

Conference • NNHSH 2015 Theme: Encounters between Nordic health, welfare and the global: Challenges and possibilities

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### Conference • NNHSH 2015

#### Theme:

### Encounters between Nordic health, welfare and the global: Challenges and possibilities

Time: May 4-5, 2015 Venue: UIB Global, University of Bergen

#### The network NNHSH is supported by FORTE

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#### **Preface**

We are pleased to announce an exciting programme for the 2015 research conference, presented by The Nordic Network for Health Research within Social Sciences and the Humanities (NNHSH). This year's theme, Encounters between Nordic health, welfare and the global: Challenges and possibilities, has attracted a range of researchers from the Nordic countries, and we look greatly forward to many interesting discussions during our two days together in Bergen!

The venue for the conference is UIB Global and Bergen Resource Centre for International Development. Note that all of the panels will take place in the seminar room at UIB Global. In order for this year's conference to be a joint event, all speakers are allotted 20 minutes each for presentation and questions. If you are joining us for the informal dinner on the evening of May 4th, please bring 350 NOK in cash to the conference registration.

We are grateful for the support we have received from:

- FORTE: Swedish Research Council for Health, Working Life and Welfare.
- UiB Global, University of Bergen.

We wish you a warm welcome to NNHSH 2015!

Anne Leonora Blaakilde, Kristofer Hansson, Karine Aasgaard Jansen and Susanne Ådahl

### Programme

### Monday May 4th

11.30	Arrival, registration with juice and sandwiches, Bergen Resource Centre for International Development
12.30	Welcome and practical information, Seminar-room UIB Global
13.00	Open lecture, Bergen Resource Centre for International Development Susanne Lundin Bodies in grey zones: An ethnographic study of the global organ trade
14.30	Coffee
15.00	Panel 1
15.40	Panel 2
19.30	Informal dinner at the conference venue

### Tuesday May 5th

09.00	Plenary speech, Seminar-room UIB Global Christine M. Jacobsen Irregular migrants and the bordering of welfare states
10.00	Coffee
10.15	Panel 3
11.15	Panel 4
12.15	Lunch
13.15	Panel 5
15.15	Coffee and <b>discussion</b> The future of NNHSH?
16.00	Departure

### Presentation of keynote talks

Open lecture, Susanne Lundin

Monday May 4th, 13.00

#### Bodies in grey zones: An ethnographic study of the global organ trade

Transplantation is one of the last centuries' most important medical breakthroughs. It prolongs and saves lives in ways that previously were not only medically unfeasible but also culturally unthinkable. However, medicine's success has led to a paradox: it creates a growing need for new cells, tissues and organs. Today's society is thus facing a series of new challenges. One such challenge is how to deal with the shortage of body parts such as organs. Another is that the human body is now, more than ever, a valuable resource and with organs' increased value come their potential profitability, fuelling desire with people to trade, traffic and sell. Transplant travel is an illustrative example of a new form of global economy that involves human bodies.

**Susanne Lundin** is a professor of ethnology in the Department of Arts and Cultural Sciences, Lund University, Sweden. Her main research areas are cultural analysis of medical praxis with regard to new regenerative medicine

such as transplantations, stem cell research, and reproductive medicine. She has numerous publications on these subjects. Her most recent book *Organ till salu* (Natur & Kultur 2014) is published in English, *Organs for sale* (Palgrave 2015, in press).

#### Plenary speech, Christine M. Jacobsen

Tuesday May 5th, 09.00

#### Irregular migrants and the bordering of welfare states

The Nordic welfare state model is structured around a discourse of equality, homogenization and universality. And yet this ambitious welfare state model is exclusivist in its protection of the citizen or legal resident. In this lecture, I will present some research findings from the NRC-funded project "Provision of welfare to irregular migrants". The focus on irregular migrants serves as a point of departure for exploring the bordering of the welfare state. To what extent are those excluded from membership in the nation-state but present within its territorial borders seen as subjects to be cared for? How are borders drawn between those who are to be included in, and excluded from, the universality of welfare services and health care? Using comparative ethnographic cases from Norway and France, I will examine how welfare provision and health care have increasingly come to be entangled with

migration control; and the dilemmas that such entanglement gives rise to at the level of legal regulation, institutional practices and lived everyday life.

Christine M. Jacobsen is a professor of social anthropology and the Director of the Centre for Women's and Gender Research at the University of Bergen. Jacobsen works mainly in the fields of gender studies, international migration and ethnic relations. Her work has focused on issues related to Muslim minorities in Europe (France and Norway) and in particular on continuities and changes in gendered religious traditions, identities and practices in a context of international migration, globalization and secular modernity. Her most recent book is *Islamic Traditions and Muslim Youth in Norway* (Brill 2011). In this lecture, she will present findings from the research project *Provision of welfare to irregular migrants* (PROVIR), which investigates the complex relationship between law, institutional practice, and irregular migrants' lived experience.

### **Panels**

#### Monday May 4th 15.00 - 15.40

### Panel 1: Border-crossing disease (p. 17)

Moderator: Susanne Ådahl, Centre for the Study of Culture and Health, Turku University

- •Kristian Bjørkdahl: Layers of legitimacy in a pandemic: One nation's perceptions of the WHO during the 2009 Swine Flu
- •Karine Aasgaard Jansen: Othering in envisioned pandemics: Findings from a qualitative questionnaire

# Panel 2: Consumerized health? Negotiating responsibility for care (p. 20)

Moderator: Anne Leonora Blaakilde, University of Copenhagen & The EGV Foundation

- Betina Dybbroe: Transformations of professional work in psychiatric health care
- Bodil Ludvigsen: Encounters between elderly people's intentions and effectiveness and managing of the municipality
- Gabriella Nilsson: Narratives of past, present and future as rhetoric tools for negotiating diabetes care practice
- Kristofer Hansson: Transforming narratives in implementation processes of Hospital Based Home Care for children with newly diagnosed diabetes

#### Panel 3: Empathy and self-help "on the move" (p. 25)

Moderator: Karine Aasgaard Jansen, Department of culture and media studies, Umeå University (aff. UIB Global)

- Marte Feiring: Three historical movements and their personal coping strategies
- Susanne Ådahl: From global emancipation to local practices: Strategies of control in everyday life of voice-hearers as presented in peer group discussions
- Niclas Hagen: Practices and relation to data in the quantification of the self. A "Third face" of Biopower?

#### Panel 4: Reproductive health and preventive practices (p. 29)

Moderator: Anne Leonora Blaakilde, University of Copenhagen & The EGV Foundation

- Annika Lillrank: Motherhood, ethnicity and experience: An analysis of resources among Somali women in relation to Finnish maternity care
- Maria Bäckman: Practical matters: Youth related sex, health and relationship clinics (UMOs) in multicultural environments
- Johanna Rivano Eckerdal: Girl virus? Information practices regarding HPV-vaccination in Swedish school healthcare environments

# Panel 5: Children, health and illness: Cultural influences on construction, meaning and management (p. 33)

Moderator: Kristofer Hansson, Department of Arts and Cultural Sciences, Division of Ethnology, Lund University

- Geraldine Brady & Sonja Olin Lauritzen: Connecting sociology of childhood perspective with the study of child health, illness and well-being
- Disa Bergnehr & Karin Zetterqvist Nelson: Where is the child? A discursive exploration of the positioning of children in research on mental-health-promoting interventions
- Terese Wilhelmsen & Randi Dyblie Nilsen: Parental adaption and resistance in diagnostic processes of children in Norway
- Liz Adams Lyngbäck: Lived parenting and cochlear implants: Exploring the life world and networks of parents living in spaces of hearing differentness

- Anette Wickström: The entanglement of practices, norms and ideals in orthodontic practice for young people
- Marie-Louse Stjerna: Food risk and place: Agency and negotiations of young people with food allergy

#### **Abstracts**

#### Panel 1: Border-crossing disease

Kristian Bjørkdahl, UNI Rokkan Centre

# Layers of legitimacy in a pandemic: One nation's perceptions of the WHO during the 2009 swine flu

In a world of globalized health care – which is not the world we live in, but to some extent the one we have been moving towards – a larger portion of the trust needed for a well-function provision of health will have to be placed in international entities, not least the WHO. The pandemic flu of 2009 is a case in point. Here was a situation where the populations of all the world's countries were potentially at risk, but where entities like responsibility, authority, and decision-making capacity had to be negotiated, constantly, to ensure publics that «we» were reacting appropriately in face of the threat. In this case, the WHO was the body which sounded the alarm, which declared the pandemic, and which issued advice throughout the pandemic's year-long rush across the world. But different national publics' access to the WHO was necessarily limited, and always mediated by national governments and national media. There was thus a drive to negotiate between and harmonize the «layers of legitimacy», that is, the positions taken, respectively, on global and national levels. As often as not, however, these negotiations failed. Especially as the pandemic drew on, critical voices were raised, both against the connections

between the WHO and Big Pharma, and against the relation between the global organization and the national ones.

For this paper, we have studied coverage of the pandemic in Norwegian newspapers which makes references to the WHO, to understand how these negotations of legitimacy were perceived by one national public. The questions we ask are: How was the international body perceived in the course of the pandemic? What was taken to be its role? What were seen to be its responsibilities, vis-a-vis national government(s)? To what extent did the public place trust in the organization?

Karine Aasgaard Jansen, Umeå University (aff. UIB Global)

# Othering in envisioned pandemics: Findings from a qualitative questionnaire

Disease travels. Moreover, pathogens spread as people meet. The interactions that facilitate the transmission of disease, particularly across national borders, entail as such both the necessity and danger of human contact (Wald 2008). Sontag (2002 [1991]) claims, for example, that the links between imagining disease and imagining foreignness, i.e. disease as coming from elsewhere, is universal. As a result of processes of othering this may, however, also contribute toward the stigmatisation of a disease or its sufferer, wherein some people and places are made into vectors of disease in and of themselves.

In this presentation I will discuss some empirical findings from a Norwegian qualitative questionnaire on lay people's experiences with and perceptions of the so-called everyday diseases of cold and flu. The questionnaire was sent out in collaboration with the Norwegian Ethnological Research (*Norsk Ethologisk Gransking*) during the autumn of 2014, and has so far generated a total of 193 responses. As examples of how infectious diseases currently spread across the world at a pace previously unmatched in history, I will focus my presentation on perceptions of pandemics as represented by some of the questionnaire's respondents: What is a pandemic, where does it come from and how does it spread? What diseases are considered to have the potential to go viral (in the word's literal sense)? Furthermore, how does this affect distributions of blame and responsibility for the spreading of such potential pandemic diseases?

#### Panel 2: Consumerized health? Negotiating responsibility for care

Betina Dybbroe, Roskilde University

#### Transformations of professional work in psychiatric health care

It is a challenge to the Nordic welfare states that there is an increase in mental illness, as a consequence of changes in "the psycho-social environment of health" (Marmot and Whitehead) and also as a consequence of "healthism" (Rose), links to the growing dominance of the medical knowledge base, that enhances medical categorisations as part of public policy. For citizens "psychiatrisation" (D. Smith) takes over where social and educational services are lacking.

In psychiatry in Denmark health and social care is being replaced by diagnostic categorisations and a more consumerized relation between the health professionals and patients as self- responsible citizens. Increasing medicalization and New Public Management reforms and standardization for cost-effectiveness intertwine with a neo-liberal health policy of a "user- focus and user involvement" that transforms psychiatric practice. Through the micro-sociological study of professionals working with patients in psychiatry, it is illuminated how patients/clients are objectified and left to care for themselves, and how professionalism is transformed into manualisation of practice, and test technologies replace meeting "significant others".

The presentation is based on the research project "Well-being in teams in three sites: psychiatry, engineering work and technical schools", (financed by the Danish Working Environment Research fund) which includes empirical studies over two years (2011-2013) in Danish Child- and Youth psychiatry. The approach has been "multisited" (Marcus 1995, Shore et. Al. 2011), and inspired by critical institutional ethnography (Smith 2005,) with an effort to recontextualise observations in relation to conflicts of power between different positions in the institutional settings.

Bodil Ludvigsen, University of Copenhagen

## Encounters between elderly people's intentions and effectiveness and managing of the municipality

Currently the Danish welfare state focuses, to a certain degree, on managing and improving effectiveness – a common ambition of the so-called competition state. This has changed the context in which local councils provide help and assistance, as e.g. a growing discontinuity among professional helpers visiting individual elderly demonstrates.

Using examples from one year of ethnographical fieldwork observing elderly people's everyday life, the aim is to demonstrate how they attempted to preserve their health, while simultaneously strove to be included as citizens on equal terms. For instance, they all took their medication and were determined to maintain training, physical activity and rehabilitation in order to uphold

their health. This was perceived as a way to sustain status quo – and be included in the society.

The aims of the competition state – to effectively assist the elderly with their medication and to improve the effectiveness of training –largely corresponded with elderly people's own intentions. They did, however, experience difficulties with changing societal goals. The increasing number of different staff members visiting them was perceived as a negative consequence, and furthermore questions prevail about the impact on both the elderly people's responsibility and guilt when not being able to comply with expectations, and when it was acceptable to stop living up to societal demands without risking the loss of citizenship rights. Applying citizenship theories the aim is to shed light on elderly people's understanding of their citizenship, rights and obligations placed upon them by the welfare state (perhaps) turning into a competition state.

Gabriella Nilsson, Lund University

# Narratives of past, present and future as rhetoric tools for negotiating diabetes care practice

The paper investigates the function of narratives of past, present and future in diabetes care practice. In 2013 the process of implementing a new evidence based care practice for children recently diagnosed with diabetes – Hospital Based Home Care – was initiated at the two pediatric diabetes care facilities at

the University Hospital of Skåne, in the south of Sweden. Implicitly reinforcing the self-care paradigm, the basis of HBHC can be referred to the neo liberal context in a globalized world. The main objective in HBHC is to enable a "family centered" care, simultaneously resulting in "early discharge" from the hospital. More specifically HBHC implies greater reliance on the parents' ability to identify, and demand, the knowledge and skills needed to be able to care for the child; and ultimately on their ability to transform the "disease" diabetes into a "lifestyle". This paper discusses a process of negotiation that arises between the health care personnel and the parents in order to achieve a corresponding long term "lifestyle perspective" of life with diabetes: HBHC implies a perspective on disease that offers greater "freedom" in the present in exchange for increased "responsibility". The parents who, however, still want "real freedom" in terms of cure from disease, hold on to narratives of future scientific breakthroughs. The personnel in turn, respond to this with narratives reminding of the unfree, dependent life with diabetes in the past. The paper thus highlights how narratives of past, present and future functions as rhetoric tools in this process of negotiation.

#### Kristofer Hansson, Lund University

# Transforming narratives in implementation processes of Hospital Based Home Care for children with newly diagnosed diabetes

In the Nordic welfare state, the health care system has a central role as provider of welfare, but today's health care is under great pressure. It is sometimes described as a smouldering volcano. There is constantly a threat of economic cutbacks, reorganization of staff and units, ever-changing patient groups, new treatments to be introduced, and so on. Some of this pressure needs to be understood from a global perspective where the welfare state must constantly adapt to a changing world. The aim of this paper is to explore how we, from a cultural analytical perspective, can understand implementation processes as a way for the health care system to adapt to a globalized world. The paper is based on observations and interviews in various environments in Lund and Copenhagen were new care methods and technologies are implemented in a health care context. They are ongoing projects were the analysis is not yet finished. In this particular paper focus is on how implementation is presented to the staff, and how new knowledge reaches out to the staff. Central for the analysis is change and how change in an organisation can be both ethnographically described and theorised. One theoretical perspective that is used is seeing how narrative creates cognitive schemas about change.

#### Panel 3: Empathy and self-help "on the move"

Marte Feiring, Oslo and Akershus University College

#### Three historical health movements and their personal coping strategies

This paper explores three historical self-help group movements, how these movements are organised, how they are structured and the work that they carry out. The analysis and discussion presented examines how these health movements and their main practices are framed by and are products of sociocultural processes (in time and space). My research question is: what do textual representations of these movements tell us about their views on coping with life challenges in different historical and cultural settings? The work described in this paper has been carried out through "close reading" textual analysis of primary and secondary sources. The three health movements included in this work, Alcoholics Anonymous (AA), Angst Ring (AR) and the Norwegian Self-help Forum (NSF) can be defined as being global, local and national. They were established in three periods of transition of the Nordic welfare model. AA was introduced into Norway in the late 1940s during the transition into a Norwegian Welfare State, AR was established around forty years later during the development of what is called the "welfare community" and NSF was formed one decade later in what I will refer to as a period of welfare mixes and "new welfare governance". This paper concludes that the

three movements apply different forms of learning to cope with health problems such as: alcoholism, anxiety and life challenges in general. AA applies what I will name a traditional kind of apprenticeship learning (mesterlæring), AR has developed modes that I will refer to as social learning and coping (mestrings-læring) and NSF, who run a National clearing house (Selvhjelp Norge) and a local self-help centre in Oslo (LINK Oslo), applies terms such as "workshop for learning and coping" (verksted for læring og mestring).

Susanne Ådahl, Turku University

## From global emancipation to local practices: strategies of control in the everyday life of voice hearers as presented in peer group discussions

This presentation is based on participant observation material collected in two peer support groups for voice hearers in Helsinki stretching over a period of 1,5 years. The local level voice hearing association Suomen Moniääniset, that trains peer support group facilitators, is a member of the global voice hearing movement Intervoice. A central ideology of Intervoice is viewing the phenomenon of voice hearing as primarily a special human trait, rather than primarily a sign of illness. The aim of this approach is to emancipate voice hearing from the dominance of biomedicine and the power of pharmaceuticals. How is this ideology seen in the way that Finnish voice hearers talk about their lifeworld in peer support groups and the types of

concerns they raise in peer group discussions? I discuss the empirical material using a Foucauldian perspective to ponder what the nature of emanicapation vs. (self-)control is in the material and what it tells us about passivity and activity in relation to the control of one's everyday life as a voice hearer. Who or what controls peer group members in the everyday life contexts they describe in the group meetings and how is control enacted in the group context itself? I present the idea of productive or creative control of the body (Allen 2011, Shusterman 2000) as a product of acting together and advising each other in the peer support group context.

Niclas Hagen, Lund University and University of Gothenburg

# Practices and relation to data in the quantification of the self. A "Third face" of Biopower?

One ongoing and profound change that has increasingly come to the foreground during the last five to ten years within the Nordic countries revolves around the impact of new digital technologies, most notably the impact of mobile digital technologies. Arguably, the most visible manifestation of this development is the smart phone. In relation to health, welfare and the global, the mobile smart phone offers radical new possibilities for each individual to gather and make use of a large amount of data about the own body and health by the way of health related mobile applications (apps). One

of the most prominent examples of these new possibilities is the Quantify Self movement, whose members practice self-tracking and self-quantification on a wide variety of phenomena, including aspects of health. On the basis of empirical material that consists of video presentations from conferences and meet ups arranged by different chapters of the QS-movement, where members present their projects, this conference paper will investigate: (1) what kind of different practices can be discerned in the presentations? (2) What kind of relations to the collected data can be distinguished in the presentations? Moreover, the last part of the paper will address the issue of power by relating the empirical material to Michel Foucault's notion of biopower and discussing whether new possibilities given through mobile digital technologies constitute a "third face" of biopower.

#### Panel 4: Reproductive health and preventive practices

Annika Lillrank, University of Helsinki

### Motherhood, ethnicity and experience: An analysis of resources among Somali women in relation to Finnish maternity care

The aim of this paper is to discuss how ethnicity and cultural background cannot solely explain migrant women's behaviour in relation to Finnish maternity care. This study departs from the salutogenic theory that defines human beings as resourceful agents. Health and wellbeing are considered as a complex interplay between an individual's ability to solve problems and to use resources available in their surroundings (Anderson, Björnberg & Eastmood 2010: 4, 21).

I conducted interviews with 11 different women who came from Russia, Somalia, Afghanistan, and Irak. The interviews were conducted between May and November 2012 with interpreters. My criteria for selecting informants were that they are 1) refugee women who have been granted a residence permit in Finland, 2) who have lived at least two years in Finland, and 3) who currently take care of their child(ren) at home. In this paper I present an indepth analyses on two Somali women. My analytic approach follows the idea that the interviewees select and evaluate important events as meaningful for a particular audience (Riessman 2008: 3).

These two case-studies highlight differences in a sense of agency, especially in an ability to identify resources in their local surroundings. Nadina was open-minded and responded with trust to offered professional help. Sayda was discontented with lacking interpretation services, which she had reason to be. However, her sense of unhappiness may have been based on difficulties to develop trust in professionals. Thus even though Nadina and Sayda belonged to the same ethnic group they had different abilities to identify resources in their local surroundings.

Maria Bäckman, Stockholm University

### Practical matters: Youth related sex, health and relationship clinics (UMOs) in multicultural environments

This paper stems from an ongoing project financed by the Swedish "Riksbankens jubileumsfond". The project focuses on the work conducted by special health clinics in Sweden directed to prevent sexual and reproductive health for people between 13-23 years of age ("ungdomsmottagningar" [UMOs]). A consequently applied ethnographic method means that the study is undertaken in the studied context. The empirical material consists of both field observations and interviews with gynecologists, midwives and welfare officers.

Many of today's burning issues relate to the individual's rights and circumstances in complex globalized societies. In particular, in contemporary Sweden a multitude of different ideas abound as to what constitutes appropriate sexual behavior. By drawing attention to the specific prerequisites relating to UMOs in multicultural settings, the project connects with current research on sexuality, gender, integration and the dissemination of information. At the same time it is clear that the Swedish UMOs (which has been a vital part of Swedish public health work among teenagers since the 1970s) – both in general and in environments in which several sexual norm systems coexist – is a surprisingly neglected research field.

In my paper I want to discuss what the globalized environment means for the staff's possibilities to create a fruitful dialogue with their clients. I also want to take into consideration how a medical view and a cultural understanding of the teenagers are negotiated in such a way that they both *challenge* and *confirm* each other.

Johanna Rivano Eckerdal, Lund University

### Girl virus? Information practices regarding HPV-vaccination in Swedish school healthcare environments

This project concerns vaccination against human papilloma virus, HPV, in Swedish school healthcare. A pilot-study included interviews with two school nurses and the coverage of HPV vaccination in three Swedish newspapers.

The media material provides a contextualization to the school nurses' local work as media to a large extent influences our understandings of health issues. Vaccinations are a medical preventive intervention of great value to society but their value for individuals have been questioned and there are polarized opinions about them. Since 2010 HPV vaccine is included in the Swedish national vaccination programme for girls (aged 10-12 years) to prevent cervical cancer. HPV is the most common sexually transmitted virus, some types may lead to cancer in e.g mouth, anus and cervix, but boys are not yet included in the programme. This may be understood as an example of how preventive measures related to sexual and reproductive health are considered to be a female responsibility. It is the parents that decide whether their children should get the vaccines offered through the vaccination programme or not. School nurses are important information sources for parents and may be viewed as representatives of society. Nevertheless nurses meet the girls. The nurses describe how they go about informing and administering the vaccine, here described as the HPV vaccination cycle, to support the girls who often are scared. The results include an overview of the distribution over time and content in the newspaper coverage of HPV-vaccination.

# Panel 5: Children, health and illness: Cultural influences on construction, meaning and management

Geraldine Brady & Sonja Olin Lauritzen, Coventry University & Stockholm University

## Connecting sociology of childhood perspective with the study of child health, illness and well-being

In the last decades we have seen a growing interest, across disciplines, in research on children's own experiences and understandings of health and illness, which we would argue is much stimulated by developments in the sociology of childhood. This development has drawn our attention to how children as a social group is placed and perceived within the structure of society, and importantly, within inter-generational relations; to seeing children as social agents and co-constructors of their social world as well as to see children as 'beings' not just 'becomings'. In this paper, we want to discuss current research that draws on the sociology of childhood and address some cross-cutting themes that we find important in the study of child health: 1) situating children within health policy, 2) practices of children's health and well-being 3) children as health actors.

Disa Bergnehr & Karin Zetterqvist Nelson, Linköping University

# Where is the child? A discursive exploration of the positioning of children in research on mental-health-promoting interventions

The present study explores the discursive positioning of children in research articles on mental-health-promoting interventions. The questions under investigation are: Are children positioned as active or passive agents? Are children's health and wellbeing contextualized, and if so how? How is 'the child' perceived; that is, how are age, gender, socioeconomic status, family structure, dis/ability, etc. accounted for? The positioning of the child as passive and formed by adults prevails; health is largely individualized and decontextualized, in that it is depicted as being contingent on the person's own capabilities. However, there are instances in which children are positioned as active subjects, their opinions are in focus, and/or their health and wellbeing are connected to social relations and context. We propose a more active discussion about how children and wellbeing are conceptualized in the outlining, implementation and research of public health interventions. Moreover, children – just like adults – should be increasingly regarded as service users who are entitled to have a say in matters that concern them. The full paper is published in Sociology of Health and Illness, 2015, 37(2).

Terese Wilhelmsen & Randi Dyblie Nilsen, School of Sport Sciences & Norwegian University of Science and Technology

## Parental adaption and resistance in diagnostic processes of children in Norway

Drawing on the Sociology of childhood and Foucauldian inspired perspectives, this paper presentation explores parental experiences of parent–professional encounters in diagnostic processes of young children enrolled in Norwegian early education and care and primary schools. By differentiating between adults in different positions, this presentation contributes to the emerging critical analyses of lay/professional encounters in the particular context of increased political emphasis on early intervention.

Based on qualitative interviews with parents, we explored how they participated and manoeuvred in encounters with professionals during processes in which their children were constructed as different in a space of normality and deviance, while also bringing their own understandings of their children to the fore. In the interviews we learned about parents' initial concerns about their young children, assessment practices and identification of the problem, or a diagnostic label. From our analysis, it appeared that parents manoeuvred between complying with and adapting to, as well as negotiating and resisting the constructions put forward by the professionals.

### Liz Adams Lyngbäck, Stockholm University

### Lived parenting and cochlear implants: Exploring the life world and networks of parents living in spaces of hearing differentness

The aim of this dissertation is to describe and explore the ways people experience parenting a deaf child who uses a cochlear implant. This will be done by focusing on the first person perspective of parents and related networks of social encounters in everyday life. The description of decision making surrounding cochlear implantation has shifted from whether or not to implant to which language, communication mode and intervention approaches should be used. The parents of this generation of children with cochlear implants are in a unique situation that is being researched primarily in areas focusing on the improvement of pediatric cochlear implantation and verbal communication per se.

In a study of the lived experience of *spaces of hearing differentness*, ideas about deafness, disability, language and activism are investigated. *Lived parenting* refers to the study of the accounts of what 'gets done' in these spaces. This entails studying experiences of encounters with other parents, medical professionals, educators and social service and rehabilitation personnel and connecting it to multi-sited ethnographic field work on enactments in

corresponding settings. Semi-structured interviews and field work have been conducted in Sweden and a south-eastern region of the United States. Preliminary findings include a deeper existential understanding of the impact of early detection of hearing impairment in parenting practices and integration of children in standard classrooms. Findings in parents' accounts include how they are engaged in early planning for future educational access. They report having the largest part of the responsibility for optimal hearing technology use and knowledge of hearing impairment in their children's schools. Being faced with 'either-or' in regards to spoken language and sign language environments rather than a parallel approach of 'both-and' is a recurring theme. The underutilization of experiential knowledge of parents of children who use cochlear implants is a clear characteristic in this qualitative investigation.

Anette Wickström, Linköping University

## The entanglement of practices, norms and ideals in orthodontic practice for young people

To be able to understand young people's perspectives of being targeted by preventive health initiatives or treated in medical care it is important to pay attention to and interpret their actions when they participate. Also important is to understand the interactive process between young people, practitioners, technology and measurements. In this paper I present an ethnographic study of state-financed orthodontic treatment with fixed appliances for young

people in which I have used several methods for understanding young people's perspectives. The aim has been to understand how divergences and norms are done in practice and how young people make meaning of the intervention. First of all, video-recordings and participant observations of three activities that precede a possible treatment have been used. Secondly, the young patients have kept video diaries throughout three different periods during the first year of treatment, starting on the very day they got braces.

First of all, the analysis shows that visualizations of divergences and of the future bite constitute an incentive for young people to desire "exceptional normal" bites. Secondly, according to Fox (2012), body technologies deterritorialize bodies from physical limitations, in the case of orthodontics, from physical "defects". But they also apply new limits to the body, that is, territorialize the body. The "braces bearers" in the study describe in their video diaries the braces as accessories that make them feel more secure and less ashamed of their smile. At the same time the technology brings them into an ordeal which makes them put lots of work into handling the apparatus and side-effects.

# Food risk and place: Agency and negotiations of young people with food allergy

Potentially life-threatening food allergies are increasing among children in the Western world. Informed by childhood studies, this article explores young people's management of food allergy risk and highlights their agency in relation to food, eating and place. Drawing on individual interviews with 10 young people who took part in a larger multi-methodological study of young people's experiences of food allergies, the findings demonstrates that the management of health risks means, to some extent, trying to control the uncontrollable. A reaction can occur at any time and to experience a severe reaction entails temporarily a loss of control. The strategies the young people develop to avoid allergic reactions can be understood both as responses to this uncertainty and as manifestations of their agency. Their risk experiences vary with place; at school and in other public places they face social as well as health risks. What we see is not agency as a voluntary choice but that young people with food allergies experience tensions between their own competence to manage different types of risks and their dependence on others to adjust to their needs. Thus, the relational aspects of young people's agency come to the fore.

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### **About NNHSH**

The Nordic Network for Health Research within Social Sciences and the Humanities aims at strengthening the cooperation between researchers of both doctoral and post-doctoral level, in the Nordic countries. The common area of research has evolved as a result of the countries' shared history of public organization and financing of care services and health promotion. Hence, the common contemporary and historical features of the Nordic countries and the development of new models of welfare constitute an important basis for the joint research interest in Nordic health policies and how the illnesses and disabilities of Nordic people are practised, interpreted, and managed in the context of a Nordic welfare model. Within this broad area we want to draw attention to crossroads between, on the one hand, health care service and health promotion and, on the other hand, the everyday life and health practices of people in the Nordic countries. This refers both to direct encounters between patients/users and professionals, but also to encounters between different discourses or interpretive frameworks of health and illness. This complex of problems adress questions about how the body and embodiment can be problematized, as well as how the experience of illness, disability and suffering can be explained and is assigned meaning by people, be they ill patients or professionals. The aim for the network is to develop cooperation and exchange of knowledge between academic work and various professional practitioners in health care and health sectors. FORTE supports the network. Homepage: http://nnhsh.org

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## Encounters between Nordic health, welfare and the global: Challenges and possibilities

In a so-called globalized world characterized by the continuous movement of people and pathogens crossing national borders, the Nordic welfare states can, arguably, no longer be studied as isolated entities removed from their broader international and geopolitical context. For example, as was aptly illustrated by the 2009 swine flu outbreak, infectious diseases spread at a pace unmatched by previous pandemics. As such, disease has the potential to rapidly affect a large number of people in places as geographically distant as Mexico and Sweden. As a consequence, public health decisions and responses are made at both the UN- and at the national level, thus emphasizing how global interests have become deeply intertwined with national concerns. Moreover, travel does not only further the transmission of disease, but also affects how public health and welfare provision and responsibilities are managed locally. Globalization and neo-liberalism have, among other things, contributed to the reframing of health and welfare as matters of bio-security and border control, rather than merely reflecting issues of well-being and care. Such processes of exclusion and inclusion influence people's health seeking-behaviours and leads, in turn, to increased social inequalities within changing Nordic welfare systems originally based on shared ideologies of "equality". However, encounters between Nordic health, welfare and the global do not necessarily

consist solely in changes or challenges in public health policies. Instead such meetings may take place in everyday interactions between for instance lay people, medical staff and the social services. To marginalised groups, such meetings may thus represent desired opportunities to improve health or living conditions.

In this conference, we welcome all contributions within the humanities and social sciences that in various ways focus on the ongoing transformation of Nordic welfare systems. We are particularly, but by no means exclusively, interested in papers that discuss the contact points between the so-called local and global when it comes to provision of and access to health and welfare across the Nordic countries. Papers may include, but are not limited to: Different aspects related to regular or irregular migration, perceptions and management of health and illness, "trafficking" of people and organs, medical tourism, disease transmission and prevention, professional mobility or "brain drain", medical pluralism, WHO's impact on national public health policies and so on.

### How to find the conference venue

The venue for the conference and the dinner is UIB Global at the central campus of the University of Bergen. UIB Global shares location with the Bergen Resource Centre for International Development and the Chr. Michelsen Institute, at Jekteviksbakken 31. Entry into the building is either vis-à-vis the ground floor of the Law Faculty, or up the stairs from Torborg Nedreaasgate.

From the hotels in the city centre, the walking distance is between 5 to 15 minutes.

http://nnhsh.org