Now You See It, Now You Don't: A Discourse View of Disability and Multidisciplinarity

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Abstract: *Disability is increasingly salient as a word and increasingly heterogeneous as a category. Multiple interest groups and professions define disability in different ways, making it impossible to achieve a unitary theoretical definition or singular model-explanation of disability as a phenomenon. It is in the interest both of disability scholars and disabled people to acknowledge the multiple understandings of disability, and to appropriate ways of thinking and talking about disability that are often seen as antithetical to a progressive understanding of disability. This particularly applies to medical language, which may be used to deepen our understanding of disability without the traditionally attendant problem of medicalization. Such a project requires a deeper engagement with the particularities of medical language, but also with chronic illness, which is sometimes dichotomized from impairment on spurious grounds. Disability studies should acknowledge the utility of medical language as a tool for people with chronic illnesses as well as impairments to conceptualize their embodied experience, and strive for ways to situate medical language within a socio-politically progressive understanding of chronic illness, impairment, and disability.*

Key words: *Disability, multidisciplinarity, discourse, models, medical language, professions.*
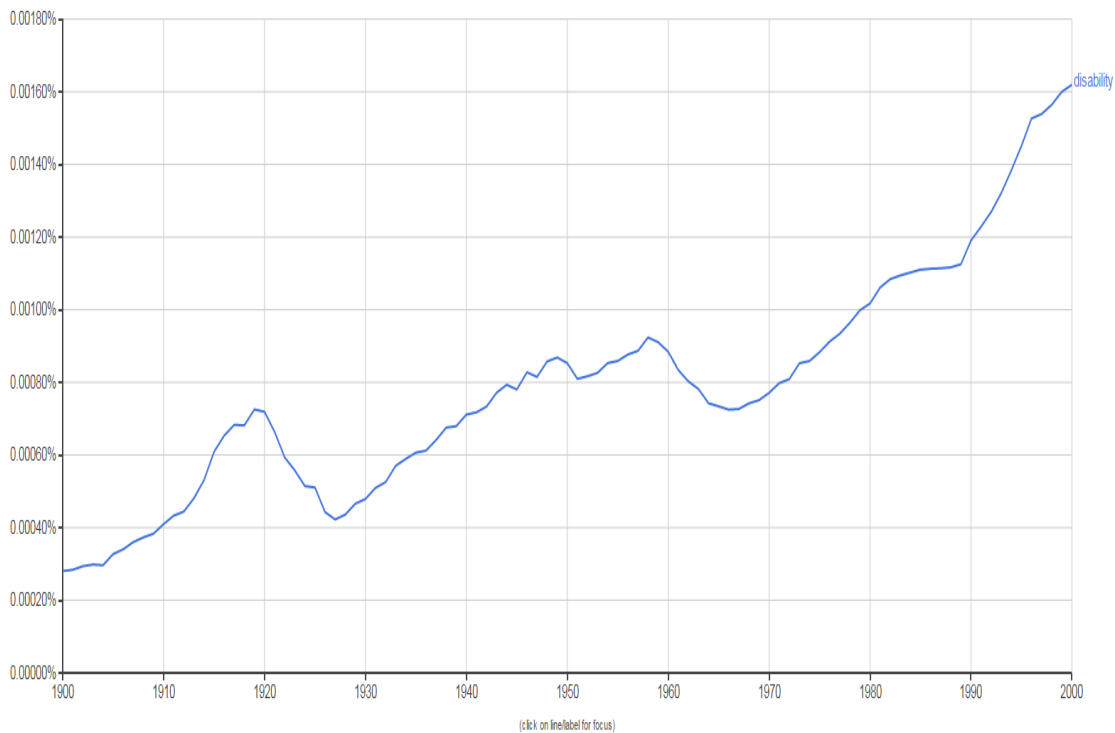
1 Introduction

Figure 1: Prevalence of the term "disability" from 1900-2000, according to Google Books

There is little doubt that symbolic representations of disability are increasingly common. Figure 1 shows the relative frequency of occurrences of the word "disability" in the Google Books corpus, a frequence which more than quintuples between 1900 and 2000. Over the same period, "disabled" tripled in frequency, with most of the increase occurring between 1970 and 1980.

This particular observation, based on these particular sources, is not in itself very sophisticated, and there are many potential explanations for it. First, there has been a decline in partly or wholly stigmatizing synonyms or approximate synonyms for "disability" or "disabled", such as "handicap", which halved in use from the mid-century to the end of the century, and "cripple", the use of which has declined steadily from 1920 onwards. Second, there are some forms of English usage that have little to do with the disability field as readers of this journal understand it – the "disabled list" in sports being one example.

It would not be surprising if the increase in prevalence for the word "disability" went hand in hand with polysemy, i.e. multiple (though semantically related) meanings for the word. In previous work, I have noted that many of the words that tend to occur alongside "disability" (their *collocates*, in linguistic terms) come from the semantic domains of welfare bureaucracies, medical assessments, pensions and benefits, and so on. This dynamic, and many points that are more tangentially related to the arguments in this article are more extensively discussed in the book *Disability and Discourse Analysis* (Grue, 2015).

The above domains are not unrelated to "disability" as it is commonly understood by scholars in the field of disability studies, but there are some significant differences. While most scholars in disability studies would prefer to use their own definition of "disability", and it seems unlikely that any two scholars would comfortably agree on a single definition, certain features have recurred consistently since the field first came into being some decades ago. Disability is widely seen to be a phenomenon with (at least) a social, political, economic, biological, psychological, and cultural dimension, and to have root causes in all of these domains. Any definition of disability that is developed by scholars of disability will address this epistemological complexity to some degree – in contrast with bureaucratic definitions, which tend to be epistemologically simple even though they may be technically quite complex.

Admittedly, the above points may also seem epistemologically simplistic as well as technically complex. The situation sketched out in the above paragraphs may be more pointedly summed up as follows: Different groups in society have come to find the word "disability" useful, even if they find it useful for different purposes. And the first proposition in this article is indeed that simple. The second proposition is equally simple, though perhaps a little more controversial to some scholars: Given the ubiquity of the word "disability", such polysemic complexity is practically inevitable. In other words, though it may be politically effective to propose a singular definition of disability along the lines of "a particular form of oppression" (UPIAS, 1976, p. 15), such definitions will eventually come to be associated with one group and position among many.

This article discusses the above propositions and their implications, which, it will be argued, are practical, political, and highly relevant to the everyday experiences of disabled people. It is sometimes argued in disability studies that the academization of the field has done little good and perhaps some considerable harm to the political cause of improving the lives of disabled people (Oliver, 1999; likely also most of Oliver post-1999), and this charge should be taken seriously. The study of the word "disability" may be undertaken for its own sake – by philosophers as well as historical linguists – but if the work is being done in disability studies, it should have implications for that field, which has real embodied people living in it.

My answer to the charge of irrelevance and abstruseness has two parts, and I'll give an indication of their content before moving on to the argument proper. Firstly, it is dangerous to ignore the complex mechanics of language in favor of simple political action. If we do not pay close, scholarly attention to the way in which definitions shift and words are co-opted, we risk saying one thing and being heard as having said something completely different. Recent political events bear out this point to some extent. Secondly, there are many ways in which scholars, perhaps particularly those of us who teach in professional education, can put the complex mechanics of language into relatively simple practice – and some ways are better than others.

I will return to this point later on. The body of the article is dedicated to he relationship between language as a form of symbolic representation, the world that is being represented, and the intermediary, socially and politically contingent entity known in some circles as "discourse" (Fairclough, 2015; Wodak, 2001). I will discuss the relationship between the

word "disability", the phenomenon of disability, and the ways in which some social agents try to theorize and model the phenomenon, chiefly using words.

2 Language and the world

There is a short story by the Argentinian writer Jorge Luis Borges called "Tlön, Uqbar, Orbis Tertius", published in the collection *Labyrinths* (Borges, 1964). Among Borges' many enigmatic stories, it is among the most convoluted and interesting, dealing with the nature of experiential and social reality, with epistemology and with the relationship between language and the world. The story partly concerns the country of Uqbar and the region of Tlön, with the narrator trying to discover whether the country and its regions really exist or not.

Their existence, crucially, is supported by semi-authoritative texts: Uqbar and Tlön are described in certain enclycopedia articles – but the articles exist only in *some* encyclopedias ("fallaciously called the *Anglo-American Encyclopaedia* (New York, 1917) [which] is a literal but delinquent reprint of the *Encyclopaedia Britannica* of 1902") (Borges, 1964, p. 3). The narrator proceeds to investigate both the country/region and the texts in question; he is ultimately convinced of the reality of Tlön, though his faith in the reality of his previously assumed world ("our world") seems to be slipping: "already a fictitious past occupies in our memories the place of another, a past of which we know nothing with certainty – not even that it is false." (Borges, 1964, p. 18)

Tlön is capable of invading our world through subtle linguistic means because it is less of a region in a foreign country than it is an epistemological point of view. The people of Tlön share certain epistemological assumptions that are foreign to us; they do not, for instance, presume the relative permanence of objects. It is not *nouns* that are central, but *verbs*, so that instead of saying "the moon rose above the water", one says "upward behind the onstreaming it mooned" (Borges, 1964, p. 8). We think that a coin lying on the pavement is the same object when it is picked up, but the people of Tlön do not. They think that a person seen from the front is not the same as a person seen from the side, even if *we* would say "it's the same person."

Borges, doing what he does best, causes a sense of epistemological and ontological vertigo in the reader. The height – or depth – from which he makes us look at the stances and positions we take for granted is enough to make us dizzy. Words need not mean what we think they mean, and neither does the world itself. Eventually, in the story, it emerges that Uqbar and Tlön are the conceptions of a secret society. It is due to their efforts that the ideas are spreading, and reality itself is in the process of being changed.

"Tlön, Uqbar, Orbis Tertius" can serve as a metaphor for many things. I want it to serve as a metaphor for disability studies, and to do so in at least two ways. First, it accurately describes the efforts of many disability activists and scholars to disseminate into the mainstream ways of thinking that have potentially radical, even world-changing implications. And the project has succeeded in many ways – not *only* through the use of language, but *partly* through the use of language. Many of the things that scholars in disability studies argue – the social construction of disability and disability universalism being to examples – have traditionally

come across as counterintuitive, marginal or just plain weird in the mainstream. Still, these days, major publications such as the New York Times regularly describe disability in ways that are deeply informed by activist and scholarly efforts. Change has occurred, in thoughts and words as well as in deeds.

Additionally, "Tlön, Uqbar, Orbis Tertius" offers more specific analogies. The aversion that the inhabitants of Tlön have towards assumptions of object consistency reminds me rather pointedly of the deconstructive attitude that most disability scholars adopt towards disability. Though "deconstruction" may not be their preferred term of art, such scholars often work to show that what society, bureaucracies, or the professions think of as "disability" – a stable category to which people either do or do not belong – is in fact a swirl of disabling processes, forceful and consequential, but also quite unstable.

While true, this can be quite difficult to explain to most people. Disability studies tries, among other things, to change what has often been termed "common sense". There used to be commonsensical notions of what cripples were, what blind folk were like, how deaf people should be compelled to read lips and vocalize. There used to be commonsensical notions about a lot of things to do with disability, long before the word disability was used in English, or its equivalents in other languages. Change did not begin with new linguistic usage, but it acquired a new potential that way. A seminal moment in Norwegian politics took place in the years 1966-67, when the word *funksjonshemming* (literally: "functional-hindrance") entered the mainstream. It (mostly) replaced older Norwegian words like *handicap* and *invalid*, the meaning of which is indicated by their English/latinate origins. To a reader of Borges, this moment seems like the one in which the world of Tlön started to seep into our world, at first accompanied by a sense of alien displacement, but eventually making it quite difficult to remember what things were like before.

2.1 Language, symbols, and discourse

"Disability" is understood differently in medicine and in politics, differently in welfare bureaucracies and in NGOs. This is trivially true, but also quite important to recognize. I think we can gain a significantly better appreciation of some of the salient dilemmas in the field of disability studies if we start to really appreciate this changing, context-sensitive meaning. And I think this appreciation will be of practical use in what is very much a *multidisciplinary* field.

There are much fewer "pure" disability scholars than there are people working on issues relevant to disability studies. I am a case in point. I work in a department of special needs education, before which I was in a department of sociology. My dissertation was in linguistics, and my doctoral research was partly funded by a faculty of health sciences. This degree of multidisciplinarity may be unusual for a disability studies scholar, or indeed scholars in most fields, but it is nevertheless common that a) people doing disability studies are fully or partially employed under a different disciplinary heading, and b) they therefore find themseles constantly having to persuade other people that disability is an important or even legitimate topic in its own right.

This is true of disability studies in a way that is different from, say, dentistry. In Borgesian terms, most people implicitly assume the ontological solidity of a tooth, from day to day and viewed from different angles. We may hypothesize that these implicit assumptions about the epistemological validity of dentistry and its adherent practices are substantially reinforced by phenomenological means, e.g. experiencing a root canal. Disability studies, however, is in the position of having to continually debate the existence and properties of its primary object of study.

It is neither possible nor desirable to make disability studies more like dentistry. If anything, disability studies must resist any impulse towards the reification of its primary object of study, since that process creates some particular obstacles to a chief disciplinary goal, i.e. improving the lives of disabled people.

These obstacles have to do with how we categorize and organize the world, the practice that was memorably referred to as "sorting things out" by Bowker and Starr (1999). I will discuss them primarily with reference to *discourse analysis*, which I believe is a very useful tool for examining the complex topic of disability. I have argued this case more extensively elsewhere (Grue, 2015); here, I'll merely note that discourse analysis is an ongoing and vibrant scholarly project which focuses on linguistic and symbolic structures in order to analyze and explain behavior and social practice.

Discourse analysis is itself a multidisciplinary project; it adds complexity. Work in the field over the last decade engages with political science, social psychology, corpus linguistics, and history, to name just a few bordering disciplines (Baker et al., 2008; Fairclough, 2015; Reisigl & Wodak, 2009). To avoid the charge of needless complexity, let me therefore argue that discourse analysis joined with disability studies is simply about closely examining the meaning that some people, institutions, and organizations attach to the word disability and its attendant concepts and symbols. This meaning, in turn influences behavior. When "disability" is assumed to refer to something as (relatively) stable and uniform as "tooth" – interesting consequences ensue.

2.2 Restroom symbolism

Disability discourse is productive of attitudes and actions, of which I'll give one very concrete example: Restroom etiquette. In this area, the interpretation of symbols, reinforced and made automatic by repeated social interaction, is conducive to a kind of behavior that requires interpretation and explanation. Specifically: Accessible restrooms are the sites of social awkwardness.

In many countries, there are three categories applicable to public restrooms: Man, woman, and disabled person – the latter almost always signified by a wheelchair user symbol. Oddly, though these categories are signified as being *symbolically distinct*, they are not in point of fact *mutually exclusive*. Neither are the categories *consistent* or *intuitive*. The matter of gender binaries is too complex to be discussed here, but I'll note that many American restrooms acknowledge the non-exclusivity of the categories by adding the wheelchair user symbol to the symbols representing men and women. In such cases, there is usually an accessible stall

placed alongside other stalls, instead of an entirely separate accessible restroom – the standard solution in most European countries.

The nonexclusivity of the categories is not much of a social problem unless the accessible restroom is locked and the key kept by staff, although this is often, annoyingly, the case. The symbolic boundaries, however, are troublesome. I know this because I am a part-time wheelchair user. That is to say, I use a large electric wheelchair every day, but I can get up from it and walk into a restroom that is too narrow to accommodate such (non-standard) wheelchairs. This means that I am regularly involved in micro-interactions centered on restroom etiquette. If I am seated in my wheelchair outside the restroom when someone exits, walking, I may the cause of anxiety or guilt. If I myself exit, walking, while someone else waits outside, sitting in *their* wheelchair, I am perhaps the object of suspicion. I have had people apologize to me for using "my" restroom, and though I haven't apologized to anyone myself, I've felt the urge to explain that yes, I really did need to use that particular restroom – I am legitimately a disabled person. Look, my wheelchair is right over there.

Accessible restrooms are almost always be marked by the wheelchair symbol. This makes a certain amount of sense. Symbols in public places need to be consistent and recognizable. But this also means that they become powerfully productive. They gain weight and substance. Their boundaries may sharpen. We say *accessible restrooms* and *disabled restrooms* and sometimes *handicapped restrooms*, we do not say *wheelchair restrooms*. But the symbols are there, and people who do not use wheelchairs, but who nevertheless need accessible restrooms, routinely become objects of social suspicion, as they do when using *accessible parking spots*, and other sites of access. This is, at least in part, a function of how we choose to signify disability accommodations, it is a function of how disability discourse currently works.

The wheelchair symbol appears singular and unified as what Ferdinand de Saussure termed a *signifier*, but it is embedded in ambiguous interpretive practices in at least two regards, making it unclear what it *signifies*. Specifically, it is unclear who counts as disabled, i.e. should legitimately have access to the accommodations that it indicates, and it is unclear what kind of accommodation is being indicated. In her book *The Question of Access: Disability, Space, Meaning*, Tanya Titchkosky (2011) investigates the University of Toronto and its level of disability accommodation. Perhaps unsurprisingly, she finds that even in a single institution, and even in a single *building*, the wheelchair symbol does not signify a single standard of access. In some cases, even if a restroom is marked as "accessible", the door may be too narrow for a wheelchair to fit through. The restroom may still be accessible to many other disabled people because it has grab bars, and so on, but, paradoxically, not to the category of people that is directly signified by the wheelchair icon.

3 Reductionist interpretations of disability: The problem of medical language and medicalization

The discourse situation surrounding the wheelchair symbol represents, I think, a microcosm of disability discourse as such. There is ambiguity surrounding the category of disability and who belongs to it, there is ambiguity surrounding the causes of disability, and there are a lot of hard-edged, dogmatic opinions on both of these ambiguous issues.

Partly, of course, this is due to truly differing political interests. But it also has to do with that the fact that there is no such thing as *language independent of social context*, in the same way that there is not foreground independent of a background. The word "disability" is *always* embedded in one discourse or another. Moreover, there are *many* discourses of disability. And they are very *different* discourses, depending on whether we are dealing with social fields such as *public policy, the NGO sector,* or *the media*.

The word "disability" refers to a number of different beasts in different areas of the social world. As disability scholars, we need to know as much as we can about both the different beasts and their habitats. This is important for *epistemological* and *strategic* reasons: We need to know about how language influences what people know, what they think they know, and how their knowledge influences their actions.

This matter is particularly pressing when it comes to medicine, health, and illness. Medical framings of disability are intertwined with medical language, which serves particular purposes and has particular areas of usage. It deals particularly with individual bodies and parts of bodies, and so is tied to explanations and analyses on this individualizing level. Such explanations and analyses may be reductionist as well as problematic other ways; this is why medicalization is a recurring topic both in disability studies and in the sociology of health and illness (Conrad, 2008; Turner, 1992; Zola, 1977).

A persistent and unresolved issue in disability studies is what to do about medicalization. Notwithstanding practical politics, a common solution has been to fight it with a different kind of language; disability activists and scholars often prefer to describe and explain disability with terms that are far removed from the medical realm, whether their vocabularies are drawn from political economy (Oliver & Barnes, 2012), phenomenology (Wendell, 1996), or the study of literature (Snyder & Mitchell, 2000).

These solutions have been extremely productive, but they have partly evaded some core problems of medical language and medicalization. To understand these problems, I'll summarize some of the criticism of medical-language approaches to disability; I think this criticism can be summed up in a *weak version* and a *strong version.*

The strong version, which is particularly associated with the British social model of disability, wholly rejects medical explanations of disability, and most medical language, as being *irrelevant* to understanding and engaging with the quintessentially *social* phenomenon of disability. The weak version argues that medical approaches are at best *insufficient*, and at worst *detrimental* to these efforts. In both versions of the critique, medical approaches are seen as being *reductive* and *narrowly* focused. Since medicine deals mostly with individual bodies and their deficiencies, medicine is poorly suited for understanding complex social phenomena such as disability.

The critique itself is reasonable on both counts, I think – the question is what comes next. How do we deal with medical approaches and medical language? They are not likely to go away. Disabled people need medicine and doctors just as much as non-disabled people, and statistically speaking even more so, and more frequently.

Here is where the strong version and the weak version of the critique should be separated. While medical language is *insufficient* for the task of explaining disability and describing the disabled experience, it is not *irrelevant* to that task. This holds true for most people who "count as disabled" in most disability studies accounts of the world.

3.1 Medical language and disability studies: Towards multidiscplinary accommodations

In Norway, as in many other countries, the disability NGO sector is a patchwork of many different organizations. Some are organized along medical-diagnostic lines, while some are organized along socio-political lines. While most of the medical-diagnostic organizations have a social and political agenda, some of the socio-political organizations are explicitly anti-medical and anti-diagnostic.

Generally, medical and socio-political language co-exists in the NGO system, for the simple reasons that 1) every NGO is in some sense a political organization, and 2) almost every disabled person needs a diagnosis in order to exercise their rights. Moreover, there is a hierarchy, or at least a structure of discourses in the NGO system, which has a lot to do with the relationships between individually embodied people and the organizations in which they are members. Generally speaking, the higher up one moves in the organizational system – towards umbrella organizations, towards professional participants and central leadership – the more salient become social and political discourses of disability.

There are many ways to look at this situation. One might argue that social and political discourses of disability – which are essentially *ways to frame, analyze, and explain disability as a social and political phenomenon* – are underdeveloped. We have not done enough to develop a vocabulary, a language, which allows most disabled people to understand themselves and their situation in a social and political way.

However, one might also argue that there is something about medical language that is *useful* to many disabled people, in their individual situations, in their individual lives. These arguments lead to somewhat different positions on the question of what to do with medicine, medical language, and medically inflected understandings of disability.

The first argument – that the social and political language is insufficiently developed – has a lot of merit. But we should think carefully about what exactly constitutes medical language, and how it is useful. Medical language has a number of very particular features. To many, it is effectively a foreign language. It is technical, sometimes impersonal, specialized, and closely tied to powerful professions and institutions. It is not easily mastered, and the people who *do* master it have often trained for years.

Precisely for these reasons, medical language is also a crucial communicative tool. It allows us to talk about bodies as well as experiences in a particular register. It has descriptive and analytical powers that cannot easily be reproduced in other registers. Interestingly, in the NGO sector, it meshes rather *well* with social and political language. While social and political language can be used to frame the interests of disabled people as a diverse and heterogeneous group, medical language can be used to operationalize particular experiences

and challenges. The challenge of implementing access, for example, can be discussed, on the level of general justifications, principles, and goals, in social and political terms. On the level of specific accommodations, the discussion must involve the sensory, motor, and intellectual capabilities of individuals.

The challenge, then, is for disability studies to recognize, engage with, co-opt, and utilize medical language and its functions. A lot of people already work at this challenge. When, for three years until 2016, I was the editor of the Scandinavian Journal of Disability Research, I routinely received manuscripts from people who worked in medicine, whether in professional, teaching, or research environments. While familiar with medical language and methodology, they subsumed these under disability studies perspectives, in order to resolve problems identified by disability studies. This is how multidisciplinarity can work – not as a melting pot, wherein disciplines lose their constitutive edges, but as a mosaic, where distinctly disciplinary contributions are preserved for the purpose of resolving complex, transdisciplinary problems.

3.2 A transdisciplinary problem: Disability studies and chronic illness

Medical language can be appropriated by social and political discourse; the Norwegian NGO sector provides one example among a great many. Similarly, social and political discourses can frame issues of patient empowerment, for instance, as well as fundamental issues of health and illness. Understanding these dynamics is particularly important for another unresolved issue in disability studies, namely the relationship between disability, impairment, and chronic illness.

For a long time, and perhaps particularly since the advent of the British social model, disability as theorized in disability studies has had an uneasy relationship with chronic illness. Much of the theorization and modeling of disabling aspects of society has been contingent upon a bracketing of variable, unstable chronic illness as substantially different from permanent, stable impairment. While it is indisputable that a great number of disabled people, perhaps a considerable majority, have chronic illnesses, it has proved difficult to theorize this fact without backsliding into medicalization of disability. One of the consequences, perhaps mainly important to academics, is a high but perhaps unwarranted degree of disciplinary fragmentation.

I am speaking here partly based on anecdotal evidence: my personal experience of spending four years working in a department of sociology, after being a PhD fellow in a multidisciplinary disability studies research group. In my case, the sociology of health and illness turned out to be a discipline both adjacent to disability studies and very distinctly cut off from it. I was initially, perhaps naïvely, surprised by the ostensible distance between the two fields. My first though was that they often dealt with the same people, and many of the social structures, and that it was strange for them to make such different assumptions about the phenomena they were studying. The disagreements could be productive, as happens when disability scholars and sociologists of health and illness engage in readings of the work of Erving Goffman or Irving Zola, but they could also be frustrating and unproductive.

The social-scientific study of health and illness, including chronic illness, differs from disability studies in many ways – some of them obvious, some of them not. The disciplines have intertwined but distinct lineages, they cite some of the same literature but often in very different ways, and they present their new nuggets of knowledge to different audiences, for different purposes. They speak different languages. Reading, for example, the prominent sociologist Arthur Frank (2010a, 2010b), I was struck by the importance placed on the *temporal* dimension of the illness experience. Simply put: If you work in the sociology of health and illness, you need to address the possibility of recovery. In disability studies, the notion of recovery is alien and an object of suspicion. This point may appear trivial. But it surprised me, and it led me to think in new ways about the particular group of people that I was studying, within the institutional framework of the sociology of health and illness.

3.3 How to talk about disability to people with chronic illness: The case of ME/CFS

My time in the Department of Sociology and Human Geography at the University of Oslo was mostly spent studying myalgic encephalopathy and chronic fatigue syndrome, which I'll bracket in this article as ME/CFS. There is much to say about that label, the constellation of diagnoses to which it refers, and the people who received those diagnoses. For now, I'll note that this is a group of people who tend to experience extreme fatigue, along with a number of other symptoms that constitute either a chronic illness or a form of semi-permanent impairment, depending on one's perspective. A more extensive discussion can be found in (Grue, 2013).

ME/CFS has a history in disability studies; it is at the center of Susan Wendell's classic *The Rejected Body* (1996), which among other things developed a phenomenological perspective on disability and disablement. However, I will note the following: Many people with ME/CFS are very, very skeptical of the language and symbols of disability, probably for the implicit and explicit links to permanence. Disability rights, wheelchairs, universal design – these are not high on the list of preferred topics in ME/CFS communities online, of which there are many (Knudsen et al., 2012). Rather, the discussion is at its loudest and most expansive when it is about etiologies, medical research, relationships with the health services, and the possibility of cure.

This does not mean that disability studies has nothing to add to our understanding of ME/CFS. Quite the contrary. But there is a problem here, and I think it is a discourse problem. In order to understand the position of people in the ME/CFS community, researchers should ideally know a lot of things – things to do with medical history and the profession of medicine, with social history and the gendering of illnesses, with the sociology of diagnosis, and with numerous aspects of clinical medical research.

What can disability studies contribute to what is already an extremely complex subfield, which does not agree on its own boundaries, nor on its current state of knowledge? One suggestion is this: To pose the very simply question: *What happens when people don't get well*? Of course there are many other things that a disability studies scholar could do with ME/CFS. But I think that one of the potentially most *useful* as well as *interesting* questions that can be posed is this one. This question is a discourse question. It puts the word *illness* in

what quickly turns out to be a social and political frame: *What do we, as a society, decide to do when people don't get well?*

This is not a question that draws on either a complex disability studies perspective or on a technical disability studies vocabulary. In fact, it stays pretty close to the vocabulary of everyday life, with just a smidge of medicine in there. But it shifts towards a social and political discourse that is enmeshed with the field of disability studies. It's a simple question with a complex answer, and it is a simple question based on a complex analysis. It is also one of the ways in which the distance between disability studies and the sociology of health and illness can be bridged. It is one of the ways that disability studies can develop its social and political discourse without turning its back on the language of health and illness, or for that matter on the language of medicine.

Many people that disability studies consider disabled do not consider themselves disabled. They consider themselves ill. I don't know whether this perception can or should be changed. But perhaps it is possible, and productive, to try to change the meaning of illness so that it coincides with a sociopolitically sophisticated sense of what it means to be disabled.

4 The purpose of disability studies

The implication of the above arguments for disability studies is that medical language should not be negated, or even replaced with sociopolitical language. This solution is unlikely to work, because there are areas of knowledge for which sociopolitical language is very poorly suited. Instead, bringing disability studies perspectives to the medical field must be a matter of engaging with the language of that field. It must be a matter of focusing both on language and the way in which it is used.

In 2005, at Kenyon College in Ohio, the writer David Foster Wallace gave a commencement speech which began with a short parable:

> There are these two young fish swimming along and they happen to meet an older fish swimming the other way, who nods at them and says "Morning, boys. How's the water?" And the two young fish swim on for a bit, and then eventually one of them looks over at the other and goes "What the hell is water?" (Bobrow, 2005)

As parables go, this is not a bad one. It is potentially about a lot of things, but I think we, here, can treat it as a parable about academia, disciplines, and the things we take for granted. We are all fish swimming in water. I began this article by noting that there is more disability in the world than there used to be. By this, I meant the *word* disability rather than the *phenomenon* of disability.

Disability – the phenomenon, though also the word – is increasingly a topic for international conventions, national initiatives, and research and scholarly interest. The academic field of disability studies is vibrant. There are conferences, journals, networks, and research projects. Simultaneously, the field of disability is in a precarious position. Many scholars of disability have jobs that do not mention disability explicitly. The level of interest in disability as a research topic does not translate into research funding that is earmarked for disability, nor

does it imply that there are many jobs available for people who want to become scholars with disability studies as their specialty.

Against the background of the *proliferation of disability as a topic* and *the precariousness of disability as a scholarly field,* I think we have a double challenge: *Talking about disability both inside and outside the discipline*, i.e., doing something about disability-in- the-world while still doing it *as disability studies scholars*. Medicine, health, and illness provides the perhaps richest source of such opportunities, but they are present to disability scholars and teachers who work in education, psychology, and in many other professions and disciplines. The discourse perspective may not solve the problems of communication and framing that they face, but I hope it may be a contribution of sorts.

Today's discipline of disability studies is an evolutionary niche. It is fertile and conducive to a lot of interesting work, but it is also narrow and at risk of evolving into further specialization. If we allow this process to continue unchecked, we are taking a major risk, because unlike many other academic disciplines, disability studies is not supported by the rich and the powerful. Niches can be fertile, but they can also be vulnerable. Disability studies must develop as an independent discipline; this is an absolute necessity for theoretical advancement and rigor, among many other things. But a double-track strategy is needed, wherein specialization combines with differentiation as well as dissemination.

What does this perspective imply? For one, it implies remembering that disability studies *is not about the interests of a narrow minority*. It is about the interests of a diverse and heterogeneous group of people, many of whom do not necessarily consider themselves disabled. We are often tempted to conflate disability as an *analytical category* with disability as a *word*. This is an error. The *word* "disability" means many things in many different contexts. The word "disability" in political (e.g. welfare contexts) means something other than what it means in medicine, or for that matter in sports.

We need to focus on the analytical category. And as an *analytical category*, disability is always in danger of being carved up and subsumed by other disciplinary categories, e.g. deviance, abnormality, marginalization, or special needs. Disseminating disability studies, which I also understand as developing disability discourse, is about teaching people, teaching our peers, how the category works – in their own words, if necessary.

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