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Conference • NNHSH 2014 Theme: Creative and able citizens: managing health and illness during the life course

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Conference • NNHSH 2014

Theme:

CREATIVE AND ABLE CITIZENS

Managing health and illness during the life course

Time: May 22-23, 2014

Venue: University of Helsinki



|

The network NNHSH is supported by FORTE

Anne Leonora Blaakilde, Kristofer Hansson,
Karine Aasgaard Jansen and Susanne Ådahl
Conference • NNHSH 2014

Theme:

Creative and able citizens: managing health
and illness during the life course

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The Department of Arts and Cultural Sciences,
Lund University
2014

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Preface

Welcome!

We are pleased to announce an exciting programme for the 2014 research conference, presented by The Nordic Network for Health Research within Social Sciences and the Humanities (NNHSH). This year's theme, "Creative and able citizens: managing health and illness during the life course", has attracted a range of researchers and PhD students from the Nordic countries. We look forward to many interesting and productive discussions during the conference!

We are grateful for the support we have received from:

- FORTE: Swedish Research Council for Health, Working Life and Welfare.
- Swedish School for Social Sciences, University of Helsinki.

We wish you a warm welcome to NNHSH 2014!

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

Program

Thursday May 22th

| | | |
|-------|--|---------------|
| 11.30 | Arrival, registration with coffee and sandwiches | |
| 12.45 | Welcome and practical information | Room 210 |
| 13.00 | Plenary speech, Sarah Atkinson Challenging personal wellbeing: critical social science, measurement and policy | Room 210 |
| 14.00 | Coffee | |
| 14.30 | Parallel sessions 1 & 2 | See catalogue |
| 20.30 | Dinner at Kuurna Ravintola Restaurant http://www.kuurna.fi | |

Friday May 23th

| | | |
|-------|--|---------------|
| 08.30 | Morning coffee | |
| 09.00 | Plenary speech, Marja-Liisa Honkasalo Arts and wellbeing – what makes it a burning topic? | Room 210 |
| 10.15 | Parallel sessions 3 & 4 | See catalogue |
| 12.00 | Lunch | |
| 13.00 | Session 5 | Room 234 |
| 14.45 | Coffee | |
| 15.15 | Closing remarks, Lars-Eric Jönsson | Room 210 |
| 16.00 | Departure | |

Presentation of keynote and closing remarks speakers

Plenary speech, Sarah Atkinson

Thursday May 22th, 13.00

Challenging personal wellbeing: critical social science, measurement and policy

The concept of subjective or personal wellbeing has become central in contemporary policy across multiple sectors including those of health, social services, education and the environment. As debate takes off around how to define and measure wellbeing both in general and in the more particular case of personal wellbeing, what might be the roles for a critical social science engagement? The key-note offers suggestions and in turn offers further questions and provocations on the topic. First, a critical social science demands that we stand back and reflect on the emergence of concepts that have seen a rise in policy popularity. In this, we assert that the meanings and uses attributed to popular policy concepts such as personal wellbeing have to be understood as imbricated within the politics and ideologies of particular times and places. Secondly, we can unpick the assumptions underpinning the ways in which concepts are mobilised into policy. In the case of personal wellbeing, despite debates on definition and measurement, most uses share common assumptions that we can tease out and interrogate in relation to the

associated policy implications. Thirdly, we can draw on the insights of critical social and cultural theories to explore alternative conceptualisations of personal wellbeing and their implications for policy. But whilst more complex, relational or intersubjective understandings bring intellectual satisfaction, the final challenge that is often little addressed within a critical social science is how to go full circle and translate such insights into feasible policy practice.

Sarah Atkinson is Professor of Geography and Medical Humanities at Durham University in the UK, where she is Co-Director of the Wolfson Research Institute for Health and Wellbeing and Associate Director of the Durham Centre for Medical Humanities. Her academic background spans anthropology and health policy with research in the Global South as well as Europe. Her research interrogates the assumptions underlying health-related practices, including interpretations of wellbeing, responsibilities for care and the radical potential of the arts. She has published across social science and medical journals, including the *BMJ* and *The Lancet*, and has been lead editor on collections of essays on: *Wellbeing and Place* (Ashgate, 2012, with Sara Fuller and Joe Painter); "Care of the Body: Spaces of Practice" (*Social & Cultural Geography*, 2011, with Vicky Lawson and Janine Wiles), "Beyond the Local Agenda: International Perspectives in Community-based Arts and Health" (*Arts & Health*, 2013, with Mike White); "Spatial Perspectives in Medical Humanities" (*Journal of Medical Humanities*, 2014, with Ronan Foley and Hester Parr) and is associate editor on the forthcoming "Companion to Critical Medical Humanities". She was part of the

WHO/TDR thematic reference group on gender and social science and is currently a member of the European Task Force on Medical Humanities. For more details of recent publications, see:
<https://www.dur.ac.uk/geography/staff/geogstaffhidden/?id=4445>

Plenary speech, Marja-Liisa Honkasalo

Friday May 23th, 09.00

Arts and wellbeing – what makes it a burning topic?

The relationship between culture and well-being has been an important topic during the last two decades in health and social services, culture politics and the arts in the Nordic countries. In Finland, the Ministry of Social Affairs and Health has in 2010 launched a specific programme for this purpose. Hundreds of development projects in this domain have been initiated and carried out in Finland during the past fifteen years, mainly funded by the ESR or other EU sources. They have together created a bulk of interesting results.

The purpose of this presentation is to shed light on the interesting relationship between culture, health and wellbeing. I will ask, from the point of view of cultural research, what makes the theme important right now and how and to what extent can the impact of cultural practices on wellbeing be studied? Artists understand what art and artistic creation is in a different way than scholars who work in the fields of social sciences and especially health

and welfare studies. An extremely interesting theme is the market economy, which in current discussions defines the contents and limits of research validity.

The points of interface between culture, health and well-being are diverse and multi-layered. According to everyday experience, one's own creative activities can create experiences of well-being and empowerment. Several artistic therapies seem to be quite effective among the ill. However, critical studies on the relationship between culture, health and well-being, indicate that the multiplicity of these causal chains is not quite understood. The problems concern the concepts, methods and research frameworks. One important and interesting tension is between the independence of art, defined by the artists and the makers of art, and the effectiveness criteria of art, held by the market economy in the post welfare state.

Marja-Liisa Honkasalo (MD, Ph.D.) is professor of culture, health and wellbeing at the University of Turku, Finland. She has worked mainly as an Academy of Finland research fellow at the University of Helsinki, at the Helsinki Collegium for Advanced Study and as Professor in Medical Anthropology at the University of Linköping, Sweden, and has also been a visiting scholar at Harvard University and at La Sapienza, Rome. She has done fieldwork mainly in Finland and West Africa. She has published monographs, edited volumes, and numerous articles on illness, death and more recently on technology of the body in a post-welfare context. Her most recent edited

volume is Culture, Suicide and the Human Condition (Berghahn Books 2014, with Miira Tuominen).

Closing remarks, Lars-Eric Jönsson

Friday May 23th, 3.15 pm

Lars-Eric Jönsson is professor of ethnology and works at the Department of Arts and Culture, Lund University. His fields of interest are the history of psychiatry as well as cultural heritage. He has written several articles on the history of psychiatry, social services, cultural heritage and the use of history. He is the editor of *Ethnologia Scandinavica*.

Parallel sessions

Thursday May 22th 14.30 – 16.15

Session 1: Past and current discourses of ability/disability (p. 18)

Room 219

Moderator: Åsa Alftberg, Department of Arts and Cultural Sciences, Division of Ethnology, Lund University

- Helena Haage, Erling Häggström Lundevaller & Lotta Vikström: Health and death differentials among disabled and abled citizens in past Sweden: a life course study of their survival chances
- Jutta Ahlbeck & Kirsi Tuohela: Threatening young citizens: managing the mind of the child in early twentieth-century Finland
- Karine Aasgaard Jansen: Vaccination and vulnerability: “risk groups” and public health measures during the 2009 swine flu pandemic in Scandinavia

Session 2: Body/mind management: cultural understandings of healthy citizenship (p. 22)

Room 234

Moderator: Susanne Ådahl, Department of Social Research (Sociology), University of Helsinki

- Jenny Eklöf: The mindfulness panacea: being mentally fit in a frantic world
- Nicole Thualagant: Performing health – working out as a health investment
- Antti Maunu, Anu Katainen, Riikka Perälä & Anni Ojajärvi: The sick and the worthless? Sociocultural dimensions of socioeconomic health disparities
- Annika Lillrank: Refugee women's health care experiences regarding pregnancy and birth in Finland

Friday May 23th 10.15 – 12.00

Session 3: Ableism: creative coping with disability (p. 27)

Room 219

Moderator: Karine Aasgaard Jansen, Department of culture and media studies, Umeå University

- Ditte-Marie From: "Virtues of health management": how to dismantle the perceived incapability of the overweight body
- Åsa Alftberg: Soundscapes and (dis)abled bodies
- Britta Lundgren: Narrating narcolepsy – centering a side effect
- Kristofer Hansson: Care practice and the child: culture analytical perspective on care in practice

Session 4: Narratives of care and self-care (p. 32)

Room 234

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

- Anna Leppo & Perälä Riikka: The remains of care in the context of pharmaceuticalisation. Opiate substitution treatment in the post-welfare state
- Riitta Vornanen, Leena Leinonen & Hannele Turunen: Narratives of people with celiac disease – the content and critical factors of lay knowledge in developing early detection of celiac disease
- Susanne Ådahl: Creating a new self: the potential of cognitive self-therapy among voice hearers
- Maria Bäckman: Conversations in group about the white cane

Friday May 23th 13.00 – 14.45 pm

Session 5: The power of expressivity and the institutional transformations of suffering (p. 37)

Room 234

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

- Karolina Ojanen & Pia Olsson: Old ages experienced and narrated: understanding ways of aging
- Georg Drakos: A model for “Narrative Care”
- Eva Marie Tveit: What freedom of expression and participation do nursing home patients have?
- Anne Leonora Blaakilde: Nursing home negotiations and narrations in challenging, transnational situations

Abstracts

Session 1: Past and current discourses of ability/disability

Helena Haage, Erling Häggström Lundevaller & Lotta Vikström, Umeå University

Health and death differentials among disabled and abled citizens in past Sweden: a life course study of their survival chances

This study follows about 35,000 individuals over their life course to examine their survival chances in 19th-century society when social welfare was limited. The aim is to detect whether people with disabilities were markedly stigmatized because they did not match contemporary perceptions of normativity and thus faced health difficulties in life, which we in accordance with the labeling theme of secondary deviance assume would be indicated by high mortality risks. We make use of Sweden's 19th-century parish registers of the Sundsvall region (digitized by the Demographic Data Base, Umeå University) to identify parishioners who the ministers defined as disabled, and to construct a reference group of abled persons. Then we employ statistical life course analyses exemplified by multivariable Cox-regression models. The results show that disability significantly jeopardized the survival of individuals but was not the only key to their untimely death, because gender determined this, too. Disability afflicted men's survival chances more evidently than the

women's. Our findings are rare in providing statistical evidence of individuals' experiences of disabilities beyond welfare institutions and because we measure the labeling effects of disability in history through life course studies. The gendered death differentials demonstrate that the disabled constituted a disadvantaged but heterogeneous collection of people whose life course must be further researched.

Jutta Ahlbeck & Kirsi Tuohela, University of Turku

Threatening young citizens: managing the mind of the child in early twentieth-century Finland

In modern secular thinking, the future of all nations lies in children. This paper examines evolving medical and psychiatric notions of childhood in Finland from the late nineteenth century onwards, and relates these to constructions of nation and citizenship. Following scholars, who argue that children and childhood started gaining intense medical and psychological attention in the mid-1900th century, we pose the question whether and to what extent this was the case in Finland as well. In so doing, the paper explores psychiatric discourses on abnormal children as portrayed in journals like *Sielun terveys* [The Healthy Soul] and in literary materials that depict evil, bad and morally ill children. The idea that a child's mind is different from that of an adult, and that children are in need of special care and protection, resulted in intellectual, but also emotional and sentimental investments in childhood. Consequently, children gained more attention. Children were,

however, not only seen as representatives of an utopian future, but also as threats to the future if they were not raised “properly”. We argue that this fear of unruly and deviant children, prone to criminality and madness, escalated in the 1930s, when The International Society for Mental Hygiene introduced its annual conferences and The Finnish Society for Mental Hygiene established an own journal, raising public concerns regarding anti-social children.

Karine Aasgaard Jansen, Umeå University

Vaccination and vulnerability: “risk groups” and public health measures during the 2009 swine flu pandemic in Scandinavia

On April 24 2009, the World Health Organization (WHO) notified the occurrence of the new influenza virus, the A (H1N1) or the so-called swine flu. Less than a week later, Danish public health authorities (Sundhedsstyrelsen) reported to the media and general public that the first case of the disease had been registered in Denmark. This was the first occurrence of swine flu in Scandinavia and as the disease spread rapidly across the region, national pandemic preparedness plans were implemented with the primary intervention being the distribution of vaccines. However, although the Scandinavian governments faced the same pandemic threat as informed by WHO and the European Centre for Disease Prevention and Control (ECDC), their response toward the outbreak differed: For example, while the Swedish and Norwegian government implemented mass vaccination, Danish authorities rather directed their efforts toward specifically defined “risk

groups”. As a result, the vaccine uptake was approximately 60 per cent in Sweden, 40 per cent in Norway, and 10 per cent in Denmark.

In this paper I investigate which groups of the population were identified by the public health authorities as being at particular risk for contracting swine flu, i.e. which bodies were perceived as “able” or not, against the particular features of the 2009 pandemic in Scandinavia. My argument is that this depended to a large degree on diverging perceptions and interpretations of the actual risks and consequences of infection on the one hand, and shifting approaches regarding public health responsibilities on the other. The main problem of the paper is to discuss on what grounds dissimilar conceptualisations of swine flu “risk groups”, may have influenced the public health measures that were employed by each country. This will be done through a comparative analysis of public evaluation reports in which the various governments (Norway and Sweden), and public health authorities (Denmark), assess their own management of the pandemic.

Session 2: Body/mind management: cultural understandings of healthy citizenship

Jenny Eklöf, Umeå University

The mindfulness panacea: being mentally fit in a frantic world

Mindfulness meditation started its academic career in the 1970s within behavioral medicine and mind-body research. Now, you find it in psychotherapy, neuroscience and clinical psychology, but also increasingly in the social sciences such as education, organization studies, social work and economics. Mindfulness meditation is offered as a secular program for healing, self-understanding and growth, and has moved from the cultural margins (Buddhism) to the mainstream, both scientifically and culturally. The variety of problems that mindfulness addresses is made possible by the fact that it actually spans both the pathological and the normal. In actual fact, it collapses that distinction regularly. By introducing readers, listeners or viewers to a mind that is “mindless” in its normal state – running on autopilot, being lost in thought, always in a doing-mode – it simultaneously pathologizes people’s normal mode of functioning. Hence, anyone endowed with a mind benefits from mindfulness meditation. What we might call “applied mindfulness science” attends almost solely to the changes a person can make internally by adjusting or self-regulating his or her own attention and outlook.

Mindfulness has been able to connect to and makes sense of collectively experienced societal changes, and offers scientifically grounded (albeit patchy) guidance on how to relate to these. Its initial focus on stress related problems – evident in the name of its first medical institution – The stress reduction clinic – resonated with growing societal concerns over the downsides of “multitasking” and “workaholism” in the 1980s, 1990s and onwards. However, it has simultaneously renegotiated what it means to be mentally fit, offering new ideals of the healthy and able citizen.

Nicole Thualagant, University of Roskilde

Performing health- working out as a health investment

Explorations of body practices have in several studies demonstrated how bodywork has become central in a society where focus is set on the *capable body* (Shilling 2008), i.e. the body that is capable of complying with societal expectations of performativity. Based on the great works of social theorists of the body, and inspired by the French anthropologist Le Breton’s approach to the body as an ideal observatory of the social context (1988), this article will explore body management as a way of ensuring performative health.

With the ambition of understanding bodywork in a (hyper)modern era, characterized by the approval of performativity, the body is here conceived as capital. The body as capital can be improved, worked upon and has an impact on how the individual distinguishes him/herself in social space. Just like Wacquant’s boxers who are considered to be “entrepreneurs in bodily capital”

(1995, 66), Danish citizens who regularly work out are in this paper considered to be investing in their body and thus developing performative health. In light of this, the paper illustrates the performativity of some Danish “gym-goers” (Crossley 2007) in their quest for managing a body, and hereby investing in health in relation to body capital. The task of this paper is more precisely to theorize on the matter of bodywork in relation to health and in this sense propose a theoretical frame that can enlighten bodywork in a “Health society” (Kickbush 2007).

Antti Maunu, Anu Katainen, Riikka Perälä & Anni Ojajärvi, University of Helsinki

The sick and the worthless? Sociocultural dimensions of socioeconomic health disparities

In Finland there are relatively wide socioeconomic health disparities. For example, in the highest income quintile men's life expectancy is 12,5 years longer than in the lowest. More than 50% of youth with psychiatric diagnosis have been raised in families who receive social assistance benefit, although less than 10% of Finnish households receive such benefit altogether. On the other hand, the income gap in Finland is smaller than in OECD countries in average. This illustrates how cultural, social and psychological factors, and not just material, contribute to health inequalities. We approach these factors through the concept of agency. Recent health studies have provided strong evidence of social trust as an important source of health and welfare. In short,

social trust is an experience of being meaningful for other people and the world in general, and thus having something to act for. This equals the idea of agency in general. In a sociological perspective, agency presupposes that the agent has some collectively shared horizon(s) of meanings and values that makes her actions meaningful and purposeful in the first place. Strong social trust produces strong agency, and it also strengthens the preconditions of mental and physical health. The other way around, weak social trust produces fragile agency that exposes the agent to various health problems.

In the paper, we approach Finnish health disparities from this perspective. We ask if there are some cultural elements in the agency of lower socioeconomic classes that makes them more vulnerable – or if there are other elements in the agency of higher socioeconomic classes that increase their resilience. We also claim that this perspective is vital in order to gain a better understanding of how objective, macro-level structures and subjective micro-level (health) behaviours interact with each other, and thus turn material conditions into lived health and sickness.

Annika Lillrank, University of Helsinki

Refugee women's health care experiences regarding pregnancy and birth in Finland

This paper explores how refugee women experience their pregnancy and birth giving in interaction with Finnish maternity care professionals. We have limited knowledge of these women's pregnancy and birth giving experiences.

These women usually arrive from poor circumstances where maternal health care is not well developed (Malin and Gissler, 2009, Malin 2011). This study departs from the salutogenic theory that defines human beings as resourceful agents. The emphasis lies in trust that resources are available if needed, and that they are sufficient to take care of the demands of individuals. In this study 11 women from Russia, Somalia, Afghanistan and Irak were interviewed by using an interpreter. My criteria for selecting informants were that they were 1) refugee women who had been granted a residence permit in Finland, 2) had lived at least two years in Finland, and 3) who, at the time of the interviews, took care of their child(ren) at home. Five women considered the received care as good. Four women with dramatic experiences were, despite of these obstacles, able to develop trust in the care providers. Two women were traumatized by the care providers' inability to recognize their need for care. The main findings highlight that these refugee women's individual ability to develop trust was essential. The ethnic background of these women could not explain their experiences. This supports the salutogenic theory that emphasizes the importance of individual resources that enables human beings to solve problems and use available resources to develop a sense of wellbeing.

Session 3: Ableism: creative coping with disability

Ditte-Marie From, Roskilde University

“Virtues of Health Management”: how to dismantle the perceived incapability of the overweight body

In researching a health problem, notions of what constitutes a healthy body naturally evolve. National strategies on how to shape bodies that deviate from a desired norm, operate on (at least) two simultaneous thriving arenas; the health arena and the arena of the virtuous and productive citizen. Some bodies carry visual traits of non-healthiness, and an increasing number already from childhood. The overweight child receives a great deal of both health and societal attention in the attempt to prevent health related diseases and financial burdens on state budgets. The overweight body can be said to communicate to its surroundings through voluminous body markers which in a society of abundance no longer signifies wealth, but rather lack of control, irresponsibility towards the common good, and ignorance on how to lead a healthy life.

The normativity of the overweight body as being insufficient in leading a healthy life and in contributing to the common good of welfare, creates a culturally embedded perception of profound incapability around overweight bodies. A societal health problem, and accordingly solution, is born: In the name of prevention, overweight children must learn to control themselves and become responsible citizens. Practices, that seek to influence the undesirable

trajectory of the overweight children's presumably heavy loaded pathway to the future, affect the overweight children's self-perception on two conflicting terms. First of all, the overweight children adopt the understanding of representing a severe health problem as their first immediate reaction to their surroundings. They formulate and reproduce the discourse of the virtuous citizen who is capable of showing responsibility and obtained control by taking actions towards leading a healthy life. But subsequently to that, overweight children are also capable of living an everyday life where being overweight does not necessarily represent a hindrance to a healthy lifestyle, i.e. an everyday life of being able despite deviant body markers.

The paper presents how visual methods of photo elicitation interviews facilitate a creative research process, as well as producing narratives of everyday life experiences. These, I argue, question the prevailing discourse of the overweight body as not being able. This paper builds on the findings of my Ph.D. study "Healthy Overweight Children" (From, 2012).

Åsa Alftberg, Lund University

Soundscapes and (dis)able bodies

One of the characteristics of modern society is considered to be an increasing amount of sounds and noise, both in volume and scope. While various locations involve different types of sounds, not everyone has equal access to these soundscapes. Additionally, sounds are not neutral but include cultural beliefs and norms. How are sounds, or lack of sounds, experienced by persons

whose access to sounds is not obvious, that is people with hearing loss? Which groups of people are excluded from the soundscapes of modern society? The empirical material of the study involves people with cochlear implants, who are deaf, but who have hearing through the use of medical technology. What are their experiences of different types of soundscapes, especially of soundscapes associated with leisure activities? What strategies do they use when they are in difficult sound environments? The starting point of this study is that disabilities, such as hearing loss, not only have medical implications but also social and cultural consequences. Disability/ability is a way of thinking about the body that is based on historical and cultural circumstances, always in close relation to the significance of space and place. By following individuals with different access to sound and noise, the hidden premises of the modern soundscapes are made visible.

Britta Lundgren, Umeå University

Narrating narcolepsy – centering a side effect

During 2009-2010 the world experienced the influenza pandemic A (H1N1), also called the “swine flu”. The National Board of Health and Welfare in Sweden recommended that the entire Swedish population should be vaccinated as a preventive measure to stop the spreading of the influenza and to mitigate the feared consequences. The vaccination with Pandemrix against swine flu was commenced in October 2009. Over 60% of the Swedish population was vaccinated, and among children the coverage was even higher.

During the summer of 2010, unexpected reports of narcolepsy in Swedish children and adolescents after vaccination with Pandemrix came to the attention of the Medical Products Agency (MPA). Over 200 cases have been estimated as having narcolepsy as a side-effect of the vaccination.

In 2010 the association Narkolepsiföreningen was founded to support these children and their families. In this paper I will use material from interviews to discuss the different creative strategies and tactics performed by both the association and the families to cope with the experience of narcolepsy. The practical and emotional reorganization of everyday life, including the different spatial and temporal rhythms of remedies and therapies, affects every family member and also their relations with friends and relatives. The narratives of everyday life with its continuous struggles disclose several creative capacities while at the same time characters, parental approaches and moral and truth are articulated.

Kristofer Hansson, Gabriella Nilsson, Irén Tiberg & Inger Hallström, Lund University

Care practice and the child: culture analytical perspective on care in practice

In this paper we want to develop an understanding of how care can be studied from a culture analytical perspective in specific care meetings. We have two different empirical materials: Observations of meetings between professionals and families with children newly diagnosed with diabetes type 1, and

interviews with professionals meeting children and youth with cochlear implants. We want to emphasise that care is not a fixed and previously defined category, but a concept that creates different cultural and social practices. Seen from this perspective care is something that is negotiable in situations where different individuals meet. In these situations our studies have shown us that it is not only professionals in health care that meet the persons and families. Instead we want to stress that the situation should be analysed as a much more complex process; it can be a collision between different professionals, between the patient's life outside the meeting and the situation of the meeting and so on. There are in this way different actors that we need to consider to understand care in practice. But as Jeannette Pols (2010) also emphasises, caring practices also include materiality that calls for making care into routine. In our paper we want to develop this perspective in relation to the requirements and conditions that childcare generate.

Pols, Jeannette (2010): 'Telecare: What Patients Care About', Annemarie Mol, Ingunn Mosel & Jeannette Pols (eds): *Care in Practice: On Tinkering in Clinics, Homes and Farms*, Bielefeld: transcript Verlag.

Session 4: Narratives of care and self-care

Anna Leppo & Riikka Perälä, University of Helsinki

The remains of care in the context of pharmaceuticalization. Opiate substitution treatment in the post-welfare state

The paper explores what the provision of care means in opioid substitution treatment (OST) within the current trends of pharmaceuticalization and austerity politics. Previous critics of pharmaceutical governance have argued that more and more of the resources of the welfare state are used to develop and provide pharmacotherapies, which not only means that less resources are available for other forms of treatment, but also that it changes the way in which we understand the care of people in need of help. In this paper we examine how pharmaceuticalization affects the everyday realization of care, and in particular the relationship between workers and patients. What remains of a more holistic notion of care if treatment consists simply of medication? Secondly, what kind of a "cure" does pharmaceuticalization offer to problems such as drug use, which are not only brain-based but also social in nature? The empirical data used in the paper is gathered from an OST clinic that dispenses methadone to people suffering from severe opiate dependency. The clinic is situated in southern Finland. The ethnographic method used in the paper provides a detailed, in-depth analysis of the different actors and relationships (both human and non-human) which characterize the pharmaceutical treatment of drug dependency on the everyday level of action. We argue that a

strong emphasis on pharmaceutical treatment may result in increased abandonment of people suffering from drug problems, especially in the neoliberalist context which focuses on cutting the costs of public services.

Leena Leinonen, Riitta Vornanen & Hannele Turunen, University of Eastern Finland

The narratives of people with celiac disease – the content and critical factors of lay knowledge in developing early detection of celiac disease

Celiac disease is one of the chronic diseases that can be latent for decades. Despite progress in medicine, only one fourth of the total cases in Finland are diagnosed. In an extensive survey study of 1612 celiac patients, the quality of life improved after diagnosis. However, significant delay in diagnosis was found (Green et al. 2001). Still, relatively little is known about personal pre-diagnostic history. In medicine, the metaphor of an iceberg is used to describe this partly hidden phenomenon, and the latent or silent characteristics of the disease.

This study was concerned with explicating the content and meaning of lay knowledge and focusing on critical factors for the early diagnosis of celiac disease. The data consists of 109 written narratives, where Finnish people diagnosed with celiac disease, analyse their history of getting diagnosed. The participants were recruited through an announcement in the national journal of celiac patients, "*Keliakialehti*".

Methodologically the study represents narrative research in illness, which is combined into the method of critical incidents (originated by Flanagan). The aim is to analyse the narratives, and find critical factors which have either promoted or inhibited detection of the disease.

The preliminary results show that critical factors which inhibit diagnosing the disease include e.g. atypical psychological or physiological symptoms or sensations, the activities of health care personnel (low levels of knowledge, somatisation or psychologisation) and other diseases, which might muddle the findings. Critical factors promoting the diagnosing of disease include e.g. clear and sudden changes in psychological or physical health, the patient as an active actor (obduracy in demanding help), the activities of health care professionals (trust in patient narratives), and the awareness of related diseases which signal the possibility of celiac disease etc.

Susanne Ådahl, University of Turku

Creating a new self: the potential of cognitive self-therapy among voice hearers

My paper sets out to discuss collective, therapeutic self-fashioning strategies used in the ethnographic context of a peer support group of Finnish voice hearers (people who hear audibly uttered voices in their minds that others cannot hear). Person-to-person support within these groups is based on creating alternatives to the medicalisation of voice hearing (also called auditory hallucinations) and creating a new sociality based on social inclusion of the

voices in one's head. The aim of the presentation is to ground my ethnographic observations of peer support creativity in the social, because as Hastrup (2007) has pointed out, creativity is a profoundly social fact, performed by individuals as part of the making of social worlds; agency, according to Hastrup, emerges from one's social actions. The performativity in these support groups is based on being true to oneself in order to achieve a coherence of mind and self and going through a process of reconciliation with the past. A key question I seek to outline is how sociality is created in these groups and how it impacts on the creation of a new self that incorporates voice selves. How is everyday experience, the ability to act (Bourdieu 1990), give meaning and to engage in inter-subjective social transactions (Kleinman 1995) linked to re-creating the self as a voice hearer?

Bourdieu, Pierre (1990). *The Logic of Practice*. Cambridge: Cambridge University Press.

Hastrup, Kirsten (2007). Performing the World: Agency, Anticipation and Creativity, Elizabeth Hallam and Tim Ingold (eds): *Creativity and Cultural Improvisation*. New York: Bloomsbury Academic.

Kleinman, Arthur (1995). *Writing at the Margin: Discourse between anthropology and medicine*. Los Angeles: University of California Press.

Conversations in group about the white cane

The Swedish Syncentral (Centre for the visually impaired) provides rehabilitation and support for visually impaired persons. The most important aid offered is the white cane. The purpose of the stick is to help the person to feel the actual surface and hereby note (and avoid) potential obstacles. Accustomed cane users can even tell the distance to a wall just from listening to the echo. But the cane does more than that; it signals to people surrounding the cane user that “here comes a visually impaired person”. The white cane is the symbol of visual impairment and is recognized as such all over the world. All this should imply that the stick ought to be the ultimate tool for visually impaired persons. It is a means for independence, it is relatively inexpensive, it requires no maintenance and it rarely fails to function. Moreover, it is a clear marker of visual impairment and thus easy for the world to see and interpret.

So one might think, but as a matter of fact, Syncentralen invests at least as much time on engaging in support conversations for cane users as on direct technique training. In spite of it being such a practical and handy tool the cane in itself also provokes a wide range of intractable and ambivalent feelings. In my paper I discuss the cane from a user perspective. The point of departure is an auto-ethnographic study of my own use (or non-use) of the stick, meetings with other visually impaired persons and activities at Syncentralen. In my paper I want to analyse the white cane as a social materiality, but I will also discuss feelings of vulnerability, shame and internalized norms of ableism.

Session 5: The power of expressivity and the institutional transformations of suffering

How can institutions in health care help people overcome emotional and social suffering? Many public, private and non-profit organizations have that concern in common. In our panel, we want to focus in particular on people's needs, constraints and opportunities to express themselves freely through various means. To freely express one's own thoughts and feelings is anything but unconditional. This privilege may on the one hand, if prevented, be a source of emotional and social suffering (Morris 1997). On the other hand, most agree that the ability to express oneself freely is a basic human need and a source of creativity. The ability of people to express themselves freely is both limited by the external circumstances of the context in which they live and by their own personal circumstances. The latter can be caused by disabilities that hinder people's ability to convey stories without the help of outsiders, to take one example (Drakos 2013, Hydén 2008). The aim is to gather participants from the Nordic countries in a workshop on this theme where one can present an ongoing project or a new project idea.

Georg Drakos

Drakos, Georg 2013. Berättande och äldreomsorg: Kroppen som hinder och resurs i berättande, Owe Ronström, Georg Drakos & Jonas Engman (red): *Folkloristikens aktuella utmaningar*. Visby: Gotland University Press.
Hydén, Lars-Christer 2008. Broken and Vicarious Voices in Narratives, Lars-

Christer Hyden & Jens Brockmeier (eds): *Health, Illness and Culture. Broken Narratives*. New York: Routledge.
Morris, David B. 1997. *Voice, Genre, and Moral Community*, Arthur Kleinman, Veena Das, and Margaret Lock (eds): *Social Suffering*. Berkeley: University of California Press.

Karoliina Ojanen & Pia Olsson, University of Helsinki

Old ages experienced and narrated. Understanding ways of aging

Simultaneously with the political and ethical discussions about old age, different creative methods for reminiscing are being developed and used in social and cultural work to improve the well-being and self-understanding of the elderly. Still, old age is an issue of public discussion often related to macro-level social policy questions. Only a few studies dealing with the social meanings of old age from an individual viewpoint and in relation to the socio-cultural order currently exist. At the University of Helsinki we have formed a multidisciplinary group (folklore, European ethnology, musicology) which aims to focus on the level of the microcosm, i.e. on different experiences of ageing. Narrating one's own life is a way of creating understanding about this microcosm of experiences and bringing forth a more multifaceted image of old age. This is why our research project is linked to both research on narration and ageing, connecting these two viewpoints to create a better understanding of how cultural meanings of old age are produced and experienced by the elderly themselves. As we see it, the valuable practical

work already carried out and its effects on participants' self-understanding and well-being have not yet been thoroughly analyzed. Using a narrative viewpoint we want to analyze both the way creative methods form the way elderly picture their lives, and how these methods are used to produce certain kinds of narrations.

In the session we would like to shortly present our research project that we have applied Academy of Finland funding for (and also give one example based on ethnographic fieldwork) on the ways emotional and social suffering exists in the everyday practices of institutionalized care. Making these practices visible is the first step to enable the institutions to overcome these problems.

Georg Drakos, Narrativ Etnografi

A Model for “Narrative Care”

How can the humanities and social sciences change the health care sector? I intend to describe a model created for this purpose, which I call “Narrative Care” (Narrativ omvårdnad). I have developed this model to be applied in the project "Creative Aging: Storytelling and Disability" implemented in 2014-15 with the support of the Swedish Arts Council. The model is also a base for my research company, Narrativ Etnografi. By adopting a method of collaboration on several levels, and with several actors, I want to try to contribute to long-lasting changes within the field of health care.

I will demonstrate how I apply the model in the aforementioned project to take advantage of the art of narration in everyday storytelling as a resource for

methods development in health care. My ambition is to create forms of mutual exchange between research and the professionals working within this field. However, a strong interest is also the exchange between artistic and scientific work. The project involves a filmmaker/ animator in addition to educators in art and music.

In an upcoming project that relates to the session's theme, I also collaborate with an author to take advantage of the often interwoven exchange between the art of narration in everyday storytelling and literature. We want to develop tools that can be used by professionals in health care, to facilitate the abilities of people to manage their own social and emotional suffering. Two problem areas justify the aim of the project. One is that the attitudes and linguistic forms that often are linked to what is "normal", has a tendency to unconsciously categorize people and their behavior as deviant in relation to what is taken for granted. The second problem area is the normative beliefs that shape our ideas about what is a "real" narrative. Both of these problem areas are often a source of social and emotional suffering. With this point of departure I want to discuss the session's overall theme.

Eva Marie Tveit, Bergen University College

What freedom of expression and participation do nursing home patients have?

This project is a part of a large intervention study, MEDCED. In MEDCED we try to reduce the use of restraint towards people with dementia in nursing

homes, by teaching and supervising staff about person-centered care. We have done both a RCT, and qualitative fieldwork, interviews and more. To our satisfaction, the use of restraint, as defined by the law and registered as such at the health authorities in the counties, were lower at baseline in our sample than earlier studies have shown. But there is a long and complex continuum from having freedom of choice and participation on the one hand, to being subjected to formal restraint on the other.

We argue that giving the patient sufficient care, creating trust and finding alternatives to the use of restraint in situations where the patient is agitated or refuses to collaborate in necessary care situations builds on knowledge of the individual patient. But how well does staff know their patients? How well do patients know staff? (The latter is important to induce trust, and enable meaningful conversation) What efforts are made to make the patients express their needs, dreams and hopes? And how are these taken into account?

Anne Leonora Blaakilde, University of Copenhagen, Christine E. Swane, The EGV Foundation, and Eva Algreen-Petersen, Municipality of Copenhagen, Dept. of Health and Elderly Care

Nursing home negotiations and narrations in challenging, transnational situations

In the city of Copenhagen a public nursing home is developing a new profile that aims at attracting older immigrants and refugees together with other

ethnic Danes in order to spend their last months or years in an institutional setting.

For more than 100 years Denmark has offered public nursing homes to frail older persons and hence represents a culture where institutional caretaking is accepted and expected. Today, the major part of homecare and nursing homes in Denmark are public or subsidised by state and municipalities. However, the immigration populations in Denmark do not utilize public help and care in old age at any significant level. This is the reason why the municipality of Copenhagen is developing a specific 'diversity profile' in an existing public nursing home in Copenhagen; Peder Lykke Centeret.

In collaboration with the EGV Foundation, the municipality of Copenhagen is conducting a research project for a period of three years while the 'diversity profile' at the nursing home is developed. The focus is particularly on the everyday life of inhabitants, but their family caregivers and staff are also interviewed. The methodological approach is phenomenological through ethnographic fieldwork and qualitative interviews. The aim is to follow the discourses and practices related to concepts of diversity as they may change during the three years, as well as the everyday life communication, care routines and rituals related to individual social and cultural needs.

This presentation will present fieldwork experiences on how negotiations and narrations take place when language is not really a medium, but an obstacle for communication. A specific case will be discussed regarding the attempts to fathom out non-spoken intentions and desires which are difficult to grasp, giving rise to various interpretations which can lead to different identifications and powerplay.

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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 address 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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Creative and able citizens: managing health and illness during the life course

As the Nordic welfare states evolve – with ideologies that focus on an increased consumption of health services – citizens are required to be productive throughout their life course. And because fewer economic resources are being invested into basic health care, and there is a move to shift more responsibility onto the individual (patient), it is becoming essential to illuminate practices that showcase the creative ways that people engage in self-care and agency in everyday-life.

This conference aims to discuss how to develop new perspectives on health and illness in the Nordic welfare states. The emphasis will be on creativity and ableism as key elements in people's and patients' constructions of meaning, especially with regard to questions about health and rehabilitation.

Among other things, the concept of creativity encompasses energy, liveliness, artfulness and agency – on both an individual and a collective level. Moreover, creativity refers to activities that are performed and practiced by able citizens and organisations. However, ableism is also a scholarly perspective that criticises traditional perceptions of normativity, particularly embodied normativity.

The conference organisers would like to invite papers that critically examine the challenges and opportunities prompted by such creativity: What sort of creative practices do people apply to attain a good life for themselves

while ill or frail? In what terms and under what circumstances are bodies perceived as being able – or not? How do such practices and attitudes affect people's experiences and expressions of health and illness? How do we as researchers contribute to the articulation of creativity and ableism, and how do these concepts affect us as professionals and fellow human beings?

How to find the conference venue

Swedish School for Social Sciences

Snellmansgatan 12 (PB 16)
00014 University of Helsinki

Web: <http://sockom.helsinki.fi/karta.html>

The closest metro station, and bus- and tram stop, is Kaisaniemi (the location is close to Kaisaniemi park and the botanical garden). From the hotels in the immediate city centre, the walking distance is between 5-20 minutes.

<http://nnhsh.org>