

## Participation for children with disability

### *A project plan for an international collaborative project between Jönköping University in Sweden and University of Pretoria in South Africa.*

The main focus for this project is **Participation** in everyday activities for children with disabilities within a child rights perspective.

#### **Purpose and aim**

The specific aim of the collaborative project is to enable cooperation between the researchers in the participating countries. The researchers are currently both independently involved in research related to **Participation** of children with disabilities in everyday activities in their respective countries. This project aims to extend on this work in a collaborative way in order to measure the extent and nature of the participation of children with disabilities in everyday activities. In this research participation is operationalized in terms of an individual's attendance, that is 'being there,' measured as frequency of attending an activity, as well as the degree of engagement while attending everyday activities at school, home and in the community.

*The research project consists of three parts:*

- 1) The concept participation for children with disabilities in low income settings, how is it measured, by whom is it measured and where is it measured? A systematic literature review.
- 2) How do parents of children with disabilities perceive participation in different cultural contexts? An interview study of parents of children with disability, conducted in Sweden and South Africa.
- 3) How do children with disabilities and their parents perceive participation in different cultural contexts? A newly developed measuring instrument on participation "Picture my participation" will be used to measure children's participation as perceived by children with disabilities and their parents. Interviews with children with disability and their parents will be conducted in order to do a comparison between parent and children's perspectives.

This application aims to develop research collaboration around this project with researchers and students at the two institutions in Sweden and South Africa. The application therefore aims to i) explore the exchange of ideas through post graduate student and researcher interaction, joint data collection, and a seminar for joint discussion of the results of the project. The application therefore covers the costs for mutual travels and visits aimed to allow collaboration between the researchers and students as well as any research costs. The project will involve collaborations between students in the programs hosted by the two institutions, in particular the Interventions in Childhood Master program and PhD in disability studies at Jönköping University as well as Masters and PhD students in Early Childhood Intervention and Augmentative and Alternative Communication at the University of Pretoria. It will also include an exchange of doctoral students /post doctoral students. It is envisaged that the project will facilitate collaboration and mutual engagement of students and researchers through various methods including workshops, seminars and courses. It is also envisaged that interactions will occur via webinars and online discussion platforms led by the researchers at both institutions in order to facilitate collaboration and student engagement. The two institutions have also applied for money together with institutions in Australia, Vietnam and Nepal for developing and validating a measuring instrument on participation for children with disabilities in LAMI countries.

#### **Survey of the field:**

Participation focuses on people's involvement in everyday activities and is considered a health related outcome important for both wellbeing and learning (WHO, 2007). There is often inequity in participation between children with and without disabilities. It is known, that children with disabilities participate less in some types of activities than their peers without disabilities (Anaby et al., 2014; Engel-Yeger, Jarus, Anaby, & Law, 2009). Although some of the factors that are associated with restricted participation are related to the health condition (e.g., physical limitations that prevent the child from walking up a hill without an aid), this disablement is only constructed within a context that does not accommodate the child's needs. Efforts in low and middle income (LAMI) countries are often directed at addressing aspects related to basic needs (e.g., food, water), whereas participation in activities of personal interest that bring happiness and social integration and inclusion are often considered a secondary priority, and this finding is magnified for children with disabilities (Lygnegård, Granlund, Huus, Donohue, & Bornman, 2013). Children with disabilities in LAMI countries, for example may need to take part in caring for the family more than children in high income countries and they also tend to have less access to education and organized leisure activities. Therefore empirical data concerning children's participation in everyday activities from high income countries cannot be generalized to children with disabilities in LAMI countries. Theories and current thinking about participation thus suffers from a situational bias since

most research on participation has been undertaken in high income context. Because of this, it is important to assess what children with disabilities are doing compared to their peers without disabilities within the same context, culture and socioeconomic background. Only when we have a common reference point can we propose context informed strategies for children with disabilities to access the same type and range of opportunities and choice as other children. Equal opportunity is a necessary requirement for social justice and equity of participation (Forsyth et al., 2010).

The United Nations Convention on the Rights of the Child (CRC) (Convention on the Rights of the child, 1989) provides a framework describing the basic human rights to which children are entitled. This document together with the more recent Convention on the Rights of People with Disabilities (CRDP) (Convention on the Rights of Persons with Disabilities, 2006), enshrines the right for all children to have full participation in the home, school and community environments. Human rights concerns tend to be particularly salient for the most vulnerable children in a population. Children with disabilities are arguably the most vulnerable members of society because of their age and disabilities which together increase their dependence on others to have their rights fulfilled (Oosterhoorn & Kendrick, 2001). In LAMI countries, this vulnerability is even greater. Participation focuses on 'people's involvement in everyday activities and can be considered to consist of two dimensions: (i) being there (attendance) and (ii) engagement (Granlund et al., 2012). The CRC and the CRDP both focus on the first participation dimension of "being there". The emphasis is on the right to be a full member of society, which is operationalized as the attendance of persons in need of special support in the same everyday activities as other people. Attending an activity, however, is not a guarantee for being engaged while attending, as stressed in the inclusion literature (Falkmer, 2012). *Engagement*, the second dimension of participation, can be seen as the intensity of involvement when present in a situation. It can be conceptualized as a snapshot of a proximal process i.e. the reciprocal interaction between a child and the environment hypothesized to be the driving force in learning and development. Such proximal processes are affected by childhood disability.

Disability is the result of the combination of a child's functional ability, the adaptability and inclusivity of the environment in which they live. Poverty is both a cause and a consequence of disability (Emmett, 2005) due in part, to the mutual reinforcement of these two conditions. The heightened exposure to risks and environmental hazards related to poverty can increase the likelihood for congenital or acquired disabilities. Likewise, disability can reinforce poverty through its negative association with education and employment. Poverty is reported to be ubiquitous in developing countries where up to 50% of the population can exhibit stunted growth from a lack of proper nutrition (Walker et al., 2007). The International Classification of Functioning, Disability and Health (ICF: WHO, 2001) and its extension for children and youth, the ICF-CY (WHO, 2007) has its foundations in the concept of person - environment interactions, and CRC. It was created to provide a universal framework for classifying and documenting disability in the context of the environment (R.J. Simeonsson, 2006; R. J. Simeonsson, Scarborough, & Hebbeler, 2006). The time a child spends engaged in stimulating activities in their everyday life is related to their current and future well-being and learning (Arvidsson, Granlund, Thyberg, & Thyberg, 2014) and is defined in the ICF-CY as participation. The ICF-CY describes participation as a health related construct. The two dimensions of participation "being there" and "being involved/engaged while being there" can be linked to facilitators and barriers in the environment. In ICF-CY five environmental domains are described; products and technology, natural environment and human-made changes to environment, support and relationships, attitudes, and service systems and policies. By linking the content of a participation instrument to ICF-codes comparisons with other studies using other ICF-CY based instruments are possible (Simeonsson et al, 2010)

LAMI countries. In a recent study by Huus et al (accepted 2015) children's self-ratings did not always overlap with primary caregiver proxy ratings, especially when more complex needs were surveyed. In addition, socioeconomic circumstances affected the agreement between self- and proxy ratings. In very poor settings, for example, children's opinions about their everyday life, differed to a larger degree from proxy ratings, than in less poor settings. Self-report measures ask the child directly about their perspectives and experiences of participation. Proxy report measures seek answers from someone other than the child, for example a care-giver. Because self-report measures collate responses from the individual who has the lived experience they are likely to have greater validity, especially in relation to measuring the engagement dimension of participation. There are also disadvantages to asking children with disabilities to self-report, including potential difficulty in understanding the questions, difficulty in recalling past events related to attendance in activities, and the potential for respondent bias related to a perceived need to provide socially acceptable answers. There are situations where proxy reports are necessary, for example when the child does not have the capacity to understand or communicate the concept being measured because of age, intellectual or communication ability. The disadvantages are, however, that the proxy does not have the same perspective as the child (Jokovic, Locker, & Guyatt, 2004). It may be advantageous to measure both the child and an appropriate proxy's perspective to

obtain comprehensive data (Soderback, Coyne, & Harder, 2011). In this project an instrument for collecting self-ratings of participation from children with disabilities in poverty settings (Imms et al, 2015) will be validated and used for data collection.

### **Project description and mode of cooperation**

This project will explore issues surrounding the understanding of disability and participation in childhood across different socio-economic contexts, since environmental conditions may affect the way in which the concept is understood and therefore implemented in interventions for children with disability. The international collaboration in this project is critical as it provides a platform from which a broad-based international knowledge base can be developed about the concept and measurement of participation.

***In Sweden,*** Dr Karina Huus, is a senior lecturer at Jönköping University, School of Health and Welfare. Karina works in the field of children's rights and participation, she has published extensively in this area and has a long experience of teaching at different levels and also supervises doctoral students. Karina will be the project leader in Sweden. She is a member of CHILD (Children -Health-Intervention-Learning- Development) research group at Jönköping University. Jönköping University is a foundation with five schools and CHILD is a research group available on two of the Schools: School of Health and Welfare and School of communication and education. CHILD is an interdisciplinary research team with many years of international experience. A key focus of the CHILD research group is ongoing education about Interventions in childhood and disability in a recently introduced Masters program. The main mode of this program is a campus based education but it also contains web lecturers and seminars

### ***In South Africa,***

Dr Shakila Dada, is a senior lecturer and researcher in the interdisciplinary research team Centre for Augmentative and Alternative Communication at the University of Pretoria and will be the project leader in South Africa. She has extensive teaching and supervision experience in the early childhood and augmentative and alternative postgraduate programs undertaken in the Centre. These include an Honors in AAC, Masters in Early Childhood Intervention, Masters in Augmentative and Alternative Communication as well as the PhD (Augmentative and Alternative Communication). All these programs have an online learning component and use a blended learning approach that combines face to face and online work. The cohort of students included in this proposal would therefore have the e-learning infrastructure in place to have continued engagement and discussions with their Swedish counterparts in between onsite contact sessions using the Blackboard Collaborate learning management system of the University of Pretoria in addition to web based communication tools such as email and Skype. The current cohort of teachers from the Centre for Augmentative and Alternative Communication are currently funded by the University of Pretoria. The technological infrastructure for student online discussions and webinars is therefore already available for continued engagement between the two countries in between contact sessions.

Dr Alecia Samuels is a staff member from South Africa working at the Centre for Augmentative and Alternative Communication. She is currently undertaking a 2 year post-doctoral research fellowship at Jönköping University and will serve as a link between the two universities once she returns to South Africa in 2017 as she has experience of working and researching in both countries and institutions.

The time that the staff put into this project will be funded by the University of Pretoria and School of Health and Welfare, Jönköping University through internal funds. The funds we are applying for will therefore be used to fund travel, accommodation and research costs for the project. Professors at the two universities will participate funded by internal money.

### **Implementing the collaborative project about participation**

The project is planned to be implemented during a three year period. During the three years, one course per year on the web will be offered for research staff, doctoral students and master students. Firstly there will be joint courses in research methodology in undertaking systematic literature reviews. The second course will be about how to conduct qualitative interviews with children. The third course will be about the concept of participation and children's rights. Lecturers from South Africa and Sweden will present these courses together and will utilize each other's expertise. It is envisaged that the students that will benefit from these courses will be from South Africa and Sweden. The South African counterparts are committed to providing an opportunity for previously disadvantaged students to be a part of this project in order to build capacity and a young cohort of researchers.

During the year one doctoral student/ post doctoral research fellow from Sweden and one from South Africa will have the opportunity to spend at least 3 months at the other research center. The aim of the visit is to enable the exchange of young researchers or experts on specific subjects to collaborate on the project and build capacity.

It is envisaged that the project will culminate in at least 2 scientific publications in which the project leaders will each be the co-authors on along with the participants in the project as well as student research projects on participation which may also be submitted for publication.

### **Year 1:**

Starts with a kick-off seminar in Sweden for the leaders of the project to meet and plan the details for the different activities and research. This seminar will take place in Sweden.

*The research project consist of three parts:*

***The first part of the research project*** is to do a systematic literature review about the concept of participation for children with disabilities in poverty settings, how is it measured, by whom is it measured and where is it measured. This will be organized by the project leaders together with research staff in both countries, a protocol must be adapted in order to review articles that correspond to the purpose.

In year one, there will be a kick- of seminar where activities and the research will be planned. There will be an opportunity to plan the systematic review protocol that will form the focus of the first year of the project. At this seminar the researchers from Sweden and South Africa will develop working groups that will plan and write scientific articles. The kick off seminar will be hosted in Sweden at the time of the International society on early intervention (ISEI) conference taking place in Stockholm 8-10 June 2016 “Children’s rights and Early Intervention”. The project leaders and researchers will present a joint conceptual paper about the project at this conference to an international audience in order to gain feedback from experts in the field.

During this first year there will be joint courses for Masters and PhD students with respect to the methodology of conducting systematic literature reviews. Masters students in both countries will then undertake a systematic review on the concept participation for children with disabilities in low income settings with respect to how is it measured, by whom is it measured and where is it measured. A master’s student from South Africa will be partnered with a student from Sweden on an individual data base. Each pair will then come together and write a joint paper on their findings from their chosen data base and the PhD/post doctoral fellow will combine the results from all data basis to assist with the journal article publication.

### **Year 2:**

***The second part of the research project*** is a semi-structured interview with parents of a children with disability. The doctoral student/post -doctoral research fellows from Sweden and South Africa will each interview 25 parents in their respective countries. The focus of the semi-structured interviews would be to identify the parent’s perceptions of their children’s participation.

In the second year of the project we will have a seminar in which the preliminary results of the project will be interpreted and discussed. The researchers will also have an opportunity to work on the joint publication. This seminar will be hosted in South Africa.

During the second year there will be a 3 month exchange visit of one doctoral student/post- doctoral research fellow.

In the second year there will be a course about qualitative research with a specific focus on conducting focus groups and interviews.

### **Year 3:**

***The third part of the research project*** is a pilot study where a newly developed instrument on participation “Picture My Participation” (Willis, Imms, Granlund Bornman & Elliott, 2015) will be field tested in South Africa and Sweden. Interviews with children with disability will be conducted in order to undertake a comparison between parent and children’s perspectives. The doctoral student/post-doctoral fellow from Sweden and South Africa will perform the interviews. The Post- doctoral fellows and senior researchers from both Sweden and South Africa will analyze the data.

In the third year it will be two seminars one in Sweden and one in South Africa. The seminar in Sweden will focus around data collection and methodology issues. The last seminar is in South Africa and will focus on the results of the project as a whole both the methodology issues as well as the specific results and there implications for children with disabilities and their families in the respective countries.

During the third year there will be a course about how the concept of participation is constructed in different countries.

#### *Project organization*

The leaders of the project group will be Karina Huus RN PhD and Shakila Dada (PhD) AAC. They will be responsible for the organization of the project and they cooperate in accordance with principles of academic freedom and good research practice. Methods, data and results will be openly accounted for. No other funding are received from other financiers. The final version of this application has been read and approved by all parties involved.

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