The invisible ones

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In disability history, people with multiple disabilities are practically invisible. This is shown by my study of a Danish institution in the period of 1880-1987[1]*. This was an institution for mentally retarded individuals who had been given up on, i.e. not believed to be within educational reach. The question is why they are also invisible in the activities that based on the theories of the social model unfold e.g. on conferences in Lancaster. Is it because they can not be expected to be active activists? Or is it because the social model is not applicable for the issues of this group? Can the social model capture the problems that people with multiple disabilities and their families face, or does an extended version of the model has to be considered, like the one suggested by the Norwegian philosopher and special pedagogue Solveig Reindal?* [2] *With reference to this model (and its emphasis of the necessity of a social relational model) and the thoughts presented by Tom Shakespeare in the book "Disability rights – and wrong", I will give my proposal for the battles that in my opinion need to be fought in order to fulfil the rights of people with multiple disabilities as well as ideas as to how we can act with respect of the bodily restrictions they live under. The views of Tom Shakespeare on how the dichotomy between the social and medical model is too simplified to encompass the complexity of the conditions that people with severe disabilities face, comply with the thoughts I made after participating in the last conference in Lancaster. In my presentation I will focus on what the concepts of the social model mean to people with multiple disabilities and the ideas we have in Denmark (VIKOM. The Danish Resource Centre of Children and Young People with Multiple Disabilities) on how the concepts and ideas of the social model can be developed to accommodate the particular issues that multiple disabilities represent.*

I was lucky enough to have the opportunity to participate in the conference in Disability Studies: Research and Learning. Lancaster University in September 2006[3]. I was happy with the many dedicated papers, but I also identified some problems in relation to my own research areas that are concerned with disability history and communication in relation to people with multiple disabilities. It struck me that the practical field was not well represented on this conference and did not seem to be of much interest either. In

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[1] Birgit Kirkebæk: *Uduelig og ubrugelig. Åndssvageasylet Karens Minde 1880-1987 (Incapable and useless. Institution of the mentally retarded Karens Minde 1880-1987)*. Forlaget SocPol, Holte 2007.

[2] Solveig Magnus Reindal: *Funksjonshemming, kroppen og subjektet. Noen grunnlagsproblemer innenfor spesialpedagogikk (Impairment, body and subject. Some fundamental problems within special education)*. Fagbokforlaget, Bergen 2007.

[3] Disability Studies Association Conference. Disability studies: Research and Learning. Lancaster University 18th – 20th September 2006.

relation to the group of multiply disabled children and adolescents that I represented, I experienced the following as a general feature of the conference:

- A weak emphasis on how the social model can be translated to the practical field in relation to people with severe degrees of impairment. People with multiple disabilities were not at all part of this thinking.
- A tendency to shut off other perspectives on how to understand the world.

In relation to the latter I found support in the lecture of Tom Shakespeare. He described the development of the concept of the "social model". And he pointed out that in the beginning the activist movement had a very restrictive perception of the social model, because it was used as a "ram" in the political system. The next step in the development of the social model was to list dichotomies:

- Medical model versus social model
- Impairment versus disability
- Disabled people versus non-disabled people.

Tom Shakespeare warned against continuing to use these old positions as a starting point for the movement. He wishes a more pluralistic debate, and in his book "Disability Rights and Wrongs" he has argued that a dichotomised polarisation of the concepts poses a threat to the continued development of the concepts[4]. Not everyone agreed with him in his analysis, but for me as a researcher looking at things from the outside and working with people with multiple disabilities and their families in the practical field, his lecture (and the book) gave hope that the issues that I see in relation to the continued development of the social model can be heard and discussed.

In my disability history research and in my research about communication and interaction with individuals whose primary modes of expression are not spoken language, I have been very inspired by the experiences and political contributions from the social model. This applies for several of the themes that were consistent at the conference in 2006:

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[4] Tom Shakespeare: *Disability Rights and Wrongs*. Routledge, London and New York 2006. About this in particular, see part I in the book.

- The hazards of a medical model (stigmatising, categorising, domineering, discriminating)
- Lack of solidarity in society and economically
- Techniques of prevention and elimination in a legal and ethical perspective
- Being perceived as a poor thing or a victim rather that a human being with own opinions of one's life

It is particular the hazards of the medical model, the lack of solidarity in society, and ideas of prevention that stand out in my *disability history research*. In relation to my *research on communication and interaction*, it is the client zing and the associated removal of freedom of speech and participation in the public life that are at the centre together with considerations on how the opportunity to form one's identity can be realised for people who have traditionally been treated from an ideology of improvement and adaptation. Human rights and equality are at stake in both cases. But where it in *disability history research* is about understanding how talking about being different *constructs* "others" as something that is separated from the normal, it is *communicatively* about understanding that freedom of speech and participation in the public life remain only words if there in the real world is no work being done to give individuals the tools and space to actually speak up. This is where *practice* enters as a project of solidarity that the advocates of the social model should be committed to.

The invisible ones

In my disability history research about the history of cognitively impaired people in Denmark (which have resulted in five books covering the period of 1880-1987[5]), I have with inspiration from Michel Focault and Zygmunt Bauman attempted to identify the acting potential of documents with regard to diagnosing and categorising "the different

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[5] Birgit Kirkebæk: *Da de åndssvage blev farlige (When the retarded became dangerous)*. Forlaget SocPol, Holte 1993.
Birgit Kirkebæk: *Defekt og deporteret. Livø-Anstalten 1811-1961 (Defective and deported. Institution of Livø 1811-1961)*. Forlaget SocPol, Holte 1997.
Birgit Kirkebæk: *Normaliseringens periode. Dansk åndssvageforsorg 1940-1970 med særligt fokus på forsorgschef N.E. Bank-Mikkelsen og udviklingen af Statens Åndssvageforsorg. (The period of normalisation. Danish care of the mentally retarded 1940-1970 with particular focus on responsible of care N.E. Bank-Mikkelsen and the development of the state care of the mentally retarded)*. Forlaget SocPol, Holte 2001.
Birgit Kirkebæk: *Letfærdig og løsagtig – kvindeanstalten Sprogø 1923-1961 (Improper and impudent – Women's institution of Sprogø 1923-1961)*. Forlaget SocPol, Holte 2004.

ones". The empirical data are medical records, correspondence, the specialist literature of the time, the written productions of the head doctors, etc. The division between normal and deviant is varying in different historical periods. People who in relation to the ideas of eugenics were perceived to be a threat to society behaviour wise and reproductively in the 1920's and -30's were in the 1950's and -60's presented as victims of poor wisdom in past times. But only sporadic changes were made in the practical settings where dependent people were placed. I will claim that the traditional logic of institutions, and domineering of people who are dependent on others persist today across buzzwords of our times such as inclusion and broadness.

This matter becomes particular evident in relation to my disability historical research about individuals who were previously diagnosed as people without hope of improvement. These were individuals with multiple disabilities, cerebral palsy, autism, severe movement disorder, Down's syndrome and psychiatric disorders who in my data from the institution Karens Minde were categorised as unteachable[6]. Not only were the "unteachable" denied opportunities of education, learning and occupation, they were also perceived as people without personal thoughts and emotions – as people who should only be cared for and disciplined.

How do the positions of the social model relate to this issue? It is evident that the hazards of the medical model pointed out by activists in Lancaster, in my material are made visible by professional attitudes that imply talking about "differentness" as a medical reality that does that a person's behaviour can readily be linked to his or her diagnosis. It also becomes clear that economical and treatment resources were spent on those who were considered to be likely to respond to treatment. Most evident is it that the professionals don't find it to be worth the effort to produce words about those who are given up on. The records for the "untreatable" are quite thin. My point is that these people were silenced out of their existence, and it is even more brutal to be made invisible that to be disciplined.

The implicit message that arise from my disability historical research about "the invisible ones" is that human worth can be put into a hierarchy, and that it is the

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[6] Birgit Kirkebæk: *Uduelig og ubrugelig. Åndssvageasylet Karens Minde 1880-1987 (Incapable and useless. Institution of the mentally retarded Karens Minde 1880-1987)*. Forlaget SocPol, Holte 2007.

borderland between normal and deviant (as it is defined in the given historical period) that professional, economical and public effort and attention is directed. Among the activists of the social model, the same tendency seems to unfold. I believe it is a problem that persons with severe mental and multiple disabilities are invisible in the activities and discourse of the social model. I believe that the activists of the social model should feel solidarity with people who are in lifelong dependency of others due to multiple disabilities and lack of spoken language. For these people the issue is basically to be perceived as a human being with thoughts, emotions, preferences and experiences, while issues with accessibility is a less prominent problem.

The invisible body

"I would join with the disability rights movement in demanding systems of care and support which maximise independence and choice, and minimise abuse, neglect and paternalism. Yet I am sceptical as to whether the independent living model can achieve all its advocates hope for. Further, I believe not only that dependency is inextricable from human existence, but also that many disabled people have needs which will inevitably generate forms of ongoing dependency which exceed typical time-limited dependencies", Tom Shakespeare writes[7].

For persons with multiple disabilities, the issue of the body is extensive. Reduced movement, reduced opportunity for sensory input, epilepsy, and continued physical dependency of care is a reality for the person as well as for the family/relatives. This is why I think it is important to involve the body. Based on among others Merleau-Ponty, the body has to be taken into account in the social model on more than a dichotomic level[8].

The Norwegian philosopher and special pedagogue Solveig Reindal believes that 4 important claims have to be considered. These are:

1. Disabilities are biological and physical realities of the body
2. Disabilities limits the individual in a) the personal and b) the social area

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[7] Tom Shakespeare: *Disability Rights and Wrongs*. Routledge, London and New York 2006: 136

[8] Maurice Merleau-Ponty: *Kroppens fænomenologi* (*Phenomenology of the body*). Det lille Forlag, Frederiksberg 1994

3. There are social barriers
4. The social barriers create doubts in relation to following one's goals. They are social barriers that have a restraining effect (discriminating)[9].

Reindal proposes a social *relational* model as a starting point for understanding impairment in special education. This model looks at the individual in a context between two sides. One the one side there are biological and physiological realities of the body, and (as a necessary condition) personal and social limitations as experienced due to reduced functioning. On the other side there are (as a sufficient condition) material and cultural social barriers and the experience of social barriers that are discriminating and restraining.

Because the model distinguishes between personal limitations in social relations and social restrictions that are applied due to the disability, it becomes possible to talk about including and excluding processes within special education. *"When using a social relational model, it is possible to recognise the importance of the effect of the disability and find compensatory solutions and adaptations, without being criticised for viewing impairment as an individual problem"*, Reindal writes (2007, p. 52, own translation).

Applied social restrictions that result in violation of freedom of speech and participation in the public life is in this connection individualising of problems, lack of professional understanding of the importance of relations for learning opportunities, lack of alternative ways of communicating, and lack of understanding of the significance of time and space to unfold own ways of acting together with others.

Below the development of interventions in relation to persons with cognitive disabilities is outlined stating the theory that is the starting point for the actions unfolding in practice. This outline shows how persons with cognitive disabilities have been perceived at different times in history and how theories about "them" have unfolded in practice. From 1970-2008 two different paths seem to be forming. One of the paths is

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[9] Solveig Magnus Reindal*: Funksjonshemming, kroppen og subjektet. Noen grunnlagsproblemer innenfor spesialpedagogikk (Impairment, body and subject. Some fundamental problems within special education)*. Fagbokforlaget, Bergen 2007.

close to the ideas that are the foundation of the social model. The other path is associated with the positions of the medical model:

1855-1880: Care and learning
Theory: It is possible to heal or improve the condition of the retards
Practice: We have to offer pedagogical intervention compared to the previously untreated.

1880-1950: Sorting and classification
Theory: It has to be determined who it is worth the effort to consider for intervention, and who has to be considered incurable and unteachable.
Practice: The professional resources have to be limited to those who can benefit from the intervention.

1950-1970: Normalisation
Theory: We have to think generally about normalisation, equal status and human rights.
Practice: Everyone can learn. Services for everyone have to be developed.

1970-2000: Training and adaptation	vs.	1970-2000: Relation and quality of life
Theory: We have to improve the condition through means of training and adaptation.		Theory: We have to support the person in developing on his or her own premises and life projects.
Practice: Programmed teaching, ADL training.		Practice: Alternative learning programmes, art projects, drama, music, work communities.

2000-2008: Specification and evidence	vs.	2000-2008: Critical science
Theory: We have to make special education scientific. Practice: Reviewing “best practice”, use of standardised methods and manuals.		Theory: We have to examine practice critically and scientifically. Practice: Action research.

The insights of the social model place themselves in relation to the positions of relation and quality of life and critical science. In practice, this means that distance has to be made from training and adaptation programmes where others define what the good life is. Distance also has to be made from readymade learning manuals to be used with certain diagnoses.

The invisible practice

People with multiple disabilities can rarely express discomfort with being research objects. They cannot through means of spoken language object to how others perceive them, and they are often denied their actions to an extend that makes it difficult to change the situation. They cannot protect themselves against discriminating interventions, and they are therefore entirely dependent on how parents and professionals view their caring job, and on how the discourse of their situation is unfolded, e.g. by the advocates of the social model. Most persons with multiple disabilities move as adolescents or adults to institutional-like living arrangements. According to Tom Shakespeare’s “matrix of caring arrangements”, “residential care” might represent time together with others, but there is no opportunity to choose who one wants to be together with, there is a high degree of dependence, routines, lack of private life, deprival of responsibility, but obviously also security[10]. Practice towards persons in this situation can be characterised by a high degree of invisibility, unless scandals reach the public through the press which has been the case in Denmark in 2007. In this case, recordings with a hidden camera showed demeaning and degrading professional treatment of persons with severe disabilities in residential living units for adults. Such

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[10] Tom Shakespeare: *Disability Rights and Wrongs*. Routledge, London and New York 2006: 149

episodes have to lead to reflections about how lifelong dependency can be handled in a decent and humane way. Tom Shakespeare cites a mother for the following statement: *“Once we stop ignoring dependency, then we are obligated to think of how dependency needs are met in a manner that is equitable to all”*[11]. But it also has to lead to reflections about how we through augmentative and alternative forms of communication (AAC) can facilitate expressive communication of these persons.

It has to be negotiated with the persons who will be using augmentative and alternative communication, which processes they wish to be part of, which communication aids they feel comfortable with, which type of symbols they believe is best for them, and which experts they think they will need in the development of their life project. When this is not possible through means of spoken language, we have to try to reach a common understanding using nonverbal communication and those communications aids that are accessible.

Concepts such as “assessment of communicative competence” and associated terms like “early stimulation” and “adapted learning” may send out the signal that it is the child (or adolescent or adult) alone who has to be stimulated or trained. These concepts can lead us to think that if only we intervene early enough and if only we train persistently enough, we will achieve the best possible result.

My belief is that this might not be the case if we consider *abilities as explanations* rather than *relations as explanations*, if we talk about *transferring* of meaning rather than *joint creation* of meaning, if we consider *adaption and training* as more important than the *person’s own development project*. In the understanding of the concept of development is the learning project of the person, the creation of the person’s identity through his or her own actions, the building of a person’s self-esteem through acting in a spirit of community and with the fundamental concepts of democracy: freedom of speech and participation in public life: to be able to express oneself – and to be listened to with respect.

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[11] Ibid.: 144

The project of democracy does not start with words, but with reading of body language, facial expressions, and attitudes. The child has to be seen and respected from the beginning. Later on augmentative and alternative communication aids can become significant through joint acting. This project requires knowledge and certain attitudes.

The criteria that one has to consider are as follows:

- *Context* (social and material conditions, opportunities and challenges, personal conditions)
- *Experience* (the experiences of the individual that can be predominantly positive or negative, does one feel hopeful or powerless, does one have positive expectations of the future)
- *Relation* (the quality of accessible relations, the attitudes one is met with)
- *Confidence* (does the interaction partner trust that the person with disabilities has something to say and communicate, is there a will to find a way to communicate)
- *Knowledge* (does the interaction partner have knowledge about and experience with communication that is based on facial and body expression and nonverbally among people in general, and does the interaction partner also have specific knowledge about how communication can be facilitated through a combination of bodily based and aided communication in relation to exactly this person)
- *Empathy* (can the interaction partner identify what is important to the Other, and does he or she make an effort to accommodate to this, in communication as well as in choice of assistive communication aids)
- *Curiosity* (is the interaction partner open towards new things that the other person thinks about, expresses, attempts to do – without stopping new initiative beforehand)

When it comes to attitudes, it is crucially about being seen and brought out of invisibility. Here the advocates of the social model can do an important job by showing solidarity with those who are traditionally ranking at the bottom of the established disability hierarchy by making these people a part of the joint political and research project. Otherwise, people with severe disabilities will remain invisible – within and without the antidiscrimination movements.