A HISTORY OF DISABILITY

Henri-Jacques Stiker, The University of Michigan Press,1999

Is the book already a classic?

At the University of Bergen, I have been participating in a social science research group on disability. Some years ago we held a seminar on the book *Disability and Culture*, edited by Benedicte Ingstad and Susan Reynolds Whyte (University of California Press, 1995). In the concluding chapter, Whyte introduces the ideas of Henri-Jacques Stiker. Whyte outlines the important contributions of Stiker's historical discourse perspective on disability. Our research group was excited to hear about Stiker's work, but unfortunately it was only published in French, a language none of us was able to read at an academic level.¹

Our research group in Bergen was not the only group of disability researchers to be enthusiastic about Whyte's presentation of Stiker. When the book edited by Ingstad and Whyte was reviewed in the journal *Disability and Society*, more than half of the review was about how valuable it was to have a presentation of Stiker's book. Not a particularly polite way of treating the very interesting book edited by Ingstad and Whyte, but I could perfectly well understand the enthusiasm of the reviewer.

For years I have waited for an English translation of the book. Last year it was brought to my attention that a translation had been published in 1999, by the University of Michigan Press. Full of expectations, I finally received a copy. And after reading it, I was not disappointed.

What is it about?

Stiker's work is a huge project. He has set out to study how disability as difference has been constructed through the ages of western civilisation. His sources are various types of documents, including genres as diverse as myths, literature,

¹ Our research group has recently had a thorough discussion av Stiker's book in the English translation. I am in dept to Jan Froestad who significantly furthered my understanding through his presentation of the book in a seminar we held on classical texts in the study of normality and deviance.

governmental documents, and sociology texts. His project is heavily inspired by Focuault's studies on the histories of knowledge. But where Foucualt is concerned with the archaeology of knowledge, Stiker sets out to study "semiotics of cultures" (p. 20). And as he points out, physical disability is a whole continent left unexplored by Foucault.

The book focuses on five historical arenas: The Bible, The Antiquity, The Middle Ages, The Classical Centuries and the Modern Age of Rehabilitation. There are numerous fascinating discussions of processes taking place during the earlier periods, and the different parts of the book expand in size as we come closer to the present. The main point of the book is how the modern rehabilitation period represents a break with the earlier ages. Disability was recognised as a difference that was part of human nature in the earlier periods, for better or worse. In the rehabilitation age, disability is a status that is treated as temporary. The goal for everyone is inclusion in what is considered normal. In earlier ages, difference could mean death, and was by this in Stiker's terms 'overvalorized'. In the rehabilitation age, difference is 'undervalorized' because it implies disappearance in the regimes of normalisation ideologies.

A History of Disability was originally published in 1982. A new edition was published in 1997, with some minor additions from the author. It is the 1997 edition that is translated to English, with a foreword by David T. Mitchell. The 1982 edition appeared before important disability studies publications such as Deborah Stone's *The Disabled State* and Mike Oliver's *Politics of Disablement*. It is impressive that Stiker already in 1982 made some important and central points, which I had previously believed Deborah Stone and Mike Oliver were the first to introduce to disability studies. This includes both tracing the history behind the construction of the category disability by the welfare state (Stone), and the contrasts between the acceptance of difference and normalisation policies (Oliver).

Why is it important?

Stiker's analysis of the rehabilitation era as different to earlier epochs is of great importance to the understanding of our present thinking about disability. The Bible sees the abnormal as a part of what is human, as a consequence of the fall of man. All Christians are ethically obliged to help. During the period of antiquity, a division was made between sickness and abnormality. The abnormal had no place among human beings, and represented the wrath of the gods. In the Middle Ages, variation was looked upon as a part of God's plan. The abnormal was part of human nature, though those labelled normal were poor and marginal. The classical period, with its growth of science, included important developments in the direction of rehabilitation and education. One example is sign language among the deaf, which was introduced in this period.

The important break happened after World War I. Most historical studies on the construction of disability point out that work-related injuries were the starting point of the modern welfare state and disability allowances. Stiker agrees with this as an important factor, but Stiker's original contribution to the understanding of the historical construction of disability is pointing out the importance of the

veterans of World War I. A vast number of soldiers were wounded and had lost bodily functions. When society returned to normal, the concept of rehabilitation emerged. The infirm should be reintegrated into the economy. What then gradually happened was that the rehabilitation discourse, which at first only related to war veterans, was extended to include all disability groups. People earlier having a position as different, became someone for whom a place in ordinary social roles was expected.

Stiker does not argue that rehabilitation and integration are to be avoided. What he sets out to do is to recognize that discourse for what it is: that Western culture cannot tolerate deformity and difference. The disabled person is expected to imitate the able. He or she has to catch up with the normal. Society is competitive, the disabled person has a burden, and this burden has to be overcome, in order for the disabled to reach the goal of everyone being identical. It is important for Stiker to point out that rehabilitation is about 'making identical' without 'making equal'. Social and economical disadvantages are not altered.

The use of stigmatised categories in the struggle for recognition among disadvantaged groups is one phenomenon that Stiker's perspectives help shed light upon. Psychiatric patients call themselves *mad*, physically disadvantaged people use the word *cripple*, the term *deaf mute* is introduced among activists in the deaf movement, and *Mongo* has been introduced to refer to people with intellectual disabilities in Scandinavia. What these terms do, apart from to stigmatise, is to represent difference. The rehabilitation regimes have not allowed difference to flourish, and difference-related concepts have survived only in spaces of harassment. Today, with growing awareness of the suppression by rehabilitation and integration ideologies, archaic and stigmatised concepts are again taken into use. In an empowerment process, the disadvantaged disabled parody established discourses by deliberately using labels banned and stigmatised in rehabilitation discourse.

An essential part of Stiker's book is the normative standpoint he takes in favour of difference. He clearly states that the celebration of difference is a path to human life, and the passion for similarity is a potential for social violence leading to repression and rejection. In the field of disability, this brings his analysis close to Mike Oliver's question of *Normality or difference?* In a broader social field, his perspective is also related to Zygmunt Bauman's analysis, describing modernity as the era of standardisation and similarity, which also led to the Holocaust, and post-modernity as an emerging era dominated by the slogan '*Difference is beautiful!*', and representing a promising potential. In the 1982 edition, Stiker was optimistic concerning social processes taking place at the time, mentioning the anti-psychiatry movement as a prime case. In his 1997 revision, he expresses disappointment that so little has happened. With regard to this point, I believe he is perhaps not as updated on international disability discourses as one would expect for a disability studies scholar.

Are there any weaknesses?

In my opinion, there is one important weakness. In his 1997 revision, Stiker is poorly informed about what is going on among disabled people. In the first French edition from 1982, Stiker pointed to the anti-psychiatry movements as promising. They advocated a protest against rehabilitation and normalisation, and celebrated the irrational as an important part of social life. In the revised French edition from 1997, which the English translation is based on, Stiker is much more pessimistic, mentioning that the potentially revolutionary anti-psychiatry movements have vanished. And he sees no other trends that weaken the normalising rehabilitation regimes.

What Stiker points out was happening in 1982, is that the disabled challenged integration and rehabilitation. "We want *our place*, and not a place that have been designated for us, similar and different, equal and different, disabled but able (valid, valorised, validated)." (p. 188) In my opinion, this is exactly the direction deaf people have been moving toward for the last 20 years. They demand recognition as different and able. Some deaf people even challenge the adequacy of the concept of disability, and instead pursue a reinterpretation of disability not as a defect, but as a characteristic of the body similar to skin-colour or sex. This is a strong international movement, and was as a model by other disability groups. This is not recognised by Stiker in his 1997 pessimism. For example, a movement apparently not known to him is the US/Canadian Mad Nation, which has radicalised several of the ideas introduced by the anti-psychiatry movement in the 1970s.

Is there inspiration for further studies?

Stiker's book focuses on the history of ideas. His purpose is to theorise. The book is not a concise history of the western disability category. It is a challenging identification of a present paradigm pursuing non-difference, and an exciting outline of the traces of this hegemonic discourse. Stiker points out that the history of rehabilitation could have been done with much more empirical detail. Such an approach could have been easier to follow, but would have made it more difficult to understand the idea of rehabilitation.

I find Stiker's theoretical focus to be a rewarding approach. For future studies in the history of disability focusing on specific institutions or certain disability groups, *A History of Disability* can serve as an important theoretical point of reference. In my opinion, all studies of disability, past or present, can strengthen their analysis by bringing in Stiker's critical perspectives concerning the idea of rehabilitation. In all social science, a main challenge is to take a critical and independent position in relation to concepts and discourses that have become part of common sense thinking. Through a social scientific study, the obvious shall be less obvious. This goal is more than fulfilled by Stiker's study of the history of ideas about disability.

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PÅ NÄRA HÅLL ER INGEN NORMAL. HANDIKAPPDISKURSER I SVENSK TELEVISION 1956-2000.

[AT CLOSE QUARTERS NO ONE IS NORMAL: DISABILITY-DISCOURSES IN SWEDISH TELEVISION 1956-2000].

Karin Ljuslinder Doctoral Thesis, University of Umeå, Sweden, February 2002.

Introduction

Very few studies have been carried out in Scandinavia about the representations of disability in television. What we know about the representations or portrayals of disability and disabled people in this media is largely based on American research. This is unfortunate, since Scandinavian and American television is hardly compatible. What characterizes Scandinavian media is the remarkably strong position of public service channels, while commercial channels heavily dominate American television.

It is therefore with pleasure we welcome Ljuslinder's dissertation about the representations of disability and disabled people in Swedish public service television. Empirically, it is a comprehensive and an ambitious project Ljuslinder has taken on, in that she covers the entire history of Swedish public service television (SVT), from 1956 to 2000. She has registered and examined all TVprograms with passages related to disability or disabled persons produced by SVT1 and SVT2 throughout the whole period, which adds up to more than 2000 programs and over 40.000 broadcasting hours. The registration is mainly based on STV's own program descriptions for the full period, and video copies of all programs related to the issue. To avoid some of the possible errors caused by insufficient program descriptions, or systematic features of SVTs description practices, she also includes several samples drawn from all programs sent in certain periods. The material has been examined from several angles and perspectives, using both quantitative and qualitative strategies, including the extent of representations in different periods, their socio-historical contexts, as well as the content and form of the representations. The main approach has been discourse analyses, especially in the version of Laclau & Mouffe. Ljusinder has also compared the outcome of the analysis with official attitudes and policies as these are expressed in social legislation on the one hand and in the formal broadcasting agreement between the Government and SVT on the other.

Public service media and the implementation of Swedish disability policy

As public service organizations, SVT1 and SVT2 are obliged to follow certain instructions and directives from the government, which give them an obligation, for example, to see that the programs as a hole are in compliance with the principle that all people are of equal value, and have the same right to freedom and dignity. SVT has also signed a special agreement with the Swedish government, in which the public service channels have agreed to take into consideration the different needs of disabled people. Programs should be accessible to people with various impairments, and some programs should also be more specifically designed for and directed to certain groups. One of the questions Ljuslinder raises in her dissertation is which role public service television plays in the implementation of Swedish disability policy, or how representations of disability in the public service channels are in compliance with goals and principles of Swedish disability policy. Not surprisingly, her conclusion is that, even though SVT is trying to promote national disability policy goals, the effect is rather the opposite. To some degree, this has to do with the fact that national policy goals typically are very idealistic, which makes them quite difficult to implement, and to assess. This is why evaluations of the implementation of national policy most often come out negative.

But it has also to do with the characteristics of TV-media as such, with how national policy goals have been interpreted, and how they have been transformed through the journalistic and esthetic standards and alternatives considered as available or proper. This brings us to the most interesting part of the analysis.

The longing for normality

So, how are disabled people and accounts of disability represented in Swedish public service television? How does TV conceptualize and give meaning to social labels like disability and disabled? First of all, passages with reference to disability and disabled people in SVT1 and SVT2 have been quite rare. Issues related to disability are represented in less than 2 hours per thousand broadcast hours (2.2 h in 1976, 1.6 h in 1986 and 1.7 h in 1996). But it started from nearly zero. In the 1960s, accounts of disability were represented in less than 1 minute per thousand broadcast hours.

According to Ljuslinder, it is also rare that disabled people are portrayed without any reference to the disability. When disability and disabled people are represented in Swedish public service media, it is most often because disability in itself is a main theme. At the same time, the most common representations of disability and disabled people are the representations of *normality*. It is most often a normative and hegemonic concept of normality that is expressed, i.e. normality is what is regarded as normal (or culturally normative or desired) in a certain culture at a certain time (represented by TV-journalists, who are always non-disabled!). The focus is most often on what disabled people manage to do *despite* their disability, or what society *makes it possible* for them to do by providing them with assisting technology. Ljuslinder suggests that this "making it possible" seems to be linked to a kind of all-embracing eagerness for normality. Ironically enough, in aiming at portraying disabled people as normal, these representations most often tend to underline the *abnormality*.

One important reason for this, according to Ljuslinder, is that the body serves as the major marker of disability. The abnormal or incomplete body becomes the focus of television representations. In communicating normality, despite the bodily artifact that underlines the abnormality, the representations serve to preserve the non-disabled myth of the normal being the shared norm, something everybody desires, and that the main character of disability is the lack of normality.

In her discourse analyses, Ljuslinder draws heavily on Laclau & Mouffe's *Hegemony and Socialist Strategy* (1985), in which they develop their most important concepts and analytical tools. Their concern is to show how language plays an important role in the forming of political conflicts and matters of dominance in society. Laclau & Mouffe's concepts and perspectives seem adequate and useful also for Ljuslinder's purpose, and help her to see the exceeding relations between articulations in the programs, and the forming of *hegemonic* representations. This represents a both stimulating and promising rudiment of the analysis. A more extensive use of Laclau & Mouffe's theoretical contribution could probably have facilitated an even deeper analysis of the more concrete discursive strategies reflected in the programs, and made the actors more visible in the analysis.

Stereotypes

Another feature of the representations of disability, disablement or disabled people in Swedish public service television is the stereotyped portraits. Ljuslinder says that the television programs fits well with Vladimir Propp's description of structural pattern of folk tales. Even though there is a "risk of confirming, rather than problematizing the excessively simplified portraits", she felt that "the advantage of being able to describe the television-stories in a comprehensible way outweighed the disadvantages" (p. 187). She could easily identify stereotypes such as the heroes, villains, victims and the eternal child.

It is, however, difficult to avoid the feeling that these stereotypes to some extent are *placed on*, rather than *detected from*, the TV-narratives. At least some of the content analyses serve to feed that suspicion. One also gets the feeling that any representation, at least if it was slightly pressed, would fit into one of these stereotypes. This is, however, a common problem in most analyses using predefined categories.

The problem of categorization

A common problem in most disability research is how to define what you are looking for. As most social inquiries these days, Ljuslinder falls in with a constructionist perspective, which, in her own words, means that "the only reality we can get in contact with, is one that, via our language, has passed through our former knowledge and experiences" (p. 184). Social reality is discursively constructed, and so is disability. The thesis contains an interesting discussion of how this represents a problem for the identification of disability, or representations of disability, in the TV-media. This is a common problem in disability research, where the category itself very often is taken as the point of departure. Ljuslinder sees this, and she deserves credit for an honest attempt to manage it, even though it slips away and returns in imperceptible ways. Since this is a general problem, it might be useful to show how it unfolds in this particular study.

Ljuslinder's solution to the problem is what she defines as a pragmatic stand, where she chooses to investigate the representations of what Swedish public service TV itself defines as disability and disabled persons. Thus, the source from where she identifies the programs portraying disability or disabled persons is mainly the STV archive of program descriptions, where she can identify programs that claim to have some reference to disability. The problem arises, however, when she exceeds the scope of STV's own definitions of disability and disabled persons, which she frequently does. For instance, how can she know that representations of disability and disabled persons in Swedish public service television, are rear? The only thing she can positively know is that it is rear to find programs, which, according to the description, have elements of disability. She doesn't know how many times disabled people have participated, or how many passages with reference or relevance to disability there is, in the other programs. Ljuslinder also concludes that; "people with disabilities are mostly represented by their disability, and as representatives of a group" (p.188). But it could very also be the case that it is only when disabled persons are represented by their disability, or as members of a group, that they are labeled in the descriptions.

Thus, in an attempt to control for some of this bias, Ljuslinder includes random samples of programs from certain periods, and even a full program-week in both SVT-channels, to see whether elements of disability were represented even in programs with no reference to disability in the description. The question, then, is how *she* identifies disability or disabled persons? She is now trapped in the categorization problem that she explicitly was trying to avoid. She is doomed to search for cultural images of disability, images that has "passed through her own former knowledge and experiences". To conclude, as she does, that "it is rare that disabled people are portrayed without any reference to the disability", can very well reflect that it is only through such references that she is able to identify disability as a phenomenon. The same goes for the conclusion that "body serves as the major marker of disability". Couldn't it be the case that the categories, or cultural images, which in themselves are based on bodily artifacts, are as much in the eyes of the spectator, in this case the researcher, as they are characteristic features of Swedish public service television?

Conclusion

I have no reason, however, to doubt the validity of Ljuslinder's main conclusions; that most representations of disability and disabled persons in Swedish public service television are representations of a normative and hegemonic concept of

normality; that the effect of such representations of normality most often is the opposite; that the body serves as an important marker of disability; and that it is first and foremost when this bodily represented disability is the prime issue, that the culturally hegemonic image of disability is represented in Swedish public service television. The last conclusion is slightly revisited to make it more consistent with Ljuslinder's own theoretical approach. The risk that some, not so hegemonic images of disability, or appearances of disabled persons where features other than the body serve as the marker, have "slipped through the net", unnoticed, is something that we have to live with. To capture such representations would probably require a more open and inductive research design. It is also likely that a more open and inductive design, with a more limited sample of programs from each period, would have given a more complex picture of the representations of disability and disabled persons in Swedish television, and a clearer picture of possible differences over time.

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