

Disability Studies as an academic field

Reflections on its development

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Serious attempts are now being made to develop disability studies as an academic field in the Netherlands. On the one hand, the field will have to establish its place in the division of academic labor. On the other hand it will need to safeguard its relevance for, and connections with, the disability movement. How is this to be accomplished? The social model of disability offered an approach that, in the Anglo-Saxon countries, provided an integration of theoretical and sociopolitical objectives. But, in the first place this approach has not achieved the same purchase outside those countries, and in the second place it is currently subject to a variety of critiques. Drawing on insights from the social study of science, in this paper we argue that the social model should not be abandoned, but must rather be refined and extended to accommodate critique. Implications for the organization of the field of disability studies are discussed.

[disability, disability studies, Netherlands, social model, institutionalization]

Introduction

What should disability studies look like as an academic field? How should it relate to other disciplines, both conceptually and organizationally? In what ways, if at all, should it be connected with the disability movement? Despite a long tradition of disability-related research in the Netherlands there was until recently no self-identifying field of 'disability studies'. As attempts are now made to establish such a field these questions acquire a new salience (Kool 2008). In this paper we offer some reflections, derived in part from the social study of science, that we feel might contribute to discussion on the future of disability studies, in the Netherlands and more generally. The argument of this paper has three parts. First, a particular approach – the 'social model of disability' – has provided disability-research with something crucial: an integrative theoretical orientation that at the same time enabled links with the disability movement to be built. It is necessary to understand the factors that, in much of the world, have impeded the adoption of this approach. Second, today, criticism of the social

model of disability is mounting. Much of this criticism we find valid, and the social model needs modification – though not abandonment. Third, we argue that this theoretical orientation has implications for how the field is best to be organized.

Disability studies in context

The Netherlands provides an interesting case for a closer look at the emergence and prospects of disability studies. Characteristic of the Dutch situation are good organization and cross-disability collaboration, identified as prerequisites for the emergence of disability studies (Albrecht, Ravaud & Stiker 2001). People with disabilities have been well organized for many years. An umbrella organization (now called the CG-Raad)¹ was established more than 30 years ago, and today this represents some 150 distinct organisations of people with disabilities and chronic illnesses. Moreover, questions of inclusion, exclusion and discrimination have been recurrent issues in public discussion. Researchers too, have shown their interest in questions pertaining to disability: there exists a thirty-year tradition of social science-based research.

One might thus think that establishing disability studies in the Netherlands is merely a matter of coordination, of pulling these existing research efforts together. However, as a recent report points out, there are two problems in this respect (Kool 2008). First, disability-related research in the Netherlands has a rather specific orientation and is strongly influenced by medical and rehabilitation perspectives (p. 12, authors' translation):

In the Netherlands there is a strong tradition of organizing research and information-collection relating to life with a handicap from an individual, medical perspective or from that of care. Research and teaching were and are largely focussed on diagnosis, treatment, revalidation.

Much of this research has been of an applied nature, intended to elucidate practical problems: more precisely, problems framed by a medical perspective. The report argues that disability has to be studied as a complex, socio-cultural phenomenon: an approach at odds with the medical/rehabilitation perspective implicit in most studies conducted in the Netherlands. The second problem is that of the coherence and scholarly quality of this work. Although individual projects may have been interesting and important, they were loose, separate studies, not leading to intellectual exchange about ideas, intellectual coherence, or theoretical advance. Dutch scholars have contributed rather little to the field of disability studies as it has emerged internationally. This criticism seems justified. We discovered that of the more than 1300 articles that have been published in the core-journal *Disability Studies* since its establishment, only 7 have been from the Netherlands (compared with 25 from Sweden and 16 from Norway).²

Comparing these characteristics of disability research in the Netherlands with developments elsewhere is instructive. Swedish sociology professor and disability researcher Mårten Söder has this to say about disability research in the Scandinavian countries:

While disability studies in the USA and UK have been dominated by researchers who themselves have an impairment and often combines political activism and research, this is not the case in Scandinavia. In Scandinavia disabilities studies have been more closely linked to the welfare state than to radical disability movements. It has, at least in Norway and Sweden, been getting its funding and legitimacy from evaluations of social reforms (Söder 2009: 70).

This sounds comparable with the situation in the Netherlands. Söder goes on to explain that a particular focus of disability research in Norway and Sweden has been the integration of people with intellectual disabilities (“a group with problems of articulating their own interest”): this may not have been true in the Netherlands. Still, the research demands of a powerfully welfare-oriented state seem to have given rise to a certain commonality. Reflecting on the situation in France, Isabelle Ville and Jean-François Ravaud also invoke aspects of national history that give French disability research (and policy) its particular character (Ville & Ravaud 2007). Prior to the middle of the 20th century, they write, “there had been no disabled persons, but war victims on the one hand and victims of work-related accidents on the other, further categories being children suffering from the after-effects of poliomyelitis, maladjusted children, etc.” (p. 139). Because these care and entitlement-related categories distinguished people in terms of the origin of their impairments, commonalities of experience were concealed. It was only with the emergence of rehabilitation medicine that they were brought together. As, later, the disability movement internationally began to emphasize rights-related issues, it encountered the egalitarian ideal enshrined in the French constitution. Since the French Revolution “equal rights have been one of the cornerstones of the French republic” (p. 140). Since the equality of all citizens is assumed, any policy of discrimination is prohibited, and “difference” could not be expressed in public. The implication, Ville and Ravaud explain, is a system “blind to difference”, in which anti-discrimination measures, but also positive discrimination in favour of people with disabilities or any other minority, becomes highly problematic.

What comparison suggests is this. How disability has been understood and studied, and the purposes such studies have typically been intended to serve, are deeply bound up with specific national political and welfare traditions. Differences in dominant traditions, between one country and the other, are a consequence of differences in political culture and of state commitments to a social welfare. For these reasons, an approach that has proven both fruitful and binding in one society has achieved less purchase in another.

Theoretical advance and (political) practice

A lot can be said (and has been said) about the nature of the distinction between ‘theoretical’ and ‘applied’ research. In our view there is no reason why a study addressing a ‘practical’ issue should not at the same time make a significant contribution to theory-development. Numerous examples can be found in the history of the social sciences.

Richard Titmuss' classic study of the blood supply comes to mind (Titmuss 1971). But the important point is that contributing to the development of a body of knowledge is not the same as providing the information needed for assessing the effectiveness of a service or a policy. This simple distinction has important implications. If all available resources are devoted toward suggesting answers to immediate problems of People with disabilities, and in the absence of theoretical reflection, no coherent body of knowledge will emerge. Given adequate resources, it is possible to commission studies of financial circumstances and labour market participation, or satisfaction with services or any number of other matters. There are many institutions and research consultants with the experience to do this work well. Such policy analytical studies are often published as technical reports. However valuable in practice these reports might be, this so-called 'grey literature' seldom has a wide circulation among (social) scientists. It is rarely the basis either for generating lines of future research or for establishing a professional reputation. Scientists (including social scientists) build their reputations by publishing in peer-reviewed journals. The peer review process should guarantee not only that the work has been competently done but also that its results are of interest to colleague-researchers. Decades ago, sociologists of science showed that just as journal publication is crucial for professional reputation, so its growth marks the development of a scientific field. In other words, the development of disability studies, internationally but also in the Netherlands specifically, depends upon the results of research being published in appropriate journals.

Volume of publications is one way of looking at the growth and development of a scientific field. Rather differently, and following Thomas Kuhn, we might say that for cognitive development to be possible what is needed is a 'paradigm' providing both suitable 'exemplars' and a theoretical framework within which the routine business of 'normal research' can take place. All this depends upon research being published in journals of repute and that many read. For a new field this can cause difficulties. If preferred questions or methods are viewed as 'deviant' access to journals may be difficult. New journals may be needed, devoted to the new specialty. In the field of disability studies this has happened, and the field now has its own dedicated journals, such as *Disability and Society*, *Journal of Disability and Policy Studies*, the *Scandinavian Journal of Disability Research*, and *ALTER*. Maintaining contact with international developments and contributing to them requires that research be subjected to peer review and published in journals such as these.

The need to produce research inspired by and relating to development of the field internationally has to be set against another consideration. How is the emerging field to relate to the disability movement: a variety of organizations with a multitude of practical and political concerns and priorities that differ from country to country? As Söder notes, the scholars who set about establishing the field in Britain and the USA, many themselves disabled, saw it as providing the analyses the movement required for its political work. The 'social model of disability' served both as fruitful paradigm for Anglo-Saxon disability studies and as a means of reconciling theory with the aspirations of the emerging disability movement, and so as the basis for political mobilization.

The social model and its critics

Tom Shakespeare, a leading figure in the field of disability studies, recalls that there were only very few people writing on this topic in 1990 when he started his PhD research. “Disability”, he writes, “was a problem for social policy and a research domain for medical sociology”. In developing his own research he took a specific focus: “trying to construct a sociology of disability by analogy with gender, race, and other forms of social division” (2005: 139). The work of scholars such as Oliver, Finkelstein and Shakespeare inspired a growing disability movement in Great Britain. The so-called social model of disability, that became a major paradigm for people working in this field, was developed in reaction to the preoccupation with the medical view of disability and the essentialist conceptualizations of physical conditions it entailed. It is noteworthy that, in reflecting on the development of disability studies in Scandinavia and France respectively, both Söder and Ville and Ravaud take the Anglo-Saxon tradition as the base-line, from which differences have to be explained. Indeed, Söder goes on to point out that in the Scandinavian countries young researchers with disabilities are starting to question the dominant “social engineering” approach in research, and to urge an approach more closely linked to the disability movement (and so more ‘Anglo-Saxon’ in its orientation).

The social model does not take the impairments of the physical body as disabling a person, but rather the social circumstances in which he or she lives with these impairments. The individual in the wheelchair is not disabled when public building or means of transportation are accessible via ramps; a deaf person is not disabled when he or she can follow a TV program with subtitles etc. In this way, disability can be studied as a socio-cultural phenomenon. In clarifying and highlighting mechanisms of social exclusion and stigmatization operative in a given society research provides ammunition to the disability movement.

The social model of disability, with its fundamental distinction between impairment and disability, has been central both to the collective struggles of the disability movement and to the development of disability studies as a field of scholarly inquiry. Today, however, some scholars, both within disability studies and working adjacent to it, question the adequacy of the social model. For example, legal scholar Adam Samaha has argued that whilst the social model points to *causes* of disadvantage, it does not provide any guide to appropriate policy measures (Samaha 2007). For this to be possible, he argues, a more comprehensive normative framework – prioritizing forms of disadvantage and justifying appropriate political and legal measures – is essential. More familiar, however, is a critique based on what some see as the over-socialised approach entailed by the social model, at the cost of attention for the embodied suffering of people with disabilities. Carol Thomas has provided a valuable analysis of the (varied but partly overlapping) objections raised by critics (Thomas 2004). In contesting the barriers imposed by social structures and by inadequate public policies, the social model has failed to acknowledge the extent to which our life experiences are constituted by and through our individual bodies, with their varying perfections and imperfections. The difficulties that people with disabilities confront

are not only a matter of access to resources and physical spaces. They are cultural and aesthetic too, but most importantly they are also embodied. Chronic pain; fatigue; the gradual loss of muscular functioning in the case of a degenerative condition; loss of memory, sight or hearing: these are central to the experience of many people with disabilities. To exclude them from consideration by insisting on a clear separation between disability and impairment is to ignore something vital.

For critics this is, in effect, to accept medicine's claim to jurisdiction over the body. The distinction should be abandoned, and the corporeal quality of disabled experience reclaimed. Thomas contrasts the critique of disability theorists such as Shakespeare with that of medical sociologists for whom impairment, though mediated by social location, is the fundamental cause of the restrictions and the exclusions that people with disabilities face in their daily lives. Though their perspectives and reference points are different, the authors all emphasize disability studies' neglect of the body. Thomas contrasts this position with that taken by Finkelstein, who refers to "forms of oppressive social reaction visited upon people with impairments": that is to say, suffered in addition to the disadvantages deriving from their impairments as such. Some restrictions on activity follow from impairment, but "these are not what is of interest in studying and combating disability" (p. 581).

Bill Hughes seeks to reconcile disability and impairment in a different way, and in so doing to bring disability studies in line with recent developments in sociology and in feminist theory. "Disabled people, "write Hughes and Paterson, "experience impairment as well as disability, not in separate Cartesian compartments, but as part of a complex interpenetration of oppression and affliction" (Paterson & Hughes 1997: 334-5). What we experience through our bodies – pain, exhaustion, resistance, exhilaration – is constitutive of all human experience (to which some would add, and all human knowledge). If the social model of disability neglects the 'lived body' of daily experience, with all its pains and its joys, then the question is 'how can this omission be rectified?' or, staying in line with recent outcries for a change of direction in the field: how to 'bring the bodies back in?' (cf. Williams & Bendelow 1998).

Paterson and Hughes argue for a phenomenological approach to what they term a 'sociology of impairments' (1999). Phenomenology rejects the Cartesian separation between mind and body. We simultaneously experience our bodies and experience through our bodies.³ Drawing on Leder's discussion of the body-in-pain (Leder 1990), they start by emphasizing that the 'normal' body, neither sick nor in pain, is normally backgrounded: it disappears from our conscious awareness. By contrast the body reappears, though problematically, as it experiences pain. Though pain is internally experienced, it also rearranges our daily living: the ways in which we deal with space, with time, with others. Reflecting on her own experience of life with multiple sclerosis S. Kay Toombs, a professional philosopher, has made a powerful case for a phenomenological account of life with a disability (Toombs 1995a, 1995b). It is through the lived body, she explains, that one orients oneself to the world (through the senses, through the placing and actions of the body), and that one actively engages with the world. In both these respects disability (in her case the loss of mobility) engenders "a profound disruption of the lived body" (1995b: 11). Her subjective experience of

space must be continually renegotiated as the progressive nature of her conditions gradually reduces her mobility. More is involved than a loss of function. There is a loss of intentionality too, as tasks can no longer be accomplished, and a sense of diminishment, of shame (p. 19).

In Carol Thomas' definition of disability, that she terms 'social relational', the restrictions deriving from disability are distinguished from those deriving from impairments. "It is entirely possible to acknowledge that impairments and chronic illness directly cause *some* restrictions of activity – but such non-socially imposed restrictions of activity do not constitute 'disability'." The term disability, for Thomas (following Finkelstein), is then to be reserved for restrictions which are "wholly social in origin", so that disability can be understood as "a form of social oppression on a par with other forms of oppression in our society associated with gender, race, class, and sexuality" (p. 581). Though, as Paterson and Hughes explain, impairment and disability are experienced as "part of a complex interpenetration of oppression and affliction", they present alternative referential frameworks.

These attempts to 'bring the body back in' derive in part from a concern by social scientists working in this field, that for research activities in disability studies "It is vital [...] not to be ghettoized, or to become insular and inward-looking, because, like these other fields (women's studies and lesbian and gay studies), this research has implications for the rest of academia" (Shakespeare 1998: 3). So a need is felt to keep in close intellectual contact with the 'mother disciplines' of the social sciences in the broadest sense, creating connections with intellectual debates there. And it is precisely here that a renewed focus on the materiality of the body can yield interesting possibilities for rapprochement, given the attention that social scientists now pay to bodies.⁴

One of the arguments for building these connections to the mainstream social science disciplines is thus intellectual. A more intensive interaction should enable disability studies not only to profit from intellectual advance and theoretical debate within those disciplines, but also to become more interesting for researchers from them. Yet Shakespeare's insistence that disability studies avoid "being ghettoized as a field of concern only to that proportion of the population experiencing impairment" (Shakespeare 1998: 257), points to the difficulty of clearly demarcating theory from its social relevance. Should theorizing reflect on the experiences of a particular, and clearly identifiable, segment of the population? Or should it reflect the view that disability is an inherent element of the human condition: that there are circumstances, and stages of life, at which everyone faces the limitations on mobility and sensory acuity, the lack of control over body and mind, that we associate with being disabled? The latter perspective implies a far broader social relevance and a far larger potential audience. (Deaf people, for example, do not identify with the notion of disability on which disability studies appears to be based. For this reason Deaf Studies has emerged as a separate and distinctive field of inquiry, and there is little collaboration between the two.) So the question of theoretical perspective implies further questions: to whom in society is research on disability (to be made) relevant? How and by whom are its results to be introduced into social and political debate?

Organizational dilemmas – some lessons

Disability studies is not unique in its quest for a structure facilitating theoretical advance and academic respectability, whilst maintaining its relevance for a change-oriented social movement. Other interdisciplinary fields, like those which have problematized discrimination based on gender, sexual preference, or ethnicity, have had similar sorts of choices to make and challenges to face. In women's studies for example, that like disability studies emerged in close connection to a particular social movement, extensive discussions took place over the tension between achieving academic status (and demonstrating the prospects for theoretical advance) and practical emancipatory goals. What can be learned from those discussions?

In the 1980s women's studies functioned as an interdisciplinary network of loosely connected researchers from various 'mother disciplines' in the social and life sciences and in philosophy. After the establishment of interdisciplinary groups of (mostly female) researchers investigating (for example) the social position of women, the question of how the field should best be organized in the future became pressing. Should the goal be institutionalisation as a distinctive academic field, or was a looser form of organization in which researchers would retain primary affiliations in established disciplines to be preferred? Writing at the time, Sandra Coyner gives two sorts of arguments in favour of the former strategy (Coyner 1983). Apart from general institutional considerations (continuity, control over resources, a degree of independence in administrative matters, possibilities to attract students to the field's own courses etc), she discusses the need to grow and build a body of knowledge. This she sees as best realised in the setting of a disciplinary structure. In order to grow as a field, some agreement about theoretical focus and important research questions and methods is necessary. Institutionalization allows and furthers an orientation to basic research, crucial to theoretical development. Coyner's view was that a Kuhnian framework, or paradigm, based in a core set of texts and exemplars, was needed to guide research. To achieve this, organizational arrangements should enable researchers to profit from each other's work, to discuss the way in which results relate to each other, and try to attract researchers from 'outside', making connections with the mother disciplines. By publishing in the field's own journals and by attending its conferences – devoting more attention to one another's work – researchers would facilitate construction of a shared language and a shared intellectual discourse. In this way a theoretical framework could grow that would organise data, yield new questions for research, and inspire other researchers. Crucially, Coyner's view was that this could only be achieved if some distance from the women's movement's immediate concerns and problems was maintained.

These reflections, written at a time when women's studies was in course of becoming organized, are of interest in considering the future of disability studies in the Netherlands today. As we pointed out earlier, disability-related research in the Netherlands has been loosely connected, dispersed, and highly oriented to practical questions and policies. Recent initiatives – the critical reviews by Kool and van Wijnen, the establishment of Disability Studies in The Netherlands aimed at creating an infrastruc-

ture for teaching and research in disability studies⁵ – point to new aspirations. After many years of orientation principally to assessing the impacts of specific policies and arrangements, to (dis)satisfactions with specific provisions, there seems now to be room for research on lived experience within a sociocultural and historic context that itself must be theorized. There are important opportunities here. Disability is not a subject that much appeals to researchers or students in the parent disciplines. Relatively few established academic anthropologists, historians or students of culture in the Netherlands are interested in disability, and it has little place in the teaching of these disciplines. On the one hand this is because of the theoretical disconnection to which (following Shakespeare) we have referred, on the other because of its apparent relevance to a rather small segment of society. Disability studies' preoccupation with definitions and demarcations (Who precisely is to count as disabled? Who can legitimately work in the field?) has added to its apparent exclusiveness. A more inclusive perspective on disability, in which disability is not only about barriers to 'doing' but also about barriers to 'being' (cf Thomas 1999), would create new opportunities for research and for cross-disciplinary collaborations.

It could be argued that the social model of disability has provided the requisite paradigm for many years. Yet, as noted earlier, criticism is mounting. Taking stock of the situation after some twenty years' work in the field, Shakespeare finds it stagnating. The most important things have been said a decade or more ago, and there is too little empirical research on what it means to live with a disability. Some argue that the social model should now be discarded, despite its inestimable value in the past – not least for the movement of people with disabilities. There are two arguments against this. First, in much of the world the social model of disability has achieved little purchase, or is unknown. This may be the result of a powerful welfare state or a deeply-rooted egalitarian ideology, as discussed earlier. But it can also be because a purely medical/rehabilitation model still enjoys unchallenged supremacy, as is the case in much of the Global South (Rieuwpaiboon & Blume 2009). Here the work of political mobilization and advocacy to which the social model lends itself so well is yet to be done. Second, it can be argued (in line with Kuhn's classic discussion of these issues) that extension and further articulation of a paradigm (in this case the social model) is the best way of proceeding until this becomes no longer possible. As has been pointed out repeatedly, the model has to be refined to accommodate differences in e.g. gender, class, or ethnicity of people with disabilities. Söder refers to this as "intersectionality". Few scholars (in the Global North at least) would deny the truth of its central claim. It is in this light that we prefer to view current calls (with which we sympathize) to acknowledge the centrality of embodiment to the experience of life with a disability, or for a more comprehensive normative framework to guide legislative change.

The theoretical benefits of extending the field's orienting paradigm in this way – building potentially fruitful connections to disciplines that share an interest in bodies and embodiment as well as in social process and collective rights – are considerable. Research on the (individual and collective) experience of disability in different societies and cultures can not only profit from, but can also contribute to, theoretical debates in disciplines such as anthropology, history, sociology, and political theory. There are

also practical benefits. Closer connections with the established disciplines should provide disability studies with greater access to strategically important resources, such as research funding and educational curricula.

At the same time, legitimacy in the eyes of the social movement of people with disabilities has to be sustained. For sustained it must be if emancipatory goals are not wholly to be lost and the field slowly to dissolve in its scholarly environment. The danger of dissolution, of co-optation by an academic culture increasingly shaped by individualist and free-market ideology, is very real. The critique is to be found already "... in spite of the important contributions disability studies scholars have made, in my estimation the field has lost its soul", William Peace declares. The reason being, that "disability studies scholars have not done enough to empower the people they study". In his view, "... every disability studies scholar must make a practical contribution to the lives of disabled people they study" (Peace 2010: 343). This uncomfortable obligation has been too readily discarded.

We certainly do not claim that these reflections provide a blueprint for the organization of disability studies, whether in the Netherlands or elsewhere. Effective institutionalization of the field will have to be adjusted to the way in which research and teaching are organized in one country or another, and these differ (as Ville and Ravaud point out for the French case). As our reference to women's studies suggests, we do however believe that much can be learned from critical reflection on the development of other fields that shared a similar commitment to reconciling theoretical advance with emancipatory social change.

Notes

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- 1 First called Gehandicaptentraad (Handicapped Council).
- 2 Data derived from Web of Science™.
- 3 For a more detailed, and ambitious, exposition of the empirical possibilities of phenomenology, see Csordas 1990. Following Merleau-Ponty, Csordas sees an approach based on embodiment as "not restricted to micro-analytic application" but as offering a new "foundation for analysis of culture and history" (p. 39).
- 4 A whole journal – *Body & Society* – is devoted to the body as an object of research.
- 5 See <http://disabilitystudies.nl/>.

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