

Introduction to the special issue: Understanding disability

By Jan Tøssebro

In everyday communication, disability tends to be seen and used as an unproblematic concept. ‘Everyone knows’ what it means – and what ‘everyone knows’ tends to be some version of a biomedical perspective. According to this perspective, disability is about a body with functional limitations, and it is caused by a health condition (a disease, disorder, injury, etc.) The political and professional conceptualisation of disability has also traditionally been based on this way of thinking.

The biomedical perspective has by now been challenged for years, and increasingly so. In 1967, a Norwegian White Paper argued that there was a need to shift focus in disability policy: not solely to address how to change disabled people so that they cope better in their environment, but also the other way around, to change the environment to fit people with impairments (St. meld. 88, 1966-67). And this actually taps the essential point of the growing criticisms: the biomedical perspective fails to take due

account of the environment. The fact that stairs are disabling people that cannot walk is a simple and almost emblematic example of the changing perspective.

What has taken place, is an ‘environmental turn’ in the understanding of disability. This change is evident in social science, policy documents in many countries, and also papers from international bodies, such as the UN (for example the “Standard Rules”, UN 1994) and the WHO (cf. for example the *International Classification of Functioning, Disability and Health*, WHO 2001). The change is less evident in everyday communication and ‘man-in-street’ conceptualisations.

The environmental turn does, however, not take the shape of one single model or understanding. It is more like a family of ideas. Within this family of ideas, there are weak versions, more or less like human ecology models. In such models the person-environment interaction – the relation between the

person and his/her man-made environment – forms the foundation for the conception of disability (earlier called ‘handicap’ in documents from international bodies). In Norway, disability has been defined as “*a mismatch between the person’s capabilities and the functional demands of the environment*”¹ or in terms of a gap between individual functioning and societal/environmental demands. Disability is thus a relationship, and it is relative to the environment. It is also situational rather than an always present essence of the person: A blind person is not disabled when speaking on the telephone, and is exceptionally able when the lights have gone out. This relational/relative understanding of disability is fairly typical of the definitions in contemporary political documents in the Nordic countries.

The so-called ‘social model of disability’ is a stronger version. I use ‘so-called’ since some would hold that there are more social models, and that the whole environmental turn is somehow social (cf. also Shakespeare in this volume). However, according to what Shakespeare calls the ‘strong social model’, disability is not just a person-environment relationship. The disability itself is caused solely by the environment. Disability is a consequence of a society that is not adapted to all people. The man-made environment is systematically creating more barriers for certain population

groups, such as people with impairments. Within such a perspective, human variation (including the fact that some people are impaired) is taken for granted. The political challenge is to change the environment in order to create equal opportunities for larger portions of the human variation – to recreate the environment in order to ‘fit’ more people.

The differences between the perspectives are of more than academic interest. The implications for policy are substantial, at least as it can be derived from the extreme positions. In a pure biomedical perspective, disability policy is about prevention and/or treatment (medical, psychological or educational) of the individual, and if this is not possible, the construction of special environments. In the social perspective, the point is to change the environment, and in particular, the man-made parts of it.

*

As already noted, the Scandinavian approach has tended to be a relatively weak version of the environmental turn. However, gradually the largely UK-based (strong) ‘social model of disability’ has become more influential. In Scandinavian debates on the understanding of disability, the ‘social model’ has gained a position more or less similar to what Latour (1987) calls ‘an obligatory passage

point': You have to discuss it before moving on. You do not necessarily have to agree, and many people don't. Most people in the Nordic countries tend to stick to a version of the human-ecology model. But nevertheless, people are usually expected to address, refer to, discuss and show familiarity with the logic of the strong version.

I guess one main reason for the growing importance of the (strong) 'social model' in the Nordic countries, is that it drives home the main point of the environmental turn much more efficiently than other versions. The role of the environment in the causation process is very clear, and the same goes for the political implications. If one really takes the human variation for granted, the environment is the problem. And if the environment is the problem, lack of accessibility, for instance, is at odds with important principles, such as equal opportunities.

But on the other hand, many would, for different reasons, argue that to rule out the individual body and the functional limitations completely, is to overstate the point. One argument would be that the social model overestimates what can be accomplished by environmental changes, for instance for people with severe cognitive disabilities. In disability rights terms, the social model also appears to be better suited for accessibility and anti-discrimination legislation, than types of legislation where eligibility criteria will have to

play a role. Another more formal argument is that in the social model, disabled people are by definition discriminated against. Disability does not *lead to* fewer opportunities, it *is* fewer opportunities. This means that disability becomes an outcome concept, and that there will thus be an urgent need for a new concept, making the following question logically adequate: Does disability (or impairment) lead to fewer opportunities/ poorer living conditions?

*

The suggested state of affairs is the background of this special issue of the *Scandinavian Journal of Disability Research*. It was also the background for setting up a plenary roundtable at a conference organised by the *Nordic Network on Disability Research* in Reykjavik, Iceland, in August 2002. The organisers invited four people to speak at the round-table; two UK scholars (Shakespeare and Thomas) and two from the Scandinavian disability research community (Söder and Tøssebro). The UK scholars are not typical 'social modelists'. They are known to be supportive of the social model, but not without reservations, objections and alternative and/ or complementary ideas.

The contributors at the round-table in Reykjavik were all invited to contribute to this special issue of *SJDR*, myself excluded. As the editor

of *SJDR* I found editing the issue a more proper role than to invite myself to contribute. In addition to the roundtable participants, two other Scandinavian social scientists were invited to contribute to the special issue (Gustavsson and Michailakis). Unfortunately, Söder was not able to accept the invitation within the deadlines for this issue.

The background of the roundtable and this special issue was, as suggested above, the UK vs. Nordic versions of social models or environmental turn. However, the profile of the publication is intended to be an open-minded appraisal of the understanding of disability. The authors address the issue from different points of departure and raise different possible new routes for the social science debate.

In the first article, Shakespeare presents and discusses the main accomplishments of the 'strong social model', and also the more recent main points of critique. He questions the very absolute distinction made between disability and impairment and argues that there is a need to bring in the psycho-emotional aspects of both impairment and disability. His conclusion is a plea for a social theory of embodiment.

The main point of Thomas is to strengthen the social relational dimension of the social model. Her use of relational should, in this context, not

be mixed up with the relational aspect of the typical Nordic approach (a relation between person and environment). Her concept is more linked to power structures and relations between social groups, analogous to, for instance, class structures. She is thus arguing the case for a political economy of disability, and more generally, the analysis of power relations involved in the impairment/non-impairment distinction. Her main point is that the social model from the beginning had this social relational kernel, but that it has gradually been overshadowed and should be brought back in.

The third article, by Michailakis, turns many of the typical conceptions upside down. His point of departure is Luhman's sociological systems theory. The main question is; from the perspective of systems theory, how is disability to be understood? He stresses the role of communication in interaction systems and also that disability reflects the observer's point of view. He argues that disability cannot be physically located in individuals, but rather in communication.

Anders Gustavsson's point of departure is a review of recent disability research. The main point is to scrutinise the role of theory and contributions to new insights and perspectives in the existing body of research. In this context, he discusses

Understanding disability

different versions of the Scandinavian understanding of disability and how this can contribute, both to the theoretical and empirical sensitivity of disability research.

The editor wishes to express his gratitude to all participants – both at the Reykjavik round-table and in this publication.

Notes

¹ “Funksjonshemming er et misforhold mellom individets forutsetninger og miljøets krav”, Regjeringens handlingsplan for funksjonshemmede (Government’s action

plan for disabled people, Norway) 1990-1993, p 6

References

- Latour, B. (1987): *Science in action*. Milton Keynes, UK, Open University Press
- Stortingsmelding (White Paper) no 88 (1966-67): *Om utviklingen av omsorgen for funksjonshemmede* (On the development of services for disabled people). Oslo
- UN - United Nations (1994): *The Standard Rules on the Equalization of Opportunities for People with Disabilities*. New York, UN
- WHO- World Health Organisation (2001): *International Classification of Functioning, Disability and Health*. Geneva, WHO