Swedish social disability research: a short version of a long story

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Over the last decades social and behavioural research about disability in Sweden has expanded considerably. The development over the last 40 years can be described in four phases of the development: early initiatives, getting integrated, getting established and late developments. It describes a journey from an activity separated from the traditional university system and mainly occupied by evaluating reforms sponsored by short-term grants to an established academic activity with a broad range of research topic and with a growing engagement in theoretical questions. During the past years, disability organizations have reacted critically as they found themselves having little influence on research that is done, a reaction that includes dissatisfaction with what is experienced as inability of researchers to make research politically relevant. What started in a society with a centralized structure and ambitious social engineering ideal now has to find its role in a more decentralized structure where reform ambitions and the role of social movements like disability organizations are different. To balance the need for autonomous research with the ambition of being politically relevant without falling for the temptation of being politically correct is one of the challenges social disability research in Sweden will have to deal with in the near future.

Keywords: disability research; research policy; relative definition; cross-disciplinary research

Introduction

Over the last decades social and behavioural research about disability in Sweden have expanded considerably. The result of this development can be read in different ways. The number of doctoral dissertations has grown, the resources allocated to this kind of research have expanded and the number of professorships in the field has multiplied (Söder 2005a). In this article, I intend to describe this development, both the content of the research and the reforms and structures that have made it possible. My focus will be on social research, that is, research that in some way relates to environmental aspects of the relation between an individual with an impairment and the surroundings, a relation that may or may not result in a disability. This delineation is not easy to uphold precisely, but my ambition is to cover what internationally has come to be called disability studies. Research that I will be referring to has mostly been done by educationalists, researchers in social work and sociologists. My emphasis will be more on social rather than pure behavioural research. Being a sociologist myself, this has probably coloured my analysis as well as my selection of examples of research. I have no ambition to cover everything that has

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been done over such a long period of time, but will try to capture the most dominant trends and give examples highlighting these.

I will first describe the development of the field chronologically. In doing so, I will describe four phases of the development: early initiatives, getting integrated, getting established and late developments. Of course, such a split in different phases is in itself arbitrary, but it is used here as a construct that can help highlight some major tracks in the development.

Early initiatives

Up till the later part of the 1960s research about disability was, with only some minor exceptions, dominated by medical (clinical or epidemiological) studies. It was not until around 1970 that more systematic initiatives to social research were taken.

One initiative was taken by the organization of parents to persons with intellectual disabilities (FUB). Using money from a nationally organized charity collection, they started a sheltered workshop and group homes for persons with intellectual disabilities. The idea was to create a model of an alternative to traditional institutions. As a part of the project, an ambitious research activity was initiated (the ALA foundation) led by a cross-disciplinary group with representatives for research in rehabilitation, social medicine, education, psychology and sociology. After a few years, the research staff came to be dominated by psychologists (led by the late Gunnar Kylén) who emphasized a holistic and relative perspective on persons with intellectual disabilities. Much of the research concerned ideologies, attitudes and treatment of persons with intellectual disabilities as well as their cognitive development.

At roughly the same time, another group of psychologists was established in Uppsala under the leadership of Lars Kebbon. This group (the MR group) studied the services for persons with intellectual disabilities explicitly applying social psychological perspectives, emphasizing the relative nature of the disability. Much of their research focused on deinstitutionalization, and the group did several studies of alternative 'open' forms of services such as day activity centres and group homes. These studies were financed by national state authorities.

The ALA and the MR groups mainly focused on persons with intellectual disabilities. Research was also initiated concerning groups with other impairments (death, visually impaired and mobility impaired), but then mostly by single researchers in response to demands from authorities. Much of this research focused on evaluating school integration, a consequence of the dismantling of segregated institutions for special education that were starting in the 1970s.

The majority of the early initiated research projects were funded by state authorities based on their needs to evaluate reforms that were taking place at the time. In that way young and engaged researchers were drawn into the field. But their situation was unsafe as their careers depended on 'soft money', short-term grants for highlighting rather limited and empirical questions posed by authorities responsible for reform activities.

A dominant political perspective on reforms at the time was the idea of social engineering. The building of the welfare state, or the 'strong society' as it was often phrased, should be done using scientific methods to investigate social problems, form a solution that could be implemented and then evaluate that reform. Researches were drawn into this process which also meant that their research was heavily influenced and steered by the needs of the reformer. Gustavsson and Söder (1990), critically

examining this development, meant that researchers were caught in the reformers' perspective, thus avoiding to pose more theoretical and critical questions which included scrutinizing the basic assumptions of the reformer.

Getting integrated

In the perspective of the social engineering, research, and especially social research, should support the welfare state and its reform ambitions. In the early 1970s, this was the motive for a reform in research policy that introduced the idea of research being organized in different sectors that was defined in relation to different policy areas. Different departments at the government office were to allocate money in order to promote research considered relevant for their field of responsibility. At the Department of Social Welfare responsibility for allocating research money was given to a committee (Delegationenför social forskning, DSF) where politicians, research-ers and different interest groups were represented. One of their prioritized areas was disability research, and they formulated a programme where the need for disability research was articulated. In this programme, four areas were given priority: factors that transformed impairments into disabilities, effects of welfare measures, language and verbal communication, effects of rehabilitation and treatment.

At roughly the same time, this problem was articulated by organizations of/for persons with disabilities. Besides wanting more research with social perspectives, they stressed that such research needed a more long-term financial basis as research done so far had to rely on short-term 'soft' money.

Another actor at this time was Swedish Council for Planning and Co-ordination of Research (Forskningsrådsnämnden, FRN), an organization with the main task of supporting research of an innovative and cross-disciplinary nature that was at risk of being neglected by other financing bodies. Disability was considered being one of those areas. FRN developed a special programme for supporting disability research and organized a special committee for allocating money to the research considered to be in line with the programme. When evaluating different applications from disability researchers, a strategy was developed where the quality of the applications was evaluated by other researchers, while its relevance for the disability field was left to the disability organizations to judge. FRN was also given the responsibility for coordinating research about disability.

The International Year of Disability, 1981, also had an influence on research in Sweden in two ways. First, the UN had recommended that all nations should try to adopt the terminology proposed by WHO in their 'International Classification of Impairments, Disabilities and Handicaps' (ICIDH). In Sweden, this leads to a discussion of terminology in general and the relative concept of disability in particular, as it had developed in Sweden (Söder 1988). Seminars were arranged and several researchers got engaged in this discussion. Second, as a part of the activities organized during the International Year of Disability, the government sponsored a reader that introduced Swedish research about disability. The majority of contribu-tion came from researchers with a social perspective, and the book became the first overview of disability research in different areas from the last two decades (Strachal 1981).

During the 1970s, there were thus several initiatives taken. Disability research received growing attention within social policy and research policy. Disability organizations became active in lobbying for more research. This attention created

growing opportunities for researchers to get funding, but the total amount allocated for disability was so far very small in comparison with other research areas, and many of the problems identified, like short-term funding, the dominance of medical and technical research, etc., still remained.

The social research in the disability filed that was funding during this phase was dominated by psychologists and researchers in education. Also disciplines like sociology and social work were represented, but so far to a lesser degree. The research that got funding was still for the most part focused on evaluating and studying the implementation of reforms, a tendency that was strengthened by the sectorial organization of research funding.

Getting established

In the early 1990s, the enthusiasm for the 'sector principle' that the state authorities should allocate research money to areas considered relevant for political purposes declined. DSF and other similar entities were dissolved, and applied social research was entrusted to a new body, the Social Scientific Research Council (SocialvetenskapligaForskningsrådet, SFR). SFR was to finance applied research and also got the formal task of coordinating social research in the field of disability.

When DSF was dissolved, some critics asked what would happen to research and research groups that had been mostly financed by DSF. The answer to their worried questions was a declaration from the Ministry of Education that the competence in different field, like disability, that had been built with DSF funding would be transformed into positions within the ordinary university system. In that way two professorships with special emphasis on disability, one in psychology at Göteborgs University and one in sociology at Uppsala University, were created. These were the first professorships in social and behavioural sciences with responsibilities to focus on disability in the country. An institute for disability research led by Professor Sven-OlofBrattgård had earlier been established in Göteborg, but that was under the faculty of medicine.

At about the same time, a Center for Disability Research was established at the university in Uppsala. The centre functioned and functions on a network basis, supporting and stimulating research in different departments of the university. It also takes on an important role in creating arenas (seminars, conferences, newsletters) for communication with actors outside the university like persons with disabilities and their organizations and service providers. It was later to be followed by similar centres at other Swedish universities and colleges. Their main role has been stimulating disability research in different ways, but to a lesser degree to carry out research on their own. An important exception to this is the Swedish Institute for Disability Research (SIDR) that was founded in 2000 as a cooperation between the universities of Linköping and Örebro. The SIDR is the only institution in Sweden that has a graduate programme in disability research. It also performs research on an interdisciplinary basis that covers medical and technical, as well as behavioural and cultural, aspects.

Broadening the evaluative questions

In the new organization of research councils, the overall responsibility for disability research was entrusted to the newly established Council for Social Science Research (SFR).

In the middle of the 1990s, the government commissioned SFR to provide an overview of Swedish disability research. The overview covered behavioural and social research (Hjelmquist, Rönnberg, and Söder 1994). The overview of behavioural research focused on perception, cognition and communication. Although it could be shown that much research concerned research description and diagnoses of impairments, this research was criticized for not linking the results to rehabilitation and intervention. Researchers were either occupied by diagnoses/descriptions or rehabilitation/intervention, but few research groups were successful in combining the two. When it comes to research about different compensatory mechanisms, it was found that research was broad and varied and also at the forefront internationally.

But more in line with the ambition of this article is the overview of social research. The report identifies several trends in social disability research. Two of these can be understood as a development and deepening of the first wave of evaluative studies of integration and deinstitutionalization reforms. Several of these studies showed that integration had mainly been of a physical type, mixing disabled with non-disabled person without any meaningful social integration. That led to an interest for social relations and how interaction between disabled and non-disabled persons works. Studies were, for example, done on how blind children interacted within their seeing friends in preschool environments (Jansson 1993), how monaural deaf people managed their disability in interaction with others (Hansson 1993) and how persons with different impairments dealt with other people's reactions to their impairments (Söder, Barron, and Nilsson 1991). Gustavsson (1992) attempted to specify the societal preconditions for social integration of persons with intellectual impairments. Using Tönnies' classic distinction between Gemeinschaft and Gesellschaft, he argues that modern societies (Gesellschaft) are characterized by social relations being formed by free choices and not (as in gemeinschaft) by stable local kinship relations. This creates a tendency to reject persons considered different and devalued. Gustavsson proposes this 'natural segregation in everyday life' as a key to understanding why integration reforms do not work as sometimes expected in creating social integration.

Another line that was emphasized as a consequence of evaluative research was what the everyday life situation for disabled persons living (physically) integrated looked like. Some of these projects were done as follow-ups of deinstitutionalization, asking to what extent and in what dimensions the 'new' everyday life differed from that in the institutions (e.g. Ericsson 1993). Other studies have focused on the clash between the rationalities of persons in their everyday lives and the professional understanding of their situation. One example is a study of families with children with diabetes and their relation to professional medicine. Richt (1992) takes his point of departure in what medical doctors usually formulates as the 'compliance problem', that is, the problem of patients not living according to the prescriptions of doctors. By studying the everyday lives of the families, he shows a fundamental clash between the norms of the everyday lives of families and the norms of medicine. Diabetes is simply something else when seen from the family perspective, than the metabolic disturbance as it appears in the clinical perspective.

Both the studies of social relations and the studies of everyday lives had up till the mid-1990s mainly been qualitative and descriptive. To the extent that they have used theoretical concepts, these have been developed through an inductive strategy, giving the analysis an empiric-close character. Studies done as broad surveys of the living

conditions of disabled persons were at this time rare, an indication that disability was emphasized more as a symbolic construction than a material reality.

Codetermination and influence

Individualism and critique of public services as bureaucratic and paternalistic grew strong in the 1980s. The value of individual choice as opposed to bureaucratic regulation was emphasized not least by neo conservatives. This was also mirrored in the discussions and research in the disability field. Consequently, several studies came to focus on the possibility for disabled people to exert influence over their one lives and living situation. Usually, these studies described a situation of powerlessness and marginalization.

In a life story-based qualitative study of the possibilities for persons with severe disabilities to influence their living situation Söder, Barron, and Nilsson (1991) identified three obstacles for that possibility. The first one was professional dominance. In many cases, professionals were described by the informants in positive words, emphasizing their competence and empathy. But in cases where their competence were questioned, which was not an unusual situation when informants had lived a whole life with complicated impairments and knew more about them and their consequences than most professionals, the empathetic professionals often turned into paternalistic dictatorial besserwissers. The second obstacle identified was bureaucratic rules that were implemented in a rigorous and insensitive way. Both these obstacles often combined with the third one, paternalistic attitudes and treatment where the disabled person was treated like an ignorant child.

In the same study, several ideal, typical patterns of influence were identified. Some of them captured marginalization and lack of power, while others described a pattern where disabled persons were capable to a large extent of governing their own lives. One such pattern was named the rebellion situation, where persons with rather severe impairments, knowledgeably and energetically were able to influence their own situation. These rebels had ambitious goals for their lives and a strong individualistic approach. Typically, none of the persons in this situation were members of disability organizations. This way of describing strong individuals that were able to influence their own situation was described in other studies as well. Solvang (1994) in a study of persons with dyslexia in Norway, Sweden and Denmark named it 'self-made mentality', while Ahlström (1994) in a study identified largely the same pattern and described it as 'fighting spirit'.

The studies of power and influence thus presented a dual picture of powerlessness and alienation on the one hand and individualistic strategies of successful steering of their own lives on the other hand. This fitted rather well into the growing emphasis in disability organization on powerlessness as a consequence of bureaucracy and paternalism, and at the same time proclaiming disabled persons' capability of being able to run their own lives.

Historical roots of present situation

An expanding field within disability research during the 1980s and 1990s was historical studies. Many of these studies focused on how disabled persons had been treated in the public institutions. Åman's (1976) ambitious study of the history of different kinds of institutions was pioneering and a source of inspiration for several

studies to come. The majority of these studies are characterized by a search for the roots of present-day institutions and practices and their connection to more general discourses in society, not seldom explicitly inspired by Foucaulian thinking. Söder (1981) studied the ideologies in the care for persons with intellectual impairments, initiatives for special education in the nineteenth century was analysed by Förnhammar (1991), the background for labour market policy for disabled persons by Blomkvist (1990), the development of orthopaedics and its consequences for disabled persons by Holme (1996) and psychiatry and mental hospitals by Eriksson (1989) and Sjöström (1992).

One explanation of the growing interest for history might be that living in a time of rapid changes (including deinstitutionalization, critique of the traditional welfare state and new public management) it feels important to find the roots of what has been in order to be better equipped to understand the present changes and possibly the future.

In the mid-1990s disability research had thus reached a more-established position than before. It had been institutionalized by getting a platform in the university system and could compete rather successfully for external funding. As mirrored in the overview from the social science research council (SRF) social disability research has also left the earlier position of mainly evaluating reforms. The scope of research questions had been broadened, and the evaluative question had been deepened by asking a more basic question on social relations and everyday life.

In terms of method, qualitative methods dominated the field. Findings in these studies seldom led to explorations into broader quantitative studies and were not often interpreted in theoretical terms. The theoretical ambitions were rather low both when it comes to importing theories and concepts from other fields and when it comes to developing more general theories from data.

This impression from the SFR overview was later confirmed by an international evaluation with the task of reviewing the state of disability research in Sweden. In analysing social research, they concluded that the preponderance of research was exploratory or descriptive in nature and found that there was a need for more theory-based work. They also noticed the absence of quantitative studies, using representative sample, in general, and, in particular, they were surprised that researchers did not make use of the rich Swedish registers and data basis (Albrecht et al. 2001). They also remarked that that once disability was integrated into the mainstream academic and funding system, it had to compete with other more established fields for grants – a challenge that might be difficult for a newly established discipline. The international evaluators characterized Swedish disability research as 'an emerging field that needs to be nurtured and developed to reach its full potential' (5). Among the measures they proposed to strengthen the discipline were structures for supporting cross-disciplinary research, increased support for postdoctoral research opportunities, the creation of arenas for dialogue and discussion and increased international visibility.

Recent developments

In the beginning of the new century, the organization of bodies funding research was changed again. A new council was established in 2001 through a merger of the Swedish Council for Social Research and the Swedish Council for Work Life Research. The new research council (FAS) took over the coordinating responsibility

for disability research. It started executing this responsibility by editing a programme for future disability research, partly built on the results of the international evaluation. The committee that formed this programme had representative for all major research councils, and thereby was cross disciplinary representing natural science/technology, medicine/caring science as well as social and behavioural science.

The committee made an ambitious attempt to find out how the costs for disability research had developed during the 1990s. Although the calculations were based on figures with some uncertainty, the general conclusion was that the total amount used for disability research by different research councils has been roughly constant during the last decade of the last century. The main sponsor for social science disability research (SFR, later FAS) had reduced its contribution during the same time. The committee proposed a doubling of the resources that would give priority to some already well-developed themes as well as less-developed that was considered strategically important. The well-developed themes were the same as had been identified by the international evaluation team: research about caring/rehabilitate interventions, qualitative social science research, language and communication and research about hearing impairments. Among the less-developed themes that were considered in need of resources were longitudinal studies, studies about ethnicity, gender and disability, neuroscience research and research about visual impairments (FAS 2001).

The FAS programme gives an indication of what areas of disability research was considered most important at the time, but their call for more resources was only effective to a lesser degree. Instead, the development during the last decade came to be characterized by a growing interest for research among disability organizations, an expanding focus on gender that also led to attention to how different categorical belongings co-varies to form the living situation of disabled persons (intersectionality) and, more generally, more interest in theory.

Participatory research

Disability organizations had, as mentioned above, been an important agent when disability research was being established. But they had, as disability research expanded, became more critical of their own role in this context. When disability research entered the university and became integrated in the academic system, dissatisfaction grew. The organizations wanted a stronger say in what should be researched and also wanted to have better control of how research was done. At least to some extent, this was influenced by disability studies, at this time an expanding field internationally. In disability studies, the distinction between research and social change was not upheld the same way it had been in Sweden, where many researchers saw their role as being 'neutral', investigating reality but not to take steps to influence that reality. To the extent that researchers had served as change agents that had mostly been as evaluators for the social engineers/reformers. They had, though, been rather careful to make the distinction between their role as researchers and the reformers role of change agent.

With a growing interest in disability studies, not least the social model of disability as it had developed in the UK, disability organizations started to voice the need for participatory research where disabled persons should not only be invited to discuss what to do research about or to discuss the results of research, but to also take an active part in the different phases of research. There had been some projects

that were organized to meet those needs, but the mainstream of disability research was still handled in a traditional way.

In a three-year project (2008–2011), disability organizations (Handikapp-förbunden, an umbrella organization for several organizations) have worked on a broad basis to further their influence in social research. Researchers and disabled persons have been discussing relevant topics for research in a series of seminars, courses have been given for raising the competence among members about research and research policy and a doctoral course has been arranged about participatory disability research (http://www.hso.se/Projektbehallare/Fran-forskningsobjekt-till-medaktors-startsida/). The activities aim to formulate a platform for a research policy and influence government as well as the funding research council to give priority to research that content-wise, as well as I regard to methods, answers to the interest of disability organizations.

While the establishing of disability research was based on research that answered to the demands of the welfare state, the scene seems now to be changing with growing demands for a much more participative role for disabled people.

Gender and intersectionality

For a long time feminist research neglected the situation and the experience of disabled women (Wendell 1996). But at the same time, disability research was rather blind to questions relating to gender. Internationally, this double neglect started to crumble away during the 1980s, but it took longer in Sweden. Research about gender and disability started to appear as smaller projects during the 1990s. Most of this research was of an empirical nature, mapping different aspects of disabled women's situation and/or comparing it to men's. It was not until the 2000s that feminist theories started to guide the research about disability (Barron 2004).

Lately, the feminist interest has also included the question of intersectionality. The concept of intersectionality aims to capture how the different categories (power axis, dimensions, variables – the terminology differs with different methodologies) interact in forming life conditions and identities of these groups. This interest was also stimulated by the fact that a common law that regulates discrimination on several grounds (gender, ethnicity, age, sexual orientation and disability) was decided in 2003. One ombudsman for supervising the observance of the law (instead of the earlier arrangement with one ombudsman for each category) was also implemented. In that context, the discussion about what different categories had in common and how they might co-vary to explain discrimination was stimulated.

Intersectionality can perhaps best be seen as a perspective that emphasizes the importance of taking different structuring conditions into account. With some simplification, the discussion about intersectionality can be said to depart from two different, though sometimes, overlapping perspectives. The first is a structural one, and the second a subjectivistic one. The structural perspective focuses on power and stratification. Gender, ethnicity and class are seen as axis of power that structure populations into those in power and those without power, oppressors and oppressed. The ambition is to understand how the positions on these different axes combine in forming the stratification of society and thereby the situation of marginalized groups. In the subjectivistic perspective, the focus is on identity. In this perspective, one is not talking as much about power axis, but of categories. Each individual belongs to several collective categories. The categorical belongings form the building bricks for

the person's identity, and the general research question is to find out how identity is constructed by using those building bricks. Within disability research, gender research is the field in which research on intersectionality has been initiated and most developed. The perspective has mostly been a subjectivist one, focusing on how disabled women form their identity (see e.g. Barron 2008).

The interest in intersectionality has led to a debate about what power axis or categories should be included in an intersectional analysis. This discussion points to some ambivalence when it comes to disability. Most authors want to include gender, class and ethnicity as the central dimensions. Age and sexual orientation are sometimes included, but seldom disability. This exclusion of disability is often done without any substantial argumentation. But Mulinari and de los Reyes in a much-quoted book (2005) are an exception on this point. They apply a structural perspective and ask themselves what are the characteristics of the power axis that should be included in an intersectional analysis. They identity four such characteristics. The first one is that it should be stable over time. The second is that it should be inexorable or unescapable. You should not be able, or at least not easily be able, to change your position on the axis. The third characteristic is that it should be antagonistic. What is good for the oppressors is bad for the oppressed and vice versa. The fourth, finally, is that the relation is of an exploitive nature. The antagonism involves that the subordinated group is being exploited. In this respect, they make a distinction between exploitation and stigmatization. Low-paid working class is, for example, exploited, but it does not need to be stigmatized. If they behave according to the norms of the capitalistic system, they do not provoke any counter reactions. Only to the extent that they provoke and question the system, will they be stigmatized as norm breakers. For other groups, the situation is the reverse. They belong to a category that is devalued and stigmatized in society because they break some central norms, but they are not exploited. According to de les Reyes and Mulinari, persons with disabilities (together with those who are breaking the hetero norm when it comes to sexuality) belong to the group that is stigmatized, but not exploited. Their situation can better be analysed in terms of discourse and identity but not as part of an intersectional perspective that focuses on the intersection of power axis where positions are subordinated in asymmetric exploitive relations.

Some authors who discuss what power axis or categories should be included in an intersectional analysis state that this is a question that cannot be given a general answer but is dependent on the nature of the research question which makes some dimensions more relevant than others (Grönvik 2007). Even so, the analysis of Mulinari and de les Reyes poses important questions to disability research about the nature of the subordination of persons with disabilities in society. When it comes to class, Marx provides us with a theory of surplus value that gives us a theoretical instrument to understand exploitation of the working class. Feminism has its theory of patriarchy. In the intersection of gender and sexuality, queer theories have developed a theoretical understanding based on the hegemony of heterosexual norms. All of these have been applied in disability research, but, as pointed out in the introduction, in a rather uncritical way, with little sensitivity to the question of to what extent these theories really capture the situation of disabled persons.

The relative dominance in disability research of a subjectistic perspective can be seen as a sign that analysis in terms of power and resources to a large extent has lacked a theoretical instrument to deal with power relations in a distinct way (Söder and Grönvik 2008). Intersectionality can be seen as a challenge to do just that and

the fact that it is getting growing attention among disability researchers in Sweden might turn out to be fruitful way forward.

Theoretical awareness

As was described above, Swedish social disability research has been rather empirical and with few contributions of a theoretical nature. This has also been pointed out by Gustavsson (2004) and was also a major point in the international evaluation of Swedish disability research. In the second phase described above, the range of topics widened, and this opened up not only for new research questions but also for new perspectives. As noticed by Gustavsson and Tössebro (2005) in an analysis of the content in *Scandinavian Journal of Disability Research*, this pluralism also brought about a growing theoretical awareness. Feminism can serve as an example. As described above, the introduction of a feminist perspective also meant applying some of the basic theoretical concepts and ideas of feminism.

This theoretical awareness meant that many researchers started discussing and applying different perspectives. By perspective in this context, I mean a position from which the world is observed. The perspective depends on the purpose of my observation as well as metatheoretical assumptions about the object under study and the world (Danermark 2005b). A perspective is not a theory, but can be looked upon as a frame within which substantial theories can be chosen or developed.

An early perspective that has for a long time been central is the relative notion of disability. This notion has been so central to the development of Swedish disability research that it will be discussed at more length in the next section.

But other perspectives have been introduced during the last years. One perspective that has been used longer than that but been used more elaborately lately is social constructivism. In the form of symbolic interactionism, it has been central in disability research for quite a while, particularly as it has been developed within labelling theory. This has been a rather weak from of constructivism that did not really question our basic taken-for-granted assumption of the existence of an objective reality independent of our way of observing and talking about it. Not least by feminism a more radical constructivism was introduced. Within feminism, a step from weak to radical constructivism was taken when the dualism between sex and gender by some was abandoned and opened up for deconstruction also of sex and body. As pointed out by Barron (2004), the sex–gender division shows striking similarities with the distinction between impairment and disability within the disability research. Much in the same way as in feminism critical analysis of this distinction opened up for more radical constructivism in disability research, where different construction of the body has been in focus. But generally, Swedish disability research cannot be unidimensionally described as either weak or strong when it comes to social constructivism. It would be better described as dominated by different, conscious or unconscious variation of constructivism.

Another perspective that has surfaced is critical realism. This perspective is critical of radical constructionist and can be said to represent a weak form of constructionist. It presupposes an objective world independent of the observer, but at the same time underlines that our knowledge about the world is influenced by social factors. It assumes that social reality is shaped by mechanisms at different levels (for example, biological, psychological and social), and that a major task for research is to identify those mechanisms (Danermark 2008). The approach thus calls for

a cross-disciplinary approach, and it is perhaps telling that this perspective has been actualized in disability research by researchers at the SIDR where cross-disciplinary studies are both a priority and a reality.

Cultural studies with its constructionist emphasis on codes, context of meanings and cultural practices have also been applied in disability research in Sweden, for example, in a study of artistic activities among intellectually disabled persons (Sauer 2004). The perspective has been developed by researchers at the Umeå University and has been applied to different aspects of disability (Lindqvist and Sauer 2007).

But the growing theoretical awareness does not only take the form of pluralism of perspectives. Several more substantial theories have also been applied in different projects. Nancy Fraser's theory on the relation and tension between redistribution and recognition in social movements has, for example, been applied in a study of Swedish disability organizations (Hugemark and Roman 2005). Michailakis has used Luhmann's systems theory both for a more critical discussion of disability research and theory (2003, 2004) and for an analysis of labour market policies for disabled persons (2006).

The theoretical awareness has thus meant a conscious elaboration of different metatheoretical perspectives as well as the application of a more general theory. Those theories have been applied in a way that make new aspects of disability visible, but more seldom have the theories been 'tested' and critically analysed against the empirical reality of disability. The next step in disability research should perhaps be that theories are not only imported but tested against the specific phenomenon of disability thereby being able to constructively develop general theories as well as disability research (Söder 2009).

Theoretical awareness can also be seen in the evaluative research. While such research earlier was largely empirical and descriptive, it is today more often than not anchored in broader sometimes theoretical questions than just the 'does it work' question that dominated the first wave of such research. One example can be studies that have followed up and analysed the reforms from the middle of the 1990s where personal assistance was introduced. The reforms were built on the idea of a voucher system where a disabled person gets money from state authorities to buy his/her own assistance. The reform has been evaluated from the perspective of individualism, in a rights' perspective as well as in the context of welfare state changes (Askheim, Andersen, and Guldvik 2004; Gynnerstedt 2004; Hugemark 2006).

Relative definition and cross-disciplinary research

Two questions have been constantly debated and discussed during the 40 years of social disability research that has been described above, the relative definition of disability and disability as a field for cross-disciplinary research. And we shall see these two questions are linked to each other.

Relative definition of disability

In an overview of Swedish disability research, Hjelmquist (2005) makes the point that the research has rested on two legs: the individual and the environment. He goes on to say: 'It is fascinating to see how the debate about which leg is most important, how we can stop them from drifting apart in a split, how they have been identified in different disciplines has been kept alive over the last thirty years' (31).

The relative definition states that disability is created in interaction between individual and environmental characteristics. The concept was first explicitly developed by state investigations during the 1970s. The disability organizations, represented in the investigating committee, were the strongest driving force behind this. For them, emphasizing the role of environment in creating disability was a way to argue for general environmental changes as central to disability politics.

Social researchers were soon to adopt this perspective, and in their 1986 programme for disability research, FRN stated that handicap (the term used at the time that has now been replaced by disability) is severe and chronic, difficulties in daily living of a physical, psychological or social nature due to impairment in interaction with the environment. From this perspective follows that disability research should focus on those factors and processes that make impairments into disabilities.

At that time, the definition can be seen as a way of criticizing the individually focused clinical perspective that had been dominant in the field. But the definition is broad and rather vague. As the quote from Hjelmkvist above indicates, the meaning of the relative perspective has constantly been discussed over the years. Some technical researchers as well as psychologists and researchers in the rehabilitation field have argued that the definition has been too wide and to much focus on environmental aspects at the expense of individual characteristics. Later on, when the British social model had become well known, others would argue that a relative perspective was too 'weak', obscuring the fact that disability was in the end the result of societal oppression and discrimination.

The relative definition and the perspective it represents had a large influence as a guiding principle for social disability research. Some Scandinavian researchers talk about it retrospectively as 'the environmental turn' (e.g. Tössebro and Kittelaa 2004). But as seen above, it also encouraged much debate and controversies, some of which were fruitful as they cleared the ground for different metatheoretical assumptions. But the fruitfulness of the perspective as heuristic and inspiring device might have been a result of the rather broad and vague definition, and such unclarities also have drawbacks. Several researchers (Söder 1999; Tössebro and Kittelaa 2004; Grönvik 2007) have, for example, noticed that many researchers declare themselves supporters of a relative perspective, but in their empirical research do not take the consequences of that declaration. Or as Tössebro and Kittelaa (2004) puts it when discussing studies of living conditions:

> The problem of most studies on living conditions and the situation for disabled people is, to state it bluntly, that many disability researchers tend to support the environmental perspective on page one, and then proceed incoherently, disregarding their proposed stance onward from page two. The declared understanding is environmentalist, but the understanding-in-use that follows is often closer to a biomedical stance rather than a human ecology model. (23)

One reason for this mismatch, besides the vagueness of the perspective, might be that disability research has been rather theoretically poor. To bridge the gap between the general relativistic perspective and empirical research, more substantial theory is needed. As stated above, such a development has characterized the last decade. Another way of putting it is to say that the relative perspective has been elaborated within the framework of more general theories. Gustavsson and Tössebro (2005)

identify five variations of the relational perspective, based on five different theoretical positions.

Cross-disciplinary research

Already from the start of discussions on disability research, as a specific domain of research, it was, particularly when discussing research policy, underlined that disability represented a multidimensional problem and that no single discipline could by itself handle these dimensions. But the cross-disciplinary research, at least if we are talking about disciplines from different faculties, has been hard to organize. This led some researchers to lower the ambition to talk about 'multidisciplinary' rather than cross-disciplinary research. The idea was for different disciplines to work side by side, learn from each other and exchange information, but not to work together from a common definition of the research problem. This was considered too tricky for example, as medicine, sociology, law studies and technology were considered too different in their perspectives to make such genuine cross-disciplinary research fruitful. Early attempts at this, for example, in the ALA group and the MR group, tended to sustain this pessimism.

The tensions between different disciplines were partly mirrored in the discussion about the relative concept of disability and the relational perspective. The FRN definition, quoted above, managed, however, to survive with minor changes as a more or less official definition. The FAS programme, from 2001, worked out by a genuinely cross-disciplinary committee, gave a definition that more directly seems to mark the cross-disciplinary nature of disability research:

> Research about impairment and disability can be social-behavioural, humanistic, technical/natural science. It can concern the individual, group or societal level. Important is the relative environmental perspective. Disability research is of a cross- and/or multidisciplinary nature. How the relative perspective is applied differs from an area to another. (8, my translation)

Compared to previous definitions, this one more obviously is a compromise between different ways of understanding the relative perspective. When discussing Swedish social research, the committee underlines that such research is often of an ideological critical and/or social constructionist nature and critical of a traditional clinical nature. They conclude that: 'It would be to restrain the development of critical social research about disability if it would be forced into institutional forms based on the clinical perspective' (FAS 2001, 19, my translation). The ambivalence surrounding cross-disciplinary research here becomes rather obvious.

This ambivalence mirrors a basic dilemma in cross-disciplinary research. Danermark (2005a) has analysed some prerequisites for cross-disciplinary research to become successful. Ontologically, the partners in such a work cannot be too far away from each other. A radical social constructionist will have difficulties working with a realist. The partners cannot be too strong reductionists, wanting to reduce interpretations and explanations to their own specialty, thereby denying the validity of other disciplines. These potential problems must, according to Danermark, be dealt with in an open dialogue without subordination of any partner under others if integration of knowledge from different disciplines shall be possible.

The ambition of developing disability research as a truly cross-disciplinary field (as different from just a multidisciplinary one) has been pronounced for more than 30 years, so far with rather thin results. Danemark's analysis underlines that the cross-disciplinary ambition, if taken seriously, is a rather complicated enterprise that poses a challenge to disability research. The question could be asked if social disability research has reached the stage, stability and maturity that can make such an enterprise meaningful.

Concluding remarks

Swedish social disability research has in 40 years developed from an activity separated from the traditional university system and mainly occupied by evaluating reforms sponsored by short-term grants to an established academic activity with a broad range of research topics with a growing engagement in theoretical questions. The first initiatives were coloured by the society and spirit of the 1970s: a belief in the 'strong society', traditional welfare policies and social engineering as the ideal for building that society. Disability had recently been established as a policy area in itself, a result of strong economic growth, shortage of labour and strong disability organizations. The demand for research as well as the interest from researchers seems to depend on this demarcation of a specific field of policy with its own problems and influential interest groups. That the early research initiatives became so close to the needs of the welfare state is perhaps not so strange considering this background. The disability organizations at the time had rather close links to the social democratic government and their pushing for the need of research was a contributing factor to the development.

During the 1990s, disability research entered the university system. Centres for disability research were founded, and professorships with emphasis on disability research were created. One consequence of this development was that the ties to the state and welfare reforms weakened. Research areas widened and research questions became not so dominated by evaluations. Some of us tried to nurture this position by arguing a free truth-seeking role for social research (see for example, Söder 2005b). This might be one of the reasons why social research seems to have had limited influence on policy at the end of the 1990s. In a project about the role of social research for the creation of anti-discrimination legislation and the institute of ombudsman for implementing the laws in different fields (there were at the time four laws and four ombudsman for discrimination due to gender, ethnicity, disability and sexual orientation, respectively), it was found that research when it comes to disability had not been very influential (unlike gender and ethnicity where it played a significant role). On the other hand, the social movement (disability organizations) is said to have had a stronger say when it comes to disability than in other fields (Hugemark and Roman, 2011).

During the present century, the development of research questions, such as gender and intersectionality feminism as well as the growing theoretical awareness, has probably benefitted from the academic position of research and researchers. But at the same time disability organizations have reacted critically, as they found themselves having little influence on research that is done, a reaction that includes dissatisfaction with what is experienced as inability of researchers to make research politically relevant.

What started in a society with a centralized structure and ambitious social engineering ideal now has to find its role in a more decentralized structure where reform ambitions and the role of social movements like disability organizations are different. To balance the need for autonomous research with the ambition of being politically relevant without falling for the temptation of being politically correct is one of the challenges social disability research in Sweden will have to deal with in the near future.

References

Ahlström, G. 1994. *Consequences of Muscular Dystrophy: Impairment, Disability, Coping and Quality of Life*. Uppsala: Center for Caring Sciences, University of Uppsala.

Albrecht, G. L., A. M. Jette, H. Petrie, and L. Siegel. 2001. *An Evaluation of Swedish Disability Research*. Stockholm: Swedish Council for Working Life and Social Research.

Åman, A. 1976. *Om den offentliga vården. Byggnader och verksamheter vid svenska vårdinstitutioner under 1800- och 1900-talen. En arkitekturhistorisk undersökning* [Public Care. Houses and Activities at Swedish Institutions for Care During the19th and 20th Centuries]. Stockholm: LiberFörlag.

Askheim, O. P., J. Andersen, and I. Guldvik. 2004. "Mye er forskjellig, men inni er vi like… Personlig assistanse i Sverige og Norge [Much Is Different, But Inside We Are All Alike… Personal Assistance in Sweden and Norway]." In *Personlig assistans och medborgarskap* [Personal Assistance and Citizenship], edited by K. Gynnerstedt, 171–199. Lund: Studentlitteratur.

Barron, K. 2004. "Genus och funktionshinder [Gender and Disability]." In *Genus och funktionshinder* [Gender and Disability], edited by K. Barron, 15–52. Lund: Studentlitteratur.

Barron, K. 2008. "Kön och funktionshinder [Gender and Disability]." In *Bara funktionshindrad? Funktionshinder och intersektionalitet* [Only Disabled? Disability and Intersectionality], edited by L. Grönvik, and M. Söder, 28–46. Lund: Gleerups.

Blomkvist, M. 1990. *Hundra år av undantag. Handikappades förhållande till lönearbete* [A Hundred Years of Being Excluded. Disabled Persons and Wage Labour]. Uppsala: Sociologiska Institutionen, Uppsala Universitet.

Danermark, B. 2005a. "Sociologiska perspektiv på funktionshinder och handikapp [Sociological Perspectives on Disability and Handicap]." In *Sociologiska perspektiv på funktionshinder och handikapp* [Sociological Perspectives on Disability and Handicap], edited by B. Danermark, 13–36. Lund: Studentlitteratur.

Danermark, B. 2005b. "Handikappforskning som tvärvetenskap. Möjligheter och utmaningar [Crossdisciplinary Disability Research. Possibilities and Challenges, in]." In *Forskning om funktionshinder. Problem – utmaningar – möjligheter* [Disability Research. Problems – Challenges – Possibilities], edited by M. Söder, 63–84. Lund: Studentlitteratur.

Danermark, B. 2008. "Intersektionalitet och kritisk realism [Intersectionality and Critical Realism]." In *Bara funktionshindrad? Funktionshinder och intersektionalite* [Only Disabled? Disability and Intersectionality], edited by M. Söder, and L. Grönvik, 137–154. Malmö: Gleerups.

de los Reyes, P., and D. Mulinari. 2005. *Intersektionalitet. Kritiska reflektioner över (o)jämlikhetens landskap* [Intersectionality. Critical Reflections on the Landscape of (in) Equality]. Malmö: Liber.

Eriksson, B. E. 1989. *Vägen till Centralhospitalet. Två studier om den anstaltsbundna sinnesjukvårdens förhistoria i Sverige* [The Way to the Mental Hospital. Two Studies of the Early History of Psychiatric Care in Sweden]. Göteborg: Diadalos.

Ericsson, K. 1993. "After Institutional Closure – on Alternative Daily Activities." In *Intellectual Disability Research. Nordic Contributions*, edited by J. T. Sandvin, and A. Frostad-Fasting, 216–226. Bodö: Nordlands forskning, 16/93.

FAS (Forskningsrådet för Arbetsliv och Socialvetenskap). 2001. *Program för forskning om funktionshinder och handikapp* [Program for Research About Disability and Handicap]. Stockholm: Swedish Council for Working Life and Social Research.

Förnhammar, S. 1991. *Från tärande till närande: Handikapputbildningens bakgrund och socialpolitiska funktion i 1800-talets Sverige* [From Vegetative to Productive. Background and Sociopolitical Function of Education for Handicapped in Sweden During the 19th Century]. Stockholm: Almqvist & Wiksell International.

Grönvik, L. 2007. *Definitions of Disability in Social Sciences. Methodological Perspectives.* Uppsala: Uppsala Universitet. Acta Universitatis Upsaliensis.

Gustavsson, A. 1992. "Livet i 'integrasjonssamfunnet': en analyse av närhetens sociala betydning [Life in the Integrated Society: An Analysis of Social the Meaning of Nearness]." In *Mot Normalt: samfunnsideologier i forandring* [Towards Normality? Ideologies of Care in Transition], edited by J. T. Sandvin, 203–244. Oslo: Kommuneforlaget.

Gustavsson, A. 2004. "The Role of Theory in Disability Research – Springboard or Straitjacket?" *Scandinavian Journal of Disability Research* 6 (1): 55–70.

Gustavsson, A., and M. Söder. 1990. *Social forskning om människor med utvecklingsstörning* [Social Research on People with Intellectual Disabilities]. Stockholm: Report from the Stockholm College of Health and Caring Sciences.

Gustavsson, A., and J. Tössebro (in collaboration with Traustadottir, R.). 2005. "Introduction: Approaches and Perspectives in Nordic Disability Research." In *Resistance, Reflection and Change. Nordic Disability Research*, edited by A. Gustavsson, J. Sandvin, R. Traustadottir, and J. Tössebro, 23–46. Lund: Studentlitteratur.

Gynnerstedt, K. 2004. "Personlig assistans och medborgarskap [Personal Assistance and Citizenship]." In *Personlig assistans och medborgarskap* [Personal Assistance and Citizenship], edited by K. Gynnerstedt, 13–28. Lund: Studentlitteratur.

Hansson, H. 1993. *Monauralt döva. Audiologiska, socialpsykologiska och existentiella aspekter* [Monauraly Death. Audiological, Social Psychological and Existential Aspects]. Stockholm: Department of Education, Stockholm University.

Hjelmquist, E. 2005. "Svensk handikappforskningspolitik [Swedish Disability Research Policy]." In *Forskning om funktionshinder. Problem – utmaningar – möjligheter* [Disability Research. Problems – Challenges – Possibilities], edited by M. Söder, 21–36. Lund: Studentlitteratur.

Hjelmquist, E., J. Rönnberg, and M. Söder. 1994. *En Svensk forskning om handicap- En översikt med social- och beteendevetenskapliga perspektiv* [Swedish Research About Disability. An Overview with Social- and BehavioralPerspectives]. Stockholm: Socialvetenskapliga forskningsrådet.

Holme, L. 1996. *Konsten att göra barn raka. Ortopedi och vanförevård i Sverige till 1920* [The Art of Straightening Children Out. Orthopedics and Disability Care in Sweden Before 1920]. Stockholm: Carlssonsförlag.

Hugemark, A. 2006. "Åter i stöpsleven: Personlig assistans mellan marknad och reglering [Back in the Melting-pot: Personal Assistance Between Market and Control]." *Socialvetenskaplig Tidskrift* 13 (4): 313–330.

Hugemark, A., and C. Roman. 2005. "Rättvisekrav och organisering [Claims for Justice and Organization]." In *Sociologiska perspektiv på funktionshinder och handikapp* [Sociological Perspectives on Disability and Handicap], edited by B. Danermark, 123–146. Lund: Studentlitteratur.

Hugemark, A., and C. Roman. 2011. *Nya problem, nya lösningar. Om tillkomsten av fyra ombudsmän mot diskriminering* [New Problems, New Solutions. On the Establihment of Four Ombudsmän Against Discrimination]. Örebro: Arbetsrapport 15, Akademin för humaniora, Utbildning och Samhällsvetenskap, Örebro universitet.

Jansson, U. 1993. "Preschool Integration of Handicapped Children in Sweden." In *Intellectual Disability Research. Nordic Contributions*, edited by J. T. Sandvinand, and A. Frostad-Fasting, 122–141. Bodö: Nordlandsforskning, 16/93.

Lindqvist, R., and L. Sauer. 2007. "Funktionshinder, kultur och samhälle [Disability, Culture and Society]." In *Funktionshinder, kultur och samhälle* [Disability, Culture and Society], edited by R. Lindqvist, and L. Sauer, 13–42. Lund: Studentlitteratur.

Michailakis, D. 2003. "The Systems Theory Concept of Disability. One is not Born a Disabled Person; One is Observed One." *Disability & Society* 18 (1): 209–229.

Michailakis, D. 2004. "Observing Disability as Communication." In *Exploring the Living Conditions of Disabled People*, edited by J. Tössebro, and A. Kittelsaa, 141–156. Lund: Studentlitteratur.

Michailakis, D. 2006. "Anställningsbarhet och funktionshinder [Employability and Disability]." *LOOP. Tidskriftenom Ledarskap Organisation och Personal* 2 (5): 50–53.

Richt, B. 1992. *Mellan två världar om konflikten mellan livets krav och doktorns önskningar* [Between Two Worlds. On the Conflict Between the Demands of Life and the Wishes of the Doctor]. Linköping: Universitetet i Linköping, Tema Hälso- och sjukvården i samhället.

Sauer, L. 2004. *Teater och utvecklingsstörning. En studie av Ållateatern* [Theater and Intellectual Disability. A Study of the Ålla Theater]. Umeå: Institutionen för social arbete.

Sjöström, B. 1992. *Kliniken tar over dårskapen. Om den moderna svenska psykiatrins framväxt* [When the Clinic Took Over Insanity. On the Evolution of Modern Swedish Psychiatry]. Göteborg: Diadalos.

Söder, M. 1981. *Vårdorganisation, Vårdideologi och integrering. Sociologiska perspektiv på omsorger om utvecklingsstörda* [Organization, Ideologies of Care and Integration. Sociological Perspectives on Care for Persons with Intellectual Disabilities]. Uppsala: Acta Universitatis Upsaliensis. Abstracts of Uppsala Dissertations from the Faculty of Social Sciences, 25.

Söder, M. 1988. "The Concept of Handicap – A Comparison Between the ICIDH and a Swedish Definition." In *Impairment, Disability and Handicap*, edited by M. Söder, 27–33. Stockholm: Swedish Council for Planning and Co-ordination of Research. Report 88: 1.

Söder, M. 1999. *Specialpedagogisk forskning mellan det kliniska och det kontextuella* [Special Education Research Between the Clinical and the Contextual]. Bodö: Nordlandsforskning, NF 8/99.

Söder, M. 2005a. "Inledning [Introduction]." In *Forskning om funktionshinder. Problem – utmaningar – möjligheter* [Disability Research. Problems – Challenges – Possibilities], edited by M. Söder, 13–20. Lund: Studentlitteratur.

Söder, M. 2005b. "Hur det är eller hur det bör vara? Om normativa inslag i social forskning om funktionshinder [How It Is or How It Ought to Be? Normativity in Social Disability Research]." In *Forskning om funktionshinder. Problem – utmaningar – möjligheter* [Disability Research. Problems – Challenges – Possibilities], edited by M. Söder, 85–102. Lund: Studentlitteratur.

Söder, M. 2009. "Tensions, Perspectives and Themes in Disability Studies." *Scandinavian Journal of Disability Research* 11 (2): 67–81.

Söder, M., K. Barron, and I. Nilsson. 1991. *Inflytande för människor med omfattande funktionshinder* [Influence for Persons with Severe Disabilities]. Stockholm: Allmänna förlaget. Bilagerapport till SOU 1990:19.

Söder, M., and L. Grönvik. 2008. "Intersektionalitet och funktionshinder [Intersectionality and Disability]." In *Bara funktionshindrad? Funktionshinder och intersektionalite* [Only Disabled? Disability and Intersectionality], edited by M. Söder, and L. Grönvik, 9–25. Malmö: Gleerups.

Solvang, P. 1994. *Biografi, normalitet og samfunn. En studie av Handikappedes veier til utdanning og arbeid i Skandinavia* [Biography, Normality and Society. A Study of Disabled Persons Ways to Education and Work]. Bergen: Sosiologisk Institutt, Universitetet i Bergen.

Strachal, G, ed. 1981. *Man kan om man får. Forskning – handikapp – samhälle* [You Can if you May. Research. Handicap – Society]. Stockholm: Liber.

Tössebro, J., and A. Kittelaa. 2004. "Studying the Living Conditions of Disabled People: Approaches and Problems." In *Exploring the Living Conditions of Disabled People*, edited by J. Tössebro, and A. Kittelaa, 17–44. Lund: Studentlitteratur.

Wendell, S. 1996. *The Rejected Body. Feminist Philosophical Reflections on Disability*. New York: Routledge.