23: Rights of disabled children)
- The Act LSS makes the Swedish context specific
 - Since 1994 persons with certain disabilities have the right by law to employ personal assistants paid by the government and/or the municipality
 - Amount of hours is evaluated and granted by officials according to degree of assistance needed to perform ADL
 - Parents employed as personal assistant for own child: challenge and opportunity!

Earlier research

About participation and family activities:

- Family routines, rituals and activities are the contextual factors that have the largest impact on young children's functioning and development (Wilder, 2008)
- Participation can be defined as involvement in a life situation and can be seen as a positive expression of health (WHO, 2001, 2007)
- Participation in family activities is important for being a part of the family system (Fiese et al, 2001)
- Young children with disabilities learn new skills better in naturally occurring activities at home than in activities designed by professionals (Dunst et al, 2001)

Earlier research

About families:

- Parents in Europe have a tendency to do more activities with their children now than almost ever before, still role division is rather traditional (Forsberg, 2009)
- Parents to children with disabilities often perceived difficulties in achieving and maintaining a sustainable everyday life where the child actively takes part and is engaged (Weisner et al, 2004)
- Parents report difficulties with promoting children's participation in everyday routines and play. AAC is seldom used in routines and activities (Gardon et al, 2011).
- Personal assistants to children with profound multiple disabilities seldom work within family activities

Earlier research

About the children

- Children with Complex Communication Needs (CNN) domostactivitiesoutsideschool with relatives in the home or close to the home (Raghavendra et al, 2010)
- Children with PMD are communicativedependent on theirparents and personal assistants. Their social networks are smallerand not the same persons are found in theirnetworks as theirfamily'snetworks(Wilder & Granlund, submitted)
- Children with severedisabiitieshaveparticipationrestrictions in homeactivities, especially morning and evningroutines, mealtimes and play (Cardon et al, 2011)

Aim and research questions

- Overall aim is to compare participation in family activities for children and teenagers with profound multiple disabilities (PMD) and children with typical functioning
 - In what family activities do the children in the two groups participate?
 - What does the degree of engagement/involvement in activities look like, in the two groups?
 - Is frequency of participation or degree of engagement related to type and degree of impairment?
 - In what family activities do assistants, other than the parents participate?

Method

- Cross sectional study design with Questionnaire CHILD-PFA
- Participants were 60 families with children/young people with multiple disabilities and 107 families having children with typical development
 - Convenience sampling through independent organizations, questionnaires sent to 300 families of children with MPD
 - Convenience sampling through snowball sampling for children with typical development
- Non-parametric tests (Chi 2 & Mann-Whitney) and descriptive statistics were used in data analyses

Participants

Families of children and young people with multiple disabilities

- 60 children and young people between 0-20 years of age who needed much support in their everyday life in the form of personal assistance. All have cognitive disability, motor disability and complex communication needs

Families of children with typical development

- 107 children with typical development 6-12 years of age

Questionnaire CHILD-PFA

No existing international/national questionnaires were found for the target group and problem area

Questionnaire was constructed

- Inspired from several other questionnaires (e.g. CAPE, King et al., 2006)
- Discussed by expert panel of researchers
- Pilot study, cognitive interviews

One web-version and one paper version (also available in English)

Questionnaire CHILD-PFA

Participation in Family Activities

63 items over 6 areas:

- Indoor activities
- Making meals
- Routines
- Outdoor activities
- Organized activities
- Outings and going on vacation

Background

- Children's abilities index
- Communication index
- Personality index
- Family set up and situation
- Degree of formal and informal support
- SES

Results: Participants with disabilities

- 36 boys, 24 girls, born 1990-2005
- Majority had severe disabilities in: motor, vision, communication, cognition and severe difficulties with social behavior
- 44 of 60 had severe health problems
- SES high: one or both parents had a academic degree from University
- Mothers worked part time and were personal assistant for the child
- 0-9 other employed personal assistants
- The family's instrumental informal social support was low

What family activities occur with high frequency?

Families with children with PMD

- Watching film**
- Watching TV
- Play with adults
- Play with peers indoors
- Listen to music**
- Rest/take a nap**

Families with children with typ.f

- Watching TV
- Play with adults
- Play with peers indoors**

- Play with other children outside**

Results: In what family activities do the children in the two groups participate with high and low frequency?

Children with PMD high frequency activity

- Watching TV/film**
- Play with adult
- Listen to music**
- Eatdinnertogheter
- Morning and bed routines

Low frequency

- Playing with peersoutside**
- Outdoor activities**
- Playing games**

Children with typ.f high frequency activity

- Wathching TV/film
- Play with adult
- Play with peersindoors**
- Eatdinnertogheter
- Morning and bed routines**
- Visiting friends and relatives**

Low frequency activity

- Taking a nap/rest**
- Visitingfamilieswithoutchildren

Results: What does the degree of Engagement/involvement in activities look like, in the two groups?

*Children with PMD
most engaged in*

- Joking/teasing interaction
- Computer games
- Play with adult
- Play with peer inside
- Eating dinner together

Activities with low engagement

- Doing the dishes
- Clean room/house
- Clean up after play/activity

*Children with typical f
most engaged in*

- Joking/teasing interaction**
- Computer games**
- Play with adult**
- Play with peer inside**
- Eating dinner together

Activities with low engagement

- Doing the dishes
- Clean room/house**
- Clean up after play/activity**

Is frequency of participation or degree of engagement related to type and degree of impairment?

Activities with strong negative relations

- Watching TV (activity level)
- Rest/nap (cogn., motor ability)
- Play with adult (activity level)
- Go for a walk (cogn.)
- Play with adult outside (vision)
- Listen to story (vision)

Activities with strong positive relations

- Games (comm.)
- Bed routines (vision)
- Visiting play park (motor)
- Play with adult outside (motor)
- Play with sand outside (motor)

Results: In what family activities do assistants, other than the parents participate?

- Going for a walk
- Together performing child's leisure activity
- Going shopping
- Having dinner together
- Training physiotherapy at home
- Playing with adult indoors/outdoors and joking around
- Going by car

Conclusions

- Activity patterns differ between families with and without disabilities
- Activities in which child has "passive role" more common for PMD children. Peer activities and participation in routines more common for children with typical functioning
- Children with PMD have high engagement in the same activities as other children but with a more varied pattern and lower average engagement
- Type and degree of impairment affects both frequency of participation and level of engagement
- Assistants other than parents are involved in activities primarily outside the family context

Further questions/further research

- What characterize families where children/young people are highly engaged in many family activities?
- How do parents and personal assistants work to facilitate child participation in homelife?
- Mixed methods design of an ongoing project which aim is to facilitate participation in family activities for children and young people with multiple disabilities

Thankyou for listening!