

Ser nyhetsbrevet konstigt ut? [Visa webversion](#).



Newsletter from the research profile CHILD, based at Jönköping University

September 2012

## Lost in Transition

### Transitions into Adulthood

Transitions primarily focuses on planned or known in advance changes in life such as starting school, puberty, moving from home but also transitions between services such as changing from child and youth based cancer care to adult cancer care. Common to the effects of transitions on individuals is that transitions make people vulnerable to both positive and negative experiences that will affect later life.



**Children and youth having long term diseases or impairments are more vulnerable to transitions** than other persons. Several of the research projects within CHILD in Jönköping and Halmstad concern transitions. In this issue of the newsletter some of our researchers that have an interest in transitions will tell about their research, with a special focus on experiences of transitions.

Professor [Mats Granlund](#), research leader of CHILD

### CHILD-researchers on Transitions into Adulthood



#### An increasing number of students with disability attend higher education

CHILD-doctoral student, [Ann Simmeborn](#), has studied how young adults with the diagnose Asperger Syndrome (AS) are doing in the higher education system (HE). [Read more](#)



#### Health innovations for involvement of children in health care decision processes

As the development of pediatric health care has evolved, increasing numbers of children surviving from serious illness or having chronic conditions reach adulthood today. The process of transition to adult health care requires participation and responsibility of the child... [Read](#) the whole article by [Jens Nygren](#), PhD, Associate Professor in Medical Science at Halmstad University.



#### Structured transition programs promote health and quality of life

To organise and coordinate transition from child health care to adult health care to promote health and quality of life are the main goal with structured transition program. When developing a transition program the perspectives of the patient, parent and health care provider should be taken into consideration. [Read](#) researcher [Helen Rönning's](#) article on the subject.



#### Neither child or adult - being a young person in cancer care

[Maria Olsson](#) is a CHILD-doctoral student in Nursing Science at School of Health Sciences at Jönköping University. "The lost tribe" is a quote from an article highlighting the situation for teenagers and young adults treated for cancer. The group of 15-29 year olds might be a lost tribe or in no man's land when it comes to cancer care today. [Read](#) the article

### CHILD-News

[Inauguration of full](#)

[Conference on Autism](#)



### professors and conferment of PhDs

On September 29, 2012, Jönköping University invites to inauguration of full professors and conferment of PhDs - and CHILD is happy to [celebrate six members](#) of the research group who will be honoured in this way.

### 34 Articles Published

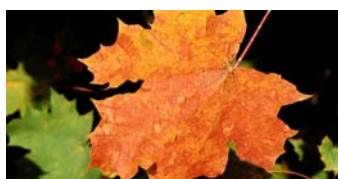
Members of the CHILD-group has [published 34 articles](#) in peer reviewed journals already this year!



Noomi Carlsson successfully defended her thesis in Medical Science at Qulturum, Jönköping on August 29, 2012.

### Spectrum Disorders

CHILD-researcher Ann-Katrin Swärd arranges a conference day on Autism Spectrum Disorders. Dr Theo Peeters and Hilde de Clercq from Opleidingscentrum Autisme in Belgium and Ann Simmeborn-Fleischer from Jönköping University give lectures on autism spectrum disorders. Sign up for the conference day on September 24, 2012! The day will be recorded for television; Kunskaapskanalen. [To the invitation](#)



### CHILD-Agenda 2012

Our next seminar will be on September 27, when professor Rune J. Simeonsson from University of North Carolina at Chapel Hill presents his research. Welcome to join us! [Agenda of fall 2012.pdf](#)



Ingallim Gimbler Berglund nailed her licentiate thesis in Nursing Science to the wall on September 6, 2012.



Gregor Maxwell defended his doctoral thesis in Disability Research on June 15, 2012.

## Report from the new CASINO-network



Relatively little of the research within all disability research concerns children. That is why CASINO are doing an in-depth analysis of the area, and so far can tell that most research there is, is quantitative with relatively little input from the children themselves. The Child and Adolescent Special Interest Network (CASINO) is a new research network that wishes to increase research done for the benefit of the children. CASINO is a network in the [Swedish Institute for Disability Research](#) in Jönköping, Linköping and Örebro. [More on CASINO](#)

## What's new in the GEDS-project?



### GEDS Summer Institute 2012

In June 2012 Jönköping University and CHILD hosted an international summer institute. The course called 'Environmental Assessment and Intervention in Early Childhood' - an international Intensive course of 7.5 ECTS about environmental assessments, was connected to the EU-US Atlantis project GEDS and to the VR research Links project and also to the Swedish Institute for Disability Research. Participating faculty came from ongoing collaboration in GEDS and between University of Pretoria and Jönköping University. In all, 23 participants and 23 lecturers. Even Swedish Radio P4 came visit us; [CHILD on air](#).

The purpose of the course was to give knowledge and understanding in order to;



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

[More on GEDS.](#)

## CHILD Newsletter

**CHILD** is a research environment at Jönköping University in Sweden. Our primary research focus is on interventions, participation, learning, health and everyday functioning in children with special needs, but also in typically developing children.

For more information, contact CHILD's research coordinator [Cecilia Allegrind](#), +46 36 10 13 76.

[CHILD's webpage](#)



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## ***An increasing number of students with disability attend higher education (HE).***

People with all kind of disabilities are more represented in our society today and have to deal with education and the labor market as everyone else. Young adults of today need an education and preferably a university exam. At universities in Sweden, the number of students with disability has increased in the last decade (Bjornsdottir & Svendsdottir, 2008; Konur, 2006; Simmeborn Fleischer, 2011). Young adult with disabilities has even more desire for an exam and professional competence, because the labor market is severe for young adults. In February 2012 (Ekonomifakta, 2012) there was approximately 147.000 young adult between 15-24 year who was unemployed.

For persons with disabilities, there are laws regulating support in different areas of the society. The law of equal treatment (SFS 2001:1286) protects students against discrimination and stipulates equal rights to all students. The law protects all persons with disability. There is also an additional resource available, the Disability Ombudsman (2011) how's function it is to oversee that the applicable laws are being observed.

One group that are more visible today is persons with the diagnose Asperger Syndrome (AS). Generally considered, citizens are required to be more outgoing, have an ability to make connections with other people and have competence in communication. These competencies are reduced for persons with AS, which means that more and more encounter difficulties in their daily lives, in the workplace and in study situations (Gillberg & Peeters, 2002; Simmebor Fleischer, 2006; Simmeborn Fleischer, 2011). There are laws like the LSS<sup>1</sup> (Law 1993: 387, 2011; Social Styrelsen, 1994; Socialstyrelsen, 2011) and SoL<sup>2</sup> that are supposed to support, among others, persons with AS in their everyday situations.

## ***Background regarding Universities in Sweden***

There are 52 universities in Sweden but not all of them have students with disabilities. For example Universities like Military Academy, The Swedish National Police Academy, University of Dance and Circus have no students with disabilities (Simmebor Fleischer, 2012 (in progress)).

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<sup>1</sup> The Swedish disability Act concerning Support and Service for Persons with Certain Functional Impairments

<sup>2</sup> The Swedish Social Service Act

At all universities in Sweden, there is a coordinator that offers students with disabilities individual consultations to discuss existing needs for educational support. The coordinator foremost function is to remove or bridge barriers in the study situation for students with disabilities. The application for support can be done either in advance of the studies, or during the term in which the need for supportive measures were observed (Stockholm University, 2011). Support and service to students with disabilities is always ultimately the responsibility of the home university. The most common support that has been offered from these coordinators is: support in taking notes, support by a mentor (often another student), personal assistant, supervision, hearing loop, reading support, technical support, sign language interpreter, study skill strategies, computer courses, group activity room or a own study room and special arrangement in education and examines (Gothenburg University, 2010; Lund University, 2010; Stockholm University, 2011; Uppsala University, 2010)<sup>3</sup>. As can be seen, support provided is primarily focused on facilitating studying with little or no focus on supporting decision making and functioning in everyday life.

At Stockholm University there is a person who organizes and put together all data that all the coordinators from all universities in Sweden reports. Every year, they report how many students that have visit them and what kind of disabilities the students have. There are a total of 8.455 student who have search for support, see table 1. The largest group of students are does with dyslexia and after that students with cognitive disabilities, and in that group students with AS is represented.

Disabilities	2011		
	Women	Men	Total
Dyslexia/specific learning difficulties	2 859	1 558	4 417
Students with visual impairment	182	106	288
Students with mobility impairment	377	192	567
Deaf/sign language speaking students (with interpreting)	106	30	136
Students with learning difficulties/disabilities ' <i>Cognitive difficulties</i> '	922	772	1 694
Hard of hearing students (without interpreting)	131	72	203
<b>Others</b>	335	151	486
<b>In all</b>	<b>4 912</b>	<b>2 879</b>	<b>7 791</b>
Other students, graduates and postgraduates made known to the coordinators by teachers, counsellors and others consulting them	434	230	664
<b>All in all</b>	<b>5 346</b>	<b>3 109</b>	<b>8 455</b>

Tabel 1. (Stockholms University, 2012)

<sup>3</sup> Four of the largest and oldest universities in Sweden

## ***Students with AS in HE***

Persons with AS have cognitive difficulties that can interfere with studies as well as with describing needs and ask for support. The demand for active participation in goal-directed planning may represent a problem for students with AS since they may have difficulties understanding the support systems. They have also difficulties to plan their studies: which books are the most important to read, when do I have to start to read before a examination, and how is a exam question be interpreted (Lipka 2006;Wessel et al. 2009 ). In all likeliness there is a number of factors, for example personal abilities and official support systems in Sweden, like LSS and SoL, that affect the outcome of the studies for the student with AS.

In earlier research there is reported that many, important to note not all, students with Asperger syndrome (AS) in higher education frequently experience problem in everyday functioning that interfere with their studies (Dillon, 2007; Simmeborn Fleischer, 2011; Smith, 2007).

## ***AS in relation to studies in higher education***

Some of the hallmark behaviors of persons with AS generate difficulties in everyday student-life. The term “everyday student-life” has been adopted from previous research in which the everyday student-life of three male students with Asperger Syndrome was investigated . The conclusion of the research was that the life of a student can think of as being in two parts: everyday life and student life (those aspects of life which are specific to being a student). For students with AS, these two intertwine and make their lives more difficult than for ordinary students (Simmeborn Fleischer, 2011).

The most common hallmark for persons with AS is the fact that persons with AS usually develop a need for *routines* (Attwood, 1998; Ehlers & Gillberg, 1994; Jackson, 2003; Simmeborn Fleischer, 2011). These routines’ can make the life quite locked-in and takes a lot of time for the person. Some routines, like taking one hours shower every morning, and you wake to late one morning. You do not have the time for one hours show, that day the person probably will go to bed again because the routine is not possible to fulfill.

Another hallmark is *Special interests*, which can be a problem for the person, the interest takes a lot of the attention and absorption (Attwood, 1998; Fleisher, 2005; Frith, 1991). Some special interest can be positive and some negative. Positive, the interests can be an advantage if it coincides with academic subjects and areas. Negative if the interest is something that the

society think is incorrect, like weapon or political inaccurate, and the persons with AS talks about this in the opened.

Persons with AS also have difficulties with focused *attention*, especially with paying attention to what other people say and do. The ability to concentrate and pay attention is often reduced; it is usually hard for persons with AS to get interested in topics outside of their own sphere of interest. They have also difficulties to understand other persons feelings and reaction and do not read body language, have difficulties facial expressions and gestures, intonation and eye contact, and there for miss information and modification of timetable, tasks and scheme. It has to do with lower *mentalization ability*. (Attwood, 1998; Ehlers & Gillberg, 1994; Simmeborn Fleischer, 2011)

Persons with AS usually *interpret literally* what is said or written. With a lower mentalization ability and interpret literally, person with AS have difficulties to understand the intent behind other people's behavior and they understand situations in a different way. (Attwood, 1998; Bogdashina, 2005; Jackson, 2003).

### **Conclusion from the case study**

Three male students with AS is represented in the results from a case study. The picture shows that it is not always easy getting the everyday student-life to work properly for students with AS. Alienation and struggle is significant for their every student-life. All three students experience difficulties in different ways. The everyday student-life of the respondents consists of finding solutions to be able to handle activities which other students mostly do not have to spend any special amount of time and energy on. Another prominent aspect is the struggle to find time to be alone and having time for their special interests. Thus, everyday student-life consists in large part of struggle with spare time and day-to-day activates. The struggle is dual and paradoxical focusing both on being accepted in the role of student and on maintaining an identity as partly alienated. Working at two fronts takes lot of energy, which in turn leads to difficulties in focusing on studies. The difficulties interacting with their student environments lead to that they themselves feel that something is not working, but they lack the skills to define the problem. They are caught in a catch 22: They do not know what support they need and the support that they have been offered becomes just another barrier. The support they received was experienced in some cases as more negative than positive, and when their interaction with their counselor did not work out, they did not go back to look for other means of support. They did not tell the counselor that the support was not working nor did they explain their reasons for not accepting the given offers of support.

The students experienced that the coordinators did not understand them and therefore there was no point in going back and asking for something else. Freedom of choice is in an illusion to these students: it is just one more complex issue for them to deal with. If freedom of choice requires that you know your needs and that you know what support to ask for, then it becomes a catch-22 situation if you cannot identify your needs and have difficulties knowing what to ask for (Simmeborn Fleischer, 2011).

To a high extent, achieving functional everyday student-life is about managing everyday activities. Only a modification of the way of offering support will give students with AS and cognitive disabilities the same opportunities as other students. More collaboration between university authorities responsible for support and their support coordinators are prompted for (Simmeborn Fleischer, 2011).

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## **Health innovations for involvement of children in healthcare decision processes**

*by Jens Nygren PhD, Associate Professor in medical science, Health innovations for children's mental health, Halmstad University.*

As the development of pediatric health care has evolved, increasing numbers of children surviving from serious illness or having chronic conditions reach adulthood today. Internationally, approximately 30% of adolescents have a chronic condition as they transit from pediatric to adult health care (Pai & Ostendorf, 2011). There are no similar statistics for Sweden as transition is first documented at enrollment at the adult health care facility. The process of transition to adult health care requires participation and responsibility of the child, however there is an overall lack of such preparedness among children today as their participation in health care decision making during adolescence is largely disregarded.

In a nationwide study of young adult cancer survivors (treated for acute lymphoblastic leukemia during 1985-1997 in Sweden) we have observed that few (14%) maintained contact with their pediatric oncology clinic and that only 28% continued clinical checkups related to their cancer treatment. Of those who had no regular contact, 39% were dissatisfied with the contact being terminated during transition to adult health care and reported a lack in knowledge on how to reestablish contact related to medical or mental health issues. Of all participants in the study, a majority reported that they lacked experience of psychosocial rehabilitation focused on knowledge formation (58%), strategies for action (66%), or support (58%) to continue life the best way possible. We conclude from this that children surviving from cancer in Sweden are not sufficiently prepared for the transition from pediatric to adult health care and that this makes them more vulnerable when it comes to managing their health in adulthood.

Allowing children to participate in decision making related to their health and health care creates skills and experiences that give them future opportunities to influence on determinants of their health and on the health care that they receive. A widespread model for patient involvement in health care is Shared decision making (SDM) that has been implemented in treatment of cancer and cardiovascular diseases in adults (Joosten et al, 2008; Clark et al, 2009; O'Conner et al, 2009). Patients that are offered to communicate their health through the SDM model have more knowledge about different treatment options and their expected outcomes and are more satisfied with decisions taken and experience less ambivalence about their treatment (O'Conner et al 2009). Despite the potential benefit of using the SDM model for communicating children's needs and views most studies examining the potential benefits of SDM in communication with children regarding their health care are focused on the perspectives of the health care providers and parents (Young et al 2006; Merenstein et al, 2005; Fiks et al 2010; Fiks et al 2011; Coyne et al 2011; Litchfield & MacDougall, 2002). The few studies that has a child perspective (Young et al 2006; Coyne et al 2011; Hughes et al 2011) demonstrates a need for research on the child's perspective in decisions about their health.

Our research is currently focused on projects that use an interdisciplinary and participatory approach for the design of digital communication tools that in different contexts involves children, their parents and health care providers in SDM. A key feature of our research and design process is the involvement of the children themselves in all parts of the process, as informers, designers, testers and end users. This ensures that both research and innovation processes are focused on the child perspective of health and decision making and that the developed services are child-friendly, age-adjusted and adapted to the cognitive and emotional developmental stage of the child.

Research that results in evidence based innovations that make children more involved in their health care will result in positive health benefits during adolescence as well as preparing their ability to participate and taking responsibility during their transition to adult care.

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# The transition process between childhood to become an adult and living with a congenitally malformed heart



by Helen Rönning

*Helén Rönning is working at Jönköping University in the department of nursing school as a lector and researcher since august 2011. Before that she was working as a nurse mainly with adults with heart diseases and congenitally malformed hearts at the University Hospital in Linköping since 1990. In 2005 she became a PhD-student and in June 2011 she finished her thesis. The title of the thesis was; Follow-up of adults with congenitally malformed hearts with focus on individualised and computer-based education and psychosocial support.*

## **A descriptive and interventional study.**

Heart anomalies are the most common form of congenital malformation and they are the most frequent cause of death among infants with birth defects<sup>1</sup>. Today more than 85 % survive into adulthood, compared to the previous 20 %<sup>1</sup>. This is a result of improvements in diagnosis, medical treatment and heart surgery. In Sweden for instance a centralisation of paediatric heart surgery to two centres in 1993, reduced the overall 30-day mortality for open heart surgery in infants and children from 9.5% to 1.9%<sup>2</sup>. Treatment of congenitally malformed hearts is aimed to reduce symptoms, but also to minimise the risk and severity of late complications<sup>3</sup>. Individuals with non-complicated heart defects have usually a normal life expectancy, rarely requiring on-going medical treatment or repeated surgery<sup>4</sup> and most of the participants registered in the Swedish registry of congenitally malformed hearts, SWEDCON had no physical limitations<sup>5</sup>.

Guidelines recommend follow-up programmes that target medical and psychosocial problems among children, adolescents and adults with congenitally malformed hearts. The goal with the regular follow-up is to minimise the risk and severity of late complications and reduce symptoms<sup>3</sup> but evidence and long-term effects is missing.

The majority of all individuals with congenitally malformed hearts have been monitored on a regular basis in the hospital outpatient clinic since childhood. The follow-up takes place every 6th month up to every 5th year depending on the heart defect and heart function. During the first years parents are completely responsible for all medical contacts and treatment for the child, but slowly during childhood and into adolescence these individuals have to take more responsibility for themselves<sup>6,7</sup>. This process has not been well described in earlier studies neither has knowledge about parents experiences about parenting children and adolescents who survives into adulthood. There are a lack of studies focussing on how parents and health-care professionals can be supportive and an active part of the transition process. Parents' importance and health-care professional's role and influence during childhood and adolescence must be illuminated.

Research on children's, and adolescents' as well as parents understanding and knowledge of the congenitally malformed heart is limited<sup>8</sup>. Adolescents with congenitally malformed hearts must take responsibility for their life and treatment which requires that they have sufficient knowledge about their heart disease, treatment and preventive measures. Thus, education related to the malformed

heart should be directed to the child directly and to the parents. It is still unclear what children, adolescents with congenitally malformed hearts and their parents know about the heart defect, treatment, and preventive measures necessary to avoid complications.

There is also missing knowledge around how the adolescents and young adults with a congenitally malformed heart perceive the growing demands in life and the effects of it. The population with congenitally malformed hearts are in wants of self-care managements of i.e. medical treatment, awareness of symptoms and contribute to regular follow-up, prophylactics of endocarditis, recommendations on physical activity, employment, sports and spare time and risk reduction in connection with pregnancy<sup>9</sup>. There is known that balance in life is important to perceive health<sup>10</sup>. Satisfying pattern of daily occupation that is healthful, meaningful, and sustainable to an individual within the context of his or her current life circumstances gives balance in life. Stress arises from an imbalance between the demands from the environment and the individual's resources and capabilities. In a study by Torel et al around 30 % of the adolescents operated in childhood for a congenitally malformed heart had post-traumatic stress disorder<sup>11</sup>. Adolescents with long-term illness or disabilities experience well-being when they are allowed to prepare for living a normal life integrated in society. Support from family, friends, health care professionals and society are essential<sup>12</sup>. To organise and coordinate transition from child health care to adult health care to promote health and quality of life are the main goal with structured transition program<sup>13</sup>. When developing a transition program the perspectives of the patient, parent and health care provider should be taken into consideration<sup>14</sup>. There has been suggested that the transition plan should be implemented at least from the age of 12 together with the child and the family<sup>15</sup> and structured education should focusing on the child and the family's needs<sup>13-15</sup>. The gap between the paediatric and adult health care has been described as a reason to uncertainty among adolescents and their families. Cooperation among health care professionals can illuminate those problems.

In conclusion there is a strong consensus about the needs of further development and improvements of the care for the transition process in this group<sup>16</sup>. There are needs of a structured transition plan where the child and family needs are in focus with regard to the child's age, maturity, compliance and medical status. Few studies so far have focused on describing and evaluating long-term effects of the follow-up process in children to become and adult living with a congenitally malformed heart.

One model for follow-up have been developed and tested by Rønning et al<sup>17</sup> for adults with congenitally malformed hearts. Focus was on individualised<sup>18</sup> and computer-based education<sup>19</sup> and psychosocial support by a multidisciplinary team with purpose to be used in the hospital out-patient clinic. The model was effective in improving and maintaining knowledge about self-management but long-term effects and the usefulness in the younger population is still unknown.

To fulfil these needs health-care professionals and researchers need to cooperate by multidisciplinary team and interdisciplinary research groups need to be developed. Longitudinal research following the child until adult age is needed.

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## **Neither child or adult – being a young person in cancer care by Maria Olsson**

*Maria Olsson is a CHILD-doctoral student in Nursing Science at School of Health Sciences at Jönköping University. The overall aim of Maria Olsson's research is to explore cancer care for teenagers and young adults in Sweden. The study includes an exploration and comparison of cancer diagnoses and prognosis of Teenagers and Young Adults, TYAs, 15-29 year olds, with cancer in Sweden. Also, focus groups interviews, with TYAs who have completed cancer treatment, will be conducted to describe their experience of the care in hospital. The result will lead to improvement of the hospital care for TYAs with cancer in Sweden*

“The lost tribe” is a quote from an article highlighting the situation for teenagers and young adults treated for cancer (Stevens 2006). In Sweden as well as in many other countries, teenagers under 18 years are treated for cancer at pediatric units while those over 18 are treated at adult units. The number of newly diagnosed cancer patients in Sweden in the ages 15-29, teenagers and young adults, is small about 600 (Cancerregistret, 2006). So when you are either 17 at a pediatric unit or 23 at an adult unit you are quite unique. Professionals working at these units might not get enough experiences in caring for this group of patients (Engvall, Skolin et al. 2011). So the group of 15-29 year olds might be a lost tribe or in no man's land when it comes to cancer care today.

The definitions of “Teenagers and Young adults” - TYA versus “Adolescents and Young adults” – AYA, varies between countries. In Great Britain it is called TYAs and referred to patients between 15- 25 years. In USA they call the group AYAs and have a span of 15-40 years. In Australia AYAs defined as 15-29 years and France TYAs 13-20 years. So today the focus on young people with cancer increase around the world, especially the western parts of the world, where the issue has been that this age group needs to be seen as a subgroup among cancer patients. In these countries the questions are raised on, what is the knowledge in aetiology of this age group, where to treat them and what kind of healthcare professionals are needed in the care for young persons (Zebrack, Mathews-Bradshaw et al. 2010). An article from the USA described the poor situation for the AYAs in outcome and increased outcome for cancer. They saw a lack of participation in clinical trials that might affect the increase in outcome (Albritton and Bleyer 2003). They saw a need for collaboration between paediatric and adult cancer care. In some countries they have developed special units for this patient group (Mulhall, Kelly et al. 2004). In England the first TYA unit was established in early 1990s. Today Great Britain has 17 units for 15-25 year olds cancer patients. In Australia, New Zealand and France they are under development and today there is one unit for TYA patients with cancer in those countries. In Australia and USA they have developed framework, guidelines for the care for TYAs with cancer. There has not been an evaluation of this care in any of these countries. They have started evaluation research in Great Britain which will be finished in a couple of years.

What have been described as needs for TYAs is age appropriate environment and information. They express the need to be able to meet other young people with cancer, “being in the same boat”. TYAs need to be taken seriously by the health care professionals (Enskar, Carlsson et al. 1997; Palmer, Mitchell et al. 2007; Smith, Davies et al. 2007).

What about TYAs treated for cancer in Sweden? There are no special TYA units in Sweden today, but there is a discussion on how the care for TYAs today should be given. The policy on

health care in Sweden is formed by the National board of health and welfare. The law is concerning healthcare from medical prevention, investigation and diagnose to treatment of illness or injury. "The Government's ambition is to create the best conceivable conditions for good patient-centred health care. Health care must be characterized by a high level of accessibility, good quality and freedom of choice for the individual. These principles are reflected in the Government's strategy on good health care (HoS, 1982). So patient's participation in health care is important.

To be able to receive knowledge on TYAs treated for cancer in Sweden we wanted to increase patient's participation by inviting them to focus group interviews. We want to hear their views on their cancer care, what is important for them, what do they need and expect from the health care professionals. We have now conducted 11 focus group interviews followed by 12 person interviews to receive information on TYAs needs. Analysis of the result is currently going on and will be done during 2012.

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Hälso- och sjukvårdslagen,

<http://www.riksdagen.se/webbnav/index.aspx?nid=3911&bet=1982:763>



**CHILD-members for**

## **Inauguration of Full Professors and Conferment of PhDs at Jönköping University 29 September 2012**



Karin Enskär was appointed full professor in Nursing Science at School of Health Sciences at Jönköping University in August 2011.



Margareta Adolffsson, PhD in Disability Research, successfully defended her doctoral thesis *'Applying the ICF/CY to identify everyday life situations of children and youth with disabilities'*, in October 2011.



Marie Golsäter, PhD in Nursing Science, successfully defended her doctoral thesis *'Hälsokurvan som pedagogiskt redskap vid hälsosamtal inom barn- och skolhälsovård'* in March 2012.



Gregor Maxwell, PhD in Disability Research, successfully defended his doctoral thesis *'Bringing more to participation – participation in school activities of persons with disability within the framework of the International Classification of Functioning, Disability and*

Health for Children and Youth (ICF-CY)' in June 2012.



Stefan Nilsson, PhD in Nursing Science, successfully defended his doctoral thesis 'KomHIT - att underlätta sjukhusbesök för barn med kommunikationssvårigheter' in 2010.



Ylva Ståhl, PhD in Nursing Science, successfully defended her thesis 'Barnhälsodataprojektet — Vilken hälsoinformation om varje barn ska elektroniskt registreras?' in April 2012.

### **CHILD also congratulates...**



Noomi Carlsson, PhD in Medical Science, who works for the County of Jönköping within the Health Care Area. She has been a PhD-student enrolled at Linköping University, but she has also been a member of the research group CHILD at Jönköping University. The 29th of August Noomi Carlsson successfully defended her doctoral thesis 'A Zero-vision for Children's Tobacco Smoke Exposure, Tobacco prevention in Child Health Care' at Qulturum in Jönköping.

## Publicerade artiklar 2012, CHILD

Granlund, M., Arvidsson, P., Niia, A., Björck-Åkesson, E., Simeonsson, R., Maxwell, G., Adolfsson, M., Eriksson-Augustine, L., Pless, M. (2012). Differentiating Activity and Participation of Children and Youth with Disability in Sweden - A Third Qualifier in ICF-CY: *American Journal of Physical Medicine & Rehabilitation*: 91(13), s84-S96 .

Maxwell, G., Alves, I.F., 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

Simmeborn Fleischer, A. (2012) The Support to students with Asperger Syndrome in Higher Education - the perspectives of three relatives and three coordinators. *International Journal of Rehabilitation Research*

Sjödin L., Buchanan A., Mundt B., Karlsson E., Falkmer T., (2012) Do vehicle grants and vehicle adaptations grants promote participation for children with disabilities? *Australian Occupational Therapy Journal*, 59, 10–16, doi: 10.1111/j.1440-1630.2011.00972.x.

Lidström, H. a,b, Granlund, M. c, Hemmingsson, H. d. (2012) Use of ICT in school: a comparison between students with and without physical disabilities *European Journal of Special Needs Education (Computer-based Assistive Technology Device for use by Children with Physical Disabilities: a Cross-sectional Study)* (ID: 635332 DOI:10.3109/17483107.2011.635332)

Adolfsson, M., Granlund, M., Pless, M. (2012). Professionals' views of children's everyday life situations and the relation to participation: *Disability and Rehabilitation*: 34(7), 581-592 .

Pless, M., & Granlund, M. (2012). Implementation of the International Classification of Functioning, Disability and Health (ICF/ICF-CY) within the context of Augmentative and Alternative Communication. *Augmentative and Alternative Communication*, 28, 11-20

Rowlands, C., Fried-Oken, M., Steiner, S., Lollar, D., Phelps, M., Simeosson, R., & Granlund, M. (2012). Developing the ICF-CY for AAC Profile and Code Set for Children Who Rely on AAC. *Augmentative and Alternative Communication*, 28, 21-32

Simeonsson, R., Björck-Åkesson, E., & Lollar, D. (2012). Communication, Disability and the ICF-CY. *Augmentative and Alternative Communication*, 28, 3-10

## Accepterade artiklar 2012

Ylvén, R., Granlund, M., & Persson, C. (accepterad). Problem solving in relation to resources in everyday life in families of children with disabilities - a pilot study. *International Journal of Rehabilitation Research*.

Falkmer, M., Nilholm, C., Granlund, M., & Falkmer, T. (accepted) From my perspective - Perceived participation in mainstream schools in students with autism spectrum conditions. *Developmental Neurorehabilitation*

## Accepterade artiklar 2011 – är de nu publicerade?

Björkman, B., Almqvist, L., Sigstedt, B., Enskär, K. (2011) "Children's experience of going through an acute radiographic examination." *Radiography*.

Lindqvist, G., Nilholm, C. (2011). Making schools inclusive? Educational leaders view on how to work with children in need of special support. *International Journal of Inclusive Education*.

Maxwell, G., Alves, I.F., Granlund, M. (in press 2011). Participation and environmental aspects in education and the ICF and the ICF-CY – findings from a systematic literature review. *Developmental Neurorehabilitation*.

Maxwell G, Koutsogeorgou E (in press 2011/2012). Using social capital to construct a conceptual International Classification of Functioning, Disability, and Health Children and Youth Version-based framework for stronger inclusive education policies in Europe. *Am J Phys Med Rehabil* 2012;91(suppl):00Y00.

Moretti M, Alves I, Maxwell G (in press 2011/2012). A systematic literature review of the situation of the International Classification of Functioning, Disability, and Health and the International Classification of Functioning, Disability, and Health-Children and Youth Version in education: a useful tool or a flight of fancy? *Am J Phys Med Rehabil* 2011;91(suppl):00-00.

Nilholm, C., Cameron, L., Persson, B. (2011). School district administrators perspectives on special education policy and practice in Norway and Sweden. *Scandinavian Journal of Disability Research*.

Proczkowska-Björklund, M., Gimbler Berglund, I., Ericsson, E. (accepted) Reliability and Validity of the Swedish version of the modified Yale Preoperativ Anxiety Scale. *Acta Anaesthesiologica Scandinavica*

Simmeborn Fleischer, A. (2011). Alienation and struggle: everyday student-life of three male students with Asperger Syndrome. *Scandinavian Journal of Disability Research*

Ullenhag, A., Almqvist, L., Granlund, M., & Krumlinde-Sundholm, L. (accepted). Cultural validity of the Children's Assessment of Participation and Enjoyment/ Preferences for Activities of Children", CAPE/PAC. *Scandinavian Journal of Occupational Therapy*

## **Submittade**

Björkman, B., Nilsson, S., Sigstedt, B., Enskär, K. (2011) "Children's pain and distress while undergoing an acute radiographic examination". *Radiography* (Submittades i november)

Gimble Berglund, I., Ericsson, E., Proczkowska-Björklund, M. and Fridlund, B. (2011) Nurse Anaesthetist's experiences and actions in relation to children's preoperative anxiety. *submitted to Journal of Perianesthesia Nursing*. Den submittades 30 Augusti



## **CHILD-research group agenda, fall 2012**

### **September 6, at 9.30 am**

Ingalill Gimbler Berglund nails her licentiate thesis to the wall at School of Health Sciences.

### **September 7, at 9-11 am**

Final Seminar, Marita Falkmer, in Ha 208 at School of Education and Communication.

### **September 13, at 1-3 pm**

CHILD-seminar on Laura Darcy's article, in Ha208 at School of Education and Communication

### **September 24, 9am-4pm**

CHILD-Conference day on Autism Spectrum Disorder, at School of Education and Communication, Room He309.

### **September 24, 10 am**

Board meeting for the Swedish Institute for Disability Research, at School of Health Sciences.

### **September 27, 1-3pm**

CHILD-seminar with Professor Rune Simeonsson from University of North Carolina at Chapel Hill. We also celebrate the coming academic festivities where 1 CHILD:er will be inaugurated full professor and 5 CHILD:ers conferred PhD's at Jönköping University. In room Ha208 at School of Education and Communication.

### **October 5, 1 pm**

Ingalill Gimbler Berglund defends her licentiate thesis '*Nurse anaesthetist's interactions and assessment of children's anxiety*' in Forum Humanum at School of Health Sciences.

### **October 5,**

50%-seminar on Patrik Arvidsson's research work, at Örebro University.

### **October 11, 1-3 pm**

CHILD-seminar on our research within CASINO - the children's research network within the Swedish Institute for Disability Research. In Gc509 at School of Health Sciences

### **October 25, 1-3 pm**

CHILD-seminar in room Ha208 at School of Education and Communication

### **November 8, 1-3 pm**

CHILD-seminar on Madeleine Sjöman's research plan.

### **November 9, 1-3 pm**

Final Seminar, Ann Simmeborn-Fleischer, in Ha208 at School of Education and Communication

### **November 22, 1-3 pm**

CHILD-seminar in Ha208 at School of Education and Communication

**November 30**

Ann Ullenhag defends her doctoral thesis at Karolinska Institutet

**December 6, 10 am**

50%-seminar on Anna Niia's research work, in Ha208 at School of Education and Communication

**December 6, 1-3 pm**

CHILD-seminar with Karin Enskär, Marie Golsäter and Maria Harder, in Gc509 at School of Health Sciences.

**December 10, December 6, 1-3 pm**

CHILD-seminar with Karin Enskär, Marie Golsäter and Maria Harder, in Gc509 at School of Health Sciences.

**December 10,**

Final Seminar, Anne-Sofie Strand, at School of Health Sciences.

**December 13, 1-3 pm**

CHILD-seminar in Ha208, School of Education and Communication.

**December 17, 10 am**

Board meeting for the Swedish Institute for Disability Research, at Linköping University.

## About the CASINO Network – research about children within SIDR

Disability research is about the complex interaction between long term health conditions, body impairments, activity limitations, participation restrictions and environmental factor. It is not about causes of health conditions or impairments or about societal trends concerning people who need support in general. Disability research has been a growing area of research in Sweden for the last twenty years. There is however, a lack of information concerning the current status of the field. Therefore, in 2011 the Swedish Council for Working Life and Social Research (FAS) was assigned by the Swedish Ministry of Health and Social Affairs to survey, in consultation with other funders, the existing research concerning obstacles to full participation in society and the workplace for people with disabilities. The assignment was carried out by the Swedish Institute for Disability Research (SIDR), Linköping and Örebro Universities (Rönnberg, Classon, Danermak & Karlsson, 2012), with the support of an expert panel of leading researchers (see [http://www.fas.se/upload/dokument/utvarderingar/Funktionshinder\\_kartl%C3%A4ggning\\_forslag.pdf](http://www.fas.se/upload/dokument/utvarderingar/Funktionshinder_kartl%C3%A4ggning_forslag.pdf)). One of the outcomes of the survey was that relatively little of the research was focused on children and youth. In addition, the survey did not provide detailed information about how research is performed in the area of children in need of additional support on top of what is provided to all children nor on what topics that are studied. The *Child and Adolescent Special Interest Network (CASINO)* in SIDR has therefore initiated an extended systematic review, based on the original SIDR one with the intent to increase the knowledge about how, and on what topics disability research concerning children and youth in Sweden is performed. After reading 2514 abstracts and 559 full text articles with at least one Swedish author 365 articles have been selected for in-depth analysis. The analysis is currently ongoing and will be presented in the next issue of the newsletter. What we can see so far is that most research is quantitative with relatively little input from the children themselves.

Professor Mats Granlund,  
Research Leader of CASINO  
[mats.granlund@hhj.hj.se](mailto:mats.granlund@hhj.hj.se)

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## 25 forskare vill förbättra för barn



**Elinor Brunnberg, professor i socialt arbete: "Barnen lärde mig ordet dissad"**  
(4:56 min)

1 av 2



Anna-Karin Axelsson och Madeleine Sjöman är båda doktorander på Högskolan i Jönköping. Foto: Mattias Sundler/Sveriges Radio

**I tre veckor ska forskare från hela världen slå sina kloka huvuden ihop och diskutera hur barn med speciella behov, som funktionshindrade, världen över ska få det bättre i vardagen.**

Publicerat torsdag 14 juni 2012 kl 17:37

Sedan en dryg vecka tillbaka befinner sig drygt 25 forskare och doktorander från Tyskland, USA, Portugal, Sydafrika och Sverige på högskolan i Jönköping. Och det som förenar dem är intresset för hur utsatta barn ska kunna få en bättre framtid och leva ett meningsfullt liv.

En av de som föreläst på temat barns rättigheter är Elinor Brunnberg som är professor i



socialt arbete. Hon har varit med i en stor internationell studie om hur utsatta barn upplever sin vardag. I Elinors Brunnbergs fall har det handlat om en grupp döva barn i Sverige.

### Lyssna!



**Mats Granlund, professor: "Det handlar om hur barn kan göra sin röst hörd"**

(6:22 min)

### Dela

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## Om P4 Jönköping

Varje dag. Året runt.

I P4 Jönköping Sveriges Radio hör du lokala nyheter, lokala aktualiteter och lokal kultur. Du bjuds på en heltäckande, angelägen kanal där du bor.

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## Business and Society

# GEDS



The School of Education and Communication together with two other EU universities and two US universities has been granted a unique project within student mobility. The project is funded by the European Union's Atlantic program and the U.S. Department of Education.

The purpose of the project is to give European graduate students the opportunity to study in the USA for six months and US graduate students the opportunity to study in Europe. Their studies have to be within children's development, education, health and wellbeing. The exchange takes place within the research program [CHILD](#). The GEDS-project takes place between 2008 and 2013.

Beside School of Education and Communication at Jönköping University five other universities take part in the project:

- [University of North Carolina Chapel Hill](#), Chapel Hill, North Carolina
- [Vanderbilt University](#), Memphis, Tennessee
- [University of Colorado](#), Denver
- [Ludwig Maximilians University](#), München
- [Porto University](#), Porto

### For further information contact:

EU: Research coordinator Cecilia Allegrind

[Cecilia.allegrind@hlk.hj.se](mailto:Cecilia.allegrind@hlk.hj.se)

US: Professor Rune J. Simeonsson

[rjsimeon@email.unc.edu](mailto:rjsimeon@email.unc.edu)

## Contact

**Eva Björck-Åkesson**

[eva.bjorck-](mailto:eva.bjorck-akesson@hlk.hj.se)

[akesson@hlk.hj.se](mailto:akesson@hlk.hj.se)

036-10 15 00

**Cecilia Allegrind**

[cecilia.allegrind@hlk.hj.se](mailto:cecilia.allegrind@hlk.hj.se)

036-10 13 76



GEDS' Summer Institute in Jönköping, Sweden, 2012.

For [GEDS' American website](#).

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Vocational Education and Training  
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| Administered by: [Cecilia Allegrind](#)

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