

**NNDR Conference
Nyborg, Denmark
2 - 4 April 2009**

Specially organized session

**Disabled People and Research on Disability
Collaborations and Conflicts**

Peter Anderberg & Rannveig Traustadóttir



UNIVERSITY OF ICELAND

Disabled People and Nordic Disability Research

**NNDR Conference,
Nyborg 2009**

Rannveig Traustadóttir

Key Question

Why have disabled people in the Nordic countries not been active in the creation and development of disability studies and disability research?

Why are disabled people not interested in disability research?

“I know it may sound very strange to you, but I don’t see myself as a disabled person”
(Nick Watson (2002), *Disability and Society*)

Disabled people's identity and self understanding

Nick Watson (2008) *Disability, identity and the management of normality*. Keynote presentation at the Icelandic Network for Disability Research

- A study of physically disabled people
- Most of the disabled people in the study did not identify as disabled
- For disabled people it is normal to be disabled

Disabled people's identity and self understanding

- Icelandic study *Growing up with Disability* - physically disabled youth
 - All experienced being “different”
 - Did not view themselves as “abnormal” or lesser than others
 - Presented themselves as similar to others
 - Wanted to be seen as other children and youth

Disabled people's identity and self understanding

Adolf Ratzka (2005): “We are profoundly ordinary people sharing the same need to feel included, recognized and loved”

(www.independentliving.org)

Despite the fact that disabled people experience discrimination and exclusion they see themselves as ordinary people

**What does this have to do with the question
“Why are disabled people in the Nordic countries
not interested in disability research?”**

- If disabled people do not identify as disabled they are less likely to want to engage with the disabled people’s movement and disability research
- They may not see disability research as relevant for themselves
- They may also want to avoid the stigma of disability that comes with being associated with issues that have to do with disability – including research and scholarship

Disabled people and the disabled people's movement

- There is a difference between disabled people in general and disabled people who are involved in the disabled people's movement
 - People who are in the disabled people's movement have decided to devote their energy to work on issues of disability
 - They should therefore see disability as relevant and be interested in disability issues – including research

Disabled people and the Disabled People's Movement

- Whether disabled people identify as disabled or not they do experience discrimination and exclusion, inaccessibility to education, housing, employment, information, transport, family life, etc.
- The disabled people's movement advocates and works to change this - demands social change, human rights and full participation

Social change in today's information and knowledge society

- Advocacy and action for social change needs to be based on sound knowledge (why change, what works, how should things change, how does change occur) and a clear vision (ideology)
- It is therefore logical to turn to disability research to support the efforts of the disabled people's movements

Traditional disability research (as well as disability policy, services, ...)

- Has been dominated by bio-medical understandings that has viewed disability narrowly, as an individual problem, as a negative aspect of human diversity, and as a personal tragedy
- Traditionally many researchers have taken the non-critical stance of ‘scientific objectivity’ – and thereby re-created and re-affirmed pathological understandings of disability and legitimized the oppression and discrimination of disabled people

Traditional disability research and social change

- Traditional disability research has made disabled people suspicious of research and researchers, non-disabled researchers in particular
- Traditional bio-medically dominated disability research did not produce the kind of knowledge that could support the disabled people's movements' work for social change

Traditional disability research and social change

- Disabled people and their movements have therefore tried to change disability research by taking part in creating a *new* kind of scholarship on disability

New Disability Studies

- Has its origins in USA and UK
- New field of study and a new concept - Disability Studies
- Roots in disabled people's movements
- Disabled researchers important as leaders
- Rejects traditional bio-medical understanding of disability
- Emphasizes social, political and cultural view of disability
- Disability is understood as socially constructed rather than a biological condition
- Closely related to demands for human rights and full participation of disabled people
- Influenced by new theoretical perspectives
- Research *for* disabled people, not just *about* them

Disability Studies and other interdisciplinary fields

- DS belongs to a group of new interdisciplinary fields of study and has developed in similar ways as
 - Feminist/ women's/ gender studies
 - Lesbian and gay/ queer studies
 - Ethnic minority studies/ multicultural studies
- Disability Studies is the newest on this branch of radical scholarship originating in the late 1950s and 60s
- DS attempts to explore disability in similar ways as gender, sexuality and ethnicity

What is “new” about Disability Studies?

- It is not new to study disability
- What is new is **how** disability is being studied

Disability Studies and the new approaches to understanding disability

- DS rejects the traditional understanding of disability as an individual and bio-medical problem, and the negative clinical understanding of disability as ‘abnormality’ and personal tragedy
- Instead the new DS attempt to create a social understanding and explore the social, cultural and economic factors/barriers that create many – and even most – of the difficulties faced by disabled people

New approach to understanding disability

- Internationally scholars from many fields (social sciences, humanities, arts,...) are creating a new way of understanding disability
- In most places disabled people have leading roles in establishing and developing disability studies and disability research
- **In the Nordic countries, however, this is not the case**
- Instead, it has largely been non-disabled people who have developed this new scholarship
- **WHY is that?**

Similarities and differences between Disability Studies and other fields

- Similarities
 - Not all women identify as feminists or take part in the women's movement
 - Not all feminists are interested in feminist research or women's studies
 - Not all people from marginalized groups identify with or take part in the liberation movement advocating for social change, or in developing liberating, emancipatory scholarship and research

Similarities and differences between Disability Studies and other fields

- Differences
 - Women (and particularly feminists) have been leaders in establishing and developing women's studies and feminist research
 - Lesbians and gay men have been leaders in establishing queer studies, etc., etc...
 - Disabled people have been leaders in establishing Disability Studies in most countries --- **but not in the Nordic lands**

Why has the development of Disability Studies been different in the Nordic Countries?

- Why have disabled people not been leading in the creation and development of Disability Studies in the Nordic countries?
- Why are disabled people not interested in Nordic disability research?
- Why do disabled people not take part in NNDR, and attend NNDR conferences?

Why are disabled people in the Nordic countries not interested in disability research?

- Of course there *are* disabled people who have taken part in disability research and NNDR
- Disabled people *do* show increasing interest in disability research
- But they have been few and have rarely been in leading positions or roles - **WHY?**

What has dominated the development of the disability field in different countries?

- The UK: The Social Model of Disability
- The US: The Independent Living Movement
- The Nordic countries: Normalization

These have been the major contributions and characteristics of the disability field in each of these countries

What has influenced the development of disability studies in different countries?

- The Social Model of Disability and the Independent Living Movement
 - Grew out of the movement of physically disabled people - and both have strong links to DS studies in the US and UK
- Normalization
 - Grew out of the intellectual disability movement and was conceptualized by non-disabled people in that movement – and it is this group that is still most strongly linked to DS in Nordic countries

Why are disabled people in the Nordic countries not interested in disability research?

- Do we find the answer in these major developments in the field of disability (social model, independent living and normalization) and how these relate to (and grew out of) the disabled people's movement?
- Is this one of the reasons Nordic disability research is still closely related to intellectual disability research and why physically disabled people are not interested in disability research?

Who are the non-disabled leaders in Nordic (and international) disability research?

- Have roots – like the disabled people's movement – in the political radicalism of the 1970s
- Many have disabled family members (parents, children, siblings...)
- Many worked in the field of (intellectual) disability
- Extended the 1970s ideas about social justice and equality to disabled people

What has characterized the development of the disability field in the Nordic lands?

Mårten Söder: Disability research in Sweden has reflected the welfare reforms, - and the disabled people's movements have been so closely involved in public welfare, policy and services that they have not risen up to activism and social change (like in the UK and USA)

(Örebro conference April 2008).

What has characterized the development of the disability field in the Nordic lands?

Tom Shakespeare (2005: 300): Disabled people in Britain “...have struggled for their rights within a welfare state which has been less supportive and generous than those in Nordic countries: the upshot is a cohort of empowered and professional physically impaired people speaking for themselves and expecting to be included in every area of life, including academia.”

(Gustavsson et al (eds.): *Resistance, reflection and change: Nordic disability research*. Lund: Studentlitteratur)

What has characterized the development of the disability field in the Nordic lands?

Tom Shakespeare's point is that disabled people in the Nordic countries have been so well off that there has been little need for activism and radicalism – not much need to work for change, including changing disability scholarship.

Why are disabled people and the disabled people's movements in the Nordic countries not interested in disability research?

Are Mårten Söder and Tom Shakespeare right?

Are the answers – at least partly:

- Strong ties to welfare policies and provisions of services
- Disabled people in the Nordic countries are so well off that there is not the same need for radical changes in policy, services and scholarship as in other countries

Why are such few disabled people in the Nordic countries involved in disability research?

- Explanations for the lack of disabled people in disability studies and disability research can be found elsewhere than in the lack of interest on behalf of disabled people
- Two other reasons seem obvious
 1. Educational barriers
 2. Population numbers

Education barriers

- Education policies
- Segregated schooling
- Low quality education
- Barriers to higher education
 - To enter universities
 - Within the universities

Population numbers

- USA – 300 million people
- UK – 60 million people
 - In these countries we find disabled disability researchers – and among them are important, active and visible strong leaders
- Nordic countries – 20 million people
 - We do not have the same numbers to draw from which can help explain how few disabled disability scholars there are in the Nordic lands
 - Means we need to make extra efforts to recruit disabled scholars to Disability Studies

Disabled People and Disability Research

- NNDR has tried to recruit disabled people – but without much success
- It is essential disabled people take leading roles in the development of disability studies and disability research in the Nordic countries, and in NNDR
- Why is that important?
- How can we work towards that?

Disabled people and disability researchers: Common interests

- Important to come together and discuss our common interests with regard to research
- The most obvious common interest is to increase funds for disability research – and lobby for funding for research that is social change oriented
- Priorities: The UN convention and its implementation is a major important common task for both research and activism

Disabled People and Disability Researchers

Conclusion

- Collaboration between disabled people and disability researchers is important – will benefit both
- Disabled people should have a say – and be leaders – in disability research. --‘Nothing about us without us’
- Important to increase the number of disabled researchers in the Nordic countries
- We need to create a forum for disabled people and researchers to come together and discuss research priorities, ways to collaborate, how to use and disseminate findings and other important issues

Rannveig Traustadóttir, Professor and Director
Centre for Disability Studies
School of Social Science
University of Iceland
rannvt@hi.is
<http://www.fotlunarfraedi.hi.is>