

Disability, Illness, and Poverty: Identities on the margin and the effects of global forces (medicine, technology and culture)

Responsible Institution:

The Rokkan Centre, Unifob/ University of Bergen (UiB)

Discipline:

The social sciences in general, medical anthropology/sociology and disability studies in particular

Course Leader:

Jan-Kåre Breivik, Researcher, Rokkan Centre, University of Bergen

Invited course leaders:

Stuart Blume, Professor, Department of Anthropology and Sociology, University of Amsterdam. Blume is also the leader of *Innovia Foundation on Medicine, Technology and Society* – a virtual research institute concerned with user perspectives on new health care technologies.

Lecturers:

Bodil Ravneberg, Researcher, Rokkan Centre, University of Bergen
Thorvald Sirnes, Researcher, Rokkan Centre, University of Bergen

Course Description, Goals and Objectives:

One of the aims of this workshop is to bring disability studies into the centre stage of social science developments. In order to do this we will draw upon fresh research and literature in the fields of medical anthropology/medical sociology and disability research. We will present new perspectives and new research in this field and invite interested recruits to join this PhD-workshop. By focusing on concepts such as “Globalization, Technologies, Disability, Illness, Poverty, Bodies and Gender” we aim at providing a fresh and up-to-date outlook on key contemporary questions and challenges. From various theoretical perspectives (political science, social anthropology, and sociology), and through in-depth analysis of empirical cases, we shall explore common questions:

- What is the relation between multiple individual identities, cultural diversity and political recognition of group differences?
- How are differences and hierarchies within groups handled?
- How does this affect public policy and service provision for disabled people and people with chronic illnesses?
- How do the new technologies and services interfere with lived experiences and personal narratives?

- What is the relation between poverty and illness/disability, and access/usability of services/technology?
- How shall we approach the new reproductive technologies, diagnostics and bioethical challenges in relation to human diversity, human suffering and disability pride issues?
- What are the key bioethical questions and dilemmas in the field of disability, illness, and poverty?

To address this multitude of questions and challenges, we will set up a PhD course with plenty of room for impressions and discussions. In order to trigger reflection and discussion, we will start the different sessions with a film/documentary. This will be followed up with short lectures and discussions. The PhD papers shall preferably be connected to at least one session topic.

Outline of the sessions/lectures/discussions:

0. Medical Anthropology meets Disability Studies – an introduction
1. Poverty and global forces
2. Rhetoric of Assistive Technologies
3. Biomedical storytelling and alternative narrations
4. Extraordinary bodies – medical interventions - technological extensions
5. Disability, illness and global forces

Friday 8 August –

Medical Anthropology meets Disability Studies

Overview of the course, introductions of faculty and students, objectives, learning methods, course paper (Blume and Breivik, 1400-1600)

Saturday 9 August –

Session 1: Poverty and global forces (introduction on the global traffic in human organs – and related issues, by Blume, 0900-0930)

Film: *Dirty Pretty Things* (UK/Africa) (0930-1100)

Discussions, group work, seminar preparation, with faculty tutors (all faculty, 1130-1300)

Sunday 10 August –

Session 2: Rhetoric of Assistive Technologies (Cochlear Implants and Wheelchairs)

Deafness – between cure and pride (Blume/Breivik, 0900-0930)

Land of Hope and Glory - Cochlear Implants (Blume 0930-1000)

Rolling Stories – Wheelchairs, Aesthetics, and Identity (Ravneberg 1000-1030)

Disability Pride and the Medical Gaze (different perspectives, all faculty 1030-1100)

Discussions, group work, seminar preparation, with faculty tutors (all faculty, 1130-1230)

Introduction to the film (1230-1300)

Film: *In the Land of the Deaf* (French) or *Sound and Fury* (USA?) or *El Cohechito* (Italy/Spain) (1400-1515)

General discussion (all faculty, 1515-1600)

Monday 11 August –

Session 3: Biomedical storytelling and alternative narrations (Blume, Breivik and Ravneberg/Sirnes 1400-1600) three-four short lectures

Tuesday 12 August –

Film/documentary: *This Beggars' Description* (Canada) or *Kabal i hjerter* (Norway) with short introduction (0900-1000)

The constructions of psychiatric diagnosis, intersections of gender, ethnicity, poverty and pride discourses (short lecture followed by discussion) (1000-1100)

Discussions, group work, seminar preparation, with faculty tutors (all faculty, 1130-1300)

Wednesday 13 August –

Session 4: Extraordinary bodies – medical interventions and technological extensions

Film: *Freaks* (USA) or *The Elephant Man* (USA) or *My Left Foot* (UK) (1130-1300)

Reproductive technologies – and bioethical challenges (Sirnes 1400-1430)

Prosthetic culture (Ravneberg 1430-1500)

Discussions, group work, seminar preparation, with faculty tutors (all faculty, 1500-1600)

Extra - theatre event: *Morning Mood – from the non-Pillars of Society* – a theatre production on homelessness by Bergen Byspill – based on text fragments from Henrik Ibsen's plays, music from Edvard Grieg's repertoire and inspired by research on homelessness at the Rokkan Centre at the University of Bergen (1800-1900)

Thursday 14 August –

Session 5: Disability, illness and global forces (at the Leprosy Museum)

Disability and stigma in developing countries (Blume 0900-0930)

The history of leprosy/Hansen's disease (Sandemo, the Leprosy Museum Bergen) (0930-1000)

Guided tour in the museum/St Jørgen's hospital (1000-1100)

Seminar 1, Paper presentation by students (all faculty, 1130-1300)
Seminar 2, Paper presentation by students (all faculty, 1400-1500)
Seminar 3, Paper presentation by students (all faculty, 1500-1600)

Friday 15 August –

Seminar 4, Paper presentation by students (all faculty, 1130-1300)
Seminar 5, Paper presentation by students (all faculty, 1400-1500)

Summary lecture - based on issues that are priorities for the students (Blume, 1500-1600)

Saturday 16 August –

Summary lecture/discussions - based on issues that are priorities for the students (all faculty, 0900-1100)

Prerequisites:

Candidates are expected to have a scientific background within disability studies, medical anthropology/sociology or other related areas.

Proficiency in the English language is required.

Target Candidates:

The course is primarily targeted for PhD students and junior faculty. MA level students will be accepted depending on space and academic qualifications.

We welcome students from any social or health science arena whose PhD dissertations involve research into key topics in this course, or who simply have curiosity about our approach and contents. When applying for attendance at this course, students have to attach an extended abstract on the essay they are going to write.

Work Required:

The activities of this course will be interspersed with Summer School Plenary Sessions, Plenary Panel Debates, exhibitions, tours, sightseeing, etc, that all Summer School participants and faculty members will engage in.

Working in five theme-based groups, students will take responsibility for preparing and leading each theme. The Course Leaders will participate as tutors in group work sessions, will attend the seminars, and will comment on the seminars and accompanying discussions at the conclusion of each day's work. Seminar presenters are expected to prepare a 15-30-minute talk, and summarise with 4-5 stimulating questions for a discussion. The last 10 minutes or so is devoted to a summary and comments by the Course Leaders – on how to develop the abstracts and ideas into good essays. All students are expected to have completed all reading well prior to the Summer School start.

About 250 hours of work is required (10 ECTS), inclusive all Bergen Summer School activities (this course plus plenary activities. Preparatory work includes completing the Required Reading prior to arrival in Bergen. Each student is to deliver 10-20-page essay (double-spaced) on a topic that fits with the overall content of the course or with any of the sessions, within four weeks after the end of the course. The paper will receive careful attention from the Course Leaders and written feedback will be provided.

At the final day of the BSRS, participants of the course will make a report on what they have learned and present it in plenary.

ECTS:

10 ECTS granted for approved course performance (full course attendance, course readings and approved essay)

Reading List:

The 700-1000 pages you shall read as part of this course must be related to our suggestions. We will not produce a paper compendium for you, but provide you with pdf-files of articles that are available, and links to where you can find online versions if possible. When it comes to the important and suggested books/book-chapters we recommend that you either buy or borrow the books. The list below can be slightly revised in the beginning of 2008, and then the list of films will be settled:

Becker, Gay (1997): *Disrupted Lives. How People Create Meaning in a Chaotic World* Berkeley; University of California Press (suggested one or more chapters)

Blume, Stuart (2000): "Land of Hope and Glory: Exploring Cochlear Implantation in the Netherlands" *Science, Technology & Human Values*, Vol. 25, No. 2, 139-166

Blume, Stuart (1997): "The Rhetoric and Counter-Rhetoric of a "Bionic" Technology", pp. 31-56 *Science, Technology, & Human Values*, Vol. 22, No. 1

Bogdan, R. (1988): *Freak show: presenting human oddities for amusement and profit*, Chicago: U. of Chicago Press (suggested one or more chapters)

Breivik, J.K. (2005): *Deaf Identities in the Making, Local Lives-Transnational Connections*, Washington DC: Gallaudet University Press, USA (one or more chapters)

Davis, Lennard J. (2002): *Bending over backwards: disability, dismodernism, and other difficult positions*, New York : New York University Press (one or more chapters)

Corcer, M. & T. Shakespeare (eds.) (2002): *disability/postmodernity: Embodying Disability Theory*, London: Continuum (one or more chapters)

Foucault, M. (1988): *Technologies of the self*, London: Tavistock (one or more chapters)

Goggin, Gerald and Chr. Newell (2003): *Digital Disability: The Social Construction of Disability in New Media*, Rowman & Littlefield Publishers (one or more chapters)

Gustavson A., Sandvin J., Traustadottir R., and J. Tøssebro (eds.) (2005): *Resistance, reflection and Change. Nordic Disability Research*. Studentlitteratur, Lund, Sweden (one or more chapters)

Haraway, D. (1991) "A Cyborg Manifesto: Science, Technology, and Socialist-Feminism in the Late Twentieth Century", pp.149-181 in Haraway: *Simians, cyborgs, and women: the reinvention of nature*, London: Routledge

Ingstad & Whyte, (eds.): *Disability in Local and Global Worlds*, Berkeley: University of California Press (one or more chapters) for instance:

Haualand, H. (2007): "The Two Week Village - The Significance of the Sacred Space" in Ingstad & Whyte, (eds.): *Disability in Local and Global Worlds*, Berkeley: University of California Press

Helgøy, I., B. Ravneberg & P. Solvang (2003): "Service Provision for an Independent Life, Disability", *Disability & Society*, Vol. 18, Number 4, June 2003 ss.471-487

Humphrey, J.C. (1999): "Disabled People and the Politics of Difference" in *Disability & Society* vol.14, No.2, pp. 173-188

Inhorn, M.C. (2003). *Local Babies, Global Science: Gender, Religion, and In Vitro Fertilization in Egypt*. Routledge. (one or more chapters)

Kleinman, Arthur, Veena Das, and Margaret Lock (eds.) (1997): *Social suffering*, Berkeley, Calif.: University of California Press (one or more chapters)

Kleinman, Arthur (1995) *Writing at the margin: discourse between anthropology and medicine* Calif.: University of California Press (one or more chapters)

Kleinman, Arthur (1988): *The illness narratives: suffering, healing, and the human condition* New York: Basic Books (one or more chapters)

Malterud K, Candib L, Code L. (2004) "Responsible and responsive knowing in medical diagnosis – The medical gaze revisited." *Nora*; 12 (1): 8-19

McRuer, Robert (2006): *Crip theory: cultural signs of queerness and disability* New York: New York University Press (one or more chapters)

Mitchell, W.J.T. (2001): "Seeing disability" in Breckenridge, C. & C. Vogler (eds): *Public Culture, Society for Transnational Cultural Studies*, Vol. 13, no. 3.

Moazam, Farhat (2006): *Bioethics And Organ Transplantation in a Muslim Society: A Study in Culture, Ethnography, And Religion*, Indiana University Press (one or more chapters)

Morris, J (2004): "Independent living and community care: a disempowering framework", in *Disability and Society*, 19 (5) , pp 427-442.

Moser, I. (2005): "On Becoming Disabled and Articulating Alternatives. The multiple modes of ordering disability and their interferences", in *Cultural Studies*, Vol. 19, No. 6 November

Moser, I. (2006): "Sociotechnical Practices and Difference. On the Interference between Disability, Gender, and Class", in *Science, Technology, & Human Values*, Vol. 31. No 5, 1-26

Nichter, Mark and Margaret Lock (eds.)(2002): *New horizons in medical anthropology* London : Routledge (one or more chapters)

Riddel, S. & N. Watson (eds.) (2003): *Disability, Culture and Identity*. Pearson Prentice Hall, Harlow (one chapter or more)

Scheper-Hughes, Nancy and Loïc Wacquant (eds.) (2002): *Commodifying bodies* London : Sage (one or more chapters)

Scheper-Hughes, Nancy (2000): "The Global Traffic in Human Organs" including comment from different authors in *Current Anthropology*, volume 41, pages 191–224

Shakespeare, Tom (2006): *Disability Rights and Wrongs*, Routledge, (one chapter or more)

Sirnes, Thorvald (2005): "Deviance or Home sacer? Foucault, Agamben and Foetal Diagnostics" in *Scandinavian Journal of disability research*, Vol. 7., no 3-4, pg: 206-219

Snyder, Sharon L. and David T. Mitchell (2006): *Cultural locations of Disability*, Chicago, University of Chicago Press (one or more chapters)

Sontag, Susan (2002): *Illness as Metaphor*. Penguin: London (one or more chapters)

Thomas, C. (2006): "Disability and Gender: Reflections on Theory and Research", in *Scandinavian Journal of Disability Research*, Volume 8, Number 2-3, pp 177 - 185

Thomson, Rosemarie Garland (1997): *Extraordinary Bodies*, New York: Columbia University Press (one or more chapters)

Vernon, A & J. Swain (2002): "Theorizing Divisions and Hierarchies: Towards a Commonality of Diversity?" in Barnes, Oliver & Barton (eds.): *Disability Studies Today*, Cambridge: Polity Press

Watson, Nick and Brian Woods (2005): "No Wheelchairs Beyond this Point: A Historical Examination of Wheelchair Access in the Twentieth Century in Britain and America", *Social Policy & Society*, 4:1, Cambridge University Press.