Definitions of Disability in Social Sciences

Methodological Perspectives

LARS GRÖNVIK
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Abstract

This dissertation examines how disability researchers define disability. It is based on four studies. The first describes different definitions of disability in disability research. The second study is a conceptual analysis of the use of disability in a sample of disability research classics. In this study, it is evident that use of the concept is all but clear. It is concluded that especially environmentally based disability definitions would benefit from further empirical investigations. The notion that environmental factors (such as barriers) are a causal aspect of disability is rather widely accepted among disability researchers. However, it has not been empirically studied to such an extent that it is possible to construct workable theories of this relationship.

The third study focuses on administrative definitions of disability and investigates the possibility of using data on disabled people that have been gathered by Swedish welfare authorities. It is concluded that rich data are available, but also that researchers must scrutinize how disability has been defined in these contexts. These authorities often start from medical understandings of disability, which may clash with contemporary understandings of disability as being environmentally based.

The fourth study is a statistical analysis of the effects of different disability definitions on dependent variables. The analyses emphasize variables often included in studies of living conditions. There are major effects of choice of disability definition on the outcome in relation to such variables.

The dissertation strongly rejects efforts to standardize disability definitions; different analytical purposes require different kinds of conceptualizations. Instead, the dissertation suggests that case-constructing reflexivity be conducted. Case-constructing reflexivity means that the researcher starts with a careful analysis of how disability is best defined in relation to the aims of the study, and continues by being constantly aware of how the choice of definition may affect sampling, analyses and results.

Keywords: disability, concept analysis, methodology, definitions, disability research

Lars Grönvik, Department of Sociology, Box 624, Uppsala University, SE-75126 Uppsala, Sweden

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Abbreviations

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<th>Description</th>
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<tbody>
<tr>
<td>ADL</td>
<td>Activities of Daily Living</td>
</tr>
<tr>
<td>AKU</td>
<td>Swedish abbreviation of “Arbetskraftsundersökningen”, the Labor Force Survey</td>
</tr>
<tr>
<td>DSC</td>
<td>Disability Statistics Center at University of California, San Francisco</td>
</tr>
<tr>
<td>EU</td>
<td>The European Union</td>
</tr>
<tr>
<td>FAS</td>
<td>Swedish Council for Working Life and Social Research</td>
</tr>
<tr>
<td>IADL</td>
<td>Instrumental Activities of Daily Living</td>
</tr>
<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>ICIDH</td>
<td>International Classification of Impairments, Disabilities and Handicaps</td>
</tr>
<tr>
<td>LASS</td>
<td>Swedish abbreviation of Lag (1993:389) om assistansersättning (the Assistance Allowance Act)</td>
</tr>
<tr>
<td>LFS</td>
<td>Labor Force Survey (English abbreviation of the Swedish “Arbetskraftsundersökningen”)</td>
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<tr>
<td>LMA</td>
<td>Swedish Labor Market Administration</td>
</tr>
<tr>
<td>LNU</td>
<td>The Swedish Level-of-Living Survey</td>
</tr>
<tr>
<td>LSS</td>
<td>Swedish abbreviation of Lag (1993:387) om stöd och service till vissa funktionshindrade (Act Concerning Support and Service for Persons with Certain Functional Impairments)</td>
</tr>
<tr>
<td>RFV</td>
<td>Swedish abbreviation of Riksförsäkringsverket (the National Social Insurance Board)</td>
</tr>
<tr>
<td>Abbreviation</td>
<td>Full Form</td>
</tr>
<tr>
<td>--------------</td>
<td>-----------</td>
</tr>
<tr>
<td>SCB</td>
<td>Swedish abbreviation of Statistik centralbyrån (Statistics Sweden)</td>
</tr>
<tr>
<td>SSA</td>
<td>Social Security Administration (United States)</td>
</tr>
<tr>
<td>UCSF</td>
<td>University of California, San Francisco</td>
</tr>
<tr>
<td>ULF</td>
<td>Swedish abbreviation of the Living Conditions Survey</td>
</tr>
<tr>
<td>VR</td>
<td>Vocational Rehabilitation</td>
</tr>
</tbody>
</table>
1. Introduction

Take a look at the picture above. What do you see? A disabled person? Probably. But why do you think the person is disabled? Because of the wheelchair? Most likely. This can be called an everyday life conceptualization of disability. The visible aid, in this case the wheelchair, identifies the person as disabled. By “checking out” a person’s functions and appearance, we identify some people as abled, others as disabled (Davis, 1995).

However, a relatively aware disability researcher can actually see no less than five different definitions of disability in this picture. Of course, s/he will see the same kind of conceptualization as the layman. Within disability research, this type of disability definition is often called a *functional definition*, because it focuses on a person’s functional limitation (e.g., Abberley, 1991). Second, the disability researcher also recognizes a definition that conceives of disability as an interaction between an individual with an impairment and an environment that lacks adaptations. This means that a person with an impairment only finds him-/herself in a disabling situation when the surroundings are inaccessible. In the picture, this is illustrated by the interaction...
between the person in the wheelchair and the stairs. Thus, a disability is nothing a person has per se, rather it is an interaction that appears in some situations but not in others. This is often called a relative or environmental definition of disability, because disability is seen as a relation between a person and her/his environment (e.g., Söder, 1987). Third, the researcher will also identify a model according to which the stairs themselves are thought to create the disability, without any connection to the person. Disability, in this case, is the same as barriers in society that keep people with impairments from fully participating in society. This definition is often called the social model of disability (e.g., Oliver, 1990). Furthermore, the researcher will see that this person has been processed by the welfare state. S/he has a mobility aid, the wheelchair, because s/he has been administratively defined (e.g., Stone, 1985) as disabled, i.e. s/he is disabled because s/he is using an aid given to “disabled people”.

The photo focuses primarily on the wheelchair, which is the artifact characterizing the whole picture. The (‘decapitated’) person plays a secondary role. This reflects a common notion of people categorized as disabled, i.e., that they are de-personalized. Their disability makes them the object of different treatments, forms of support and so forth. This will likely cause the disability researcher to wonder how this person defines her-/himself. Does s/he conceive of her-/himself as disabled? Thus, a fifth definition appears, a subjective definition of disability.

The complexity does not end with these five definitions, however. As you can see, it is rather difficult to determine whether this is a man or a woman. However, the hairy arm may cause us to conclude that it is a male. The fact that disabled people are de-genderized (consider public toilets, where there are three genders represented: ladies, gentlemen and disabled), both in general and in theories of disability, has been observed by feminist researchers. For this reason, contemporary (social scientific) definitions of disability have been criticized for not being sensitive to the intersection between disability and gender. Such criticisms consider that a “proper” definition must recognize disability as a gendered phenomenon (e.g., Thomas, 1999).

Thus, the man-on-the-street conceptualization of disability can be much more complex if we look at the same picture with a sociological or social scientific gaze. This means that when a researcher says s/he is researching disability, we cannot be really sure about what disability means. S/he might be interested in people or architecture, or the welfare state bureaucracy, or identities, or some kind of mixture of these.

But does this really matter empirically? Or is it only another example of the social scientific preoccupation with making things more complicated than necessary? I think it does matter. Take a look at the figure below. It provides an initial empirical introduction to the consequences of different disability definitions.
Figure 1. The number disabled people in Sweden according to four different studies.

This figure shows the number of disabled people in Sweden, according to four different reports (National Board of Health and Welfare, 2006; National Social Insurance Board, 2002; Statistics Sweden, 2005; Szebehely, Fritzell, & Lundberg, 2001). As is evident, the number of disabled people in Sweden differs a great deal across the different studies. In fact, the range is from just over 50,000 persons to 1.3 million. And, as you can see, these rather impressive differences occur both within and between the three definitions presented in the figure. Thus, one cannot easily answer the question “How many disabled people are there in Sweden?” Disability means different things in different studies.

1.1 Why do Different Definitions Occur?

It is not a matter of chance that different definitions occur. Different definitions have been devised to suit different purposes. Sometimes a new definition is created based on criticism of another definition. This is, for instance, the story of the environmental definition and the social model of
disability (Hughes, 2002), both of which emerged as a reaction to the functional definition, foremost among people in the disability movements in the UK and Sweden. They felt that the functional definition was far too focused on the individual and on functional limitations. There was, they claimed, a need for a new definition that took disabling barriers in the surroundings into account.

This is one example of how purposes may give rise to new definitions of disability. So, let us take a quick look at the purposes underlying some of the definitions depicted in the photo above.

First, even if functional definitions are often criticized for not taking environmental aspects of disability into account, there are certain affirmative purposes of this definition. One such area is rehabilitation, which demands some kind of definition of disability that takes the body as its point of departure. Measuring needs and the kind of actions required to restore functions necessitates this kind of definition. Furthermore, there is an ongoing interest in comparing, for instance, the number of disabled people in different countries. Such censuses or surveys need to be able to “count heads”, and traditionally such head counting has been conducted using functional definitions (United Nations, 1990, 1996, 2003). Thus, professions involved in rehabilitation, aids and statistics, for instance, may need definitions of disability that start from a functional understanding of the concept.

Second, as mentioned above, the purpose of the social model of disability was originally to move the gaze from the individual to the surroundings. As also mentioned, especially parts of the disability movement in the UK pointed out the push for such a definition, and the original version was proposed by one of the British disability organizations, the Union of the Physically Impaired Against Segregation (1975). Some disability researchers have also adopted this model.

The social model claims that disability is a property of the environment, not of the human being. Today, most social researchers accept the notion of the environment as a causal (although partial) agent of disability. Thus, an analysis of the society, intended to detect inaccessibilities and barriers, is dependent on a definition of disability that enables identification of such barriers. Naturally, a definition that focuses solely on the body is not suited to such purposes.

Third, the relative or environmental definition of disability has almost the same history as the social model. One could even say that the environmental definition is the Nordic version of the British social model. As in the UK, the environmental definition stems from the disability movement and has the same purpose as the social model, i.e., to move the gaze from the individual body to the environment. This approach to disability has been acknowledged by politicians and is the conceptual basis of Swedish disability policies.

Fourth, as has been stated above, the purpose of the administrative definition is to solve the distributive problems of the welfare state (Stone, 1985).
Defining some people as disabled and some as not allows authorities to distribute support to some people, but at the same time provides arguments for not giving support to others. Although some people long for a society in which everyone who thinks s/he needs support gets support, the realist picture is quite the opposite. Most countries, in the EU as well as outside, are fighting the rising costs of social security. This will likely strengthen the need for definitions that clearly indicate who should receive and who should not. Thus, two important agents of the administrative definition are politicians and welfare authorities.

Finally, feminist critique, among others, has stressed the importance of a subjective understanding of disability (Morris, 1991; Thomas, 1999; Wendell, 2001). Intersectionality and identity studies require definitions of disability that take the subjective experience into account. This part of disability studies has mushroomed during recent years, both in publications and at conferences (e.g., Asch, 2004; Fredäng, 2003; McRuer, 2006; O'Neill & Hird, 2001; Omansky Gordon & Rosenblum, 2001; Paterson & Hughes, 1999; Society for Disability Studies, 2005, 2006; Wilson, 2004). Without a subject, there is no identity construction to study.

However, defining disability subjectively is not only a matter for research. As mentioned above, efforts are being made among disability activists and individuals to re-define disability to mean something positive. In this perspective, disability is taken into account as a positive aspect of a person’s identity. I’ll return to this issue later on.

Thus, we can conclude that different definitions develop in order to suit different purposes. In the table below, I have tried to summarize these different purposes and to give some examples of the relevant agents behind them.

<table>
<thead>
<tr>
<th>Type of Definition</th>
<th>Criteria</th>
<th>Purpose (examples)</th>
<th>Agents (examples)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Functional Definition</td>
<td>Disability as a lack of or restrictions of bodily functions.</td>
<td>“Head-counting” in surveys and censuses, assess need for rehabilitation, training, equipment, etc.</td>
<td>Statistical bureaus, medical professions.</td>
</tr>
<tr>
<td>Relative Definition</td>
<td>Disability appears in the relation between a person with impairment(s) and inaccessible surroundings.</td>
<td>Turn the gaze from solely depicting individuals as disabled to the relationship between individuals and surroundings.</td>
<td>Disability movement, policy-makers.</td>
</tr>
<tr>
<td>Social Model of Disability</td>
<td>Disability is the oppression of and a</td>
<td>Turn the gaze from individuals to barriers</td>
<td>Disability Movement</td>
</tr>
</tbody>
</table>
barrier against people with impairments and oppressive processes within society.

<table>
<thead>
<tr>
<th>Administrative Definition</th>
<th>Disabled people are those categorized by the welfare state as being in need of or eligible for certain support systems.</th>
<th>Delimit categories of people eligible for certain benefits and supports.</th>
<th>Welfare authorities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Subjective Definition</td>
<td>People perceiving themselves as disabled, irrespective of the basis of such perceptions.</td>
<td>Identity construction, filter question in censuses and surveys.</td>
<td>Disability movement</td>
</tr>
</tbody>
</table>

But although it is easy to understand why different definitions of disability occur, and even why we may need them, a manifold of definitions can create troubles. Methodologically speaking, one wonders whether different definitions of disability will give rise to different results. For instance, will my way of defining the category of “disabled people” affect the outcomes of my studies? It is these kinds of issues around which the present dissertation revolves.

1.2 Aims of the Study

As has been stated above, disability researchers conceptualize disability in different ways. The purpose of the current study has been to look at different definitions from a methodological perspective. This overall purpose has been broken down into three different sub-purposes. An initial aim has been to map out the different definitions that are used and consider how they are constructed. This aim is foremost emphasized in Article I. A second aim has been to study how disability researchers use disability definitions in practice. This aim is foremost emphasized in Article II and III. Finally, a third aim of the dissertation has been to study whether different definitions of disability affect the research findings. Will different definitions give different results? Are there, for instance, differences in unemployment rates among people defined in different ways as “disabled”? This aim is foremost emphasized in Article IV.

Thus, the reader should keep in mind that the present dissertation does not aim to formulate the ultimate definition of disability. Quite the contrary, while reading the text it should become clear that I strongly reject such an aim.
1.3 Disability in the Present Study

Given that this is a dissertation on definitions of disability, it would certainly be wise to say something about how I use the term myself. I cannot give a general description of how it is used in the articles, because these have been written at different stages in the research process, and my own use of the term has shifted during this time. Thus, my use of the term disability may differ. However, in this introductory text, the frame story, I have tried to be consistent. As will be evident later on, I do not have a preference for a certain disability definition, at least not currently. Thus, I have tried to situate myself outside definitional battles and preferences in my writing. It is not an easy task to strike a balance between different conceptualizations, but I have tried to use expressions that signal a distance to the definitions I am discussing. This is why I prefer to use expressions such as “people categorized as disabled”. However, such expressions are lengthy and might be unnecessarily cumbersome. For that reason, I sometimes use the term “disabled people” or just “disabled”. These two expressions are to be viewed as synonyms to “people categorized as disabled”. Hopefully, the context will explain what “disabled” or “disability” means at any given point.

1.4 A Short Note on Disposition

The present dissertation has been written in a form that in Swedish is called sammanläggningsavhandling. The “official” translation of this term is Comprehensive Summary. This means that the dissertation consists of a comprehensive summary (also called a frame story) and a number of (four in this dissertation) enclosed articles. The purposes of this comprehensive summary (which is the part of the dissertation you are reading right now) are, besides summarizing the research findings, to combine the results and show what they have to say in general. Thus, the articles focus on different “details” of disability definitions, while the frame story takes a broader approach to the question. One can say that the articles have been painted with a small brush and the summary with a broad one.

Because the articles are painted with a small brush, many questions surrounding the writing of these works have not been presented in the articles. But there are of course certain questions and contexts that have guided and affected me during the different phases in which the articles have been written. In order to provide a contextualization of the different works, the next chapter (2) will be a presentation of my journey, from my first tottering steps into this research project until the final phases.

Underlying this research project has been the categorization of certain people as disabled. Categorization per se is not discussed in the articles. However, categorization is a tricky question. Categorizations of people have
proved to be, among other things, a very effective way of oppressing certain groups of people, even executing them. As a rather logical consequence, social scientists (and others) have looked upon the practice of categorizing people with a great deal of suspicion. For this reason, in Chapter 3 I present my perspective on categorization, both its difficulties and usefulness.

In Chapter 4, the overall conclusions of this dissertation are presented. Based upon these, which mostly express the dilemmas of contemporary use of disability definitions, I suggest some remedies for the problems I have identified.

Finally, Chapter 5 summarizes the enclosed four articles. The frame story ends with acknowledgements and references.
2 Context and Methodology

As mentioned, most of the research I conducted during my time as a Ph.D. student has been presented in articles. The article form seldom gives you the opportunity to discuss the context in which the article was written. But there is, of course, a story behind every written work. And, I think many will agree that, as a Ph.D. student, your thoughts on your topic shift rapidly. In my works this is rather easy to trace. I started out thinking mostly as a positivist, but end up with a rather decomposed perspective on disability definitions. In order to help the reader understand this journey, this section will provide some details on the different contexts and thoughts that have affected me in different stages. This is also an attempt to offer some methodological remarks on articles, in cases where it feels necessary to continue the rather compressed descriptions provided in the articles. In addition, in the end of this chapter, I will express some of my “bird’s-eye-view experiences” of studying other disability researchers’ work on disability definitions.

It might be wise to read the articles, or at least the summaries in Chapter 5, before you continue reading the present chapter, which presupposes some knowledge of the content of the articles.

My journey began more than a year before I started the graduate program. I was working as an analyst at the National Social Insurance Agency, specializing on the situation for people receiving support directed to people categorized (administratively) as disabled. Rather quickly, I realized that the picture of the living conditions of this category could easily be summarized with three words: not so good. In 2001, the Welfare Commission published their report on the development of welfare and living conditions for disabled people in Sweden. Their results showed a more positive picture of the living conditions than my data did, although some of their findings were depressing. This got me rather interested in the fact that different studies on disabled people gave considerably different results. In these first stumbling steps into the field of disability definitions, I could conclude that both the welfare commission and myself were using definitions of disability that were closely

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1 In February 1999, the Swedish Government appointed a special “Welfare Commission” whose task it was to describe and assess the development of welfare in Sweden during the 1990s, i.e. to write a “Welfare Balance Sheet”. The background was the great economic recession in Sweden during the same time, which had great impacts on the welfare system. An English summary of the whole work of the Commission can be found in Scandinavian Journal of Public Health, 2003, volume 31, supplement 60.
related to the body, i.e. definitions based upon functional limitations. The difference, though, was that the welfare commission was using a “traditional” functional definition, while I was using data produced using an administrative definition of disability.

While I was becoming more and more interested in this issue, the Swedish Council for Working Life and Social Research (FAS) published an evaluation of Swedish Disability research (Albrecht, Jette, Petrie, & Siegel, 2001). In this report, the evaluators expressed, among other things, a great fascination with our Swedish system of keeping records, concluding that

> [t]he national system of record keeping in Sweden and access to nationally representative panels and cohort studies is a strength and could be exploited to facilitate disability research. Disability research should be encouraged to capitalize on the availability of these data (p. 6).

This was something that attracted my interest. My experience from the National Social Insurance Agency was that large bodies of data were gathered and archived at different authorities, but that these data remained unknown to researchers. I was rather convinced that a number of interesting disability research projects could be based on these data, but I was still trying to solve the definitional puzzle. How was disability conceptualized in these registers?

During fall 2001, I had the opportunity to meet and discuss my thoughts with Professor Mårten Söder, who later became my supervisor. We decided to write an application for research funding based upon both the definitional problems and the evaluation group’s observations of the national records. Our application was accepted by FAS, and the journey started in January 2003.

At this time, I was rather passionate about finding a way to correct the inconsistencies caused by the different definitions of disability. Even if I had accepted the fact that different definitions of disability existed, I understand in retrospect that I found it very hard to accept that they gave different results. What disability research needed, I thought, was a way to adjust incorrect results. I was rather convinced that my dissertation would present a way to free results from the bias caused by choice of definition and to instead obtain the true values. Today, I would probably put citation marks around both incorrect results and true values, but at that time, I was certain my project was to develop “Grönvik’s method of adjustment of disability data”. However, this eagerness decreased progressively during the work on this dissertation, and now, four years later, I have no intention to adjust any data.

In the following sections, I will make some comments on each of the four articles. The length of these comments varies. Some of the articles have rather complex stories, while others have been the result of relatively smooth work.
2.1 Sorting the Field: Article I

My first step in this project was to map out the different definitions of disability present in contemporary disability research. This part of the project, aimed at getting a grip on things, was focused on in the first article. I had already identified two different ways of defining disability, functionally and administratively. In addition, because I had been working within welfare authorities and evaluating disability policies, I had been in contact with the Nordic environmental definition. Thus, I could identify at least three different definitions of disability.

At this moment, I also came across two other ways of defining disability: subjectively and according to the social model of disability. But this phase also put me in contact with different critiques of these definitions. One such critique has been elaborated from feminist perspectives, criticizing the disappearance of the body and the individual in environmental models, such as the social model of disability. Another critique, related to this feminist position, is the postmodern suspicion toward the possibility of creating universal and all-embracing definitions of disability. Both these two critiques are addressed in the article. However, I have not depicted them as established definitions. I think they have contributed relevant critique against established definitions, but I cannot say that they have suggested alternatives. Feminist approaches to disability tend to vary considerably, something I think is analytically useful; instead of “closing” this perspective to only one approach, feminist researchers have launched several analytical frameworks. But this also makes it difficult to identify the feminist definition of disability.

Regarding the postmodern approaches, the very creation of the postmodern definition of disability would be a paradox. The very idea of postmodern thought is the fluidity of such definitions.

My classification of these two perspectives as approaches rather than definitions may be interpreted as a critique or as an inferiorization of them. Quite the contrary, I think there is great potential in taking a critical position instead of launching still another definition of disability.

As you can see, I start this article with the statement that I regard disability as a social construct. However, I rather quickly add what may be called a traditional quantitative vocabulary. I state that it is necessary to have clear theoretical definitions and corresponding operational definitions. There are two reasons for jumping between a traditionalist quantitative perspective and social constructivism. The first reason is rather simple, the other more complex. Starting with the simple reason, one way for me to grasp this question of how to analyze the use of disability definitions was through an article by Aspinall (2001). In his article, Aspinall examines how data on ethnicity are collected in sociological studies of health and illness. He discusses both how ethnicity is operationalized and how it is theoretically conceptualized. This inspired me to start looking at whether disability definitions could be exam-
ined using the same kind of framework, i.e. by studying how disability researchers define disability theoretically and operationally, and how these two definitional levels were interrelated (validity). This way of thinking followed me for a long time. I knew it was not the ultimate way of thinking about disability, but I could not find another (methodological) way to do this. Actually, it was only rather late in the project that I understood that what I was looking for actually was lacking. I will return to this in Chapter 4 on case-constructing reflexivity.

The second reason is more complex and illustrates an ambivalence that has followed me throughout this project. This has to do with the rising understanding of disability as a social construct, something that clashed with my considerable interest in empirical research, which more or less requires empirically identifiable cases. How could I reconcile the rising understanding of disability as something that is not “real” and still empirically study the “reality” of it? This ambivalence, together with my preoccupation with a theoretical vs. operational framework, explains the somewhat irrational shifts between two rather different standpoints in this article. In Chapter 3 and 4, one possible way of handling this question is discussed.

First, I was a bit doubtful about including this article in my dissertation. I didn’t think it had anything substantial to say; it was only a “map” of different definitions. But I concluded that if I didn’t focus on this question in one of the articles, I would have to do it here in the frame story, only to introduce readers to the area of disability definition. In retrospect, I can conclude that it was a correct decision to include this article.

2.2 Deepening the Analysis of Disability Concepts: Article II

In the second article, I delved into the disability research discourse more deeply. I was interested in understanding how researchers use the concept of disability in their research. I did not aim at providing a full picture, but at collecting a sample of texts that disability researchers felt were central to their work. My own knowledge of what were considered the central texts in this discourse was of course limited. In order to get some help with identifying such texts, I sent out an e-mail to a mailing list for disability researchers.2 This gave rather scanty results. However, I did get some suggestions, but mostly related to authors, not specific texts. I discussed the suggestions with some colleagues who helped me identify names to focus on. I checked, rather randomly, some textbooks on disability research from both the US and the UK to see which works of these authors were cited. As with many review

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2 The Disability Research mailing list operated by Centre for Disability Studies, University of Leeds.
articles, my sampling was quite eclectic. However, sampling is always selective, which means that certain directions in or perspectives on disability research were not sampled in this part of the project. Significant to the sample I selected is that new directions in disability studies are not represented. Among these, queer perspectives, postmodern perspectives and feminist perspectives can be mentioned. One must keep in mind, however, that this sample of texts does not have any ambition to cover the whole body of central works, but is only a very small sample thereof. However, even if I did work with a small sample, I am rather convinced that I covered such variation that my purpose was achieved. Additional texts would hardly have altered the results. Even after finishing my work on this article, I have found the same kind of problems in other texts on disability issues. For that reason, I regard my findings in this article as quite solid.

As mentioned, my data consisted of texts. However, I did not apply any conventional methods of text analysis. As described above, my interest in these texts was rather limited; I was focused on discovering how they were using the concept of disability. As a consequence, my way of analyzing these texts focused on identifying passages in which I could recognize the authors’ way of using the concept. After examining the texts, I was able to conclude that denotations of disability occurred in two different forms, a rather direct form, which I call stipulative definitions, and a more indirect or contextual definitions, something I call applied definitions. Thus, my analyses of these texts focused on identifying these two kinds of definitions and checking the correspondence between them. This strong emphasis on (and limitation to) definitional issues makes it hard to put an established “label” on my way of analyzing the texts. Certainly, it is a kind of concept analysis, but my analytical procedure cannot easily be compartmentalized.

My early strategy to approach disability definitions via a theoretical vs. operational definition scheme can also be traced in Article II. In an early phase of the analysis, I was using theoretical instead of stipulative definitions, and operational instead of applied definitions. Also, validity was used instead of consistency. But that terminology caused major problems. First, most of the texts were not based upon quantitative empirical studies. Rather, they mostly consisted of theoretical and qualitative studies. Second, I could conclude early on that the problem was not only related to the relationship between theoretical and empirical aspects of their studies; there were definitional problems with the texts that were not related to such a clear-cut division. For this reason, it was during the work on this article that I finally abandoned the theoretical-operational definitional scheme. I re-read the texts and could conclude that the problems were foremost related to issues of when researchers make statements on what disability is and how researchers use the concept in relation to their empirical work or in secondary analyses of already published results.
2.3 Rich Data, but Bad Theories? Article III

As mentioned in the beginning of this chapter, one of the purposes of the present project has been to find out whether and how administrative registers could be used in disability research – a purpose that was included owing to the interesting comment on national records in the evaluation of Swedish Disability Research (Albrecht, Jette, Petrie, & Siegel, 2001). This part of the project was mostly focused in this work, Article III.

This was probably the most difficult article to write. What I try to do here is discover whether our manifold records on Swedish citizens can be used in disability research. I have always been interested in quantitative methods, especially when applied to large data sets. At the same time, and somewhat emphasized when I wrote this article, I have been fascinated by what the environmental turn in disability research discourse has implied. However, administrative definitions of disability tend to conceptualize disability as an individual property. I concluded that these administrative registers could provide disability researchers with rich data on living conditions, but with few possibilities to combine them with contemporary theories of disability, running the risk of facing the same dilemma as Tøssebro and Kittelsaa (2004) have formulated so well:

The problem with most studies of 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 […] (p. 23).

This article is a good example of the ambivalence I have been facing throughout this entire project. I saw all the possibilities to conduct great empirical studies, but I also saw the limited possibilities to work with the concept of disability in a thoughtful way. But such work is not completely impossible; there are options, which I will return to in Chapter 4.

2.4 Disability and Statistics: Article IV

When I began the present research project, I was rather convinced that it would be mostly an empirically based project. My initial plan was to conduct a comprehensive survey in which “disabled people” would be asked to answer different items, which would enable me to construct different definitions of disability. Asking whether they had any functional limitations, received any support directed to disabled people, and whether they experienced any barriers in society would allow me to create categories of people who are functionally defined, administratively defined and defined as dis-
abled according to the social model of disability. However, rather early in the project, I discovered a crucial difficulty with this method. Most likely, people would mark “yes” on both questions on functional limitations, receiving benefits from the welfare system, and experiencing barriers in the society. Consequently, I would face the problem of rather extensive overlaps. Several of the statistical techniques I was planning to use, and used, are sensitive to dependence between categories that are compared, i.e., when a case represents more than one category. Thus, I would not be able to make the kind of comparisons I had intended to do. I had to abandon the idea of conducting a survey. What I needed was samples based upon different definitions of disability, samples that were independent of each other. In parallel with my initial investigations for Article III, I discovered that there was a possibility to obtain the kind of data I needed through registers and surveys at different welfare authorities and Statistics Sweden. It was not possible to obtain data on all of the definitions I present in Article I, but at least three of them were represented in available data: functional, administrative and subjective definitions. Thus, I decided to limit the number of definitions to compare and started to elaborate a study based upon secondary data. Early after I made this decision, I contacted Statistics Sweden to get the data I needed. However, it took Statistics Sweden almost two years to process my request, which forced me to spend more time on theoretical studies than previously planned. In retrospect, I think the delays at Statistics Sweden had some benefits. They gave me the opportunity to delve rather deeply into the theoretical questions of disability definitions, which helped to prepare me for my empirical analyses.

In late fall of 2005, my data finally arrived and I was able to study the consequences of different definitions empirically.

2.5 A Pitiful Dichotomy

In parallel with my work on this last article, I had the opportunity to spend three months at the Disability Statistics Center (DSC) at University of California, San Francisco (UCSF). Being at the DSC and talking to people who were facing this issue in their everyday work was an amazing experience. Also, I had full access to the Center’s file cabinet. This was a goldmine for me. They had collected almost everything written in English on measurement and definitions of disability. Most of these texts were not accessible from Sweden, mostly because they were not listed in the databases I had access to at Uppsala University. Suddenly, I was able to review what Americans had been doing on this topic since the early 60s until today. What I didn’t know when I arrived in the US was that this topic had been a major question there during the 60s. The reason was that the Social Security Administration (SSA) was concerned about the lack of proper data on which
to base forecasts of the costs of disability benefits. They were in need of better data on the distribution of disability among American citizens. This made it possible for a group of researchers (mostly sociologists) to research different notions of disability.

But reading these early texts also made me rather certain about something that I had suspected for quite some time: There seemed to be a rather distinct division between researchers interested in disability definitions, a division that separates those interested in disability in theory and those interested in disability in empirical research. Theoreticians did not seem to make any effort to apply their thoughts to empirical science and empiricists showed little interest in theory. This matter can be illustrated by an interesting event that took place in 1997. Sheri Tepper and her co-researchers (Tepper, Sutton, Beatty, & DeJong, 1997) published an article in Disability and Rehabilitation showing how figures on disability prevalence in the US were highly affected by the choice of definition and also that the estimate of care expenditures shifted greatly between these different definitions. This article caused plenty of discussion and two years after it was published, the same journal published no less than six comments on the original article (Chatterji, Ustun, & Bickenbach, 1999; Cwikel, 1999; Joslyn, 1999; Kriegsman & Deeg, 1999; Mehlman & Neuhauser, 1999; Pfeiffer, 1999). However, none of the commentators actually made any substantial references to contemporary theoretical achievements in the field. Generally speaking, they were all fixed in an operationalization of disability as an individual phenomenon, neglecting all new thoughts of disability as something that is environmentally constructed. At the same time, theoreticians showed no interest in this debate. The article by Tepper et al. and comments on it have never been discussed or referred to in the flagship of disability theoreticians, the journal Disability & Society.3

Both the theoretical and the empirical directions are certainly needed. But lack of cross-fertilization has been a rather frustrating phenomenon for researchers who understand research as a question of both theory and empirical data (Eriksen & Næss, 2004; Shakespeare, 2005a, 2005b; Söder, 1987, 2004; Tøssebro & Kittelsaa, 2004).

To me, this division is closely related to my own ambivalence, mentioned above, between empirical research and theoretical knowledge of disability as a social construct. Thus, when I, in my dissertation, try to situate myself in between these two approaches to disability definitions, I share the same frustration as the authors mentioned above. This ambivalence/frustration has, as mentioned, followed me since the beginning of this project. But I think it is possible to handle this problem – to combine theoretical/constructivist insights with “hard-core” empirical research, something that I discuss in the following two chapters.

3 According to Social Sciences Citation Index, accessed March 5th, 2007.
3. Categorizing People

Categories of people and categorization have been contested topics in social sciences. The most evident reason for this, I think, is the fact that categories have a tendency to become assumptions about the natural. Certain people are behaving in a certain way because they belong to a certain group. Categorization, then, gives us the opportunity to explain certain actions. Women, for instance, enjoy care-taking because they are women. “Womanhood” explains why women take parental leave to a larger extent than men do. This kind of causal explanation based upon different categorizations has been challenged within the social sciences, i.e., in terms of gender (e.g., Butler, 1990; Kroon, 2007), sexuality (e.g., Jagose, 1996; Turner, 2000; Warner, 1999), and ethnicity (e.g., hooks, 1994).

The present dissertation revolves around the categorization of certain people as “disabled”. While some disability researchers have taken this category for granted, others have challenged the very possibility of grouping people in this way. To me, this has been a rather ambivalent issue throughout my dissertation work. As I say in Chapter 2, my great interest in empirical (disability) studies, which more or less require identifiable cases, has clashed with my increasing understanding of disability as a construct. Thus, I am rather suspicious about speaking of “disabled people” (or “disabling environments”) in a general way, but at the same time, my empirical interest in these kinds of studies is based on identification of certain people as “disabled” or certain environments as “disabling”. Reading works in which disability has been treated from a naive realist perspective has made me critical of such texts based on their unreflected use of the concept, but reading hard-core constructivist texts on the same topic has made me critical of these texts’ lack of empirical applicability. Is it possible to find a position from which cases are categorized in order to be researchable, but that also takes into account the notion that disability is a construct? I do think that there are possibilities to work from such a position. But before I get into this, some additional background discussion is needed.

From a simplistic perspective, categorization can be seen as labeling process. We call certain things apples, others pears; some people are heterosexuals, others homosexuals. The names are only “stickers” glued onto natural phenomena. This can be viewed as a realist approach to categorization. Others may think that the world actually is constituted by these labels.
Unless we invent the terms females and males, there will not be any males and females. The distinction between social constructionist and realist approaches to categorization has been described by Jonathan Potter in the following way:

In realist discourse, where language is the mirror of nature, categorization is understood as a rather banal naming process; the right word is assigned to the thing that has the appropriate properties. In contrast, in the discourse of the construction yard that I have been elaborating, categorization is much more consequential. It is through categorization that the specific sense of something is constituted (Potter, 1996, p. 177. Emphasis in original.).

The rather convincing impact of such notions – that categories “make up” the world, rather than merely naming it – has been shown empirically by, among others, Michel Foucault (1965; , 1991). In fact, Foucault’s focus was not so much on the particular field he was researching, but on the very construction of the subject and the objectification of such subjects within these different fields (Rabinow, 1991).

Scientists interested in the invention of such categories have showed, convincingly, how instable these categories are. Truths about dichotomies such as woman/man, homosexual/heterosexual, black/white, for instance, have been challenged, and these taken-for-granted dichotomies have been deconstructed. As a result of such endeavors, voices have been raised in support of abandoning the use of categories. One core argument coming from such anti-categorical standpoints has been that the continued use of categories will reproduce the inequalities and oppressions that have become possible through categorization. That is, if we deconstruct a category, we also deconstruct the inequalities deriving from the category (McCall, 2005). Racism, homophobia and sexism are possible because of categorization on the basis of race, sexuality and gender.

History is rich with examples of this kind of oppression. Turning to disability, the categorization of certain people as “abled” and others as “disabled” has enabled limitations of the civil rights of the latter group.4

As a consequence of such limitations, deconstructive traditions have been, and are, present within the disability studies discourse as well. One such strategy involves introduction of the concept differently abled. This is used

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4 Restrictions in marrying (Carey, 2003) and involuntary sterilizations of people categorized as disabled, for instance, have been a state-sanctioned practice all over the world (Engwall, 2004; Park & Radford, 1998; Runcis, 1998). Furthermore, eugenics has been an established practice in the US and Europe (emphasized during the Holocaust) in order “to engineer a ‘healthy’ body politic (Mitchell & Snyder, 2003, p. 844).” Even if these cruelties belongs to the past, some argue that this dark history has been put into practice again, through prenatal diagnostics and genetic screening (Kerr & Shakespeare, 2002; Le Breton, 2004). A new era of eugenics is under way, it is said. Such modern eugenics is made possible by categorization according to the abled/disabled dichotomy.
to break the dichotomy between disabled/abled, arguing that the category of disability is made up of ableist reasons. The strategy has been criticized, however. Eli Clare calls it a strategy used by non-disabled people to “cushion us from the cruelty of language (…)” (Clare, 1999, p. 69). Similarly, Nancy Mairs says that differently abled partakes of the same semantic hopefulness that transformed countries from “undeveloped” to “underdeveloped”, then to “less developed,” and finally to “developing” nations. People have continued to starve in those countries during the shift. Some realities do not obey dictates of language (Mairs, 1986, p. 10).

However, some disability researchers have identified the potential of deconstructing the abled/disabled dichotomy. A substantial development of such thoughts can be found in the works of Lennard J. Davis (Davis, 1995, 2002a, 2002b). In his deconstruction of the disabled/abled dichotomy, he takes the invention of normalcy as a starting point. According to Davis, disability arises as a consequence of the invention of the “average man”. This made it possible to show averages (interpreted as normal values) for a wide range of parameters of the human body, such as blood pressure, blood sugar level, etc. This invention of the “normal” allowed identification of people who deviate from normality, i.e. disabled people. Thus, Davis advocates abandonment of “normality” as a basis for categorizing people. Instead, he thinks of us all as disabled in contemporary society, or as Davis writes, within “dismodernism”. It is not only those categorized as disabled who need different kinds of helps and aids (such as different kinds of technology). We are all dependent on certain technologies, experts and so forth. Thus,

[i]n a dismodernist mode, the ideal is not a hypostatization of the normal (that is, dominant) subject, but aims to create a new category based on the partial, incomplete subject whose realization is not autonomy and independence but dependency and interdependence. This is a very different notion from subjectivity organized around wounded identities; rather, all humans are seen as wounded (Davis, 2002a, p. 30)

Based on these kinds of thoughts, it has been stated that there is a subversive potential in the deconstruction of socially constructed categories. Subsequently, the use of categories for methodological reasons within the (social) sciences has been met with suspicion. The logic here is that researchers applying such categorizations are more likely to reproduce inequalities than overcome them.

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Footnote 5: The invention of these kinds of thoughts is connected to the Belgian statistician Adolphe Quetelet (1796-1874), who, at the beginning of the nineteenth century, began measuring certain physical properties of the body to determine how the “average man” was constituted.
But there are researchers who have tried to find a position from which the use of categories can be defended, while still keeping a critical position against the tendency to think of categories as truths. McCall (2005) has tried to find such a position. She has proposed an *intercategorical approach* that begins with the observation that there are relationships of inequality among already constituted social groups, as imperfect and ever changing as they are, and takes those relationships as the center of analysis. The main task of the [inter-, *my insertion*]categorical approach is to explicate those relationships, and doing so requires the provisional use of categories (p. 1784-1785).

McCall’s point is that such use of categories will focus on the relationship between categories, rather than on the characteristics of people within a certain category. This is not a case of simply retaining categories; what McCall suggests is an analytical position that is far more complex than only stating that categories exist and are indispensable for (social) research. As a consequence, categories are not suitable as points of departure in research, i.e. as a premise for being able to study a certain group; rather, the *relationship* between categories will be the focal point. To exemplify, using this approach in disability studies means that “disabled people” cannot be studied unless the relationship between “abled” and “disabled” is studied. As stated in the excerpt above, the intercategorical approach to research aims at explaining this relationship, rather than at taking the category of “disabled” for granted. And such an endeavor presupposes the use of categories.

I am rather strongly attracted to McCall’s approach. I think that there is potential in using already established categories. One rather evident reason for such approach is, as mentioned, the possibility it gives to study inequalities. Although we may prefer a society without patriarchy, racism, ableism and so on, it is rather difficult not to notice that such phenomena exist. Moreover, there is, I think, a political risk in the deconstruction of categories. The administrative definition of disability, for instance, functions as a distributive category, the intention being to support people with certain needs. If disability as a category were to be abandoned, then the transfer of welfare would be a rather tricky task. Thus, as Söder (1989) states,

> [t]he social meaning inherent in those ideologies [non-labeling approaches, my note] – that disability is nothing dramatic and disabled persons should be treated ‘as if’ they did not have any disability – neatly fits the ambitions of forces that want to reduce public spending (p. 125).

Additionally, what also complicates the complete rejection of categories is that several categories that formerly have been considered marginalizing have later been redefined in terms of, for instance, power and pride, e.g. Deaf Power, Black Power, Gay Pride (Solvang, 2000). Thus, abandoning
certain categorizations implies that it will not be possible to hold certain identity positions.

Although I am attracted to McCall’s deliberate position, there are also problems with this approach. McCall has a rather unproblematic relationship to “already constituted groups”. In her article, she seems to imply that researchers have some kind of direct access to these constituted groups. The problem, according to McCall, does not seem to be how these “already constituted groups” are represented in research; rather, the problem she points out seems to be that these groups tend to be numerous:

[...]the incorporation of gender as an analytical category into such an analysis [in which several categories are added] assumes that two groups will be compared systematically—men and women. If the category of class is incorporated, then gender must be cross-classified with class, which is composed (for simplicity) of three categories (working, middle, and upper), thus creating six groups. If race-ethnicity is incorporated into the analysis, and it consists of only two groups, then the number of groups expands to twelve. And this example makes use of only the most simplistic definitions (McCall, 2005, p. 1786).

I would say that even “the most simplistic definitions” are problematic. Even if a researcher, in line with McCall’s arguments, is aware of the instabilities and imperfections of already constituted groups or categories, s/he will find that these categorizations are represented in several ways “out there”. It is not only a matter of “picking” the abled/disabled categorization (or class categorization for that matter); the researcher must make a decision on how this dichotomy is to be represented in her/his research. And irrespective of the level of “simplicity”, this decision gives rise to several questions. How is this dichotomy best represented with respect to my research question? What kind of data are available? As Article IV shows, such decisions may have considerable effects on the results. Thus, there is something lacking from McCall’s approach, something that I think can explain several of the findings obtained here. This “something” is an awareness of how we create the categories we use in our research. The next chapter will discuss this topic in depth. But first let us recall the major findings of the present dissertation.
4. Conclusions: The Future of Disability Definitions

In brief, the findings presented here are as follows:

- Several definitions of disability are in use in contemporary research. They sometimes have conceptual similarities, but are more often contradictory. Disability sometimes has to do with a human being, sometimes with an environment and sometimes with an identity.

- Classical works on disability contain considerable definitional problems. How disability is defined fluctuates greatly both within and between the different works analyzed in Article II. Frequently, these texts suit as springboards to contemporary definitional approaches, implying that historical dilemmas in disability conceptualizations reoccur.

- Different definitions of disability will lead to great differences in research outcomes. This was known prior to the present project, but the research presented here shows that the impacts of definitions on outcomes (e.g., level of living indicators) are even greater than we have previously realized.

There are those who consider these kinds of findings problematic. Tepper, Sutton, Beatty and DeJong (1997), for instance, have conducted research similar to mine, and they have called for standardization of disability definitions. This would, according to them, solve the problems pointed out above. The most widely known attempt is probably the *International Classification of Functioning, Disability and Health*, in which, it is said, desires for a standardized and universalistic definition are satisfied (Bickenbach, Chatterji, Badley, & Üstün, 1999; World Health Organization, 2001; Üstün et al., 2001).

However, such attempts are what Dimitris Michailakis, from his perspective based on Luhmann’s system theory, calls
... theoretically naïve. There is no single observation position, no single distinction, and no system from which one can observe the individual in relation to all aspects: biological, psychic and social (Michailakis, 2003, p. 219).

This is also, I would add, a statement based on an unsatisfactory understanding of why different definitions of disability exist. As I discuss in the introduction, it is not a matter of chance that several definitions of disability have been developed.

Thus, different definitions suit different purposes. Consequently, universalizing the disability definition will only create an analytical rigidity that I think we should try to avoid. Instead, the study aim should determine what type of disability definition is applied.

However, although it is quite easy to defend as well as endorse the existence of diversified definitions of disability, we still have some major methodological issues that need to be dealt with. The articles in the present dissertation point out the need for more thoughtful work on definitional issues. In this chapter, I will present some ideas on how this can be done, but first let us take a look at some plausible reasons for the apparent lack of such thoughtful work.

As stated earlier, the problem of definition is not limited to the field of disability research. Quite the contrary, definitional dilemmas seem to characterize fields focusing on people defined using what is sometimes called “soft-data”⁶ (Bulmer, 2001; Petersen, 1986). This leads to the suspicion that there is something general, rather than particular within the disability research field that creates this problem. There are probably several reasons, but I have identified one that may explain this issue.

Owing to my interest in methodology and the methodological focus of this dissertation, I have combed the market for books and articles on methodology. Unfortunately, these have mostly been a source of frustration rather than help and inspiration. This is because my primary interest has not been in the construction of items and questionnaires, how to conduct interviews or observations, or how to be a really sophisticated data analyst; rather my interest has been in questions of how populations and/or cases (i.e., units of analysis) are defined in empirical settings. But such discussions are seldom, I can almost say never, provided. One possible exception is the anthology What is a Case?, edited by Ragin and Becker (1992), in which the contributors try to sort out what cases are. However, the authors’ perspective is from the sociology of knowledge and they provide little help for someone interested in the issues addressed here.

⁶ In this context, soft-data should not be confused with the Swedish soft-data debate (a debate between proponents of qualitative methods versus proponents of quantitative methods, during the 60’s). In this context, Petersen (1986) is using “soft-data” to tag such characteristics that tend to fluctuate in conceptualizations. In contrast, Petersen depicts characteristics such as age and gender as “hard-data".
The continuing lack of descriptions/discussions of constructions of populations/cases (and impacts of such constructions) in methodological texts might actually constitute the problems being studied in the present dissertation. Frankly speaking, as social scientists, we are not trained to put time and effort into this part of the research process. We might be highly skilled in taking representative samples and getting behind gatekeepers, but we generally lack skill in analyzing our own construction of our cases.

Let us look at two empirical examples, one from a book that is mainly about qualitative techniques and one from a book about quantitative techniques. In their book, *Ethnography*, Martyn Hammersley and Paul Atkinson (1995) give the following description of the “people” sampled:

> The sampling of persons may be undertaken in terms of fairly standard ‘face-sheet’ demographic criteria. That is, depending on the particular context, one may sample persons by reference to categories of gender, ‘race’, ethnicity, age, occupation, educational qualifications, and so on (p. 50, emphasis added).

Ethnicity, for instance, as well as disability and other created categories of people are notorious for being difficult to delineate (e.g. Aspinall, 2001; Petersen, 1986). But when the same concepts are applied in research in the sampling process, they suddenly lose their well-known ambiguity. It is, I think, rather perplexing when Hammersley and Atkinson depict sampling as something that can be accomplished by following “fairly standard ‘face-sheet’ demographic criteria.”

The same kind of neglect can be found in the realm of quantitative methods. In *Research Methods in Social Sciences*, (Frankfort-Nachmias & Nachmias, 1996, p. 180, emphasis in original) provide the following definition of a population:

> A single member of a sampling population (e.g., a voter, a household, an event) is referred to as a sampling unit. Usually, sampling units have numerous attributes, one or more of which are relevant to the research problem.

Note that the above excerpt is not followed by any discussion of the problem of considering sampling units as having “numerous attributes”. From my perspective, it would be more apt to think of these attributes as ascribed.

What we need, but what I feel we lack today, is what I would like to call case-constructing reflexivity. By this, I mean a constant awareness of our choice of definitions and of the consequences of choosing definitions.⁷

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⁷ In this context, case refers both to the quantitative and the qualitative sphere. Quantitative researchers may be more comfortable with the term “respondent”, while qualitative researchers probably prefer the term I have chosen, case.
By using the term *reflexivity*, I run the risk of putting myself in the middle of a rather complex conceptual debate. In contemporary social sciences, the term reflexivity refers both to a concept in social theories (e.g., Giddens, 1991) and to the awareness among researchers that they are selves and subjects in knowledge production, i.e. emphasizing the influence of the researcher’s subject positions on the knowledge that is produced. This represents both a movement away from the problematic idealistic norm of “objectivity” and an awareness of the impossibility of “looking from nowhere” (Pillow, 2003). As the concept of reflexivity is used in the present context, it is more related to the latter than to the former.

There is, however, no generally accepted definition of what reflexivity implies as a methodological matter. For the present purposes, it is sufficient to view reflexivity as

> [...] an ongoing self-awareness during the research process which aids in making visible the practice and construction of knowledge within research in order to produce more accurate analyses of our research (Pillow, 2003, p. 178)

Reflexivity as a methodological question has been celebrated, foremost within qualitative research. It has also been looked at as a possibility to increase the validity of qualitative research and as a means of giving research a sounder basis on which to build representations of “the other”. This, of course, has been a major question in ethnography, given its basis in colonial history (privileged white men going to remote places to observe and describe primitive tribes, as if this were possible from an objective, non-position standpoint). Reflexivity, then, has been thought of as a way to introduce a critical consciousness among researchers

> [...] of how the researcher’s self-location (across for example, gender, race, class, sexuality, ethnicity, nationality), position, and interests influence all stages of the research process (Pillow, 2003, p. 178)

Even if proponents of reflexivity state that this awareness should follow the researcher through the entire research process, we can easily conclude that reflexivity seems to occur in some phases, but not necessarily in others. The original claim, as depicted above, has to do with the representation of the other. This issue will affect both the choice of research topic, data collection (*in situ*), data analysis and presentation of results. As a consequence, texts on reflexivity in ethnography emphasize these phases of the research process (e.g., Davies, 2002; Denzin & Lincoln, 2003; Ellis & Bochner, 2003; Ham-

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8 To Giddens, reflexivity is a characteristic of late modern society. As the power tradition has over people’s way of living decreases, it has become increasingly important for people to reflect upon how they are living, what constitutes them, and how they would like their life course to be, characteristics that Giddens gathers in the concept reflexivity.
mersley & Atkinson, 1995; Lincoln & Guba, 2003; Pillow, 2003). During data collection, for instance, Hammersley and Atkinson (1995) suggest that

By including our own role within the research focus, and perhaps even systematically exploiting our participation in the settings under study as researchers, we can produce accounts of the social world and justify them without placing reliance on futile appeals to empiricism, of either positivist or naturalist varieties (p. 21-22).

Turning to the question of representation, some ethnographers have tried to limit their own authority as a “presenter” to such an extent that they “[…]hand the presentation over to the ‘other’ by employing extensive use of transcripts of recordings with little or no commentary or overt analysis (Davies, 2002, p. 16).”

What is not emphasized, though, is the researcher’s *a priori* construction of “the setting” and “the other”. How were these discovered? How were they chosen? Such questions indicate an often-neglected part of reflexivity, namely construction of the case. The texts referred to immediately above show the same kind of shortcomings as does the text on sampling referred to earlier. Irrespective of the many reminders of the need for reflexivity in the research process – the need to reflect upon the researcher’s construction of the case – the unit of analysis tends to be under-communicated. That construction of the case is not taken into account is mainly explained, I think, by the fact indicated above: As social scientists, we are not trained to reflect upon our construction of cases. That is why efforts to underscore the need for reflexivity in the research process have not taken notice of the stage in which the case is constructed.

As stated, I argue that reflexivity is also of great importance to the construction of the research subject as a case. Whether this construction is based upon common taken-for-granted assumptions about disability, prior research, ideological standpoints, the position of the researcher or, more likely, a mix of all these, it is vital that we determine how it affects the outcome.

Moreover, case-constructing reflexivity is not only about keeping track of the researcher’s construction of the case, it is also a question of reflecting upon the connection between the specific research question and how disability is defined based on this question. This means that it is not enough to tell how disability has been defined in a certain study, one should also provide an explanation of why.

Thus, when introducing the term case-constructing reflexivity, I am not solely referring to the “confession-tales” (e.g., Ellingson, 1998) of the researcher as a subject. This is also a matter of being able to present some kind

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9 However, it should be mentioned that especially ethnographic works sometimes contain interesting descriptions of how certain people or settings are discovered. But the effects of this discovery on results, analyses and conclusions are seldom reflected upon.
of rationale (both to oneself and to the reader) for why the case (disability) has been defined as it has.

I have tried to keep this introduction of case-constructing reflexivity as general and as applicable as possible, irrespective of methodological preferences. However, there are differences between, for instance, qualitative, quantitative and secondary analysis research techniques that cannot be overlooked. Let us look at some examples of these techniques.

I think many would agree with the claim that quantitative research has more “fixed” phases than qualitative research does. One example of this is sampling and data analysis. In quantitative research, sampling is always carried out before data analysis, while in qualitative research, these phases tend to be merged. In fact, initial data analysis may affect subsequent sampling. Thus, in quantitative research, case-constructing reflexivity will be an issue when making decisions on sampling frames. The researcher has to decide how disability is best represented in the study. Functionally? Administratively? Subjectively? Environmentally? As Article IV shows, this decision will affect the research outcome.

But case-constructing reflexivity does not only concern decisions related to sampling. It is also relevant during data analyses. In quantitative research, the question concerns how my decisions on the construction of the sampling frame may affect my results. Thus, case-constructing reflexivity is an ongoing process, but may be more emphasized during some steps.

Qualitative research follows a different logic. For the most part, qualitative sampling techniques, such as snowball sampling, do not make any *a priori* definitions of the sample of cases. This means that, to the qualitative researcher, the process of case-constructing reflexivity will be an inductive matter, i.e. during the analysis and construction of conclusions, he/she must reflect upon the impact of how the cases were created. There are some examples of this kind of inductive theorizing in relation to disability definitions. Although the setting is quantitative, researchers have restructured theoretical definitions from operational definitions (Burkhauser, Weathers II, & Schroeder, 2006). In this example, the ICF was used as the theoretical benchmark for the questionnaire items that were analyzed. Case-constructing reflexivity in qualitative research does not necessarily have to be based on such theoretical starting points. Another, probably more attractive, route is to use field notes and documentation on how, where and when cases were selected/contacted. However, the question is not so much about how case-constructing reflexivity is concretely conducted; the core question is that such reflexivity is in fact performed.

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10 Of course, there is always a first step, i.e., the first person that the researcher contacts (something that certainly is a subject to case-constructing reflexivity), but subsequent cases are not necessarily defined by the researcher.
Turning to secondary analysis, case-constructing reflexivity will take a third shape. Article II depicts in particular the consequences of not applying case-constructing reflexivity. This means that the problem is not avoided even if the research project does not include a case-selecting phase. Thus, neither the use of already gathered data nor the use of already presented research results implies that case-constructing reflexivity is not needed. In these cases, case-constructing reflexivity will instead entail evaluating how the sources used have defined disability. To exemplify this issue, Article III focuses on the fact that administrative data on disabled people are seductively easy to access and often contain rich information on, for instance, level of living indicators. However, these kinds of data are often produced as a residual to the administrative processing of people who claim they need support from the welfare system. As Article III shows, such a process relies rather heavily on medical records and, as a consequence, functional definitions of disability. Consequently, when disability researchers, starting from an environmental understanding of disability, use these kinds of data, they run the risk of imposing an understanding of disability on material that differs greatly from such an interpretation. This is why case-constructing reflexivity is such a crucial issue.

4.1 Time to End

The concept of disability has fascinated several researchers. Stiker (1999) searched through archives and old texts to follow how it has changed throughout history. Ingstad and Reynolds Whyte (1995) collected anthropological accounts to help us understand its different cultural meanings. But disability will mean different things even at the same time and in the same culture. I once thought of this as a problem, but today I have concluded that disability must continue to be a volatile concept. The purpose of using the concept of disability should guide us in how we define its meaning, and our definition ought to be well-considered and explicit. But we should not judge ourselves too hard in our use of the concept. It will slip away, and there will be conceptual shifts. I have noticed it myself in my own writing; it is quite difficult to keep a firm grip on it. But those of us interested in disability issues can try to avoid the most serious misconceptions. I have suggested one way of achieving this, that is, by applying case-constructing reflexivity, which may elucidate the choice of definition and its possible effects on analyses and results. Although this may be of some help, I am rather certain that disability will continue to be a bit of a puzzle, but what an interesting puzzle it is.
5. Summary of Articles

*Paper I: Disability – a concept with many meanings* [Funktionshinder ett mångtydigt begrepp]

This article has a descriptive purpose. It sketches the “families” of definitions of disability that appear in contemporary disability research. In addition, the article tries to map out the ontological roots of these definitional families, and how they could conceivably be defined operationally. Five different definitions are presented. First, definitions based on diagnosis and/or functional ability, i.e. functional definitions, start from an understanding of disability as an individual phenomenon. This is a rather common strategy for creating categories of “disabled people”, and can be found in living conditions surveys and censuses all over the world. Second, the social model is described. This model was developed by parts of the disability movement in the UK during the 1970s. It was foremost formulated as a critique against the functional definition, as this kind of definition tends to see the individual as the “problem”. The social model aims to move the gaze from the individual to the society, stating that disability emerges due to barriers in the surroundings and oppression of people with impairments. The empirical consequence of this model is that disability is to be found in the society and in the ways that society acts towards people with impairments. Thus, disability has nothing to do with bodies or bodily functions. Third, the relative or environmental definition of disability is presented. This definition conceives of disability as an interaction between a person with an impairment (or impairments) and an inaccessible environment. Thus, disability is neither an individual property nor environmental; disability is a description of a certain situation. This definition is well established as the conceptual basis of disability policies in Sweden. Fourth, disability support and benefit systems give rise to administrative definitions of disability. Because these kinds of benefit/support systems have certain eligibility criteria, only some people will gain access to them. You may, for instance, have to be of certain age and/or have a certain kind and degree of functional limitations to be granted support. Thus, only those who fulfill such criteria will be considered as disabled according to an administrative definition. Fifth, even if a person is not considered disabled – neither in terms of the functional nor the admin-
istrative definition – the person may perceive her-/himself as disabled, i.e. the person is subjectively defined as disabled.

Also, the article provides a review of the critiques aimed at these different families of definitions, coming from, e.g., feminist and postmodernist stand-points. I conclude in this article that, first, contemporary definitions of disability lack conceptual clearness. Second, I argue, in line with earlier research on this topic, that disability researchers generally do not provide information on how disability (in fact) has been defined, which makes it rather difficult to evaluate – even use – the research findings. Third, I suggest that our intellectual efforts should not be put into finding the “correct” definition of disability. Rather, efforts should focus on actually determining and describing how disability has been defined.

Paper II: The Fuzzy Buzz Word. Conceptualisations of Disability in Disability Research Classics


The analysis focused on the authors’ use of disability as a concept. As an analytical device, this use of the concept was studied through identification of two different types of definitions: stipulative and applied. The first type arises when the researcher makes explicit claims about what disability is, such as “by disability I mean…”. The second type, applied definition, has to do with the definition of disability in practice. This can be found by discovering what kind of data the researcher is using, e.g. how disability has been operationalized in a particular survey.

As a second phase of the analysis, these two types of definitions were compared. Three major problems were identified. The first recurrent problem was a lack of external consistency. This problem occurred when the researcher’s own definition of disability (stipulative) did not match the applied definition. Second, a lack of internal consistency could be observed in almost all of the analyzed works. This problem occurs when the researcher changes the meaning of disability in her/his own use of the concept, without making any explicit comments on such changes. A third problem, limited to a couple of the texts, was the lack of any definitions at all.

I conclude that the definitional confusion found in these texts can partially be explained by the lack of proper theorizing about disability. Historically, disability has been defined as a medical property, but all of the analyzed texts have strived to understand disability as being relatively environmen-
tally dependent. The problem, however, is that such an account has not been theorized. Instead, the notion that disability is caused (partially or completely) by environmental factors has been an *a priori* assumption. The lack of theoretical, as well as empirical, studies showing how this causal factor is shaped has made it rather difficult to work with disability as an environmental concept. For this reason, I conclude that more research is needed if we are to understand how the environment functions as a causal factor of disability. Based upon such research, we may be able to construct a theory of the causal connection between environment and disability.

**Paper III: Composing populations of disabled people using administrative registers**

This article deepens the analysis of administrative definitions. Administrative definitions have their own history and cannot easily be put into the “general” history of disability definitions. This family of definitions stems from the welfare states and their need to differentiate “eligible” from “non-eligible” people. This article contains both a review of earlier works on this definition and a conceptual discussion on the use of this kind of data in disability research. Four crucial issues regarding administrative definitions are addressed. First, while the disability research discourse has established an understanding of disability as connected to the environment (understood both as physical and social/cultural), the welfare system processing of “disabled” people primarily understands disability as a medical phenomenon. The determination of people’s eligibility to receive support from the systems is based upon medical records. In order to get help, you have to prove (through statements from physicians or paramedical professionals) that you have a medical condition that disables you. Thus, one has to keep in mind that there may be a conceptual difference between contemporary disability theories and data on people administratively defined as disabled.

The second conceptual issue concerns the specificity of administrative definitions. One such aspect is the age criterion. It is rather common that disability benefits are intended for people under the age of 65, i.e., they are not accessible to people defined as “elderly”. Depending on how disability is defined, this age criterion may imply that large groups of disabled people are excluded. A functional limitation perspective on disability, for instance, will show that disability is positively correlated with age; elderly people are more likely to be disabled than are younger people, but the elderly are not included in the administrative records because of the age criterion.

Third, administrative definitions may vary over time. Ambitions to widen or restrict the inflow to a certain benefit may cause variation in the eligibility criteria. Transitional rules sometimes allow people to continue to receive the benefit even if they do not fulfill new criteria. As a consequence, the operating definition of the target group does not have to be in accordance with the actual group of receivers.
Fourth and last, because administrative definitions tend to vary both within and between welfare systems, opportunities for using these kinds of data in, for instance, cross-national comparisons are limited.

In the article, these four issues are illustrated using data from The Swedish Social Insurance Agency and The Swedish Labor Market Administration.

I conclude that disability researchers should make more use of data sources found at welfare authorities, but that the conceptual issues stressed in this article have to be kept in mind.

**Paper IV: Defining Disability. Effects of Disability Concepts on Research Outcomes**

This article is a statistical analysis of how different definitions of disability affect the outcome in relation to a sample of dependent variables. Three different definitions are compared: a functional definition, administrative definitions, and a subjective definition. The functional definition was collected from the Living Conditions Survey, produced by Statistics Sweden. Two administrative definitions were included; these were intended to cover two benefits that have been of interest to (Swedish) disability researchers during the past decade. These two are (receivers of) *Assistance Allowance* and receivers of support specified in the Act Concerning Support and Service to Persons with Certain Functional Impairments. Data on receivers of the first benefit were collected from the National Social Insurance Agency, while data on the second benefit were retrieved from the National Board of Health and Welfare. A subjective definition was retrieved from the Labor Force Survey, conducted by Statistics Sweden. Labor market participation, educational level and income were used as dependent variables. Also, the background variables sex, age distribution and living arrangements were analyzed. All these variables were collected from different registers at Statistics Sweden, which also conducted the compilations of the different data sets.

The results show that there are major differences between these definitions. Using a functional limitation approach, disability is highly correlated with age. Older people are more likely to have disabilities than are younger people. However, using an administrative definition, which often limits disability support to those under the age of 65, the age distribution takes on a reverse pattern. In general, people defined as disabled according to administrative definitions are more likely to have a lower education, lower income and lower participation rate on the labor market than are those defined by the functional and the subjective definition. I conclude in this article that the relationship between research outcomes and disability definitions must be studied further. However, irrespective of what such research finds, disability researchers must become more aware of how they define disability and re-
flect upon how such definitions may affect their results. Methodology has to be given more priority in disability research.
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