

BOOK REVIEW

Definitions of Disability in Social Sciences. Methodological Perspectives.

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Even though most people have a fairly clear idea about what is meant by disability, it turns out to be a rather controversial and problematic concept in social research and policy. The debate has taken two different and decoupled directions: (1) the theoretical debate on the understanding of disability; and (2) the operational issue of definitions in empirical research. This publication, the doctoral dissertation of Lars Grönvik, addresses both, and is among the few contributions that try to bridge the gap.

The theoretical debate is well known. The point of departure is that disability traditionally has been defined in medical and functional terms; it is about limitations of bodily or mental functions. This understanding has been increasingly contested, and in theoretical debates it is (perhaps) an outdated point of view. But in practice it is not that easy to get rid of. Basically the criticisms were raised because the medical understanding ignored the impact of the environment in the process of disablement. The alternative environmentalist understanding exists in different versions: a strong social model that argues that disability is caused solely by the environment, and a weaker version that is socio-ecological in nature and points to the relation or interaction between the individual and the environment. The debate is not purely academic, but has clear policy implications. A medical understanding will focus on the limitations of the organism and meet it with medical treatment and rehabilitation. From the perspective of a social model, the creation of a less disabling environment will be the primary policy choice. The growing popularity of ideas such as universal design is related to this conceptual shift.

The operational issue has been less explicitly discussed. In most research projects one has just moved ahead guided by practical possibilities and pragmatic considerations. Frequently the definition of disability has been linked to receiving certain services or benefits. The definitions used in surveys by statistical bodies have been criticised from a theoretical point of view, but disability research as such has not been much involved in the attempts to solve the definitional problems in this type of research. The issue is, however, very important. In Norway, surveys with different definitions have ended up

with prevalence rates ranging from 7 to 32%. In an EC survey, the prevalence based on self-classification varied from 8% in Italy to 30% in Finland. It is very likely that such differences in rates also affect research findings.

The aims of Grönvik's dissertation is to address three interlinked questions: (1) to map the different definitions that has been employed in theoretical and empirical research; (2) to scrutinise consistency in use of definitions in research reports; and (3) to explore whether definitions affect results. The purpose is not to identify some kind of "best definition", but to explore the landscape. The dissertation consists of an introduction and four papers, three of them so far published.

The first paper maps the definitions that are around. Grönvik describes definitions based on diagnosis and/or functional limitations, administrative classifications (service users/benefit recipients), a disabling environment, and the interaction between the individual and the environment. Apart from the fact that subjective definitions or self-classification is only briefly mentioned, the overview seems adequate and the discussion about the potential of the various definitions in empirical research reasonable. Among other things, he points out that the "politically correct" social model appears to be difficult to operationalise and may thus be difficult to employ in empirical research.

The second paper discusses the definition of disability in five "classical" or frequently cited texts in disability research (Oliver, Barnes, Zola, Groce and Albrecht). He shows at least three problems: lack of definitions, external inconsistency (the definition in use is different from the explicit definition) and internal inconsistency (the definition in use varies through the text). The clearest example is Barnes' "Discrimination in Britain" which defines disability according to the "strong social model" but discusses discrimination based on statistics that employ a functional or medical definition. In other cases, the lack of consistency may seem less problematic, but the main point is clearly driven home: even in classical texts, some of them explicitly arguing about definitions, the author is hardly able to stick to one definition in a consistent way. Grönvik also makes another important observation: in some definitions of disability, there seems to be a lack of clarity regarding what are social consequences of disability and what is involved in the causation. It is however important to keep these things separate. If not, there is a risk that one defines disability as oppression and then finds that disabled people are oppressed.

The third paper addresses administrative definitions used in Swedish disability research. The paper shows that depending on which service or benefit is used to identify disabled people, there will be differences in prevalence, age and gender distribution, etc. The paper could be read as a warning about some of the most frequently used definitions in empirical research, but I read it more as an attempt to make clear the limitations of different definitions, and that it rarely is disability as such that is defined. Such definitions are based on eligibility criteria that change of time and are constructed by the structure of welfare measures. Thus, they tend to be useless in international comparison.

The fourth paper uses Swedish data sources to compare outcomes by employing four different definitions: a subjective definition (self-classification used in labour market surveys), a functional definition (used in living condition surveys) and two administrative definitions (assistance allowance and LSS, used in Swedish disability research). Results show dramatic consequences for variables such as living arrangements, income, education, and labour market participation.

The discussion raised in paper three and four is important for disability research, and the results are as such convincing. However, for a Norwegian it is odd to compare results based on self-definition with results based on receiving services/benefits meant for severely disabled people. It is almost like comparing apples with apple cores or peel. The administrative definitions he discusses appear not to be designed for all disabled people, but for a much more limited group with extensive service needs. Thus, it seems more to the point to focus on definitions intended to do the same, that is, the functional and the subjective definitions. In that case, the dramatic differences disappear, but significant and substantial differences persist – in age distribution, gender distribution, marriage, and income. Actually, the dramatic differences in relation to administrative definitions (which is expected) draws attention away from the important differences between operationalisations intended to do the same job.

Debates on the definitions and understanding of disability have been around for quite some time, but have for some odd reason been limited to theoretical discussions where links between theory and operationalisation are rare. But in empirical research and social reports, the operational part is of utmost importance, not least when one comes to a fuzzy concept like disability. Therefore the dissertation of Grönvik is a very welcome contribution. I also appreciate that he does not try to sort out one right or best definition. His point of departure is that different definitions suit different purposes, but we have to be consistent, critical and aware of the strengths and shortcomings of the different ways of identifying disabled people in research.

The dissertation also exists in an audio-book version and has an easy-read summary.

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