



Newsletter from the research profile CHILD, based at Jönköping University

#1 2012

February

CHILD's Research Leader



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CHILD Agenda

March 1st, 1-4 pm
(nb!)

Seminar on Marie Golsäter's dissertation in Gc509 at School of Health Sciences. We also discuss 'Informed Consent'.

March 9th, 1 pm
Marie Golsäter defends her dissertation in Forum Humanum at School of Health Sciences

March 15th, 1-3 pm
Seminar on Ylva Ståhl's dissertation at School of Education and Communication in Ha 208

March 29th, 1-3 pm
Seminar on Anne-Sofie Strand's article in Gc509 at School of Health Sciences

April 12th, 1-3 pm

Participation and Family Involvement

In this issue of CHILD's newsletter we focus on participation of children and youth with long term conditions or impairments in family activities, school and leisure activities.

- The articles below illustrate commonalities between children in different gaes having different conditions or impairments and also that different ways of operationalizing participaion and collecting data on participation can be used to build up a stronger knowledge base concerning participation in everyday life for children and youth that need additional support, says Mats Granlund.

Press 'Läs' for Mats Granlund's continued introduction

Läs →

Participation in Leisure Activities for Children with and without Disabilities



To identify facilitators and hinders for participation in leisure activities for children with disabilities is essential to enable interventions with the aim to enhance the level of participation in children with disabilities.

- Children with disabilities meet restrictions in their participation, says researcher Anna Ullénhag.

- This is of concern, since participation is believed to contribute to a child's development, health and well-being.

Läs →

Participation in Family Activities of Children with Profound Multiple Disabilities



To what extent do children with profound multiple disabilities (PMD) take part in family activities? CHILD-researchers Jenny Wilder and Anna Karin Axelsson wish to add scientific knowledge to the field.

- The overall aims with our work, Jenny Wilder explains, are to study occurrence of

Seminar on Ann Simmeborn-Fleischer's article in Ha 208 at School of Education and Communication

April 26th, 1-3 pm
Seminar on Sara Hvit's 'mantle/kappa' in Gc509 at School of Health Sciences

April 27th, 1 pm
Ylva Ståhl defends her dissertation in Forum Humanum at School of Health Sciences

May 10th, 1-3 pm
CHILD-seminar in Ha208 at School of Education and Communication

May 24th, 1-3 pm
Seminar on Berit Björkman's article in Gc509 at School of Health Sciences

June 4th-20th
Intensive Course, Global Education and Developmental Studies

June 14th
ICU-CHILD research group from Mälardalen's Högskola visits us

June 15th
Gregor Maxwell defends his dissertation at School of Education and Communication

CHILD's Research Coordinator



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33 articles

family activities in families that have a child with PMD, the participation (attendance and involvement) in family activities of these children, to investigate the 'role' of personal assistants in family activities and to identify facilitating factors for participation in family activities for children with PMD.

Läs

Participation from Two Perspectives – the Frequency of Attending and the Intensity of Involvement



- It is important to represent participation from both a frequency of attending and an intensity of involvement perspective to avoid any reductionist issues related to focussing on only one, says CHILD-researcher Gregor Maxwell. Gregor Maxwell presents in his research a new way of looking at participation that provides a more balanced way of representing the construct and brings in involvement, which has previously not been successfully done.

Läs

Have the Child in Focus rather than the Diagnosis



- Everone interviewed expressed that this research situation was the first where the child was in focus rather than the cancer diagnosis, says CHILD-researcher Laura Darcy.
- Even though the incidence of cancer among children is highest in the 1-6 year age group, there are very few published studies describing these children's health or wellbeing. This

initial finding highlights the necessity of research involving children. Read on to learn more about Laura Darcy's research methods.

Läs

CHILD becomes a member of SIDR



INSTITUTET FÖR HANDIKAPPVETENSKAP
SWEDISH INSTITUTE FOR DISABILITY RESEARCH

As of the start of 2012 Jönköping University became a full member of the Swedish Institute for Disability Research (SIDR) with a special responsibility for coordinating research concerning children that need additional support on top of what is given to all children. The work has already started...

Läs

published in
2011

Members of the CHILD-group published in all 33 articles in peer reviewed journals during 2011. Press and take part of the [list of CHILD-articles](#) (pdf, 170 kB).

CHILD hosts an Intensive Summer Institute

In June Jönköping University will host GEDS Summer Institute focused on measuring and intervening with children's environment (4-20 of June). Researchers from the USA, Germany, Portugal, South Africa and Sweden will be involved. Join us, either take the course (master students or doctoral students) or just join the parts that are of interest.

Läs 

Professor Monika Bullinger visited Jönköping University



Professor in Psychology, Monika Bullinger from Universität Hamburg (in the photo), visited Jönköping University in February. Monika Bullinger's research interests are children, health, quality of life, rehabilitation research and development of research methods. CHILD-researcher *Christina Peterson* gives us a glimpse from Monika Bullinger's seminar. (In Swedish)

Läs 

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Participation and Family Involvement

We are in the middle of an intensive working period with a lot of activities going on in the CHILD research environment. Concerning our doctoral students we have had final seminars for Inga-Lill Gimbler (pain management in children), Gregor Maxwell (participation and ICF-CY) and Nina Klang (logical coherence of the ICF-CY). Marie Golsäter is soon defending her thesis focused on health dialogues and a tool to support health dialogues with children. Several research projects are in an intensive period of data collection. It has led to intense discussions in the group concerning informed consent and how to ensure that young children know what they consent to. Other discussions have concerned how to measure health and well-being in very young children. We will return to these topics later on in new issues of the newsletter.

Today's topic is participation in every day life contexts such as family activities, leisure activities and school. Participation can be seen as a multidimensional concept that involves at least two dimensions, being there and being engaged when being there. The concept can be applied to most every day context such as home, leisure and school, and also to different environmental levels such as individuals, close environments, such as classrooms or family and the contact between people in the close environment and different service organizations. In this issue we focus on participation of children and youth with long term conditions or impairments in family activities, school and leisure activities. The articles illustrate commonalities between children in different areas having different conditions or impairments and also that different ways of operationalizing participation and collecting data on participation can be used to build up a stronger knowledge base concerning participation in everyday life for children and youth that need additional support.



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professor in Disability Research at Jönköping University

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Participation in Leisure Activities for Children with and without Disabilities



by Anna Ullenhag. Anna Ullenhag is living in Uppsala and has been working as a physiotherapist mainly with children at the habilitation centers in Uppsala and Örebro, The University Children's hospital in Uppsala and at the Folke Bernadotte hemmet. Since 2008 she is a PhD student at the National School of Health and Science at Karolinska Institutet In Stockholm and employed at Mälardalen University. Anna is also working at the institution of physiotherapy at Uppsala university.

The WHO defines participation as a persons' involvement in a life situation and to participate in a life situation will give the child a sense of belonging, opportunities to make friendships, development of social and physical skills and competences and promote long term physical and mental health (1). Children with disabilities meet restrictions in their participation and several studies have reported that children with disabilities are involved in more quiet solitary recreational activities and participate with less intensity compared to children without disabilities (2-4). This is of concern, since participation is believed to contribute to child's development, health and well-being.

To identify facilitators and hindlers for participation in leisure activities for children with disabilities is essential to enable interventions with the aim to enhance the level of participation in children with disabilities. The Obstacles for participation revealed in the literature can be both personal and environmental factors (5, 6). Pain, mobility problems, communication disorders, mental or cognitive retardations are examples of personal related factors that are identified to decrease the participation level (7, 8). Another personal factor discussed in the literature to have an effect on the child's participation is age and gender. Preschool children prefer to do recreational activities together with their families whereas adolescents are more involved in social activities together with friends. Girl's seems to prefer to be involved in skill-based and social activities, whereas Boys enjoy participating more in physical activities (9, 10).

Environmental factors recognized in the literature as hindlers for participation are; problems with transportation, the building environment, attitudes and Service systems and fewer municipal resources (11, 12). The family orientation and preferences for activities and the educational level of the parents are other important environmental factors that influence the child's participation level. A higher educational level of parents is associated with a more pronounced activity in skill-based and physical activities of the child (4, 13). For children with disabilities it also seems to be important to be included in the mainstream school and not segregated into special schools or classes to emphasize inclusion (14, 15).

It is crucial to use reliable and valid measurement instruments to identify important personal and environmental facilitators or obstacles for participation. A newly developed instrument from Canada is *The Children's Assessment of Participation and Enjoyment/Preferences for Activities of Children, CAPE/PAC* (9). The CAPE is a discriminative self-reported instrument aimed for children with and without disabilities aged 6 to 21 years which has provided evidence of reliability and validity. The CAPE consists of 55 leisure activity items of five dimensions of participation, namely;

- 1) diversity (the number of activities the child performs)
- 2) intensity (how often the activity is done)
- 3) where the activity is taken place
- 4) with whom
- 5) how enjoyable the activity is

The CAPE provides three levels of scoring: (I) overall participation score, (II) scores of participation in 40

informal and 15 formal activities and (III) scores reflecting participation divided in five activity types; recreational (12 items), active physical (13 items), social(10 items), skill-based (10 items) and self-improvement activities (10 items). The PAC is a parallel measure of the child's preferences for activities including the same 55 leisure items as in the CAPE.

Before using a measure instrument in a new context it is important to make a culture validation for the intended population. In this ongoing research project we have made a cultural validation of the CAPE for Swedish children. By semi structured group interviews we gathered information about available leisure activities for children. In total 14 semi structured group interviews were held with children with and without disabilities aged 6-15 years. Group interviews with parents were also performed. The children were recruited from schools selected to represent different regions of Sweden; rural/urban areas, different landscape and socioeconomic areas, which may influence the variety of leisure activities. The children answered questions about activities done outside the school curriculum and interviews resulted in long lists of leisure activities. Researchers independently matched the activities to the original activity items in the CAPE and 16 new potential activities were added to the original activities in the CAPE. The modified version of the CAPE was tested on 337 children without disabilities aged 6 to 17 years. Only activities performed by more than 10% of the sample were included in a final proposed Swedish version of the CAPE.

The proposed Swedish version of the CAPE will include 55 items; three original activities are supposed to be exchanged by three new activities and ten new examples will be added. The result indicated that minor differences existed in the patterns of participation between the cultures in Sweden and Canada. In Sweden school clubs are uncommon instead Swedish children attend to after school recreational centers. The activity "volunteer work" including fundraising for charity was not recognized as a leisure activity done by the Swedish children and only 6% of the Swedish children were taking art lessons. The informal activity 'outdoor play' was missing in the original CAPE and nearly 60% of the Swedish children were spending their leisure time playing outdoors in the nature. In the Swedish version, the standardized mean outcome of the diversity scores was significantly higher for all activity types than the standardized mean of the original CAPE which indicates that the Swedish version is more valid for Swedish children.

There is a gap of knowledge of how children with and without disabilities in Sweden participate in leisure activities. A comparison of the patterns of participation in leisure activities between Swedish children with and without disabilities was performed. Analysis was also done to explore if age, gender and disability could predict the level of participation and enjoyment of activity.

In total 337 children without disabilities and 55 children with disabilities aged 6 to 17 years responded to the CAPE. The children without disabilities were the same sample described above and the children with disabilities were recruited from 13 different habilitation centers represented diverse regions of Sweden. The inclusion criteria was children with disabilities related to the central nervous system and/or musculoskeletal or neuromuscular problems and only children without, or with mild intellectual retardation were included, because it was important that all of the participating children understood the questions.

The result showed that children with disabilities participated in a higher number of activities but with less intensity compared to children without disabilities. There was a tendency that younger children, girls and children with disabilities participated in more diverse activities than older children, boys and children without disabilities. The main predictor of the intensity score was occurrence of disability and children with disabilities participated with less intensity. Age and gender were the main predictors of the variance in enjoyment scores. Younger children and boys enjoyed the leisure activities most.

References

1. WHO WHO. The international classification of functioning, disability and health. Geneva, Switzerland 2001.
2. Engel-Yeger B, Jarus T, Anaby D, Law M. Differences in patterns of participation between youths with cerebral palsy and typically developing peers. *Am J Occup Ther.* 2009 Jan-Feb;63(1):96-104.
3. Law M, Petrenchik T, King G, Hurley P. Perceived environmental barriers to recreational, community, and school participation for children and youth with physical disabilities. *Arch Phys Med Rehabil.* 2007 Dec;88(12):1636-42.
4. Shikako-Thomas K, Majnemer A, Law M, Lach L. Determinants of participation in leisure activities in children and youth with cerebral palsy: systematic review. *Phys Occup Ther Pediatr.* 2008 May;28(2):155-69.

5. Mihaylov SI, Jarvis SN, Colver AF, Beresford B. Identification and description of environmental factors that influence participation of children with cerebral palsy. *Dev Med Child Neurol*. 2004 May;46(5):299-304.
6. Imms C, Reilly S, Carlin J, Dodd K. Diversity of participation in children with cerebral palsy. *Dev Med Child Neurol*. 2008 May;50(5):363-9.
7. Simpkins SD, Ripke M, Huston AC, Eccles JS. Predicting participation and outcomes in out-of-school activities: similarities and differences across social ecologies. *New Dir Youth Dev*. 2005 Spring(105):51-69, 10-1.
8. Petronyte G, Zaborskis A. The influence of individual and regional factors on association between leisure time physical activity and psychological complaints among adolescents in Europe. *Cent Eur J Public Health*. 2009 Dec;17(4):215-9.
9. King G, King, S., Rosenbaum, p., Kertoy, M., Law, M., Hurley, P., Hanna, S., Young, N., editor. *Children's Assessment of Participation and Enjoyment & Preferences for Activities of Children*. San Antonio: Harcourt Assessment Inc; 2004.
10. Sweden S. Living Conditions, Report no 116, Children's Leisure Time. In: Welfare S, editor. *Statistics Sweden in Stockholm: Statistics Sweden; 2009*. p. 1-54.
11. Fauconnier J, Dickinson HO, Beckung E, Marcelli M, McManus V, Michelsen SI, et al. Participation in life situations of 8-12 year old children with cerebral palsy: cross sectional European study. *BMJ*. 2009;338:b1458.
12. King G, Law M, King S, Rosenbaum P, Kertoy MK, Young NL. A conceptual model of the factors affecting the recreation and leisure participation of children with disabilities. *Phys Occup Ther Pediatr*. 2003;23(1):63-90.
13. Feldman Amy F MJJ. The role of school-based extracurricular activities in adolescent development: A comprehensive review and future directions. *Review of educational research*. 2005 75(2):159-210.
14. Holt L. (Dis)abling children in primary school micro-spaces: geographies of inclusion and exclusion. *Health Place*. 2003 Jun;9(2):119-28.
15. Michelsen SI, Flachs EM, Uldall P, Eriksen EL, McManus V, Parkes J, et al. Frequency of participation of 8-12-year-old children with cerebral palsy: A multi-centre cross-sectional European study. *Eur J Paediatr Neurol*. 2008 Jun 19.

 Tillbaka

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Participation in Family Activities of Children with Profound Multiple Disabilities

by Jenny Wilder & Anna Karin Axelsson



In the photo: Anna Karin Axelsson and Jenny Wilder is giving a conference on participation. Jenny Wilder is a senior lecturer in Special Needs Education and has a PhD in Psychology. Her present research concerns children with multiple disabilities and their participation in family activities.

Anna Karin Axelsson is a PhD-student in disability research. Her research project is focusing on children with profound disabilities and their participation in family activities.

Participation in Family Activities of Children with Profound Multiple Disabilities

In our studies (funded by the Swedish Inheritance Fund) we investigate the participation in family activities of children with profound multiple disabilities (PMD). Research about children with PMD and their involvement in life situations have been focused on participation in leisure activities but not explicitly about child involvement in family activities of children with PMD. With our research we wish to add scientific knowledge to the field. The practical aim is to develop a parent support material for how to facilitate child participation in family activities, together with the association JAG. The overall aims of this research are to study occurrence of family activities in families that have a child with PMD, the participation (attendance and involvement) in family activities of these children, to investigate the 'role' of personal assistants in family activities and to identify facilitating factors for participation in family activities for children with PMD.

There is an estimated number of 3 500 children with profound multiple disabilities (PMD) living in Sweden. Children with PMD are a heterogeneous group in terms of the origin of the impairment as well as functioning and behavior. When having a PMD, profound physical disabilities are combined with learning disabilities, sensory impairments and most often medical complications and these disabilities can partly explain the restriction the children have in their activity and participation. Life situations of children with PMD are specifically set by the context of the family environment which is built up by family activities. In our studies a family activity is defined as an activity that the family do together in everyday life when several family members take part. Furthermore, in our studies we apply the definition of the family made by Hanson and Lynch (2004), the family is 'a unit that defines itself as a family including individuals who are related in blood and marriage as well as those who have made the commitment to share their lives'. For children with PMD support from others is vital for them to have the possibilities to participate in their everyday life and thus in their family's activities. This has been enabled in Sweden with the legislation by the Act LSS which gives the

right and possibility to persons with PMD to employ personal assistants. Personal assistants work at home in the family setting and are often expressed to be in the closest circle of life partners for children with severe multiple disabilities (Wilder, 2008). Personal assistance can enhance child participation in family activities in the way that personal assistants work by the principle of acting as the arms and legs of the child or youth. When this is put into real practice the personal assistant will set the scene for communication and participation in the child's everyday life.

Our first study focused on the occurrence of family activities in families of children with PMD and child attendance in these activities. A descriptive, comparative study of two family groups was performed. The two groups were one group of 60 families with children with PMD aged between five and 20, and one group of 107 families with children with typical development (TD) aged between five and 10. The questionnaire Child-PFA was distributed by paper- and web version. In Child-PFA, part A included background questions about the family and the child, for example family constellation, socioeconomic status (SES) and child ability levels. Part B included 55 listed family activities organized in six domains: Indoors activities, Mealtimes, Routines, Outdoor activities, Organized activities, Outings and Going on holiday.

Results showed that there was a difference of occurrence of listed family activities in the two family groups where the majority of the activities occur more often in the family group TD. Also the frequencies of attendance of the children in the activities differed in the two groups where the children with TD commonly attended more often in the activities in all areas. When the occurrence of family activities in group PMD was investigated further, relations were found between occurrence and family total income, child motor ability, child cognition, child health and also child behavior. The hypothesis: occurrence of family activities to some extent differs in the two family groups and child attendance diverges, was thus supported. Considering a long-term perspective, these differences of occurrence of family activities and child attendance are likely to turn out to be significant for child development and everyday functioning.

The next steps in our research project are to investigate further differences in levels of engagement in family activities between the two groups of families but also in more detail what the engagement of the children with PMD look like and how it can be facilitated. Preliminary results about engagement show that there are few differences in what activities that engage children, although level of engagement differs indicating that children with PMD show lower levels of engagement.

References

- Axelsson, A.K & Wilder, J. (submitted). Frequencies of occurrence and child attendance in family activities, a comparative study of children with profound multiple disabilities and children with typical development. *Journal of Developmental and Physical Disabilities*.
- Hanson, M J. & Lynch, E W. (2004) *Understanding families: approaches to diversity, disability, and risk*. Baltimore: P.H. Brookes.
- Wilder, J. (2008). *Proximal processes of children with profound multiple disabilities*. Doctoral thesis, Department of Psychology, Stockholm University.





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Participation from Two Perspectives – the Frequency of Attending and the Intensity of Involvement



by Gregor Maxwell. Gregor Maxwell work in disability research and is enrolled as a doctoral student with the Swedish Institute for Disability Research. He is part of the CHILD research group and he specifically investigates how activity and participation in school activities of children with disabilities can be conceptualized, measured and operationalized with the help of the ICF-CY framework.

Participation from two perspectives – the frequency of attending and the intensity of involvement

The need to provide clarity on the participation construct is currently well debated in the literature with a number of studies discussing how to measure participation (Badley, 2008; Coster & Khetani, 2008; Maxwell, Alves, & Granlund, 2012; Maxwell, Eriksson-Augustine, & Granlund, submitted; McConachie, Colver, Forsyth, Jarvis, & Parkinson, 2006). Participation can be focused on the right to be in the same activities as other children in school or/and the level of engagement when being in a school activity (Granlund et al., 2012); these two perspectives of participation have two conceptual roots, both of which relate to functioning within a context: sociology and developmental psychology (Granlund, 2006; Maxwell, et al., 2012). Participation based on the sociological root focuses on the availability of and access to everyday activities and describes participation as equal to frequency of attending the same activities as others. Participation based on the psychological root focuses on the child's intensity of involvement or engagement within an activity and whether the environment is accommodated to the child and accepted by the child. The environment itself is an intrinsic part of the participation experience in both these dimensions as it acts as a pre-requisite and 'scene-setter' (Badley, 2008) as well as a context that facilitates or hinders participation. Although involvement is referred to it within a psychology context, it is not related to a medical perspective as it consists of a subjective experience of participation, which includes the child's perception of the situation.

Building on the conceptual re-working of participation is the recent model developed by Granlund and Simeonsson (Granlund, 2009, see figure; Simeonsson, Carlson, Huntington, McMillen, & Brent, 2001) in which the two aspects of participation (frequency of attending and intensity of involvement or engagement) exist as a spectrum of participation related to five environmental dimensions of conditions for participation. The dimensions were originally proposed by Simeonsson et al. (1999) as dimensions of access based on a model of access to health (Penchansky & Thomas, 1981).



Figure. Environment dimensions of opportunity as a proposed measure of participation.

The above model contains five central dimensions concerning the environment: Availability describes the objective possibility to engage in a situation. In terms of services it refers to the objective provision of facilities or resources. Accessibility describes whether you can, or perceive that you can, access the context for the situation. Affordability covers not only financial constraints but also whether the amount of effort in both time and energy expenditure is worth the return to engage in the situation. Accommodability describes whether a situation can be adapted. Acceptability covers people's acceptance of a person's presence in a situation. If there is an expression of values or common beliefs which are of a subjective nature then this is also acceptability. These five dimensions represent environmental or 'scene setting' (Badley, 2008) factors which directly influence participating in an activity and represent the intrinsic link between participation and the context.

It is argued here that it is important to represent participation from both a frequency of attending and an intensity of involvement perspective to avoid any reductionist issues related to focussing on only one. This new way of looking at participation provides a more balanced way of representing the construct and brings in involvement, which has previously not been successfully done.

References

- Badley, E. M. (2008). Enhancing the conceptual clarity of the activity and participation components of the International Classification of Functioning, Disability, and Health. *Social Science & Medicine*, 66(11), 2335-2345.
- Coster, W., & Khetani, M. A. (2008). Measuring participation of children with disabilities: Issues and challenges. *Disability & Rehabilitation*, 30(8), 639 - 648.
- Granlund, M. (2006). Studies of participation related to ICF-CY. Paper presented at the Invited presentation MHADIE meeting, Prague, Czech Republic. <http://urn.kb.se/resolve?urn=urn:nbn:se:hj:diva-5082>
- Granlund, M. (2009). Environmental dimension of participation related to ICF-CY. Paper presented at the Invited presentation MURINET meeting, Zürich, Switzerland. <http://www.hhj.hj.se/doc/8320&personid=33>
- Granlund, M., Arvidsson, P., Niiä, A., Björck-Akesson, E., Simeonsson, R. J., Maxwell, G., . . . Pless, M. (2012). Differentiating Activity and Participation of Children and Youth with Disability in Sweden: A Third Qualifier in the International Classification of Functioning, Disability, and Health for Children and Youth? *American Journal of Physical Medicine & Rehabilitation*, 91(13) Supplement(1), S84-S96.
- Maxwell, G., Alves, I., & Granlund, M. (2012). Participation and environmental aspects in education and the ICF and the ICF-CY: Findings from a systematic literature review. *Developmental Neurorehabilitation*, 15(1), 63-78. doi: doi:10.3109/17518423.2011.633108
- Maxwell, G., Eriksson-Augustine, L., & Granlund, M. (submitted). Does thinking and doing the same thing

amount to involved participation? Empirical explorations for finding a measure of intensity for a third ICF-CY qualifier. Child: care, health and development.

McConachie, H., Colver, A. F., Forsyth, R. J., Jarvis, S. N., & Parkinson, K. N. (2006). Participation of disabled children: how should it be characterised and measured? *Disability and Rehabilitation*, 28(18), 1157-1164.

Penchansky, R., & Thomas, J. W. (1981). The Concept of Access: Definition and Relationship to Consumer Satisfaction. *Medical Care*, 19(2), 127-140.

Simeonsson, R. J., Bailey, D. D., Scandlin, D., Huntington, G. S., & Roth, M. (1999). Disability, Health, Secondary Conditions and Quality of Life: Emerging Issues in Public Health. In R. J. Simeonsson & L. N. McDevitt (Eds.), *Issues in Disability & Health: The Role of Secondary Conditions in Quality of Life*. Chapel Hill, NC: University of North Carolina.

Simeonsson, R. J., Carlson, D., Huntington, G. S., McMillen, J. S., & Brent, J. L. (2001). Students with disabilities: a national survey of participation in school activities. *Disability and Rehabilitation*, 23(2), 49-63.

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INSTITUTET FÖR HANDIKAPPVETENSKAP
SWEDISH INSTITUTE FOR DISABILITY RESEARCH

CHILD becomes a member of SIDR

As of the start of 2012 Jönköping University became a full member of the Swedish Institute for Disability Research (SIDR) with a special responsibility for coordinating research concerning children that need additional support on top of what is given to all children.

Why a full membership in SIDR?

Jönköping University, and especially CHILD, has cooperated with SIDR for a number of years but has now chosen full membership alongside Örebro University and Linköping University. It will gain us full access to the large research network of SIDR and provide opportunities to have a stronger impact on the future development of disability research.

CHILD:s contribution

What we bring to SIDR is knowledge and skills concerning children that need additional support and their life circumstances and also research methods adapted to that area of research. Our special area of responsibility will be Children and Adolescent Special Interest Network (CASINO). The aims of CASINO are:

- 1) to keep SIDR members updated on research concerning children that need additional support,
- 2) to identify common research interests within different SIDR research environments to facilitate networking and research funding applications,
- 3) to provide seminars and doctoral courses related to children in need of additional support and research methodology.

Wide definitions are used

As you can see a wide definition of disability (in need of additional support for every day functioning on top of what is provided to all children) will be used focusing not only on traditional impairments but also on long term health conditions such as diabetes and mental health problems.

The work has already started!

The work with CASINO has already started. Currently *Stefan Nilsson* and *Gregor Maxwell* at the CHILD group in collaboration with *Stefan Carlstein* (bibliometrician) conduct a systematic literature review of research in Sweden concerning this group of children (2006-2011). The collaboration with SIDR will gain the whole CHILD group not only those of us who are focusing their research on children with traditional impairments. More information about the literature review will follow in CHILD:s next newsletter.

Professor Mats Granlund

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Environmental Assessment and Intervention in Early Childhood, 7.5 ECTS

An Intensive course of 7.5 ECTS about environmental assessments will be held in Jönköping in June 2012. The course will be for both master and Ph.D. students with different examinations. The purpose of the course is to give knowledge and understanding in order to:

- o Assess children's natural environments
- o Analyze the child in relationship to the environment: in an interactional framework
- o Use a hierarchical system levels model in understanding environmental influences
- o Use a transactional model to analyze child-environment interactions over time
- o Describe environment in inclusive education
- o Use a sociocultural model in understanding child functioning

Participating faculty will come from ongoing collaboration in GEDS and between University of Pretoria and Jönköping University: *Rune J. Simeonsson*, Professor in Education, *Ana Pinto*, Professor in Psychology, *Donna Wittmer*, Professor in Early Childhood Education, *Dale Farran*, Professor in Education, *Eva Björck-Åkesson*, Professor in Special Education, *Mats Granlund*, Professor in Disability Research, *Irene Zipper*, assistant Professor in Social Work, *Juan Bornman*, Professor in Augmentative and Alternative Communication, *Dana Donohue*, Ph.D. in Psychology.

The course will be connected to the EU-US Atlantis project GEDS and to the VR research Links project. The course will be held in collaboration between the School of Health Sciences and the School of Education at Jönköping University and Mats Granlund will be the course leader. It will be held in localities at School of Education and Communication in Jönköping.

For further information or to sign up, please contact cecilia.allegrind@hik.hj.se



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Newsletter from the research profile CHILD, based at Jönköping University

Professor Monika Bullinger på besök i Sverige

Referat från professor Monika Bullingers besök på Högskolan i Jönköping, februari 2012.

Professor Monika Bullinger har under många år arbetat med frågor rörande livskvalitet och välbefinnande hos barn och ungdomar med långvarigt ohälsotillstånd (long term Health conditions). Hon talade om tre olika perspektiv på hälsorelaterad livskvalitet. Det epidemiologiska perspektivet med välbefinnande kopplat till funktion, det kliniska perspektivet med utvärdering av behandlingseffekter och slutligen det hälsoekonomiska perspektivet, där vinster med behandling är det centrala. Man måste fråga sig om livskvalitet är ett relevant begrepp; kan vi jämföra livskvalitet dimensioner för barn och vuxna? Är det ett tillförlitligt sätt att mäta och hur kan vi jämföra då utvecklingsnivån hos barn skiljer sig mycket mellan olika åldrar? Vidare måste vi fundera på hur vi ska göra då vi vill fånga de mycket svårt sjuka eller funktionsnedsatta barnens perspektiv, då de inte har möjlighet att svara själva. Hur tillförlitlig är så kallad "proxy" mätning?

Några av de projekt som Monika Bullinger är involverad i är QoLISSY (Quality of Life In Short Stature Youth), som leds tillsammans med Sahlgrenska Universitetssjukhuset där syftet är att utveckla ett livskvalitetsinstrument för barn med tillväxtproblem. Detta projekt pågår. Det europeiska forskningsprojektet RESPECT (Relating Expectations and Needs to the Participation and Empowerment of Children in Clinical Trials) handlar om att förbättra barns hälsa i Europa genom att underlätta och utveckla möjligheten till testning av mediciner för barn i åldrarna 0-17 år, utan att utsätta dem för onödiga kliniska prövningar. Projektet ska dels ta reda på vilka faktorer som är viktiga för att familjer med barn ska vilja delta i kliniska prövningar, men även ta reda på vilket stöd man bör erbjuda familjer som väljer att vara med i klinisk prövning. Även detta projekt genomförs i samverkan med Sahlgrenska Universitetssjukhuset, Drottning Silvias barnsjukhus. Dessa båda projekt leds av dr John Chaplin, som arbetar på Drottning Silvias barnsjukhus, centrum för pediatrik tillväxtforskning i Göteborg. John deltog också under seminariet den här dagen.

Monika Bullinger har varit en av de ledande inom projektet DISABKIDS där instrumentet med samma namn utvecklats parallellt i flera europeiska länder samtidigt. Genom EU-finansiering kunde projektet genomföras med att utveckla ett instrument för att mäta hälsorelaterad livskvalitet hos barn med långvarigt ohälsotillstånd. Moduler för olika sjukdomar har också utvecklats, som t.ex. diabetes, epilepsi och hudsjukdom. Ett parallellt projekt genomfördes också samtidigt där syftet var att utveckla ett livskvalitet instrument riktat till friska barn (KIDSCREEN). Proxy formulär har också utvecklats för olika ålderskategorier inom båda projekten. Under det senaste året har kvalitetsregister för barn och ungdomar allt mer efterfrågat instrument för att mäta hälsorelaterad livskvalitet, då detta har varit en brist i dessa register. I framtiden kan vi förhoppningsvis se en ökad möjlighet till förbättrad uppföljning vad gäller barn och ungas hälsa och välbefinnande, samt möjligheten att öka forskningstillgängligheten inom kvalitetsregister i Sverige.

Christina Peterson

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